Development and Testing of an Instrument to Measure the Quality of Children’s End-of-Life Care from the Parents’ Perspective

by

Kimberley Ann Widger

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

Lawrence S. Bloomberg Faculty of Nursing
University of Toronto

© Copyright by Kimberley Ann Widger 2012
Development and Testing of an Instrument to Measure the Quality of Children’s End of-Life Care from the Parents’ Perspective

Kimberley A. Widger

Doctor of Philosophy

Lawrence S. Bloomberg Faculty of Nursing
University of Toronto

2012

Abstract

Background: The Senate of Canada asserts that quality end-of-life care is the right of every Canadian. Yet, little is known about the quality of end-of-life care for dying children and their families.

Purpose: The study purpose was to develop and test an instrument to measure parents’ perspectives on the quality of care provided to families before, at the time of, and following the death of a child.

Methods: In study Phase I, key components of quality pediatric end-of-life care were synthesized through a systematic review of research literature then validated and extended through focus groups with bereaved parents. In Phase II, instrument items were developed to assess structures, processes, and outcomes important to quality end-of-life care, then tested for content and face validity by health professionals and bereaved parents. In Phase III, the instrument was administered to bereaved mothers from across Canada and psychometric testing conducted.
Results: Instrument items were developed based on review of 67 manuscripts and 3 focus groups with 10 parents. The Content Validity Index for the instrument was 0.84 as assessed by 7 health professionals. The instrument was assessed by 6 bereaved parents for face and content validity as well as their cognitive understanding of the items. In the final phase, 128 mothers completed the instrument and 31 of those completed it twice. Initial evidence for test-retest reliability, internal consistency, and construct validity was demonstrated for 7 subscales: Connect with Families, Involve Parents, Share Information with Parents, Share Information among Health Professionals, Support Parents, Provide Care at Death, and Provide Bereavement Follow-up. Additional items with demonstrated content validity only were grouped into three domains: Support the Child, Support Siblings, and Structures of Care.

Implications: This study is a significant step forward in comprehensive measurement of the quality of children’s end-of-life care. The instrument provides a mechanism for feedback to health professionals, health systems, and policy makers to improve care provided to families facing the death of a child.
Dedication

I dedicate my thesis work to four important women in my life, who unfortunately did not live to see me complete my PhD. First to my great-grandma, Clara Knox (1902 – 1996), who bought me my very first nursing uniform and was so thrilled that I became a nurse. To my great-great aunt, Joy Little (1909 – 2011), and my grandma, Elizabeth Widger (1916 – 2011), who were both bereaved mothers and watched adult sons struggle with and die from cancer. We had many interesting conversations about the impact of having an ill and dying child regardless of the age of the child or mother. And finally to my grandma, Eileen Jenkins (1923-2010), who wanted to know all the details of every accomplishment in my life so she could put it in her local newspaper. All four of these women at times wondered why I kept going back to school, but they each cheered me every step of the way and were so proud that I had and was able to take advantage of so many opportunities that were never available to them.
Acknowledgments

Special thank you to all of the parents who took part in my research. It was wonderful at times and yet so painful at other times to hear the best and worst of their experiences with health professionals who provided care to their child and family. I pledge to continue my work to ensure all families experience only the best possible care in future. Thanks in particular to Joanie, Val, and Jonathan who provided support and advice from a parent’s perspective throughout my research.

Thank you to Dr. Ann Tourangeau, my thesis supervisor. Her guidance and support from our first meetings in an Oakville coffee shop with my infant son asleep beside us, and throughout my program made it possible for me to successfully complete my PhD. She gave me the flexibility to focus on my family when needed and to pursue every learning opportunity available to me both within and apart from her own program of research. Over the years she also gave me big hugs or a kick in the butt when needed. It has been an honor to have Ann as my supervisor.

Before I met Dr. David Streiner, I was told by the end of my PhD I still would not know as much as he knows in his little finger about instrument development. This prediction is likely true and was more than a little intimidating when I started. However, it has been wonderful to have someone so incredibly knowledgeable, who is so willing to share that knowledge and provide guidance in an understandable and humorous way that never made me feel I was lacking. It has been a privilege to work with David.

Thank you to Dr. Rose Steele for being a member of my thesis committee. Her calm and gentle nature, and her wealth of knowledge and expertise in pediatric palliative care, nursing, research, and writing have been a huge source of inspiration and support to me both in my own research and in the development of my career. It has been such a pleasure and an honor to get to know and work with Rose throughout my PhD.

Thank you to my collaborators at each of the 10 recruitment sites. Their patience and hard work in assisting me to meet all of the local ethics and administrative requirements as well as for recruiting mothers to take part, made it possible for me to do this study. I sincerely appreciated their support and ongoing interest in my work.
Thank you to Heather Thomson and Margaret Saari, my research assistants, who coordinated all of the survey mailings and entered all of the data from the returned surveys. When I had to be away I knew everything related to the study was in good hands.

I want to acknowledge the financial support I received throughout my PhD program. My sources of funding included: Canadian Institutes for Health Research, Innovation Fund in Children’s Palliative Care Research, Canadian Child Health Clinician Scientist Program, New Emerging Team – Transitions in Pediatric Palliative and End-of-Life Care, Canadian Nurses Foundation, and the University of Toronto. In particular, I want to thank Drs. Rose Steele, Betty Davies, Susan Cadell, Hal Siden and Lynn Straatman with the New Emerging Team – Transitions in Pediatric Palliative and End-of-Life Care who supported my work but also gave me the opportunity to assist in writing papers, book chapters, and grants as well as to be involved in other research in pediatric palliative care. I look forward to future collaborations!

Thank you to my colleagues at the University of Toronto, the Hospital for Sick Children, and the IWK Health Centre, friends both near and far, and extended family, too numerous to mention, who took an interest in my work, and provided well-wishes, encouragement, and support throughout my studies.

Dr. Sheri Price has now shared two life-changing journeys with me. The first was the journey into motherhood and the second was this journey to ‘PhD.’ We have shared the joys and triumphs as well as the tears and frustrations that come with both journeys – especially when they overlap! Neither journey would have been as much fun and fulfilling without Sheri by my side. Who knows where this friendship will lead us next!

My biggest concern with moving to a new city far from family support, and going back to school was finding someone to look after my children when I could not be with them. Then I met Kim Williams. She and all of her family (Taylor, Ashley, Brooke, Jaime and Kimberley) welcomed and love Rebecca and Ryan as one of their own. Kim’s warm heart and unending flexibility with changed schedules made it possible for me to head off on the train or further away knowing my children were well cared for and happy. I truly could not have done this PhD without Kim and her family in our lives!!
Thank you to Steve and Carol Rankin, first for giving me their son, and for all their wonderful support over these years of study and beyond. They were always interested in what I was doing, took time to read some of my thesis and ask questions, came to help Mike with the kids when I was away, and cheered for my every accomplishment.

Thank you to my parents, Mary and Gordon Widger, and my sister Kelly. Even though they lived far away they provided endless love and support through long phone calls listening to my latest trials and tribulations, incredibly relaxing summer vacations with all our activities planned (how wonderful to not have to think!), editing services, menu planning and cooking advice, parenting advice, and personal shopping services for every special occasion. Thank you for making me who I am today. I love you very much!

Last, but certainly not least, thank you to Mike, Rebecca, and Ryan for all of their love, support, and encouragement. Mike promised that if I followed him off to the ‘big city’ I would be able to pursue my goal of returning to school. It took a little longer to finish than I hoped, and I am still not ready to start a ‘real job,’ but Mike has patiently supported me in every way possible to follow my dreams. I have been blessed with two happy and healthy children, who kept me grounded throughout my studies, gave me a wonderful distraction when needed, and have remained, for the most part, blissfully unaware of what I was off doing while they were at school. Thank you for being the light of my life!
Table of Contents

CHAPTER 1: BACKGROUND ...................................................................................................... 1
  1.1 End-of-Life, Palliative, and Bereavement Care ............................................................... 2
  1.2 Models for Pediatric End-of-Life Care in Canada .......................................................... 3
  1.3 Importance of Quality Pediatric End-of-Life Care .......................................................... 4
    1.3.1 The Ill Child’s Perspective ......................................................................................... 4
    1.3.2 The Parent’s Perspective ............................................................................................. 7
    1.3.3 The Sibling’s Perspective ........................................................................................... 8
  1.4 Defining Quality Care ........................................................................................................... 9
  1.5 Domains and Indicators of Quality End-of-Life Care ...................................................... 10
  1.6 Options for Evaluating Quality of End-of-Life Care ...................................................... 11
  1.7 Purpose ................................................................................................................................ 14

CHAPTER 2: LITERATURE REVIEW ....................................................................................... 16
  2.1 Domains of Quality Pediatric End-of-Life Care ............................................................... 17
    2.1.1 Connect with Families .............................................................................................. 17
    2.1.2 Involve Parents ......................................................................................................... 20
    2.1.3 Alleviate Suffering .................................................................................................... 21
    2.1.4 Share Information ...................................................................................................... 24
    2.1.5 Provide Bereavement Care ....................................................................................... 26
  2.2 Conclusion .......................................................................................................................... 29
  2.3 Addendum ........................................................................................................................... 29
    2.3.1 Connect With Families ............................................................................................. 30
    2.3.2 Involve Parents ......................................................................................................... 31
    2.3.3 Alleviate Suffering .................................................................................................... 31
    2.3.4 Share Information ...................................................................................................... 32
    2.3.5 Provide Bereavement Follow-up .............................................................................. 33
    2.3.6 Summary ................................................................................................................... 34

CHAPTER 3: METHODS ............................................................................................................. 35
  3.1 Foundational Work ............................................................................................................. 35
    3.1.1 Identification of the Measurement Framework ...................................................... 35
    3.1.2 Initial Identification of Domains and Indicators ..................................................... 36
3.2 Phase I: Focus Groups ........................................................................................................ 37
  3.2.1 Purpose ..................................................................................................................... 37
  3.2.2 Sample and Recruitment ......................................................................................... 37
  3.2.3 Procedure .................................................................................................................. 37
  3.2.4 Analysis .................................................................................................................... 38
3.3 Phase II: Item Development and Initial Testing ................................................................. 38
  3.3.1 Purpose ..................................................................................................................... 38
  3.3.2 Item Development .................................................................................................... 39
  3.3.3 Testing with Health Professionals ............................................................................ 40
  3.3.4 Testing with Parents ................................................................................................. 41
3.4 Phase III: Instrument Administration and Psychometric Testing .................................... 42
  3.4.1 Purpose ..................................................................................................................... 42
  3.4.2 Sample and Setting ................................................................................................... 42
  3.4.3 Procedures ................................................................................................................. 45
  3.4.4 Data Analysis ............................................................................................................ 47
CHAPTER 4 RESULTS ................................................................................................................ 53
4.1 Phase I Results .................................................................................................................... 53
  4.1.1 Sample Description ................................................................................................... 53
  4.1.2 Revised Domains and Indicators ............................................................................. 53
  4.1.3 Impact of Research Participation .............................................................................. 63
4.2 Phase II Results ................................................................................................................... 64
  4.2.1 Instrument Items ....................................................................................................... 64
  4.2.2 Health Professional Testing Results ......................................................................... 65
  4.2.3 Parent Testing Results .............................................................................................. 67
4.3 Phase III Results ................................................................................................................. 68
  4.3.1 Recruitment and Sample ........................................................................................... 68
  4.3.2 ‘Connect with Families’ Subscale Analysis ............................................................. 70
  4.3.3 ‘Involve Parents’ Subscale Analysis ........................................................................ 73
  4.3.4 ‘Share Information’ Subscale Analysis .................................................................... 75
  4.3.5 ‘Alleviate Suffering’ Subscale Analysis ................................................................... 80
  4.3.6 ‘Provide Bereavement Follow-up’ Subscale Analysis ............................................. 90
List of Tables

Table 2.1: Indicators for ‘Connect with Families’
Table 2.2: Indicators for ‘Involve Parents’
Table 2.3: Indicators for ‘Alleviate Suffering’
Table 2.4: Indicators for ‘Share Information’
Table 2.5: Indicators for ‘Provide Bereavement Follow-up’
Table 4.1: Revised Indicators for ‘Connect with Families’
Table 4.2: Revised Indicators for ‘Involve Parents’
Table 4.3: Revised Indicators for ‘Alleviate Suffering’
Table 4.4: Revised Indicators for ‘Share Information’
Table 4.5: Revised Indicators for ‘Provide Bereavement Follow-up’
Table 4.6: Number of Items Developed by Type and Domain
Table 4.7: Final Number of Items by Domain and Type for Phase III Testing
Table 4.8: ‘Share Information’ Stand-Alone Item Results
Table 4.9: Sample Follow-up Item Results
Table 4.10: ‘Support the Child’ Stand-Alone Item Results
Table 4.11: ‘Support Siblings’ Stand-Alone Item Results
Table 4.12: ‘Provide Bereavement Follow-up’ Stand-Alone Item Results
Table 4.13: ‘Structures of Care’ Item Results
Table 4.14: ‘Impact of Participation’ Item Results
Table 4.15: Final Number of Items by Domain and Type Following Phase III Testing
List of Appendices

Appendix A: Phase I Advertisement to Recruit Parent Participants for Focus Groups
Appendix B: Phase I Telephone Script to Recruit Parents for Focus Groups
Appendix C: Phase I Consent for Parent Focus Groups
Appendix D: Phase I Parent Focus Group Script and Questions
Appendix E: Phase I Items on Impact of Participation
Appendix F: Phase I Items for Background and Demographic Information
Appendix G: Phase II Recruitment Email to Health Professionals
Appendix H: Phase II Information Letter and Instructions for Health Professionals
Appendix I: Phase II Telephone Script to Recruit Parent Participants
Appendix J: Phase II Parent Consent for Participation
Appendix K: Phase III Introductory Letter to Mothers about the Study
Appendix L: Phase III Mother’s Consent for Participation
Appendix M: Phase III Mother’s Consent for Participation in Reliability Testing
Appendix N: Phase III Letter and Items for Structural Assessment of Hospital/Hospice
Appendix O: Final Indicators with First Draft of Instrument Items
Appendix P: Instrument with Health Professional Testing Results
Appendix Q: Instrument with Parent Testing Results
Appendix R: Phase III Instrument
Appendix S: Recruitment Details by Site
Appendix T: Participant Demographics
Appendix U: Structural Assessment Results
Appendix V: Factor Analysis Results
Appendix W: Final Instrument Items
CHAPTER 1: BACKGROUND

Over 3500 children under 19 years of age die each year in Canada. About one third of these deaths are due to motor vehicle accidents, drowning, and other traumas. The remainder are due to a variety of acute and chronic illnesses (Statistics Canada, 2009). Regardless of the cause or circumstances of death, the Senate of Canada asserts that quality end-of-life care is the right of every Canadian (Subcommittee of the Standing Senate Committee on Social Affairs, Science, and Technology, 2000). Unfortunately, indicators of quality end-of-life care for children are not well defined nor is the quality of children’s end-of-life care routinely assessed in Canada.

Research related to quality of care for children, and particularly end-of-life care, lags behind developments in quality of care research for adults (Dougherty & Simpson, 2004). This lack of research may be due in part to the many advances that have been made in preventing and treating diseases in children. Cancer deaths have decreased (Smith & Gloekler Ries, 2002), rates of sudden infant death have dropped (Canadian Foundation for the Study of Infant Deaths, 2008), and many infants who would have only lived days or weeks now live full lives (Craft, 2004). Unfortunately, children still die.

A child’s death is considered to be an aberration of nature, whereas a child’s rescue from death is viewed as a triumph (Foley & Whittam, 1990). Children represent hope for the future; their death is perceived as a loss to society as well as to an individual family. It is, therefore, important that the child’s death is dealt with intelligently, humanely, lovingly, and with utmost consideration for the physical, psychosocial, and spiritual well-being of the dying child and for the well-being of parents, siblings, extended family, community, and the health professionals who care for the child.

Recent studies suggest that quality of end-of-life care is not what it should be for dying children and their families. Children experience a great deal of suffering from pain and other symptoms left inadequately treated (Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006; Kreicbergs et al., 2005; Theunissen et al., 2007; Wolfe et al., 2000), parents feel abandoned by health professionals both before and after their child’s death (Kreicbergs et al., 2005; Sirkia, Saarinen, Ahlgren, & Hovi, 1997; Widger & Picot, 2008; Woodgate, 2006), parents’ opinions are not sought or respected (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Widger & Picot,
Health professionals report having received little training and being un-prepared to effectively treat pain and symptoms, emotionally support dying children and their families, or deal with the ethical issues that may be present at end of life (Clarke & Quin, 2007; Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Davies et al., 2008; Docherty, Miles, & Brandon, 2007; Feudtner et al., 2007; Hilden et al., 2001; Wolfe et al., 2000; Wolfe, 2000). Assessment of and improvements in the quality of pediatric end-of-life care have been identified as research priorities by national bodies both in Canada and the United States (Canadian Hospice Palliative Care Association [CHPCA], 2006; Field & Behrman, 2003). This study is a significant step towards assessing and improving the quality of end-of-life care for dying children and their families.

1.1 End-of-Life, Palliative, and Bereavement Care

Palliative care for children focuses on alleviating the physical, social, psychological, and spiritual suffering experienced by children and families while promoting quality of life, fostering family connections, and sustaining hope despite the likelihood of death. It is a family-centered approach that includes shared decision-making and sensitivity to the family’s cultural and spiritual values, beliefs, and practices (CHPCA, 2006; Field & Behrman, 2003). Pediatric palliative care incorporates care provided at the time of death and during the year or more following the death; called bereavement care or bereavement follow-up. Pediatric palliative care is generally thought of in terms of its application to life-threatening or life-limiting illness, with the principles ideally being applied from the time of diagnosis through end-of-life and into bereavement (Frager, 1996). It may be difficult to determine prospectively when the end-of-life period begins, given the complexity of childhood illnesses that lead to death and their generally unpredictable nature (Mack & Wolfe, 2006). Parents whose child dies from an illness where death is an “expected” outcome still may not be intellectually or emotionally aware that it is actually happening until hours before death occurs (Valdimarsdottir et al., 2007). For children whose death occurs shortly after birth or is the result of an acute illness or trauma, end-of-life care may be provided for only hours or minutes before the death (Donaldson & Field, 1998). While the focus of care in these deaths is generally on attempts at saving the child from
death, there has been recent recognition that the principles of palliative care still apply regardless of the cause or circumstances of death (Gillis, 2008).

The end-of-life period may be associated with the greatest suffering for the family, but may also be the time health professionals can have the greatest impact on long term outcomes for the family. For families whose child dies of an acute illness or trauma, the end-of-life period may be the only contact they will have with health professionals. If the child dies after a prolonged illness, the family may have long established relationships with health professionals prior to the end-of-life period. If parents feel abandoned by those health professionals at the time of or following their child’s death, they may question the sincerity of the connections that were developed with health care professionals before the death (deJongBerg & Kane, 2006). As well, the child’s death and the care provided at that time will be the final memories that parents will have of their child (Woodgate, 2006). Therefore, the way end-of-life care is provided may have greater impact on the parents, in terms of long term outcomes, than care given earlier in the disease course.

For the purpose of this study, ‘end-of-life’ refers to the time immediately before, at the time of, and after the child’s death. The period of time before the death is somewhat dependent on the circumstances of the death and may range from hours to weeks. The circumstances that precipitated the child’s death may include prolonged illness or an acute event or illness.

1.2 Models for Pediatric End-of-Life Care in Canada

A recent Canadian study documented models for providing end-of-life care and the number of children cared for through existing specialized Pediatric Palliative Care Services (Widger et al., 2007). In 2002, there were seven pediatric palliative care services based in tertiary care centers and one freestanding children’s hospice. The palliative care services staff generally provided care through consultation with the involved care team while the hospice staff provided direct care to the child and family. Even when children who died from causes such as accidents, falls, and drowning were excluded, only 5% of children who died in Canada during 2002 were seen by one of the specialist services. Nearly half of the children who were cared for by these services died at home. This finding was in sharp contrast to other researchers who found that the vast majority of children die in hospitals, and most often in intensive care settings within
those hospitals (Carter et al., 2004; Drake, Frost, & Collins, 2003; Feudtner, Christakis et al., 2002; McCallum, Byrne, & Bruera, 2000; van der Wal, Renfurm, van Vught, & Gemke, 1999). Unfortunately, these studies do not assess differences in the quality of end-of-life care provided through a specialist palliative care service versus other services, nor do they assess quality differences based on whether the child received care at home, in intensive care settings, in general hospital wards, or in hospices. The Senate of Canada has called for increased services for end-of-life care to allow Canadians, children included, to have more options to choose from in terms of where care is provided and where death occurs (Subcommittee of the Standing Senate Committee on Social Affairs, Science, and Technology, 2000). As well, the Senate reported the need for increased education for all health professionals about pain and symptom management and principles of palliative care to improve the quality of end-of-life care in Canada regardless of the location of care or the circumstances of the death. As of 2011, there were eight hospital based pediatric palliative care services and five children’s hospices with two additional hospices under construction (Widger et al., in press). Presumably, the increase in formal children’s palliative care and hospice programs is due to a belief that these dedicated services are able to provide higher quality palliative and end-of-life care to children and their families than non-specialist services. However, there is no research evidence to support this assumption.

1.3 Importance of Quality Pediatric End-of-Life Care

1.3.1 The Ill Child’s Perspective

There is very little research available on what children view as priorities for end-of-life care or what quality care at the end of life would mean to them. A recent review of the use of patient reported outcomes in pediatric oncology end-of-life research found only four studies that explicitly included the child’s view (Hinds et al., 2007). In two of these studies children prospectively reported on their pain and other symptoms (Goldman et al., 2006; Monteiro Caran, Dias, Seber, & Petrilli, 2005). One study with 20 children, aged 10 to 20 years, who had been involved in end-of-life decision-making found children’s decisions were based on the following: wanting to help others, the ability to have fun, wanting to stay at home, avoiding further pain and suffering, and avoiding being kept alive on machines (Barrera, D'Agostino, Gammon, Spencer, & Baruchel, 2005; Hinds et al., 2005; Hinds, Oakes, Hicks, & Anghelescu,
Decisions were also sometimes based on what the child thought his/her family wanted even if it did not fit with the child’s personal wishes. One study that included 3 children aged 7 to 15 years and 9 parents explored perspectives on health-related quality of life when at end of life (Barrera et al., 2005). The children expressed the following needs: to be normal and to have fun, to receive honest information about what was happening to them, and to protect their parents. Children have also demonstrated an awareness of their illness progression and demonstrated insight into the worry and sadness of their parents and caregivers (Davies et al., 2005). In a study of 29 ill children receiving care through a children’s hospice program, the children identified the things they liked best about the hospice program including: the home-like environment, being made to feel special, spending time with their family and with other kids, and having their own room, television, and video recorder (Davies et al., 2005). In a presentation of an interview with a 13 year old boy with multiple relapses of leukemia, the child expressed his concerns about how his family would cope without him and that he wanted to be treated like a normal kid. He also had concerns about what it would be like to be dead and if he would forget his family (Hurwitz, Duncan, & Wolfe, 2004).

Un fortunately, research indicates that care provided to children at end of life does not fit well with these glimpses of what children might actually want and need. Most children who died in hospital died in an intensive care setting, usually after having received assisted ventilation during their hospital stay (Carter et al., 2004; Drake et al., 2003; Feudtner, Christakis et al., 2002; McCallum et al., 2000; van der Wal et al., 1999). Do not resuscitate orders were generally completed only in the final day of life (Carter et al., 2004; Drake et al., 2003; Feudtner, Christakis et al., 2002; McCallum et al., 2000; van der Wal et al., 1999). Feudtner, Christakis et al. (2002) found that children with complex, chronic conditions had longer hospital stays and were mechanically ventilated for a longer period of time prior to death than children without complex, chronic conditions. The same researchers also found that the percentage of children with complex, chronic conditions who died at home rose significantly over their 18-year period of study (Feudtner, Silveira, & Christakis, 2002). This trend suggests that as home care services improved, more children and families took advantage of this option. Similarly, a Canadian study found greater numbers of children died at home when they received palliative care in a city with more available comprehensive home care services.
However, only 44% of children cared for by a formal pediatric palliative care service died at home (Widger et al., 2007).

Most children received opioids prior to death, but documentation of ongoing symptom assessment and treatment was poor (Carter et al., 2004; Drake et al., 2003; Feudtner, Christakis et al., 2002; McCallum et al., 2000; van der Wal et al., 1999). Several researchers documented the prevalence of at least one and generally several physical, psychological, social, and spiritual symptoms in children at end-of-life including pain, fatigue, breathlessness, anorexia, weight loss, seizures, difficulty sleeping, nausea/vomiting, anxiety, fear, and nervousness (Collins, Stevens, & Cousens, 1998; Contro et al., 2002, 2004; Goldman et al., 2006; Hongo et al., 2003; Jalmsell et al., 2006; Mack et al., 2005; Mallinson & Jones, 2000; Monteiro Caran et al., 2005; Sirkia et al., 1997; Theunissen et al., 2007; Wolfe et al., 2000).

A classic study from the 1970s indicated that children with cancer knew they were dying even if death was never discussed with them, which was the common practice at the time (Bluebond-Langner, 1978). Unfortunately, 30 years later there may still be a reluctance to talk to children about their impending death even when they are cognitively able to do so. Sourkes (1995, 1996) has shared many stories of her work with terminally ill children and how even very young children are able to articulate knowledge of their impending death when given the tools and space to do so. In one study, discussion of death with the dying child was documented in only one of every eight charts of cognitively intact children over the age of six years (McCallum et al., 2000). In another study, only 34% of parents reported talking with their child about death prior to that child’s death from cancer (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004b). In a study of children’s perceptions of communication with their physician, one child suggested that adults should be approaching children to see how they are rather than the child having to bring up issues with the adult. Other children in the study indicated that they hid their emotions so as not to upset or disappoint their parents (Hsiao, Evan, & Zeltzer, 2007).

While health care professionals have little direct knowledge about what children themselves want in terms of their end-of-life care, they know even less about the impact on the child of an experience that is not in keeping with what his/her wishes might be. Children have a right to a peaceful death free from pain and other physical symptoms and as free as possible from
psychological, social, or spiritual suffering. Assessment of and improvements in the quality of pediatric end-of-life care will ensure this right is respected.

1.3.2 The Parent’s Perspective

Caring for a child with a life-limiting illness impacts parents physically, emotionally, financially, and spiritually (Steele & Davies, 2006). A child’s death is known to cause the most intense, long lasting, and overwhelming type of grief (Rando, 1986). Many studies have demonstrated the prevalence of intense pain and sadness, shock, anger, guilt, depression, anxiety, loneliness, mental distress, decreased marriage satisfaction, complicated grief, stress, increased alcohol use, and post-traumatic stress disorder in parents who have experienced the death of a child (Aho, Tarkka, AstedtKurki, & Kaunonen, 2006; Barrera et al., 2007; deCinque et al., 2006; Dyregrov, Nordanger, & Dyregrov, 2003; Goodenough, Drew, Higgins, & Trehewie, 2004; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004a; Laakso & Paunonen-Ilmonen, 2001; Miles, 1985; Murphy, Johnson, Chung, & Beaton, 2003; Murphy, Johnson, Wu, Fan, & Lohan, 2003; Sirkia, Saarinen, & Hovi, 2000; Spooren, Henderick, & Jannes, 2000-2001; Vance, Boyle, Najman, & Thearle, 1995). Bereaved parents, mothers in particular, have a higher rate of death from unnatural causes such as motor vehicle accidents in the first three years after the death than non-bereaved parents (Li, Hansen, Mortensen, & Olsen, 2003). Death rates from cancer and circulatory, gastrointestinal, and other diseases begin to increase in bereaved mothers compared with non-bereaved mothers 10 years after the child’s death (Li et al., 2003). Mothers are also at higher risk for smoking-related cancers possibly due to a stress-induced high-risk lifestyle following the child’s death (Li, Hansen, Mortensen, & Olsen, 2002; Li, Johansen, Hansen, & Olsen, 2002). Bereaved parents also have an increased incidence of heart attack and multiple sclerosis (Li et al., 2002, 2004). Bereaved parents have higher rates than non-bereaved parents of completed suicide, particularly in the first month after the child’s death, and higher rates of hospitalization for affective disorders, schizophrenia, and substance abuse in the first year after the death (Li, Laursen, Precht, Olsen, & Mortensen, 2005; Qin & Mortensen, 2003).

On the other hand, some studies have noted positive changes resulting from the experience of a child’s death, including greater appreciation for life, personal growth, and new social relationships (Aho et al., 2006; Barrera et al., 2007; Laakso & Paunonen-Ilmonen, 2001). There
is little understanding about the interventions or supports needed to foster positive outcomes for parents after the child’s death. Some researchers have found links between parents’ satisfaction with care, or assessment of care quality, and their coping ability or emotional state in the years after the child’s death (Kreicbergs et al., 2005; Meert, Thurston, & Sarnaik, 2000; Seecharan, Andresen, Norris, & Toce, 2004; Spooren et al., 2000-2001; Surkan, Dickman, Steineck, Onelov, & Kreicbergs, 2006). In particular, one study found the emotional attitudes of health professionals at the time of the child’s death predicted the intensity of both early and long term grief, while the adequacy of information given to parents prior to the child’s death was a predictor of the intensity of long-term grief (Meert, Thurston, & Thomas, 2001). Another study found access to psychological support, offers for counseling, and opportunities for discussions about the child’s condition with the attending physician prior to the child’s death were associated with parents being more likely to have worked through their grief 4 to 9 years post-loss. Mothers were also more likely to have worked through their grief if a meeting occurred with the involved health professionals after the child’s death (Kreicbergs, Lannen, Onelov, & Wolfe, 2007). Parents, fathers in particular, were less likely to have psychological problems after the child’s death if they were clearly informed of their child’s impending death (Valdimarsdottir et al., 2007). Improvements in the quality of care provided prior to, at the time of, and following a child’s death may have great impact on the parent’s short and long term physical, psychosocial, and spiritual health and future costs to the health system. It is important to adequately assess the quality of end-of-life care provided to the child and family in order to further explore these linkages.

1.3.3 The Sibling’s Perspective

Siblings are sometimes referred to as ‘forgotten mourners’ (Packman, Horsley, Davies, & Kramer, 2006). Indeed, bereaved siblings have reported that during their brother or sister’s illness, everyone asked about the dying child and after the death everyone asked about their parents, but no one ever asked how they were doing (Horsley & Patterson, 2006). Parents were often caught up with the needs of the dying child and their own grief, and they had limited time and energy left for the siblings either before or after the death (deCinque et al., 2006; Horsley & Patterson, 2006; Martinson & Campos, 1991). Siblings have reported wanting to receive honest information about what to expect, to have their sibling’s pain and suffering managed,
and to have time with their parents and family prior to the child’s death (Davies et al., 2005; Freeman, O’Dell, & Meola, 2003; Martinson & Campos, 1991; Nolbris & Hellstrom, 2005). In the months and years after the death, siblings may experience reactions similar to those experienced by bereaved parents including intense pain, shock, numbness, loneliness, anger, fear, anxiety, depression, guilt, confusion, sleeping problems, physical symptoms, behavior problems, difficulties at school, drug or alcohol use, and thoughts of suicide (Balk, 1983; Davies, 1988, 1991; Fanos & Nickerson, 1991; Forward & Garlie, 2003; Nolbris & Hellstrom, 2005; Sirkia et al., 2000). Siblings have reported keeping many of these feeling to themselves as they do not want to add to their parents’ pain, grief, or worry (Forward & Garlie, 2003; Horsley & Patterson, 2006; Martinson & Campos, 1991) and because they feel too different from their peers to be able to share concerns with them (Davies, 1991; Fanos & Nickerson, 1991; Forward & Garlie, 2003). Also similar to bereaved parents, some bereaved siblings have reported positive effects such as a sense of personal growth, maturity, and appreciation for life (Balk, 1983; Davies, 1991; Forward & Garlie, 2003). Some studies have shown that siblings tend to do better with their long-term grief if they were involved in some aspect of providing care to their sibling before the death (Martinson & Campos, 1991), if they were able to rely on their families for support both before and after the death (Horsley & Patterson, 2006; Martinson & Campos, 1991), and if their family is cohesive and socially active (Balk, 1983; Davies, 1988; Institute of Medicine, 2006). As noted above, parents are often overwhelmed by their own grief, but there may be a role for health professionals both in directly supporting siblings and in ensuring the parents receive the highest quality of care and support so they are better able to support their surviving children.

1.4 Defining Quality Care

The Institute of Medicine defined quality of care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Institute of Medicine, 2006, para.3). The quality of health services is most often assessed and evaluated using a health services model described by Donabedian (Aday, Begley, Lairson, & Balkrishnan, 2004; Donabedian, 1988; Higginson & Harding, 2007). The model can be used at the macro level to assess population health or at the micro level to assess the delivery of clinical care and its impact on the health of
the individual (Aday et al., 2004). The model includes three basic components: structure, process, and outcome. Structure refers to the availability, organization, and financing of services, as well as the physical, social, and economic environment where services are delivered (Aday et al., 2004). Process includes the interactions between the patient or family and the health care providers during care delivery (Aday et al., 2004). Outcomes usually involve a change in the health status of the individual, but can also include increased knowledge of health conditions, changes in behavior related to health, or patient and family satisfaction with the care received and its outcomes (Donabedian, 1988). Structure, process, and outcome are linked together conceptually in the model: the way healthcare is structured influences the processes of care which in turn influences the outcomes experienced by the recipients of care (Aday et al., 2004). Thus, all three components of the model should be included in any assessment of the quality of health care.

In examining Donabedian’s model in relation to the quality of pediatric end-of-life care, the expected health status outcome for the child is death, which cannot be changed. However, one can improve the quality of that death (Wallston, Burger, Smith, & Baugher, 1998). One can also improve health outcomes for the family, including reducing the incidence of depression, anxiety, post-traumatic stress, guilt, and complicated grief. Previous research has linked some structures and processes of care to these health outcomes for parents (Kreicbergs et al., 2005, 2007; Meert et al., 2000, 2001; Seecharan et al., 2004; Spooren et al., 2000-2001; Surkan et al., 2006; Valdimarsdottir et al., 2007). Examination of pediatric end-of-life care through assessment of the structures and processes of care at the micro level of clinical care and their impact on outcomes of a high quality death for the child, improved health status for the parents, and increased satisfaction with care is one method to identify the structure and process changes required to improve the quality of pediatric end-of-life care.

1.5 Domains and Indicators of Quality End-of-Life Care

Barriers to assessing the quality of end-of-life care include the lack of identified structures, processes, and outcomes which indicate quality, as well as reliable and valid methods for measuring them. Some researchers in adult palliative care have asked patients and family members to identify components of quality care or of a ‘good death’ (Emanuel & Emanuel, 1998; Heyland et al., 2006; Steinaufer, Christakis et al., 2000; Steinaufer, Clipp et al., 2000;
Steinhauser et al., 2001). Some instruments have been developed to measure these components from the perspective of the adult patient and/or family members (Curtis et al., 2002; Kristjanson, 1993; Morita et al., 2004; Sulmasy & McIlvane, 2002; Teno, Clarridge, Casey, Edgman-Levitan, & Fowler, 2001; Yun et al., 2006). There has been much less work in examining the quality of children’s end-of-life care (Dougherty & Simpson, 2004). There are some available standards, guidelines, and conceptual models, primarily compiled by national organizations, that used expert health professionals’ opinions to identify the domains of quality pediatric palliative care, end-of-life, family centered-care, or general pediatric care (Andresen, Nanda, & Toce, 2002; Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003; CHPCA, 2006; Dokken et al., 2001; Donnelly, Huff, Lindsey, McMahon, & Schumacher, 2005; European Association for Palliative Care Task Force on Palliative Care for Children and Adolescents, 2007; Homer et al., 1999; King, Rosenbaum, & King, 1995; Truog, Meyer, & Burns, 2006; Widger & Wilkins, 2004; Widger, Steele, Oberle, & Davies, 2009). Specifics of how to measure the quality of care within each of the identified domains are generally not included in these publications. However, in four cases the domains were developed as the basis for instruments to ask parents to evaluate the quality of care in family-centered care, general pediatric care, or end-of-life care. The domains are similar across documents but are reflective of the purpose for which they were developed. Some categorize care in small components, for example, separating the physical, psychological, developmental, and spiritual care of the child, while others simply incorporate all of the components into a single domain called ‘care of the child.’ As most of these domains were developed through health professional’s opinions, more work is needed to include the family perspective in systematically identifying domains of quality end-of-life care for children and to develop instruments to measure the quality of care according to the identified domains.

1.6 Options for Evaluating Quality of End-of-Life Care

Several options exist for methods and perspectives to evaluate the quality of pediatric end-of-life care. Existing work in adult palliative and end-of-life care highlights some of these options that could be applied in a pediatric setting, including use of administrative databases, chart reviews, and surveys from the perspective of health professionals, the patient, or family
members. Each of these options will be briefly explored in terms of applicability to a pediatric setting.

Some researchers have used administrative databases to assess the quality of adult end-of-life care. In one study two outcomes used that were deemed indicative of quality care were a high number of deaths at home and a low number of transfers between care settings in the days before death (Grunfeld et al., 2006). However in children, these outcomes may not be as indicative of quality end-of-life care. Parents may want their child in a hospital or even intensive care setting rather than at home to ensure everything possible is done to keep their child alive. As well, parents may want their child transferred in the hours before death from one setting to another that is more comfortable or familiar to them. Some families want their child home as much as possible, but do not want the actual death to occur in their home as they fear it will be difficult to continue living in the house where their child died. Other families may want the exact opposite, wishing for the child to be in hospital until it is absolutely clear that nothing else can be done to cure the child and death is imminent. Then they may want the child transferred home to a more private relaxed setting for the actual death. Parents may want this transfer even with the possibility that the child could die en route (Longden & Mayer, 2007).

Structures, processes, and outcomes may be evaluated by chart reviews to see how well the care recorded in the charts meets with the accepted standards of care. However, the details of care are often not recorded sufficiently to decide whether or not the care meets the standard (Mangione-Smith & McGlynn, 1998).

Teno suggested that “the most important outcome variable for examining the quality of care of the dying is whether health care providers understood and responded to the expectations and preferences of the dying patient and their loved ones” (1999, p.169). This outcome may be assessed by asking the health professionals who cared for the family if this outcome was achieved. Health professionals may be seen as able to provide the most objective assessment of the quality of a child’s death as they may not share the same emotional attachment as parents. However, health professionals may have a biased belief that all care they provide is of the highest quality, when this may in fact not be true. One study found little relationship between pediatric oncologists’ and parents’ assessments of care (Mack et al., 2005). It is important to have multiple perspectives on the quality of care but patients and families are likely in the best
position to assess if their expectations and preferences were assessed and met. Unfortunately, children may be non-verbal due to young age, the type of illness they have, or similar to some adult patients, may be too weak to participate in research as they near death. As well, if the assessment is to include quality of care at the time of and following the death, the child would not be able to provide his/her perspective. Family-centered care is the norm in pediatrics and is based on the recognition that there are, in effect, two patients – the child and the family (Homer et al., 1999). Parents are the natural choice to provide a perspective on the quality of care received both by their child and by their family before, at the time of, and following the child’s death. Research comparing adult patients’ and their family members’ assessments of care quality found that the greatest congruence was between perspectives of patients and the family members they lived with or saw everyday (Larsson, Larsson, & Carlson, 2004). In pediatric care, parents generally spend a great deal of their time with the ill child and may be the best proxy for the experience of the child. The importance and use of the parent perspective in evaluating quality of end-of-life care is supported by the Institute of Medicine (Field & Behrman, 2003) in the United States, the Canadian Council on Health Services Accreditation (2006) and CHPCA (2006) in Canada, and the Association for Children with Life-Threatening or Terminal Conditions and their Families (2003) in the United Kingdom. However, as of yet, there is no psychometrically sound instrument to measure the quality of children’s end-of-life care from the parents’ or any other perspective.

Satisfaction is one outcome that has been identified as a component of quality care (Donabedian, 1988). Satisfaction has not been well conceptualized in the literature (Aspinal, Addington-Hall, Hughes, & Higginson, 2003). Some researchers have found that satisfaction levels are influenced by demographic variables (Aspinal et al., 2003). In end-of-life care, there is a concern that families have very low levels of expectation and, therefore, are easily satisfied with care (Teno, 1999). There is some evidence that families tend to report high levels of satisfaction even when care seems to be of poor quality (Wolfe et al., 2000). Due to these issues with satisfaction surveys, particularly in end-of-life care, it was evident that an instrument needed to be developed that focuses primarily on parent reports on the structures and processes of the care provided rather than asking only about satisfaction ratings. However, items relating to global satisfaction with each domain of care and overall satisfaction with the quality of end-of-life care provided were included in the instrument.
1.7 Purpose

Quality end-of-life care is the right of every dying child (Subcommittee of the Standing Senate Committee on Social Affairs, Science, and Technology, 2000). Quality pediatric end-of-life care is important to ensure the best possible short- and long-term health outcomes for the ill child, siblings, and parents. Research indicates that changes are needed to improve the quality of pediatric end-of-life care (Jalmsell et al., 2006; Kreicbergs et al., 2005; Theunissen et al., 2007; Wolfe et al., 2000); however, quality must be adequately assessed before improvements can be made. There are several possible approaches to assessing care quality. Ultimately, several perspectives and methods will be needed for a comprehensive assessment of the quality of pediatric end-of-life care. Each of these methods must incorporate reliable and valid measures of care quality. Therefore, an essential step in assessing quality of pediatric end-of-life care is to develop a measure for one method and one perspective. The purpose of this research was to develop and test an instrument to measure the quality of end-of-life and bereavement care provided to families who have experienced the death of a child, from the perspective of the parent. The use of an instrument with bereaved parents was chosen because:

1. In end-of-life care, the family perspective is considered to be the most important.

2. Parents are direct recipients of care in addition to proxies for care the child received.

3. Parents are able to provide a perspective on the whole experience including care provided before, at the time of and following the death.

4. Parents have a central role in supporting the dying child and surviving siblings.

The focus of this study was on the development and initial testing of the instrument. The purpose of the instrument is to assess the quality of children’s end-of-life care. Results from future assessments using the instrument will be used to inform health professionals, the public, and politicians about what should be done to improve care provided to dying children and their families; assist those directly involved in providing end-of-life care to continuously evaluate and improve the care that they provide; and support systematic research on the effects of different clinical and organizational models for end-of-life care.
The following chapter presents a review of the literature that delineates the domains of quality pediatric end-of-life care from the parents’ perspective. These domains were confirmed and extended through focus groups with bereaved parents and used as the basis for instrument development. The instrument was initially tested for face and content validity, and then administered to a sample of bereaved mothers. Reliability and validity of the instrument was assessed through exploratory factor analysis, internal consistency, test-retest, and hypothesis testing. Each step in this process is described more fully in the following chapters.
CHAPTER 2: LITERATURE REVIEW

A comprehensive review of the literature was undertaken to identify and synthesize parents’ perspectives on the domains of quality pediatric end-of-life care. These domains formed the blueprint for the instrument to measure the quality of care given to children and families before, at the time of, and following a child’s death. An electronic search of Medline and Cumulative Index to Nursing & Allied Health Literature (CINAHL) databases was conducted in March 2008. Search terms and keywords from three areas were mapped to MeSH headings and then combined: 1) type of care - palliative, terminal, hospice, bereavement, or end-of-life, 2) method of assessing care - quality of health care, quality care, needs assessment, outcomes, outcome assessment, program evaluation, questionnaires, surveys, or data collection, and 3) population – parents, mothers, fathers, family, or sibling. Results were then limited to papers published in 1997 or later, in English, and related to children (0 – 18 years). In the CINAHL database results were also limited to research papers.

Between the two databases, over 550 papers were identified and examined first by title, then by abstract, and then by full paper. At each stage papers were excluded if they did not report on some aspect of parents’ perceptions of the palliative, end-of-life, or bereavement care provided to the family by health professionals. Conference abstracts, dissertations, and case studies were also excluded. The reference list from papers selected and from any review papers identified in the search were also checked for additional potential references. The final review included 67 papers reporting results of 51 separate studies. Some additional papers which included results from these same studies were excluded because the focus of the paper was not specific to parent perceptions of the care provided. The studies were not specifically assessed for scientific rigor as it is important to include the full depth and breadth of possible indicators of quality pediatric end-of-life care at this early stage of instrument development (Fayers & Hand, 1997; Streiner & Norman, 2003). Each paper was read and findings specific to parent perspectives on the care provided by health professionals were highlighted. Each paper was reviewed again to identify themes and to group similar findings or topic areas together across studies. Because several studies focused on single aspects of care such as decision-making or bereavement follow-up rather than on the entire experience of end-of-life care, the frequency of specific findings was not calculated.
Based on literature identified in the review, five domains or components of clinical care needed by families from health professionals to ensure quality pediatric end-of-life care were identified. These domains were: connect with families, involve parents, alleviate suffering, share information, and provide bereavement care. These domains and the associated indicators are described in detail below. Each domain is summarized in a table with identification of the important structures, processes, and outcomes that should be included in the instrument for that domain. The focus of the instrument is on processes of care. Some of the structures of care may be outside of the perspective of parents. For example, a lack of connection between the family and health professional could be due to a structural issue such as a shortage of staff, but is likely experienced by the parent as abandonment or avoidance of the family which would be a process issue. Therefore, parents should not be asked if there was a staff shortage, but should be asked how they experienced their interactions with staff. Parents should be asked to report on structures such as the availability of private rooms.

2.1 Domains of Quality Pediatric End-of-life Care

2.1.1 Connect with Families

The connections or human relationships between health professionals and all family members were identified as crucial to quality care (Brosig, Pierucci, Kupst, & Leuthner, 2007; Contro et al., 2002, 2004; Davies & Connaughty, 2002; Heller & Solomon, 2005; Hinds et al., 1997; 2000; Hsiao et al., 2007; James & Johnson, 1997; Macnab, Northway, Ryall, Scott, & Straw, 2003; Meert et al., 2000; Meert, Thurston, & Briller, 2005; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Ritholz, Burns, & Truog, 2006; Oliver, Sturtevant, Scheetz, & Fallat, 2001; Robinson, Thiel, Backus, & Meyer, 2006; Sharman, Meert, & Sarndaik, 2005; Sirkia et al., 1997; Widger & Picot, 2008; Wocial, 2000). These connections were important in developing trust in the health professional (Hinds et al., 2000; Hsiao et al., 2007; Wocial, 2000). Parents needed to interact with health professionals who had good communication and interpersonal skills (Contro et al., 2002, 2004; Davies & Connaughty, 2002; Hannan & Gibson, 2005; Hays et al., 2006; Hsiao et al., 2007; Parker, Maddocks, & Stern, 1999; Rini & Loriz, 2007; Seecharan et al., 2004; Sharman et al., 2005; Steele, Davies, Collins, & Cook, 2005; Surkan et al., 2006) including compassion (Antle, Barrera, Beaune, D'Agostino, & Good, 2005; Contro et al., 2002, 2004; Davies & Connaughty, 2002; James & Johnson, 1997; McHaffie, Lyon,
Fowlie, 2001; McHaffie, Lyon, & Hume, 2001; Meert et al., 2000, 2005; Meyer et al., 2002; 2006; Rini & Loriz, 2007; Robinson et al., 2006), gentle concern (Davies & Connaughty, 2002; Pector, 2004b; Woodgate, 2006), care and sensitivity particularly when breaking bad news (Contro et al., 2002, 2004; Dangel, FowlerKerry, Karwacki, & Bereda, 2000; Hsiao et al., 2007; Mack et al., 2005; Meert et al., 2000, 2005; Oliver et al., 2001; Pector, 2004b; Rini & Loriz, 2007; Sirkia et al., 1997; Spooren et al., 2000-2001; Surkan et al., 2006; Wisten & Zingmark, 2007), and a sense of humor (Davies & Connaughty, 2002; Pector, 2004b; Steele, 2002, 2005a, 2005b). Some studies found parents also appreciated health professionals who knew their limits in not being able to cure a child of his/her disease and who did not act as if they were omnipotent (Brinchmann, Forde, & Nortvedt, 2002; Davies et al., 1998; Skene, 1998; Wocial, 2000). Participants in Davies and Connaughty’s study described the need for ‘small acts of human kindness’ and to make care more humane through letting parents know the professional is affected by the child and the situation. Simple acts of smiling, making eye contact, showing emotion, and physical contact with a hand on the shoulder were appreciated by parents and fostered connections with the health professional (Davies et al., 1998; Heller & Solomon, 2005; Macdonald et al., 2005; Pector, 2004a; Sharman et al., 2005; Wocial, 2000).

Some parents felt avoided or abandoned by health professionals before or at the time of death (deCinque et al., 2006; Pector, 2004a; Rini & Loriz, 2007). Some parents revealed that single incidents related to lack of communication and interpersonal skills on the part of health professionals contributed to intense emotional distress long after the event (Contro et al., 2002, 2004; Meert et al., 2007; Pector, 2004a; Rini & Loriz, 2007; Surkan et al., 2006; Widger & Picot, 2008).

Parents wanted individual care and attention rather than to be treated as just another patient and family (Brosig et al., 2007; Hsiao et al., 2007; James & Johnson, 1997; McHaffie, Lyon, & Hume, 2001). Some parents felt that quality care was related to how well the health professional knew the child (Heller & Solomon, 2005). As well, parents appreciated when health professionals took the time to get to know all the members of the family, including siblings, and the family’s situation apart from that related to the ill child (Contro et al., 2002, 2004; James & Johnson, 1997; Maynard, Rennie, Shirtliffe, & Vickers, 2005; Parker et al., 1999; Steele, 2002; Steele & Davies, 2006; Surkan et al., 2006; Tomlinson et al., 2006).
Parents identified the need for continuity of caregivers, preferably from diagnosis to death (Contro et al., 2002, 2004; Davies et al., 1998; Davies & Connaughty, 2002; Hammes, Klevan, Kempf, & Williams, 2005; Heller & Solomon, 2005; Hsiao et al., 2007; James & Johnson, 1997; Steele, 2002, 2005a, 2005b; Woodgate, 2006). Heller and Solomon found that having a consistent group of caregivers who had a good connection with the family led to better continuity of information and better quality of care overall. Without this continuity, parents were more anxious and perceived increased suffering for their child. However, some parents were able to quickly develop trusting relationships with previously unknown professionals when the health professionals were able to connect on a human level with the family (Meert et al., 2005; Meyer et al., 2002, 2006). Similarly, parents whose child was cared for in a pediatric hospice welcomed the new relationships because they identified a need for involvement of professionals with specific expertise, skills, and competence in palliative care (Steele et al., 2005). Easy access to health professionals, whether they were new or old to the family, was important (Hays et al., 2006; Hsiao et al., 2007; James & Johnson, 1997; Meyer et al., 2002; 2006; Seecharan et al., 2004; Surkan et al., 2006). Some parents suggested the use of email, family/staff journals, and setting specific ‘office hours at the bedside’ as methods to facilitate access (Meyer et al., 2002, 2006).

Table 2.1: Indicators for ‘Connect with Families’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Indicators</th>
</tr>
</thead>
</table>
| Process   | Accessibility and continuity of health professionals  
Connection between health professionals and all family members  
Individualized care  
Not feeling avoided or abandoned  
Trust between health professionals and family  
Health professionals have good communication skills, appropriate sense of humor, and demonstrate sensitivity when breaking bad news  
Small acts of human kindness demonstrated |
| Outcome   | Satisfaction with the connections between health professionals and the family |
2.1.2 Involve Parents

Parents wanted to be recognized as the experts on their child and as the central, consistent figures in their child’s life. As such, they wanted health professionals to seek out and respect their opinions, observations, and concerns about their child (Brinchmann et al., 2002; Heller & Solomon, 2005; Hinds et al., 1997; Hsiao et al., 2007; James & Johnson, 1997; Laakso & Paunonen-Ilmonen, 2001; Meyer et al., 2006; Steele, 2002, 2005a, 2005b; Vickers & Carlisle, 2000; Widger & Picot, 2008; Wocial, 2000; Woodgate, 2006). Some parents felt that making decisions for the child was inherently a parent role, but not all wanted to have complete responsibility for final decisions (Brinchmann et al., 2002; Brosig et al., 2007; Contro et al., 2002, 2004; Hays et al., 2006; Hinds et al., 1997, 2000; McHaffie, Lyon, & Hume, 2001; Meert et al., 2000; Meyer et al., 2002, 2006; Pector, 2004b; Sharman et al., 2005; Votta et al., 2001; Wocial, 2000). Once decisions were made, parents needed to feel that their decisions were supported and not criticized (Brosig et al., 2007; Hammes et al., 2005; Pector, 2004b; Sharman et al., 2005; Tomlinson et al., 2006; Woodgate, 2006).

Some parents wanted to learn to provide all of their child’s care as part of their parent role, especially if there was an option to care for their child at home. Responsibility for all aspects of their child’s care gave some parents a greater sense of control over their situation. Some parents simply could not trust anyone else to provide the care (Antle et al., 2005; Brosig et al., 2007; Rini & Loriz, 2007; Steele, 2005b). Others parents became overburdened with providing illness care and felt unable to simply be a parent to their child (Dangel et al., 2000; James & Johnson, 1997; Skene, 1998; Vickers & Carlisle, 2000; Wocial, 2000; Woodgate, 2006).

The sanctity of the parent-child relationship was fundamental to care (Meyer et al., 2002, 2006; Sharman et al., 2005; Skene, 1998; Wocial, 2000). ‘Normal’ parent activities like bathing, feeding, or holding the child even in the midst of the technology that was being used to support the child’s life allowed parents to develop or continue their bond with their child and sometimes to also be able to say good-bye to their child (Brosig et al., 2007; Meert et al., 2005; Meyer et al., 2006; Pector, 2004a, 2004b; Rini & Loriz, 2007; Robinson et al., 2006; Sharman et al., 2005; Steele et al., 2005; Wocial, 2000). Parents appreciated praise for their parenting role and skills, which also helped to strengthen their relationship with their child and their view of their role (Antle et al., 2005; Steele, 2002). The days, hours, and minutes leading up to the
child’s death was the last opportunity a parent had to be a ‘good parent’ to the child. Similar to others, Woodgate found parents identified their ability to be physically present, emotionally supportive, and an effective advocate for their child as key to viewing themselves as good parents in the years after their child’s death (James & Johnson, 1997; Meert et al., 2000; Meert, 2005; Rini & Loriz, 2007; Sharman et al., 2005; Vickers & Carlisle, 2000; Votta et al., 2001; Woodgate, 2006). For some parents, physical presence included witnessing life-threatening events, particularly when the child died during this event (Aherns, Hart, & Maruyama, 1997; Meert et al., 2005; Rini & Loriz, 2007; Wisten & Zingmark, 2007). Some parents preferred not to be present for their child’s death (McHaffie, Lyon, & Hume, 2001; Skene, 1998). Some wanted active involvement in caring for their child’s body after the death or at least to know the body was being cared for in a respectful manner (Pector, 2004a; Widger & Picot, 2008).

Table 2.2: Indicators for ‘Involve Parents’

<table>
<thead>
<tr>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structure</strong></td>
</tr>
<tr>
<td>Space for parent to be physically present with child</td>
</tr>
<tr>
<td><strong>Process</strong></td>
</tr>
<tr>
<td>Health professionals demonstrate respect for parent view and support decisions</td>
</tr>
<tr>
<td>Parent feels supported in their role as parent</td>
</tr>
<tr>
<td>Parent’s desired level of involvement in child’s physical care is respected</td>
</tr>
<tr>
<td>Parent given opportunity to be present for life-threatening events</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
</tr>
<tr>
<td>Satisfaction with level of involvement in decision-making and in child’s care</td>
</tr>
</tbody>
</table>

2.1.3 Alleviate Suffering

Alleviating the suffering of individual family members and the family as a whole has been conceptualized as a single domain because of the interconnectedness of the family’s suffering and the focus on family-centered care. Care for the whole family, or family-centered care, is fundamental to pediatric care and in particular to pediatric end-of-life care, in part because of the dependence of the child on the family (Bartell & Kissane, 2005). Family systems theory suggests that when one family member is ill, all family members are affected and will suffer (Wright, Watson, & Bell, 1996). Sharman et al. found that parents suffer by watching their child suffer (Sharman et al., 2005). Similarly, parents’ needs are met when the child’s needs are met (James & Johnson, 1997). Siblings may suffer directly because of the loss of the ill child, but also indirectly because the parent may be too focused on the ill child to meet sibling needs.
(D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008; deCinque et al., 2006; Horsley & Patterson, 2006; Martinson & Campos, 1991; Skene, 1998). Provision of quality care includes care to alleviate the suffering of each individual and of the family as a whole.

Several researchers identified pain and a number of other physical, emotional, and spiritual symptoms that caused a great deal of suffering in children at end-of-life (Collins et al., 1998; Contro et al., 2002, 2004; Jalmsell et al., 2006; Mack et al., 2005; Sirkia et al., 1997; Theunissen et al., 2007; Wolfe et al., 2000). Adequate treatment of the child’s symptoms at the time of death, particularly when life support was withdrawn, was crucial for parents (Collins et al., 1998; Davies & Connaughty, 2002; Kreicbergs et al., 2005; McHaffie, Lyon et al., 2001; Steele et al., 2005). Parents identified the need for technically skilled and competent practitioners in the area of symptom management, particularly at the time of death, and regardless of location of care (Collins et al., 1998; Contro et al., 2002, 2004; Dangel et al., 2000; Hannan & Gibson, 2005; Hays et al., 2006; Kreicbergs et al., 2005; Macnab et al., 2003; McHaffie, Lyon et al., 2001; Meert et al., 2005; Meyer et al., 2002, 2006; Parker et al., 1999; Pector, 2004b; Seecharan et al., 2004; Steele, 2002, 2005a, 2005b; Steele et al., 2005; Surkan et al., 2006). Kreicbergs et al. (2005) found parents were less likely to perceive their child’s moment of death as difficult if there was a health professional physically present at that moment. As well, lack of oncologist involvement in the end-of-life care of children with cancer was associated with increased suffering from pain (Wolfe et al., 2000).

Parents wanted access to psychosocial support to assist in dealing with their own suffering including fears, depression, guilt, grief, anger, and uncertainty, as well as assistance with practical needs such as food, transportation, and finances (Brosig et al., 2007; Collins et al., 1998; Dangel et al., 2000; deCinque et al., 2006; Kreicbergs et al., 2007; Macnab et al., 2003; Meert et al., 2005; Parker et al., 1999; Pector, 2004a; Spooren et al., 2000-2001; Steele et al., 2005; Steele & Davies, 2006; Surkan et al., 2006; Theunissen et al., 2007). Spiritual or religious activities like baptism, Last Rites, praying, or reading holy scriptures were important for some families (Brosig et al., 2007; Meert et al., 2005; Meyer et al., 2002, 2006; Pector, 2004b; Robinson et al., 2006; Sharman et al., 2005; Steele et al., 2005). Some parents wanted to connect with clergy or a faith community to meet spiritual needs and to assist in finding meaning in their situation (Brosig et al., 2007; Davies et al., 1998; Macnab et al., 2003; Meert
et al., 2000, 2005; Meyer et al., 2002, 2006; Oliver et al., 2001; Pector, 2004b; Robinson et al., 2006; Steele, 2002, 2005a, 2005b; Wisten & Zingmark, 2007). Parents reported the need to have health professionals support hope and facilitate finding positive aspects of the situation (Antle et al., 2005; Contro et al., 2002, 2004; Davies & Connaughty, 2002; Hsiao et al., 2007; Laakso & Paunonen-Ilmonen, 2001; Pector, 2004b; Robinson et al., 2006; Steele, 2002, 2005a, 2005b; Tomlinson et al., 2006; Wocial, 2000). However, parents also wanted health professionals to be comfortable talking about death (Dangel et al., 2000; Davies & Connaughty, 2002; Rini & Loriz, 2007; Steele et al., 2005). Parents cautioned that clichés such as ‘this was meant to be’ or referring to the deceased child as an angel may be comforting for the health professional, but they minimized the impact of the death for the family (Pector, 2004a, 2004b). Parents needed to find their own meaning in the death (Robinson et al., 2006).

It is not reasonable to expect that all suffering at the time of and immediately following a child’s death can be alleviated by health professionals. However, provision of the highest quality care can alleviate the unnecessary suffering and will not add to the suffering. Research indicates controllable factors such as noise, lack of privacy and control, and inadequate space or opportunity for all of the family to be together needlessly add to suffering (Antle et al., 2005; Collins et al., 1998; Contro et al., 2002, 2004; Dangel et al., 2000; Davies et al., 1998; Hannan & Gibson, 2005; James & Johnson, 1997; Macnab et al., 2003; Rini & Loriz, 2007; Vickers & Carlisle, 2000). Parents wanted the death to be the best it could be in terms of meeting their and their child’s needs and wishes (McHaffie, Lyon, & Hume, 2001). Parents expressed that they did not always know what they needed or what might be possible at the time of death (James & Johnson, 1997; Pector, 2004b; Rini & Loriz, 2007). Being presented with options that they would not otherwise have identified themselves, such as having death occur outside or at home when life support was discontinued, was an identified support for parents (Pector, 2004b). Parents believed their child’s peaceful death reflected that they had made the right choices and that they did all that they could for their child (Davies et al., 1998; Hinds et al., 2000; Vickers & Carlisle, 2000). Researchers found that families could be assisted to create final memories and begin to process their experience when health professionals were present for the expression of emotions and encouraged the family to be together and take as much time as needed after the death (Davies & Connaughty, 2002; Hannan & Gibson, 2005; Laakso & Paunonen-Ilmonen, 2001; Macnab et al., 2003; McHaffie, Lyon et al., 2001; Meert et al., 2005; Pector, 2004a,
2004b; Rini & Loriz, 2007; Spooren et al., 2000-2001; Steele et al., 2005; Wisten & Zingmark, 2007).

Table 2.3: Indicators for ‘Alleviate Suffering’

<table>
<thead>
<tr>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structure</strong></td>
</tr>
<tr>
<td>Privacy</td>
</tr>
<tr>
<td>Space for all family members</td>
</tr>
<tr>
<td>Noise minimized</td>
</tr>
<tr>
<td><strong>Process</strong></td>
</tr>
<tr>
<td>Child’s physical, emotional, social, and spiritual symptoms are assessed and treated</td>
</tr>
<tr>
<td>Parents’ and siblings’ emotional, social, and spiritual suffering are assessed and treated</td>
</tr>
<tr>
<td>Assistance provided for nutrition, transportation, and financial needs of family</td>
</tr>
<tr>
<td>Opportunity to conduct any rituals</td>
</tr>
<tr>
<td>Family not rushed</td>
</tr>
<tr>
<td>Health professionals are technically competent</td>
</tr>
<tr>
<td>Hope is supported</td>
</tr>
<tr>
<td>Health professional is present and supportive at time of death if wished by family</td>
</tr>
<tr>
<td>Options for timing and location of death provided if life support is withdrawn</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
</tr>
<tr>
<td>Child’s death is free from suffering and respects needs and wishes of child and family</td>
</tr>
<tr>
<td>Satisfaction with treatment of all child’s symptoms</td>
</tr>
<tr>
<td>Satisfaction with support of parents</td>
</tr>
<tr>
<td>Satisfaction with support of siblings</td>
</tr>
</tbody>
</table>

2.1.4 Share Information

Parents wanted complete, honest, and concrete information without medical jargon, particularly around treatment options, side effects, the child’s deteriorating condition, and what to expect at the time of death (Brosig et al., 2007; Collins et al., 1998; Contro et al., 2002, 2004; Davies et al., 1998; Davies & Connaughty, 2002; deCinque et al., 2006; Hammes et al., 2005; Hannan & Gibson, 2005; Hinds et al., 1997, 2000; Hsiao et al., 2007; James & Johnson, 1997; Kreicbergs et al., 2007; Laakso & Paunonen-Ilmonen, 2001; Mack et al., 2005; McHaffie, Lyon et al., 2001; McHaffie, Lyon, & Hume, 2001; Meert et al., 2000, 2005, 2007; Meyer et al., 2002, 2006; Parker et al., 1999; Seecharan et al., 2004; Sharman et al., 2005; Sirkia et al., 1997; Skene, 1998; Steele, 2002, 2005a, 2005b; Steele et al., 2005; Surkan et al., 2006; Tomlinson et
Parents found it time-consuming and energy depleting when they had to find information on their own or learn through trial and error (James & Johnson, 1997; Steele, 2002, 2005a, 2005b; Steele et al., 2005). Some parents suggested the need for information and assistance should be anticipated and offered before the parents ask for it (D'Agostino et al., 2008; deCinque et al., 2006; Meert et al., 2005; Steele, 2002, 2005a, 2005b; Steele et al., 2005). Parents in one study described the helpfulness of having a knowledgeable and experienced health professional as a “coach” to prepare and walk them through the experience (Rini & Loriz, 2007).

Some parents reported having difficulty processing new information or learning new tasks and suggested health professionals use non-technical language, slow down, sit with parents, and allow extra time for discussions and decision-making (Brinchmann et al., 2002; Contro et al., 2002, 2004; Davies et al., 1998; Hinds et al., 2000; McHaffie, Lyon et al., 2001). The timing and pacing of information was important for parents to allow them to absorb the reality of the situation and make informed decisions (McHaffie, Lyon, & Hume, 2001; Meert et al., 2007; Votta et al., 2001). Parents often felt rushed in making decisions and some suggested that information be given earlier to allow for ongoing discussions and decision-making with a clearer mind rather than waiting for a crisis that was often fraught with emotion (Hammes et al., 2005; Macdonald, Liben, & Cohen, 2006; Meert et al., 2000; Sharman et al., 2005).

While parents appreciated detail and concrete information about what was happening with their child, they sometimes needed assistance in putting all the details together to interpret the meaning for their child (Meert et al., 2005; Rini & Loriz, 2007). On the other hand, some parents found the information overwhelming and preferred not to know all the details so they could focus on living a normal life (James & Johnson, 1997). Therefore, ongoing assessments of how much and what types of information parents wanted were important (Davies & Connaughty, 2002; Maynard et al., 2005; Pector, 2004a; Steele, 2002, 2005a, 2005b). This assessment also needed to include how much information should be offered directly to the child (Hays et al., 2006; Hsiao et al., 2007; Mack et al., 2005). In one study, age had little to do with parents’ assessment of whether or not their child was old enough to be included in discussions and decisions. There was wide variation in the ages some parents felt were too young to
include, ranging from 4 months to 13 years, and the age at which other parents felt the child was old enough to be included, ranging from 2 to 25 years (Mack et al., 2005).

Parents generally wanted to have consistent information from health professionals (Contro et al., 2002, 2004; Heller & Solomon, 2005; Hsiao et al., 2007; Maynard et al., 2005; Meert et al., 2005, 2007; Meyer et al., 2002, 2006; Pector, 2004b; Widger & Picot, 2008), although some valued being able to hear all opposing viewpoints held by various team members (Meert et al., 2000; Meyer et al., 2002, 2006). One study found parents who believed they received conflicting information also believed their child experienced more suffering from pain (Wolfe et al., 2000). It was distressing for parents when health professionals did not communicate with each other and parents had to repeat the same information to each health professional (Antle et al., 2005; Collins et al., 1998; Hammes et al., 2005; James & Johnson, 1997; Macdonald et al., 2005; Pector, 2004a; Steele, 2005b; Widger & Picot, 2008).

Table 2.4: Indicators for ‘Share Information’

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Structure</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Health professionals give complete, honest, consistent, and concrete information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health professionals respect the amount of information desired by parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information given to prepare parents for the death</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information given about what to expect at the time of death</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information needs anticipated by the staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adequate time provided to share information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information offered appropriately to child by health professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Information is appropriately shared among health professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Outcome</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Satisfaction with information given to parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Satisfaction with information given to child</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Satisfaction with information shared among health professionals</td>
</tr>
</tbody>
</table>

2.1.5 Provide Bereavement Care

Bereavement care began at the time of death often with the collection of mementos such as pictures, locks of hair, and hand/footprints (Aherns et al., 1997; deJongBerg & Kane, 2006;
Laakso & Paunonen-Ilmonen, 2001; Macnab et al., 2003; Meert et al., 2005; Oliver et al., 2001; Pector, 2004b; Rini & Loriz, 2007; Skene, 1998; Widger & Picot, 2008). Some families later regretted not taking mementos (deJongBerg & Kane, 2006), but others were distressed when mementos, particularly pictures, were taken against their wishes (Skene, 1998). Some parents expressed appreciation for assistance with or information on arranging funerals (Dangel et al., 2000; deJongBerg & Kane, 2006; Macnab et al., 2003; Pector, 2004a; Rini & Loriz, 2007).

When options for autopsy and organ/tissue donation were not discussed with parents, some had lingering regrets that an opportunity to help another child or to answer some questions about their own child’s death was missed (Aherns et al., 1997; Macdonald et al., 2006; Oliver et al., 2001; Widger & Picot, 2008). When autopsies were done, parents wanted the results in a timely and compassionate manner (Macdonald et al., 2006; Meert et al., 2007; Rini & Loriz, 2007; Wisten & Zingmark, 2007).

Follow-up care after the child’s death was identified as important in several studies, yet often lacking (Aherns et al., 1997; Collins et al., 1998; Contro et al., 2002, 2004; D'Agostino et al., 2008; Dangel et al., 2000; Davies et al., 1998; Davies & Connaughty, 2002; deJongBerg & Kane, 2006; Dent, 2002; Hannan & Gibson, 2005; Heller & Solomon, 2005; James & Johnson, 1997; Kreicbergs et al., 2005; Macdonald et al., 2005; Macnab et al., 2003; McHaffie, Laing, & Lloyd, 2001; Meyer et al., 2002, 2006; Parker et al., 1999; Pector, 2004b; Sirkia et al., 1997; Widger & Picot, 2008; Wisten & Zingmark, 2007; Woodgate, 2006). Parents sometimes felt abandoned after the death, which added to their grief (D'Agostino et al., 2008; deCinque et al., 2006; Heller & Solomon, 2005; Meert et al., 2007; Spooren et al., 2000-2001; Widger & Picot, 2008). Similar components of care prior to the death were also important in follow-up care, such as compassion, good communication skills, sharing information, supporting decisions, and demonstrating personal interest in and respect for the family (Dent, 2002; Meert et al., 2007). Parents often wanted to meet with health professionals after the death to discuss autopsy results, clarify the events leading to and the circumstances of the death, and be reassured that everything possible was done and the right decisions were made (Brosig et al., 2007; Kreicbergs et al., 2005, 2007; Macdonald et al., 2006; McHaffie et al., 2001; Oliver et al., 2001; Pector, 2004a, 2004b; Spooren et al., 2000-2001; Wisten & Zingmark, 2007; Woodgate, 2006). However, returning to the hospital can be very difficult for some parents so holding the meeting in another location or ensuring proper supports for the parents are in place is important.
Other bereavement follow-up activities such as letters, calls, hospital memorial services, and health professional attendance at the funeral were important means of support to show parents that their child and family truly impacted on the health professional (Davies et al., 2007; deCinque et al., 2006; deJongBerg & Kane, 2006; Kreicbergs et al., 2005; Macdonald et al., 2005; Meert et al., 2005, 2007; Pector, 2004b; Widger & Picot, 2008; Woodgate, 2006). Written information about grief or other sources of support for all members of the family were important (D'Agostino et al., 2008; deCinque et al., 2006; deJongBerg & Kane, 2006; Pector, 2004a; Rini & Loriz, 2007), as well as information to share with extended family and friends on how to support bereaved parents (deCinque et al., 2006; deJongBerg & Kane, 2006). The importance of bereavement support groups was mentioned in a few studies with parents noting the need for a safe place to express emotions and meet others who were effectively coping with grief (D'Agostino et al., 2008; Davies et al., 2007; deJongBerg & Kane, 2006; Laakso & Paunonen-Ilmonen, 2001). However, such groups certainly were not a fit for every parent, and may not be available due to geographic distances between bereaved families (deJongBerg & Kane, 2006).

<table>
<thead>
<tr>
<th>Structure</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memorial service held by health centre</td>
<td>Support groups available through health centre</td>
</tr>
<tr>
<td>Support groups available through health centre</td>
<td>Written information provided</td>
</tr>
<tr>
<td>Process</td>
<td>Desired mementos collected</td>
</tr>
<tr>
<td>Assistance with funeral arrangements offered</td>
<td>Autopsy discussed sensitively</td>
</tr>
<tr>
<td>Autopsy discussed sensitively</td>
<td>Organ/tissue donation discussed sensitively</td>
</tr>
<tr>
<td>Autopsy results received in a timely manner</td>
<td>Follow-up meeting with health professionals offered after child’s death</td>
</tr>
<tr>
<td>Parents did not feel abandoned after the death</td>
<td>Health professionals continued to have contact with the family (calls, letters, etc.)</td>
</tr>
<tr>
<td>Outcome</td>
<td>Satisfaction with the follow-up support provided by the health centre</td>
</tr>
</tbody>
</table>

Table 2.5: Indicators for ‘Provide Bereavement Care’
2.2 Conclusion

Most research reviewed on parent perspectives of palliative and end-of-life care has focused on specific illnesses (e.g., cancer), populations (e.g., neonatal), locations of care (e.g., home, ICU), or aspects of care (e.g., involvement in decision-making). When findings from each of these studies were synthesized, several domains of quality pediatric end-of-life care emerged from the parents’ perspective. These results fit well with various existing standards, norms, and guidelines that are available for pediatric palliative and end-of-life care (Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003; CHPCA, 2006; Dokken et al., 2001), some of which have been available for a number of years. Unfortunately, many studies reviewed indicated that care was still not provided in a way that met the needs of the family. Improvements in care are still needed. A reliable and valid instrument for measuring quality of pediatric end-of-life care is needed to assess the current quality of care and identify specific structures, processes, and outcomes of care that need improvement. As improvements are made, the instrument can measure the impact of these improvements on the structures, processes, and outcomes of quality end-of-life care.

Researchers in the reviewed studies, who used some type of instrument to assess perspectives on care, developed or adapted their own instrument and tests of reliability and validity were not completed beyond face or content validity testing. Rigorous development and adequate psychometric testing of an instrument to assess quality of pediatric end-of-life care from the parent’s perspective is imperative.

2.3 Addendum

The search strategy used in March 2008 to identify papers for inclusion in the original literature review was re-run in August 2011 to identify newly published papers that may provide additional information about domains and indicators for quality pediatric end-of-life care. Since 2008, 18 papers were published about parents’ perspectives on care provided by health professionals to dying children and their families. Some of these papers contained additional findings from studies included in the original literature review for this study (Dussel et al., 2009, 2010; Lannen et al., 2010; Meert et al., 2008). The same survey used in one of the original studies of parents of children with cancer (Wolfe et al., 2000) was used in two subsequent studies with new samples (Heath et al., 2009, 2010; Wolfe et al., 2008). Results
from these two studies are presented in three papers published since 2008. These three papers are included in the review below but offer little new information about domains and indicators because the topics covered by the survey were unchanged. The remaining 12 papers include results from 11 studies. Each of the 18 papers was reviewed to assess support for the indicators as described above and to identify potential indicators not found in the original literature review. Results are presented below according to the five domains used in the original review but these results were not used in the initial development of the instrument.

2.3.1 Connect With Families

As in previous studies, several researchers identified the relationship between health professionals and families as highly valued by parents (Gordon et al., 2009; Hale, Long, Sanderson, & Carr, 2008; Hinds et al., 2009; Konrad, 2008; Meert et al., 2008; Midson & Carter, 2010; Monterosso & Kristjanson, 2008; Moro et al., 2011). Trust in the health care professionals was a fundamental component of the relationship (Hale et al., 2008; Moro et al., 2011). These relationships were fostered when health professionals were sincerely warm, caring, and compassionate in their interactions with families (Konrad, 2008; Meert et al., 2008; Monterosso, Kristjanson, & Phillips, 2009). Accessible and consistent care providers who were able to just be present with families also fostered the connection between health care professionals and families (Hale et al., 2008; Konrad, 2008; Meert et al., 2008; Midson & Carter, 2010; Monterosso & Kristjanson, 2008; Monterosso et al., 2009; Williams et al., 2009). Parents valued health professionals who were genuinely interested in them and took time to uncover and assess unique child and family needs so individualized care could be provided (Gordon et al., 2009; Hinds et al., 2009; Konrad, 2008; Meert et al., 2008; Midson & Carter, 2010; Monterosso & Kristjanson, 2008). Some parents highlighted the long-lasting positive impact on the family of unexpected kind acts by health professionals because these acts often demonstrated a unique understanding of the family’s needs or a special connection to the family (Monterosso & Kristjanson, 2008). On the other hand, some parents also highlighted the long-lasting negative emotional impact of thoughtless words or careless interactions with health professionals (Gordon et al., 2009; Konrad, 2008).
2.3.2 Involve Parents

Researchers found that parents wanted to be a part of the health care team (Gordon et al., 2009; Konrad, 2008; Monterosso & Kristjanson, 2008). Parents appreciated health professionals who fostered this role by respecting parents’ wishes and decisions (Hale et al., 2008; Hinds et al., 2009; Moro et al., 2011; Williams et al., 2009), valuing parents’ unique knowledge of their child, being open to parents’ observations and opinions, and demonstrating a willingness to listen to and learn from parents (Hale et al., 2008; Konrad, 2008; Monterosso & Kristjanson, 2008). Parents valued health professionals who respected the parents’ role as advocates for the child without labeling parents as hyper-vigilant or overprotective (Konrad, 2008). Parents wanted health professionals to support and respect their efforts to be a ‘good parent’ by offering opportunities for ‘normal’ parent activities such as holding or just being with the child (Hinds et al., 2009; Monterosso & Kristjanson, 2008; Williams et al., 2009), making decisions in the child’s best interests, preventing the child’s suffering, and advocating for the child’s needs (Hinds et al., 2009).

2.3.3 Alleviate Suffering

Parents highlighted the importance of pain and symptom management in reducing suffering and ensuring a pain-free and comfortable end-of-life period for the child (Hale et al., 2008; Monterosso & Kristjanson, 2008; Williams et al., 2009). Several researchers explored the prevalence of symptoms during the end-of-life period as reported by parents whose child died of cancer. The most common symptoms included pain, fatigue / weakness, changes in behavior, changes in appearance, and breathing difficulties (Heath et al., 2010; Pritchard et al., 2008; Wolfe et al., 2008).

Parents in one study indicated that they were reluctant to ask health professionals for help with their own needs because they wanted the focus to be on their child (Konrad, 2008). Yet, these parents indicated that they had serious struggles in coping with their child’s impending death and appreciated when health professionals took time to ask about their needs. Parents valued emotional support in dealing with their own anger, pain, sadness, fears, and guilt (Konrad, 2008; Williams et al., 2009). Some parents indicated they wanted to be asked about their spiritual or religious beliefs and to be connected with their faith community (Hinds et al.,
Parents identified a need to balance hope and despair (Konrad, 2008; Moro et al., 2011) and appreciated when health professionals supported hope without offering false hopes (Gordon et al., 2009; Meert et al., 2008; Monterosso & Kristjanson, 2008). Parents also wanted assistance with practical needs such as finances (Hinds et al., 2009) and food, as well as having bathing or showering facilities available for family members to use (Hale et al., 2008).

Siblings’ needs were raised by parents in a few studies (Heath et al., 2009; Konrad, 2008; Monterosso et al., 2009). Parents wanted health professionals to recognize the impact of illness and death on siblings and be involved in providing support (Konrad, 2008). Parents also identified their need for additional information and support on how they could best support and prepare siblings for the child’s death (Heath et al., 2009).

When a child’s death is expected, parents often wish to have the child die at home. However, in one study, parent planning of the location of death was found to be more important than the actual location (Dussel et al., 2009). When a home death was not possible, opportunities to have the death in the hospital but outside of an intensive care unit setting was identified as helpful for parents (Wolfe et al., 2008). Wherever the death occurred, parents welcomed the opportunity to spend as much time as they wished with their child’s body rather than being rushed to leave the hospital (Midson & Carter, 2010).

2.3.4 Share Information

Researchers identified both general components of how information should be shared with parents as well as specific topics that need to be discussed. Generally, parents wanted honest, accurate information (Hinds et al., 2009; Meert et al., 2008; Monterosso & Kristjanson, 2008) presented in easy to understand terms without medical language (Gordon et al., 2009; Meert et al., 2008; Moro et al., 2011; Williams et al., 2009). Parents were frustrated when information was confusing or conflicting (Heath et al., 2009; Hinds et al., 2009; Meert et al., 2008). Health professionals who encouraged parents to ask questions and took time to answer them were valued (Gordon et al., 2009; Monterosso & Kristjanson, 2008; Williams et al., 2009). While parents wanted adequate information about all aspects of their child’s condition and care (Meert et al., 2008; Monterosso et al., 2009; Moro et al., 2011), they also appreciated careful
pacing and timing of this information so they could take a break as needed to make sense of the information provided (Meert et al., 2008; Williams et al., 2009).

As much of the information shared by health professionals was bad news or about difficult topics, parents wanted information to be shared in a sensitive and caring manner and at an appropriate time (Heath et al., 2009; Lannen et al., 2010). Specific topics parents wanted information about included use of life-sustaining treatments (Heath et al., 2009), risks and benefits of all treatment options (Dussel et al., 2009), and preparation for both appearance and behavioral changes in the child as death nears (Pritchard et al., 2008; Williams et al., 2009). An additional topic area identified as important in several studies was raising the possibility or likelihood of the child not surviving the illness (Dussel et al., 2009; Lannen et al., 2010; Meert et al., 2008; Midson & Carter, 2010; Monterosso & Kristjanson, 2008; Wolfe et al., 2008). Lack of discussions about the possibility of death were closely linked to parents’ belief that health professionals gave false hope that the child would survive the illness (Gordon et al., 2009; Meert et al., 2008; Monterosso & Kristjanson, 2008). False hope was seen as detrimental to parents’ ability to prepare for the child’s death.

Some parents felt they needed to coordinate all of the health professionals involved in their child’s care due to poor communication amongst them (Konrad, 2008). Parents identified the importance of health professionals sharing information with each other to prevent giving conflicting or confusing information to parents (Hale et al., 2008; Meert et al., 2008).

2.3.5 Provide Bereavement Follow-up

Parents valued follow-up care and ongoing connection with the health professionals who provided care to the child and family (Monterosso & Kristjanson, 2008). Components of follow-up care identified as important by parents included: providing mementos or keepsakes (Midson & Carter, 2010; Roose & Blanford, 2011; Williams et al., 2009), assistance with funeral arrangements (Roose & Blanford, 2011; Williams et al., 2009), providing emergency contact numbers, offering support groups (Williams et al., 2009), providing written support information, making phone calls to talk with parents (Roose & Blanford, 2011), and addressing sibling grief (Roose & Blanford, 2011; Williams et al., 2009). The opportunity for a follow-up meeting with health professionals was appreciated but not all parents were ready for this type
of meeting at the time that it was offered (Midson & Carter, 2010). When parents did attend a meeting, some were frustrated when there were still unanswered questions (Midson & Carter, 2010). When the meeting included sharing of autopsy results parent generally found the meeting to be informative and helpful, but the timeliness of these meetings was important (Sullivan & Monagle, 2011).

2.3.6 Summary

An instrument was used in some of the studies to measure various aspects of care. In two studies this was the same instrument used in previous research but there was no evidence of additional reliability or validity testing (Heath et al., 2009, 2010; Wolfe et al., 2008). Monterosso et al. (2009) used several existing instruments about caregiver needs when caring for a child with cancer at home. These instruments were not specific to children’s end-of-life care. Midson et al. (2010) developed and used an instrument in a quality improvement program at a children’s hospital but the instrument and its development were not described in any detail. There was a more detailed description of an instrument developed and used by Williams et al. (2009) for assessment of care surrounding withdrawal of life-sustaining treatments in neonates. The instrument was developed based on interviews with bereaved parents and then responses of a small group of social workers, rather than parents, were used to assess the internal consistency of subscales. The researchers indicated plans to conduct further psychometric testing of the instrument with other professional groups, as well as with parents in the future. As in earlier research, testing of instruments used in research with bereaved parents to assess care provided by health professionals has consisted primarily of content and face validity testing. The instrument developed by Williams and colleagues has had some additional testing but not with parents.

Overall, review of this new literature did not indicate a need for any additional domains. There were a few findings that may have altered how some of the indicators and instrument items were worded if this literature would have been available at the time the instrument was developed. Any changes based on this new literature that could be made to the instrument for use in future research are included in the Chapter 5 discussion.
CHAPTER 3: METHODS

Although there is some variation among experts, it is generally agreed that there are six steps in developing an instrument for measurement in healthcare research. These six steps are: identify the measurement framework, identify domains and indicators of the construct, develop the instrument, conduct initial testing, administer the instrument, and conduct psychometric testing (Pett, Lackey, & Sullivan, 2003; Streiner & Norman, 2003; Waltz, Strickland, & Lenz, 2005).

In this study, these six steps were conducted through foundational work and through the three study phases to develop and test an instrument that measures the quality of pediatric end-of-life care from the parents’ perspective.

Foundational work included identification of the measurement framework and identification of the initial domains and indicators of quality pediatric end-of-life care through a comprehensive review of existing literature. Phase I of the study consisted of focus groups with bereaved parents to validate and extend the domains and indicators identified through the literature. Phase II included development of the items comprising the body of the instrument and initial testing of the items with both health professionals and parents. Phase III included administration of the instrument to a sample of bereaved mothers from across Canada and psychometric testing of the instrument. Details of the foundational work and procedures for the three phases of the study are provided below.

3.1 Foundational Work

3.1.1 Identification of the Measurement Framework

Waltz et al. (2005) identified two types of frameworks for measurement: criterion-referenced and norm-referenced. A criterion-referenced measure is used to assess performance in relation to predetermined criteria. A norm-referenced measure is used to obtain scores that allow for comparison or differentiation between participants. This early stage of instrument development focused on developing items and assessing their validity and reliability. Therefore, the current instrument is norm-referenced. Once the reliability and validity of the instrument is established, additional work could be done to identify a minimum cut off score for each item or subset of items. Care at or above this score would be considered to be of good quality and care below
this score would be considered to be of inadequate quality. It may be useful in the future to develop the instrument into a criterion-referenced measure in this way.

3.1.2 Initial Identification of Domains and Indicators

The domains and indicators of the construct to be measured, in this case quality of pediatric end-of-life care, were identified initially through a comprehensive review and synthesis of previous research with parents about end-of-life care. The domains are: connect with families, involve parents, alleviate suffering, share information, and provide bereavement care. Indicators within each of these domains are primarily effect indicators which indicate the presence of an underlying construct (Fayers & Hand, 1997; Streiner, 2003a) such as health professionals’ ability to connect with families. The items within each domain make up a ‘scale.’ High correlations among all of the observed indicators are expected because they are all affected by the presence of the same underlying construct. Theoretically, there are an infinite number of effect indicators that could be chosen to make up a particular scale. The instrument as a whole is considered an ‘index.’ An index consists of items, or in this case groups of items, representing causal indicators that define the construct, namely quality of pediatric end-of-life care (Fayers & Hand, 1997; Streiner, 2003a). Causal indicators are generally not highly correlated with each other, so each indicator is important (Fayers & Hand, 1997; Streiner, 2003a). An overall poor quality of care score will not reflect the same set of indicators for each person (Fayers & Hand, 1997). For example, a parent may report receiving good information but not being valued for his or her expertise as a parent. Another parent may have felt included in the care team but experienced a lack of bereavement follow-up. The two experiences would yield a similar low quality of end-of-life care score on the index even though different areas of care were lacking for each parent. Identifying the instrument as several scales within an index impacted how items were identified for inclusion in the instrument and in choosing the appropriate methods for assessing the reliability and validity of the instrument (Streiner & Norman, 2003).
3.2 Phase I: Focus Groups

3.2.1 Purpose

The purposes of Phase I focus groups were to verify and extend the identified domains of quality pediatric end-of-life care found in the literature with bereaved parents. The focus groups were also used to generate ideas for specific language for items and response options that were meaningful for parents. We also sought parents’ perceptions of the best method and time to approach parents to participate in the third phase of the study.

3.2.2 Sample and Recruitment

Parents were recruited through a number of newsletters and web-sites associated with Bereaved Families of Ontario, the Team for Research with Adolescents and Children in Palliation and Grief at the Hospital for Sick Children, and the Perinatal Bereavement Support Organization as well as by word of mouth. See Appendix A for the advertisement that was placed in newsletters/websites. Parents were asked to contact the principal investigator (PI) by telephone or email to indicate their interest in participating. The PI contacted interested parents by telephone to provide further details of the study and assess the eligibility of the parent for inclusion in the study (see Appendix B). Initially, only parents of children who died in a hospital after an admission of at least 24 hours were sought. However, about half of the parents who contacted the PI had a child die at home. All parents had extensive experience with hospital care prior to the death, so the inclusion criteria were expanded to include these parents. Other inclusion criteria were that the parent was the biological, step, or adoptive parent of the child who died; the parent experienced the death of a child aged 19 years or less; and the death occurred at least one year prior to the study. Parents of children who were stillborn or parents who did not speak English were excluded.

3.2.3 Procedure

The focus groups were planned, conducted, and analyzed using the procedures outlined in “The Focus Group Kit” by Morgan and Krueger (Morgan & Krueger, 1998). Focus groups were held in Toronto and Hamilton and were moderated by the PI with the assistance of a research assistant (RA). Each focus group began with the introduction of the PI and the RA. The
purpose of the study and expectations for the group were reviewed and each participant signed a consent form (Appendix C). At the beginning of the group, parents were given a $40 token of appreciation for taking part in the focus group. The focus groups were moderately structured as parents were asked to comment broadly on what quality end-of-life care meant to them, and then more specifically on the domains previously identified in the literature review (Morgan, 2007). A less structured approach would be used if the literature review had not been done. See Appendix D for the script used to guide the focus groups. The discussion also included review and completion of questions related to the impact of participating in the research (see Appendix E) and questions about background and demographics (see Appendix F). Focus group discussions were recorded and transcribed verbatim.

3.2.4 Analysis

Responses to the items on demographics and impact of participating were entered into SPSS. Frequencies and means were calculated to summarize responses and describe the group of parents that took part in the focus groups.

Focus group transcripts were analyzed after each group to allow initial findings to be incorporated into the next group. Content analysis of the transcripts was completed by the PI and guided by the following three questions developed by Krueger (2007):

1. What was confirmed?
2. What was challenged?
3. What was new?

The domains and indicators of quality pediatric end-of-life care identified through the literature review were revised and refined based on the focus group analysis. Focus group findings and the revised domains and indicators are presented in Chapter 4.

3.3 Phase II: Item Development and Initial Testing

3.3.1 Purpose

The purpose of Phase II was to develop the items that made up the body of the instrument and conduct initial testing of the instrument. Health professionals were asked to assess content
validity of each item and the instrument as a whole as well as identify the domain being measured by each item. Parents were then asked to assess content and face validity as well as their cognitive understanding of instrument items.

3.3.2 Item Development

The instrument included three sections. The main section contained items about the structures, processes, and outcomes related to quality of pediatric end-of-life care. One section included items to gather demographic and background information. The final section included items to assess the emotional impact on the parent of participating in the study.

3.3.2.1 Items related to structure, process, and outcomes of care

The domains and indicators of quality pediatric end-of-life care identified through the literature review and focus groups provided the blueprint for developing the instrument items. Most items had five response options on an adjectival scale, usually reflecting the frequency of a particular aspect of care occurring, and ranged from “never” to “always.”

The instrument was based on the idea that the most important determinant of quality end-of-life care is how well the unique needs of each patient and family were assessed and met (Heyland et al., 2006; Teno, 1999). Therefore, items were worded to reflect differences in needs (e.g., How often did health professionals give you the right amount of information about your child’s condition?) rather than assuming every family wants the same thing (e.g., detailed information). The level of care quality (high vs. low) was determined by whether or not a particular need was met. However, for the hospital or hospice trying to improve care, it was important to know how to improve care in that area. Follow-up questions were then used to determine if too much or not enough support was given in the particular area of need. Additionally, at the end of each section of the instrument, there were items to assess the parents’ overall satisfaction with the particular domain of care. As well, open-ended questions were included to allow respondents to identify any areas missed that were important to the care given to their child or family, and to provide any additional comments or details not covered in the closed-ended questions. These responses assisted with interpretation and revision of the instrument. Towards the end of the instrument, there were a few questions about the structural aspects of care such as availability of areas for parents to sleep, parking, and food.
3.3.2.2 Items related to demographics

The items used to collect demographic and background information about the parent, child, and siblings were developed initially for the focus groups and then revised in each stage of the study based on feedback from parents and health professionals.

3.3.2.3 Items related to emotional impact

The emotional impact on parents of participating in this type of research has not been well-studied. Items to assess how parents were impacted emotionally by taking part in the research were developed for the focus groups. These items were used and revised at each stage of the study based on parent and health professional feedback. Assessment of the impact of participation on the parent in each phase of the research adds to the limited body of knowledge in this area.

3.3.3 Testing with Health Professionals

3.3.3.1 Sample and recruitment

Health professionals were asked to act as judges in assessing the content validity of the instrument. The group of judges invited to take part in this phase were selected based on their clinical and research expertise in various areas of pediatric end-of-life and/or palliative care. Each judge had also previously indicated that he/she might be interested in assisting with recruitment in the third phase of the study. Judges were initially contacted through email by the PI and invited to take part in the study (see Appendix G). Those willing to participate were sent by email or courier a package with the consent form, instructions on how to assess the instrument, and the instrument.

3.3.3.2 Procedure and analysis.

The information letter and instructions sent to the judges are included in Appendix H. The instructions included an explanation of the purpose of the instrument, why it is important, why they were chosen to assess the instrument, the conceptual foundation of the instrument, who the instrument is designed to be used with, and the process for how they were to assess the instrument (Grant & Davis, 1997). Judges were asked to rate each item on a four point scale: 1 = not representative of quality care, 2 = item needs major revisions to be representative of
quality care, 3 = item needs minor revisions to be representative of quality care, and 4 = item is representative of quality care. A content validity index was calculated for each item by calculating the proportion of judges who rated the item as a 3 or 4 (Polit & Beck, 2006). Items that received a rating less than 0.80 were revised. The content validity index for the entire instrument was calculated by averaging the content validity indexes for each item in the instrument (Polit & Beck, 2006). An acceptable index is 0.80 or higher (Grant & Davis, 1997). Judges were also asked to suggest any wording changes that may make an item clearer, to help develop subscales by assessing which domain (within quality end-of-life care) the item was measuring, and to assess whether or not the instrument as a whole was a comprehensive measure of quality pediatric end-of-life care.

3.3.4 Testing with Parents

3.3.4.1 Sample

Parents who participated in the focus groups and indicated on the consent form they were willing to have continued involvement in the study were contacted by email to participate in Phase II. As well, a few parents who contacted the PI after the focus groups were completed and agreed to have their contact information kept were approached by the PI to participate in Phase II. Once parents agreed by email to hear more about this phase of the study, the PI contacted the potential participant by telephone (see Appendix I).

3.3.4.2 Procedure and analysis

The PI met with each parent in person for about two hours. A consent form was completed at the beginning of the meeting (Appendix J). The assessment of validity with parents was much less formal than the procedure used with health professionals. Cognitive testing was done by having the parent read and re-phrase each item back to the PI and/or talk through how he/she chose the item response. The PI took notes on the parent’s comments and incorporated possible changes from each interview into the next interview to see which words or questions appealed to the most parents. This process assisted with identifying and revising items that were worded ambiguously, were unclear in their intended meaning, or had an unexpected negative connotation (Knafl et al., 2007). To assess content validity, the parent was asked at the end of the instrument if all aspects of quality end-of-life care were included (Streiner & Norman,
Face validity was assessed by asking if the items seemed to relate to quality of end-of-life care (Pett et al., 2003; Streiner & Norman, 2003; Waltz et al., 2005). Items were revised, deleted, or added as indicated by the parents’ comments to finalize the instrument for Phase III testing.

3.4 Phase III: Instrument Administration and Psychometric Testing

3.4.1 Purpose

The purpose of Phase III was to administer the instrument to a sample of bereaved mothers and conduct psychometric testing of the instrument.

3.4.2 Sample and Setting

While both mothers and fathers took part in the focus groups and initial testing of the instrument, only mothers were asked to participate in Phase III of the study. In previous research that has sought both parents’ perspectives, only about 25% of the final samples across all studies were actually fathers (Macdonald, Chilibeck, Affleck, & Cadell, 2010). As well, only two fathers took part in the first two phases of the current study. This means that previous research with ‘parents’ is really research with mothers. It also indicates that it may be more difficult to recruit fathers into this type of research. The small amount of research that has been done indicates that there may be some differences in mothers’ and fathers’ experiences and perspectives on end-of-life care. Clinical experience suggests health professionals are more effective at meeting mothers’ needs than fathers’ needs. Therefore, it is important to study the two perspectives separately to guide health professionals on how best to support mothers and fathers as part of the child’s end-of-life care. The inclusion of both parents in the current study would have required a two-fold increase in the sample size in order to assess both perspectives and properly assess reliability and validity of the instrument for mothers and fathers. Fathers will likely be the focus of future development of the instrument, but for the current study mothers were the focus.

Potential participants were identified according to the following inclusion criteria:

1. Mother was the biological, step, or adoptive parent of the deceased child.
2. Child died between 6 months and 36 months prior to time of survey mailing. This time frame was chosen based on the advice of parents who took part in the focus groups and to have a fairly homogeneous group of participants in terms of the time since death. It was also chosen in order to increase the likelihood of getting a large enough sample to take part in Phase III of the study. At one site (Canuck Place Children’s Hospice), the internal review board elected to contact mothers between 12 and 36 months after the child’s death due to concerns over the emotional impact on mothers prior to the one year anniversary of the child’s death.

3. Child died in hospital or hospice after an admission of at least 24 hours. The majority of children die in hospitals. Therefore, this population was chosen as the main focus for this initial development of the instrument. Mothers from two inpatient children’s hospices (Canuck Place in Vancouver and Roger’s House in Ottawa) were also included to facilitate hypothesis testing to assess validity. An admission of at least 24 hours was used to ensure that the mother would have had time for contact with health professionals at the hospital/hospice and could assess the care provided by the health professionals.

4. Child was aged 19 years or younger at time of death. This age range is consistent with the ages of children who receive care in most Canadian children’s hospitals/hospices.

5. Mother able to read English. The survey was only available in English at this stage of development.

6. Cause of death could be due to acute or chronic illness or trauma. In the focus groups and previous research, cause of death made little difference in what parents wanted from health professionals and what they identified as important to quality end-of-life care.

Mothers were excluded if:

1. The infant died within 48 hours of birth. The rationale for this exclusion is that mothers who just gave birth may have been quite ill during this time and may not have been involved in the child’s care to the degree that they are able to report on the care provided by health professionals.

2. The child died in a hospice and received only terminal care in the hospice (for example if the child was transferred from hospital to the hospice for withdrawal of ventilator
support). The rationale for this exclusion is that instrument items cover the last week to
days of life, so if care was provided by both the hospital and the hospice during this
time it may be difficult for mothers to distinguish which centre provided which
components of care. For this initial administration of the instrument we have chosen to
include mothers of children who received end-of-life care in only one setting.

3. The mother requested to have no further contact from the hospital (such as for
bereavement follow-up support).

4. Either parent had been implicated in the death of the child. (At one site this criterion
was expanded to include any family member implicated in the death, at the request of
the local research ethics board.) Most sites also excluded families where there was any
type of legal proceedings underway or expected against the hospital in relation to the
child’s care.

3.4.2.1 Setting

Phase III participants (mothers) were recruited through 10 children’s hospitals and hospices
across Canada with the assistance of a local investigator at each site: IWK Health Centre,
Halifax, NS; Hospital for Sick Children and Sunnybrook Health Sciences Centre, Toronto, ON;
Children’s Hospital of Eastern Ontario and Roger’s House, Ottawa, ON; McMaster Children’s
Hospital, Hamilton, ON; Children’s Hospital London Health Sciences Centre, London, ON;
Winnipeg Children’s Hospital, Winnipeg, MB; Stollery Children’s Hospital, Edmonton, AB;
and Canuck Place Children’s Hospice, Vancouver, BC. Initially, BC Women’s and Children’s
Hospital was also going to be a recruitment site; however, a process for accessing contact
information for eligible mothers could not be worked out in a timely manner and the site was
not included in the study.

3.4.2.2 Sample size

The sample size needed for Phase III to allow for adequate psychometric testing of the
instrument was dependent upon the number of items within each subscale of the instrument.
Streiner and Norman (2003) suggested that 5 to 10 participants per item are needed to conduct
the appropriate tests of reliability and validity for a new instrument. Since each domain of the
instrument was a small scale, the sample size was based on the number of items in the largest
domain, rather than on the number of items in the whole instrument. There were 30 items in the largest domain; therefore, 150 to 300 Phase III participants were required. A smaller sub-sample was also needed to assess test-retest reliability of the instrument. The size of the sub-sample was chosen based on the work of Cicchetti (1999, 2001) who demonstrated that a sample of greater than 50 participants did not significantly increase the precision of reliability estimates.

3.4.2.2.1 Feasibility of sample size. Each site provided an estimate of the number of eligible mothers who could be contacted through their site, giving a total of 1000 potential participants. In a previous survey using a similar method of recruitment and a similar population located in Nova Scotia, nearly 30% of eligible families could not be contacted due to a change in address. Of the families who were contacted, 65% agreed to take part in the study. Overall, just fewer than 50% of those originally eligible actually took part in the study (Widger & Picot, 2008). Since the current study included several larger urban areas, we anticipated more frequent issues with incorrect addresses rather than mothers not being interested in the study. We expected to attain a sample size of 300 participants in the study.

3.4.3 Procedures

Research Ethics Board (REB) approval was obtained at the University of Toronto and at each site prior to beginning recruitment at that site. Some sites also required a separate process for administrative approval before recruitment could begin. Recruitment procedures varied somewhat across sites due to requirements by local REBs. At all sites, contact information (name and address) for eligible mothers was obtained through review of health records or an administrative database held by the local investigator, such as for bereavement follow-up. Once eligible mothers were identified, at most sites a letter about the study was sent to the mother from someone who provided care to the family prior to the child’s death or who provided bereavement follow-up care to the family. At one site (Sunnybrook Health Sciences Centre), the letter was sent by someone who may have provided care before the death but who was not involved in providing bereavement follow-up. At another site (Winnipeg Children’s Hospital) the letter was mailed from the manager of the health records department. The invitation letter sent from each site is included in Appendix K. The letter included a brief description of the study. At most sites, the letter included instructions to return an enclosed card in a self-
addressed and stamped envelope if the mother did NOT wish to take part in the study. If the card was not received at the originating site within three weeks, the survey booklet was mailed. At three sites (Children’s Hospital London Health Sciences Centre, Winnipeg Children’s Hospital, and Canuck Place Children’s Hospice), an opt-in method of recruitment was used. At these sites the letter was mailed to the mother with instructions to contact the PI at the University of Toronto if she wished to take part in the study. The letter included a self-addressed stamped envelope that could be returned to the PI as well as a telephone number and email address that could be used to contact the PI to indicate willingness to receive a copy of the survey.

The survey booklet included the consent form and the instrument to be completed. The consent form for each participating site is included in Appendix L. A self-addressed stamped return envelope was provided for mothers to return the completed survey to the PI at the University of Toronto. Completion and return of the survey signified consent. A second copy of the consent form was provided in the packages with instructions for the mother to keep the copy for her own records. There were no reminders or follow-up contact made with non-responders at all but one site. At Canuck Place Children’s Hospice, a reminder letter was sent to everyone who was initially mailed a letter. This letter was sent without the knowledge of the PI at the University of Toronto. The REBs at the University of Toronto and the University of British Columbia were notified of this protocol violation. One additional survey was received after this reminder.

At the end of the booklet, mothers were asked if they would agree to repeat the instrument by mail in one to two weeks to facilitate assessment of test-retest reliability of the instrument. If they agreed, they provided their mailing address to the PI at the University of Toronto. The second survey was mailed out by the PI from the University of Toronto and returned to the University of Toronto. The repeat survey booklet included a consent form (Appendix M) to remind mothers about the details of the study. In this consent, mothers were reminded of their right to change their mind once the second survey was received. If they no longer wished to take part in that portion of the research, mothers were instructed to simply not return the second survey. Mothers who initially agreed to take part in reliability testing in Phase III but then did not return the second survey still had their initial survey included in the results. The consent
form with the second survey reminded mothers of their right to withdraw from the entire study at that point and included details on contacting the PI if they wished to have their initial survey withdrawn. There were no reminders sent to mothers who did not return the survey for reliability testing. Return of the completed second survey signified consent for that portion of the study. The option of participating in reliability testing was not offered to mothers recruited through the Children’s Hospital London Health Sciences Centre due to the small number of potential participants and the timing being too close to the holiday season.

Once all survey packages were mailed, the local investigator provided the PI with a summary of the number of letters mailed, the number of opt-out cards received, the number of survey packages mailed and the number of letters and/or surveys marked return to sender. For those sites that used an opt-in process, local investigators provided a summary of the number of letters mailed and the number of letters that came back marked return to sender. These summaries were used to determine response rates. As well, each local investigator was asked to complete a short survey about the structural aspects of their hospital or hospice. The information letter and survey items are included in Appendix N. The responses to these questions were used to provide a description of each site that took part in the study, as well as to facilitate the hypothesis testing portion of data analysis.

3.4.4 Data Analysis

Participant responses on completed instruments were entered into the IBM SPSS 19.0 statistical program and double checked by two research assistants. SPSS was used for all analysis. Item responses were scored as 0 and 1, or from 0 to 4 or 0 to 6 depending on the number of response options. Item numbers 7, 17, 35, 47, and 133 were reverse scored so that a high score on each item was indicative of high quality care. Missing data were treated as systematic rather than random as particular questions did not apply or the mother did not recall the detail sufficiently to answer the question. Therefore, no imputation was implemented for missing data. The initial analysis of data included an examination of frequencies and means, standard deviations, ranges and distributions of responses (as appropriate for the type of data acquired) for each item to determine if there were any outliers or potential errors in data entry. Summary statistics were compiled for demographic and background variables of participants and their children as well as for the questions on the impact of participating in the study. Content analysis to identify
themes was conducted on responses to open-ended questions or other comments made on the instrument.

### 3.4.4.3 Psychometric Testing

The study was designed to assess initial evidence for reliability and validity of the instrument when used with a population of English-speaking mothers who experienced the death of a child in a hospital or hospice after a minimum stay of 24 hours. The instrument was designed and tested as five unique scales comprising a larger index rather than as one measure as a whole (Fayers & Hand, 1997; Streiner, 2003a). Validity refers to how well an instrument measures what it is designed to measure and relates to the degree of confidence that can be placed in the inferences drawn from scores on the instrument (Pett et al., 2003; Streiner & Norman, 2003; Waltz et al., 2005). Content and face validity are crucial in testing an index (Streiner & Norman, 2003) and were assessed in Phase II of the study. After the instrument was administered, validity of each subscale was assessed through exploratory factor analysis (EFA) and hypothesis testing. Reliability reflects the amount of random and systematic error inherent in any measure (Streiner & Norman, 2003). Two measures of reliability for each subscale were assessed: internal consistency and test-retest reliability. Internal consistency was used to assess the degree to which all of the items in the subscale were tapping into the same construct (Streiner, 2003b). Test-retest reliability was used to assess how reproducible the results of the instrument were under similar conditions (Streiner, 2003a). The specific procedures for each of these assessments are provided below.

#### 3.4.4.3.1 Exploratory factor analysis

EFA was conducted to determine construct validity of each scale within the instrument. EFA is a data driven approach used to generate hypotheses by identifying sets of relationships among large groups of items. In EFA a correlation matrix is used to identify which items belong together and which items do not fit the model generated from the data (Pett et al., 2003; Streiner & Norman, 2003; Waltz et al., 2005). Based on EFA, items that do not strongly correlate with other items are considered for deletion from the instrument. However, clinical and theoretical judgment are also important considerations in interpreting EFA results, as items that should be deleted based on factor analysis results may be ones considered clinically or theoretically fundamental to the concept being measured (Juniper, Guyatt, & King, 1994).
A correlation matrix was generated for items in each subscale. Items with correlations less than 0.3 or greater than 0.9 were considered for deletion. The Measure of Sampling Adequacy (MSA) was calculated for each item using an antiimage correlation matrix, and the Kaiser-Meyer-Olkin MSA was calculated as a summary for each subscale. Items with a MSA of less than 0.70 were considered for deletion. When the summary value (recalculated when items were deleted) was greater than 0.70, analysis continued with an assessment of the factor structure (Norman & Streiner, 2008).

EFA was conducted on each subscale using principal axis factoring and eigenvalues greater than one to generate factors. Only one factor for each subscale was expected, but when more than one factor was identified, a varimax rotation was used to improve interpretation of the factors (Norman & Streiner, 2008; Pett et al., 2003). When there was at least a three to one ratio between the first and subsequent eigenvalues, analysis was forced to one factor to assess for best fit with data (Reise, Horan, & Blanchard, 2011). Similarly, when there were a number of cross-loadings greater than 0.3 on multiple factors, the analysis was rerun with fewer factors to find the simplest solution (Costello & Osborne, 2005). Items with loadings less than 0.3 on the factor were considered for deletion (Norman & Streiner, 2008). A summary score for the subscale was calculated with and without items that were being considered for deletion to determine the impact of the item on the overall score for the subscale and to assist with decision-making about which items to retain or delete. The theoretical foundation of the instrument developed in study Phase I, as well as clinical and research experience of the PI with this population were considered in the final decision on which items to retain or delete.

3.4.4.3.2 Internal consistency. Inter-item correlations and item-total correlations were examined using items that remained following factor analysis of each subscale. Redundant items were chosen for elimination based on an inter-item correlation of 0.80 or higher. Items that correlated less than 0.2 with the total score were also considered for elimination. Cronbach’s alpha was calculated for each domain with the remaining items. Cronbach’s alpha between 0.7 and 0.9 was considered to provide evidence for internal consistency of the subscale (Streiner, 2003b).
3.4.4.3.3 Subscale, Outcome and Stand-Alone Item Scores. Using only items retained following EFA and assessment of internal consistency, a summary score for each subscale was calculated by summing response scores on each item and dividing by the highest possible score for the subscale. When dichotomous response option items were included in a summary score, a ‘yes’ response was given a score of four and a ‘no’ response was scored as zero. This method of scoring ensured these items would contribute equally to the summary score as those items with five response options scored from zero to four. When responses were missing, a summary score was still calculated for participants who answered at least two thirds of the items in the subscale based on scoring conventions from other scales (Personal Communication, R. Croxford, June 29, 2011). The maximum score for the subscale was adjusted for each participant based on the number of items that were answered. A linear transformation of the summary score was made so that summary scores were on a scale of 0 to 100 to facilitate comparison of subscale scores on the same metric.

Each subscale had at least one associated outcome item that measured satisfaction with the area of care. Response options were on a seven point scale ranging from ‘completely dissatisfied’ to ‘completely satisfied.’ These items were scored by calculating the mean score across all respondents and making a linear transformation of the mean score to a 0 to 100 scale so that outcome items were on the same metric as the subscale summary scores. A linear transformation to a scale of 0 to 100 was also done on four additional outcome items: 1) item 54 about the child’s overall suffering from symptoms had five response options ranging from ‘not at all’ to ‘constantly,’ 2) item 101 about peacefulness of the child’s death had five response options ranging from ‘not at all peaceful’ to ‘extremely peaceful,’ 3) item 102 about whether or not the child experienced a ‘good death’ had five response options ranging from ‘disagree strongly’ to ‘agree strongly,’ and 4) item 136 about the overall rating of the quality of end-of-life care had five response options ranging from ‘poor’ to ‘excellent.’

While some items were deleted from the instrument based on EFA results, others were not included in summary subscale scores but were retained as stand-alone items in the instrument. Some of these items were follow-up items to provide information on how to make improvements in care and were not designed to be part of subscale scores. Others were about specific areas of care or specific topics of discussion that should occur as part of high quality
care. Important information about how care was provided would be lost if responses to these items were combined into a summary scale score. Responses to these items were summarized by reporting frequencies of responses for items with dichotomous or Likert scale response options and means for items with an adjectival scale. These stand-alone item results were kept within the description of the subscale for which they were originally developed through study Phase I and II, although some were moved to fit with groupings of stand-alone items. For example, all items relating to the needs of siblings both before and after the child’s death are reported within the original domain of ‘Alleviate Suffering.’

3.4.4.3.4 Test-retest reliability. A subsample of participants completed the instrument twice. An intra-class correlation coefficient (ICC) was calculated for each revised subscale to compare scores from the two time periods (Streiner & Norman, 2003) using a two-way random effects model with a single measure and absolute agreement of scores. A value of 0.75 or higher was considered to provide evidence for test-retest reliability of each subscale (Cicchetti, 1999).

3.4.4.3.5 Hypothesis testing. Construct validity was assessed by developing hypotheses about expected differences between groups in subscale scores and then comparing subscale summary scores between these groups to determine whether expected differences were found (Streiner & Norman, 2003). Initially, six different hypotheses were developed to assist in testing construct validity. However, the homogeneity of the pediatric palliative care programs and the relatively low number of respondents from hospices and from hospitals without pediatric palliative care teams led to difficulties in testing most of these hypotheses. Evidence for construct validity was based on significantly (p<0.05) higher quality of care scores when: 1) children were cared for by a pediatric palliative care team either in hospital or in a hospice; and 2) a comprehensive bereavement follow-up program was in place at the hospital or hospice where the child died (for ‘Provide Bereavement Follow-up’ subscale only). Evidence for construct validity was also based on the hypothesis that there would be significant correlations (p<0.05) between each revised subscale summary score and scores on four outcome items: 1) the corresponding item assessing satisfaction (items 18, 28, 42, 49, 74, 134), 2) overall quality of end-of-life care (item 136), 3) peacefulness of death (item 101), and 4) ‘good death’ (item
The ‘Provide Bereavement Follow-up’ subscale was expected to significantly correlate only with the satisfaction item rather than all four outcomes.
CHAPTER 4 RESULTS

4.1 Phase I Results

4.1.1 Sample Description

Between April and June 2009, 3 focus groups were held with a total of 10 parents in the Toronto and Hamilton areas. There were 8 biological mothers and 2 biological fathers who took part in the groups. Their mean age was 44.5 years (range 38 to 51 years); 6 were married, 2 were widowed, 2 were separated; and 8 had a college diploma or university degree. Nearly two thirds reported a yearly family income of $60,000 or more, 90% were Caucasian, and 40% were Catholic.

The mean age of the children who died was 5 years (range 5 days to 15 years); 7 were girls and 3 were boys; 4 of them had cancer, 5 had a congenital illness, and 1 had a neuromuscular condition. The majority of the children (80%) had a least one sibling. On average, parents took part in the focus groups 5 years after their child had died, but the range was 1 to 18 years. All but two parents knew that their child was likely to die at least one month before it happened; however, one parent knew for less than a day. The location of the children’s deaths was equally split between home and intensive care units. Most of the families (70%) received some care through a specialized pediatric palliative care team.

The five domains of quality end-of-life care for children that were first identified by examining previous research with parents were confirmed by parents in the focus groups. The focus group findings helped to expand and clarify the indicators that comprised each domain. Each domain is described below. Changes made to domain indicators based on focus group findings are highlighted. Illustrative quotes from participating parents and a table with the revised list of indicators are included within the section on each domain.

4.1.2 Revised Domains and Indicators

4.1.2.1 Connect with Families.

One indicator developed from the literature review included the need for health professionals to have good communication skills, an appropriate sense of humor, and sensitivity when breaking
bad news. Following the focus groups, having a sense of humor was removed as parents felt that while humor may be a part of good communication, it was not a requirement. ‘Good communication skills’ was separated into its own indicator. Parents emphasized the need for sensitivity and compassion at all times, not just when breaking bad news. Therefore, the indicator was altered to reflect this parent assertion. One mother described a particularly difficult situation when she was with her daughter in an intensive care unit near the end of her daughter’s life. The situation illustrates the lack of connection between the health professional and the family, as well as poor communication skills and a lack of sensitivity and compassion on the part of the health professional.

It was two days before [she] died and [the doctor] came to do rounds…they were just outside the door; the door was open… she said to everybody, “Well, this one is circling the drain.” And then she just carried on a conversation and I thought, she doesn’t even have a name. I don’t even have a name. [The doctor] was so disconnected from my daughter. And all of a sudden my daughter’s life was in her hands.

Two indicators were added to the domain following focus groups. First, parents discussed the importance of having a good fit between the health professional and the family. Parents recognized that this may not always be possible but felt that as part of high quality care, there should be some choices about who was a member of the care team. As one father said, “It’s not personal. It might be you remind me of my mother-in-law. We never got along that well. The last person I want on my team right now is my mother-in-law.”

The second addition to the list of indicators was the need for health professionals to be human. As one mother stated, “Take the coat off and be human.” She went on to describe her sense that some health professionals acted as though they were better than her and they were not able to admit mistakes or apologise when mistakes were made.

One mother described a particular experience where she felt a strong connection developed very quickly with health professionals who had good communication skills, provided individualized care, and demonstrated acts of kindness.

I took [my daughter] on a trip and we ended up in emergency with a fever and I was trying to get her to a hockey game because she was a fanatic…And they were so amazing there. They gave her some fluids, they hired a taxi… they had her go to the
game and brought her right back. And they kept her room and they said ‘We’re so excited for her!’ and joking with her. They made it such a special day.

Table 4.1: Revised Indicators for ‘Connect with Families’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process</td>
<td>Accessible and consistent health professionals involved in care</td>
</tr>
<tr>
<td></td>
<td>Connection between health professionals and all family members</td>
</tr>
<tr>
<td></td>
<td>Health professionals have good communication skills</td>
</tr>
<tr>
<td></td>
<td>Health professionals demonstrate sensitivity and compassion at all times</td>
</tr>
<tr>
<td></td>
<td>Health professionals are ‘human’</td>
</tr>
<tr>
<td></td>
<td>‘Fit’ between health professional and family</td>
</tr>
<tr>
<td></td>
<td>Individualized care</td>
</tr>
<tr>
<td></td>
<td>Parent/child did not feel avoided or abandoned</td>
</tr>
<tr>
<td></td>
<td>Trust between health professionals and family</td>
</tr>
<tr>
<td></td>
<td>Small acts of human kindness demonstrated</td>
</tr>
<tr>
<td>Outcome</td>
<td>Satisfaction with the connections between health professionals and the family</td>
</tr>
</tbody>
</table>

4.1.2.2 Involve Parents

Within the domain of involve parents, there were no indicators added or deleted following the focus groups. However, a few indicators were expanded or made more specific to address areas parents felt were important to quality care.

Parents discussed the need to be physically present in order to support their child in difficult times throughout the illness, rather than just at end of life. The structural indicator about having this space available was expanded to include all times during the child’s illness. One mother described her frustration at not being able to stay with her son after he had surgery and was cared for in the intensive care unit:

… just give me a chair and I won’t move. I don’t need a bed. But, they did not allow me to stay … I was able to go back to his hospital room and spend the night there, but I didn’t sleep and I worried all night—not just for myself, but for him, because the fact of him waking up in an unknown place and being drugged up… I can understand that both parents... you can only have one person, but at least one parent or one person there for
the child should he or she wake up or... because [my child] would have been terrified.
…and he was fine, but I wasn’t. That was a big thing.

Parents’ desire to be physically with their child was especially important to high quality care when there was a life-threatening event occurring. One mother described her wish to be with her child in the emergency room when she became very ill and yet concern that she was a hindrance to the care her daughter was receiving. This mother was not asked to leave the room, but she was also not specifically supported to stay with her child.

I wasn’t asked to leave but I did sort of stay out of the way some of the time even though it killed me to do that figuring that she would get better care if I wasn’t standing there. Even though that’s where my place should have been is right beside her the whole time. It wasn’t about being over their shoulders. I was so not wanting to compromise her care that I would back out of the room from time to time and that was really bad. But I did.

Parents also talked about wanting health professionals to not only support but to strengthen their identity and role as a parent. This was particularly important for parents of very young children who had little chance to ‘parent’ their newborn. But even when the child was older, parents reported sometimes feeling as if they were no longer the child’s parent. One mother described the few days she had with her newborn daughter before she died:

They had me pumping milk, but that’s about all that I was able to do. We did have one nurse who was with us the night she died. To me that woman was like an angel, because she was the one who did things with her that I never got a chance to do. She would touch her and she changed her. Just because she was so ill. The first time we held her was when they had removed her from life support. In hindsight, there’s a lot of stuff that I wish we had done that we either at the time didn’t think of or were never given the opportunity. That’s how I dealt with my guilt. That I did the best I could at the time.

Parents sincerely appreciated when health professionals sought out and listened to any parental concerns as well as respected any wishes or requests that the parent made.

As soon as we got the diagnosis … I’m like I have lead pipes in the house. Could it just be lead poisoning? [The doctor said,] “You know what I don’t think so but let’s give that a try.” That’s all you want. Let’s give it a whirl, let’s take the chance.

The outcome indicator of satisfaction within the domain of involving parents was expanded from focusing solely on the parent role in decision-making to be more encompassing of the parent role in all aspects of care.
Table 4.2: Revised Indicators for ‘Involve Parents’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Space for parent to be physically present with child throughout care</td>
<td>Health professionals seek out and listen to parent’s views/concerns</td>
<td>Satisfaction with level of involvement in child’s care</td>
</tr>
<tr>
<td>Health professionals respect parent’s wishes</td>
<td>Parent feels supported and strengthened in their role as parent</td>
<td></td>
</tr>
<tr>
<td>Parent’s desired level of involvement in child’s physical care is respected</td>
<td>Parent given opportunity to be present for life-threatening events</td>
<td></td>
</tr>
</tbody>
</table>

4.1.2.3 Alleviate Suffering

Effective assessment and management of the dying child’s symptoms was not specifically raised by parents as being important to quality care. Yet when asked about this area one mother responded, “That’s all that matters.” Another mother mentioned that her child had some issues with secretions at the time of death and that she had great difficulty listening to the sound of the secretions. One father also mentioned that he felt his daughter “had been butchered” during the time she was cared for in hospital.

Initially, practical needs of siblings and parents were included as a separate indicator from one related to emotional, social, and spiritual needs. Following the focus groups, the two indicators were combined into one. As well, parents indicated that they felt health professionals should anticipate their needs rather than simply assess them. Along this line, a new indicator was added about the need for health professionals to offer options to families and an opportunity for them to fulfil wishes or access appropriate services. One mother expressed her frustration when health professionals kept asking her what she wanted to do without giving her any options.

Like I deal with this everyday! Why don’t you tell me what I’m allowed, give me some options. I like to have my options and then I’ll pick from that. I don’t think it should be up to me as a distraught, bereaved parent, to be trying to figure out what is okay and what’s not; or what’s available and what’s not.

Parents talked about the need for quiet and private space for all family members to be with the child particularly when death was drawing near. Parents appreciated having as much time with
their child as they needed but also acknowledged that some families may want to leave the hospital fairly soon after the child’s death. One mother, whose child died at home, described the long wait for her child to be taken to the funeral home. She was upset that it did not happen more quickly. The indicator related to the family not feeling rushed after the death was expanded to include respect for the family’s choice of how slowly or quickly things occur after the death.

The indicator about hope was clarified by parents in the focus groups to reflect that hope be supported by health professionals but not at all costs. This assertion was related to some of the issues raised within the domain of sharing information. Parents felt it was the health professionals’ role to raise the possibility of death but to still support hopefulness for the family.

A new indicator was added about sensitive and respectful care of the child’s body after death. One mother was upset when her daughter’s clothes were returned to her in a plastic bag and she kept envisioning her child as cold and naked.

Put clothes back on the baby or child. Treat the deceased as you would your own, period. Plain and simple. I think fulfilling those wishes is really important because it goes a long way to helping the parents to feel like they are being cared for as well and acknowledged, and that their child is.

One father described the care of his daughter and family in the last hours of her life in a way that illustrated many indicators of the domain of alleviating suffering:

There’s a parenting room. It’s a private room and it looks nothing like any other part of the hospital; kind of like a hotel room. And there was the opportunity provided for us to take our daughter in there and be with her when she took her final breath. As many tubes and stuff that she was all tied up into, it was done with great sensitivity, it was done at our own pace, there was some coaching around, “This is what will happen when we take her off the life support, and we don’t imagine that she will be here long after that moment.” We essentially lied down on the bed with her, and it was beautiful. Before that... oh, and I should say and afterwards, we had an opportunity to bathe her, we had an opportunity to take little footprints of her. It was all a blur of course, at the time, but looking back on it, I mean those are timeless for us now—absolutely timeless. And to think that that was available. That’s incredible care.
Table 4.3: Revised Indicators for ‘Alleviate Suffering’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quiet and private space offered for all family members</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Process</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offer options &amp; opportunity to access services, fulfill wishes</td>
<td></td>
</tr>
<tr>
<td>Family’s choice of pace is respected</td>
<td></td>
</tr>
<tr>
<td>Child’s physical, emotional, social, &amp; spiritual symptoms are assessed and treated</td>
<td></td>
</tr>
<tr>
<td>Parents’/siblings’ emotional, social, practical, &amp; spiritual needs are anticipated, assessed, and treated</td>
<td></td>
</tr>
<tr>
<td>Hope is supported (but not at all costs)</td>
<td></td>
</tr>
<tr>
<td>Options for timing / location of death provided if life support is withdrawn</td>
<td></td>
</tr>
<tr>
<td>Child’s death respects wishes of child and family</td>
<td></td>
</tr>
<tr>
<td>Sensitive / respectful care of the body</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s death free from suffering</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with treatment of all child’s symptoms</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with support of parents</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with support of siblings</td>
<td></td>
</tr>
</tbody>
</table>

4.1.2.4 Share Information

Within the domain of share information a new indicator was added about health professionals sharing information with parents that included “the big picture.” One father described his experience in which he felt that everyone looked at their own “piece” of his daughter but no one took the time to put all of those pieces together. A new indicator was also added about the need for health professionals to raise the possibility of the child’s death with parents. The same father felt strongly that it was the health professionals’ responsibility to bring up the possibility of death as this was a very difficult subject for a parent to broach even if they were thinking it.

No one in ICU over five weeks would say that our daughter was dying, because she was medically stable. But everything was going wrong. There was just no way she would probably ever walk again. There was almost no way to conceive that she would do anything more than be continually diminished but no one would bring up the idea of end of life. We seem, at times, to be in a very intervention focussed, all delivery of care mode. How can a parent ask a question if it’s not raised by anyone? To many parents it’s like giving up… Our doctors admitted to us, we just never took a step back and said
look, let’s wait; let’s look over the whole thing, let’s check in, let’s think about this afresh.

One mother did bring up the possibility of her child’s death with health professionals and felt they did not take her concern seriously. This mother sought out a great deal of information about her daughter’s cancer on her own and felt the information given to her by health professionals was incomplete, inconsistent, and misleading.

Then I would get frustrated with them and say well, you told me this… oh, there may be a few cells left. In a way that we’re very pleased with the way surgery went, but there’s just a few cells left. Well that’s life or death. When you present it to me like that, I stopped trusting what they were saying. Then I would research and they’d say stop researching. Then when I said I was looking at the odds, and they said there’s only two odds – 0 and 100, but it’s not true. Because the more it developed, because of where the tumour was, because of the necrosis, because there’s still cells left, because of this, because of that, I knew my daughter kept falling in the worse scenario, but they wouldn’t allow me to go there. I wish they’d gone there with me instead of me going on my own.

Similarly, many parents felt health professionals should anticipate the questions or concerns that parents might have and then take the time to assess and respect the type and amount of information parents wanted. Some parents felt it was always up to them to try to figure out the questions or the right way to ask questions to obtain the most important information.

We ended up feeling that if we didn’t ask the right question… if we couldn’t find what the issue was to ask, it wasn’t going to be given to us. What difference does it make to know how much they ate if the real issue is…something entirely different? We were constantly listening to hear what they were trying to say that was more than just the words because they weren’t always clear.

Parents wanted information specifically about what to expect at the time of death. One mother received a pamphlet which outlined the common signs and symptoms as death approaches. This mother reported that the pamphlet was difficult to read at first, but when her son started having some of these symptoms, she knew what to look for and felt well prepared for what was happening. Another mother shared quite a different experience on the night her daughter died.

I think people are really afraid to offer that information and in retrospect, I would have liked to have known, because … the night that she died, we happened to have two nurses arrive at our house, and looking back, I know that they came because they knew she was close to dying. ..But, we were missing some supplies, so my husband decided to go back to the hospital and get them… And, he wasn’t there when she died. I think,
in retrospect, if they had told us how close she was to dying, he could have been there. It was a huge regret for him.

Parents spoke about the importance of information sharing between health professionals and family members, including the dying child when appropriate. They also stressed the importance of having information shared among the health professionals caring for the child.

I think it’s important for the doctors to have communication with each other. The surgery [we had] it’s not something that they do daily, so… they kind of like to follow-up. And then about a year ago, I get a call from the doctor saying, “We’re just following up on [your daughter]. We wonder how everything is.” And I said, “Well, she passed away a week after she was born” and he’s like, “Oh my God, I’m so sorry but the doctors never sent those reports to us”.

Parents also highlighted the importance of team and family meetings to facilitate sharing of information among everyone involved with a child.

But the lack of family meetings and I think the hospitals know that getting all the specialists together at one time, maybe early before there are problems or to resolve a really serious bad incident. You get everybody together on the same page, looking in each other’s eyes, able to read each other. At least you can walk out of that room kind of knowing. They don’t want to do that. That’s this department, that’s that department. No, those departments need to come together for the care of the patient – plain and simple.

Table 4.4: Revised Indicators for ‘Share Information’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professionals give complete, truthful, consistent, &amp; concrete information</td>
<td></td>
</tr>
<tr>
<td>Information must include “the big picture”</td>
<td></td>
</tr>
<tr>
<td>Health professionals assess and respect amount / type of information desired by parents</td>
<td></td>
</tr>
<tr>
<td>Possibility of death must be raised and discussed by health professionals</td>
<td></td>
</tr>
<tr>
<td>Information given about what to expect at the time of death</td>
<td></td>
</tr>
<tr>
<td>Information needs anticipated by the staff</td>
<td></td>
</tr>
<tr>
<td>Adequate time provided to share information</td>
<td></td>
</tr>
<tr>
<td>Information offered appropriately to child by health professionals</td>
<td></td>
</tr>
<tr>
<td>Information is appropriately shared among health professionals</td>
<td></td>
</tr>
<tr>
<td>Team/family meetings held</td>
<td></td>
</tr>
<tr>
<td>----------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with information given to parents</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with information given to child</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with information shared among health professionals</td>
<td></td>
</tr>
</tbody>
</table>

### 4.1.2.5 Provide Bereavement Care

Parents were adamant that bereavement follow-up must be offered as part of the care offered by health professionals. One father noted:

> Our experience was zero follow-up at all. Even from the team; the incredibly, expensively well supported team. No grief counselling even…millions of dollars were put into my child’s care... but smaller things make a huge life-long difference.

On the other hand one mother described the continued contact she had with the nurses who had cared for her son, although it was primarily initiated by her:

> I went in on a regular basis to see the nurses, and they always welcomed me and asked me to come in. Like, it was never like, “Oh hi, I’m busy.” It was like they made a point to stop to talk to me and so forth. To me, I felt like I wasn’t just a number, it felt like they still cared, because they dropped anything just to come and talk to me.

Two indicators removed from the bereavement care domain were the availability of support groups and provision of written information. The two indicators were too specific as parents indicated both may be important for some parents but not for all. High quality care did not require support groups to be available at the hospital, but parents felt health professionals should be aware of these and other community resources and provide that information to parents. Similarly, written information may not be needed by all families but could be one of many options for providing information.

On the other hand, one father described the importance of a memorial service that was specifically provided by the hospital:

> If you’ve ever been, it’s a remarkable experience. Just a couple of weeks ago….. It’s just unbelievable to see that there’s hundreds and hundreds of people there… there’s a lot of loss that is being memorialized and being remembered. There’s 350 butterflies all released simultaneously. Those are meaningful things that, you know that the hospital… is directly involved in to help us remember and to help us to realize that they remember and recognize the enormity of these losses.
Several parents described the mementos of their children that were obtained with the assistance of health professionals. Parents indicated that they did not always think of the various options for collecting mementos and appreciated when health professionals anticipated and offered to assist with this need.

[The nurse] put this little book together and it has her last leg measurements and everything. She asked if I wanted anything done. I said I really wanted her footprints and handprints and a lock of hair. So she did all that. Then she went down to the gift shop and she bought... and she told me later it was out of her own pocket that she did this. But she bought her a little outfit that was all hand knitted by the Auxiliary in pink with the bonnet and everything, and a little miniature teddy bear which she tied to this thing. But that was just a really nice touch. Still, I had no phone numbers or information or anything.

<table>
<thead>
<tr>
<th>Table 4.5: Revised Indicators for ‘Provide Bereavement Care’</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indicators</strong></td>
</tr>
<tr>
<td><strong>Structure</strong></td>
</tr>
<tr>
<td><strong>Process</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
</tr>
</tbody>
</table>

4.1.3 Impact of Research Participation

All parents who took part in Phase I reported that this type of research was valuable. All participants reported they took part in the study as a way to help others and 80% took part so they could talk about their experiences. Other reasons for taking part included to contribute to education of health professionals and to make improvements in care. Half of the participants reported that the experience was a little painful, while the remainder reported that it was not at
all painful. None of the parents reported that they regretted taking part and all reported that they would recommend to other bereaved parents that they take part in a similar study.

Parents were asked how they might have responded if they had received a phone call or something in the mail from the hospital where their child died asking if they would give feedback about the care. Parents felt this was an important opportunity that should be offered to all bereaved parents.

So, to me it’s a really respectful thing to do and I think it’s good practice for health care providers to find out if that plant that is being delivered a year later, is that a good idea is it not, or should we modify our programs.

Inviting them to participate in evaluating what happened is just respectful I think and also healing in a sense. It’s another way of honouring that experience and saying your child’s not forgotten and your experience might make it better for other people.

However, one parent stressed the importance of how the information is used:

We need reassurance where the information goes and how it actually impacts the people in the process that we experience along the way. It becomes even more purposeful when we know that it’s getting back to the caregivers.

Parents also provided feedback on the best time to approach parents for feedback and the best way to provide feedback. Parents reported that flexibility was key in both aspects. Parents felt that six months after the child’s death was the earliest parents should be contacted to provide feedback about the quality of care received. They suggested that parents be given the option to say no at that time but give permission to be contacted again in few months as later on they might be more prepared to discuss care provided. When providing feedback, parents felt they should be given the option to do so through an in-person interview, by telephone, by a hand-written survey, or by computer. When asked which option they would choose, in-person was chosen most frequently followed by hand-written, computer, and telephone, in that order.

4.2 Phase II Results

4.2.1 Instrument Items

At least one item was developed for each of the indicators constructed through the literature review and focus group analysis. Table 4.6 indicates the number of items developed within
each domain related to care structures, processes, and outcomes. As described in the methods section, some follow-up items were developed to obtain more specific information about care processes to assist health professionals to develop strategies to improve care. The number of follow-up items in each domain is also included in the table. Items assessing satisfaction with care are the outcome items included at the end of each section of the instrument. In addition, there were six items developed to assess structures of care. An item to assess the overall rating of the quality of end-of-life care was also included in the instrument.

Table 4.6: Number of Items Developed by Type and Domain

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Process Items</th>
<th>Follow-up Items</th>
<th>Outcome Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connect with Families</td>
<td>16</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Involve Parents</td>
<td>8</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Share Information</td>
<td>24</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Alleviate Suffering</td>
<td>38</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Provide Bereavement</td>
<td>24</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Structures of Care</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Overall Quality Rating</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Following the items to assess structures, processes, and outcomes of care, there were 17 items asking for respondent background and demographic information. The instrument concluded with nine items and one open-ended question to assess the impact on the parents of completing the instrument. All items are included in Appendix O with the associated indicator.

4.2.2 Health Professional Testing Results

Emails were sent to 10 health professionals inviting them to take part in content validity testing of the instrument. Nine agreed to take part and seven returned the completed instrument. Participants included two physicians, four advanced practice nurses, and one social worker. An additional health professional returned the instrument during the study period when parents were assessing the instrument. Comments from this person were included in the final revision of the instrument as appropriate.
4.2.2.1 Content Validity Index

Health professionals were asked to assess 128 items in the body of the instrument including items related to processes and outcomes, as well as follow-up items. The item on symptoms was treated as a single item for this assessment. For 111 items, all participants rated the item as a 3 or 4 resulting in a content validity index of 0.87 (an index higher than 0.80 is needed to say the instrument is content valid) for the body of the instrument. The range of content validity scores for individual items was 0.67 to 1.0. The score for each item is included in Appendix P along with the original item and the revised version of the item based on health professional feedback. The lowest rating was given to the question about symptoms experienced by the child. The concerns expressed were related to how the question would be formatted rather than whether the item was an appropriate question. Other expressed concerns were about how well parents would understand certain terms: good communication skills, fit, connection, small acts of kindness, and human side. Many of these items had also been discussed in detail at thesis committee meetings. However, the language used came directly from the focus groups with parents. The wording of these items was retained but the specific terms were underlined and in some cases alternate wording suggestions were included in brackets. These terms were specifically discussed with parents who took part in testing the instrument. Even when an item was rated highly by health professionals, there were suggestions for simplifying wording that were incorporated into this revision of the instrument. Two new open ended items asking about the best and worst experiences with health professionals were added to the end of the instrument at the suggestion of the reviewers. All item revisions and new items are included in Appendix P.

The instrument also contained six items related to structures of quality pediatric end-of-life care. Only one of these items was rated as a 3 or 4 by all participants. For the remaining 5 items, one item scored 0.50, one scored 0.71 and the remaining items were scored 0.86. Participants felt that these items may be important to care but were not unique to end-of-life care. Items were revised somewhat based on the health professionals’ suggestions but all items were retained and discussed with parents in the next phase of testing to give parents the final say in the appropriateness of the items in relation to high quality care.
The Content Validity Index of the entire instrument including the items about structures, processes, outcomes, and follow-up was 0.84.

4.2.2.2 Quality Domains Assessment

Participants were asked to indicate which of the five domains of quality end-of-life care each item was measuring. There was greater than 70% agreement on domain for 80% of items. For items where there was less than 70% agreement among participants, participants’ responses, domain definitions, and the original intent of the item were reviewed. In each case, one domain was selected to be used to create the subscales for psychometric testing in the final analysis. The domain for each item is included in Appendix P with a “*” beside the domains that lacked agreement among participants.

4.2.3 Parent Testing Results

There were six parents who took part in the parent testing component of Phase II. Most parents had also taken part in the focus groups, but two parents were new to the study. Participants included five mothers and one father. Their mean age was 45.5 years (range 35 to 53 years), 5 were married, 1 was widowed, and 4 had a college diploma or university degree. Two thirds reported a yearly family income of $60,000 or more and all were Caucasian.

The mean age of the children who died was 5 years (range 4 months to 11 years); 4 were girls and 2 were boys; and 1 of them had cancer, 4 had a congenital illness, and 1 had a neuromuscular condition. The majority of the children (66%) had a least one sibling. On average, parents took part in the second phase of the study 5 years after their child had died, but the range was 1 to 18 years. All but two parents knew that their child was likely going to die at least one month before it happened. However, one parent knew for less than a day and one did not know until it happened. Most of the children died at home while two died in intensive care hospital settings. Half of the families received some care through a specialized pediatric palliative care team.

The original items as they were presented to parents along with the revised items following the parents’ review are included in Appendix Q. Parents were also asked to review the introductory statements for each section of the instrument. All parents were supportive of keeping the items
related to structures of care and added an additional structural assessment item asking if there was a comfortable place for parents to sleep with or near their child. Parents felt that most of these questions were not unique to end-of-life care but were critically important as a very difficult situation was often made much worse if these structures were lacking. Item revisions suggested by parents made the items easier to understand. Overall, parents felt that the instrument was complete and that items did relate to quality end-of-life care. One mother asked at the end of the meeting if the instrument described the care that she was supposed to have received as her child was dying. Unfortunately her experience did not match well with the indicators of high quality care.

The final number of items in each domain by type of item is included in Table 4.7. The final version of the instrument developed for Phase III testing is attached as Appendix R.

Table 4.7 Final Number of Items by Domain and Type for Phase III Testing

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Process Items</th>
<th>Follow-up Items</th>
<th>Outcome Items</th>
<th>Open-ended items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connect with Families</td>
<td>17</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Involve Parents</td>
<td>8</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Share Information</td>
<td>23</td>
<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Alleviate Suffering</td>
<td>35</td>
<td>8</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Provide Bereavement</td>
<td>25</td>
<td>5</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Follow-up</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structures of Care</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Overall quality rating</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

4.3 Phase III Results

4.3.1 Recruitment and Sample

Recruitment was conducted separately at each site between July and December 2010. Across all sites, 771 letters were sent to eligible mothers informing them of the study. At sites using an opt-out process for recruitment, 584 introductory letters were mailed, 42 letters were returned due to unknown addresses, and 46 mothers returned the enclosure card asking not to be
contacted about the study. Surveys were mailed to 496 potential participants with an additional 26 survey envelopes returned due to unknown address. Surveys were received from 110 participants for a response rate of 21.3% using the opt-out recruitment process. At sites using an opt-in process for recruitment, 187 introductory letters were mailed, 15 letters were returned due to unknown address, and 26 mothers returned the card or emailed the investigator to request a copy of the instrument. Complete surveys were received from 20 participants for a response rate of 11.6% using the opt-in recruitment process.

Across all sites, a total of 130 surveys were returned. One survey was removed from the sample because fewer than half of the items were completed. Another was removed from the sample because the child died at home. One survey completed by a father was kept in the sample as it was felt gender differences would not be evident with only one father. One was completed by a grandmother and it was also kept in the sample since she indicated she was the primary caregiver of the child. Although the sample includes one father and one grandmother, participants are still referred to as ‘mothers’ for simplicity.

Two surveys were completed by mothers whose children were in hospital less than 24 hours. The inclusion criterion of being in hospital for at least 24 hours was arbitrary and based on the idea that mothers may not have had enough interactions with health care professionals in order to assess the quality of care provided. These two surveys were included in the analysis as the mothers obviously felt they were able to respond to the questions.

One survey was completed by a mother whose child died only three months prior to the survey being completed. Mothers were not to be sent information about the study earlier than six months after the child’s death out of respect for their grieving process and concern that it would be emotionally difficult for mothers to respond to the questions at this stage of their grief. It was unfortunate this mother was sent a survey so soon after her child’s death. Since she chose to complete the survey, we included her responses.

Responses from 128 participants (108 using opt-out recruitment procedures and 20 using opt-in recruitment procedures) were included in the analysis, giving an overall response rate of 18.6%. Of those who returned the survey, 89 indicated they were willing to complete the survey a second time for reliability testing. A total of 31 surveys were returned for reliability testing.
The mean time between the two surveys being completed was 42.5 days (range 21 to 107 days, SD 19.4). Appendix S includes further details about recruitment and the number of participants at each site.

Mothers completed the survey on average 22.2 months (SD 9.6) after the child’s death. The mean age of the mothers was 36.5 years (SD 8.3) with a range of 18 to 63 years. Most participants were married (80.5%), had at least a college diploma or university degree (64.1%), had a total family income of $50,000 per year or more (74.2%), and were born in Canada (82.8%). The mean age of the children at the time of death was 4.1 years (SD 6.2) with a range of 2 days to 19.8 years, with slightly more girls (51.6%) than boys. A wide range of diagnoses were represented in the sample and grouped according to the International Statistical Classification of Diseases and Related Health Problems 10\textsuperscript{th} Revision (ICD-10) (World Health Organization, 2007). The largest group of diseases was “Congenital Malformation, Deformation and Chromosomal Abnormalities”, with 23.4% of children in the study falling into this category. A palliative care team was involved with 42.2% of the participating families. An additional 18% of mothers were not sure if a palliative care team was involved. Involvement of the palliative care team ranged from three days to seven years (median 9 days; IQR = 101.75) prior to the child’s death. Further demographic information about participants and their children is included in Appendix T.

The local investigator at each recruitment site completed the structural assessment survey. Survey results are included in Appendix U. Hospital-based pediatric palliative care services were very similar in terms of when they were established, number of full-time equivalent positions, and services offered. The two hospices had many more staff, palliative care beds, and family areas than the hospitals, but only eight participants were recruited through the two sites. Only 25 participants were recruited through hospitals that did not have a pediatric palliative care team.

4.3.2 ‘Connect with Families’ Subscale Analysis

4.3.2.1 Exploratory Factor Analysis

The ‘Connect with Families’ subscale included the first 17 items in the instrument. Due to missing responses, using a list-wise deletion, responses from 119 participants were used in the
analysis. All 17 items were first assessed using a correlation matrix. Inter-item correlations ranged from 0.32 to 0.90. The highest inter-item correlation was between items 10 and 11 which ask separately if the respondent and family were treated as unique. Several other items in this section include both the respondent and family together rather than separating into two items. The two items seemed redundant; therefore, item 11 (about family) was deleted from further analysis. In future versions of the instrument, the two items could be combined into one for further testing (e.g. How often did health professionals treat you and your family as unique?). The new inter-item correlations ranged from 0.32 to 0.82. In the antiimage correlation matrix, all MSA scores were 0.92 or higher, so all items were retained. Since the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.94, analysis continued with an assessment of the factor structure. Using principal axis factoring, only one factor had an eigenvalue greater than one accounting for 62.65% of the variance. The lowest factor loading was 0.53, so all items were retained. The factor loadings are included in Appendix V.

4.3.2.2 Internal Consistency

Cronbach’s alpha for the 16 items retained following factor analysis was 0.96. This value is high indicating some redundancy within the scale. While respondent burden may be a concern with the length of the instrument overall, all items were felt to be important to both content and face validity of the ‘Connect with Families’ subscale. All 16 items were retained to comprise the scale score.

4.3.2.3 Scale Summary and Outcome Item Scores

The summary score for the 128 participants who completed at least 10 of the 16 items included in the subscale was 77.73 (SD 18.77) on a scale of 0 to 100. Scores ranged from 10.94 to 100. The mean score on a scale of 0 (completely dissatisfied) to 100 (completely satisfied) for the item on satisfaction with the connections with health professionals was 80.79 (SD 25.90).

4.3.2.4 Test-Retest Reliability

Summary scores for the revised ‘Connect with Families’ subscale were compared for the 31 participants who completed the instrument twice. The ICC of 0.90 indicated differences in scores between the two time periods were more likely due to random error.
4.3.2.5 Hypothesis Testing

Higher summary scores on the ‘Connect with Families’ subscale were expected when the child and family received care from the palliative care team. Summary scores were higher but not statistically significantly higher when the family reported receiving care from a pediatric palliative care team (80.79 versus 75.62; p = 0.14). The ‘Connect with Families’ subscale score was also expected to have significant correlations with scores for each of four associated outcome items. The subscale score was statistically significantly correlated with satisfaction with the connections with health professionals (r = 0.84; p < 0.001); overall rating of quality of end-of-life care (r = 0.72; p < 0.001); peacefulness of death (r = 0.37; p < 0.001); and ‘good death’ (r = 0.36; p < 0.001). Based on hypothesis testing, there was some evidence for the validity of the ‘Connect with Families’ subscale as there was support for four of the five hypotheses tested.

4.3.2.6 Additional Comments

A consistent theme in response to the open-ended item asking for comments about relationships with health professionals was the difficulty thinking of all health professionals as one group. Physicians, nurses, and social workers were the professional groups most commented on as being either wonderfully supportive or cold and distant. The majority of comments indicated very supportive relationships with most health professionals: “There was NOT one health professionals that did not treat my child as if they were caring for their own. They were all excellent which made it all a little more comfortable when dealing with it all.” Others commented on the negative effects of even a few “not so professional professionals.” One mother noted:

Although most health professionals were kind and supportive a few were colder and more distant/business-like. Even though these people were very few, they affected us and my daughter particularly, quite significantly. For example a 12 hour shift with a nurse that was impatient or abrupt was very stressful for her as she was very ill and needed to feel safe with those looking after her.
4.3.3 ‘Involve Parents’ Subscale Analysis

4.3.3.1 Exploratory Factor Analysis

The ‘Involve Parents’ subscale included eight items (20 – 27). Due to missing responses, using a list-wise deletion, responses from 95 participants were used in the analysis. The lower number of participants included in the analysis was primarily due to item 26 where 21 participants indicated they did not experience a life-threatening event; therefore, giving at least 21 missing responses for items 26 and 27. The eight items in the domain were first assessed using a correlation matrix. Inter-item correlations ranged from 0.23 to 0.82. The lowest correlations were for two items related to involvement and support of parents during life-threatening events (26 and 27). In the antiimage correlation matrix, all MSA scores were 0.72 or higher, with the lowest score for item 26. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.80, so analysis continued with an assessment of the factor structure. Using principal axis factoring, two factors had an eigenvalue greater than one with the first accounting for 56.17% and the second accounting for 14.59% of variance. Using a varimax rotation, items 20 – 24 loaded greater than 0.64 on the first factor and items 25 – 27 loaded greater than 0.47 on the second factor. Items 23, 24, 25, and 27 cross loaded greater than 0.3 on both factors. Items making up the second factor seemed to relate to a more physical involvement in the child’s care whereas others were more about mothers’ opinions or expertise on their child being respected. The ratio between the two eigenvalues was 4.5:1.2, giving support for the possibility of only one factor rather than two. EFA was rerun forcing the analysis to include only one factor. The lowest factor loading was 0.50 indicating that the single factor was still a fit with the data. The factor loadings for both the one and two factor solutions are included in Appendix V. Summary scores were calculated using items 20 – 24 and using items 20 – 27. The mean summary scores for the two versions of the subscale were compared using a paired t-test. There was no significant difference in the two means (p = 0.6), providing further evidence that all eight items could be included together as a single subscale. These eight items were kept as one scale based on EFA results, comparison of summary scores, and the theoretical basis of the instrument developed in study Phase I.
4.3.3.2 Internal Consistency

Cronbach’s alpha for the eight items comprising the ‘Involve Parents’ subscale was 0.88. The lowest item-total correlation was 0.49 for item 26. While item 26 consistently scored low in the various tests, given the high internal consistency when all eight items are included and the need to have an instrument for future use that can be easily scored, all items were kept in the ‘Involve Parents’ subscale rather than splitting it into two smaller subscales.

4.3.3.3 Scale Summary and Outcome Item Scores

The mean summary score for the 128 participants who completed at least 5 of the 8 items included in the subscale was 72.93 (SD 22.71) on a scale of 0 to 100. Scores ranged from 3.57 to 100. The mean score on a scale of 0 (completely dissatisfied) to 100 (completely satisfied) for overall satisfaction with involvement in the child’s care was 77.86 (SD 27.31).

4.3.3.4 Test-Retest Reliability

Summary scores for the ‘Involve Parents’ subscale were compared for the 31 people who completed the instrument twice. The ICC of 0.82 indicated that the differences in scores between the two time periods were more likely due to random error.

4.3.3.5 Hypothesis Testing

Higher summary scores for the ‘Involve Parents’ subscale were expected when the child and family received care from the palliative care team. This hypothesis was supported (78.32 versus 67.90; p = 0.015). The ‘Involve Parents’ subscale scores were also expected to have significant correlations with scores for four associated outcome items. The subscale scores were positively and statistically significantly correlated with satisfaction with the involvement in the child’s care (r = 0.77; p < 0.001); overall rating of quality of end-of-life care (r = 0.60; p < 0.001); peacefulness of death (r = 0.31; p < 0.001); and ‘good death’ (r = 0.32; p < 0.001). Validity of the ‘Involve Parents’ subscale was demonstrated through support for all five hypotheses tested.

4.3.3.6 Additional Comments

Several mothers commented that at times they were treated as if they were in the way, or felt as if they were not really a parent to the child. One mother commented:
My daughter was a newborn and my first baby. I wished the nurses had offered to let me change and bathe her. They did it as part of their jobs and I figured I would get to when she came home. She never came home.

Some mothers reported frustration that their concerns about the child’s condition were not taken seriously. Sometimes mothers were not allowed to be with their child during procedures. Mothers found the wait away from their child, sometimes for hours with no updates, to be lonely, scary, and frustrating. Other mothers were grateful to health professionals for actively involving them in every aspect of daily care and procedures. One mother commented, “Staff facilitated our presence and, in fact, even ICU encouraged me to sleep with my son as it relaxed him.”

4.3.4 ‘Share Information’ Subscale Analysis

4.3.4.1 Exploratory Factor Analysis

The ‘Share Information’ subscale included items 30 – 32, 34 – 41, 45 – 48, 77, 84 and 100. Item 41 was about sharing information with the child; however, 100 participants indicated the item was not applicable due to young age or inability of the child to communicate during the last week of life. This item was left out of EFA but kept as a stand-alone item. Items 77 and 84 along with their follow-up questions (78 – 80 and 85 – 89) and item 100 asked about specific discussions that should occur as part of high quality care: raising the possibility of death, discussing treatment options, and preparing for death. These items had little correlation with other items, which was not surprising given their specific nature whereas the other items were more generally related to sharing information. These items were left as stand-alone items separate from the subscale. Similarly, items from the ‘Provide Bereavement Follow-up’ subscale specific to discussion of autopsy and organ and tissue donation (items 107 – 112) were grouped with these stand-alone items since they were all about specific topics for information sharing. Depending on the circumstances of the child’s death, these two topics can be discussed before a child dies rather than occurring as part of bereavement follow-up. Information about grief, community resources, and autopsy results is generally provided as part of a bereavement follow-up program so items 122 - 130 were left as part of the bereavement subscale.
The remaining 15 items (30 – 32, 34 – 40, 45 – 48) were first assessed using a correlation matrix. Inter-item correlations ranged from 0.13 to 0.84. The lowest inter-item correlations were for items 30 (how information was shared) and 47 (parents sharing medical details of the child’s condition). Item 30 included examples of using emails or written information for communication. These methods of sharing information may be more applicable in longer term illnesses but may be less important in the last week of life. Another example given in item 30 was having another person present when information is shared. This is quite a different aspect of care than using email to share information and is better captured in some of the items within the ‘Connect with Families’ subscale. Therefore, item 30 was deleted from the instrument. Item 47 was retained due to the high degree of face validity with parents. In the antiimage correlation matrix, all MSA scores were 0.86 or higher, so 14 items were retained for further analysis. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.91, so analysis continued with an assessment of the factor structure.

Using principal axis factoring, two factors had an eigenvalue greater than one with the first accounting for 53.5% and the second for 9.28% of variance. In the rotated factor matrix (Appendix V) items 45 to 48, which were all about sharing information among health professionals rather than between health professionals and parents, loaded strongly onto the second factor. Based on these results two distinct domains were identified from the ‘Share Information’ subscale. The first domain included items 31, 32, 34-40 and was called ‘Share Information with Parents.’ The second domain included items 45 – 48 and was called ‘Share Information among Health Professionals.’ These two domains were examined separately for the remainder of the analysis.

4.3.4.2 Internal Consistency

Cronbach’s alpha for the 9 items retained in the ‘Share Information with Parents’ subscale and the 4 items in the ‘Share Information among Health Professionals’ subscale was 0.90 and 0.86 respectively. The lowest item – total correlation across both subscales was 0.50 for item 40. All items were retained to comprise the two scale scores.
4.3.4.3 Scale Summary, Outcome, and Stand-Alone Item Scores

The mean summary score for the 128 participants who completed at least 6 of the 9 items in the ‘Share Information with Parents’ subscale was 69.81 (SD 20.40), while 126 participants completed at least 3 of 4 items in the ‘Share Information among Health Professionals’ subscale for a mean score of 74.24 (SD 19.78). The range of scores was 5.56 to 100 and 12.5 to 100 in the two scales respectively.

There were three items about overall satisfaction related to sharing information. The mean scores on a 0 (completely dissatisfied) to 100 (completely satisfied) scale for each were as follows: 76.43 (SD 26.91) for information shared between the participant and health professionals; 77.29 (SD 29.54) for information shared between health professionals and the child; and 78.05 (SD 25.86) for information shared among health professionals.

Items 41, 77 – 80, 84 – 89, 100, and 107 - 112 were kept in the instrument as stand-alone items. Response summaries for these items are reported in Table 4.8.

Table 4.8: ‘Share Information’ Stand-Alone Item Results

<table>
<thead>
<tr>
<th>Item</th>
<th>Response options or Scale Range</th>
<th>N (% or Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. How often did health professionals respect your wishes about how much to involve your child in talks about his/her illness?</td>
<td>0 (never) to 4 (always)</td>
<td>3.21 (1.17)</td>
</tr>
<tr>
<td></td>
<td>Note: Item not applicable for 100 respondents</td>
<td></td>
</tr>
<tr>
<td>77. Did you have a discussion with health professionals about the possibility your child would not survive his/her illness?</td>
<td>Yes</td>
<td>111 (86.7%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>14 (10.9%)</td>
</tr>
<tr>
<td></td>
<td>Don’t Remember</td>
<td>2 (1.6%)</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>1 (0.8%)</td>
</tr>
<tr>
<td>78. If yes, was this possibility discussed in a sensitive manner?</td>
<td>0 (not at all) to 4 (completely sensitive)</td>
<td>3.23 (1.06)</td>
</tr>
<tr>
<td>79. If yes, how appropriate was the timing of the discussion in the course of the illness?</td>
<td>0 (not at all appropriate) to 4 (completely appropriate)</td>
<td>3.08 (1.09)</td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td>Count</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>80. Do you wish this possibility would have been discussed sooner or later?</td>
<td>A lot sooner</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>A little sooner</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>No, the timing was completely appropriate</td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>A little later</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>A lot later</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>17</td>
</tr>
<tr>
<td>84. Did health professionals ever talk about stopping or not starting life-sustaining treatments?</td>
<td>Yes</td>
<td>103</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Don’t Remember</td>
<td>5</td>
</tr>
<tr>
<td>85. If yes, was this discussion about treatments done in a sensitive manner?</td>
<td>0 (not at all appropriate) to 4 (completely appropriate)</td>
<td>3.09</td>
</tr>
<tr>
<td>86. If yes, how appropriate was the timing of the discussion about treatments?</td>
<td>0 (not at all appropriate) to 4 (completely appropriate)</td>
<td>2.98</td>
</tr>
<tr>
<td>87. Do you wish this discussion about treatments would have happened sooner or later?</td>
<td>A lot sooner</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>A little sooner</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>No, the timing was completely appropriate</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>A little later</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>A lot later</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>26</td>
</tr>
<tr>
<td>88. When a child has treatments like a ventilator removed, this can sometimes be done at a time that will best meet the needs of the family. Were you given a choice about when treatments would be stopped?</td>
<td>Yes</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Don’t remember</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>No treatments stopped</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>5</td>
</tr>
<tr>
<td>89. If treatment was stopped, was it done at the time you wished?</td>
<td>Stopped way too soon</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Stopped a bit too soon</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Stopped when I wished</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Continued a bit too long</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Continued way too long</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>38</td>
</tr>
<tr>
<td>100. How well informed were you about what to expect at the time of your child’s death?</td>
<td>0 (not at all informed) to 4 (completely informed)</td>
<td>2.5</td>
</tr>
<tr>
<td>107. Did health professionals ever talk about whether or not your child could be an organ donor?</td>
<td>Yes</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>73</td>
</tr>
<tr>
<td></td>
<td>Don’t Remember</td>
<td>10</td>
</tr>
</tbody>
</table>
108. If yes, was the timing of this discussion appropriate?  
(Note: proportions based on 44 respondents)  
<table>
<thead>
<tr>
<th>Timing</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much too soon</td>
<td>3 (6.8%)</td>
</tr>
<tr>
<td>A little too soon</td>
<td>5 (11.4%)</td>
</tr>
<tr>
<td>Appropriate</td>
<td>32 (72.7%)</td>
</tr>
<tr>
<td>A little too late</td>
<td>3 (6.8%)</td>
</tr>
<tr>
<td>Much too late</td>
<td>1 (2.3%)</td>
</tr>
</tbody>
</table>

109. If yes, was this discussion done in a sensitive way?  
<table>
<thead>
<tr>
<th>Sensitivity</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not at all) to 4 (completely sensitive)</td>
<td>3.33 (0.92)</td>
</tr>
</tbody>
</table>

110. Did health professionals ever discuss an autopsy for your child?  
<table>
<thead>
<tr>
<th>Response</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>102 (79.7%)</td>
</tr>
<tr>
<td>No</td>
<td>22 (17.2%)</td>
</tr>
<tr>
<td>Don’t Remember</td>
<td>4 (3.1%)</td>
</tr>
</tbody>
</table>

111. If yes, was the timing of this discussion appropriate?  
(Note: proportions based on 102 respondents)  
<table>
<thead>
<tr>
<th>Timing</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much too soon</td>
<td>5 (4.9%)</td>
</tr>
<tr>
<td>A little too soon</td>
<td>13 (12.7%)</td>
</tr>
<tr>
<td>Appropriate</td>
<td>79 (77.5%)</td>
</tr>
<tr>
<td>A little too late</td>
<td>4 (3.9%)</td>
</tr>
<tr>
<td>Much too late</td>
<td>1 (1.0%)</td>
</tr>
</tbody>
</table>

112. If yes, was this discussion done in a sensitive way?  
<table>
<thead>
<tr>
<th>Sensitivity</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not at all) to 4 (completely sensitive)</td>
<td>3.12 (1.08)</td>
</tr>
</tbody>
</table>

### 4.3.4.4 Test-Retest Reliability

Summary scores for the ‘Share Information with Parents’ subscale were compared for the 31 participants who completed the instrument twice. The ICC of 0.81 indicated differences in scores between the two time periods were more likely due to random error. The ‘Share Information among Health Professionals’ was also assessed for test-retest reliability and yielded an ICC of 0.88, indicating differences were likely due to random error.

### 4.3.4.5 Hypothesis Testing

‘Share Information with Parents’ subscale scores were expected to be statistically significantly higher when a family was seen by the palliative care team. This hypothesis was supported (73.77 versus 65.67; p = 0.04). The ‘Share Information with Parents’ subscale score was also expected to have significant correlations with scores for each of four associated outcome items. The subscale score was positively and statistically significantly correlated with satisfaction with information shared between health professionals and parents (r = 0.82; p < 0.001); overall rating of quality of end-of-life care (r = 0.63; p < 0.001); peacefulness of death (r = 0.34; p < 0.001); and ‘good death’ (r = 0.33; p < 0.001). Validity of the ‘Share Information with Parents’ subscale was demonstrated by support for all five hypotheses tested.
‘Share Information among Health Professionals’ subscale scores were not statistically significantly higher when a family received care from the palliative care team (73.74 versus 72.92; p = 0.83). The ‘Share Information among Health Professionals’ subscale score was also expected to have significant correlations with scores for each of four associated outcome items. The subscale score was statistically significantly correlated with satisfaction with information shared among health professionals (r = 0.85; p < 0.001); overall rating of quality of end-of-life care (r = 0.63; p < 0.001); peacefulness of death (r = 0.29; p = 0.001); and ‘good death’ (r = 0.37; p < 0.001). There was some evidence for the validity of the ‘Share Information among Health Professionals’ subscale based on support for four of the five hypotheses tested.

4.3.4.6 Additional Comments

Some mothers felt information was withheld to protect them and support hope. They expressed frustration at being unprepared for the child’s death and felt they may have done things differently if they had realized sooner that the child might die. On the other hand one mother commented, “Information was honest, completely honest – no matter how hurtful, which gave me the tools to cope and deal and prepare as best I could for her passing.”

Some mothers expressed pleasant surprise at how well information was shared among health professionals given the huge number of them involved in providing care. Others commented on the difficulties encountered with constantly changing teams of health professionals:

We got very frustrated with pulmonology telling us one thing, then cardiology would come around and say something completely different, then the NICU doctor would change plans again. Every doctor that took over from the last would change treatment, prognosis, etc. Very confusing and frustrating. No one seemed to agree on any general plan and changed it willy nilly.

4.3.5 ‘Alleviate Suffering’ Subscale Analysis

4.3.5.1 Initial Subscale Analysis and Revisions

Initial attempts to generate a correlation matrix using the items developed for the ‘Alleviate Suffering’ subscale were unsuccessful. Three key factors influencing these challenges were: 1) the number of missing responses due to items being not applicable, 2) the number of items with dichotomous response options, and 3) the large number of items in the subscale. Prior to
further attempts to conduct EFA, each item and the associated responses were examined more closely to look for patterns of missing data as well as the topic and relevance of each item.

Items related to alleviating the suffering of the dying child, siblings, and parents were initially conceptualized as comprising one domain. However, subscale items were separated into three groups (child, sibling, and parents) for further analysis as this approach seemed a better fit with the data and still made sense conceptually.

As noted earlier, the majority of children were too young or otherwise unable to make their wishes or concerns known, which led to missing responses on items related to the child’s suffering. Item 52 was deleted from the instrument as it related to relationships with friends or school. Considering the focus of the instrument was on the last week of life, it is likely this item would primarily apply to cognitively intact adolescents, which would be a very small proportion of patients. To assess social needs, future versions of the instrument could add ‘loneliness’ to the list of symptoms in item 53. Up to 53 participants indicated they were ‘unsure’ whether or not the child suffered from a particular symptom. It is concerning that mothers may be left wondering in the years after their child’s death whether or not he or she was in pain or experiencing any other unpleasant symptom. High quality care should include discussion of symptoms and alleviation of any concerns parents have that their child might be suffering in some way. All of the ‘unsure’ responses to items 53a-h and 54 were recoded with a score of 2 which was the same as a response of ‘somewhat’ and fell in the middle of the response scale. A correlation matrix was generated for items 51 and 53a-h. The majority of the correlations were less than 0.3 except for the symptoms sadness, anxiety, and fear, which all correlated greater than 0.7 with each other. These items specific to the child’s experience were left as a group of stand-alone items rather than making further attempts to incorporate the items into a subscale. The group of items was called ‘Support the Child.’

The next group of items examined related to the experience of siblings (item 63, 65, and 71). In 48 families the ill child had no siblings which led to a number of missing responses for these items. EFA was attempted, and although the correlations were all higher than 0.37, the MSA scores were all below 0.7 and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.58. Support of siblings is an important component of high quality care as indicated by previous research (Contro et al., 2002), as well as by the significant number of comments by
participants in this section of the instrument about sibling needs. The items were left as stand-alone items. Two items (124, 125) on support for sibling grief after the child’s death were added, and the group of five items was called ‘Support Siblings’.

The original ‘Alleviate Suffering’ subscale contained a number of follow-up items where the initial question asked how often the right amount of support was given in a particular area and the follow-up question asked if the respondent wished for more or less support in that area. The expectation was that the same number of people who responded ‘always’ to the first question would indicate they always received the right amount of support in response to the second question, while the remainder would indicate either more or less support was needed. However, in the follow-up question many more than expected indicated they had the right amount of support. An example of this type of question with the frequency of responses is included in Table 4.9

<table>
<thead>
<tr>
<th>Item</th>
<th>Response options</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often did health professionals provide the right amount of support for your <strong>practical</strong> needs (for example access to food, a place to stay, transportation)?</td>
<td>Never</td>
<td>6 (4.7)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>14 (10.9)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>13 (10.2)</td>
</tr>
<tr>
<td></td>
<td>Mostly</td>
<td>39 (30.5)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>54 (42.2)</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>2 (1.6)</td>
</tr>
<tr>
<td>Do you wish you had more or less <strong>practical</strong> support?</td>
<td>A lot more</td>
<td>21 (16.4)</td>
</tr>
<tr>
<td></td>
<td>A little more</td>
<td>36 (28.1)</td>
</tr>
<tr>
<td></td>
<td>No, I always had the right amount</td>
<td>69 (53.9)</td>
</tr>
<tr>
<td></td>
<td>A little less</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>A lot less</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>2 (1.6)</td>
</tr>
</tbody>
</table>

In all but one of these types of follow-up questions, participants indicated they wanted a little or a lot more support in the area assessed. Since the follow-up questions did not work quite as expected, and did not really seem to add new information, they were deleted from the instrument (items 56, 58, 60, 62, 64, 66). Item 33, from the ‘Share Information’ subscale, was a similar follow-up item and was also deleted from the instrument. Follow-up item 83, which asked about whether health professionals focused too much on cure or too much on death, was retained. Responses to this item were a little more varied with 11.2% indicating health
professionals were too focused on cure and 28% indicating health professionals were too focused on death. As the item’s responses were on a Likert scale, it was not included within a subscale but retained as a stand-alone item to provide important information that can lead to improvements in practice.

Items 90, 91, 92, 93, 95, and 98 had yes/no response options, which are a challenge to include in EFA (Pett et al., 2003). Items 93 and 95 asked if health professionals asked about religious practices and who should be present at death respectively. Subsequent items asked if their wishes were respected about religious practices (item 94), which family and friends were present at death (item 96), and which health professionals were present at death (item 97). On reflection, one would need to have asked about wishes in order to be able to respect them. Nearly 20% of participants indicated that they could not remember if they were asked specifically about the two areas but still responded to the follow-up items saying if their wishes were respected. Items 93 and 95 were deleted from the instrument as they were redundant with the subsequent items (items 94, 96, 97). A related item asked whether or not a health professional was present at the time of death (items 98) as a lead in to the subsequent item that asked whether or not it was helpful to have a health professional present (item 99). The presence of a health professional at the time of death has been associated with a less difficult moment of death in previous research (Kreicbergs et al., 2005). It may be that items 98 and 99 would be correlated with the child’s symptoms at the time of death (which were not specifically assessed in the instrument) or the experience of a peaceful death. Item 99 was included in the analysis as parents should be the ones to assess whether or not the presence of a health professional at the time of death was helpful. In future, the item could be re-written to ask if it was helpful to have a health professional present at death, with one of the responses being ‘no health professional present,’ rather than having two separate items.

Item 90 asked whether a choice was given about location of death, while the two follow-up questions asked if the death occurred in the location that was wished by the parent (item 91) and the child (item 92). Recent research with families whose child had cancer indicates that it may be more important to discuss options and plan for location of death (usually home versus hospital) than to have the death occur in a particular location (Dussel et al., 2009). For a population that includes deaths due to a much wider variety of illnesses or accidents, a home
death may not be an option available to the family. Regardless of the cause or circumstances of the death, high quality end-of-life care should include offering families a private and comfortable setting within the hospital, when possible. Based on this recent research, only item 90 was retained for further analysis while items 91 and 92 were deleted from the instrument.

4.3.5.2 Exploratory Factor Analysis

Following the above revisions to the original ‘Alleviate Suffering’ subscale, 16 remaining items (items 55, 57, 59, 61, 67, 68, 69, 70, 72, 81, 82, 90, 94, 96, 97, 99) were assessed using a correlation matrix. Several inter-item correlations were less than 0.3 and some items correlated negatively with the one dichotomous response option that was present in the analysis (item 90 about location of death). The items with the most correlations less than 0.3 were items 90, 99 (helpfulness of the presence of a health professional), and 55 (support for practical needs). It was unclear why the correlations with item 55 were low. All three items were initially retained for further assessment. In the antiimage correlation matrix, MSA scores were less than 0.7 for items 82, 90, and 96. Since item 90 consistently scored low it was removed from EFA but left as a stand-alone item due to its conceptual relevance to high quality care as described above.

The analysis was rerun without item 90 and the correlation matrix re-examined. Item 97 about respecting wishes for which health professionals were present at the time of death no longer had any correlations greater than 0.3. This item was also removed and the analysis re-run again. The correlation matrix was much improved. All MSA scores were greater than 0.78, and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.84, so analysis continued with an assessment of the factor structure.

Using principal axis factoring with varimax rotation, two factors had an eigenvalue greater than one with the first accounting for 54.3% and the second for 8.9% of the variance. Items which loaded onto the first factor were about support of parents, while several items that loaded onto the second factor were specific to care provided at the time of death. The items were then split into two subscales: one with items relating to overall support of the parents (items 55, 57, 59, 61, 67, 68, 69, 70, 72, 81, 82) and the second relating to care provided at the time of death (items 90, 94, 96, 97, 99, 113, 114). Conceptually, it made sense to have a separate domain about support for parents as domains about support for the dying child and support for siblings.
were established through the above analysis. As well, a domain specific to care provided at the time of death fit conceptually with some existing standards and guidelines for pediatric palliative care (Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003; CHPCA, 2006; Widger & Wilkins, 2004).

With the possibility of two new smaller subscales, items 90 and 97, which were deleted as part of the initial analysis of the subscale, were brought back in for testing in the new subscales. As well, two items in the “Provide Bereavement Follow-up” subscale about how the child’s body was cared for (item 113) and whether parents had enough time with their child after the death occurred (item 114) were also included in this part of the analysis. These two items were initially written with the intent of being in the ‘Alleviate Suffering’ subscale, but were placed into the ‘Provide Bereavement Follow-up’ subscale by health professionals who assessed the instrument in Phase II. Item 115 was a follow-up to item 114 to ask if things moved too slowly or too quickly after the child’s death. Only eight people responded to the item and only one indicated things moved too slowly after the child’s death. The item did not seem relevant to respondents and was deleted.

EFA was conducted with the 11 items (55, 57, 59, 61, 67, 68, 69, 70, 72, 81, 82) about supporting parents. In the correlation matrix only two correlations were less than 0.3 so all items were retained. In the antiimage matrix the lowest MSA value was 0.77 and the overall Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.85. Initially two factors had eigenvalues greater than one. The three items loading on the second factor were about hope and having a health professional to guide them through end-of-life care. Only four items (55, 70, 72, and 82) did not cross load greater than 0.3 on both factors. As well, there was a 6:1 ratio in eigenvalues between the first and second factors suggesting that a single factor may be appropriate. In the interests of having fewer rather than adding more subscales to the instrument and to remain conceptually congruent with the domains on support for the child and siblings, EFA was forced to one factor. The lowest factor loading on the one factor solution was 0.51, so all items were retained as one subscale. The factor matrices for the one and two factor solutions are included in Appendix V.

EFA was then conducted on the seven items (90, 94, 96, 97, 99, 113, 114) specific to care at the time of death. In the correlation matrix, all correlations were greater than 0.3 except for item 90
about location of death. In the antiimage matrix the two items with dichotomous response options had MSA scores less than 0.7 (items 90 and 114) with an overall Kaiser-Meyer-Olkin Measure of Sampling Adequacy of 0.78. All items were retained; however, a factor matrix could not be generated. The analysis was forced to one factor which explained 53.41% of the variance. Factor loadings were greater than 0.59 except for item 90 which loaded 0.24. All items were retained together based on clinical judgment, the conceptual basis of the instrument, and to have a more user friendly instrument for future use. The factor matrix is included in Appendix V.

4.3.5.2.1 Revised subscales. Through the above analysis the ‘Alleviate Suffering’ subscale was changed significantly. The original large subscale was divided into two smaller groupings of items or domains called ‘Support the Child’ (stand-alone items 51, 53a – 53h), and ‘Support Siblings’ (stand-alone items 63, 65, 71, 124, 125), as well as two separate subscales called ‘Support Parents’ (items 55, 57, 59, 61, 67, 68, 69, 70, 72, 81, 82), and ‘Provide Care at Death’ (items 90, 94, 96, 97, 99, 113, 114). One additional stand-alone item (83) was retained in the instrument as a follow-up to the ‘Support Parents’ subscale.

A review of comments added by participants in all sections of the instrument indicated that suffering was a consistent theme throughout the experience rather than being a separate component of care. Although the items are grouped differently than what was established a priori for this instrument, the groupings fit with some other proposed domains of pediatric palliative care (Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003; CHPCA, 2006; Widger & Wilkins, 2004) and make sense theoretically and clinically.

4.3.5.3 Internal Consistency

Cronbach’s alpha for the 11 items in the ‘Support Parents’ subscale was 0.92, with the lowest item-total correlation at 0.49 for item 70. All items were retained in the subscale. Cronbach’s alpha for the 7 items in the Provide Care at Death subscale was 0.76. The lowest item-total correlation was 0.23 for item 90 on location of death.
4.3.5.4 Scale Summary, Outcome, and Stand-Alone Item Scores

The mean summary score for the 128 participants who completed at least 7 of 11 items in the ‘Support Parents’ subscale was 69.82 (SD 22.36). Scores ranged from 6.82 to 100. The mean summary score for the 124 participants who completed at least 5 of 7 items in the ‘Provide Care at Death’ subscale was 83.86 (SD 16.23) with a range of 17.86 to 100.

A number of items assessing satisfaction and other outcomes were included in the original ‘Alleviate Suffering’ subscale. The mean score for the child’s overall level of suffering on a 0 to 100 scale was 60.74 (SD 26.38), while the mean score on a scale of 0 (completely dissatisfied) to 100 (completely satisfied) for satisfaction with support to ease the child’s suffering was 77.60 (SD 27.74). The mean satisfaction score on a 0 to 100 scale for support of the mother and support of the siblings was 77.03 (SD 26.53) and 66.14 (SD 32.85) respectively. Participants were asked to describe the peacefulness of the atmosphere at the time of the child’s death. The mean score on a scale of 0 (not at all peaceful) to 100 (extremely peaceful) was 64.80 (SD 32.24). Participants were also asked how much they agreed with the statement that their child experienced a ‘good death.’ The mean score on a scale of 0 (disagree strongly) to 100 (agree strongly) was 60.04 (SD 33.04).

The first stand-alone item related to ‘Support the Child’ asked how often health professionals looked at all of the child’s needs. The item was rated from 0 (never) to 4 (always). The second item asked how much suffering the child experienced from eight different symptoms. Each symptom was rated from 0 (not at all) to 4 (constantly). The mean score for each item is presented in Table 4.10.
Table 4.10: ‘Support the Child’ Stand-Alone Item Results

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>51. How often did health professionals look at all the needs of your child (physical, emotional, social, developmental, and spiritual needs)?</td>
<td>2.9 (1.10)</td>
</tr>
<tr>
<td>53. During your child’s last week or days of life while in the hospital, how much would you say your child seemed to suffer from each of the following symptoms?</td>
<td></td>
</tr>
<tr>
<td>Symptom</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>1.92 (1.15)</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td>0.76 (1.09)</td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td>2.89(1.27)</td>
</tr>
<tr>
<td>Bleeding</td>
<td>0.89 (1.25)</td>
</tr>
<tr>
<td>Seizures</td>
<td>0.85 (1.28)</td>
</tr>
<tr>
<td>Sadness</td>
<td>1.72 (1.06)</td>
</tr>
<tr>
<td>Anxiety / Worry</td>
<td>1.49 (1.13)</td>
</tr>
<tr>
<td>Fear</td>
<td>1.54 (1.16)</td>
</tr>
</tbody>
</table>

Scores for the five items about ‘Support Siblings’ are presented in Table 4.11. There were some differences in the number of respondents for each item. Additional comments next to the items indicated that some siblings were very young or lived far away from where the child was receiving care; therefore, not all items were applicable even if there were siblings in the family. The number of respondents is included in brackets at the end of each item.

Table 4.11 ‘Support Siblings’ Stand-Alone Item Results

<table>
<thead>
<tr>
<th>Item</th>
<th>Response options or Scale Range</th>
<th>N (%) or Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>63. How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital? (N = 78)</td>
<td>0 (never) to 4 (always).</td>
<td>2.37 (1.40)</td>
</tr>
<tr>
<td>65. How often did health professionals guide you on how you could support your other children while you child was in hospital? (N = 78)</td>
<td>0 (never) to 4 (always)</td>
<td>1.85 (1.36)</td>
</tr>
<tr>
<td>71. How often did health professionals allow and encourage your other children to visit when they wished? (N = 80)</td>
<td>0 (never) to 4 (always)</td>
<td>2.91 (1.47)</td>
</tr>
<tr>
<td>124. Did someone from the hospital offer you information about your other children’s grief? (N = 84)</td>
<td>Yes</td>
<td>54 (65.1%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>22 (26.5%)</td>
</tr>
<tr>
<td></td>
<td>Don’t Remember</td>
<td>7 (8.4%)</td>
</tr>
<tr>
<td>125. If yes, how helpful was this information? (N = 54)</td>
<td>0 (not helpful at all) to 4 (extremely helpful)</td>
<td>2.20 (1.03)</td>
</tr>
</tbody>
</table>
One additional stand-alone item followed up on item 82 about how often health professionals had the right balance between focusing too much on cure or too much on death. In response to item 83, 3.9% indicated the focus was ‘way too much on cure,’ 7.0% indicated ‘a little too much on cure,’ 19.5% indicated ‘a little too much on death’, and 7.8% indicated the focus was ‘way too much on death.’ For 59.4% of respondents, health professionals were able to maintain the right balance. An additional 2.3% did not respond to the question.

4.3.5.5 Test-Retest Reliability

The ICC was 0.83 when comparing scores from the first and second testing of the ‘Support Parents’ subscale. For the ‘Provide Care at Death’ subscale the ICC was 0.81, indicating that differences between the two time periods were more likely due to random error in both subscales.

4.3.5.6 Hypothesis Testing

Higher mean scores on the ‘Support Parents’ subscale were expected when the family was seen by the palliative care team. This hypothesis was supported (76.40 versus 64.44; p = 0.006). The ‘Support Parents’ subscale score was also expected to have significant correlations with scores for each of four associated outcome items. The subscale score was positively and statistically significantly correlated with satisfaction with support provided by health professionals while in hospital (r = 0.77; p < 0.001); overall rating of quality of end-of-life care (r = 0.73; p < 0.001); peacefulness of death (r = 0.47; p < 0.001); and ‘good death’ (r = 0.39; p < 0.001). Validity of the ‘Support Parents’ subscale was demonstrated through support of all five hypotheses tested.

‘Care at Death’ subscale scores were expected to be statistically significantly higher when a family was seen by the palliative care team. This hypothesis was supported (88.19 versus 80.25; p = 0.006). There was no associated item to assess satisfaction with care at the time of death as this was a new subscale. The ‘Care at Death’ subscale score was expected to have significant correlations with scores for the remaining three outcome items. The subscale score was positively and statistically significantly correlated with the overall rating of quality of end-of-life care (r = 0.65; p < 0.001); peacefulness of death (r = 0.58; p < 0.001); and ‘good death’ (r = 0.41; p < 0.001). Validity of the ‘Care at Death’ subscale was demonstrated based on support of all four hypotheses tested.
4.3.5.7 Additional Comments

Many of the comments about support of the family related to sibling needs. Several mothers reported frustration that other siblings were not allowed to visit, or only visited once just before the child died. Others were thankful for support given to siblings:

Her sisters made three bracelets with the counselor to ‘bind’ the three of them. We all (siblings too) were involved in her care (example: asking a sibling what scented soap she would use for a sponge bath).

Generally, the comments about care at the time of death were quite positive with appreciation expressed for having ‘favorite’ staff with the family:

During the time of our child’s death we were assigned a nurse – our favorite nurse and she 100% helped us for her entire shift and only us. She pulled us through by saying what was needed and sometimes saying nothing.

4.3.6 ‘Provide Bereavement Follow-up’ Subscale Analysis

4.3.6.1 Exploratory Factor Analysis

Although 6 of the 10 sites that took part in the study reported having a formal bereavement follow-up program available to all families who had a child die at their hospital / hospice, there seemed to be a great deal of inconsistency in the type of follow-up that families received. As well, two hospitals that had seemingly comprehensive programs did not have anyone in the position of bereavement coordinator for part of the time that participants in the study should have been receiving care. A number of the items in this section had dichotomous response options asking if various aspects of bereavement follow-up were offered. The follow-up item to each asked about the helpfulness of that aspect of care. EFA was attempted on just these follow-up items (106, 121, 123, 127, 129, 132). However, the resulting correlation matrix had many low correlations and several negative correlations. Given the variability in what was offered as part of even formal bereavement programs, this finding is not surprising. In terms of assessing the quality of care, it is important to consider each aspect of bereavement follow-up separately: first in terms of whether or not it was provided and then whether or not it was helpful for the family. A high quality program would offer more of the seven key components of bereavement follow-up that have been identified in the literature including: gathering mementos, funeral arrangements, at least one contact after death, grief information, community
resource information, a meeting, and a memorial service. A score could be calculated by counting the number of ‘yes’ responses to the items which asked about each of these areas. Unfortunately, item 131 about memorial services asked if the mother attended the service rather than if she was invited to one. There were a few comments indicating an invitation was received but the mother was unable to attend, often due to distance from the health centre. In future versions, the item should be revised to ask if the mother was invited to a service and then how helpful it was, with one of the response options being ‘did not attend.’ It may also be helpful to have a space for the mother to indicate why she did not attend the service. This information may help with planning future memorial services.

### 4.3.6.2 Summary, Outcome, and Stand-Alone Item Scores

A summary score for bereavement follow-up was calculated by recoding item 118 as ‘yes’ if at least one contact occurred after the child’s death, and then counting the number of ‘yes’ responses to items 103, 105, 118, 122, 126, and 128. The mean score was 3.85 (SD 1.33) with a possible maximum score of 6. Scores ranged from 1 to 6 with only 11.7% of participants having been offered all 6 assessed components of a high quality bereavement follow-up program.

The mean score on a 0 (completely dissatisfied) to 100 (completely satisfied) scale for satisfaction with bereavement follow-up was 61.64 (SD 29.87).

Although a summary score for ‘Provide Bereavement Follow-up’ was calculated, the responses to all items are provided below to give a sense of which aspects of bereavement follow-up were most commonly offered.

#### Table 4.12: ‘Provide Bereavement Follow-up’ Stand-Alone Item Results

<table>
<thead>
<tr>
<th>Item</th>
<th>Response options or Scale Range</th>
<th>N (%) or Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>103. Did health professionals suggest and offer to create mementos of your child?</td>
<td>Yes</td>
<td>121 (94.5%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>4 (3.1%)</td>
</tr>
<tr>
<td></td>
<td>Don’t Remember</td>
<td>3 (2.3%)</td>
</tr>
<tr>
<td>104. Did health professionals respect your wishes about the mementos that you wanted to have?</td>
<td>0 (no respect at all) to 4 (extremely respectful)</td>
<td>3.58 (0.73)</td>
</tr>
</tbody>
</table>
105. Did health professionals offer to help you make any arrangements for funerals or other religious customs?  
| Yes       | 61 (47.7%) |
| No        | 47 (36.7%) |
| Don’t Remember | 20 (15.6%) |

106. If yes, how helpful was this assistance for you?  
0 (not at all helpful) to 4 (extremely helpful)  
3.03 (0.99)

107. Did health professionals from the hospital offer to continue contact with your family through calls or letter after your child died?  
| Yes       | 83 (64.8%) |
| No        | 22 (17.2%) |
| Don’t Remember | 23 (18.0%) |

108. About how many contacts with health professionals from the hospital have you had since your child died?  
Range : 0 – 100  
Note: 80% of sample had 7 contacts or less  
5.76 (10.49)

109. Would you say this number of contacts was the right amount, too many or too few?  
| Much too many | 1 (0.8%) |
| A little too many | 2 (1.6%) |
| The right amount | 65 (50.8%) |
| A little too few | 39 (30.5%) |
| Much too few | 12 (9.4%) |
| Missing | 9 (7.0%) |

110. What kind of contacts have you had? (Check all that apply)  
| Phone calls | 75 (58.6%) |
| Cards or letters | 92 (71.9%) |
| Meetings | 42 (32.8%) |
| Counseling | 25 (19.5%) |
| Email | 19 (14.8%) |
| Memorial Service | 9 (7.0%) |

111. If contact continued, how helpful was it for you?  
0 (not helpful at all) to 4 (extremely helpful)  
2.45 (1.13)

112. Did someone from the hospital offer you information about your grief?  
| Yes       | 106 (82.8%) |
| No        | 12 (9.4%) |
| Don’t Remember | 10 (7.8%) |

113. If yes, how helpful was this information?  
0 (not helpful at all) to 4 (extremely helpful)  
2.20 (1.12)

114. Did someone from the hospital offer you information about community resources available close to your home?  
| Yes       | 53 (41.4%) |
| No        | 56 (43.8%) |
| Don’t Remember | 19 (14.8%) |

115. If yes, how helpful was this information?  
0 (not helpful at all) to 4 (extremely helpful)  
2.09 (1.20)

116. Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or autopsy results (if one was done)?  
| Yes       | 52 (40.6%) |
| No        | 63 (49.2%) |
| Don’t Remember | 13 (10.2%) |

117. If you had a meeting, was it helpful for you?  
Note: Meeting held for 44 families  
0 (not helpful at all) to 4 (extremely helpful)  
2.68 (1.12)
130. If an autopsy was done, did you receive the results in a timely manner?
Note: proportions based on 49 respondents

<table>
<thead>
<tr>
<th>Timeliness</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not timely at all</td>
<td>24 (49.0%)</td>
</tr>
<tr>
<td>Somewhat timely</td>
<td>18 (36.7%)</td>
</tr>
<tr>
<td>Very timely</td>
<td>7 (14.3%)</td>
</tr>
</tbody>
</table>

131. Have you attended a memorial service held by the hospital where your child died?

<table>
<thead>
<tr>
<th>Response</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>45 (35.2%)</td>
</tr>
<tr>
<td>No</td>
<td>71 (55.5%)</td>
</tr>
<tr>
<td>No service offered / missing</td>
<td>12 (9.4%)</td>
</tr>
</tbody>
</table>

132. If yes, how helpful was the memorial service for you?

<table>
<thead>
<tr>
<th>Helpfulness Score</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (not helpful at all) to 4 (extremely helpful)</td>
<td>2.53 (1.24)</td>
</tr>
</tbody>
</table>

133. Did you ever feel avoided or abandoned by health professionals from the hospital after your child’s death?

<table>
<thead>
<tr>
<th>Experience</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (always) to 4 (never)</td>
<td>2.60 (1.26)</td>
</tr>
</tbody>
</table>

4.3.6.3 Test-retest Reliability

The test-retest reliability of the summary score for ‘Provide Bereavement Follow-up’ was calculated. Given the length of time between the two tests (mean 42.5 days) it is possible that additional bereavement services were provided between the two tests. Not surprisingly the ICC was 0.52 with a slight increase in mean scores from Time 1 to Time 2.

4.3.6.4 Hypothesis Testing

‘Provide Bereavement Follow-up’ subscale scores were expected to be statistically significantly higher when a palliative care team was involved in the child’s care. Higher mean subscale scores were also expected when the child was cared for in a hospital/hospice that reported having a comprehensive bereavement follow-up program for all families. The first hypothesis was not supported (3.9 versus 4.04; p = 0.65), but there was support for the second (4.16 versus 3.60; p = 0.02). As most hospitals that had a pediatric palliative care team also had a bereavement follow-up program for all families in the hospital, this finding is not surprising.

‘Provide Bereavement Follow-up’ subscale scores were expected to be statistically significantly correlated with satisfaction with bereavement follow-up. This hypothesis was supported (r = 0.28; p = 0.002). There was some evidence for the validity of the Provide Bereavement Follow-up’ subscale based on support for two of the three hypotheses tested.

4.3.6.5 Additional Comments

Many mothers commented on the lack of support after the child’s death and frustration with trying to find needed supports:
All of the help we’ve received with counseling, support groups, etc. we had to find on our own, which wasn’t an easy process. After the insane rollercoaster ride, with crisis after crisis and agonizing decisions to make often on a daily basis, the trauma of watching our child get sicker and sicker, the hours spent at the hospital for 2.5 months and the decision to remove life support, we were a shell of our former selves, hardly able to cope with ourselves let alone our two [young] kids at home. Then suddenly it’s all over and you go home and there is nothing. We felt as though we were dropped off an edge of a cliff.

Some mothers reported initiating contact themselves in the months after the child’s death, sometimes as part of fundraising efforts. Contacts that were made by health professionals were much appreciated:

Staff who cared for her in two different hospitals sent notes to us about how they were affected by our daughter and her death. These notes were astounding to us, but even more, they made us feel less alone since we were a long distance from home and these health professionals were the only people who shared her death with us. We were very touched by their kindness.

4.3.7 ‘Structures of Care’ Results

The seven items that assessed structures such as space, playrooms, parking, and food were left as stand-alone items. Items 140 – 143 and 145 were rated on a 0 (never) to 4 (always) scale. Items 144 and 146 were rated on a 0 (not at all) to 4 (extremely) scale. The number of respondents and mean scores for each item are included in Table 4.13.

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>140. How often was there enough room for you to be with your child while in hospital?</td>
<td>127</td>
<td>3.18 (1.03)</td>
</tr>
<tr>
<td>141. How often was there a comfortable place for you to sleep at or near the hospital?</td>
<td>118</td>
<td>2.87 (1.37)</td>
</tr>
<tr>
<td>142. How often were there playrooms or other child-friendly space for your other children while you were at the hospital?</td>
<td>71</td>
<td>2.76 (1.33)</td>
</tr>
<tr>
<td>143. How often was food readily available for your family while you were at the hospital?</td>
<td>124</td>
<td>2.73 (1.26)</td>
</tr>
<tr>
<td>144. Would you say food at the hospital was affordably priced?</td>
<td>121</td>
<td>1.91 (1.11)</td>
</tr>
<tr>
<td>145. How often were you easily able to find parking at the hospital?</td>
<td>121</td>
<td>3.03 (0.99)</td>
</tr>
<tr>
<td>146. Would you say parking at the hospital was affordably priced?</td>
<td>118</td>
<td>1.30 (1.27)</td>
</tr>
</tbody>
</table>
4.3.7.1 Additional Comments

Families who received parking passes or meal vouchers were grateful. However, it seemed many did not get this assistance or received it for only a short time before the child’s death. Several mothers commented that both parking and accommodation were far from where the child was, and that it was scary to go outside at night to these other locations. Accommodations in the hospital, particularly when the child was in an intensive care unit, were lacking: “It felt like a third world country to see worn out parents claiming seats to sleep on in the waiting room.” When families were at the hospital for long periods of time many commented that the food got monotonous with little variation in what was available. Food was often not available on nights and weekends.

4.4.8 Overall Quality Ratings Results

Participants were asked to rate the overall quality of end-of-life care provided to the child and family on a five point scale from ‘poor’ to ‘excellent.’ Only 32.8% of participants rated the care as ‘excellent.’ The mean score standardized on a 0 to 100 scale was 71.80 (SD 27.12).

4.4.8.1 Additional Comments

Overall comments were very positive and appreciative of the care received, generally noting “the staff…made a terrible event as bearable as possible.” Mothers most often commented on the relationships with health professionals as the best experience with the health care system. Other positive experiences frequently mentioned were getting to hold their child in the last hours of life and mementos, such as hand castings, created by staff. Reports of the worst experiences were quite varied. Miscommunication or insensitive communication by health professionals were most commonly mentioned along with not being able to hold the child long or frequently enough, and a lack of pain management.

4.4.9 Impact of Participation

At the end of the instrument, participants were asked nine questions about how they were impacted by taking part in the study. Responses to these items are summarized in Table 4.14.
Table 4.14: ‘Impact of Participation’ Item Results

<table>
<thead>
<tr>
<th>Item</th>
<th>Response options or Scale Range</th>
<th>N (%) or Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How beneficial did you find completing this survey was for you?</td>
<td>0 (not at all) to 4 (extremely)</td>
<td>1.84 (1.11)</td>
</tr>
<tr>
<td>2. How much stress or pain would you say completing this survey has caused you?</td>
<td>0 (none) to 4 (extreme amount)</td>
<td>1.76 (0.99)</td>
</tr>
<tr>
<td>3. How much pain or stress were you expecting when you agreed to do this survey?</td>
<td>0 (none) to 4 (extreme amount)</td>
<td>1.65 (1.06)</td>
</tr>
<tr>
<td>4. Overall would you say participating in this study had a positive or negative effect on you?</td>
<td>Very negative</td>
<td>1 (0.8%)</td>
</tr>
<tr>
<td></td>
<td>A little negative</td>
<td>9 (7.0%)</td>
</tr>
<tr>
<td></td>
<td>Neither positive or negative</td>
<td>58 (45.3%)</td>
</tr>
<tr>
<td></td>
<td>A little positive</td>
<td>41 (32.0%)</td>
</tr>
<tr>
<td></td>
<td>Very positive</td>
<td>17 (13.3%)</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>2 (1.6%)</td>
</tr>
<tr>
<td>5. Do you regret participating in this study?</td>
<td>Yes</td>
<td>1 (0.8%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>127 (99.2%)</td>
</tr>
<tr>
<td>6. Would you recommend to another bereaved parent that they participate in a similar study?</td>
<td>Yes</td>
<td>108 (84.4%)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10 (7.8%)</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>10 (7.8%)</td>
</tr>
<tr>
<td>7. How valuable is it to do research about parents views on the quality of end-of-life care given by health professionals?</td>
<td>0 (not at all) to 4 (extremely)</td>
<td>3.57(0.65)</td>
</tr>
<tr>
<td>8. Why did you agree to take part in this study? (Check all that apply)</td>
<td>To help others in a similar situation</td>
<td>119 (93.0%)</td>
</tr>
<tr>
<td></td>
<td>So I could talk about the experience I had</td>
<td>58 (45.3%)</td>
</tr>
<tr>
<td></td>
<td>Was pressured by family/friends/researcher</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>To say thank you</td>
<td>4 (3.1%)</td>
</tr>
<tr>
<td></td>
<td>To make changes in the health system</td>
<td>4 (3.1%)</td>
</tr>
<tr>
<td>9. Which do you think would be the best way to ask parents the survey questions in future research? (Respondents asked to rank in order of preference – frequencies indicate number of respondents who selected the option as their first or second choice)</td>
<td>Telephone</td>
<td>16 (12.5%)</td>
</tr>
<tr>
<td></td>
<td>Written</td>
<td>107 (83.6%)</td>
</tr>
<tr>
<td></td>
<td>In person</td>
<td>40 (31.3%)</td>
</tr>
<tr>
<td></td>
<td>Internet</td>
<td>74 (57.8%)</td>
</tr>
</tbody>
</table>

4.4.9.1 Additional Comments

Participants were generally thankful for the opportunity to take part in this research and were comforted “to know people care enough to look at the process.” Many commented on the
emotional difficulty of responding to the questions but did so in an effort to improve care for other families: “It is always difficult to go back to painful memories but if my experiences can improve things for other families – I look at it as doing what I can for my son and hopefully another family will have fewer struggles.” A few who completed the survey two to three years after the child’s death commented that they wished the survey had been sent sooner and suggested six months after the death would have been better. One participant commented that fathers should also be included in this type of survey. Similarly, on one of the opt-out cards returned during recruitment, one mother wrote that she would not take part in any research that did not also include the father’s perspective.

4.5 Conclusion

The purpose of the study was to develop and test an instrument to measure the quality of end-of-life care for children from the perspective of bereaved parents. The instrument was developed according to Donabedian’s (1988) health services model for assessing quality of care. This model consists of three linked components: structures, processes, and outcomes. A comprehensive review of the literature was used to identify structures, processes, and outcomes relevant to quality end-of-life care for children. Through the literature review, a conceptual framework was developed consisting of five domains important to quality end-of-life care for children: Connect with Families, Involve Parents, Share Information, Alleviate Suffering, and Provide Bereavement Follow-up. These domains and associated indicators were confirmed and extended through focus groups with bereaved parents in study Phase I. Instrument items were developed based on the revised indicators. Instrument items were primarily focused on assessing processes of care, but items were also developed to assess structures of care, outcomes of care, demographics, and emotional impact on parents of participating in the study. Content and face validity of the instrument was demonstrated through assessments by health professionals and parents in study Phase II.

The instrument and associated conceptual framework underwent substantial revisions through testing with bereaved mothers in study Phase III. The original instrument consisted of 143 items. The revised instrument consists of 126 items on structures, processes, and outcomes of quality end-of-life care for children, plus open-ended items and items on demographics and impact of participation in the study. The revised instrument is made up of 10 domains or topic
areas (listed in Table 4.15) which form the revised conceptual framework for quality pediatric end-of-life care. The 10 domains include 7 subscales (Connect with Families, Involve Parents, Share Information with Parents, Share Information among Health Professionals, Support Parents, Provide Care at Death, and Provide Bereavement Follow-up), all of which have at least one associated outcome item and one open-ended item. Some subscales (Share Information with Parents, Support Parents, and Provide Bereavement Follow-up) have associated items which stand-alone from the subscale score but fit within the subscale topic. These items provide specific additional information about the quality of care provided to a dying child and his/her family that is important to keep separate from a combined subscale score. There were three other domains not associated with a subscale score: Support the Child, Support Siblings, and Structures of Care. These domains consist of stand-alone items, as well as some outcome and open-ended items. Content and face validity of all stand-alone and outcome items was demonstrated in study Phase II. A final item to rate overall quality of care and some concluding open-ended items complete the instrument. The final number of items in the instrument by domain and item type is provided in Table 4.15. A list of items in each domain is included in Appendix W, grouped by type (subscale, stand-alone, outcome, or open-ended).

### Table 4.15: Final Number of Items by Domain and Type Following Phase III Testing

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Subscale Items</th>
<th>Stand-Alone Items</th>
<th>Outcome Items</th>
<th>Open-ended items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connect with Families</td>
<td>16</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Involve Parents</td>
<td>8</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Share Information with Parents</td>
<td>9</td>
<td>18</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Share Information among Health Professionals</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Support the Child</td>
<td>0</td>
<td>9</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Support Siblings</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Support Parents</td>
<td>11</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Provide Care at Death</td>
<td>7</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Provide Bereavement Follow-up</td>
<td>6*</td>
<td>13</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Structures of Care</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

*Although a summary score was created for ‘Provide Bereavement Follow-up’ these items should also be examined as stand-alone items.*
The internal consistency of each subscale was demonstrated by Cronbach’s alphas ranging from 0.76 to 0.96. Test-retest reliability of each subscale, except Provide Bereavement Follow-up, was demonstrated by ICC ranging from 0.81 to 0.90. The ICC for Provide Bereavement Follow-up was 0.52 which was below the 0.75 criterion for reliability. Validity of each subscale was demonstrated through EFA and support for the majority of hypotheses tested. Only four of five hypotheses tested for the Connect with Families, Share Information among Health Professionals, and Provide Care at Death subscales were supported. As well, only two of three hypotheses for the Provide Bereavement Follow-up subscale were supported. Overall, there was excellent initial evidence for internal consistency, test-retest reliability, and construct validity of each subscale.
CHAPTER 5: DISCUSSION

5.1 Domains and Indicators of Quality End-of-Life Care for Children

Through a comprehensive review of research literature published prior to 2008 and focus groups with parents in study Phase I, five domains of quality end-of-life for children were initially identified along with a number of associated indicators. The updated literature review conducted in August 2011 did not uncover additional domains (see section 2.3). In study Phase III, the number of domains was expanded to 10 through splitting some original domains into smaller ones. Each of the 10 domains is discussed below and the decision-making process for splitting domains, where applicable, is highlighted. Assessment of validity and reliability in the ‘Connect with Families,’ ‘Share Information among Health Professionals’ and ‘Provide Bereavement Follow-up’ domains is particularly highlighted as not all results were as expected. Although the focus of this study was not to draw conclusions about the quality of care provided, results about care quality for some domains are discussed in light of other research findings as further evidence for content validity of the instrument developed. Discussion of each domain includes recommendations for further research, education, and / or clinical practice where relevant.

5.1.1 Connect with Families

Items comprising the ‘Connect with Families’ domain were written to assess care provided to the child and family by all involved health professionals. Several mothers commented in this section that it was sometimes difficult to assess care provided by health professionals as a whole rather than to assess care provided by specific professional groups. Other researchers have asked parents separately about the care provided by each profession, such as physicians and nurses, or even more specifically about care provided by the primary care physician/oncologist, other physicians/oncologists, home care nurses, social workers, dietitians, and activity coordinators (Heath et al., 2009; Monterosso et al., 2009; Wolfe et al., 2000). While a similar separation was considered when instrument items were developed, items were written to focus on health professionals as a whole. The most important rationale for this decision was to reduce respondent burden. The high Cronbach’s alpha of 0.96 indicates there is
some redundancy in the subscale of 16 items. However, it was difficult to identify items for deletion due to the high face validity of all items as assessed by parents. A larger sample and item response theory could be used in future research to assist with identifying items that could be deleted from this domain. Future development of the instrument could also include review of items in this domain with parents in an effort to include only those most representative of the overall intent of the domain. The reduced number of items could then be used to measure the connections with each professional group separately while still trying to keep the total number of items as low as possible.

It was hypothesized that care by a pediatric palliative care team would result in statistically significant higher scores in the ‘Connect with Families’ subscale. This hypothesis was not supported. Except for the two hospices included in the study, all of the pediatric palliative care teams worked as consultants to the primary care team rather than providing front-line care. The lack of significantly higher scores may reflect the large number of health professionals involved in the day-to-day care of a dying child and the assessment of all of these health professionals as a single group by mothers. Parents in one other study recognized the additional skills brought by health professionals with specific training in end-of-life care (Konrad, 2008). If the ‘Connect with Families’ subscale was revised as indicated above, a separate assessment of connections with members of the pediatric palliative care team could be included. One would expect the total score from this assessment to be higher than scores for other professional groups or teams. Support for this hypothesis would lend further support for validity of the subscale. Additionally, if there were a larger number of participants who received care in a hospice setting, one would expect the ‘Connect with Families’ subscale scores to be higher for this group. This hypothesis could also be tested in future research.

In terms of recommendations for education and clinical practice, the summary score for this subscale was 77.7 out of 100 and satisfaction was 80.8 out of 100. These scores are relatively high in comparison with some of the other subscales. However, mothers still added comments about particularly negative interactions with some health professionals. Other researchers have identified the long lasting negative impact of these types of encounters (Contro et al., 2002, 2004; Gordon et al., 2009; Konrad, 2008; Meert et al., 2007; Pector, 2004b; Rini & Loriz, 2007; Surkan et al., 2006; Widger & Picot, 2008). It is important that all health professionals
are given training and education about how to appropriately connect with patients and families so these negative encounters are eliminated.

5.1.2 Involve Parents

In the first instrument draft, one item in the ‘Involve Parents’ subscale asked if health professionals helped the mother to feel as though she was a ‘good parent.’ Based on feedback from health professionals and parents in study Phase II, the term ‘good parent’ was replaced to ask if health professionals helped the mother feel she was doing the best she could for her child (item 23). Part of the concern raised by health professionals, in particular, was the lack of definition of the term ‘good parent.’ Researchers in one of the studies included in the addendum literature review asked parents how they defined the term ‘good parent’ and what strategies health professionals might use to support them to be good parents (Hinds et al., 2009). Virtually all of the strategies identified by Hinds and colleagues as supporting ‘good parents’ were already included in the instrument across all subscales except ‘Share Information among Health Professionals.’ The notion of being a ‘good parent’ is important because researchers have suggested that parents’ view of themselves as having been a ‘good parent’ may help with better coping in the years after the death (Hinds et al., 2009; Woodgate, 2006).

These findings suggest two potential considerations for future research. Firstly, the wording of item 23 could be changed to use the term ‘good parent,’ particularly if some of the definition from Hinds and colleagues was included. Secondly, an outcome item could be added to the instrument to ask parents if looking back on the child’s end-of-life period, they feel they were a ‘good parent.’ One would expect this outcome to correlate with scores from all subscales except ‘Share Information among Health Professionals’ since interventions identified by Hinds and colleagues as helpful are included in several domains. The addition of this outcome would provide opportunity for further assessment of the validity of the instrument. In terms of education and clinical practice, health professionals who provide care to dying children and their families may want to consider asking parents about their definition of a good parent and how the health professional might support them in achieving this goal.
5.1.3 Share Information with Parents

In study Phase III, the ‘Share Information’ domain was split into two separate domains named ‘Share Information with Parents’ and ‘Share Information among Health Professionals’. Results from exploratory factor analysis indicated two factors may be present. Conceptually, this split was appropriate as information-sharing with parents may be unrelated to information-sharing among health professionals. Therefore, the ‘Share Information’ domain was split into two domains.

The ‘Share Information with Parents’ domain consists of a 9-item subscale focused broadly on how information was shared, as well as a number of additional items focused on specific topics that parents indicated were important to discuss. The mean subscale score (69.8 out of 100) and mean satisfaction score (76.4 out of 100) were among the lowest domain scores in the instrument. Similar findings from other researchers lend additional support for the content validity of this domain. Monterosso et al. (2009) found that parents of children who died from cancer wanted more information about many aspects of care even if they also indicated that their information needs had been met in that area. Other researchers have also identified the importance of health professionals being skilled in the provision of comprehensive, honest information in easy to understand language (Gordon et al., 2009; Hinds et al., 2009; Meert et al., 2008; Moro et al., 2011). The ability to share information appropriately and comprehensively is an important area to be included in education for all health professionals.

In the stand-alone items related to information-sharing, it was interesting to note that while the majority of parents (86.7%) indicated they had a discussion with health professionals about the possibility that their child might not survive his/her illness, 24.2% of those parents wished the discussion had happened ‘a lot’ or ‘a little’ sooner. Only 4.7% felt that health professionals raised this issue too early in the disease course. Additional support for content validity of these items was found particularly in the appended literature review. Several researchers identified parents’ desire to be told earlier about the likely death of their child to enable better preparation for this inevitable outcome. Lack of discussion about the possibility of death was closely linked to the idea of health professionals giving false hope, which parents did not find helpful (Gordon et al., 2009; Meert et al., 2008; Midson & Carter, 2010). Research findings included in the original literature review seemed to focus on supporting and facilitating hope (Antle et al.,
2005; Contro et al., 2002, 2004; Davies & Connaughty, 2002; Hsiao et al., 2007; Laakso & Paunonen-Iilmonen, 2001; Pector, 2004b; Robinson et al., 2006; Steele, 2002, 2005a, 2005b; Tomlinson et al., 2006; Wocial, 2000). Following study Phase I focus groups, the indicator on supporting hope was expanded to indicate that hope should not be supported at all costs. The associated item in the instrument asked how often health professionals were able to maintain a balance between hope for a cure and preparation for death. Nearly 60% of respondents indicated health professionals were able to maintain this balance. The items about hope are part of the ‘Support Parents’ subscale in the revised instrument while the items about discussion of death are in the ‘Share Information with Parents’ domain. Ideally, in future research a large enough sample would be available to assess the factor structure of the instrument as a whole rather than examining each domain separately. This assessment would give clearer guidance on how items should be organized into domains. It may be that these items are correctly placed into separate domains, or they could be together in one domain.

In terms of recommendations for education and clinical practice, health professionals should be aware of parents’ interest in talking earlier about the possibility of death. Physicians may be reluctant to raise the possibility of death with parents as it is obviously a difficult topic and there may be concern about taking away parents’ hope particularly if there is prognostic uncertainly. Maintaining a balance between ongoing hope for a cure and preparation for death is a delicate but important skill for health professionals.

5.1.4 Share Information among Health Professionals

Four of the five hypotheses tested for the ‘Share Information among Health Professionals’ were supported. Subscale scores were not statistically significantly higher when a pediatric palliative care team provided care to the child and family. As pediatric palliative care teams work as consultants, having this additional team involved may actually add another differing opinion into how care is provided to a family, which may explain the lack of difference in scores. One might expect a greater difference in scores when the child dies in a hospice as there is generally just one team providing care at this time. Unfortunately, due to the small number of participants who received end-of-life care at a hospice, this hypothesis could not be tested. In future research, it would be helpful to have a larger sample who received care in a hospice to facilitate further validity testing of the subscale. In terms of implications for clinical practice, members
of pediatric palliative care teams should ensure appropriate sharing of information among all care providers when providing consultation services to health professionals and families.

### 5.1.5 Support the Child

Indicators and items comprising the ‘Support the Child’ domain were originally conceptualized as part of ‘Alleviate Suffering’ along with items relating to support of parents and siblings. Originally, all these items were grouped together based on Family Systems Theory and the idea that suffering of one family member affects the suffering of other family members (Wright et al., 1996). While this may still hold true, health professionals generally target specific supportive interventions to specific family members. Hence the items relating to supporting the child, supporting parents, and supporting sibling were separated into their own domains.

Items in ‘Support the Child’ were focused on the child’s pain and symptom management. Content validity of these items is strengthened by being inclusive of symptoms common in a variety of childhood conditions that may lead to death and that have been identified by other researchers as concerning to parents. In study Phase III, mothers reported the child suffered ‘constantly’ or ‘a lot’ from pain (28%), breathing difficulties (63.3%), sadness (13.3%), and anxiety (12.8%). These items were based on items used by Wolfe et al. (2000) in a landmark study that highlighted the high prevalence of pain and other symptoms in the last month of life for children dying from cancer. These items have also been used in two other studies that included parents of children who died from cancer. In one study (Wolfe et al., 2008), parents reported that children suffered ‘a great deal’ or ‘a lot’ from pain (47%), dyspnea (37%), and anxiety (39%). In the second study (Heath et al., 2010), parents reported that children suffered ‘a great deal’ or ‘a lot’ from pain (45%) and dyspnea (20%). Differences in the proportions of children’s suffering from each symptom are likely reflective of the population included in each study. In the current study, a higher number of infants may have contributed to lower reports of anxiety; while a higher number of deaths in intensive care units where children are more likely to require ventilator support may have contributed to higher reports of breathing difficulties.

Study findings and results of research included in the appended literature review indicate some symptoms that could be added to this section of the instrument for future research. The item assessing how well the child’s social needs were met during the end-of-life period was deleted.
as part of the analysis in study Phase III. ‘Loneliness’ could be added to the list of symptoms to ensure the indicator about the child’s social needs is still measured in the instrument. Fatigue was not included in the symptom list since it is most relevant to children with cancer and it was expected that the number of respondents whose child died of cancer would be relatively low. Cancer was actually the second largest disease group, so future versions of the instrument could include an item reflecting this symptom. Changes in behavior and appearance were two symptoms identified by researchers as concerning to parents in the appended literature review (Pritchard et al., 2008). These symptoms could also be added to the list included in this instrument.

5.1.6 Support Siblings

Only 80 of the 128 mothers who completed the survey had children other than the one who died. Some of these siblings were very young or lived far away from the hospital where the child received care, so many of the items related to siblings were not applicable even when there was a sibling in the family. The importance of supporting siblings was highlighted in many of the comments mothers added to the instrument and in findings from other researchers (Contro et al., 2002; deCinquè et al., 2006; Heath et al., 2009; Konrad, 2008; Monterosso et al., 2009; Roose & Blanford, 2011). The items about sibling needs were retained in the instrument as stand-alone items because they had good content and face validity. These items should be tested in future research with a larger number of families who have multiple children in order to assess the reliability and validity of creating a subscale with these items. However, future research should also include development of an instrument to measure siblings’ perceptions of the care they received rather than only having their parents speak for them.

5.1.7 Support Parents

It was clear from Phase I focus groups and the literature review that not all parents need or want the same things from health professionals. Instrument items were worded to reflect this finding by asking how often parents received the ‘right amount’ of support in whatever aspect of care the item was focused. The follow-up question to these items asked if parents wished they had more or less support in the area. These follow-up questions were deleted from the instrument because the vast majority of those who responded indicated that more support was
needed, thus adding little new information for health professionals. However, it was interesting to note that many respondents who said they did not ‘always’ get the right support in the first question did not specify in the second question if more or less support was needed. This finding may indicate that parents do not expect or want health professionals to meet all of their needs.

In the adult cancer literature, similar findings were reported by Steele and Fitch (Fitch & Steele, 2010a, 2010b; Steele & Fitch, 2008a, 2008b) where many study participants had unmet needs in all areas assessed, but not all wanted assistance from health professionals to meet those needs. The researchers explored this finding further by interviewing patients with lung cancer about their needs and how they wanted those needs met (Steele & Fitch, 2008b). Some reasons for not asking for or wanting help with identified needs included being self-sufficient and having other support networks outside of the treatment setting to meet needs. However, some patients perceived health professionals as too busy to meet their needs or believed that if health professionals had not raised a particular issue there likely was nothing that could be done to meet that need. Similarly, parents who took part in focus groups or responded to open-ended items in the instrument commented that they often did not know what was possible or what their options were for how care could be provided. They relied on health professionals to raise issues that could or should be addressed. Konrad (2008) also found parents reluctant to identify personal needs to health professionals, although they appreciated when health professionals asked about their needs. These findings suggests that health professionals should not only anticipate and conduct a comprehensive assessment of families’ needs at end-of-life but should recognize and respect parents’ autonomy to decide if and what type of help is required for any identified needs (Steele & Fitch, 2008a). Provision of comprehensive information about all aspects and options for care may empower parents to make informed decisions about the type of care that will best meet their needs. These findings also support the content validity of current wording of instrument items to reflect differences in parent needs and of items specific to health professionals anticipating family needs (items 34 and 67).

5.1.8 Provide Care at Death

Items comprising the ‘Provide Care at Death’ subscale were originally part of the ‘Alleviate Suffering’ subscale. As described above, the ‘Alleviate Suffering’ subscale was split into three groups of items relating to supporting the child, supporting siblings, and supporting parents.
The items specific to care provided at the time of death were initially left with those about supporting parents. Through exploratory factor analysis, two subscales were identified: one with items specific to supporting parents and the second with items specific to care provided at the time of death. Some well-established guidelines for provision of pediatric palliative care (Association for Children with Life-Threatening or Terminal Conditions and their Families, 2003; CHPCA, 2006) include care provided at the time of death as a separate domain, providing conceptual support for separating these items into two unique domains because they offered conceptual foci. As this was a new domain, there was no associated outcome item about parents’ overall satisfaction with the care provided at death. This item should be added to maintain consistency across the instrument and be tested in future research.

5.1.9 Provide Bereavement Follow-up

‘Provide Bereavement Follow-up’ had the lowest subscale score (3.9/6) and the lowest satisfaction rating (64.6/100) by mothers compared with all subscales. However, the subscale also had the weakest evidence of reliability and validity. Exploratory factor analysis could not be conducted as many items had dichotomous response options and those that did not had very low or negative correlations with other items. Internal consistency was not assessed given the lack of correlations among items. An ICC of 0.52 did not support the test-retest reliability of the subscale. Assessment of all other subscales included testing five hypotheses, while only three hypotheses could be tested for this subscale and one of these was not supported.

One issue with the subscale was the design of items to measure individual interventions that may be included as part of bereavement follow-up. Recognizing that all parents may not want the same thing, items were worded to ask whether or not a particular intervention was offered. The interventions included in the instrument were those most commonly mentioned in the literature or in study Phase I focus groups as being important components of bereavement follow-up. However, it is important to note that there is little evidence for the effectiveness of any of these interventions in helping families cope with the grief experienced when a child dies (Thompson et al., 2011). While health professionals at each recruitment site indicated that many of these components are meant to be offered to families, not all components are consistently offered due to funding issues or not having a coordinator to oversee program implementation. This inconsistency contributed to low correlation among mothers’ responses to
items in the subscale as well as difficulty implementing exploratory factor analysis and tests of internal consistency to assess psychometric properties. As noted in the results section, since there was a mean time of 42 days between the first and second completion of the instrument, it is possible that mothers received additional components of bereavement follow-up during this time as reflected in the low ICC and a slightly higher score at Time 2. As well, mothers may have viewed the instrument as part of bereavement follow-up leading to increased scores when the instrument was completed for the second time.

Based on findings from Phase I focus groups, comments from mothers who completed the instrument, as well as findings from other researchers (Contro et al., 2002; D'Agostino et al., 2008; Macnab et al., 2003; Meyer et al., 2006; Monterosso & Kristjanson, 2008; Skene, 1998; Widger & Picot, 2008), it seems that parents value continued support from the health professionals who provided care to the child and family. While the subscale to measure this area has content and face validity, additional reliability and construct validity testing are needed. For now, the items can be used primarily as stand-alone items. If the instrument were to be used as part of a quality improvement program at a hospital, subscale items could reflect those components offered as part of bereavement follow-up at that hospital. The number of interventions parents report being offered could be simply counted as was done in this study. However, it is also important to ask parents whether the interventions they received were helpful, as was done in this instrument. In future research it would be valuable to use the instrument to explore whether provision and parents’ perception of the helpfulness of these interventions is linked to long-term grief or coping outcomes.

In the appended literature review, one additional component of bereavement follow-up was identified that could be added to the instrument. Williams et al. (2009) identified the need to provide parents with emergency contact numbers when they leave the hospital with their child. In this same study, a number of very specific items about bereavement follow-up were included in an instrument administered to Social Workers. Some of these items could be considered for addition to future versions of the instrument developed in the current study.
5.1.10 Structures of Care

The indicators for the ‘Structures of Care’ domain were originally part of the ‘Alleviate Suffering’ domain developed in Phase I. When instrument items were developed in Phase II, items related to structures of care were developed and placed into a separate section of the instrument primarily based on Donabedian’s (1988) model for assessing quality of care. Some of these structures are related to the practical needs of the family for food, a place to stay, and transportation. Support for practical needs is assessed by one item in the ‘Support Parents’ subscale (item 55). However, it is important to assess both whether important structures are available in a hospital (kitchen facilities, playrooms, parking, and a place to sleep) as well as whether health professionals assist parents to access these resources. Both these aspects are included in the instrument.

Comments from participants in study Phases II and III indicated that while some of the structures included in the instrument may not be specific to end-of-life care, the lack of availability of appropriate accommodation for families, food, and parking can significantly add to the distress of families. Other researchers have also indicated a need for greater attention to these structures of care when assessing quality of pediatric end-of-life care (Hale et al., 2008; Midson & Carter, 2010). The need for appropriate bathing facilities for families when they are spending a great deal of time at the hospital was mentioned by one researcher (Hale et al., 2008). An item could be added to the instrument to assess this structure of care.

Similar to the bereavement follow-up subscale, there was little relationship found among each of the structures assessed. The presence of any given structure did not result in a greater likelihood of any other structure being present. The items comprising the ‘Structures of Care’ domain were retained as stand-alone items because they have good content and face validity. An outcome item could be added to the domain to assess overall satisfaction with hospital facilities since all of the other domains have this type of item. Not including this outcome item in the initial development of the instrument was an oversight.

5.2 Process Issues

Through this study, a great deal of information and experience was obtained on the process of conducting research with bereaved parents. Some challenges encountered in conducting the
study are discussed along with recommendations for how to administer the instrument in the future. Key areas discussed are recruitment issues and impact of participation on parents.

5.2.1 Recruitment Issues

Recruitment of a sufficient sample size for Phases I and III of the study was a significant issue. In Phase I, it was difficult to find a way to reach bereaved parents. Contact with parents was sought through two chapters of ‘Bereaved Families of Ontario,’ a group that provides support to families who have experienced the death of any family member – not just a child. Although newsletters from these groups were widely distributed, it was unknown how many bereaved parents actually received information about study focus groups. Initially, recruitment plans for Phase III were similar to Phase I, with advertisements inviting parents to take part in the study to be placed in newsletters, on websites, or in newspapers across Canada. Given the very low number of responses from Canada’s largest city for the focus groups, and the relatively large number of participants needed for Phase III, a different approach was needed. Possible alternate approaches were identified through review of recruitment methods employed in other research, as well as through discussions with focus group participants.

Parents in Phase I focus groups indicated the importance of knowing the information they provided to the researcher would be shared with the health professionals who provided end-of-life care to their child and family. This response resonated with how researchers in all but one study included in the literature review contacted parents through the setting where care was provided. This method allowed results to be shared directly with the site from which participants were recruited. Thus, for study Phase III the decision was made to contact mothers through specific hospitals / hospices across Canada. With this approach, a written report for each participating site with site-specific results was made possible. This recruitment method led to a sufficient number of participants to conduct psychometric testing, even though the overall response rate was still relatively low. The low response rate is a concern for future use of the instrument in research or as part of quality improvement initiatives. Some factors that may have contributed to the low response rate included the method of administering the instrument, timing of initial parent contact, and use of opt-in versus opt-out methods of recruitment. Each area is addressed below with suggestions for how to improve response rates when the instrument is administered in the future.
5.2.1.1 Method of Administration

Parents in Phase I focus groups were asked if questions about quality of care should be asked in person, by telephone, in written format, or by computer. Participants indicated that it would be best for parents to have a choice about how to take part in this type of research. While this would be ideal, participants may respond differently to questions depending on the method used to ask the questions, particularly when questions are of a sensitive nature (Addington-Hall, Walker, Jones, Karlsen, & McCarthy, 1998; Dillman, 2000; Tourangeau & Yan, 2007). Differences may be due to social desirability or unintended “coaching” by the research assistant when assisting with completing the questions by telephone or in-person compared with a written format. The original plan was to use telephone interviews for Phase III. Most parents in the focus groups indicated telephone would be their last choice for completing an instrument of this type. Their first choice was in-person interviews and their second choice was a written instrument. Given the large geographical area that most pediatric hospitals in Canada serve, the instrument could not be easily administered in-person due to travel costs.

Wolfe et al. (2000) conducted similar surveys by telephone with parents of children who died of cancer. However, they switched to using a written format and reported little differences in response rates or reports of stress by parents (Personal Communication, Joanne Wolfe & Veronica Dussel, August 5, 2009). At this early stage of instrument development, it was important that all parents complete the instrument in the same format. Based on parent recommendations, discussions with other researchers, and ease of administration, a written format was chosen for use in study Phase III.

Where focus group participants felt the in-person interviews would be the best for parents, those who took part in Phase III indicated a written instrument was best. It is not surprising that those who preferred a particular method agreed to participate in research that used that method. One would think that offering multiple methods of taking part would result in a higher response rate. Interestingly, Wolfe et al. (2008) reported little difference in response rates between two studies with similar populations when the survey was offered by telephone only (72% response rate) versus when parents were given the option of completing the survey by telephone, in person, or on paper (71% response rate). In future research, it would be helpful to offer parents
multiple formats to participate in this type of research and to further study the effect of different methods of administration on response rates and reports of quality end-of-life care.

In some previous studies where a mailed survey was used, researchers also made a follow-up telephone call to parents to ask if the survey was received and if there were any questions about the survey or the study (Kreicbergs et al., 2004a; Midson & Carter, 2010; Wolfe et al., 2000). Another method used with mailed surveys to increase response rate involves repeated rounds of mailing the survey, reminder cards, and additional copies of the survey to non-responders (Dillman, 2000). It is possible that the response rate across all sites may have increased by employing any of these methods. However, due to privacy issues, the local clinicians who assisted with recruitment would have needed to make these individual follow-up phone calls or track responders and non-responders for repeat mailings. These additional requirements seemed too burdensome to ask of local clinician collaborators. As well, at some sites it is likely that the local ethics board would see these types of reminders as too intrusive for bereaved parents and not approved this approach. At one site, a reminder letter was inadvertently sent to all potential participants, but only one additional survey was received after this reminder. If a written format is used to administer the instrument in the future, a follow-up telephone call should be used to help improve response rates.

5.2.1.2 Timing of Parent Contact

The timing of mailing the survey may have impacted response rates. In previous research, bereaved parents were contacted as early as three months after the death of their child (Meert et al., 2008) while other researchers waited until at least four years after the child’s death (Kreicbergs et al., 2004a; Meert et al., 2008). Participants in Phase I focus groups indicated parents could be contacted as early as three to six months after their child’s death to participate in this type of research. At one recruitment site, members of the ethics review board required that parents only be contacted once they were past the one year anniversary of the child’s death due to concerns about grief being too intense in the first year after death. There was no correlation found between the time after death that the instrument was completed and either mothers’ reports of degree of stress or pain caused by completing the instrument ($r = 0.02, p = 0.87$), or on reported positive or negative effects of taking part ($r = 0.09, p = 0.29$). As well, two mothers who completed the survey more than two years after their child’s death suggested that
a survey at six months might be better as they were worried they had forgotten specific details of the child’s care. On the other hand, one group of researchers found an unusually low response rate (32.3%), as compared with other studies they had done with similar populations (response rates of 48% to 76%), when they contacted parents 6 to 10 months after the child’s death (Pritchard et al., 2008). Those researchers noted that some parents (15 of 161 approached to take part) felt the timing of the study was too soon after the child’s death.

There is little evidence to guide the most appropriate time to contact parents to take part in this type of research. In Phase I focus groups, participants indicated that each parent would likely feel differently about what they were willing to take part in and when. They suggested parents be initially contacted at six months but be given the option to be contacted again in a few months if they were not ready to provide feedback at that point. Given the timelines of the current study, it was not possible to allow parents this flexibility. However, in future research it would be ideal to approach parents six months to one year after the child’s death and offer three options: 1) agreeing to take part, 2) refusing to take part but agreeing to be contacted again in six months, or 3) refusing to take part and requesting to not be contacted again. This method of approaching parents may improve response rates although it also may increase study timelines and costs.

5.2.1.3 Opt-in versus Opt-out

Based on requirements of the research ethics board at each recruitment site, both opt-in and opt-out methods of contacting and recruiting mothers were used. There was a significant difference in response rates between the two methods (11.6% using opt-in versus 21.3% using opt-out). There are at least two possible explanations for this difference. Mothers recruited through the opt-out process may have felt pressure to complete the instrument once it was in their hands, thus resulting in a higher response rate. However, none of the mothers indicated feeling pressured by the researchers in their responses to items assessing the impact of participating in the study. Another possible explanation is that mothers recruited through the opt-in method did not have the energy to do the extra step of returning the enclosure card to indicate willingness to receive a copy of the instrument. Hinds et al. (2007) reported lower response rates when there were multiple steps required of parents prior to participating in research. In that stud, there were six additional steps required from parents rather than the one
additional step in this study. However, in this study the extra step may have been an additional burden on parents that contributed to lower response rates.

In this study, at one site there was an issue with using the opt-out method of recruitment. Although there was a three-week window between mailing the letter and mailing the instrument, seven additional opt-out cards were received after the surveys had been mailed. As well, at least two mothers received the survey package before the letter. Both these mothers indicated they would complete the instrument once they spoke with the researcher and realized they were not meant to receive the survey ‘out of the blue.’ It is possible that other mothers also received the survey package before the letter and were upset by this but did not contact the researcher and did not complete the instrument. It is impossible to control the speed of mail delivery unless a courier service is used to deliver letters and survey packages. However a courier service would significantly increase research costs. Parents could be asked to leave a voice mail at a toll free number or send an email to the researcher before a certain date to indicate their desire not to receive further contact to prevent opt-out cards and survey packages crossing in the mail. Alternatively, the time between mailing the letter and the instrument could be extended to four weeks although this may cause another issue. In a previous study the recruitment process included a letter with an opt-out card followed by a phone call two to three weeks later to administer the instrument if the parent was willing (Widger & Picot, 2008). The researcher was contacted by a couple of parents who wanted to take part in the study but were becoming anxious while waiting for the phone call to complete the instrument. These parents wanted to take part in the study but also wanted to ‘get it over with.’ It may be best to contact parents first by letter and then by phone to see if the letter was received and if they are willing to take part, rather than risking a parent receiving a survey package with no warning or waiting for a prolonged time to receive the survey package.

The opt-out method of recruitment would be preferable to use in future research to increase response rates even though this method has other challenges. Study findings indicate that parents do not feel unduly pressured by the researcher when this method of recruitment is used.
5.2.2 Impact of Participation on Parents

Study findings support existing research about parents’ willingness to share the story of their child’s death and provide input to help other families (Collins et al., 1998; Contro et al., 2002; Monterosso et al., 2009; Pritchard et al., 2008; Widger & Picot, 2008; Woodgate, 2006). Parents appreciated the opportunity to ‘give back’ to others through research as a way of making sense of their experience or having the child ‘live on’ through the study. While a few parents (7.8%) indicated that study participation had a little or very negative impact, the vast majority did not regret taking part (99.2%) and would recommend to another bereaved parent to take part in a similar study (84.4%). Several researchers have found no parent reports of negative impact or distress caused by research participation (Dyregrov, 2004; Hinds, Burghen et al., 2007; Hynson, Aroni, Bauld, & Sawyer, 2006; Scott, Valery, Boyle, & Bain, 2002). However, in other studies parents did report emotional difficulty (45%) (Meyer et al., 2002), negative or very negative impact (28%) (Kreicbergs, Valdimarsdottir, Steineck, & Henter, 2004), or being upset by the questions (21%) (Pritchard et al., 2008). Even when parents were upset or found it emotionally difficult to take part in this type of research, they still found the study beneficial or were not any more upset than they expected to be when they agreed to participate (Kreicbergs, Valdimarsdottir, Steineck et al., 2004; Pritchard et al., 2008). Taking part in this type of research is certainly not easy for bereaved parents. However, it would seem parents are able to decide whether or not they are able to cope with the emotional impact of revisiting the child’s death in this specific way (Hinds, Burghen et al., 2007). It is still up to the researcher to assess for any negative impact of participating in a study and find ways to minimize it. In future research, it would be helpful to compare amongst or within studies to determine whether timing, method of initial contact (opt-in versus opt-out procedures), and method of taking part (telephone, in-person, written, or computer surveys) affect the emotional impact of participating in this type of research.

5.2.3 Summary of Recommendations for Research Process

Based on the above discussion about the process of sensitively conducting research with bereaved parents while maximizing response rates, an ideal recruitment process could be conducted in the following way:
1) Eligible parents (six months to one year after the child’s death) are contacted by a health professional previously known to them through a letter with information about the study. The letter would include a phone number and email address where parents can leave a message to indicate if they do not want to take part. The letter should also indicate a date after which they will receive a phone call from the researcher if they have not opted out.

2) Parents are contacted by phone two to three weeks after the letter is mailed to see if they received the letter about the study. If not, the study is explained if the parent is willing to hear more about it. If there are no additional questions about the study, the parent is given the option of declining to participate, declining for now but consenting to be contacted again in six months, or agreeing to take part in the study.

3) If the parent agrees to take part in the study, he/she is offered four options for completing the instrument: telephone, in-person interview, completing a written instrument, or completing the instrument via a website. Arrangements are then made for whatever method the parent chooses.

4) The instrument used in the study should include items to assess the emotional impact on parents of taking part in the study.

If this recruitment process was followed, analysis should include assessment of the impact of this process on parent response rates and emotional impact of participation. The instrument developed in this study would require additional assessment of its reliability and validity when administered using a method other than a written format.

5.3 Study Limitations

There are a number of known and unknown limitations in this study. Possible study limitations include recall bias, low response rate, method of factor analysis, and researcher bias. Each limitation is discussed below along with its potential impact on the reliability and validity of study findings.

5.3.1 Recall Bias

One limitation of the study was its retrospective nature. Participants were asked to accurately recall events that occurred at least six months previously. It is possible that parents’ perceptions
of events that occurred at the time of their child’s death may have changed over time as part of the grieving process (Teno & Coppola, 1999). However, in a previous study, surveys were completed by parents up to eight years after the death of their child and researchers found no correlation between the interval since death and the degree of the child’s suffering reported by the parents (Wolfe et al., 2000). Similarly, researchers in another study found the length of time since death did not change parents’ reports of how long before death they were aware the child would die (Valdimarsdottir et al., 2007). The length of time between the child’s death and interviews with parents in previous research has ranged from a few weeks to many years. It is likely that the circumstances of the child’s death and the care received during that time remain clear in the memory of the parent for the rest of the parent’s life (Addington-Hall & McPherson, 2001; Heath et al., 2009). In the current study, test-retest reliability was assessed. Previous research has not included this type of testing with this population. Results indicated that mothers’ responses to instrument subscales (except Provide Bereavement Follow-up) were consistent over time with differences in scores more likely due to random error. Therefore, there was evidence for the test-retest reliability of the instrument and a reduced risk of recall bias.

Ideally both the dying child and parents would be asked to evaluate the quality of the care they received at the time they are receiving it. However, this method raises ethical issues about contacting families in the midst of what is likely an emotional, stressful time. A retrospective method was chosen to overcome this ethical issue while recognizing the threat of a retrospective method on the reliability of the study.

5.3.2 Response Rate

A second limitation of the study was the overall low response rate. Response rates varied at each participating site ranging from 6.8% to 34.8%. Response rates in other studies focused on bereaved parents have ranged from 17% (Williams et al., 2009) to 80% (Kreicbergs et al., 2005). One concern with a low response rate is potential differences in responses from those who took part in the study and those who did not. Differences between responders and non-responders are a threat to the internal validity of the study. The study did not include a method for assessing if participants differed in some way from those who could not be contacted or chose not to take part in the study. Parents who had a particularly positive or negative
experience around their child’s death or who were coping poorly may have been more or less likely to participate. Some previous studies have included chart reviews of the entire eligible sample to assess differences between responders and non-responders on demographic factors and key care variables. Some researchers have found no differences on key demographic or care variables (Heath et al., 2009; Widger & Picot, 2008). However, Wolfe et al. (2000) found a greater number of non-participating parents had cardiopulmonary resuscitation provided to their child at the time of death than participating parents. Knapp, Madden, Curtis, Sloyer, and Shenkman (2010) found significantly lower response rates when the child was Black, non-Hispanic, or when the child was at the mid-stage of their illness as opposed to newly diagnosed or near the end of their life. The impact of these differences on study findings is unknown.

Due to potential differences in responders and non-responders, a low response rate may lead to a sample that is not representative of the population being studied and is a threat to the external validity of the study. If the primary purpose of the study was to assess the quality of end-of-life care provided to children and their families then the low response rate limits generalizability of the findings. However, the primary purpose of this study was to develop and test a new instrument. A wide range of responses and diverse experiences is most important to have in the sample when conducting initial psychometric test on a new instrument (Streiner & Norman, 2003). Since the sample was drawn from 10 different hospitals and hospices across Canada and included a range of ages and diagnoses of the deceased children, it is likely the needed variation in participant experiences was present.

5.3.3 Method of Factor Analysis

Since the instrument was conceptualized as an index consisting of several small scales, exploratory factor analysis was conducted separately on each of the hypothesized domains. Some of the items were moved amongst domains during Phase III analysis based on initial factor analysis results as well as on revised conceptualization of some domains. Ideally, exploratory factor analysis would have been conducted on the entire instrument to have better evidence for which items belong in which domains and for the overall validity of the instrument. Given the large number of items in the instrument, a sample of 750 to 1500 participants would have been required to conduct exploratory factor analysis on the instrument as a whole. In future research, achieving this sample size may be possible if multiple
recruitment sites beyond just those in Canada are used and recruitment is conducted over several years.

5.3.4 Researcher Bias

This study was essentially conducted by a single researcher under the guidance of a supervisory committee. Findings from studies included in the initial literature review and the focus groups may have been interpreted and grouped into domains differently by a different researcher or team of researchers. The use of focus groups and the involvement of health professionals and parents in Phase II was one method implemented to minimize the impact of bias from a single researcher. Preliminary study results have been presented at conferences and in education sessions with health professionals. These sessions have been well received with health professionals seeming to find the way the domains have been conceptualized as useful for their clinical practice. Researcher bias may be a threat to the internal validity of the study. However, steps were taken to minimize this bias whenever possible.

5.4 Recommendations

5.4.1 Ongoing Development and Testing

Assessment of reliability and validity of an instrument is an ongoing process (Streiner & Norman, 2006). The purpose of this study was to test the reliability and validity of the instrument when used with English speaking mothers who experienced the death of a child after an admission of at least 24 hours in a hospital or hospice setting. A number of items were deleted from the instrument in this first round of psychometric testing. As discussed above, there are several retained items that could be reworded and some items that could be added to the instrument prior to further testing. Additional research is needed to assess the reliability and validity of the instrument, once all suggested revisions are incorporated, with the same population. The revised version could also be assessed for reliability and validity with fathers and in different formats, such as a web-based version. Translation into French and other languages for testing may also be valuable for further development of the instrument.
5.4.2 Instrument Uses

Once the instrument has been established as reliable and valid with both mothers and fathers, the instrument could be used to explore the effects of different clinical and organizational models to provide end-of-life care on the quality of care. Ideally, the instrument could be used in continuous quality improvement programs at pediatric hospitals and hospices across Canada to conduct ongoing assessments of the quality of pediatric end-of-life care. Results could be used to inform health professionals, the public, and decision-makers about what should be done to improve care provided to dying children and their families. Identification of areas where care needs to be improved is a crucial step to ensure every dying Canadian child and his/her family receives the highest possible quality of care.

Study findings indicated correlations between high quality care and short-term outcomes such as mothers’ satisfaction with care, a peaceful death, and a ‘good death’ for the child. Ultimately, one would hope that provision of high quality care impacts long-term outcomes for bereaved family members such as improved physical, emotional, social, and spiritual health. Existing research indicates some links between the way care is provided prior to the child’s death and how parents cope in the years after the death (Kreicbergs et al., 2005; Meert et al., 2000; Seecharan et al., 2004; Surkan et al., 2006). However, as there has not previously been a method for measuring overall quality of care, there is little evidence of its long-term impact on family health outcomes. Once the instrument has been established as reliable and valid it could be used to explore the long-term impact of high quality care.

The 10 domains that form the conceptual model on which the instrument is based could be used as a guide for educating health professionals on how to anticipate, assess, and meet the needs of dying children and their families. Several important areas for education were highlighted above in the discussion of each domain. Similar to the quality improvement research conducted by Midson and Carter (2010) in the United Kingdom, the conceptual model could also guide development of a pediatric end-of-life care pathway that may help ensure families receive all components of high quality care as identified in this study.
5.5 Significance

The death of a child causes parents an immense amount of suffering. Care provided by health professionals has the potential to add to and magnify that suffering or to give parents the supports and tools to cope with that suffering. Study findings indicate that quality of pediatric end-of-life care can be measured so that improvements can be made in the care provided. Quality of care results from this instrument development study indicate there is room for improvement in the quality of pediatric end-of-life care and how families are supported in the midst of their suffering. The major contribution of this study is the identification of 10 domains important to high quality pediatric end-of-life care, as well as a reliable and valid way of measuring these domains from the perspective of mothers who experienced the death of a child in a hospital or hospice. Although bereaved parents have been surveyed about their views on the care provided by health professionals in previous research, none of these surveys have been subjected to a similar degree of psychometric testing. As well, these surveys have not been specifically developed around an established model for assessing quality of care such as that developed by Donabedian (1988). This study is an important step forward in promoting the highest quality care for dying children and their families.

5.6 Conclusion

It is not possible for any health professional to fix or remove the intense pain or suffering that parents experience when their child is dying, nor do parents expect this. However, parents do expect health professionals to attend to the needs of the dying child, the parents, and the siblings and to not add needlessly to their suffering.

In this study, structures, processes, and outcomes of care were identified and assessed in 10 domains: Connect with Families, Involve Parents, Share Information with Parents, Share Information among Health Professionals, Support Parents, Support the Child, Support Siblings, Provide Care at Death, Provide Bereavement Follow-up, and Structures of Care. High quality structures and processes of care in these areas are linked to important outcomes including increased parent satisfaction in each domain and overall quality ratings, as well as to parent reports of the child experiencing a ‘good death’ and a ‘peaceful death.’ Attention to these structures and processes of care will assist health professionals, administrators, and decision-
makers to support children and families in the midst of their suffering and ensure that their suffering is not magnified.

Quality end-of-life care is the right of every Canadian. Until we can accurately assess the quality of care provided we will not know where to make improvements and nor the impact of changes in practice on care quality or outcomes for families. This three-phase study was a significant step forward in creating a reliable and valid instrument to facilitate this process and improve end-of-life care for Canadian children and their families.
References


Sharman, M., Meert, K., & Sarnaik, A. (2005). What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine, 6*(5), 513-518.


Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L., & Tulsky, J. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association, 284*(19), 2476-2482.

Steinhauser, K., Clipp, E., McNeilly, M., Christakis, N., McIntyre, L., & Tulsky, J. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine, 132*(10), 825-832.


Appendix A: Phase I Advertisement to Recruit Parent Participants for Focus Groups

Measuring the Quality of Children’s End-of-Life Care
Investigators: Kimberley Widger (PhD Candidate) and Dr. Ann Tourangeau (PhD Candidate Supervisor)

Are you the parent of a child who died in a Canadian hospital?

Are you the parent of a child who died at home after a life-limiting illness?

We are looking for parents to take part in a study about the quality of care provided to dying children and their families. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed.

If your child (aged 19 years and under) died in a hospital at least one year ago, after an admission of at least 24 hours you can take part OR if your child died at home at least one year ago after a life-limiting illness you can take part. For this study you will be asked to attend a focus group with other parents held in the Toronto or Hamilton area to talk about your experiences and what you feel is important to providing the highest quality care. The focus groups will last about 2 hours. The focus groups will be held in English.

For more information, or if you are interested in taking part in this study please contact Kimberley Widger at 416-978-2859 or kim.widger@utoronto.ca. Please leave your name and phone number so we can contact you to talk more about the study.
Appendix B: Phase I Telephone Script to Recruit Parents for Focus Groups

Hello, May I speak to_______________?

My name is Kimberley Widger. You left your number by phone/email with the University of Toronto because you were interested in taking part in a study about the quality of end-of-life care that children and their families receive. I am the person who is doing the study. Are you still interested in hearing more about the study?

If NO – Thank you very much for your time. (Terminate Call)
If YES – Do you have 10 minutes or so to talk now about the study or would you prefer I call back at another time? (Either continue or book time to call back.)

I am a PhD student in nursing at the University of Toronto. My research is all about working to improve the care that is given to dying children and their families. To help with this, I am talking to parents about their experiences with health professionals before, at the time of and after their child died. I want to ask parents questions that will help us to see what we are doing well and what we need to do to improve. For the first part of the study we will be having focus groups to talk to parents. If you wanted to take part, I would ask you to come to a group with up to seven other parents. You may know some of these parents or they may all be strangers to you. I cannot tell you who will be there ahead of time.

We will hold the focus groups in the Toronto/Hamilton area in a private room. We expect each focus group to last about 2 hours. I will run the group with a research assistant. In the focus group we will ask what you think health professionals should do to give the highest quality care to children and their families. All of the discussion will be audiotape recorded and then written out on paper. We do this so we can review what was said after the group and make sure we did not miss anything.

Before I tell you any more, I would like to ask you a few questions to make sure that you are eligible to take part in this study. Just answer yes or no to each question:

1. Are you the biological, step, or adoptive mother or father of the child who died? Yes/No
2. Was your child 19 years old or less when he/she died? Yes/No
3. Did your child die at least 1 year ago? Yes/No
4. Did your child die in a Canadian hospital? Yes/No
5. Was your child in the hospital for 24 hours or longer before he/she died? Yes/No

Eligibility criteria are not met if parent answers no to any one of the first 3 questions. Explain reason to parent and thank them for their interest and time. (Note: If death occurred less than one year ago, but all other responses are yes, discuss possibility of participation in future phase of the study). If the response to questions 4 and/or 5 are no, then discuss briefly with parent the circumstances of the death. If the death was a “planned” home death or within 24 hours of admission but the death was due to a life-threatening illness and the parent feels they had enough interactions with health professionals prior to the death to comment on what high quality care should look like, then continue below with study description.

If all responses are “yes” then eligibility criteria are met. Continue with study description below.
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop taking part in the focus group at any time. If you become upset the investigator can spend time talking with you. The investigator can also refer you to someone else to help you if you wish. There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death.

At the end of the focus group you will receive $40 to thank you for sharing your experiences with us. If you come to the group but decide to withdraw from the study part way through the group, you will still get the full amount. If you agree to attend the group but then do not come to the group, you will not get the money. We will provide drinks and snacks during the focus group.

If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes.

The results from this phase of the study will be used in the next phases. If you want to take part in the next phase of the research as well, you can tell me that at the focus group.

Do you have any questions about the study or what is involved in taking part?

Would you like to take part in the study?

If NO – Thank you very much for your time. (Terminate Call)

If YES – I will book times for the focus groups when I have six to eight parents that live in the same general area willing to take part in the study.

Can you tell me the neighborhood/city that you live in? __________

Can you tell me generally what time of day or week is good for you?

Days  Evenings  Weekends

I will call you back in the next couple of weeks to book a time for the focus group. Thank you very much for your time today and I look forward to meeting with you.
Appendix C: Phase 1 Consent for Parent Focus Group

Title of Research Project: Measuring the Quality of Children’s End-of-life Care

What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we will have focus groups with parents. We will ask parents what they believe is important to quality end-of-life care for children and their families. We will have between 3 and 5 focus groups with 6 to 8 parents in each group. All groups will be held in the Toronto or Hamilton area. The second phase will involve creating the survey questions about quality care. The questions will be based on what parents said was important during the focus groups. When all the questions are created, we will ask health professionals and parents to review the questions to make sure they are clear and easy to understand. We will also ask if the questions seem to be about quality care and if anything is missing. Between 5 and 10 parents will take part in phase two of the study. The third phase of the study will involve about 100 parents. These parents will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the first phase of our research. If you want to take part in the other phases of the research you can tell us this at the end of this consent form. If you only want to take part in this first phase of the research, that is fine too.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 1 year ago. You must be the biological, step, or adoptive parent of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital after being admitted for at least 24 hours or died within 24 hours due to a life-threatening illness or at home due to a life-threatening illness. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
We will hold the focus groups in the Toronto or Hamilton area in a private room. We expect each focus group to last about 2 hours. There will be 6 to 8 parents in each group. The groups
will be led by the main investigator and a research assistant. In the focus group, we will ask what you think health professionals should do to give the highest quality care to children and their families. All of the discussion will be audiotape recorded and then written out on paper. We do this so we can review what was said after the group and make sure we did not miss anything.

**What are the risks of taking part in this study?**
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop taking part in the focus group at any time. If you decide to stop, anything you have said during the group up to that time will still be included in our analysis. If you become upset the investigator can spend time talking with you. The investigator can also refer you to someone else to help you if you wish.

**What are the benefits of taking part in this study?**
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

**How will my privacy and confidentiality be maintained?**
Confidentiality can only be guaranteed to the extent permitted by law. Confidentiality can only be maintained if parents who take part in the group do not talk about what went on in the group with other people. The audiotapes will be erased after the discussion has been written out on paper. Your name and other identifying information will be removed and kept separate from the data. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The results from this phase of the study will be used in the next phases. If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you at the end of this consent form. Updates about the study and results will be posted on the following website: (TBA). There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that will be made using the results from this study will be free for use by any health professional who wishes to use it. The investigator will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
At the end of the focus group you will receive $40 to thank you for sharing your experiences with us. If you come to the group but decide to withdraw from the study part way through the group, you will still get the full amount. If you agree to attend the group but then do not come to the group, you will not get the money. We will provide drinks and snacks during the focus group session.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca
If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

**How do I get a copy of the results of the study?**
You may ask for a copy of the final reports from this study.

☐ I would like to receive a copy of the final report for the first phase of this study.

☐ I would like to receive a copy of the final report for the whole study.

If so, please provide an email address or a mailing address where you would like the results sent.

________________________
________________________

**How do I take part in the next phases of the study?**

☐ I am willing to be contacted by the investigators to take part in the second and/or third phase of the study. Contact telephone number: _________________________________

**CONSENT**

I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. I consent to having the focus group discussion tape recorded. A copy of this form has been given to me. I voluntarily consent to take part in this study.

________________________  __________________________  __________________
Participant Name (Print)  Participant Signature  Date

________________________  __________________________  __________________
Name of Person Witnessing Consent  Witness Signature  Date

(Print)
Appendix D: Parent Focus Group Script and Questions

Welcome everyone and thank you so much for taking the time to come and meet with us today to share your thoughts and experiences. You will be helping us to improve the quality of care that is given to dying children and their families in the future.

My name is Kim Widger. I am a PhD candidate and this study is part of my PhD work. I will lead the discussion today. This is Ashley. She is a research assistant who will be with us today to help take notes and make sure our discussion is recorded.

Before we get started I want to review a few things that I talked with each of you about on the phone before you came to the group, and I need each of you to sign a consent form saying that you are willing to take part in this study.

Today we will be talking about what you think health professionals should do to give the highest quality care to children and their families. All of the discussion will be audiotape recorded and then written out on paper. We will use what you tell us in this phase of the study in the next phases of the study where we will be making a survey to ask more parents about the quality of end-of-life care that they and their child received.

As the researchers, we will be talking about what you tell us today, but we will not share your names or your child’s name or any of your specific information with anyone else. All of that information will be removed from what you tell us today. While we will do everything that we can to keep your information confidential, we cannot guarantee that others in the group will not talk about what went on in the group.

(Distribute and sign consent forms. Leave a copy with each participant.)

Does anyone have any questions before we get started?

(Have participants introduce themselves and say a little bit about their child. Then continue with questions)

1. What does quality end-of-life care mean to you?

2. What are the most important things health professionals should do to provide high quality end-of-life care to children and their families?
   Prompt: You may want to think of things that actually happened to you or that you wish had happened to you.

3. Based on research with other parents I developed a list of areas and some items within each of those areas that parents felt were important (show list of domains then each domain with its indicators separately – see attached). How do they fit with what we have been talking about today? What would you add or remove? (Ask about the domains as a whole and then the indicators within each domain.)

4. How important is it for bereaved parents to be asked for feedback about the care they and their family received?
5. What is the best way to approach parents and ask them for their feedback?
   Prompt: Do you think the telephone, written questions, in-person interviews or questions
   on the web would be the best?

6. When is the best time to ask?
   Prompt: Do you think questions should be asked in the first few weeks? After 6 months?
   After a year? Longer?

7. One concern with doing this type of research with bereaved parents is that it will be
   emotionally difficult for them to talk about their child and the experiences around their death.
   What do you think about this concern? (Show impact questions and ask for feedback on
   wording of items i.e. painful vs. emotionally difficult. Have participants complete the questions
   related to their experience in the focus group).

8. When we ask parents about the care that they received we will also need to ask a few
   questions about the child and how and where they died. We will also need to ask some questions
   about the parent who is answering the questions. (Show questions on background and
demographics and ask for feedback on wording and order of questions. Have participants
complete the questions on background and demographics.)

9. To finish our group we will review the main points of what we have talked about today.
(Present points) Is there anything anyone would like to add or do you have any questions or
comments about your experience today?

10. Thank you for your time and thoughtful comments in our group.
## Domains and Indicators of Quality Children’s End-of-Life Care

<table>
<thead>
<tr>
<th>Domain</th>
<th>Indicators</th>
</tr>
</thead>
</table>
| **Connect with Families** | Accessible and consistent health professionals involved in care  
Connection between health professionals and all family members  
Individualized care  
Parent/child did not feel avoided or abandoned  
Trust between health professionals and family  
Health professionals have good communication skills, appropriate sense of humor, and demonstrate sensitivity when breaking bad news  
Small acts of human kindness demonstrated  
Satisfaction with the connections between health professionals and the family |
| **Involve Parents** | Space for parent to be physically present with child  
Health professionals demonstrate respect for parent view and support decisions  
Parent feels supported in their role as parent  
Parent’s desired level of involvement in child’s physical care is respected  
Parent given opportunity to be present for life-threatening events  
Satisfaction with level of involvement in decision-making and in child’s care |
| **Alleviate Suffering** | Opportunity to conduct any rituals  
Privacy  
Space for all family members  
Noise minimized  
Family not rushed  
Child’s physical, emotional, social & spiritual symptoms are assessed and treated  
Parents'/siblings’ emotional, social & spiritual suffering are assessed and treated  
Assistance provided for nutrition, transportation, and financial needs of family  
Health professionals are technically competent  
Hope is supported  
Health professional is present and supportive at time of death if wished by family  
Options for timing and location of death provided if life support is withdrawn  
Child’s death free from suffering and respects needs and wishes of child & family  
Satisfaction with treatment of all child’s symptoms  
Satisfaction with support of parents  
Satisfaction with support of siblings |
| **Share Information** | Health professionals give complete, honest, consistent, & concrete information  
Health professionals respect the amount of information desired by parents  
Information given to prepare parents for the death  
Information given about what to expect at the time of death  
Information needs anticipated by the staff  
Adequate time provided to share information  
Information offered appropriately to child by health professionals  
Information is appropriately shared among health professionals  
Satisfaction with information given to parents  
Satisfaction with information given to child  
Satisfaction with information shared among health professionals |
| **Provide Bereavement Care** | Memorial service held by health centre  
Support groups available through health centre  
Written information provided  
Desired mementos collected  
Assistance with funeral arrangements offered  
Autopsy discussed sensitively  
Organ/tissue donation discussed sensitively  
Autopsy results received in a timely manner  
Follow-up meeting with health professionals offered after child’s death  
Parents did not feel abandoned after the death  
Health professionals continued contact with the family (calls, letters, etc.)  
Grief information provided  
Satisfaction with the follow-up support provided by the health centre |
Appendix E: Phase I Items on Impact of Participation

1. How valuable is it to conduct research about parent’s views on the quality of care given by health professionals?
   - Not valuable
   - A little valuable
   - Very valuable

2. Why did you agree to participate in this research study? (Check all that apply)
   - ___ To help others in a similar situation
   - ___ So I could talk about the experience I had
   - ___ Was pressured by my family/friend
   - ___ Was pressured by the researcher
   - ___ Other (please explain) ________________________

3. How painful was it to participate in this study?
   - Very painful
   - A little painful
   - Not painful at all

4. Compared to what you might have been expecting, were the questions:
   - More painful than expected
   - About what I expected
   - Less painful than expected

5. Overall would you say participating in this study had a positive or a negative effect on you?
   - Very positive/A little positive/Neither positive or negative/A little negative/Very negative

6. Do you regret participating in this study?
   - Yes
   - No

7. Would you recommend to another bereaved parent that they participate in a similar study?
   - Yes
   - No

8. Which do you think would be the best way to ask parents the survey questions? (check one)
   - ___ A researcher asking the parent questions over the phone
   - ___ A written survey the parent fills out by themselves
   - ___ A researcher asking the parent questions in person
   - ___ A survey that the parent fills out on a website
   - ___ Other (please explain)

9. Please share any other comments about how participating in this study has affected you.
Appendix F: Items for Background and Demographic Information

**Background**
1. What was the name of your child who died? _________________
2. Was your child a boy or a girl?
   - ☐ Boy
   - ☐ Girl
3. What was the date of his/her birth? __________________________ dd/mm/yy
4. What was the date he/she died? _____________________________ dd/mm/yy
5. What was the cause of death? (if known) _____________________
6. What was his/her diagnosis? (if applicable)_________________
7. Where did he/she die?
   - Hospital name ________________ (indicate community hospital or tertiary centre)
     - ☐ ICU/NICN
     - ☐ ER
     - ☐ another unit
     - ☐ other ________________
8. How long was he/she in hospital during that last stay before he/she died? ________ days
9. Approximately how long before __________’s death did you know that he/she was likely to die?
   - ☐ 6 months or more
   - ☐ 1 month to 6 months
   - ☐ Days to 1 month
   - ☐ Less than 7 days
   - ☐ 1 day or less
   - ☐ I didn’t know until it happened
10. Was there a palliative, hospice, or supportive care team or service involved in your child’s care?
    - ☐ Yes
    - ☐ No
    - ☐ Don’t know
11. Was there a bereavement service connected with the hospital that provided care to you after your child died?
    - ☐ Yes
    - ☐ No
    - ☐ Don’t know
12. Including your child who died, how many children do you have? ___________
**Demographics**

1. What is your relationship to the child who died?
   - Biological mother
   - Biological father
   - Adoptive mother
   - Adoptive father
   - Step mother
   - Step father

2. What year were you born in? ______________

3. What is your current marital status?
   - Married or living as married
   - Divorced or separated and not presently remarried
   - Never married
   - Widowed
   - Other (please specify): ____________________________

4. What is the highest level of schooling you have completed?
   - Elementary school or less
   - Some high school
   - High school diploma
   - Some college (including CEGEP) or trade school (but did not complete a diploma)
   - Diploma from college or trade school
   - Attended university (but did not complete a degree)
   - University degree
   - Post-graduate degree
   - Other (please specify): ____________________________

5. What is your total family income?
   - under $20,000
   - $20,000 – $39,999
   - $40,000 - $60,000
   - above $60,000

6. Which ethnic or cultural groups do you (or the majority of your ancestors) belong? List more than one if necessary. _________________________________________

7. Which religion do you belong to (if any)? ____________________________
Appendix G: Phase II Recruitment Email to Health Professionals

Dear _______,

We are conducting a study to develop and test an instrument to measure the quality of end-of-life care provided to families before, at the time of and following the death of the child, from the perspective of the parent. The study is being conducted in three phases. In the first phase, we conducted 3 focus groups with a total of 10 parents. These parents assisted us in identifying the domains and indicators of quality pediatric end of life care. We have now developed instrument items based on these domains and indicators. We are currently conducting Phase II of the study which involves assessment of the content validity of the items and the instrument as a whole by expert health professionals. Parents will also be asked to assess content and face validity of the instrument and their cognitive understanding of the items. The instrument will be revised based on the feedback of health professionals and parents taking part in this phase. In Phase III the instrument will be administered to a sample of 300 bereaved mothers from across Canada and psychometric testing of the instrument will be conducted.

We would like you to take part in this study due to…. (e.g., your experience in providing end-of-life care in intensive care settings; your experience providing pediatric palliative care; etc.). Your participation in this phase of the study will be valuable in the development of a psychometrically sound instrument that will ultimately be used to improve the quality of end-of-life care provided to dying children and their families.

If you agree to take part, we will send you a package with the instrument and detailed instructions of how to assess content validity. We will ask that you return the completed package to us within two weeks of receiving it.

If you have any questions or you are interested in participating please respond by email and let us know if you prefer to receive an electronic or hard copy of the package. If you wish a hard copy, please provide a mailing address where we can send the package of information to you in the next few days.

Thanks so much for your time.

Sincerely,

Kimberley Widger (PhD Candidate)
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto
130-155 College Street, Toronto, ON, M5T 1P8
kim.widger@utoronto.ca

Dr. Ann Tourangeau (PhD Candidate Supervisor)
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto
130-155 College Street, Toronto, ON, M5T 1P8
416-978-6919
ann.tourangeau@utoronto.ca
Appendix H: Phase II Information Letter and Instructions for Health Professionals

Title of Research Project: Measuring the Quality of Children’s End-of-life Care

What is the purpose of this research?
We are conducting a study to develop and test an instrument to measure the quality of end-of-life care provided to families before, at the time of, and following the death of the child, from the perspective of the parent. The focus is on families whose child died in a hospital or hospice after an admission of at least 24 hours. The study is being conducted in three phases. In the first phase, we conducted 3 focus groups with a total of 10 parents. These parents assisted us in verifying and extending the domains and indicators of quality pediatric end-of-life care which had been initially developed through a comprehensive review of the literature. We have now developed instrument items based on these domains and indicators. We are currently conducting Phase II of the study which involves assessment of the content validity of the items and the instrument as a whole by expert health professionals. Parents will also be asked to assess content and face validity of the instrument, as well as their cognitive understanding of the items. The instrument will be revised based on the feedback of health professionals and parents taking part in this phase. In Phase III the instrument will be administered through a mailed survey to a sample of at least 300 bereaved mothers from across Canada and psychometric testing of the instrument will be conducted.

We invite you to take part in this phase of the study due to your content expertise from…. (e.g., your experience in providing end-of-life care in intensive care settings; your experience providing pediatric palliative care; etc.). Your participation in this phase of the study will be valuable in the development of a psychometrically sound instrument that will ultimately be used to improve the quality of end-of-life care provided to dying children and their families.

What is involved in taking part in this study?
On the attached form you are asked to judge how representative items are of the content domain of quality pediatric end-of-life care for parents who experienced the death of a child in a health centre or hospice after an admission of at least 24 hours. You are asked to rate the clarity of each item. We would appreciate any suggested revisions which will assist us in refining the instrument. Also, you are asked to indicate which of the five domains of quality pediatric end-of-life care each item measures. At the end of the form you are asked to rate how comprehensive the entire instrument is and to indicate any questions that you think should be added to or deleted from the instrument.

Please see the attached description and definitions of the five domains of quality pediatric end-of-life care along with the specific instructions for assessing the content validity of the items related to these domains.

You may complete the form electronically or print the form / request a hard copy and complete it on paper. If completing the form electronically please return it by email to kim.widger@utoronto.ca.
If you wish to return a completed hard copy please mail it to:

Knemerly Widger RN MN  
PhD Candidate  
Lawrence S. Bloomberg Faculty of Nursing  
University of Toronto  
130 - 155 College Street  
Toronto, Ontario   M5T 1P8

What are the risks/benefits of taking part in this study? 
There is no risk or benefit to you in taking part in this study.

How will my privacy and confidentiality be maintained? 
Your name and other identifying information will be removed and kept separate from your answers to the questions. All returned documents will be identified only by code number and kept in a locked filing cabinet at the University of Toronto. Any electronic information will be kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study? 
The results from this phase of the study will be used in the next phase. If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. You can ask to have a copy of the results sent to you; see the end of this consent form. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm

The final survey that will result from this study will be free for use by any health professional who wishes to use it. The investigator will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study? 
There is no financial cost to you for taking part in this study. We expect it will take you 2 to 3 hours to complete the content validity testing form.

Who do I contact if I have questions? 
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at (416-946-3928) or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

How do I get a copy of the results of the study? 
You may ask for a copy of the final report from the study.  
☐ I would like to receive a copy of the final report for this study. 
If so, please provide an email address or a mailing address where you would like the results sent.

I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. A copy of this form has been given to me. I voluntarily consent to take part in this study. Return of the completed forms will signify your consent to participate in this study.

Thank you for your time and contribution to our study.
Instructions

Instrument Format:
The instrument is designed around the three components of quality health care: structures, processes, and outcomes. The main focus of the instrument is on the processes of care. There are ‘satisfaction’ questions to assess the outcomes of care. Both the process and outcome questions are designed to measure the five domains of quality pediatric end-of-life care and are part of the content validity testing. As well, we have created a few questions on the structures of care (parking, facilities available, etc.). We ask you to assess the relevance and clarity of the structure items but you will not need to assess which domain they fit into. The instrument also includes some open ended items (which will have more space for writing in the final version), as well as questions about demographics and the impact on mothers of completing the questionnaire. We have included these questions in this document for your information only, so that you have a sense of the full survey. Once Phase II of the study is completed (review by both health professionals and parents) and the final revisions to the items are made, the entire survey will be professionally designed and printed to make it as clear as possible for parents to read and follow. The final version for parents will also include introductory statements for each section. We have left these out of your version as they would lead you to which domain the section is intended to measure. You will also see through this version that we only refer to care in hospital. Mothers of children who died in a hospice will receive a version of the instrument that says hospice in place of hospital throughout (but will otherwise be exactly the same), as we want to be clear which care setting we are asking them to evaluate.

Population:
The instrument is designed to be used with parents who experienced the death of a child 19 years of age or less in a hospital or hospice after an admission of 24 hours or more. The cause of death may be an acute or chronic illness or trauma. Stillbirths and deaths within the first 48 hours of life will be excluded. Mothers completing the instrument are instructed to think about the last week to days of the child’s life when responding to the items.

Content Validity Testing:
Content validity testing includes an assessment of the representativeness and clarity of the items as well as an indication of which domain the item is measuring.

Representativeness - degree to which the item reflects and measures the construct of quality pediatric end-of-life care. Each item is to be rated for representativeness on a 4 point scale:

1 = the item is not representative of quality pediatric end-of-life care
2 = the item needs major revisions to be representative of quality pediatric end-of-life care
3 = the item needs minor revisions to be representative of quality pediatric end-of-life care
4 = the item is representative of quality pediatric end-of-life care

Clarity – the item is well-written, distinct, and at an appropriate reading level. Please use the comment boxes beside each item to indicate if the item needs to be reworded to make it more clear. Suggestions are appreciated. If the comment box is left blank, we will assume the item is clear as written.

Content Domain – Based on the literature and focus groups, we have determined five domains of quality pediatric end-of-life care. For each item please indicate which of the following domains you believe the item is measuring. There may be some overlap among domains but please choose the best single response for each.

CF = Connect with Families focuses on the relationships between health professionals and family members including communication skills, sensitivity, accessibility and consistency of health professionals, and provision of individualized care.

IP = Involve Parents focuses on health professionals’ demonstration of respect for the opinions and wishes of parents about their child and on health professionals’ support for parents in their role as parents.
AS = Alleviate Suffering includes the assessment, prevention, and treatment of physical, emotional, social, and spiritual suffering of the ill child, parents, and siblings, particularly at the time of the child’s death.

SI = Share Information includes information that is shared with family members, with the ill child and among health professionals.

BC = Provide Bereavement Care includes all of the care provided after the child dies, such as continued contact with health professionals, collection of mementos, and provision of information about grief and community resources. This domain also includes discussions related to autopsy and organ and tissue donation.

NOTE: ONLY FIRST PAGE OF DOCUMENT AND FINAL QUESTIONS TO THE EXPERT REVIEWERS ARE INCLUDED BELOW

Quality of Pediatric End-of-Life Care: Content Validity Testing

When completing the form by computer please highlight the number/letters that correspond with your rating. If completing a hard copy of the form please circle your ratings on the right hand side of the page. Please note that you do not need to respond to the item (on the left) you only need to rate it (on the right).

Instructions for parents: When answering the following questions think about all of the health professionals (including doctors, nurses, social workers, child life specialists, etc.) at the hospital who took care of your child and family during the last week or days of your child’s life.

Most of the questions ask about you and your family. Your family includes your child who was ill and your immediate family.

<table>
<thead>
<tr>
<th>Quality Items</th>
<th>Representativeness</th>
<th>Quality Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often did health professionals demonstrate good communication skills?</td>
<td>1 2 3 4</td>
<td>CF IP AS SI BC</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td>Comments:</td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How often did health professionals demonstrate sensitivity to you and your family?</td>
<td>1 2 3 4</td>
<td>CF IP AS SI BC</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td>Comments:</td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How often was there a close connection between you and your family and the health professionals who cared for your child?</td>
<td>1 2 3 4</td>
<td>CF IP AS SI BC</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td>Comments:</td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
END OF INSTRUMENT ITEMS:

**Overall rating**: Please rate the degree to which the instrument reflects and measures the construct of quality pediatric end-of-life care.

_____ 1 = the instrument is not representative of quality pediatric end-of-life care
_____ 2 = the instrument needs major revisions to be representative of quality pediatric end-of-life care
_____ 3 = the instrument needs minor revisions to be representative of quality pediatric end-of-life care
_____ 4 = the instrument is representative of quality pediatric end-of-life care

Are there any questions that should be added?

Are there any questions that should be deleted? (Please write the number of any questions you think should be deleted).
Appendix I: Phase II Telephone Script to Recruit Parent Participants

Hello, May I speak to ________________?
My name is Kimberley Widger. You took part in a focus group with me about XX months ago (OR contacted me about taking part in a focus group). At that time you said that you were interested in taking part in the next phase of the study. Are you still interested in doing that?

If NO – Thank you very much for your time. (Terminate Call).
If YES – Do you have 10 minutes or so to talk now about this part of the study or would you prefer I call back at another time? (Either continue or book a time to call back)

Since we had the focus groups I have been looking at all the things parents told me about quality care. I used what parents told me in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In this second phase of the study we will ask parents to review the questions to make sure they are clear and easy to understand. We will also ask if the questions seem to be about quality care and if anything is missing. Between 5 and 10 parents will take part in phase two of the study.

If you agree to take part in this phase of the study I will meet with you in person or by telephone. I will read or have you read each question on the survey. For each question I will ask you to tell me what the question means to you or what you are thinking about as you choose your answer. At the end of all the questions I will ask you if you think the questions were related to quality of end-of-life care. I will also ask if you think there is anything missing from the survey. I will write down notes about what you tell me. It may take up to 2 hours to answer and talk about all of the questions with me.

It is your choice whether or not to take part in this phase of the study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop taking part in the study at any time. If you become upset I will can spend time talking with you. I can also refer you to someone else to help you if you wish. There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death.

At the end of the session you will receive $40 as thanks for sharing your experiences with me. If you start the questions but decide to stop part way through the questions you will still get the full amount.

If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. The results from this phase of the study will be used in the next phases.

Do you have any questions about the study or what is involved in taking part? Would you like to take part in the study?
If NO – Thank you very much for your time. (Terminate Call)
If YES – Would you prefer to meet in person or to talk by telephone? (Arrange time and place to meet or talk by telephone). Thank you very much for your time today and I look forward to talking further with you.
Appendix J: Phase II Parent Consent for Participation

Title of Research Project: Measuring the Quality of Children’s End-of-life Care

What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In this second phase of the study we will ask parents to review the questions to make sure they are clear and easy to understand. We will also ask if the questions seem to be about quality care and if anything is missing. Between 5 and 10 parents will take part in phase two of the study. The third phase of the study will involve about 300 mothers. These parents will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the second phase of our research.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 1 year ago. You must be the biological, step, or adoptive parent of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or at home after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study the main investigator will meet with you in person or by telephone. She will read each question on the survey to you or have you read it to yourself. For each question she will ask you to tell her what the question means to you or what you are thinking about as you choose your answer. At the end of all the questions she will ask you if you think the questions were related to quality of end-of-life care. She will also ask if you think there is anything missing from the survey. She will write down notes about what you tell her. It may take up to 2 hours to answer and talk about all of the questions.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result...
of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you become upset the investigator can spend time talking with you. The investigator can also refer you to someone else to help you if you wish.

**What are the benefits of taking part in this study?**
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

**How will my privacy and confidentiality be maintained?**
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The results from this phase of the study will be used in the next phase. If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you at the end of this consent form. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that will be made using the results from this study will be free for use by any health professional who wishes to use it. The investigator will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
At the end of the session you will receive $40 to thank you for sharing your experiences with us. If you start the questions but decide to stop part way through the questions you will still get the full amount.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-946-3928 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca

If you have questions about your rights as a research participant, please contact Jill Parsons, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-5806 or by email: jc.parsons@utoronto.ca

**How do I get a copy of the results of the study?**
You may ask for a copy of the final report from the study.

☐ I would like to receive a copy of the final report for this phase of this study.
If so, please provide an email address or a mailing address where you would like the results sent.

__________________________
__________________________
CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. A copy of this form has been given to me. I voluntarily consent to take part in this study.

Participant Name (Print)   Participant Signature   Date

Name of Person Witnessing Consent (Print)   Witness Signature   Date
Appendix K: Phase III Introductory Letters to Mothers

Sunnybrook Health Sciences Centre, Toronto, ON

McMaster Children’s Hospital, Hamilton, ON

Stollery Children’s Hospital, Edmonton, AB

Canuck Place Children’s Hospice, Vancouver, BC

Children’s Hospital of Eastern Ontario and Roger’s House, Ottawa, ON

IWK Health Centre, Halifax, NS

Health Sciences Centre Winnipeg, Winnipeg, MN

Children’s Hospital London Health Sciences Centre, London, ON

Hospital for Sick Children, Toronto, ON

Opt-out and opt-in enclosure cards
Dear (Mother’s name),

Sunnybrook Health Sciences Centre is taking part in a study that you may be interested in. The study is called ‘Measuring the Quality of Children’s End-of-Life Care.’ It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Dr. Sharyn Gibbins is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 3 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

Thank you for considering taking part in this study.

Sincerely,
Dear (Mother's name),

McMaster Children's Hospital is taking part in a study that you may be interested in. The study is called ‘Measuring the Quality of Children's End-of-Life Care.’ It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Dr. Katrin Scheinemann is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 3 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

Thank you for considering taking part in this study.

Sincerely,
Dear (Mother's name),

The Stollery Children's Hospital is taking part in a study that you may be interested in. The study is called 'Measuring the Quality of Children's End-of-Life Care.' It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Dr. Dawn Davies is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 3 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

Thank you for considering taking part in this study.

Sincerely,

Dr. Dawn Davies
Dear Parent(s),

Canuck Place Children’s Hospice is taking part in a study that may interest you. The study is about the quality of children’s end-of-life care. I am the researcher who is involved in the study from our hospice. This is the third phase of a larger study conducted by Kimberley Widger for her PhD work under the supervision of Dr. Ann Tourangeau at the University of Toronto. This larger study’s purpose is to develop a survey to study the quality of care mothers and their child received before, at the time of, and following the death of the child. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from mothers both what is going well and what needs to be changed. In conducting this study, we hope to help improve the care given to dying children and their families in the future. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We got your name and address through the health records department at Canuck Place Children’s Hospice. We are contacting you now because you are the mother of a child who died at least 6 months ago at the hospice. We would like you to complete a survey about the care you, your family, and your child received from the hospital. It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. If you feel emotional stress and wish to speak with someone or have any questions or concerns about the study please contact me at 604-875-2776 or by email at hsiden@cw.bc.ca or Kimberley Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca. These people can spend time talking with you or assist you to find the support that you need.

If you are interested in taking part in the study, please let us know by completing and returning the enclosed card in the envelope provided. You can also contact the main researcher by phone (416-978-2859) or by email (kim.widger@utoronto.ca) and leave a message with your name and address. If you tell us that you want to take part in the study, the survey package will be mailed to you. The survey package will give you more details about the study so you can decide if you want to take part. It will also have the survey in the package for you to complete if you decide to take part in the study.

Thank you for considering taking part in this study.

Sincerely,

Hal Siden, MD, MHSc, FRCPC
hsiden@canuckplace.org

Version 2 June 10, 2010
Lynn Grandmaison Dumond, RN(EC), MScN
Advanced Practice Nurse
Palliative Care Outreach Program
Children's Hospital of Eastern Ontario (CHEO)
401 Smyth Rd, Ottawa, ON K1H 8L1
613-523-6300 ext. 610

September 7, 2010

Mrs.________
________________
_______________
___________

Dear Mrs._______

The Children’s Hospital of Eastern Ontario (CHEO) is collaborating in a study called ‘Measuring the Quality of Children’s End-of-Life Care’. We are sending this letter as we thought you might be interested in participating.

The study is being led by two researchers from the University of Toronto, and mothers from across Canada are being asked to participate. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Lynn Grandmaison Dumond, is an Advanced Practice Nurse for the Palliative Care Outreach Program at CHEO and she is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to children who are dying and their families. We would like to hear from mothers regarding what went well and what we could have done better. By taking part in this study you will help to ensure that care given to children and their families in the future is the best that it can be.

We understand that answering a survey about the care your child received at end of life may be emotionally difficult but we feel that your input will help us do a better job providing care to other children and their families. Should you feel distress at any point and need support, you can call Lynn Grandmaison Dumond (613-523-6300 #610). She will forward your call to a member of the CHEO Bereavement Team.

We respect your wishes if you decide not to participate in this study. If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 3 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

Thank you for considering taking part in this study.

Sincerely,
Dear (Mother's name),

The IWK Health Centre is taking part in a study that you may be interested in. The study is called ‘Measuring the Quality of Children’s End-of-Life Care’. Grace MacConnell is the researcher who is involved in the study from our hospital. The study is being led by Kimberley Widger for her PhD work under the supervision of Dr. Ann Tourangeau at the University of Toronto. Mothers from across Canada will take part in the study. The researchers are doing this study because it is important to provide the highest quality of care possible to dying children and their families. They want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 3 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

Thank you for considering taking part in this study.

Sincerely,
Dear (Mother's name),

Health Sciences Centre Winnipeg is taking part in a study that you may be interested in. The study is about the quality of children’s end-of-life care. It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Simone Stenekes is the researcher who is involved in the study from Health Sciences Centre Winnipeg.

Please be assured that we respect your wishes, and in order to preserve your confidentiality, the researchers need your permission before they can review your child’s medical record, or get any information regarding your child. We will keep your information, and that of your child’s confidential unless you agree to participate in the study.

If you are interested in taking part in the study, complete and return the enclosed card in the envelope provided. If you choose not to respond to this request, no further communication will be sent to you. You can also contact the main researcher by phone (416-978-2859) or by email (kim.widger@utoronto.ca) and leave a message with your name and address. If you tell her that you want to take part in the study, the survey package will be mailed to you. The survey package will give you more details about the study so you can decide if you want to take part. It will also have the survey in the package for you to complete if you decide to participate in the study.

If you have any questions or concerns about the study you may contact the researchers directly by telephone or email:

- Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca
- Simone Stenekes from the Winnipeg Health Science Centre at 204-787-2464 or sstenekes@wrha.mb.ca.

The researchers believe that it is important to provide the highest quality of care possible to dying children and their families. They want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.
Thank you for considering taking part in this study.

Sincerely,

[Signature]

Mr. Dana Erickson, BA, CGA, CRM
Vice-President & Chief Administrative Officer
Health Sciences Centre Winnipeg

DEE/jl
Dear (Mother’s name),

The Children’s Hospital London Health Sciences Centre is taking part in a study that you may be interested in. The study is about the quality of children’s end-of-life care. It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Lisa Pearlman is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you are interested in taking part in the study, please let us know by completing and returning the enclosed card in the envelope provided. You can also contact the main researcher by phone (416-978-2859) or by email (kim.widger@utoronto.ca) and leave a message with your name and address. If you tell us that you want to take part in the study, the survey package will be mailed to you. The survey package will give you more details about the study so you can decide if you want to take part. It will also have the survey in the package for you to complete if you decide to take part in the study.

If you have any questions or concerns about the study please contact Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Lisa Pearlman from Children’s Hospital London Health Science Centre at 519.685.8500 ext. 52288 or lisa.pearlman@lhsc.on.ca.

Thank you for considering taking part in this study.

Sincerely,

Name
Dear (Mother's name),

The Hospital for Sick Children is taking part in a study that you may be interested in. The study is called ‘Measuring the Quality of Children’s End-of-Life Care.’ It is being led by two researchers from the University of Toronto, but will include mothers from across Canada. Kimberley Widger and Dr. Ann Tourangeau are the two main researchers. Laura Beaune is the researcher who is involved in the study from our hospital. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

If you do not want to be contacted further about this study please return the enclosed card in the envelope provided. If I do not hear from you in the next 2 weeks, I will mail the survey package to you. The survey package will give you more details about the study and what is involved. It will also have the survey in the package for you to complete if you wish to do so.

If you have any questions or concerns about the study please contact Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Laura Beaune from SickKids at 416-813-7654 ext. 3372 or laura.beaune@sickkids.ca.

Thank you for considering taking part in this study.

Sincerely,

Staff name
Enclosure cards for opt-out and opt-in recruitment

Opt-out recruitment cards:

Please return this card in the envelope provided if you DO NOT want to be contacted about this study.

I do not want to be contacted about this study.

Name: _______________________________
Address:______________________________
____________________________________
____________________________________

Please return this card to:

Kimberley Widger
Lawrence S. Bloomberg Faculty of Nursing
155 College Street, Suite 130
Toronto ON, M5T 1P8

Opt-in recruitment card:

Please return this card in the envelope provided if you want to be contacted about this study.

Name: ________________________
Address:_______________________
____________________________________
____________________________________

Please return this card to:

Kimberley Widger
Lawrence S. Bloomberg Faculty of Nursing
155 College Street, Suite 130
Toronto ON, M5T 1P8
Appendix L: Phase III Mother’s Consent for Participation

Sunnybrook Health Sciences Centre, Toronto, ON

McMaster Children’s Hospital, Hamilton, ON

Stollery Children’s Hospital, Edmonton, AB

Canuck Place Children’s Hospice, Vancouver, BC

Children’s Hospital of Eastern Ontario, Ottawa, ON

Roger’s House, Ottawa, ON

IWK Health Centre, Halifax, NS

Health Sciences Centre Winnipeg, Winnipeg, MN

Children’s Hospital London Health Sciences Centre, London, ON

Hospital for Sick Children, Toronto, ON
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children's end-of-life care.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff directly involved with the study as well as representatives of the Sunnybrook Research Ethics Board (to check on the study)
will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The main focus of the study is to look at all of the mothers’ answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
There are no financial costs to you for taking part in this study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Sharyn Gibbins from Sunnybrook Health Sciences Centre at 416-323-6313 or sharyn.gibbins@sunnybrook.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email: rachel.zand@utoronto.ca. Or you may call Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at 416-480-4276.

**How do I get a copy of the results of the study?**
I would like to receive a copy of the final report for this study. If so, please provide an email address or a mailing address where you would like the results sent.

---

**CONSENT**
Continuing to answer the questions in the survey means that I give my consent to take part in this study.
I agree that:

1) You have explained this study to me. You have answered all my questions.

2) You have explained the possible harms and benefits (if any) of this study.

3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sunnybrook.

4) I am free now, and in the future, to ask questions about the study.

5) I have been told that my child’s medical records will be kept private. You will give no one information about me, unless the law requires you to.

6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.

7) I have read and understood this consent form. I agree, or consent, to take part in this study.

Please keep this copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end of the booklet there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mothers’ answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name will not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Dr. Katrin Scheinemann from McMaster Children’s Hospital at 905-521-2100 ext 73818 or by email at kschein@mcmaster.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email: rachel.zand@utoronto.ca

How do I get a copy of the results of the study?
I would like to receive a copy of the final report for this study. If so, please provide an email address or a mailing address where you would like the results sent.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep this copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place for you to tell us if you are willing to do the survey again at the end of the survey after you are done all of the questions.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mothers’ answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name will not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kimberley Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Dr. Dawn Davies from the University of Alberta at 780-407-7210 or dawn.davies@albertahealthservices.ca if you have any concerns.

If you have any concerns about the research or your rights as a participant you can contact 780-492-2615 or contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca

How do I get a copy of the results of the study?
I would like to receive a copy of the final report for this study. If so, please provide an email address or a mailing address where you would like us to send the final results from the study. (Note: If you are willing to do the survey again in 1 to 2 weeks there is place at the end of all the questions to give us your address. Writing your address here only means that you want a copy of the results sent to you.)

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep this copy for your own records.
What is the purpose of this research?
This is the third phase of a larger study conducted by Kimberley Widger for her PhD work. This larger study's purpose is to develop a survey to study the quality of care parents and their child received before, at the time of, and following the death of the child. We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from mothers both what is going well and what needs to be changed. In conducting this study, we hope to help improve the care given to dying children and their families in the future. We will also see how well the questions work to measure the quality of children's end-of-life care.

Invitation
You are being invited to take part in this research study because you are the mother of a child who died at least 6 months ago in a hospital or hospice.

YOUR PARTICIPATION IS VOLUNTARY
It is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to take part, you will be asked to fill out a survey. If you decide to take part in this study, you are still free to withdraw at any time. You do not need to give any reasons for your decision.

If you do not wish to take part, you do not have to give any reason for your decision. Medical care which you or your family receive now or in the future will not change based on your decision.

Please take time to read the following information carefully. Feel free to discuss it with your family, friends, and doctor before you decide.

Who is conducting this study?
The study is being funded by the Innovation Fund in Children's Palliative Care Research at The Hospital for Sick Children; a Canadian Institutes for Health Research Fellowship; and by the Canadian Child Health Clinician Scientist Program, Career Enhancement Program.

The investigators in the study have no conflicts of interest to declare.

What is involved in taking part in this study?
If you agree to take part in this study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You
do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you feel emotional stress and wish to speak with someone please contact Kimberley Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Hal Siden from Canuck Place Children’s Hospice at 604-875-2776 or by email at hsiden@cw.bc.ca. These people can spend time talking with you or assist you to find the support that you need.

**What are the benefits of taking part in this study?**
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child's death.

The results of this study will help other families who may be facing the death of a child in the future.

**How will my privacy and confidentiality be maintained?**
Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any electronic information will be kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The main focus of the study is to look at all of the mothers’ answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child's death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use them. We will not receive any money from other people who want to use the survey.

**What are the financial costs of taking part in this study?**
There are no financial costs to you for taking part in this study. You will not be reimbursed in any way for taking part in the study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Dr. Hal Siden at 604-875-2776 or by email at hsiden@cw.bc.ca; Kimberley Widger at 416-978-2859 or by email at kim.widger@utoronto.ca; or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca. You may also contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 (Toll Free Number 1-877-822-8598) or e-mail RSIL@ors.ubc.ca

**How do I get a copy of the results of the study?**
The results of this study will be posted on the study website likely by the fall of 2011: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm

If you agree to have the results of the study mailed or emailed directly to you from the investigators, please write your email address or a mailing address where you would like the results sent.

CONSENT

If you wish to take part in this research study and are comfortable with the procedures described in this form, please complete the attached survey and mail it back to us.

Please keep this copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about an hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Lynn Grandmaison Dumond (CHEO site collaborator) from CHEO at 613-523-6300 ext. 601 or lgrandmaisondumond@cheo.on.ca if you have any concerns.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep this copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about an hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
**How will my privacy and confidentiality be maintained?**
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
There are no financial costs to you for taking part in this study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Lynn Grandmaison Dumond (CHEO site collaborator) from CHEO at 613-523-6300 ext. 601 or lgrandmaisondumond@cheo.on.ca if you have any concerns.

---

**CONSENT**

I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep this copy for your own records.
Quality of Children’s End-of-Life Care
Version June 24, 2010

Mother’s Consent for Participation and Instrument
Title of Research Project: Measuring the Quality of Children’s End-of-life Care

What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you feel emotional stress and wish to speak with someone please contact Kimberley Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Grace MacConnell from the IWK at 902-470-7984 or grace.macconnell@iwk.nshealth.ca. These people can spend time talking with you or assist you to find the support that you need.

Principal Investigator
Kimberley Widger RN MN
PhD Candidate
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario MST 1P8
Phone: 416-978-2859
Fax: 416-978-8222
kim.widger@utoronto.ca

PhD Candidate Supervisor
Dr. Ann Tourangeau RN PhD
Associate Professor
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario MST 1P8
Phone: 416-978-6919
Fax: 416-978-8222
ann.tourangeau@utoronto.ca

Site Investigator
Grace MacConnell RN MN CNHPC(C)
Clinical Nurse Specialist
Pediatric Palliative Care Service
IWK Health Centre
Phone: 902-470-7984
grace.macconnell@iwk.nshealth.ca

Funding:
The Innovation Fund in Children’s Palliative Care Research, The Hospital for Sick Children
Canadian Institutes for Health Research Fellowship
Canadian Child Health Clinician Scientist Program, Career Enhancement Program
What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child's death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. Identifying information will not be shared between the researchers at the IWK and the University of Toronto at any time. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Only the study investigators and research staff who are directly involved with the study as well as representatives of the IWK Research Ethics Board (to check on the study) will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Grace MacConnell from the IWK Health Centre at 902-470-7984 or grace.macconnell@iwk.nshealth.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto at 416-946-3389 or by email: rachel.zand@utoronto.ca or Bev White, Manager, Research Ethics & Information Officer, IWK Health Centre at 902-470-8520 or by email bev.white@iwk.nshealth.ca

How do I get a copy of the results of the study?
I would like to receive a summary of the final report for this study. If so, please provide an email address or a mailing address where you would like the results sent.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Return of the completed survey means I give my consent to take part in this study.

Please keep this copy for your records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

We invite you to take part in the third phase of the study.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained? Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Information will be kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study? The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study? There are no financial costs to you for taking part in this study.

Who do I contact if I have questions? If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Simone Stenekes from the Winnipeg Regional Health Authority at 204-787-2464 or sstenekes@wrha.mb.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email: rachel.zand@utoronto.ca

How do I get a copy of the results of the study? I would like to receive a copy of the final report for this study. If so, please provide an email address or a mailing address where you would like the results sent.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep this copy for your records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. This research is part of the PhD work of the main investigator (Kimberley Widger). Our goal is to develop a survey to ask mothers about the quality of care they received and identify areas that need to be changed. By taking part in this study you may help to ensure that care given to dying children and their families in the future is the best that it can be.

We need 300 mothers to answer a survey so we can learn about the quality of care that they received. About 50 of these mothers will be from the London area. We will also see how well the questions work to measure the quality of children’s end-of-life care.

What is involved in taking part in this study?
If you agree to take part in this part of the study you will need to answer the questions in the booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions.

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at anytime.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you are experiencing emotional stress you may contact Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Lisa Pearlman from Children’s Hospital London Health Sciences Centre at 519.685.8500 ext. 52288 or lisa.pearlman@lhsc.on.ca. Kim or Lisa can talk further with you and assist you to find sources of support. As well, you may find information on the following websites helpful in coping with your child’s death: http://www.bereavedfamilies.net/  http://tcfcanada.net/

What are the benefits of taking part in this study?
You will not benefit directly from taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death.

The results of this study will help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information will be kept on a secure computer and will be password protected. Identifying information will not be emailed.
to anyone at any time. Only the study investigators and research staff directly involved with the study will be able to look at the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the financial costs of taking part in this study?
There are no financial costs to you for taking part in this study. You will not be reimbursed in any way for taking part in the study.

Are there any conflicts of interest for the researchers?
The researchers in this study have no conflicts of interest related to the study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Lisa Pearlman from Children’s Hospital London Health Science Centre at 519.685.8500 ext. 52288 or lisa.pearlman@lhsc.on.ca. You may also contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca.

If you have questions about your rights as a research participant, please contact Dr. David Hill, Scientific Director, Lawson Health Research Institute at (519) 667-6649. You may also contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email rachel.zand@utoronto.ca.

How do I get a copy of the results of the study?
The results of this study will be posted on the study website likely by the fall of 2011: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm
If you agree to have the results of the study mailed or emailed directly to you from the investigators, please write your email address or a mailing address where you would like the results sent.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. This research is part of the PhD work of the main investigator (Kimberley Widger). Our goal is to develop a survey to ask mothers about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.
We need 300 mothers to answer a survey so we can learn about the quality of care that they received. We will also see how well the questions work to measure the quality of children’s end-of-life care.

What is involved in taking part in this study?
If you agree to take part in this part of the study you will need to answer the questions in this booklet. All of the questions are about your experiences before, during, and after the death of your child. At the end there are a few questions about yourself and your child and about what it was like for you to answer all of the questions. It will take about 1 hour to answer all of the questions. We also need 50 mothers to answer all of these questions again in about 1 to 2 weeks. There is a place at the end of the survey for you to tell us if you are willing to do the survey again.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you are experiencing emotional stress you may contact Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Laura Beaune from SickKids at 416-813-7654 ext. 3372 or laura.beaune@sickkids.ca. Kim or Laura can talk further with you and assist you to find sources of support. As well, you may find information on the following websites helpful in coping with your child’s death: http://www.bereavedfamilies.net/ http://tcfcanada.net/

What are the benefits of taking part in this study?
You will not benefit directly from taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death.
The results of this study will help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff directly involved with the study as well...
as the SickKids Clinical Research Office Monitor (to check on the study) will be able to look at the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mothers’ answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study. You will not be reimbursed in any way for taking part in the study.

Are there any conflicts of interest for the researchers?
The researchers in this study have no conflicts of interest related to the study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Laura Beaune from SickKids at 416-813-7654 ext. 3372 or laura.beaune@sickkids.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca. Or you may call the SickKids Research Ethics Manager at (416) 813-5718.

How do I get a copy of the results of the study?
I would like to receive a copy of the final report for this study.
If so, please provide an email address or a mailing address where you would like the results sent.

CONSENT
It is your choice to take part in this study. You can stop at any time or decide not to return the survey. Any care you may receive from SickKids will not be affected in any way.

Answering the survey questions and mailing the survey to the University of Toronto means that I give my consent to take part in this study. I agree that:

1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private. You will give no one information about me, unless the law requires you to.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 and 2 of this consent form. I agree, or consent, to take part in this study.

Please keep this copy for your own records.
Appendix M: Phase III Mother’s Consent for Participation in Reliability Testing

Sunnybrook Health Sciences Centre, Toronto, ON

McMaster Children’s Hospital, Hamilton, ON

Stollery Children’s Hospital, Edmonton, AB

Children’s Hospital of Eastern Ontario, Ottawa, ON

Roger’s House, Ottawa, ON

IWK Health Centre, Halifax, NS

Health Sciences Centre Winnipeg, Winnipeg, MN

Hospital for Sick Children, Toronto, ON
Title of Research Project: Development and testing of an instrument to measure parents’ perspectives of the quality of children’s end-of-life care

What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password...
protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff directly involved with the study as well as representatives of the Sunnybrook Research Ethics Board (to check on the study) will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
There are no financial costs to you for taking part in this study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Sharyn Gibbins from Sunnybrook Health Sciences Centre at 416-323-6313 or sharyn.gibbins@sunnybrook.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email: rachel.zand@utoronto.ca. Or you may call Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at 416-480-4276.

**CONSENT**
Continuing to answer the questions in the survey means that I give my consent to take part in this study.

I agree that:

1) You have explained this study to me. You have answered all my questions.

2) You have explained the possible harms and benefits (if any) of this study.

3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sunnybrook.

4) I am free now, and in the future, to ask questions about the study.

5) I have been told that my child’s medical records will be kept private. You will give no one information about me, unless the law requires you to.

6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.

7) I have read and understood this consent form. I agree, or consent, to take part in this study.

Please keep this copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to complete the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca
What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm . There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at (416-978-2859) or by email at kim.widger@UTORONTO.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@UTORONTO.ca

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@UTORONTO.ca

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this part of the study.

A copy of this consent is included with this survey package.
Please keep the copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to do the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about 1 hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the
child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

**How will my privacy and confidentiality be maintained?**
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

**What will happen with the results of the study?**
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
There are no financial costs to you for taking part in this study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kimberley Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Dr. Dawn Davies from the University of Alberta at 780-407-7210 or dawn.davies@albertahealthservices.ca if you have any concerns.

If you have any concerns about the research or your rights as a participant you can contact 780-492-2615. If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca

**CONSENT**
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this part of the study.

Please keep the copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to complete the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing...
Quality of Children's End-of-Life Care
Version May 30, 2010

the death of their child in the future.

How will my privacy and confidentiality be maintained? Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study? The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm . There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study? There are no financial costs to you for taking part in this study.

Who do I contact if I have questions? If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Lynn Grandmaison Dumond (CHEO site collaborator) from CHEO at 613-523-6300 ext. 601 or lgrandmaisondumond@cheo.on.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca. You may also contact the Chair of the Research Ethics Board at CHEO, for information regarding your rights in research studies at 613-737-7600 ext. 3272, although this person cannot provide any health-related information about the study.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this part of the study.

Please keep the copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to complete the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to speak and understand English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Lynn Grandmaison Dumond (CHEO site collaborator) from CHEO at 613-523-6300 ext. 601 or lgrandmaisondumond@cheo.on.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca. You may also contact the Chair of the Research Ethics Board at CHEO, for information regarding your rights in research studies at 613-737-7600 ext. 3272, although this person cannot provide any health-related information about the study.

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this part of the study.

Please keep the copy for your own records.
Quality of Children’s End-of-Life Care
Version June 24, 2010

Title of Research Project: Measuring the Quality of Children’s End-of-life Care

What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to complete the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca

Principal Investigator
Kimberley Widger RN MN
PhD Candidate
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario MST 1P8
Phone: 416-978-2859
Fax: 416-978-8222
kim.widger@utoronto.ca

PhD Candidate Supervisor
Dr. Ann Tourangeau RN PhD
Associate Professor
Faculty of Nursing
University of Toronto
130 - 155 College Street
Toronto, Ontario MST 1P8
Phone: 416-978-6919
Fax: 416-978-8222
ann.tourangeau@utoronto.ca

Site Investigator
Grace MacConnell RN MN CNHPC(C)
Clinical Nurse Specialist
Pediatric Palliative Care Service
IWK Health Centre
Phone: 902-470-7984
grace.macconnell@iwk.nshealth.ca

Funding:
The Innovation Fund in Children’s Palliative Care Research, The Hospital for Sick Children
Canadian Institutes for Health Research Fellowship
Canadian Child Health Clinician Scientist Program, Career Enhancement Program
What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child's death. They are happy to have a chance to help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. Identifying information will not be shared between the researchers at the IWK and the University of Toronto at any time. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Only the study investigators and research staff who are directly involved with the study as well as representatives of the IWK Research Ethics Board (to check on the study) will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother's answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child's name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child's death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Grace MacConnell from the IWK Health Centre at 902-470-7984 or grace.macconnell@iwk.nshealth.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto at 416-946-3389 or by email: rachel.zand@utoronto.ca or Bev White, Manager, Research Ethics & Information Officer, IWK Health Centre at 902-470-8520 or by email bev.white@iwk.nshealth.ca

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Return of the completed survey means I give my consent to take part in this study.

Keep this copy for your records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. Our goal is to develop a survey to ask parents about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be.

This research is part of the PhD work of the main investigator (Kimberley Widger). The research has three phases. In the first phase we had focus groups with parents. We asked parents what they thought was important to quality end-of-life care for children and their families. We used what parents told us in the focus groups to develop survey questions. These survey questions ask parents about the quality of care they and their child received. In the second phase of the study we asked parents to review the questions to make sure they were clear and easy to understand. We are now doing the third phase of the study which will involve about 300 mothers. These mothers will answer all of the questions so we can learn about the quality of care that they received. Part of the third phase includes having 50 mothers do the survey twice so we can see how well the questions work to measure the quality of children’s end-of-life care. We invite you to do the survey for a second time.

Who can take part in this study?
To take part in this study you must have experienced the death of a child at least 6 months ago. You must be the biological, step, or adoptive mother of the child who died. The child who died must have been 19 years old or less at that time. The child must have died in a hospital or in a hospice after being admitted for at least 24 hours. You must be able to read English to take part in this study.

What is involved in taking part in this study?
If you agree to take part in this phase of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about 1 hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you have changed your mind about doing this survey a second time, you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey, please contact the main investigator (Kimberley Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca.

What are the benefits of taking part in this study?
There is no direct benefit to you for taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death. They are happy to have a chance to help other families who may be facing the death of their child in the future.
How will my privacy and confidentiality be maintained?
Confidentiality can only be guaranteed to the extent permitted by law. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Information will be kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. You can ask to have a copy of the results sent to you. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Simone Stenekes from the Winnipeg Regional Health Authority at 204-787-2464 or sstenekes@wrha.mb.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at 416-946-3389 or by email: rachel.zand@utoronto.ca

CONSENT
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this study.

Please keep the copy for your own records.
What is the purpose of this research?
We are doing this research because we believe it is important to provide the highest quality of care possible to dying children and their families. We want to hear from parents both what is going well and what needs to be changed. This research is part of the PhD work of the main investigator (Kimberley Widger). Our goal is to develop a survey to ask mothers about the quality of the care they received and identify areas that need to be changed. By taking part in this study you will help to ensure that care given to dying children and their families in the future is the best that it can be. For this part of the study we are mostly testing how well the questions work to measure the quality of children’s end-of-life care.

What is involved in taking part in this study?
If you agree to take part in this part of the study you will need to answer the questions in this booklet. This survey is exactly the same as the survey you completed the first time. It will take about an hour to answer all of the questions. You do not need to remember what your answers were the first time. Just answer the questions as if you had not done them before.

What are the risks of taking part in this study?
It is your choice whether or not to take part in this study. This research deals with a sensitive topic. You may feel emotional stress as a result of taking part. You do not need to answer any question that is uncomfortable for you in any way. You can also stop answering all of the questions at any time. If you are experiencing emotional stress you may contact Kim Widger from the University of Toronto at 416-978-2859 or by email at kim.widger@utoronto.ca or Laura Beaune from SickKids at 416-813-7654 ext. 3372 or laura.beaune@sickkids.ca. Kim or Laura can talk further with you and assist you to find sources of support. As well, you may find information on the following websites helpful in coping with your child’s death: http://www.bereavedfamilies.net/ http://tcfcanada.net/

If you have changed your mind about doing this survey a second time you do not need to do it. Just throw it away. We will still use your answers from the first time you did the survey unless you ask us to remove them. If you want us to destroy your answers to the first survey please contact the main investigator (Kim Widger) at 416-978-2859 or by email at kim.widger@utoronto.ca

What are the benefits of taking part in this study?
You will not benefit directly from taking part in this study. Some parents do find it helpful to talk about their child and their experiences at the time of the child’s death.

The results of this study will help other families who may be facing the death of their child in the future.

How will my privacy and confidentiality be maintained?
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. Your name and other identifying information will be removed and kept separate from your answers to the questions. All papers will be identified only by code number. These papers will be kept in a locked filing cabinet at the University of Toronto. Any information kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only
the study investigators and research staff who are directly involved with the study as well as the SickKids Clinical Research Office Monitor (to check on the study) will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. These reports will be based on the answers of only the mothers whose child died at that particular place. Your name will not be used in the reports. The answers from everyone who was at that hospital or hospice will be grouped together. If the results of any part of the study are made publicly available or are published or presented at conferences or meetings, any identifying information will be removed or changed. Direct quotes may be used when the results are shared, but your or your child’s name would not be included in these quotes. Updates about the study and results will be posted on the following website: http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm. There are also links on this page to other websites that you may find helpful in coping with your child’s death.

The survey questions that we have developed in this study will be free for use by any health professional who wishes to use it. We will not receive any money from other people who want to use the survey.

What are the costs of taking part in this study?
There are no financial costs to you for taking part in this study. You will not be reimbursed in any way for taking part in the study.

Are there any conflicts of interest for the researchers?
The researchers in this study have no conflicts of interest related to the study.

Who do I contact if I have questions?
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at 416-978-2859 or by email at kim.widger@utoronto.ca, or Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca. You may also contact Laura Beaune from SickKids at 416-813-7654 ext. 3372 or laura.beaune@sickkids.ca if you have any concerns.

If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca. Or you may call the SickKids Research Ethics Manager at (416) 813-5718.

CONSENT
It is your choice to take part in this study. You can stop at any time or decide not to return the survey. Any care you may receive from SickKids will not be affected in any way.

Answering the survey questions and mailing the survey to the University of Toronto means that I give my consent to take part in this study. I agree that:

1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private. You will give no one information about me, unless the law requires you to.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to 3 of this consent form. I agree, or consent, to take part in this study.

Keep this copy for your records.
Appendix N: Phase III Letter and Items for Structural Assessment of Hospital/Hospice

Title of Research Project: Measuring the Quality of Children’s End-of-life Care

We are conducting a study to develop and test an instrument to measure the quality of end-of-life care provided to families before, at the time of, and following the death of the child, from the perspective of the parent. The focus is on families whose child died in a hospital or hospice after an admission of at least 24 hours. The study is being conducted in three phases. In the first phase, we conducted 3 focus groups with a total of 10 parents. These parents assisted us in verifying and extending the domains and indicators of quality pediatric end-of-life care which had been initially developed through a comprehensive review of the literature. In Phase II the instrument was developed and then assessed by both health professionals and bereaved parents. Phase III of the study has just begun and involves administration of the instrument by mail to a sample of at least 300 bereaved mothers from across Canada and psychometric testing of the instrument.

As part of the psychometric testing of the instrument we need to have information about structural aspects of each of the participating hospitals and hospices. We will use this information in hypothesis testing with the instrument. We invite you to take part in this phase of the study to provide this information. Your participation in this phase of the study will be valuable in the development of a psychometrically sound instrument that will ultimately be used to improve the quality of end-of-life care provided to dying children and their families.

What is involved in taking part in this study?
If you agree to take part, I will ask 6 questions about the structural aspects of your hospital/hospice. These questions will take 5 to 10 minutes to answer. I can also send you the questions by email if you prefer.

What are the risks/benefits of taking part in this study?
There is no risk or benefit to you in taking part in this study.

How will my privacy and confidentiality be maintained?
Your name will be removed and kept separate from your answers to the questions. All returned documents will be identified only by code number and kept in a locked filing cabinet at the University of Toronto. Any electronic information will be kept on a secure computer and will be password protected. Identifying information will not be emailed to anyone at any time. Only the study investigators and research staff who are directly involved with the study will have access to the study data. All paper files related to the study with identifying information will be shredded on or before September 30, 2012.

What will happen with the results of the study?
The main focus of the study is to look at all of the mother’s answers from across Canada together. We will also prepare a report for each of the hospitals and hospices that take part to identify what is going well and what needs to be improved at that hospital or hospice. If the results of any part of the study are made publicly available or are published or presented at conferences, any identifying information will be removed or changed. Updates about the study and results will be posted on the following website:
http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm
The survey questions that will be made using the results from this study will be free for use by any health professional who wishes to use it. The investigator will not receive any money from other people who want to use the survey.

**What are the costs of taking part in this study?**
There is no cost to you for taking part in this study.

**Who do I contact if I have questions?**
If you have any questions about the study or any concerns after you take part you may contact Kim Widger at (416-946-3928) or by email at kim.widger@utoronto.ca or Dr. Ann Tourangeau at 416-978-6919 or by email at ann.tourangeau@utoronto.ca If you have questions about your rights as a research participant, please contact Rachel Zand, Health Sciences Ethics Review Office, University of Toronto, at telephone 416-946-3389 or by email: rachel.zand@utoronto.ca

**CONSENT**
I understand that taking part in this study is my choice. I may withdraw at any time without any consequences. Any questions I have about the study were answered. I understand that I will not benefit from my involvement in the study. Continuing to answer the questions in the survey means that I give my consent to take part in this part of the study.

**Questions on Structural Aspects of Care**

1. a) Do you have a formal Pediatric Palliative Care Program at you Hospital/Hospice? Yes   No
   
   If Yes:

   b) When did this program begin? __________ (month/year)
   
   c) How many FTE positions are associated with the program? __________FTE
   
   d) What professions (and FTE for each) are represented in this program?

   - Physician ___ No      ___Yes   FTE?______
   - Nurses ___ No      ___Yes   FTE?______
   - Advanced Practice Nurse ___ No      ___Yes   FTE?______
   - Social Worker ___ No      ___Yes   FTE?______
   - Spiritual Care Provider ___ No      ___Yes   FTE?______
   - Physio/OT ___ No      ___Yes   FTE?______
   - Music Therapist ___ No      ___Yes   FTE?______
   - Other Therapist (Specify ____________) ___ No      ___Yes   FTE?______
   - Child Life Worker ___ No      ___Yes   FTE?______
   - Other profession (Specify ____________) ___ No      ___Yes   FTE?______

2. Do you have a program or person responsible for providing (or overseeing) follow-up support for every family whose child dies and was cared for at your hospital/hospice?  No    Yes.
   If yes, please indicate the professional background of the person/people involved in the program and briefly describe the program:

   ___________________________________________________________________________________
   ___________________________________________________________________________________

3. Do you have a memorial service at your hospital/hospice?   Yes    No
4. a) How many beds are in your hospital/hospice? _____ beds
   b) How many pediatric beds are in your hospital/hospice? _____ beds
   c) How many beds are designated for palliative/end-of-life care? _____ beds

5. a) How many parent/family rooms are in your hospital/hospice? __________
   b) How many playrooms are in your hospital/hospice? __________
   c) Any other designated areas for family? If so please describe.
_____________________________________________________________________________
_____________________________________________________________________________

6. Are there any other structural aspects of your program or facility that you think impact on the quality of pediatric end-of-life care provided?
_____________________________________________________________________________
_____________________________________________________________________________

Thanks so much for your time!
Appendix O: Final Indicators with First Draft of Instrument Items

Connect with Families

HP have good communication skills
How often did health professionals demonstrate good communication skills?
   Never / Rarely / Sometimes / Mostly / Always

HP demonstrate sensitivity and compassion at all times
How often did health professionals demonstrate sensitivity to you and your family?
   Never / Rarely / Sometimes / Mostly / Always

Connection between HP and all family members
How often was there a close connection between you and your family and the health professionals who cared for your child? Never / Rarely / Sometimes / Mostly / Always
How often did health professionals show acceptance of you and your family in a non-judgmental way?
   Never / Rarely / Sometimes / Mostly / Always

Trust between HP and family
How much did you trust the health professionals caring for your child?
   Not at all / Not very much / Somewhat / Mostly / Completely

‘Fit’ between HP and family
How often was there a good fit between health professionals and your family?
   Never / Rarely / Sometimes / Mostly / Always

HP are ‘human’
How often did health professionals act as if they were superior to you?
   Never / Rarely / Sometimes / Mostly / Always
How often did health professionals show you their “human” side?
   Never / Rarely / Sometimes / Mostly / Always

Individualized care
How often did health professionals treat you as a unique individual?
   Never / Rarely / Sometimes / Mostly / Always
How often did health professionals treat your child as a unique individual?
   Never / Rarely / Sometimes / Mostly / Always

Small acts of human kindness demonstrated
How often did you experience small acts of kindness from health professionals while you were in hospital? Never / Rarely / Sometimes / Mostly / Always
Accessible and consistent HP involved in care
How often was it easy to access the health professionals caring for your child?

Never / Rarely / Sometimes / Mostly / Always

How often were health professionals approachable in addressing your concerns?

Never / Rarely / Sometimes / Mostly / Always

How often did health professionals make sure at least one team member worked consistently with you and your family?

Never / Rarely / Sometimes / Mostly / Always

How often did you know which health professional was in charge of your child’s care?

Never / Rarely / Sometimes / Mostly / Always

Parent/child did not feel avoided or abandoned
How often did you and your family feel avoided or abandoned by health professionals before your child’s death?

Never / Rarely / Sometimes / Mostly / Always

Satisfaction with the connections between HP and the family
Overall, how satisfied were you with the connections between you and your family and the health professionals caring for your child?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Involve Parents

HP seek out and listen to parent’s views/concerns
How often did health professionals ask for your opinions or concerns about your child?

Never / Rarely / Sometimes / Mostly / Always

How often did you feel trusted as the “expert” on your child?

Never / Rarely / Sometimes / Mostly / Always

HP respect parent’s wishes
How often did health professionals respect your wishes for your child’s care?

Never / Rarely / Sometimes / Mostly / Always

Parent feels supported and strengthened in their role as parent
How often did health professionals help you to feel that you were a good parent?

Never / Rarely / Sometimes / Mostly / Always

How often did health professionals support you in your role as a parent?

Never / Rarely / Sometimes / Mostly / Always

Parent’s desired level of involvement in child’s physical care is respected
How often were you involved in your child’s care to the extent that you wanted to be?

Never / Rarely / Sometimes / Mostly / Always
Parent given opportunity to be present for life-threatening events
How often were you invited to be with your child during difficult or life threatening events (for example if CPR was done, right after surgery, during tests etc.)?

   No difficult or life threatening events / Never / Rarely / Sometimes / Mostly / Always

If there were difficult or life-threatening events, how often were health professionals available to support you during these events?  Never / Rarely / Sometimes / Mostly / Always

Satisfaction with level of involvement in child’s care
Overall, how satisfied were you with your involvement in your child’s care?

   Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Share Information
HP assess and respect amount / type of information desired by parents
How often did health professionals let you choose the amount of information that you wanted?

   Never / Rarely / Sometimes / Mostly / Always

How often did health professionals let you choose the type of information that you wanted?

   Never / Rarely / Sometimes / Mostly / Always

How often did health professionals respect the type of information that you wanted?

   Never / Rarely / Sometimes / Mostly / Always

How often did health professionals give you the right amount of information about your child’s condition?  Never / Rarely / Sometimes / Mostly / Always

Information needs anticipated by HP
How often did health professionals anticipate your need for information (seem to know what you might need before you even asked)?  Never / Rarely / Sometimes / Mostly / Always

HP gave complete, truthful, consistent, & concrete information
How often was the information you received about your child consistent from one health professionals to the next?  Never / Rarely / Sometimes / Mostly / Always

How often did health professionals give information to you and your family that was confusing?

   Never / Rarely / Sometimes / Mostly / Always

How often did you feel health professionals gave truthful information to you and your family about your child?  Never / Rarely / Sometimes / Mostly / Always

How often did health professionals give you concrete information (for example showing you test results) that you wanted to know about your child?

   Never / Rarely / Sometimes / Mostly / Always

How often did health professionals give you complete information about your child?

   Never / Rarely / Sometimes / Mostly / Always
Information must include “the big picture”
How often did health professionals talk about ‘the big picture’ for your child’s condition (for example rather than just how his/her heart or lungs were working)?

Never / Rarely / Sometimes / Mostly / Always

Adequate time provided to share information
How often did health professionals provide enough time when talking with you and your family so you did not feel rushed? Never / Rarely / Sometimes / Mostly / Always

Information offered appropriately to child by HP
How often did health professionals respect your wishes about how much to involve your child in these discussions about their illness? Never / Rarely / Sometimes / Mostly / Always / Not applicable (for example if child was too young or unable to communicate)

Information is appropriately shared among HP
From your perspective, how often was information appropriately shared among health professionals?

Never / Rarely / Sometimes / Mostly / Always

How often were you the one to tell health professionals the medical details of your child’s condition?

Never / Rarely / Sometimes / Mostly / Always

How often did it seem that health professionals planned together so they were all working towards the same goals for your child’s care? Never / Rarely / Sometimes / Mostly / Always

Team/family meetings held
How often did you take part in family and team meetings about your child’s care?

Never / Rarely / Sometimes / Mostly / Always

Possibility of death must be raised and discussed by HP
Did you have discussions with health professionals about the possibility your child would not survive his/her illness? Yes / No / Don’t remember

If yes, was this discussion done in a sensitive manner?

Not at all / Not very sensitive / Somewhat sensitive/ Mostly sensitive / Completely sensitive

If yes, how appropriate was the timing of this discussion?

Not at all appropriate / Not very appropriate / Somewhat appropriate / Mostly appropriate / Completely appropriate

**If the timing of the discussion was not completely appropriate, do you wish it would have been discussed sooner or later? A lot sooner / A little sooner / A little later / A lot later

Did health professionals ever discuss the possibility of stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)? Yes / No / Don’t remember

If yes was this discussion done in a sensitive manner?

Not at all / Not very sensitive / Somewhat sensitive/ Mostly sensitive / Completely sensitive
If yes, how appropriate was the timing of this discussion?

Not at all appropriate / Not very appropriate / Somewhat appropriate / Mostly appropriate / Completely appropriate

**If the timing of the discussion was not completely appropriate, do you wish it would have been discussed sooner or later? A lot sooner / A little sooner / A little later / A lot later

Information given about what to expect at the time of death

How well informed were you about what to expect at the time of your child’s death?

Not at all informed / A little informed / Somewhat informed / Mostly informed / Completely informed

Satisfaction with information given to parents

Overall, how satisfied were you with the information shared between you and the health professionals caring for your child?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Satisfaction with information given to child

Overall, how satisfied were you with the information shared between health professionals and your child?

Child too young / Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Satisfaction with information shared among HP

Overall, how satisfied were you with the information shared among the health professionals caring for your child?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Alleviate Suffering

Child’s physical, emotional, social & spiritual symptoms are assessed and treated

How often did health professionals look at all the needs of your child (physical, emotional, social, and spiritual needs) instead of just the physical needs?

Never / Rarely / Sometimes / Mostly / Always

How often did health professionals assist your child to maintain relationships with his/her friends or with his/her school? Not applicable / Never / Rarely / Sometimes / Mostly / Always

During your child’s last week or days of life while in the hospital, how much would you say your child appeared to suffer from each of the following symptoms?

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>Constantly</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Nausea or Vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Breathing difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Bleeding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Overall, which of the following describes the amount of suffering your child experienced as a result of his/her symptoms? Would you say he/she suffered:

Not at all / A little / Somewhat / A lot / Constantly

Parents'/siblings’ emotional, social, practical & spiritual needs anticipated, assessed, and treated

How often did health professionals provide the right amount of support for your practical needs (for example: access to food, a place to stay, transportation)?

Never / Rarely / Sometimes / Mostly / Always

**If you did not always get the right amount of practical support, do you wish you had more or less?**

A lot more / A little more / A little less / A lot less

How often did health professionals provide the right amount of support for your emotional needs?

Never / Rarely / Sometimes / Mostly / Always

**If you did not always get the right amount of emotional support, do you wish you had more or less?**

A lot more / A little more / A little less / A lot less

How often did health professionals provide the right amount of support for your spiritual needs?

Never / Rarely / Sometimes / Mostly / Always

**If you did not always get the right amount of spiritual support, do you wish you had more or less?**

A lot more / A little more / A little less / A lot less

How often did health professionals provide the right amount of support for your social needs?

Never / Rarely / Sometimes / Mostly / Always

**If you did not always get the right amount of support, do you wish you had more or less?**

A lot more / A little more / A little less / A lot less
How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital?

No other children / Never / Rarely / Sometimes / Mostly / Always

**If your other children did not always get the right amount of support, do you wish they had more or less?**  A lot more / A little more / A little less / A lot less

How often did health professionals provide guidance to you on how you could support your other children during the time your child was in hospital?

No other children / Never / Rarely / Sometimes / Mostly / Always

**If you did not always get the right amount of guidance, do you wish you had more or less?**  A lot more / A little more / A little less / A lot less

Some parents describe having a health professional who was able to “coach” or guide them during their child’s end of life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of “coach”?

Never / Rarely / Sometimes / Mostly / Always

**Offer options & opportunity to access services, fulfill wishes**

How often did health professionals recognize and try to fulfill any of your family’s special requests or wishes?  Never / Rarely / Sometimes / Mostly / Always

How often did health professionals assist you in accessing any additional services that you might need?

Never / Rarely / Sometimes / Mostly / Always

**Quiet and private space offered for all family members**

How often was your family given private space to be with your child?

Never / Rarely / Sometimes / Mostly / Always

How often was your family given quiet space to be with your child?

Never / Rarely / Sometimes / Mostly / Always

How often did health professionals allow and encourage your other children to visit as much as they wished?  No other children / Never / Rarely / Sometimes / Mostly / Always

How often did health professionals allow extended family members to visit as often as they wished?  Never / Rarely / Sometimes / Mostly / Always

**Hope is supported (but not at all costs)**

How often did health professionals support your hopes for your child?

Never / Rarely / Sometimes / Mostly / Always

How often did health professionals find the right balance in assisting you to continue hoping for the best possible outcome (cure or survival of the illness) for your child while also making plans in case that outcome did not happen?

Never / Rarely / Sometimes / Mostly / Always
**If health professionals did not always get the right balance, would you say they focused too much on survival or too much on death?**

*Way too much on survival / A little too much on survival / A little too much on death / Way too much on death*

**Options for timing / location of death provided if life support is withdrawn**

Once it was clear that your child was likely to die, were you given choices about where this might happen (for example: going home, going to a hospice, or moving to a more private room or area of the hospital)? *Yes / No / Can’t Remember / No choices possible as my child died very suddenly*

If yes, did your child die where you wanted him/her to die? *Yes / No*

If yes, did your child die where he/she wanted to die?

*Yes / No / Child too young or unable to make wishes known*

When a child has treatments like a ventilator removed, this can often be done at a time that will best meet the needs of the family (for example: it may be delayed for hours or days to allow certain people to visit or time for specific rituals). Were you given a choice about when treatments (like a ventilator) would be stopped? *Yes / No / Can’t remember / No treatments were stopped*

**If treatment was stopped, was it done at the time you wished?**

*Treatments stopped way too soon / Treatments stopped a bit too soon / Treatments stopped when I wished / Treatments continued a bit too long / Treatment continued way too long*

**Child’s death respects wishes of child & family**

Did health professionals ask if there were any cultural / religious rituals that you and your family might want around the time of your child’s death? *Yes / No / Don’t remember*

Did health professionals respect any cultural / religious rituals that you and your family wanted around the time of your child’s death?

*No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful*

Did health professionals ask who you wanted to be with you and your family when your child died? *Yes / No / Don’t remember*

Did health professionals respect your wishes for which family members should be present when your child died?

*No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful*

Did health professionals respect your wishes for which health professionals should be present when your child died?

*No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful*

Was a health professional with you and your family when your child died?

*Yes / No / Don’t Remember*
If yes, how helpful was it to have a health professional with you?

Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful

Family’s choice of pace is respected
Did you feel rushed by health professionals to leave the hospital after your child’s death?

Extremely rushed / Very rushed / Somewhat rushed / Not very rushed / Not at all rushed

Would you say there were delays after your child’s death that prevented you from leaving the hospital as quickly as you wished?

Disagree strongly / Disagree somewhat / Neither agree or disagree / Agree somewhat / Agree strongly

Sensitive / respectful care of the body
Were health professionals sensitive and respectful when caring for your child’s body after death?

Not at all / Not very sensitive / Somewhat sensitive / Mostly sensitive / Completely sensitive

Child’s death free from suffering
Some people use the word peaceful to describe the atmosphere at the time of a person’s death. Which of the following best describes the atmosphere at the time of your child’s death?

Not at all peaceful / A bit peaceful / Somewhat peaceful / Very peaceful / Extremely peaceful

Although the death of a child is always a tragedy, some parents are able to describe their child’s dying process as a good death. All things considered, would you say your child experienced a “good death”?  

Disagree strongly / Disagree somewhat / Neither agree or disagree / Agree somewhat / Agree strongly

Satisfaction with support of child
Overall, how satisfied were you with support provided to alleviate your child’s suffering by health professionals at the hospital?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Satisfaction with support of parents
Overall, how satisfied were you with support provided to you by health professionals at the hospital?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied

Satisfaction with support of siblings
Overall, how satisfied were you with support provided to your other children by health professionals at the hospital?

Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied
Provide Bereavement Care

**Anticipate and offer to collect mementos**
Did health professionals suggest and offer to collect mementos (for example: lock of hair, pictures, hand/foot prints) of your child? Yes / No / Don’t remember
Did health professionals respect your wishes about the mementos that you wanted to have?
   No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful

**Assistance with funeral arrangements offered**
Did health professionals offer to assist you in making any arrangements for funerals or other religious customs? Yes / No / Don’t remember
If yes, how helpful was this assistance for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful

**Grief and community resource information provided**
Did someone from the hospital/hospice offer you information about grief after the death of a child? Yes / No / Don’t remember
If yes, how helpful was this information for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
Did someone from the hospital/hospice offer you information about your other children’s grief?
   Yes / No / Don’t remember / Don’t have other children
If yes, how helpful was this information for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
Did someone from the hospital/hospice offer you information about community resources available close to your home? Yes / No / Don’t remember
If yes, how helpful was this information for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful

**Organ/tissue donation discussed sensitively**
Did health professionals ever discuss the possibility of your child being an organ or tissue donor?
   Yes / No / Don’t remember
**If yes, was the timing of this discussion appropriate?**
   Much too soon / A little too soon / Appropriate / A little too late / Much too late
If yes, was this discussion done in a sensitive manner?
   Not at all / Not very sensitive / Somewhat sensitive/ Mostly sensitive / Completely sensitive

**Autopsy discussed sensitively**
Did health professionals ever discuss doing an autopsy on your child?
   Yes / No / Don’t remember
**If yes, was the timing of this discussion appropriate?**
Much too soon / A little too soon / Appropriate / A little too late / Much too late
If yes, was this discussion done in a sensitive manner?
   Not at all / Not very sensitive / Somewhat sensitive / Mostly sensitive / Completely sensitive
Autopsy results received in a timely manner
If an autopsy was done did you receive the results in a timely manner?
   Autopsy not done / Not at all timely / Somewhat timely / Very timely
Follow-up meeting with HP offered after child’s death
Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or the autopsy results (if one was done)? Yes / No / Don’t remember
If yes, was this meeting helpful for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
HP offer continued contact with the family (calls, letters, etc.)
Did health professionals from the hospital / hospice offer to continue contact with your family through calls or letters after your child died?
   Yes / No / Don’t remember
**If contact continued how often did it happen?
   Much too often / A little too often / The right amount / Too few contacts / Much too few contacts
If contact continued, how helpful was it for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
Parents did not feel abandoned after the death
How often did you feel avoided or abandoned by health professionals from the hospital after your child’s death? Never / Rarely / Sometimes / Mostly / Always
Memorial service held by health centre
**Have you attended a memorial service held by the hospital where your child died?
   Yes / No / No service offered / Don’t remember
If yes, how helpful was the memorial service for you?
   Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
Satisfaction with the follow-up support provided through health centre
Overall, how satisfied were you with the support provided through the hospital in the months after your child died?
   Completely dissatisfied / Mostly dissatisfied / Neither Satisfied nor Dissatisfied / Mostly satisfied / Completely satisfied
Global item for end of survey:
Overall how would you describe the quality of care provided by health professionals during your child’s last week or days of life?

Poor / Fair / Good / Very good / Excellent

Items on Structures of Care
Space for parent to be physically present with child throughout care
How often was space provided for you to be with your child while in hospital?

Never / Rarely / Sometimes / Mostly / Always

Food available and reasonably priced
How often was food readily available for your family while you were at the hospital?

Never / Rarely / Sometimes / Mostly / Always

Would you say the food at the hospital was affordably priced?

Not at all / A little / Somewhat / Very / Extremely

Parking available and reasonably priced
How often were you easily able to find parking at the hospital?

Never / Rarely / Sometimes / Mostly / Always

Would you say the parking at the hospital was affordably priced?

Not at all / A little / Somewhat / Very / Extremely

Space available for child’s siblings at the hospital
How often were there playrooms or other space available for your other children while you were at the hospital?

No other children / Never / Rarely / Sometimes / Mostly / Always
## Appendix P: Instrument with Health Professional Testing Results

<table>
<thead>
<tr>
<th>Original Items</th>
<th>CVI</th>
<th>Quality Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How often did health professionals demonstrate good communication skills?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals use good communication skills?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How often did health professionals demonstrate sensitivity to you and your family?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals show sensitivity to you and your family?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How often was there a close connection between you and your family and the health professionals who cared for your child?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did you feel a close connection (relationship) to the health professionals who cared for your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How often did health professionals show acceptance of you and your family in a non-judgmental way?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals accept you and your family without judging you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. How much did you trust the health professionals caring for your child?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very much</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Rating</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------</td>
<td>------------------------</td>
</tr>
<tr>
<td>6. How often was there a good fit between health professionals and your family?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. How often did health professionals act as if they were superior to you?</td>
<td>0.86</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals act as if they were better than you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. How often did health professionals show you their “human” side?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. How often did health professionals treat your child as a unique individual?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals treat your child as a unique person?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. How often did health professionals treat you as a unique individual?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals treat you as a unique person?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comment: Should we ask about family as well?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. How often did you experience small acts of kindness from health professionals while you were in hospital?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Rating</td>
<td>CF</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>--------</td>
<td>-----</td>
</tr>
<tr>
<td>12. How often was it easy to access (contact?) the health professionals caring for your child?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often were health professionals approachable when talking about your concerns?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. How often were health professionals approachable in addressing your concerns?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

New: How often were health professionals approachable when talking about your concerns?

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. How often did health professionals make sure at least one team member worked consistently with you and your family?</td>
<td>0.86</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

New: How often was there at least one team member working consistently with your family?

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. How often did you know which health professional was in charge of your child’s care?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. How often did you and your family feel avoided or abandoned by health professionals before your child’s death?</td>
<td>0.86</td>
<td>CF</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

New: Did you and your family ever feel avoided or abandoned by health professionals before your child’s death?

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>17. Overall, how satisfied were you with the connections between you and your family and the health professionals caring for your child?</td>
<td>1.0</td>
<td>CF</td>
</tr>
<tr>
<td>Completely dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely satisfied</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

New: Overall, how satisfied were you with your connections (relationships) to the health professionals caring for your child?
18. Please add any other comments you would like to share about your relationship with the health professionals who cared for your child and family.

19. How often did health professionals ask for your opinions or concerns about your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

20. How often did you feel trusted as the “expert” on your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

21. How often did health professionals respect your wishes for your child’s care?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

22. How often did health professionals help you to feel that you were a good parent (providing the best care for your child)?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

23. How often did health professionals support you in your role as a parent?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

24. How often were you involved in your child’s care to the extent that you wanted to be?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

   **New**: How often were you as involved in your child’s care as you wanted to be?
25. How often were you invited to be with your child during difficult or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)?
   - No difficult or life threatening events
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

26. If there were difficult or life-threatening events, how often were health professionals available to support you during these events?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

27. Overall, how satisfied were you with your involvement in your child’s care?
   - Completely dissatisfied
   - Mostly dissatisfied
   - Neither satisfied nor dissatisfied
   - Mostly satisfied
   - Completely satisfied

28. Please add any other comments you would like to share about your involvement in your child’s care.

__________________________________________________________________________.

29. How often did health professionals let you choose the type of information that you wanted?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

30. How often did health professionals respect the type of information that you wanted?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

   **New:** How often did health professionals give you the type of information that you wanted?
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. How often did health professionals let you choose the amount of information that you wanted?</td>
<td>0.86</td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>32. How often did health professionals give you “the right amount” of information about your child’s condition?</td>
<td>1.0</td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>33. How often did health professionals anticipate your need for information (seem to know what you might need before you even asked)?</td>
<td>1.0</td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>34. How often was the information you received about your child consistent from one health professional to the next?</td>
<td>1.0</td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>New: How often was the information you received about your child the same from one health professional to the next?</td>
<td></td>
</tr>
<tr>
<td>35. How often did health professionals give information to you and your family that was confusing?</td>
<td>1.0</td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
</tbody>
</table>
36. How often did you feel health professionals gave truthful information to you and your family about your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   0.86  SI

37. How often did health professionals give you concrete information (for example showing you test results) that you wanted to know about your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   1.0  SI

38. How often did health professionals give you complete information about your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   1.0  SI

39. How often did health professionals talk about ‘the big picture’ for your child’s condition (for example rather than just how his/her heart or lungs were working)?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   .86  SI

   New: How often did health professionals give you complete information about your child?

   New: How often did health professionals talk about ‘the big picture’ for your child’s condition (for example not just how his/her heart or lungs were working)?

40. How often did health professionals provide enough time when talking with you and your family so you did not feel rushed?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   1.0  SI
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>Gradation</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. How often did health professionals respect your wishes about how much to involve your child in discussions about his/her illness?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>New: How often did health professionals respect your wishes about how much to involve your child in talks about his/her illness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. From your perspective, how often was information appropriately (properly?) shared among health professionals?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>43. How often were you the one to tell health professionals the medical details of your child’s condition?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>44. How often did it seem that health professionals planned together so they were all working towards the same goals for your child’s care?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>45. How often did you take part in family and team meetings about your child’s care?</td>
<td>1.0</td>
<td>SI</td>
</tr>
</tbody>
</table>

Not applicable (for example child too young or not able to communicate)
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. Overall, how satisfied were you with the information shared between you and the health professionals caring for your child?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>- Completely dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Neither satisfied nor dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. Overall, how satisfied were you with the information shared between health professionals and your child?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>- Child too young</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Neither satisfied nor dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>48. Overall, how satisfied were you with the information shared among the health professionals caring for your child?</td>
<td>1.0</td>
<td>SI</td>
</tr>
<tr>
<td>- Completely dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Neither satisfied nor dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>49. Please add any other comments about how information about your child’s care was shared with you and your family, or among health professionals.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. How often did health professionals look at all the needs of your child (physical, emotional, social, and spiritual needs) instead of just the physical needs?</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>- Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51. How often did health professionals assist your child to maintain relationships with his/her friends or with his/her school?</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>- Not applicable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

New: How often did health professionals help your child to keep up relationships with his/her friends or school?
52. During your child’s last week or days of life while in the hospital, how much would you say your child seemed to **suffer** from each of the following symptoms? (response options for each symptom are: Not at all / A little / Somewhat / A lot / Constantly)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Bleeding</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Seizures (convulsions?)</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Sadness</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Anxiety (worry?)</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Fear</td>
<td>Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td>Other: Specify_________</td>
<td></td>
</tr>
</tbody>
</table>

**NOTE:** for parents this question will be laid out with the response options beside each symptom.

53. Overall, which of the following describes the amount of suffering your child experienced as a result of his/her symptoms? Would you say he/she suffered:

- Not at all
- A little
- Somewhat
- A lot
- Constantly

**New:** Overall, which of the following describes the amount of suffering your child had from his/her symptoms?

54. How often did health professionals provide the right amount of support for your practical needs (for example access to food, a place to stay, transportation)?

- Never
- Rarely
- Sometimes
- Mostly
- Always

**New:** How often did health professionals provide the right amount of support for your emotional needs (for example feeling cared about, feeling listened to)?

55. If you did not always get the right amount of practical support, do you wish you had more or less?

- A lot more
- A little more
- A little less
- A lot less

**Comments:** For these type of questions a more clearly laid out “skip” pattern will help with the reviewers concerns. If parents answer “always” to the previous question, they will be directed to skip this one, so the stem could be shortened to “Do you wish you had more or less practical support?”

56. How often did health professionals provide the right amount of support for your emotional needs?

- Never
- Rarely
- Sometimes
- Mostly
- Always

**New:** How often did health professionals provide the right amount of support for your emotional needs (for example feeling cared about, feeling listened to)?
<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you did not always get the right amount of emotional support, do you wish you had more or less?</td>
<td>0.86</td>
<td>AS</td>
</tr>
</tbody>
</table>
| A lot more
A little more
A little less
A lot less                                                                                                                                                             |
| Comments: see #55                                                                                                                                                                                      |       |      |
| How often did health professionals provide the right amount of support for your spiritual needs?                                                                                                      | 1.0   | AS   |
| Never
Rarely
Sometimes
Mostly
Always                                                                                                                                                                                               |
| If you did not always get the right amount of spiritual support, do you wish you had more or less?                                                                                                               | 1.0   | AS   |
| A lot more
A little more
A little less
A lot less                                                                                                                                                             |
| Comments: see #55                                                                                                                                                                                      |       |      |
| How often did health professionals provide the right amount of support for your social needs?                                                                                                         | 0.86  | AS   |
| Never
Rarely
Sometimes
Mostly
Always                                                                                                                                                                                               |
| New: How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your friends)? |
| If you did not always get the right amount of support for your social needs, do you wish you had more or less?                                                                                         | 0.71  | AS   |
| A lot more
A little more
A little less
A lot less                                                                                                                                                             |
| Comments: see #55                                                                                                                                                                                      |       |      |
| How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital?                                                        | 1.0   | AS   |
| No other children
Never
Rarely
Sometimes
Mostly
Always                                                                                                                                                                                               |
63. If your other children did not *always* get the right amount of support, do you wish they had more or less?
   - A lot more
   - A little more
   - A little less
   - A lot less
   **0.86**
   **AS**
   **Comments:** see #55

64. How often did health professionals provide guidance to you on how you could support your other children during the time your child was in hospital?
   - No other children
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   **1.0**
   **AS**
   **New:** How often did health professionals guide you on how to support your other children while your child was in hospital?

65. If you did not *always* get the right amount of guidance about supporting your other children, do you wish you had more or less?
   - A lot more
   - A little more
   - A little less
   - A lot less
   **0.86**
   **AS**
   **Comments:** see #55

66. Some parents describe having a health professional who was able to “coach” or guide them during their child’s end-of-life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of “coach”?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
   **1.0**
   **AS**
<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
<th>AS</th>
</tr>
</thead>
<tbody>
<tr>
<td>67. How often did health professionals recognize and try to fulfill any</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>of your family’s special requests or wishes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals assist you in accessing any</td>
<td></td>
<td></td>
</tr>
<tr>
<td>additional services that you might need?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often was your family given private space to be with your</td>
<td></td>
<td></td>
</tr>
<tr>
<td>child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often was your family given private time with your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often was your family given quiet space to be with your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often was your family given quiet time with your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals allow and encourage your other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>children to visit as much as they wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No other children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals allow and encourage your other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>children to visit when they wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals allow extended family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>to visit as often as they wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: How often did health professionals allow extended family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>to visit when they wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
73. Overall, how satisfied were you with support provided to alleviate your child’s suffering by health professionals at the hospital?
- Completely dissatisfied
- Mostly dissatisfied
- Neither satisfied nor dissatisfied
- Mostly satisfied
- Completely satisfied

74. Overall, how satisfied were you with support provided to you by health professionals at the hospital?
- Completely dissatisfied
- Mostly dissatisfied
- Neither satisfied nor dissatisfied
- Mostly satisfied
- Completely satisfied

75. Overall, how satisfied were you with support provided to your other children by health professionals at the hospital?
- No other children
- Completely dissatisfied
- Mostly dissatisfied
- Neither satisfied nor dissatisfied
- Mostly satisfied
- Completely satisfied

76. Please add any other comments about how you and your family were supported by health professionals while your child was in the hospital.

77. Did you have discussions with health professionals about the possibility your child would not survive his/her illness?
- Yes
- No
- Don’t remember

78. If yes, was this possibility discussed in a sensitive manner?
- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

79. If yes, how appropriate was the timing of this discussion?
- Not at all appropriate
- Not very appropriate
- Somewhat appropriate
- Mostly appropriate
- Completely appropriate
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>80. If the timing of the discussion was not completely appropriate, do you wish it would have been discussed sooner or later?</td>
<td>1.0</td>
<td>SI * Note: Skip pattern will be clear here so first half of sentence will not be needed (see #55)</td>
</tr>
<tr>
<td>A lot sooner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little sooner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little later</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lot later</td>
<td></td>
<td></td>
</tr>
<tr>
<td>81. How often did health professionals support your hopes for your child?</td>
<td>1.0</td>
<td>AS *</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>82. How often did health professionals find the right balance in assisting you to continue hoping for the best possible outcome (cure or survival of the illness) for your child while also making plans in case that outcome did not happen?</td>
<td>0.86</td>
<td>AS New: How often did health professionals find the right balance in helping you hope for the best possible outcome (cure or survival of the illness) for your child while also making plans in case that outcome did not happen?</td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>83. If health professionals did not always get the right balance, would you say they focused too much on survival/cure or too much on death?</td>
<td>1.0</td>
<td>AS * Note: see #55</td>
</tr>
<tr>
<td>Way too much on survival/cure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too much on survival/cure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too much on death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Way too much on death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>84. Did health professionals ever discuss the possibility of stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)?</td>
<td>1.0</td>
<td>AS * New: Did health professionals ever talk about stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)?</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85. If yes, was this discussion about stopping treatments done in a sensitive manner?</td>
<td>1.0</td>
<td>AS *</td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>1.0</td>
<td>AS *</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-----</td>
<td>------</td>
</tr>
</tbody>
</table>
| 86. If yes, how appropriate was the timing of this discussion about stopping treatments?  
   - Not at all appropriate  
   - Not very appropriate  
   - Somewhat appropriate  
   - Mostly appropriate  
   - Completely appropriate |     |      |
| 87. If the timing of the discussion about treatments was not completely appropriate, do you wish it would have been discussed sooner or later?  
   - A lot sooner  
   - A little sooner  
   - A little later  
   - A lot later |     |      |
| Note: see #55                                                          |     |      |
| 88. When a child has treatments like a ventilator removed, this can often be done at a time that will best meet the needs of the family (for example it may be delayed for hours or days to allow certain people to visit or to give time for specific rituals). Were you given a choice about when treatments (like a ventilator) would be stopped?  
   - Yes  
   - No  
   - Can’t remember  
   - No treatments were stopped |     |      |
| 89. If treatment was stopped, was it done at the time you wished?  
   - Treatments stopped way too soon  
   - Treatments stopped a bit too soon  
   - Treatments stopped when I wished  
   - Treatments continued a bit too long  
   - Treatment continued way too long |     |      |
| 90. Once it was clear that your child was likely to die, were you given choices about where this might happen (for example going home, going to a hospice, or moving to a more private room or area of the hospital)?  
   - Yes  
   - No  
   - Can’t remember  
   - No choices possible as my child died very suddenly |     |      |
<table>
<thead>
<tr>
<th>Question</th>
<th>1.0</th>
<th>AS *</th>
</tr>
</thead>
<tbody>
<tr>
<td>91. Did your child die where you wanted him/her to die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Did your child die in the place that you wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>92. Did your child die where he/she wanted to die?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child too young or unable to make wishes known</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Was your child where he/she wanted to be when he/she died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Add response: Unsure, not discussed with child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>93. Did health professionals ask if there were any cultural / religious /spiritual rituals that you and your family might want around the time of your child’s death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>94. Did health professionals respect any cultural / religious / spiritual rituals that you and your family wanted around the time of your child’s death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>95. Did health professionals ask who you wanted to be with you and your family when your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>96. Did health professionals respect your wishes for which family members should be present when your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Did health professionals respect your wishes for which family members you wanted with you when your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>97. Did health professionals respect your wishes for which health professionals should be present when your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Did health professionals respect your wishes for which health professionals you wanted with you when your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Value</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>98. Was a health professional with you and your family when your child died?</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t Remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>99. If yes, how helpful was it to have a health professional with you?</td>
<td>1.0</td>
<td>AS *</td>
</tr>
<tr>
<td>Not at all helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>100. How well informed were you about what to expect at the time of your child’s death?</td>
<td>1.0</td>
<td>SI *</td>
</tr>
<tr>
<td>Not at all informed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little informed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat informed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly informed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely informed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>101. Some people use the word peaceful to describe the atmosphere at the time of a person’s death. Which of the following best describes the atmosphere at the time of your child’s death?</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>Not at all peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>102. Although the death of a child is always a tragedy, some parents are able to describe their child’s dying process as a good death. All things considered, would you say your child experienced a “good death”?</td>
<td>1.0</td>
<td>AS</td>
</tr>
<tr>
<td>Disagree strongly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree somewhat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree somewhat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree strongly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>103. Did health professionals ever discuss the possibility of your child being an organ or tissue donor?</td>
<td>1.0</td>
<td>BC *</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**New:** Did health professionals ever talk about whether or not your child could be an organ or tissue donor?
<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>104. If yes, was the timing of this discussion appropriate?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Much too soon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- A little too soon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Appropriate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- A little too late</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Much too late</td>
<td></td>
<td></td>
</tr>
<tr>
<td>105. If yes, was this discussion done in a sensitive manner?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Not at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Not very sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Somewhat sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>106. Did health professionals ever discuss doing an autopsy on your child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Don't remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>107. If yes, was the timing of this discussion appropriate?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Much too soon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- A little too soon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Appropriate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- A little too late</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Much too late</td>
<td></td>
<td></td>
</tr>
<tr>
<td>108. If yes, was this discussion done in a sensitive manner?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Not at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Not very sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Somewhat sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mostly sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Completely sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>109. Did health professionals suggest and offer to collect mementos of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your child (for example lock of hair, pictures, hand/foot prints)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Don't remember</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*New: Did health professionals ever discuss doing an autopsy on your child?*

*New: Did health professionals ever discuss an autopsy for your child?*

*New: If yes, was this discussion done in a sensitive way?*
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>110. Did health professionals respect your wishes about the mementos</td>
<td>1.0</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>that you wanted to have?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>111. Did health professionals offer to assist you in making any</td>
<td>1.0</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>arrangements for funerals or other religious customs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember</td>
<td></td>
<td></td>
</tr>
<tr>
<td>112. If yes, how helpful was this assistance for you?</td>
<td>1.0</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>Not at all helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>113. Were health professionals sensitive and respectful when caring</td>
<td>1.0</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>for your child’s body after death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>114. Did you feel rushed by health professionals to leave the hospital</td>
<td>1.0</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>after your child’s death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all rushed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>115. Would you say there were delays after your child’s death that</td>
<td>0.86</td>
<td>Extremes, BC</td>
</tr>
<tr>
<td>prevented you from leaving the hospital as quickly as you wished?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree strongly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree somewhat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither agree or disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree somewhat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree strongly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>116. Please add any other comments about the discussions or events</td>
<td></td>
<td></td>
</tr>
<tr>
<td>that happened at the time of your child’s death.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
<td>BC</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td>117. Did health professionals from the hospital offer to continue</td>
<td>Yes, No, Don’t remember</td>
<td>1.0</td>
</tr>
<tr>
<td>contact with your family through calls or letters after your child died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>118. If contact continued, how often did it happen?</td>
<td>Much too often, A little too often,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The right amount, Too few contacts,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Much too few contacts</td>
<td></td>
</tr>
<tr>
<td>New: If contact continued, about how many contacts have you had?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would you say this number of contacts was the right amount, too many or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>too few?</td>
<td>Much too many, A little too many,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The right amount, A little too few,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Much too few</td>
<td></td>
</tr>
<tr>
<td>119. If contact continued, how helpful was it for you?</td>
<td>Not at all helpful, A little helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somewhat helpful, Very helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely helpful</td>
<td></td>
</tr>
<tr>
<td>120. Did someone from the hospital offer you information about grief</td>
<td>Yes, No, Don’t remember</td>
<td>1.0</td>
</tr>
<tr>
<td>after the death of a child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>121. If yes, how helpful was this information for you?</td>
<td>Not at all helpful, A little helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somewhat helpful, Very helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely helpful</td>
<td></td>
</tr>
<tr>
<td>122. Did someone from the hospital offer you information about your</td>
<td>Yes, No, Don’t remember, Don’t have</td>
<td>1.0</td>
</tr>
<tr>
<td>other children’s grief?</td>
<td>other children</td>
<td></td>
</tr>
<tr>
<td>123. If yes, how helpful was this information for you?</td>
<td>Not at all helpful, A little helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somewhat helpful, Very helpful,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely helpful</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
<td>Code</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>124. Did someone from the hospital offer you information about community resources available close to your home?</td>
<td>Yes, No, Don’t remember</td>
<td>1.0</td>
</tr>
<tr>
<td>125. If yes, how helpful was this information for you?</td>
<td>Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td>1.0</td>
</tr>
<tr>
<td>126. If an autopsy was done, did you receive the results in a timely manner?</td>
<td>Autopsy not done, Not at all timely, Somewhat timely, Very timely</td>
<td>1.0</td>
</tr>
<tr>
<td>127. Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or the autopsy results (if one was done)?</td>
<td>Yes, No, Don’t remember</td>
<td>1.0</td>
</tr>
<tr>
<td>128. If yes, was this meeting helpful for you?</td>
<td>Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td>1.0</td>
</tr>
<tr>
<td>129. Have you attended a memorial service held by the hospital where your child died?</td>
<td>Yes, No, No service offered, Don’t remember</td>
<td>1.0</td>
</tr>
<tr>
<td>130. If yes, how helpful was the memorial service for you?</td>
<td>Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td>1.0</td>
</tr>
</tbody>
</table>
131. How often did you feel avoided or abandoned by health professionals from the hospital after your child’s death?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

   **New:** Did you feel avoided or abandoned by health professionals from the hospital after your child’s death?

| 0.86 | BC |

132. Overall, how satisfied were you with the support provided through the hospital in the months after your child died?
   - Completely dissatisfied
   - Mostly dissatisfied
   - Neither satisfied nor dissatisfied
   - Mostly satisfied
   - Completely satisfied

| 1.0 | BC |

133. Please add any other comments about the support provided through the hospital in the months after your child’s death. ________________________________.

134. Overall how would you describe the quality of care provided to your child and family by health professionals from the hospital?
   - Poor
   - Fair
   - Good
   - Very good
   - Excellent

| 1.0 |  |

135. Please add any other comments about the overall care your child and family received through the hospital. ________________________________

**NEW:** 136. What was the best experience you had with the health care system during your child’s illness?

**NEW:** 137. What was the worst experience you had with the health care system during your child’s illness?

138. How often was space provided for you to be with your child while in hospital?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

| 0.5 |  |

**New:** How often was there a big enough space for you to be with your child while in hospital?
139. How often were there playrooms or other space available for your other children while you were at the hospital?
   - No other children
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

<table>
<thead>
<tr>
<th>139. How often were there playrooms or other space available for your other children while you were at the hospital?</th>
<th>0.86</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>New:</strong> How often were there playrooms or other child-friendly space for your other children while you were at the hospital?</td>
<td></td>
</tr>
</tbody>
</table>

140. How often was food readily available for your family while you were at the hospital?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

<table>
<thead>
<tr>
<th>140. How often was food readily available for your family while you were at the hospital?</th>
<th>0.71</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments: Larger issue</td>
<td></td>
</tr>
</tbody>
</table>

141. Would you say the food at the hospital was affordably priced?
   - Not at all
   - A little
   - Somewhat
   - Very
   - Extremely

<table>
<thead>
<tr>
<th>141. Would you say the food at the hospital was affordably priced?</th>
<th>0.86</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments: Larger issue</td>
<td></td>
</tr>
</tbody>
</table>

142. How often were you easily able to find parking at the hospital?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

<table>
<thead>
<tr>
<th>142. How often were you easily able to find parking at the hospital?</th>
<th>1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments: Larger issue</td>
<td></td>
</tr>
</tbody>
</table>

143. Would you say the parking at the hospital was affordably priced?
   - Not at all
   - A little
   - Somewhat
   - Very
   - Extremely

<table>
<thead>
<tr>
<th>143. Would you say the parking at the hospital was affordably priced?</th>
<th>0.86</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments: Larger issue</td>
<td></td>
</tr>
</tbody>
</table>

144. Please share any other comments you have about the facilities available to you and your family while at the hospital.

________________________________________

________________________________________

254
Overall rating: Please rate the degree to which the instrument reflects and measures the construct of quality pediatric end-of-life care. (Each reviewer’s response is indicated by an X – one person did not answer)

_____ 1 = the instrument is not representative of quality pediatric end-of-life care
__X__ 2 = the instrument needs major revisions to be representative of quality pediatric end-of-life care
__X__ 3 = the instrument needs minor revisions to be representative of quality pediatric end-of-life care
XXXX 4 = the instrument is representative of quality pediatric end-of-life care
Appendix Q: Instrument with Parent Testing Results

When answering the following questions think about all of the health professionals (including doctors, nurses, social workers, child life specialists, etc.) at the hospital who took care of your child and family during the last week or days of your child’s life.

Most of the questions ask about you and your family. Your family includes your child who was ill and your immediate family.

The first questions ask about your relationship with the health professionals who cared for your child and family. Please think about what these relationships were like in the last week of days of your child’s life.

<table>
<thead>
<tr>
<th>Original Items</th>
<th>New Items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. How often did health professionals use good communication skills?</strong></td>
<td><strong>1. How often did health professionals communicate well with you and your family?</strong></td>
</tr>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
<tr>
<td><strong>2. How often did health professionals show sensitivity to you and your family?</strong></td>
<td><strong>2. How often were health professionals sensitive to you and your family’s feelings?</strong></td>
</tr>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
<tr>
<td><strong>3. How often did you feel a close connection (relationship) to the health professionals who cared for your child?</strong></td>
<td><strong>3. How often did you feel a close connection to the health professionals who cared for your child?</strong></td>
</tr>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
<tr>
<td><strong>4. How often was there a “good fit” between health professionals and your family?</strong></td>
<td><strong>No changes</strong></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>5. How often did health professionals accept you and your family without judging you?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>5. How often did you feel health professionals accepted you and your family without judging you?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>6. How much did you trust the health professionals caring for your child?</td>
<td>Not at all, Not very much, Somewhat, Mostly, Completely</td>
</tr>
<tr>
<td>7. How often did health professionals act as if they were better than you?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>8. How often did health professionals show you their “human” side?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>9. How often did health professionals treat your child as a unique person?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>10. How often did health professionals treat you as a unique person?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td><strong>New Item</strong>: 11. How often did health professionals treat your family as unique?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>12. How often did you experience small acts of kindness from health professionals while you were in hospital?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>13. How often was it easy to access (contact) the health professionals caring for your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>14. How often were health professionals approachable talking about your concerns?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>15. How often was there at least one team member working consistently with your family?</td>
<td>No changes</td>
</tr>
<tr>
<td>16. How often did you know which health professional was in charge of your child’s care?</td>
<td>No changes</td>
</tr>
<tr>
<td>17. Did you and your family ever feel avoided or abandoned by health professionals before your child’s death?</td>
<td>No changes</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>18. Overall, how satisfied were you with your connections (relationships) to the health professionals caring for your child?</td>
<td>Completely dissatisfied, Mostly dissatisfied, Neither satisfied nor dissatisfied, Mostly satisfied, Completely satisfied</td>
</tr>
<tr>
<td>19. Please add any other comments you would like to share about your relationship with the health professionals who cared for your child and family.</td>
<td></td>
</tr>
<tr>
<td>The next few questions focus on how health professionals involved you in your child’s care.</td>
<td></td>
</tr>
<tr>
<td>20. How often did health professionals ask for your opinions or concerns about your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>21. How often did you feel trusted as the “expert” on your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>22. How often did health professionals respect your wishes for your child’s care?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>23. How often did health professionals help you to feel that you were a good parent (providing the best care for your child)?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>18. Overall, how satisfied were you with your relationships with the health professionals who cared for your child before his/her death?</td>
<td>Completely dissatisfied, Mostly dissatisfied, Somewhat dissatisfied, Neither satisfied nor dissatisfied, Somewhat satisfied, Mostly satisfied, Completely satisfied</td>
</tr>
<tr>
<td>19. Please add any other comments you would like to share about your relationship with the health professionals who cared for your child and family.</td>
<td></td>
</tr>
<tr>
<td>The next few questions ask how health professionals involved you in your child’s care during the last week or days of your child’s life.</td>
<td></td>
</tr>
<tr>
<td>23. How often did health professionals help you to feel that you were doing the best you could for your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>24. How often did health professionals support you in your role as a parent?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>25. How often were you as involved in your child’s care as you wanted to be?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>26. How often were you invited to be with your child during difficult or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)?</td>
<td>No difficult or life threatening events (Skip to question 27), Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>27. If there were difficult or life-threatening events, how often were health professionals available to support you during these events?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>28. Overall, how satisfied were you with your involvement in your child’s care?</td>
<td>Completely dissatisfied, Mostly dissatisfied, Neither satisfied nor dissatisfied, Mostly satisfied, Completely satisfied</td>
</tr>
</tbody>
</table>
29. Please add any other comments you would like to share about your involvement in your child’s care.
____________________________________

The next few questions ask about the information that was shared between health professionals and your family as well as among health professionals.

30. How often did health professionals let you choose the type of information that you wanted?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

30. How often did health professionals let you choose how information was shared with you (for example: written information, use of email, having someone else with you when information was shared)?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

30. How often did health professionals give you the type of information that you wanted?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

31. How often did health professionals let you choose the amount of information that you wanted?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

31. How often did health professionals let you choose the amount of information that you wanted shared with you?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

32. How often did health professionals give you “the right amount” of information about your child’s condition?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always (Skip to question 34)

No changes
<table>
<thead>
<tr>
<th>Question</th>
<th>New Item: 33. Do you wish you had more or less information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>34. How often did health professionals anticipate your need for information (seem to know what you might need before you even asked)?</td>
<td>34. How often did health professionals seem to know what information you might need before you even asked?</td>
</tr>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>35. How often did health professionals give information to you and your family that was confusing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>36. How often did you feel health professionals gave truthful information to you and your family about your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>37. How often did health professionals give you concrete information (for example showing you test results) that you wanted to know about your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>38. How often did you feel health professionals gave you complete information about your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Item Deleted (too much overlap with truthful and big picture)</th>
</tr>
</thead>
<tbody>
<tr>
<td>37. How often did health professionals show you your child’s test results, X-rays, or scans when you wanted to see them?</td>
<td>37. How often did health professionals show you your child’s test results, X-rays, or scans when you wanted to see them?</td>
</tr>
<tr>
<td>I did not want this kind of information</td>
<td>I did not want this kind of information</td>
</tr>
<tr>
<td>Never</td>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
<td>Always</td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>38. How often did health professionals talk about ‘the big picture’ for</td>
<td>Never, Rarely, Sometimes, Mostly,</td>
</tr>
<tr>
<td>your child’s condition (for example not just how his/her heart or lungs</td>
<td>Always</td>
</tr>
<tr>
<td>were working)?</td>
<td></td>
</tr>
<tr>
<td>39. How often did health professionals provide enough time when talking</td>
<td>Never, Rarely, Sometimes, Mostly,</td>
</tr>
<tr>
<td>with you and your family so you did not feel rushed?</td>
<td>Always</td>
</tr>
<tr>
<td>40. How often did you take part in family and team meetings about your</td>
<td>Never, Rarely, Sometimes, Mostly,</td>
</tr>
<tr>
<td>child’s care?</td>
<td>Always</td>
</tr>
<tr>
<td>41. How often did health professionals respect your wishes about how</td>
<td>Not applicable (for example child</td>
</tr>
<tr>
<td>much to involve your child in talks about his/her illness?</td>
<td>too young or not able to</td>
</tr>
<tr>
<td>42. Overall, how satisfied were you with the information shared</td>
<td>Completely dissatisfied, Mostly</td>
</tr>
<tr>
<td>between you and the health professionals caring for your child?</td>
<td>dissatisfied, Somewhat dissatisfied, Neither satisfied nor dissatisfied, Mostly satisfied, Completely satisfied</td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 43. Overall, how satisfied were you with the information shared between health professionals and your child? | Child too young  
Completely dissatisfied  
Mostly dissatisfied  
Neither satisfied nor dissatisfied  
Mostly satisfied  
Completely satisfied |
| 44. Please add any other comments about how information about your child was shared with you, your child, and your family. | Section moved around and split into two, but content unchanged |
| 45. How often was the information you received about your child the same from one health professional to the next? | Never  
Rarely  
Sometimes  
Mostly  
Always |
| 46. From your perspective, how often was information appropriately (properly?) shared among health professionals? | Never  
Rarely  
Sometimes  
Mostly  
Always |
| 47. How often were you the one to tell health professionals the medical details of your child’s condition? | Never  
Rarely  
Sometimes  
Mostly  
Always |
| 48. How often were you the one to tell health professionals the medical details of your child’s condition because they didn’t seem to know? | Never  
Rarely  
Sometimes  
Mostly  
Always |
48. How often did it seem health professionals planned together so they were all working towards the same goals for your child’s care?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

49. Overall, how satisfied were you with the information shared among the health professionals caring for your child?
   - Completely dissatisfied
   - Mostly dissatisfied
   - Neither satisfied nor dissatisfied
   - Mostly satisfied
   - Completely satisfied

50. Please add any other comments about how information about your child’s care was shared with you and your family, or among health professionals.

The next few questions ask about the support given to your child and family by health professionals.

51. How often did health professionals look at all the needs of your child (physical, emotional, social, and spiritual needs) instead of just the physical needs?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

52. How often did health professionals help your child to keep up relationships with his/her friends or school?
   - Not applicable
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

51. How often did health professionals look at all the needs of your child (physical, emotional, social, developmental, and spiritual needs)?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

52. How often did health professionals help your child to keep up relationships with his/her friends or school?
   - Not applicable
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>53. During your child’s last week or days of life while in the hospital, how much would you say your child seemed to <strong>suffer</strong> from each of the following symptoms?</td>
<td>Response options: Not at all / A little / Somewhat / A lot / Constantly</td>
</tr>
<tr>
<td></td>
<td>Pain, Nausea or vomiting, Breathing difficulties, Bleeding, Seizures (convulsions?), Sadness, Anxiety (worry?), Fear</td>
</tr>
<tr>
<td></td>
<td>Other: Specify_________</td>
</tr>
<tr>
<td>54. Overall, which of the following describes the amount of suffering your child had from his/her symptoms? Would you say he/she suffered:</td>
<td>Not at all, A little, Somewhat, A lot, Constantly</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>55. How often did health professionals provide the right amount of support for your practical needs (for example access to food, a place to stay, transportation)?</td>
<td>Never, Rarely, Sometimes, Mostly, Always (Skip to Question 57)</td>
</tr>
<tr>
<td>56. Do you wish you had more or less practical support?</td>
<td>A lot more, A little more, A little less, A lot less</td>
</tr>
</tbody>
</table>

No change
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>57. How often did health professionals provide the right amount of support for your emotional needs (for example feeling cared about, feeling listened to)?</td>
<td>Never, Rarely, Sometimes, Mostly, Always (Skip to Question 59)</td>
</tr>
<tr>
<td>57. How often did health professionals provide the right amount of support for your emotional needs (for example feeling listened to, accepting your feelings)?</td>
<td>Never, Rarely, Sometimes, Mostly, Always (Skip to Question 58)</td>
</tr>
<tr>
<td>58. Do you wish you had more or less emotional support?</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>A lot more, A little more, A little less, A lot less</td>
</tr>
<tr>
<td>59. How often did health professionals provide the right amount of support for your spiritual needs?</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>Never, Rarely, Sometimes, Mostly, Always (Skip to Question 61)</td>
</tr>
<tr>
<td>60. Do you wish you had more or less spiritual support?</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>A lot more, A little more, A little less, A lot less</td>
</tr>
<tr>
<td>61. How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your friends)?</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>Never, Rarely, Sometimes, Mostly, Always (Skip to Question 63)</td>
</tr>
<tr>
<td>62. Do you wish you had more or less social support?</td>
<td>No change</td>
</tr>
<tr>
<td></td>
<td>A lot more, A little more, A little less, A lot less</td>
</tr>
<tr>
<td>Question</td>
<td>No change</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>63. How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Question 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always (Skip to Question 65)</td>
<td></td>
</tr>
<tr>
<td>64. Do you wish your other children had more or less support?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Questions 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always (Skip to Question 67)</td>
<td></td>
</tr>
<tr>
<td>65. How often did health professionals guide you on how to support your other children while your child was in hospital?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Questions 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always (Skip to Question 67)</td>
<td></td>
</tr>
<tr>
<td>66. Do you wish you had more or less guidance about supporting your other children?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Questions 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always (Skip to Question 67)</td>
<td></td>
</tr>
<tr>
<td>67. Some parents describe having a health professional who was able to “coach” or guide them during their child’s end-of-life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of “coach”?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Questions 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always (Skip to Question 67)</td>
<td></td>
</tr>
<tr>
<td>67. Some parents describe having a health professional who was able to “coach” or guide them during their child’s end-of-life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of guide?</td>
<td></td>
</tr>
<tr>
<td>No other children (Skip to Questions 67)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>68. How often did health professionals recognize and try to fulfill any</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>of your family’s special requests or wishes?</td>
<td></td>
</tr>
<tr>
<td>69. How often did health professionals assist you to get any additional</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>services that you might need?</td>
<td></td>
</tr>
<tr>
<td>70. How often was your family given private time with your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>70. How often was your family given quiet space to be with your child?</td>
<td>Delete (overlap with above and with structure question)</td>
</tr>
<tr>
<td>71. How often did health professionals allow and encourage your other</td>
<td>No other children, Never, Rarely, Sometimes, Mostly,</td>
</tr>
<tr>
<td>children to visit when they wished?</td>
<td>Always</td>
</tr>
<tr>
<td>72. How often did health professionals allow extended family members to</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>visit when they wished?</td>
<td></td>
</tr>
<tr>
<td>72. How often did health professionals allow and encourage extended</td>
<td></td>
</tr>
<tr>
<td>family members / friends to visit when you wished?</td>
<td></td>
</tr>
</tbody>
</table>
### 73. Overall, how satisfied were you with support given to alleviate (lessen, ease?) your child’s suffering by health professionals at the hospital?  
- Completely dissatisfied  
- Mostly dissatisfied  
- Neither satisfied nor dissatisfied  
- Mostly satisfied  
- Completely satisfied

### 74. Overall, how satisfied were you with support given to ease your child’s suffering by health professionals at the hospital?  
- Completely dissatisfied  
- Mostly dissatisfied  
- Somewhat dissatisfied  
- Neither satisfied nor dissatisfied  
- Somewhat satisfied  
- Mostly satisfied  
- Completely satisfied

### 75. Overall, how satisfied were you with support given to your other children by health professionals at the hospital?  
- No other children  
- Completely dissatisfied  
- Mostly dissatisfied  
- Neither satisfied nor dissatisfied  
- Mostly satisfied  
- Completely satisfied

### 76. Please add any other comments about how you and your family were supported by health professionals while your child was in the hospital.  
__________________________________

The next few questions ask more specifically about the discussions and events that happened just before and after your child died.

### 77. Did you have discussions with health professionals about the possibility your child would not survive his/her illness?  
- Yes  
- No (Skip to question 81)  
- Don’t remember (Skip to question 81)

No change
78. If yes, was this possibility discussed in a sensitive manner?
   - Not at all
   - Not very sensitive
   - Somewhat sensitive
   - Mostly sensitive
   - Completely sensitive

79. If yes, how appropriate was the timing of this discussion?
   - Not at all appropriate
   - Not very appropriate
   - Somewhat appropriate
   - Mostly appropriate
   - Completely appropriate (Skip to Question 81)

79. If yes, how appropriate was the timing of the discussion in the course of the illness?
   - Not at all appropriate
   - Not very appropriate
   - Somewhat appropriate
   - Mostly appropriate
   - Completely appropriate (Skip to Question 81)

80. Do you wish this possibility would have been discussed sooner or later?
   - A lot sooner
   - A little sooner
   - A little later
   - A lot later

81. How often did health professionals support your hopes for your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

82. How often did health professionals find the right balance in helping you hope for the best possible outcome (cure or survival of the illness) for your child while also making plans in case that outcome did not happen?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always (Skip to Question 84)

82. How often did health professionals find the right balance in helping you hope for the best possible outcome (cure or longer life) for your child while also making plans in case that outcome did not happen?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always (Skip to Question 84)

83. Would you say health professionals focused too much on survival or too much on death?
   - Way too much on survival
   - A little too much on survival
   - A little too much on death
   - Way too much on death

83. Would you say health professionals focused too much on cure or too much on death?
   - Way too much on cure
   - A little too much on cure
   - A little too much on death
   - Way too much on death
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No change</th>
<th>No</th>
<th>Can't remember</th>
<th>No treatments were stopped (Skip to Question 90)</th>
</tr>
</thead>
<tbody>
<tr>
<td>84. Did health professionals ever talk about stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (Skip to Question 88)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember (Skip to Question 88)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>85. If yes, was this discussion about treatments done in a sensitive manner?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>86. If yes, how appropriate was the timing of this discussion about treatments?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely appropriate (Skip to Question 88)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>87. Do you wish this discussion about treatments would have been sooner or later?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lot sooner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little sooner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little later</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lot later</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>88. When a child has treatments like a ventilator removed, this can often be done at a time that will best meet the needs of the family (for example it may be delayed for hours or days to allow certain people to visit or to give time for specific rituals). Were you given a choice about when treatments (like a ventilator) would be stopped?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No treatments were stopped (Skip to question 90)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>89. If treatment was stopped, was it done at the time you wished?</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments stopped way too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments stopped a bit too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments stopped when I wished</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments continued a bit too long</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment continued way too long</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90. Once it was clear that your child was likely to die, were you given choices about where this might happen (for example going home, going to a hospice, or moving to a more private room or area of the hospital)?</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No choices possible as my child died very suddenly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>91. Did your child die in the place that you wished?</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>92. Was your child where he/she wanted to be when he/she died?</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child too young or unable to make wishes known</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsure, not discussed with child</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>93. Did health professionals ask if there were any cultural / religious / spiritual rituals that you and your family might want around the time of your child’s death?</td>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>93. Did health professionals ask if there were cultural / religious / spiritual practices that you and your family might want around the time of your child’s death?</td>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>94. Did health professionals respect any cultural / religious rituals that you and your family wanted around the time of your child’s death?</td>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>94. Did health professionals respect cultural / religious / spiritual practices that you and your family wanted around the time of your child’s death?</td>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response Options</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>95. Did health professionals ask who you wanted to be with you and your family when your child died?</td>
<td>Yes, No, Don't remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>96. Did health professionals respect your wishes for which family members you wanted with you when your child died?</td>
<td>No respect at all, A bit respectful, Somewhat respectful, Very respectful, Extremely respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>97. Did health professionals respect your wishes for which health professionals you wanted with you when your child died?</td>
<td>No respect at all, A bit respectful, Somewhat respectful, Very respectful, Extremely respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>98. Was a health professional with you and your family when your child died?</td>
<td>Yes, No (Skip to Question 100), Don't Remember (Skip to Question 100)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>99. If yes, how helpful was it to have a health professional with you?</td>
<td>Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>100. How well informed were you about what to expect at the time of your child’s death?</td>
<td>Not at all informed, A little informed, Somewhat informed, Mostly informed, Completely informed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>101. Some people use the word peaceful to describe the atmosphere at the</td>
<td>Not at all peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>time of a person’s death. Which of the following best describes the</td>
<td>A bit peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>atmosphere at the time of your child’s death?</td>
<td>Somewhat peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely peaceful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>102. Although the death of a child is always a tragedy, some parents</td>
<td>Disagree strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>are able to describe their child’s dying process as a “good death”.</td>
<td>Disagree somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All things considered, would you say your child experienced a “good</td>
<td>Neither agree or disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>death”?</td>
<td>Agree somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agree strongly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>103. Did health professionals suggest and offer to collect mementos</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(for example: lock of hair, pictures, hand/foot prints) of your child?</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Don’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>104. Did health professionals respect your wishes about the mementos</td>
<td>No respect at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>that you wanted to have?</td>
<td>A bit respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somewhat respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely respectful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>105. Did health professionals offer to help you make any arrangements</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>for funerals or other religious customs?</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Don’t remember</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>106. If yes, how helpful was this assistance for you?</td>
<td>Not at all helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A little helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somewhat helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Extremely helpful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>107. Did health professionals ever talk about whether or not your child could be an organ or tissue donor?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (Skip to Question 109)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember (Skip to Question 109)</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>108. If yes, was the timing of this discussion appropriate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too late</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much too late</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>109. If yes, was this discussion done in a sensitive way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>110. Did health professionals ever discuss an autopsy for your child?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (Skip to Question 113)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t remember (Skip to Question 113)</td>
<td>No change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>111. If yes, was the timing of this discussion appropriate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appropriate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little too late</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much too late</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>112. If yes, was this discussion done in a sensitive way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>113. Were health professionals sensitive and respectful when caring for your child’s body after death?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not very sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely sensitive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
114. Some parents want to stay with their child for a long time after he/she dies, while others want to leave the hospital fairly quickly. Were you given as much time as you wanted with your child after he/she died?
   Yes  (Skip to Question 116)
   No

115. If no, did you feel that you were rushed to leave or that things happened too slowly and you were not able to leave as quickly as you wished?
   Much too rushed
   A little rushed
   A little slow
   Much too slow

116. Please add any other comments about the discussions or events that happened at the time of your child’s death.

The next few questions ask about the care you and your family received through the hospital in the days and months after your child died.

117. Did health professionals from the hospital offer to continue contact with your family through calls or letters after your child died?
   Yes
   No
   Don’t remember

118. If contact continued, about how many contacts have you had? _____

119. Would you say this number of contacts was the right amount, too many or too few?
   Much too many
   A little too many
   The right amount
   A little too few
   Much too few

120. What kind of contacts have you had? (Check all that apply)
   ____ phone calls
   ____ cards or letters
   ____ meetings
   ____ counseling
   ____ Other (Please specify ____________ )

**New Item:**
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>122. Did someone from the hospital offer you information about your grief?</th>
</tr>
</thead>
</table>
| 121. If contact continued, how helpful was it for you? | Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful | 122. Did someone from the hospital offer you information about your grief?  
| | No change | Yes  
| | | No (Skip to Question 124)  
| | | Don’t remember (Skip to Question 124) |
| 122. Did someone from the hospital offer you information about grief after the death of a child? | Yes  
| | No (Skip to Question 124)  
| | Don’t remember (Skip to Question 124) | |
| 123. If yes, how helpful was this information for you? | Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful | No change |
| 124. Did someone from the hospital offer you information about your other children’s grief? | Yes  
| | No (Skip to Question 126)  
| | Don’t have other children (Skip to Question 126)  
| | Don’t remember (Skip to Question 126) | No change |
| 125. If yes, how helpful was this information for you? | Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful | No change |
| 126. Did someone from the hospital offer you information about community resources available close to your home? | Yes  
| | No (Skip to Question 126)  
<p>| | Don’t remember (Skip to Question 126) | No change |
| 127. If yes, how helpful was this information for you? | Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful | No change |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>No change</th>
</tr>
</thead>
<tbody>
<tr>
<td>128. Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or the autopsy results (if one was done)?</td>
<td>Yes, No, Don’t remember</td>
<td></td>
</tr>
<tr>
<td>129. If you had a meeting, was it helpful for you?</td>
<td>No meeting held, Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td>No change</td>
</tr>
<tr>
<td>130. If an autopsy was done, did you receive the results in a timely manner?</td>
<td>Autopsy not done, Not at all timely, Somewhat timely, Very timely</td>
<td>No change</td>
</tr>
<tr>
<td>131. Have you attended a memorial service held by the hospital where your child died?</td>
<td>Yes, No (Skip to Question 133), No service offered (Skip to Question 133), Don’t remember (Skip to Question 133)</td>
<td>No change</td>
</tr>
<tr>
<td>132. If yes, how helpful was the memorial service for you?</td>
<td>Not at all helpful, A little helpful, Somewhat helpful, Very helpful, Extremely helpful</td>
<td>No change</td>
</tr>
<tr>
<td>133. Did you feel avoided or abandoned by health professionals from the hospital after your child’s death?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
<td>No change</td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>134. Overall, how satisfied were you with the support provided through the hospital in the months after your child died?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Completely dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely satisfied</td>
<td></td>
<td></td>
</tr>
<tr>
<td>135. Please add any other comments about the support provided through the hospital in the months after your child’s death.</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>_____________________________________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>136. Overall how would you describe the quality of care provided to your child and family by health professionals from the hospital?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>137. Please add any other comments about the overall care your child and family received through the hospital.</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>_____________________________________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>138. What was the best experience you had with the health care system during your child’s illness?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>_____________________________________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>139. What was the worst experience you had with the health care system during your child’s illness?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>_____________________________________________________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>140. How often was there a big enough space for you to be with your child while in hospital?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
<tr>
<td>140. How often was there enough room for you to be with your child while in hospital?</td>
<td>No change</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The next few questions ask about the facilities available to you and your family while you were in the hospital.
<table>
<thead>
<tr>
<th>New item: 141. How often was there a comfortable place for you to sleep at or near the hospital?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>142. How often were there playrooms or other child-friendly space for your other children while you were at the hospital?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No other children</td>
</tr>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>143. How often was food readily available for your family while you were at the hospital?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>144. Would you say the food at the hospital was affordably priced?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
<tr>
<td>A little</td>
</tr>
<tr>
<td>Somewhat</td>
</tr>
<tr>
<td>Very</td>
</tr>
<tr>
<td>Extremely</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>145. How often were you easily able to find parking at the hospital?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
</tr>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Mostly</td>
</tr>
<tr>
<td>Always</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>146. Would you say the parking at the hospital was affordably priced?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
</tr>
<tr>
<td>A little</td>
</tr>
<tr>
<td>Somewhat</td>
</tr>
<tr>
<td>Very</td>
</tr>
<tr>
<td>Extremely</td>
</tr>
</tbody>
</table>
147. Please share any other comments you have about the facilities available to you and your family while at the hospital.
___________________________________

No change

The next few questions ask for details about your child who died and your background.

1. Was your child who died a boy or a girl?
   - Boy
   - Girl

2. What was the date of his/her birth? ________________________ dd/mm/yy

3. What was the date he/she died? ______________________ dd/mm/yy

4. What was the cause of his/her death? (if known) ________________________

5. What was his/her diagnosis? (if known)_______________________

6. Where did he/she die?
   - Intensive care unit
   - Emergency room
   - Another unit in the hospital (Please specify__________)
   - At a children’s hospice
   - Other ________________

7. How long was he/she in hospital during that last stay before he/she died? ________days

8. Approximately how long before your child’s death did you think that he/she was likely to die?
   - More than 6 months
   - 1 month to 6 months
   - 8 days to less than 1 month
   - 1 day to 7 days
   - Less than 1 day
   - I didn’t know until it happened

9. Was the palliative or supportive care team involved in your child’s care? (Note: At XX hospital this team includes……..)
   - Yes   For about how long before your child’s death were they involved? _____days ______months
   - No
   - Don’t know

10. Has more than one of your children died?
    - Yes   If yes, how many of your children have died? _________
    - No
    - Including any of your children who have died, how many children do you have? _________

11. What is your relationship to the child who died?
    - Biological mother
    - Adoptive mother
    - Step mother
12. What year were you born in? _____________

13. What is your current marital status?
   - Married or living as married
   - Divorced or separated and not presently remarried
   - Never married
   - Widowed
   - Other (please specify): ________________________

14. What is the highest level of schooling you have completed?
   - Elementary school or less
   - Some high school
   - High school diploma
   - Some college (including CEGEP) or trade school (but did not complete a diploma)
   - Diploma from college or trade school
   - Attended university (but did not complete a degree)
   - University degree
   - Post-graduate degree
   - Other (please specify): _________________________________

15. What is your total family income?
   - under $25,000
   - $25,000 – $49,999
   - $50,000 – $99,999
   - $100,000 or more

16. Which of the following groups best describes your ethnic background? Please choose all that apply.
   - Aboriginal (e.g., Inuit, Métis, North American Indian)
   - Arab/West Asian (e.g., Armenia, Egypt, Iran, Lebanon, Morocco)
   - Black (e.g., Africa, Somali)
   - Black Caribbean (e.g., Haiti, Jamaica)
   - British (English, Irish, Scottish, Welsh)
   - Chinese
   - European (North, e.g., Sweden, Norway, Finland)
   - European (East, e.g., Romania, Ukraine, Belarus)
   - European (South, e.g., Spain, Portugal, Greece, Italy)
   - European (West, e.g., France, Germany, Austria)
   - Filipino
   - Japanese
   - Korean
   - Latin American (Mexico, Central America, South America, Caribbean, Cuba, Dominican Republic and Puerto Rico)
   - South Asian (Bangladesh, Bengal, East India, Goan, Gujarat, Pakistan, Punjab, Sinhalese, Sri Lanka, Tamil and South Asian locations not elsewhere)
   - South East Asian (e.g., Thailand, Malaysia, Indonesia)
   - Other _________________________________
17. What, if any, is your religious practice? Please choose all that apply.
- Buddhist
- Catholic
- Hindu
- Islam
- Jewish
- Orthodox
- Protestant
- Sikh
- Spiritual, but not religious
- None
- Other _________________________

This is the end of the survey. We are aware that the survey deals with sensitive issues. Therefore, we would like to know how you felt while answering it.

1. How valuable is it to conduct research about parents’ views on the quality of care given by health professionals?
   Not at all        A little        Somewhat        Very       Extremely

2. Why did you agree to participate in this research study? (Check all that apply)
   ___ To help others in a similar situation
   ___ So I could talk about the experience I had
   ___ Was pressured by my family/friend
   ___ Was pressured by the researcher
   ___ Other (please explain) _________________________

3. How beneficial did you find completing this survey was for you?
   Not at all        A little        Somewhat        Very       Extremely

4. How much stress or pain would you say completing this survey has caused you?
   None     A little        Some       A lot     Extreme amount

5. How much stress or pain were you expecting when you agreed to do this survey?
   None     A little        Some       A lot     Extreme amount

6. Overall would you say participating in this study had a positive or a negative effect on you?
   Very negative   A little negative   Neither positive or negative   A little positive   Very positive

7. Do you regret participating in this study?
   Yes                      No

8. Would you recommend to another bereaved parent that they participate in a similar study?
   Yes                      No

9. Which do you think would be the best way to ask parents the survey questions in future research or if a hospital wanted to do this survey regularly?
   (Place #1 by your first choice, #2 by your second choice, #3 by your third choice)
   ___ A person asking the parent questions over the phone
   ___ A written survey the parent fills out by themself
   ___ A person asking the parent questions in person
10. Please share any other comments about how taking part in this study has affected you.

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Thank you for taking time to answer our questions. As mentioned, we need 50 mothers to complete the survey again in about 2 weeks. If you are willing to do this survey again, please write your name and address below so we can send you the survey again.

Name:_________________________________

Address:_______________________________

______________________________________

______________________________________
Appendix R: Phase III Instrument
Quality of Children’s End-of-Life Care Survey
Quality of Children’s End-of-Life Care Survey

When answering the following questions think about all of the health professionals (including doctors, nurses, social workers, child life specialists, etc.) at the hospital who took care of your child and family during the last week or days of your child’s life.

Most of the questions ask about you and your family. Your family includes your child who was ill and your immediate family.

For each question please place an X in the box beside the answer that you have chosen.

Please start by telling us today’s date: __________________________

The first set of questions asks about your relationship with the health professionals who cared for your child and family. Please think about what these relationships were like in the last week or days of your child’s life.

1. How often did health professionals communicate well with you and your family?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

2. How often were health professionals sensitive to you and your family’s feelings?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

3. How often did you feel a close connection to the health professionals who cared for your child?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

4. How often was there a “good fit” between health professionals and your family?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

5. How often did you feel health professionals accepted you and your family without judging you?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

6. How much did you trust the health professionals caring for your child?
   - Not at all
   - Not very much
   - Somewhat
   - Mostly
   - Completely

7. How often did health professionals act as if they were better than you?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always

8. How often did health professionals show you their “human” side?
   - Never
   - Rarely
   - Sometimes
   - Mostly
   - Always
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often did health professionals treat your child as a unique person?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often did health professionals treat you as a unique person?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often did health professionals treat your family as unique?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often did you experience “acts of kindness” from health professionals while you were in hospital?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often was it easy to contact the health professionals caring for your child?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often were health professionals open to talking about your concerns?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often was there at least one team member working consistently with your family?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>How often did you know which health professional was in charge of your child’s care?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>Did you and your family ever feel avoided or abandoned by health professionals before your child’s death?</td>
<td>Never, Rarely, Sometimes, Mostly, Always</td>
</tr>
<tr>
<td>Overall, how satisfied were you with your relationships with the health professionals who cared for your child before his/her death?</td>
<td>Completely dissatisfied, Mostly dissatisfied, Somewhat dissatisfied, Neither satisfied nor dissatisfied, Somewhat satisfied, Mostly satisfied, Completely satisfied</td>
</tr>
<tr>
<td>Please add any other comments you would like to share about your relationship with the health professionals who cared for your child and family.</td>
<td></td>
</tr>
</tbody>
</table>
The next few questions ask how health professionals involved you in your child’s care during the last week or days of your child’s life.

20 How often did health professionals ask for your opinions or concerns about your child?
- Never
- Rarely
- Sometimes
- Mostly
- Always

21 How often did you feel trusted as the “expert” on your child?
- Never
- Rarely
- Sometimes
- Mostly
- Always

22 How often did health professionals respect your wishes for your child’s care?
- Never
- Rarely
- Sometimes
- Mostly
- Always

23 How often did health professionals help you to feel that you were doing the best you could for your child?
- Never
- Rarely
- Sometimes
- Mostly
- Always

24 How often did health professionals support you in your role as a parent?
- Never
- Rarely
- Sometimes
- Mostly
- Always

25 How often were you as involved in your child’s care as you wanted to be?
- Never
- Rarely
- Sometimes
- Mostly
- Always

26 How often were you given a choice whether or not to be with your child during difficult procedures or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)?
- No difficult procedures or life threatening events
  ✅ SKIP TO QUESTION 28
- Never
- Rarely
- Sometimes
- Mostly
- Always

27 How often were health professionals available to support you during difficult procedures or life threatening events?
- Never
- Rarely
- Sometimes
- Mostly
- Always

28 Overall, how satisfied were you with your involvement in your child’s care during the last week or days of his/her life?
- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

29 Please add any other comments you would like to share about your involvement in your child’s care.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
The next few questions ask about the information shared between health professionals and your family during the last week or days of your child’s life.

30 How often did health professionals let you choose how information was shared with you (for example: written information, use of email, having someone else with you when information was shared)?
- Never
- Rarely
- Sometimes
- Mostly
- Always

31 How often did health professionals let you choose the amount of information that you wanted shared with you?
- Never
- Rarely
- Sometimes
- Mostly
- Always

32 How often did health professionals give you “the right amount” of information about your child’s condition?
- Never
- Rarely
- Sometimes
- Mostly
- Always

33 Do you wish you had more or less information?
- A lot more
- A little more
- No, I always had the right amount
- A little less
- A lot less

34 How often did health professionals seem to know what information you might need before you even asked?
- Never
- Rarely
- Sometimes
- Mostly
- Always

35 How often did health professionals give information to you and your family that was confusing?
- Never
- Rarely
- Sometimes
- Mostly
- Always

36 How often did you feel health professionals gave truthful information to you and your family about your child?
- Never
- Rarely
- Sometimes
- Mostly
- Always

37 How often did health professionals show you your child’s test results, X-rays, or scans when you wanted to see them?
- I did not want this kind of information
- Never
- Rarely
- Sometimes
- Mostly
- Always

38 How often did health professionals talk about ‘the big picture’ for your child’s condition (for example not just how his/her heart or lungs were working)?
- Never
- Rarely
- Sometimes
- Mostly
- Always

39 How often did health professionals provide enough time when talking with you and your family so you did not feel rushed?
- Never
- Rarely
- Sometimes
- Mostly
- Always
40 How often did you take part in family and team meetings about your child’s care?
- Never
- Rarely
- Sometimes
- Mostly
- Always

41 How often did health professionals respect your wishes about how much to involve your child in talks about his/her illness?
- Not applicable (for example child too young or not able to communicate)
- Never
- Rarely
- Sometimes
- Mostly
- Always

42 Overall, how satisfied were you with the information shared between you and the health professionals caring for your child?
- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

43 Overall, how satisfied were you with the information shared between health professionals and your child?
- Child too young
- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

44 Please add any other comments about how information about your child was shared with you, your child, and your family.

---

The next few questions ask about the information that was shared from one health professional caring for your child to the next health professional.

45 How often was the information you received about your child the same from one health professional to the next?
- Never
- Rarely
- Sometimes
- Mostly
- Always

46 From your perspective, how often was information appropriately shared among health professionals?
- Never
- Rarely
- Sometimes
- Mostly
- Always

47 How often were you the one to tell health professionals the medical details of your child’s condition because they didn’t seem to know?
- Never
- Rarely
- Sometimes
- Mostly
- Always
48 How often did it seem health professionals planned together so they were all working towards the same goals for your child’s care?

- Never
- Rarely
- Sometimes
- Mostly
- Always

49 Overall, how satisfied were you with the information shared among all the health professionals caring for your child?

- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

50 Please add any other comments about how information about your child’s care was shared among health professionals.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

51 How often did health professionals look at all the needs of your child (physical, emotional, social, developmental, and spiritual needs)?

- Never
- Rarely
- Sometimes
- Mostly
- Always

52 How often did health professionals help your child to keep up relationships with his/her friends or school?

- Does not apply to my child
- Never
- Rarely
- Sometimes
- Mostly
- Always

53 During your child’s last week or days of life while in the hospital, how much would you say your child seemed to suffer from each of the following symptoms?

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>Constantly</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathing difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bleeding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seizures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sadness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety / Worry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: Specify</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Quality of Children’s End-of-Life Care
Version May 26, 2010
Overall, which of the following describes the amount of suffering your child had from his/her symptoms? Would you say he/she suffered:

- Not at all
- A little
- Somewhat
- A lot
- Constantly
- Unsure

How often did health professionals provide the right amount of support for your practical needs (for example access to food, a place to stay, transportation)?

- Never
- Rarely
- Sometimes
- Mostly
- Always

Do you wish you had more or less practical support?

- A lot more
- A little more
- No, I always had the right amount
- A little less
- A lot less

How often did health professionals provide the right amount of support for your emotional needs (for example feeling listened to, accepting your feelings)?

- Never
- Rarely
- Sometimes
- Mostly
- Always

Do you wish you had more or less emotional support?

- A lot more
- A little more
- No, I always had the right amount
- A little less
- A lot less

How often did health professionals provide the right amount of support for your spiritual needs?

- Never
- Rarely
- Sometimes
- Mostly
- Always

Do you wish you had more or less spiritual support?

- A lot more
- A little more
- No, I always had the right amount
- A little less
- A lot less

How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your family and friends)?

- Never
- Rarely
- Sometimes
- Mostly
- Always

Do you wish you had more or less social support?

- A lot more
- A little more
- No, I always had the right amount
- A little less
- A lot less

How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital?

- No other children ➔ SKIP TO QUESTION 67
- Never
- Rarely
- Sometimes
- Mostly
- Always
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>64 Do you wish your other children had more or less support?</strong></td>
<td>- A lot more</td>
</tr>
<tr>
<td></td>
<td>- A little more</td>
</tr>
<tr>
<td></td>
<td>- No, I always had the right amount</td>
</tr>
<tr>
<td></td>
<td>- A little less</td>
</tr>
<tr>
<td></td>
<td>- A lot less</td>
</tr>
<tr>
<td><strong>65 How often did health professionals guide you on how you could support your other children while your child was in hospital?</strong></td>
<td>- No other children ▶ SKIP TO QUESTION 67</td>
</tr>
<tr>
<td></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>66 Do you wish you had more or less guidance about supporting your other children?</strong></td>
<td>- A lot more</td>
</tr>
<tr>
<td></td>
<td>- A little more</td>
</tr>
<tr>
<td></td>
<td>- No, I always had the right amount</td>
</tr>
<tr>
<td></td>
<td>- A little less</td>
</tr>
<tr>
<td></td>
<td>- A lot less</td>
</tr>
<tr>
<td><strong>67 Some parents describe having a health professional who was able to “coach” or guide them during their child’s end-of-life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of guide?</strong></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>68 How often did health professionals try to fulfill any of your family’s special requests or wishes?</strong></td>
<td>- No special requests made</td>
</tr>
<tr>
<td></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>69 How often did health professionals assist you to get any additional services that you might need?</strong></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>70 How often was your family given private time with your child before he/she died?</strong></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>71 How often did health professionals allow and encourage your other children to visit when they wished?</strong></td>
<td>- No other children</td>
</tr>
<tr>
<td></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>72 How often did health professionals allow and encourage extended family members / friends to visit when you wished?</strong></td>
<td>- Never</td>
</tr>
<tr>
<td></td>
<td>- Rarely</td>
</tr>
<tr>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td>- Mostly</td>
</tr>
<tr>
<td></td>
<td>- Always</td>
</tr>
<tr>
<td><strong>73 Overall, how satisfied were you with support given to ease your child’s suffering by health professionals at the hospital?</strong></td>
<td>- Completely dissatisfied</td>
</tr>
<tr>
<td></td>
<td>- Mostly dissatisfied</td>
</tr>
<tr>
<td></td>
<td>- Somewhat dissatisfied</td>
</tr>
<tr>
<td></td>
<td>- Neither satisfied nor dissatisfied</td>
</tr>
<tr>
<td></td>
<td>- Somewhat satisfied</td>
</tr>
<tr>
<td></td>
<td>- Mostly satisfied</td>
</tr>
<tr>
<td></td>
<td>- Completely satisfied</td>
</tr>
</tbody>
</table>
Overall, how satisfied were you with support given to you by health professionals at the hospital?

- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

Overall, how satisfied were you with support given to your other children by health professionals at the hospital?

- No other children
- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

Please add any other comments about how you and your family were supported by health professionals while your child was in the hospital.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

The next few questions ask more specifically about the discussions and events that happened just before and after your child died.

Did you have discussions with health professionals about the possibility your child would not survive his/her illness?

- Yes
- No ➔ SKIP TO QUESTION 81
- Don’t remember ➔ SKIP TO QUESTION 81

If yes, was this possibility discussed in a sensitive manner?

- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

If yes, how appropriate was the timing of the discussion in the course of the illness?

- Not at all appropriate
- Not very appropriate
- Somewhat appropriate
- Mostly appropriate
- Completely appropriate

Do you wish this possibility would have been discussed sooner or later?

- A lot sooner
- A little sooner
- No, the timing was completely appropriate
- A little later
- A lot later

How often did health professionals support your hopes for your child?

- Never
- Rarely
- Sometimes
- Mostly
- Always

How often did health professionals find the right balance in helping you hope for the best possible outcome (cure or longer life) for your child while also making plans in case that outcome did not happen?

- Never
- Rarely
- Sometimes
- Mostly
- Always
83 Would you say health professionals focused too much on cure or too much on death?

- Way too much on cure
- A little too much on cure
- No, health professionals always had the right balance
- A little too much on death
- Way too much on death

84 Did health professionals ever talk about stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)?

- Yes
- No
- Don’t remember

85 If yes, was this discussion about treatments done in a sensitive manner?

- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

86 If yes, how appropriate was the timing of this discussion about treatments?

- Not at all appropriate
- Not very appropriate
- Somewhat appropriate
- Mostly appropriate
- Completely appropriate

87 Do you wish this discussion about treatments would have happened sooner or later?

- A lot sooner
- A little sooner
- No, the timing was completely appropriate
- A little later
- A lot later

88 When a child has treatments like a ventilator removed, this can sometimes be done at a time that will best meet the needs of the family (for example it may be delayed so certain people can visit or to give time for specific rituals). Were you given a choice about when treatments would be stopped?

- Yes
- No
- Can’t remember
- No treatments stopped

89 If treatment was stopped, was it done at the time you wished?

- Treatments stopped way too soon
- Treatments stopped a bit too soon
- Treatments stopped when I wished
- Treatments continued a bit too long
- Treatment continued way too long

90 Once it was clear that your child was likely to die, were you given choices about where this might happen (for example going home, going to a hospice, or moving to a more private room or area of the hospital)?

- Yes
- No
- Can’t remember
- No choices possible as my child died very suddenly

91 Did your child die in the place that you wished?

- Yes
- No

92 Was your child where he/she wanted to be when he/she died?

- Child too young or unable to make wishes known
- Yes
- No
- Unsure, not discussed with child

93 Did health professionals ask if there were cultural/religious/spiritual practices that you and your family might want around the time of your child’s death?

- Yes
- No
- Can’t remember
94 Did health professionals respect cultural/religionspiritual practices that you and your family wanted around the time of your child’s death?
- No respect at all
- A bit respectful
- Somewhat respectful
- Very respectful
- Extremely respectful

95 Did health professionals ask who you wanted to be with you and your family when your child died?
- Yes
- No
- Don’t remember

96 Did health professionals respect your wishes for which family members or friends you wanted with you when your child died?
- No respect at all
- A bit respectful
- Somewhat respectful
- Very respectful
- Extremely respectful

97 Did health professionals respect your wishes for which health professionals you wanted with you when your child died?
- No respect at all
- A bit respectful
- Somewhat respectful
- Very respectful
- Extremely respectful

98 Was a health professional with you and your family when your child died?
- Yes
- No  ➔ SKIP TO QUESTION 100
- Don’t remember  ➔ SKIP TO QUESTION 100

99 If yes, how helpful was it to have a health professional with you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

100 How well informed were you about what to expect at the time of your child’s death?
- Not at all informed
- A little informed
- Somewhat informed
- Mostly informed
- Completely informed

101 Some people use the word peaceful to describe the atmosphere at the time of a person’s death. Which of the following best describes the atmosphere at the time of your child’s death?
- Not at all peaceful
- A bit peaceful
- Somewhat peaceful
- Very peaceful
- Extremely peaceful

102 Although the death of a child is always a tragedy, some parents are able to describe their child’s dying process as a “good death”. All things considered, would you say your child experienced a “good death”?
- Disagree strongly
- Disagree somewhat
- Neither agree or disagree
- Agree somewhat
- Agree strongly

103 Did health professionals suggest and offer to create mementos (for example: lock of hair, pictures, hand/foot prints) of your child?
- Yes
- No
- Don’t remember

104 Did health professionals respect your wishes about the mementos that you wanted to have?
- No respect at all
- A bit respectful
- Somewhat respectful
- Very respectful
- Extremely respectful

105 Did health professionals offer to help you make any arrangements for funerals or other religious customs?
- Yes
- No  ➔ SKIP TO QUESTION 107
- Don’t remember  ➔ SKIP TO QUESTION 107
106 If yes, how helpful was this assistance for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

107 Did health professionals ever talk about whether or not your child could be an organ or tissue donor?
- Yes
- No ← SKIP TO QUESTION 110
- Don’t remember ← SKIP TO QUESTION 110

108 If yes, was the timing of this discussion appropriate?
- Much too soon
- A little too soon
- Appropriate
- A little too late
- Much too late

109 If yes, was this discussion done in a sensitive way?
- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

110 Did health professionals ever discuss an autopsy for your child?
- Yes
- No ← SKIP TO QUESTION 113
- Don’t remember ← SKIP TO QUESTION 113

111 If yes, was the timing of this discussion appropriate?
- Much too soon
- A little too soon
- Appropriate
- A little too late
- Much too late

112 If yes, was this discussion done in a sensitive way?
- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

113 Were health professionals sensitive and respectful when caring for your child’s body after death?
- Not at all
- Not very sensitive
- Somewhat sensitive
- Mostly sensitive
- Completely sensitive

114 Some parents want to stay with their child for a long time after he/she dies, while others want to leave the hospital fairly quickly. Were you given as much time as you wanted with your child after he/she died?
- Yes ← SKIP TO QUESTION 116
- No

115 If no, did you feel that you were rushed to leave or that things happened too slowly and you were not able to leave as quickly as you wished?
- Much too rushed
- A little rushed
- A little slow
- Much too slow

116 Please add any other comments about the discussions or events that happened at the time of your child’s death.

[Add comments here]

The next few questions ask about the care you and your family received through the hospital in the days and months after your child died.

117 Did health professionals from the hospital offer to continue contact with your family through calls or letters after your child died?
- Yes
- No
- Don’t remember
118 About how many contacts with health professionals from the hospital have you had since your child died?_____

119 Would you say this number of contacts was the right amount, too many or too few?
- Much too many
- A little too many
- The right amount
- A little too few
- Much too few

120 What kind of contacts have you had?
(Check all that apply)
- Phone calls
- Cards or letters
- Meetings
- Counseling
- Other     (Please specify ______________)

121 If contact continued, how helpful was it for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

122 Did someone from the hospital offer you information about your grief?
- Yes
- No ← SKIP TO QUESTION 124
- Don’t remember ← SKIP TO QUESTION 124

123 If yes, how helpful was this information for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

124 Did someone from the hospital offer you information about your other children’s grief?
- Don’t have other children ← SKIP TO QUESTION 126
- Yes
- No ← SKIP TO QUESTION 126
- Don’t remember ← SKIP TO QUESTION 126

125 If yes, how helpful was this information for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

126 Did someone from the hospital offer you information about community resources available close to your home?
- Yes
- No ← SKIP TO QUESTION 128
- Don’t remember ← SKIP TO QUESTION 128

127 If yes, how helpful was this information for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

128 Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or the autopsy results (if one was done)?
- Yes
- No
- Don’t remember

129 If you had a meeting, was it helpful for you?
- No meeting held
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

130 If an autopsy was done, did you receive the results in a timely manner?
- Autopsy not done
- Not at all timely
- Somewhat timely
- Very timely
131 Have you attended a memorial service held by the hospital where your child died?
- Yes
- No
- No service offered
- Don’t remember

132 If yes, how helpful was the memorial service for you?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

133 Did you feel avoided or abandoned by health professionals from the hospital after your child's death?
- Never
- Rarely
- Sometimes
- Mostly
- Always

134 Overall, how satisfied were you with the support provided through the hospital in the months after your child died?
- Completely dissatisfied
- Mostly dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Mostly satisfied
- Completely satisfied

135 Please add any other comments about the support provided through the hospital in the months after your child's death.

136 Overall how would you describe the quality of end-of-life care provided to your child and family by health professionals from the hospital?
- Poor
- Fair
- Good
- Very good
- Excellent

137 Please add any other comments about the overall care your child and family received through the hospital.

138 What was the best experience you had with the health care system during your child's end-of-life care?

139 What was the worst experience you had with the health care system during your child's end-of-life care?

The next few questions ask about the facilities available to you and your family while you were in the hospital.

140 How often was there enough room for you to be with your child while in hospital?
- Never
- Rarely
- Sometimes
- Mostly
- Always

141 How often was there a comfortable place for you to sleep at or near the hospital?
- Never
- Rarely
- Sometimes
- Mostly
- Always

142 How often were there playrooms or other child-friendly space for your other children while you were at the hospital?
- No other children
- Never
- Rarely
- Sometimes
- Mostly
- Always

143 How often was food readily available for your family while you were at the hospital?
- Never
- Rarely
- Sometimes
- Mostly
- Always

144 Would you say the food at the hospital was affordably priced?
- Not at all
- A little
- Somewhat
- Very
- Extremely

145 How often were you easily able to find parking at the hospital?
- Never
- Rarely
- Sometimes
- Mostly
- Always

146 Would you say the parking at the hospital was affordably priced?
- Not at all
- A little
- Somewhat
- Very
- Extremely

147 Please share any other comments you have about the facilities available to you and your family while at the hospital.

Please continue on the next page
The next few questions ask for details about your child who died and your background. These questions are important so we can describe the group of children the study is about. We also need to describe the group of mothers who filled out the survey.

1. Was your child who died a boy or a girl?
   - Boy
   - Girl

2. What was the date of his/her birth?
   ______________________

3. What was the date he/she died?
   ______________________

4. What was the cause of his/her death?
   (if known) ______________________

5. What was his/her diagnosis?
   (if known) ______________________

6. Where did he/she die?
   - Intensive care unit
   - Emergency room
   - Another unit in the hospital
     (Please specify ______________________)
   - At a children's hospice
   - Other ______________________

7. How long was he/she in hospital during that last stay before he/she died? ________ days

8. Approximately how long before your child's death did you think that he/she was likely to die?
   - More than 6 months
   - 1 month to 6 months
   - 8 days to less than 1 month
   - 1 day to 7 days
   - Less than 1 day
   - I didn’t know until it happened

9. Was the palliative care team involved in your child's care? (Note: At Stollery Children's Hospital this team includes Dr. Dawn Davies, Kelly Adams, Tara Wren, and Carmen Victoor).
   - Yes  If yes, for about how long before your child’s death were they involved? _____ days _____ months
   - No
   - Don’t know

10a. Has more than one of your children died?
    - Yes  If yes, how many of your children have died?
      ______
    - No

10b. Including any of your children who have died, how many children do you have? ________

11. What is your relationship to the child who died?
    - Biological mother
    - Adoptive mother
    - Step mother
    - Other (please specify): ______________________

12. What year were you born in? ___________

13. What is your current marital status?
    - Married or living as married
    - Divorced or separated and not presently remarried
    - Never married
    - Widowed
    - Other (please specify): ______________________
14 What is the highest level of schooling you have completed?
- Elementary school or less
- Some high school
- High school diploma
- Some college (including CEGEP) or trade school (but did not complete a diploma)
- Diploma from college or trade school
- Attended university (but did not complete a degree)
- University degree
- Post-graduate university degree
- Other (please specify):

15 What is your total family income?
- under $25,000
- $25,000 – $49,999
- $50,000 – $99,999
- $100,000 or more

16 Were you born in Canada?
- Yes
- No, if no how many years have you lived in Canada?

17 What, if any, is your religious practice? Please choose all that apply.
- Buddhist
- Catholic
- Hindu
- Islam
- Jewish
- Orthodox
- Protestant
- Sikh
- Spiritual, but not religious
- None
- Other

This is the end of the survey. We are aware that the survey deals with sensitive issues. Therefore, we would like to know how you felt while answering it.

1 How beneficial did you find completing this survey was for you?
- Not at all
- A little
- Somewhat
- Very
- Extremely

2 How much stress or pain would you say completing this survey has caused you?
- None
- A little
- Some
- A lot
- Extreme amount

3 How much stress or pain were you expecting when you agreed to do this survey?
- None
- A little
- Some
- A lot
- Extreme amount

4 Overall would you say participating in this study had a positive or a negative effect on you?
- Very negative
- A little negative
- Neither positive or negative
- A little positive
- Very positive

5 Do you regret participating in this study?
- Yes
- No

6 Would you recommend to another bereaved parent that they participate in a similar study?
- Yes
- No
7 How valuable is it to do research about parents’ views on the quality of end-of-life care given by health professionals?

- Not at all
- A little
- Somewhat
- Very
- Extremely

8 Why did you agree to take part in this research study? (Check all that apply)

- To help others in a similar situation
- So I could talk about the experience I had
- Was pressured by my family/friend
- Was pressured by the researcher
- Other (please explain)

9 Which do you think would be the best way to ask parents the survey questions in future research or if a hospital wanted to do this survey regularly? (Place #1 by your first choice, #2 by your second choice, #3 by your third choice)

- A person asking the parent questions over the phone
- A written survey the parent fills out by themself
- A person asking the parent questions in person
- A survey that the parent fills out on a website
- Other (please explain)

10 Please share any other comments about how taking part in this study has affected you.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for taking time to answer our questions.
As mentioned at the beginning of the survey, we need 50 mothers to do the survey again in about 2 weeks. If you are willing to do this survey again, please write your name and address below so we can send you the next survey.

By giving us your name and address you agree to be contacted by mail to receive the second survey. Your participation in the second part of the study is voluntary. You can change your mind at any time. If you give us your name and address and then decide you do not want to do the second survey, simply throw it out when you receive it. If you have any questions please contact the main researcher at the University of Toronto, Kimberley Widger at 416-978-2859 or by email at kim.widger@utoronto.ca

Name:_________________________________
Address:_________________________________
______________________________________
______________________________________

Please return this survey in the envelope provided to:

Kimberley Widger
Lawrence S. Bloomberg Faculty of Nursing
155 College Street, Suite 130
Toronto ON, M5T 1P8
**Appendix S: Recruitment Details by Site**

<table>
<thead>
<tr>
<th>Site</th>
<th>Date and # letters mailed</th>
<th># Letters return to sender</th>
<th># Opt out cards returned</th>
<th>Date and # surveys mailed</th>
<th># Surveys return to sender</th>
<th># Surveys returned</th>
<th>Response rate</th>
<th># Reliability surveys mailed</th>
<th># Reliability surveys returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sunnybrook Health Sciences Centre</td>
<td>July 7 51</td>
<td>3</td>
<td>5</td>
<td>July 28 43</td>
<td>4</td>
<td>9</td>
<td>20.5%</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Stollery Children’s Hospital</td>
<td>July 21 90</td>
<td>6</td>
<td>5</td>
<td>Aug 11 79</td>
<td>5</td>
<td>24</td>
<td>30.4%</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Children’s Hospital of Eastern Ontario</td>
<td>Sept 8 40</td>
<td>4</td>
<td>1</td>
<td>Sept 29 35</td>
<td>0</td>
<td>9</td>
<td>25.0%</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Roger’s House</td>
<td>Sept 8 20</td>
<td>0</td>
<td>1</td>
<td>Sept 29 19</td>
<td>0</td>
<td>3</td>
<td>15.0%</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Winnipeg Children’s Hospital*</td>
<td>Sept 10 77</td>
<td>10</td>
<td>NA</td>
<td>13</td>
<td>NA</td>
<td>10</td>
<td>14.9%</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>IWK Health Centre</td>
<td>Sept 29 24</td>
<td>1</td>
<td>1</td>
<td>Oct 26 22</td>
<td>0</td>
<td>8</td>
<td>34.8%</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Canuck Place Hospital’s Hospice*</td>
<td>Oct 8 74</td>
<td>0</td>
<td>NA</td>
<td>6</td>
<td>NA</td>
<td>5</td>
<td>6.8%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>McMaster Children’s Hospital</td>
<td>Oct 15 44</td>
<td>3</td>
<td>3***</td>
<td>Nov 12 38</td>
<td>2</td>
<td>11</td>
<td>28.2%</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Children’s Hospital London Health Sciences Centre*</td>
<td>Nov 15 36</td>
<td>5</td>
<td>NA</td>
<td>7</td>
<td>NA</td>
<td>5</td>
<td>16.1%</td>
<td>Not offered</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>771</strong></td>
<td><strong>57</strong></td>
<td><strong>46</strong></td>
<td><strong>522</strong></td>
<td><strong>26</strong></td>
<td><strong>128</strong></td>
<td><strong>18.6%</strong></td>
<td><strong>89</strong></td>
<td><strong>31</strong></td>
</tr>
</tbody>
</table>

* These sites used an opt-in process therefore surveys were mailed over a few weeks as requests came in.
** an additional 7 opt-out cards were returned after the surveys were mailed.
*** one additional opt-out card was returned after the surveys were mailed.
## Appendix T: Participant Demographics

<table>
<thead>
<tr>
<th>Mother’s mean age (SD)</th>
<th>36.5 years (8.3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>% Married</td>
<td>80.5</td>
</tr>
<tr>
<td>% Divorced / Separated</td>
<td>9.4</td>
</tr>
<tr>
<td>% Never Married</td>
<td>8.6</td>
</tr>
<tr>
<td>% Widowed</td>
<td>1.6</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>% High school diploma or less</td>
<td>17.2</td>
</tr>
<tr>
<td>% Some college / university</td>
<td>18.7</td>
</tr>
<tr>
<td>% College diploma</td>
<td>25</td>
</tr>
<tr>
<td>% University degree</td>
<td>25.8</td>
</tr>
<tr>
<td>% Post graduate degree</td>
<td>13.3</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
</tr>
<tr>
<td>% under $25000</td>
<td>9.7</td>
</tr>
<tr>
<td>% $25,000 - $49,999</td>
<td>16.1</td>
</tr>
<tr>
<td>% $50,000 - $99,999</td>
<td>39.5</td>
</tr>
<tr>
<td>% $100,000 or more</td>
<td>34.7</td>
</tr>
<tr>
<td><strong>Religious Practice</strong></td>
<td></td>
</tr>
<tr>
<td>% Catholic</td>
<td>31.4</td>
</tr>
<tr>
<td>% Protestant</td>
<td>25.2</td>
</tr>
<tr>
<td>% Spiritual not Religious</td>
<td>19.7</td>
</tr>
<tr>
<td>% None or Atheist</td>
<td>15.0</td>
</tr>
<tr>
<td>% Other (Aboriginal, Buddhist, Hindu, Muslim, Orthodox)</td>
<td>8.7</td>
</tr>
<tr>
<td>% Not born in Canada</td>
<td>17.2</td>
</tr>
<tr>
<td><strong>Mean years living in Canada (SD)</strong></td>
<td>20.4 (12.1)</td>
</tr>
<tr>
<td>% Experienced death of more than one child</td>
<td>7.8</td>
</tr>
<tr>
<td>% Children in the family (including deceased)</td>
<td></td>
</tr>
<tr>
<td>% one child</td>
<td>24.8</td>
</tr>
<tr>
<td>% two children</td>
<td>40.8</td>
</tr>
<tr>
<td>% three children</td>
<td>21.6</td>
</tr>
<tr>
<td>% four or more children</td>
<td>12.8</td>
</tr>
<tr>
<td><strong>Child’s mean age (SD)</strong></td>
<td>4.1 years (6.2)</td>
</tr>
<tr>
<td>% Girls</td>
<td>51.6</td>
</tr>
<tr>
<td><strong>Diagnosis (based on ICD 10 categories)</strong></td>
<td></td>
</tr>
<tr>
<td>% Infectious diseases</td>
<td>5.5</td>
</tr>
<tr>
<td>% Neoplasms</td>
<td>16.4</td>
</tr>
<tr>
<td>% Endocrine and metabolic diseases</td>
<td>7.0</td>
</tr>
<tr>
<td>% Diseases of the nervous system</td>
<td>10.2</td>
</tr>
<tr>
<td>% Diseases of the circulatory system</td>
<td>7.0</td>
</tr>
<tr>
<td>% Diseases of the digestive system</td>
<td>6.3</td>
</tr>
<tr>
<td>% Conditions originating in the perinatal period</td>
<td>14.1</td>
</tr>
<tr>
<td>% Congenital malformations, deformations and chromosomal abnormalities</td>
<td>23.4</td>
</tr>
<tr>
<td>% External causes</td>
<td>3.1</td>
</tr>
<tr>
<td>% Other</td>
<td>2.3</td>
</tr>
<tr>
<td>% Missing</td>
<td>4.7</td>
</tr>
<tr>
<td>Location of death</td>
<td>% intensive care</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td></td>
<td>% hospital unit</td>
</tr>
<tr>
<td></td>
<td>% hospice</td>
</tr>
<tr>
<td>Was a palliative care team involved?</td>
<td>% yes</td>
</tr>
<tr>
<td></td>
<td>% no</td>
</tr>
<tr>
<td></td>
<td>% not sure</td>
</tr>
<tr>
<td>Mean time palliative care team involved (SD)</td>
<td>151.0 days (441.9)</td>
</tr>
<tr>
<td>Time before death mother thought child likely to die</td>
<td>% &gt; 6 months</td>
</tr>
<tr>
<td></td>
<td>% 1 – 6 months</td>
</tr>
<tr>
<td></td>
<td>% 8 days – &lt; 1 month</td>
</tr>
<tr>
<td></td>
<td>% 1 – 7 days</td>
</tr>
<tr>
<td></td>
<td>% &lt; 1 day</td>
</tr>
<tr>
<td></td>
<td>% when it happened</td>
</tr>
</tbody>
</table>
## Appendix U: Structural Assessment Results

<table>
<thead>
<tr>
<th>Hospital/Hospice Name&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Sunnybrook</th>
<th>McMaster</th>
<th>Stollery</th>
<th>Canuck</th>
<th>CHEO</th>
<th>Roger’s</th>
<th>IWK</th>
<th>Winnipeg</th>
<th>London</th>
<th>SickKids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total FTE&lt;sup&gt;2&lt;/sup&gt; Positions</td>
<td>NA</td>
<td>NA</td>
<td>2.2</td>
<td>54</td>
<td>6.1</td>
<td>20.2</td>
<td>3.0</td>
<td>1.9</td>
<td>1.0</td>
<td>2.4</td>
</tr>
<tr>
<td>Bereavement Follow-up</td>
<td>Formal program</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Phone calls / letters</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Return visit</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memorial Service</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Grief Information</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Resources</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beds</td>
<td>Hospital Total</td>
<td>42</td>
<td>138</td>
<td>115</td>
<td>9</td>
<td>150</td>
<td>8</td>
<td>281</td>
<td>170</td>
<td>56</td>
</tr>
<tr>
<td>Pediatric</td>
<td>42</td>
<td>138</td>
<td>115</td>
<td>9</td>
<td>150</td>
<td>8</td>
<td>125</td>
<td>170</td>
<td>56</td>
<td>369</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>9</td>
<td>0</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Family facilities</td>
<td>Family / parent rooms</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>14</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Playrooms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Other family areas</td>
<td>1 small room with cooking area, play area, computer, and TV</td>
<td>Family Centre</td>
<td>Meeting rooms, gardens</td>
<td>Living room, quiet room, library, kitchen</td>
<td>Park, kitchen, living room</td>
<td>RMD Room, play garden</td>
<td>RMD Room</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

<sup>1</sup> Sunnybrook Health Sciences Centre (Sunnybrook); McMaster Children’s Hospital (McMaster); Stollery Children’s Hospital (Stollery); Canuck Place Children’s Hospice (Canuck); Children’s Hospital of Eastern Ontario (CHEO); Roger’s House (Roger’s); IWK Health Centre (IWK); Winnipeg Children’s Hospital (Winnipeg); Children’s Hospital London Health Sciences Centre (London); Hospital for Sick Children (SickKids).

<sup>2</sup> Full Time Equivalents (FTE)
Appendix V: Factor Analysis Results

‘Connect with Families’ Factor Matrix

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF14. How often were health professionals open to talking about your concerns?</td>
<td>.848</td>
</tr>
<tr>
<td>CF10. How often did health professionals treat you as a unique person?</td>
<td>.835</td>
</tr>
<tr>
<td>CF8. How often did health professionals show you their &quot;human&quot; side?</td>
<td>.834</td>
</tr>
<tr>
<td>CF2. How often were health professionals sensitive to you and your family's feelings?</td>
<td>.826</td>
</tr>
<tr>
<td>CF9. How often did health professionals treat your child as a unique person?</td>
<td>.826</td>
</tr>
<tr>
<td>CF4. How often was there a &quot;good fit&quot; between health professional and your family?</td>
<td>.821</td>
</tr>
<tr>
<td>CF3. How often did you feel a close connection to the health professional who cared for your child?</td>
<td>.813</td>
</tr>
<tr>
<td>CF6. How much did you trust the health professionals caring for your child?</td>
<td>.807</td>
</tr>
<tr>
<td>CF17. Did you and your family ever feel avoided or abandoned by health professionals before your child's death?</td>
<td>.807</td>
</tr>
<tr>
<td>CF5. How often did you feel health professionals accepted you and your family without judging you?</td>
<td>.798</td>
</tr>
<tr>
<td>CF13. How often was it easy to contact the health professionals caring for your child?</td>
<td>.798</td>
</tr>
<tr>
<td>CF7. How often did health professionals act as if they were better than you?</td>
<td>.767</td>
</tr>
<tr>
<td>CF1. How often did health professional communicate well with you and your family?</td>
<td>.728</td>
</tr>
<tr>
<td>CF12. How often did you experience &quot;acts of kindness&quot; from health professionals while you were in hospice?</td>
<td>.688</td>
</tr>
<tr>
<td>CF16. How often did you know which health professional was in charge of your child's care?</td>
<td>.621</td>
</tr>
<tr>
<td>CF15. How often was there at least one team member working consistently with your family?</td>
<td>.533</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

a. 1 factors extracted. 4 iterations required.
‘Involve Parents’ Two-Factor Solution

Rotated Factor Matrix

<table>
<thead>
<tr>
<th>IP23. How often did health professionals help you to feel that you were doing the best you could for your child?</th>
<th>Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>IP20. How often did health professionals ask for your opinions or concerns about your child?</td>
<td>.849</td>
</tr>
<tr>
<td>IP24. How often did health professionals support you in your role as a parent?</td>
<td>.825</td>
</tr>
<tr>
<td>IP22. How often did health professionals respect your wishes for your child's care?</td>
<td>.747</td>
</tr>
<tr>
<td>IP21. How often did you feel trusted as the &quot;expert&quot; on your child?</td>
<td>.705</td>
</tr>
<tr>
<td>IP26. How often were you given a choice whether or not to be with your child during difficult procedures or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)?</td>
<td>.639</td>
</tr>
<tr>
<td>IP27. How often were health professionals available to support you during difficult procedures or life threatening events?</td>
<td>.090</td>
</tr>
<tr>
<td>IP25. How often were you as involved in your child's care as you wanted to be?</td>
<td>.424</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 3 iterations.
‘Involve Parents’ One-Factor Solution

<table>
<thead>
<tr>
<th>Factor Matrixa</th>
<th>Factor 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP23. How often did health professionals help you to feel that you were doing the best you could for your child?</td>
<td>.893</td>
</tr>
<tr>
<td>IP24. How often did health professionals support you in your role as a parent?</td>
<td>.826</td>
</tr>
<tr>
<td>IP20. How often did health professionals ask for your opinions or concerns about your child?</td>
<td>.772</td>
</tr>
<tr>
<td>IP22. How often did health professionals respect your wishes for your child's care?</td>
<td>.755</td>
</tr>
<tr>
<td>IP27. How often were health professionals available to support you during difficult procedures or life threatening events?</td>
<td>.691</td>
</tr>
<tr>
<td>IP21. How often did you feel trusted as the &quot;expert&quot; on your child?</td>
<td>.623</td>
</tr>
<tr>
<td>IP25. How often were you as involved in your child's care as you wanted to be?</td>
<td>.544</td>
</tr>
<tr>
<td>IP26. How often were you given a choice whether or not to be with your child during difficult procedures or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)?</td>
<td>.500</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

a. 1 factor extracted. 5 iterations required.


### Rotated Factor Matrix

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI32. How often did health professionals give you &quot;the right amount&quot; of information about your child's condition?</td>
<td>.791</td>
<td>.355</td>
</tr>
<tr>
<td>SI38. How often did health professionals talk about &quot;the big picture&quot; for your child's condition (for example not just show how his/her hear tor lungs were working)?</td>
<td>.684</td>
<td>.285</td>
</tr>
<tr>
<td>SI34. How often did health professionals seem to know what information you might need before you even asked?</td>
<td>.660</td>
<td>.402</td>
</tr>
<tr>
<td>SI39. How often did health professionals provide enough time when talking with you and your family so you did not feel rushed?</td>
<td>.645</td>
<td>.406</td>
</tr>
<tr>
<td>SI36. How often did you feel health professionals gave truthful information to you and your family about your child?</td>
<td>.644</td>
<td>.529</td>
</tr>
<tr>
<td>SI31. How often did health professionals let you choose the amount of information that you wanted shared with you?</td>
<td>.633</td>
<td>.207</td>
</tr>
<tr>
<td>SI37. How often did health professionals show you your child's test results, X-rays, or scans when you wanted to see them?</td>
<td>.579</td>
<td>.234</td>
</tr>
<tr>
<td>SI35. How often did health professionals give information to you and your family that was confusing?</td>
<td>.516</td>
<td>.272</td>
</tr>
<tr>
<td>SI40. How often did you take part in family and team meetings about your child's care?</td>
<td>.496</td>
<td>.186</td>
</tr>
<tr>
<td>SI46. From your perspective, how often was information appropriately shared among health professionals?</td>
<td>.384</td>
<td>.805</td>
</tr>
<tr>
<td>SI45. How often was the information you received about your child the same from one health professional to the next?</td>
<td>.346</td>
<td>.800</td>
</tr>
<tr>
<td>SI48. How often did it seem health professionals planned together so they were all working towards the same goals for your child's care?</td>
<td>.423</td>
<td>.769</td>
</tr>
<tr>
<td>SI47. How often were you the one to tell health professionals the medical details of your child's medical condition because they didn't seem to know?</td>
<td>.189</td>
<td>.592</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.
### ‘Support Parents’ Two-Factor Solution

**Rotated Factor Matrix**

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS61. How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your family and friends)?</td>
<td>0.828</td>
<td>0.321</td>
</tr>
<tr>
<td>AS69. How often did health professionals assist you to get any additional services that you might need?</td>
<td>0.736</td>
<td>0.445</td>
</tr>
<tr>
<td>AS55. How often did health professionals provide the right amount of support for your practical needs (for example access to food, place to stay, transportation)?</td>
<td>0.688</td>
<td>0.116</td>
</tr>
<tr>
<td>AS57. How often did health professionals provide the right amount of support for your emotional needs (for example feeling listened to, accepting your feelings)?</td>
<td>0.677</td>
<td>0.431</td>
</tr>
<tr>
<td>AS68. How often did health professionals try to fulfill any of your family's special requests or wishes?</td>
<td>0.676</td>
<td>0.473</td>
</tr>
<tr>
<td>AS72. How often did health professionals allow and encourage extended family members/friends to visit when you wished?</td>
<td>0.618</td>
<td>0.281</td>
</tr>
<tr>
<td>AS59. How often did health professionals provide the right amount of support for your spiritual needs?</td>
<td>0.561</td>
<td>0.444</td>
</tr>
<tr>
<td>AS70. How often was your family given private time with your child before he/she dies?</td>
<td>0.406</td>
<td>0.297</td>
</tr>
<tr>
<td>AS82. How often did health professionals find the right balance in helping you hope for the best possible outcome for your child while also making plans in case that outcome did not happen?</td>
<td>0.180</td>
<td>0.927</td>
</tr>
<tr>
<td>AS81. How often did health professionals support your hopes for your child?</td>
<td>0.370</td>
<td>0.619</td>
</tr>
<tr>
<td>AS67. Some parents describe having a health professional who was able to &quot;coach&quot; or guide them during their child's end of life care. How often was there a health professionals involved with your family who acted as this type of guide?</td>
<td>0.425</td>
<td>0.559</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.
### ‘Support Parents’ One-Factor Solution

#### Factor Matrix

<table>
<thead>
<tr>
<th>Factor Matrix</th>
<th>Factor 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS69. How often did health professionals assist you to get any additional services that you might need?</td>
<td>.858</td>
</tr>
<tr>
<td>AS61. How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your family and friends)?</td>
<td>.843</td>
</tr>
<tr>
<td>AS68. How often did health professionals try to fulfill any of your family's special requests or wishes?</td>
<td>.830</td>
</tr>
<tr>
<td>AS57. How often did health professionals provide the right amount of support for your emotional needs (for example feeling listened to, accepting your feelings)?</td>
<td>.804</td>
</tr>
<tr>
<td>AS59. How often did health professionals provide the right amount of support for your spiritual needs?</td>
<td>.720</td>
</tr>
<tr>
<td>AS67. Some parents describe having a health professional who was able to &quot;coach&quot; or guide them during their child's end of life care. How often was there a health professional involved with your family who acted as this type of guide?</td>
<td>.678</td>
</tr>
<tr>
<td>AS81. How often did health professionals support your hopes for your child?</td>
<td>.667</td>
</tr>
<tr>
<td>AS82. How often did health professionals find the right balance in helping you hope for the best possible outcome for your child while also making plans in case that outcome did not happen?</td>
<td>.663</td>
</tr>
<tr>
<td>AS72. How often did health professionals allow and encourage extended family members/friends to visit when you wished?</td>
<td>.661</td>
</tr>
<tr>
<td>AS55. How often did health professionals provide the right amount of support for your practical needs (for example access to food, place to stay, transportation)?</td>
<td>.604</td>
</tr>
<tr>
<td>AS70. How often was your family given private time with your child before he/she dies?</td>
<td>.506</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

a. 1 factor extracted. 4 iterations required.
**Provide Care at Death** One-Factor Solution

### Factor Matrix*

<table>
<thead>
<tr>
<th>Question</th>
<th>Factor 1</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS97. Did health professionals respect your wishes for which health</td>
<td>0.842</td>
<td></td>
</tr>
<tr>
<td>professionals you wanted with you when your child died?</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>BC113. Were health professionals sensitive and respectful when caring</td>
<td>0.786</td>
<td>1</td>
</tr>
<tr>
<td>for your child's body after death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AS94. Did health professionals respect cultural/religious/spiritual</td>
<td>0.736</td>
<td></td>
</tr>
<tr>
<td>practices that you and your family wanted around the time of your child's</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>death?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AS96. Did health professionals respect your wishes for which family</td>
<td>0.719</td>
<td></td>
</tr>
<tr>
<td>members or friends you wanted with you when your child died?</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>AS99. If yes, how helpful was it to have a health professional with you?</td>
<td>0.698</td>
<td>1</td>
</tr>
<tr>
<td>BC114. Some parents want to stay with their child for a long time after</td>
<td>0.594</td>
<td></td>
</tr>
<tr>
<td>he/she dies, while others want to leave the hospital fairly quickly.</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Were you given as much time as you wanted with your child after he/she</td>
<td></td>
<td></td>
</tr>
<tr>
<td>died?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AS90. Once it was clear that your child was likely to die, were you given</td>
<td>0.243</td>
<td></td>
</tr>
<tr>
<td>choices about where this might happen (for example going home,</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>going to a hospice, or moving to a more private room or area of the</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hospice?)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Extraction Method: Principal Axis Factoring.

a. 1 factor extracted. 6 iterations required.
Appendix W: Final Instrument Items

Connect with Families Domain

Connect with Families Subscale Items
1. How often did health professionals communicate well with you and your family? Never / Rarely / Sometimes / Mostly / Always
2. How often were health professionals sensitive to you and your family’s feelings? Never / Rarely / Sometimes / Mostly / Always
3. How often did you feel a close connection to the health professionals who cared for your child? Never / Rarely / Sometimes / Mostly / Always
4. How often was there a “good fit” between health professionals and your family? Never / Rarely / Sometimes / Mostly / Always
5. How often did you feel health professionals accepted you and your family without judging you? Never / Rarely / Sometimes / Mostly / Always
6. How much did you trust the health professionals caring for your child? Not at all / Not very much / Somewhat / Mostly / Completely
7. How often did health professionals act as if they were better than you? Never / Rarely / Sometimes / Mostly / Always
8. How often did health professionals show you their “human” side? Never / Rarely / Sometimes / Mostly / Always
9. How often did health professionals treat your child as a unique person? Never / Rarely / Sometimes / Mostly / Always
10. How often did health professionals treat you as a unique person? Never / Rarely / Sometimes / Mostly / Always
11. How often did you experience “acts of kindness” from health professionals while you were in hospital? Never / Rarely / Sometimes / Mostly / Always
12. How often was it easy to contact the health professionals caring for your child? Never / Rarely / Sometimes / Mostly / Always
13. How often were health professionals open to talking about your concerns? Never / Rarely / Sometimes / Mostly / Always
14. How often was there at least one team member working consistently with your family? Never / Rarely / Sometimes / Mostly / Always
15. How often did you know which health professional was in charge of your child’s care? Never / Rarely / Sometimes / Mostly / Always
16. Did you and your family ever feel avoided or abandoned by health professionals before your child’s death? Never / Rarely / Sometimes / Mostly / Always

Connect with Families Outcome Item
Overall, how satisfied were you with your relationships with the health professionals who cared for your child before his/her death? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat dissatisfied / Mostly satisfied / Completely satisfied

Connect with Families Open-Ended Item
Please add any other comments you would like to share about your relationship with the health professionals who cared for your child and family
Involve Parents Domain

Involve Parents Subscale Items
1. How often did health professionals ask for your opinions or concerns about your child? Never / Rarely / Sometimes / Mostly / Always
2. How often did you feel trusted as the “expert” on your child? Never / Rarely / Sometimes / Mostly / Always
3. How often did health professionals respect your wishes for your child’s care? Never / Rarely / Sometimes / Mostly / Always
4. How often did health professionals help you to feel that you were doing the best you could for your child? Never / Rarely / Sometimes / Mostly / Always
5. How often did health professionals support you in your role as a parent? Never / Rarely / Sometimes / Mostly / Always
6. How often were you as involved in your child’s care as you wanted to be? Never / Rarely / Sometimes / Mostly / Always
7. How often were you given a choice whether or not to be with your child during difficult procedures or life threatening events (for example if cardiopulmonary resuscitation [CPR] was done, right after surgery, during tests etc.)? No difficult procedures or life threatening events / Never / Rarely / Sometimes / Mostly / Always
8. How often were health professionals available to support you during difficult procedures or life threatening events? Never / Rarely / Sometimes / Mostly / Always

Involve Parents Outcome Item
Overall, how satisfied were you with your involvement in your child’s care during the last week or days of his/her life? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied

Involve Parents Open-Ended Item
Please add any other comments you would like to share about your involvement in your child’s care.

Share Information with Parents Domain

Share Information with Parents Subscale Items
1. How often did health professionals let you choose the amount of information that you wanted shared with you? Never / Rarely / Sometimes / Mostly / Always
2. How often did health professionals give you the right amount of information about your child’s condition? Never / Rarely / Sometimes / Mostly / Always
3. How often did health professionals seem to know what information you might need before you even asked? Never / Rarely / Sometimes / Mostly / Always
4. How often did health professionals give information to you and your family that was confusing? Never / Rarely / Sometimes / Mostly / Always
5. How often did you feel health professionals gave truthful information to you and your family about your child? Never / Rarely / Sometimes / Mostly / Always
6. How often did health professionals show you your child’s test results, X-rays, or scans when you wanted to see them? I did not want this kind of information / Never / Rarely / Sometimes / Mostly / Always
7. How often did health professionals talk about “the big picture” for your child’s condition (for example not just how his/her heart or lungs were working)? Never / Rarely / Sometimes / Mostly / Always

8. How often did health professionals provide enough time when talking with you and your family so you did not feel rushed? Never / Rarely / Sometimes / Mostly / Always

9. How often did you take part in family and team meetings about your child’s care? Never / Rarely / Sometimes / Mostly / Always

Share Information with Parents Stand-Alone Items

1. How often did health professionals respect your wishes about how much to involve your child in talks about his/her illness? Never / Rarely / Sometimes / Mostly / Always / Not applicable (for example if child was too young or unable to communicate)

2. Did you have discussions with health professionals about the possibility your child would not survive his/her illness? Yes / No / Don’t remember

3. If yes, was this possibility discussed in a sensitive manner? Not at all / Not very sensitive / Somewhat sensitive / Mostly sensitive / Completely sensitive

4. If yes, how appropriate was the timing of the discussion in the course of the illness? Not at all appropriate / Not very appropriate / Somewhat appropriate / Mostly appropriate / Completely appropriate

5. Do you wish this possibility would have been discussed sooner or later? A lot sooner / A little sooner / No, the timing was completely appropriate / A little later / A lot later

6. Did health professionals ever talk about stopping or not starting life-sustaining treatments (such as cardiopulmonary resuscitation [CPR], ventilator, antibiotics, transfusions, or artificially delivered food or fluids)? Yes / No / Don’t remember

7. If yes, was this discussion about treatments done in a sensitive manner? Not at all / Not very sensitive / Somewhat sensitive / Mostly sensitive / Completely sensitive

8. If yes, how appropriate was the timing of this discussion about treatments? Not at all appropriate / Not very appropriate / Somewhat appropriate / Mostly appropriate / Completely appropriate

9. Do you wish this discussion about treatments would have happened sooner or later? A lot sooner / A little sooner / No, the timing was completely appropriate / A little later / A lot later

10. When a child has treatments like a ventilator removed, this can sometimes be done at a time that will best meet the needs of the family (for example it may be delayed so certain people can visit or to give time for specific rituals). Were you given a choice about when treatments would be stopped? Yes / No / Can’t remember / No treatments stopped

11. If treatment was stopped, was it done at the time you wished? Treatments stopped way too soon / Treatments stopped a bit too soon / Treatments stopped when I wished / Treatments continued a bit too long / Treatments continued way too long

12. How well informed were you about what to expect at the time of your child’s death? Not at all informed / A little informed / Somewhat informed / Mostly informed / Completely informed

13. Did health professionals ever talk about whether or not your child could be an organ or tissue donor? Yes / No / Don’t remember

14. If yes, was the timing of this discussion appropriate? Much too soon / A little too soon / Appropriate / A little too late / Much too late

15. If yes, was this discussion done in a sensitive way? Not at all / Not very sensitive / Somewhat sensitive / Mostly sensitive / Completely sensitive
16. Did health professionals ever discuss an autopsy for your child? Yes / No / Don’t remember
17. If yes, was the timing of this discussion appropriate? Much too soon / A little too soon / Appropriate / A little too late / Much too late
18. If yes, was this discussion done in a sensitive way? Not at all / Not very sensitive / Somewhat sensitive/ Mostly sensitive / Completely sensitive

Share Information with Parents Outcome Items
1. Overall, how satisfied were you with the information shared between you and the health professionals caring for your child? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither Satisfied nor Dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied
2. Overall, how satisfied were you with the information shared between health professionals and your child? Child too young / Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied

Share Information with Parents Open-Ended Item
Please add any other comments about how information about your child was shared with you, your child, and your family.

Share Information among Health Professionals Domain

Share Information among Health Professionals Subscale Items
1. How often was the information you received about your child the same from one health professionals to the next? Never / Rarely / Sometimes / Mostly / Always
2. From your perspective, how often was information appropriately shared among health professionals? Never / Rarely / Sometimes / Mostly / Always
3. How often were you the one to tell health professionals the medical details of your child’s condition because they didn’t seem to know? Never / Rarely / Sometimes / Mostly / Always
4. How often did it seem health professionals planned together so they were all working towards the same goals for your child’s care? Never / Rarely / Sometimes / Mostly / Always

Share Information among Health Professionals Outcome Item
Overall, how satisfied were you with the information shared among all the health professionals caring for your child? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied

Share Information among Health Professionals Open-Ended Item
Please add any other comments about how information about your child’s care was shared among health professionals.

Support Child Domain

Support Child Stand Alone Items
1. How often did health professionals look at all the needs of your child (physical, emotional, social, developmental, and spiritual needs)? Never / Rarely / Sometimes / Mostly / Always
During your child’s last week or days of life while in the hospital, how much would you say your child seemed to suffer from each of the following symptoms?

2. Pain  Not at all / A little / Somewhat / A lot / Constantly / Unsure
3. Nausea or vomiting  Not at all / A little / Somewhat / A lot / Constantly / Unsure
4. Breathing Difficulties  Not at all / A little / Somewhat / A lot / Constantly / Unsure
5. Bleeding  Not at all / A little / Somewhat / A lot / Constantly / Unsure
6. Seizures  Not at all / A little / Somewhat / A lot / Constantly / Unsure
7. Sadness  Not at all / A little / Somewhat / A lot / Constantly / Unsure
8. Anxiety / Worry  Not at all / A little / Somewhat / A lot / Constantly / Unsure
9. Fear  Not at all / A little / Somewhat / A lot / Constantly / Unsure

Support Child Outcome Items
1. Overall, which of the following describes the amount of suffering your child had from his/her symptoms? Would you say he / she suffered:  Not at all / A little / Somewhat / A lot / Constantly / Unsure
2. Overall, how satisfied were you with support given to ease your child’s suffering by health professionals at the hospital?  Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied

Support Siblings Domain

Support Siblings Stand-Alone Items
1. How often did health professionals provide the right amount of overall support to your other children during the time your child was in hospital?  No other children / Never / Rarely / Sometimes / Mostly / Always
2. How often did health professionals guide you on how you could support your other children while your child was in hospital?  No other children / Never / Rarely / Sometimes / Mostly / Always
3. How often did health professionals allow and encourage your other children to visit when they wished?  No other children / Never / Rarely / Sometimes / Mostly / Always
4. Did someone from the hospital/hospice offer you information about your other children’s grief?  Don’t have other children / Yes / No / Don’t remember
5. If yes, how helpful was this information for you?  Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful

Support Siblings Outcome Item
Overall, how satisfied were you with support given to your other children by health professionals at the hospital?  No other children / Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied
Support Parents Domain

Support Parents Subscale Items
1. How often did health professionals provide the right amount of support for your practical needs (for example access to food, a place to stay, transportation)? Never / Rarely / Sometimes / Mostly / Always
2. How often did health professionals provide the right amount of support for your emotional needs (for example feeling listened to, accepting your feelings)? Never / Rarely / Sometimes / Mostly / Always
3. How often did health professionals provide the right amount of support for your spiritual needs? Never / Rarely / Sometimes / Mostly / Always
4. How often did health professionals provide the right amount of support for your social needs (for example feeling cared about, maintaining relationships with your family and friends)? Never / Rarely / Sometimes / Mostly / Always
5. Some parents describe having a health professional who was able to “coach” or guide them during their child’s end of life care. This health professional was someone who was able to anticipate family needs, prepare and support the family throughout the process, and give helpful options and suggestions about things to do. How often was there a health professional involved with your family who acted as this type of guide? Never / Rarely / Sometimes / Mostly / Always
6. How often did health professionals try to fulfill any of your family’s special requests or wishes? No special requests made / Never / Rarely / Sometimes / Mostly / Always
7. How often did health professionals assist you to get any additional services that you might need? Never / Rarely / Sometimes / Mostly / Always
8. How often was your family given private time with your child before he / she died? Never / Rarely / Sometimes / Mostly / Always
9. How often did health professionals allow and encourage extended family members / friends to visit when you wished? Never / Rarely / Sometimes / Mostly / Always
10. How often did health professionals support your hopes for your child? Never / Rarely / Sometimes / Mostly / Always
11. How often did health professionals find the right balance in helping you hope for the best possible outcome (cure or longer life) for your child while also making plans in case that outcome did not happen? Never / Rarely / Sometimes / Mostly / Always

Support Parents Stand Alone Item
Would you say health professionals focused too much on cure or too much on death? Way too much on cure / A little too much on cure / No, health professionals always had the right balance / A little too much on death / Way too much on death

Support Parents Outcome Item
Overall, how satisfied were you with support given to you by health professionals at the hospital? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat dissatisfied / Mostly satisfied / Completely satisfied

Support Parents Open-Ended Item
Please add any other comments about how you and your family were supported by health professionals while your child was in the hospital.
Provide Care at Death Domain

Provide Care at Death Subscale Items
1. Once it was clear that your child was likely to die, were you given choices about where this might happen (for example going home, going to a hospice, or moving to a more private room or area of the hospital)? Yes / No / Can’t Remember / No choices possible as my child died very suddenly
2. Did health professionals respect cultural / religious / spiritual practices that you and your family wanted around the time of your child’s death? No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful
3. Did health professionals respect your wishes for which family members or friends you wanted with you when your child died? No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful
4. Did health professionals respect your wishes for which health professionals you wanted with you when your child died? No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful
5. How helpful was it to have a health professional with you when your child died? No health professional was with us / Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
6. Were health professionals sensitive and respectful when caring for your child’s body after death? Not at all / Not very sensitive / Somewhat sensitive/ Mostly sensitive / Completely sensitive
7. Some parents want to stay with their child for a long time after he / she dies, while others want to leave the hospital fairly quickly. Were you given as much time as you wanted with your child after he / she died? Yes / No

Provide Care at Death Outcome Items
1. Some people use the word peaceful to describe the atmosphere at the time of a person’s death. Which of the following best describes the atmosphere at the time of your child’s death? Not at all peaceful / A bit peaceful / Somewhat peaceful / Very peaceful / Extremely peaceful
2. Although the death of a child is always a tragedy, some parents are able to describe their child’s dying process as a good death. All things considered, would you say your child experienced a “good death”? Disagree strongly / Disagree somewhat / Neither agree nor disagree / Agree somewhat / Agree strongly

Provide Care at Death Open-Ended Item
Please add any other comments about the discussions or events that happened at the time of your child’s death.

Provide Bereavement Follow-up Domain

Provide Bereavement Follow-up Subscale (**) and Stand-Alone Items
1. **Did health professionals suggest and offer to create mementos (for example: lock of hair, pictures, hand/foot prints) of your child? Yes / No / Don’t remember
2. Did health professionals respect your wishes about the mementos that you wanted to have? No respect at all / A bit respectful / Somewhat respectful / Very respectful / Extremely respectful
3. **Did health professionals offer to help you make any arrangements for funerals or other religious customs?** Yes / No / Don’t remember
4. If yes, how helpful was this assistance for you? Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
5. Did health professionals from the hospital offer to continue contact with your family through calls or letters after your child died? Yes / No / Don’t remember
6. **About how many contacts with health professionals from the hospital have you had since your child died? _____
7. Would you say this number of contacts was the right amount, too many or too few? Much too many / A little too many / The right amount / A little too few / Much too few
8. What kind of contacts have you had? (Check all that apply) Phone calls / Card or letters / Meetings / Counseling / Email / Other (Please Specify _______
9. If contact continued, how helpful was it for you? Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
10. **Did someone from the hospital offer you information about your grief?** Yes / No / Don’t remember
11. If yes, how helpful was this information for you? Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
12. **Did someone from the hospital offer you information about community resources available close to your home?** Yes / No / Don’t remember
13. If yes, how helpful was this information for you? Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
14. **Were you offered a follow-up meeting with health professionals to discuss what happened at the time of your child’s death and/or the autopsy results (if one was done)?** Yes / No / Don’t remember
15. If you had a meeting, was it helpful for you? No meeting held / Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
16. If an autopsy was done did you receive the results in a timely manner? Autopsy not done / Not at all timely / Somewhat timely / Very timely
17. Have you attended a memorial service held by the hospital where your child died? Yes / No / No service offered / Don’t remember
18. If yes, how helpful was the memorial service for you? Not at all helpful / A little helpful / Somewhat helpful / Very helpful / Extremely helpful
19. Did you feel avoided or abandoned by health professionals from the hospital after your child’s death? Never / Rarely / Sometimes / Mostly / Always

**Provide Bereavement Follow-up Outcome Item**
Overall, how satisfied were you with the support provided through the hospital in the months after your child died? Completely dissatisfied / Mostly dissatisfied / Somewhat dissatisfied / Neither satisfied nor dissatisfied / Somewhat satisfied / Mostly satisfied / Completely satisfied

**Provide Bereavement Follow-up Open-ended Item**
Please add any other comments about the support provided through the hospital in the months after your child’s death.
Structures of Care Domain

Structures of Care Stand Alone Items
1. How often was there enough room for you to be with your child while in hospital?  
   Never / Rarely / Sometimes / Mostly / Always
2. How often was there a comfortable place for you to sleep at or near the hospital?  
   Never / Rarely / Sometimes / Mostly / Always
3. How often were there playrooms or other child-friendly spaces for your other children
   while you were at the hospital?  
   No other children / Never / Rarely / Sometimes / Mostly / Always
4. How often was food readily available for your family while you were at the hospital?  
   Never / Rarely / Sometimes / Mostly / Always
5. Would you say the food at the hospital was affordably priced?  
   Not at all / A little / Somewhat / Very / Extremely
6. How often were you easily able to find parking at the hospital?  
   Never / Rarely / Sometimes / Mostly / Always
7. Would you say parking at the hospital was affordably priced?  
   Not at all / A little / Somewhat / Very / Extremely

Structures of Care Open-Ended Item
Please share any other comments you have about the facilities available to you and your family
while at the hospital.

Overall Quality Domain

Overall Quality Outcome Item
Overall how would you describe the quality of end-of-life care provided to your child and
family by health professionals from the hospital?  
   Poor / Fair / Good / Very Good / Excellent

Overall Quality Open-Ended Items
1. Please add any other comments about the overall care your child and family received
   through the hospital.
2. What was the best experience you had with the health care system during your child’s end-of-life care?
3. What was the worst experience you had with the health care system during your child’s end-of-life care?