Practical Virtues:
An Evidence-Based Ethical Framework for Approaching
End-of-Life Care in the Neonatal Intensive Care Unit

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Institute of Health Policy, Management, and Evaluation
University of Toronto

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Abstract

The challenges surrounding end-of-life care in newborns, including the moral weight of decisions, best interest standards, and parental involvement in decision-making, require an interprofessional approach in order to minimize moral distress and moral residue.

The objectives of this project were to describe professional perspectives on end-of-life care in the neonatal intensive care unit, to compare and contrast these perspectives with the identified needs and perspectives of parents, and to construct a framework based on these to aid health care professionals in the approach to neonatal end-of-life care.

First, using qualitative interviews, the attitudes and experiences of 43 health care professionals were explored. Participants identified the roles, challenges, and quality indicators related to meeting parents’ and infants’ needs at end-of-life. Broad categories included: clinical expertise and moral sensitivity; communication; guidance, support, and relationships; shared decision-making; and end-of-life planning and care. Health care professionals identified challenges to team function and quality of care related to consistency of caregivers, communication, and consensus on the interprofessional team.
Next, using ethical analysis based in virtue theory, the experiences of 11 parents of infants who died following withholding/withdrawal of life-sustaining treatment were compared to those of the 43 health care professionals and used to inform a framework for approaching neonatal end-of-life care. Both individual virtues of character and virtues ascribed to the interprofessional team were important to providing good quality communication, shared decision-making, and care at end-of-life. The resulting ethical framework involves five steps: i) identifying the components of moral event(s); ii) defining the virtues important in meeting parents’ and baby’s needs; iii) applying combinations of these virtues in clinical context in order to iv) practice moral action; and iv) reflect on the process.

Next steps include the application and evaluation of this virtue-based ethical framework to end-of-life care in the neonatal intensive care unit.
Acknowledgments

I would first like to acknowledge the members of the original With Care team: from McMaster University (Hamilton), J. Cairnie, L. Lohfeld, C. Patey, V. Fines, K. Schwarzer, T. Sabourin, and J. Aylward; from the Hospital for Sick Children (Toronto), C. Newman and J. Hellmann; and parent advocates, H. Harrison (US) and H. & A. Williams (Canada).

Next I acknowledge the members of my thesis committee, A. Laupacis (University of Toronto), J. Gibson (University of Toronto), and H. Kirpalani (McMaster, and original member of the With Care team) for their support in the completion of this dissertation.

I also acknowledge the funding agencies, Physician Services Inc. Foundation for the resident research grant which initiated this project and to the Canadian Institute for Health Research for the Doctoral Research Award which allowed for its completion.

I express thanks to my friends and family who didn’t complain (too much) about my remaining a student ‘forever’.

I express gratitude and respect for the members of the NICU interprofessional team, those who took part in the interviews for this project and those with whom I have the privilege of working every day.

Finally, I have the utmost gratitude, respect, and compassion for the parents who lost infants and still shared their stories in order to improve the care we deliver to other babies and families.
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Appendix 1: Interview guide for professional interviews

List of Abbreviations

AAP American Academy of Pediatrics
EOL End-of-life
FCC Family centred care
HCP Health care professional
NICU Neonatal intensive care unit
QOL Quality of life
RT Respiratory therapist
WLST Withholding/withdrawal of life-sustaining treatment
Chapter 1
Introduction

1.1 The ‘With Care’ Project

The purpose of this bioethics and health services research dissertation was to study end-of-life (EOL) shared decision-making and practices in the Neonatal Intensive Care Unit (NICU) in order to improve care for families and support practitioners. This thesis work is situated within a larger mixed methods interprofessional project, ‘With Care’ (PI: C. Williams) (see Figure 1).

The first phase of the ‘With Care’ project involved a qualitative analysis of interviews with parents whose infants died in the NICU following withholding/withdrawal of life-sustaining treatment (WLST). Results of this phase have been previously reported (Williams, et al., 2009; Williams, Munson, Zupancic, & Kirpalani, 2008).

The second phase of the ‘With Care’ project, and the subject of this dissertation, involved interviews with health care professionals (HCPs), comparative ethical analysis of HCP and parent interviews and the development of a conceptual framework illustrating an approach to ethical issues at EOL in the NICU. Specifically, this phase i) described the experiences of HCPs, ii) contrasted the views of parents and HCPs, and iii) developed a framework for EOL care and decision-making using a virtue theory lens, based on these findings.

The post-dissertation phase of the ‘With Care’ project will involve: i) piloting and evaluating the virtue-based ethical framework to EOL care in a NICU context; and ii) developing and implementing an interprofessional curriculum for EOL care and decision-making for NICU teams.
1.2 Key gaps in neonatal end-of-life care

Bereaved parents in the NICU emphasize the importance of communication, shared decision-making, and the personal characteristics of HCPs in EOL care (Williams, et al., 2009). HCPs describe the challenges they face in providing EOL care and the personal and professional consequences of this difficult work. Ethical issues revolving around the moral status of the newborn, the determination of best interest, and the exercise of shared decision-making by parents and HCPs, particularly when there is clinical or moral uncertainty, challenge the provision of good quality EOL care. There is a knowledge gap in understanding whether and to what extent parents and HCPs’ goals and expectations are complimentary in defining good quality EOL care in the NICU and in addressing moral uncertainty in EOL decision-making.
There is also a practice gap in specifying and implementing conditions for good quality EOL care, including relevant EOL decision-making policies, training and education of HCPs, and evaluating shared decision-making practices. In this dissertation, I will argue that an interprofessional framework for good quality EOL care in the NICU normatively grounded in virtue theory and empirically constructed from the experiences of both parents and HCPs contributes to bridging these gaps.

1.2.1 The ethics-quality gap

Quality EOL care for newborns involves ensuring a ‘good death’ for infants while honouring the values of families. In the study of quality EOL care there is a gap in empirically-based ethical guidance for clinical practice. This is especially apparent when statistical outcome measures shape the basis of decision-making and individual values become less important than clinical guidelines (Adcroft & Willis, 2005). Unit guidelines and policy documents reflect the privileged role of rationality, predictability and certainty. Harrison and Smith warn these may become sham moralities (Harrison & Smith, 2004). In the face of uncertain prognoses and imprecise outcomes, guidelines or protocols are difficult to enforce. In addition, caregivers often struggle to apply ethical principles to practical decision-making when complex dilemmas don’t have easily identifiable ‘right answers’. Similarly, caregivers often lack the necessary tools and resilience to deal with the weight and consequences of moral conflict related to EOL issues in the newborn.

1.2.2 The interprofessional practice gap

Gingell-Epstein describes an ethically important gap in the interprofessional practice of EOL care in the NICU (Gingell Epstein, 2010). She highlights challenges in interprofessional communication and collaboration, suggesting that nurses and doctors in particular work in silos. One reason she cites is the lack of a common language regarding the shared moral work involved in EOL care (Gingell Epstein, 2010). The consequences of this lack of a common language include breakdown in collaboration amongst team members particularly regarding EOL decision-making in cases of ‘futility’ and responding to the urgency of suffering (Gingell Epstein, 2010).
1.2.3 How the dissertation addresses the gaps

With the overall aim to improve EOL care and decision-making for families and caregivers in the NICU, the methodology of this dissertation sought to answer the following research questions:

- What are the attitudes and experiences of HCPs concerning good quality EOL care in the NICU, including how these are similar or different across health professions?
- How are the attitudes and experiences of parents and professionals regarding good quality EOL care and its challenges similar or different?
- How might virtue theory provide an appropriate ethical foundation to improve understanding of and practice in good quality EOL care within the interprofessional team and with parents?

To address these questions, the objectives of this dissertation were:

1. To describe professional perspectives on EOL care and decision-making in the NICU
2. To compare and contrast these perspectives with the identified needs and perspectives of parents whose infants died following WLST (from Phase 1) using a virtue theory lens
3. To construct an ethical framework based on i) and ii), grounded in virtue theory, to aid HCPs in the approach to EOL care and decision-making in the NICU

1.3 Chapter outline

This dissertation is divided into six chapters.

Chapter 1, the introductory chapter, outlines the practice gaps and the context of this empirical work within the overall interprofessional education and quality improvement project, ‘With Care’.

Chapter 2 reviews the literature, identifying the clinical and ethical challenges of EOL care in the NICU as well as the consequences to quality of care and caregivers. A rationale for the work is also presented.
Chapter 3 introduces Virtue Theory, the theoretical foundation underlying the methodology of the project as well as the theory grounding the final product, an ethical framework for approaching EOL care in the NICU.

Chapter 4 outlines the research design and methods along three specific objectives: i) describing the perspectives of HCPs on EOL in the NICU, ii) comparing the perspectives of parents and HCPs using a virtue theory analysis, and iii) developing an ethical framework for EOL care.

Chapter 5 presents the empirical results and ethical analysis related to the three outlined objectives. First the context of the work as described by HCPs is explored highlighting the clinical and moral challenges and comparing experiences across professional roles. Next, the virtues important to providing good quality EOL care are outlined based on the comparative perspectives of HCPs and parents. Finally the application of virtues in clinical contexts as the foundation of an ethical framework is illustrated.

Chapter 6 discusses the results of the empirical work in the context of the literature and evaluates the characteristics of a virtue-based framework for EOL care in the NICU. The strengths and limitations of the study are reviewed as are future applications and considerations for work in this area.
Chapter 2
Clinical and ethical context of end-of-life care in the neonatal intensive care unit

In this chapter, the clinical and organizational context of EOL care in the NICU is described. Next, definitions, challenges, and measures of quality EOL care are introduced. Subsequently, the ethical issues arising at EOL that influence HCPs’ ability to provide good quality care are explored. Finally, the need for an ethical framework to address the issues and consequences involved in EOL care in the NICU is justified.

2.1 The clinical background and context

More children die in the neonatal period than during any other time in childhood (Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006). The leading causes of death of infants in high income countries are extreme prematurity, congenital/genetic anomalies, and catastrophic neurological injury (Berger & Hofer, 2009).

Duff and Campbell first described in 1973 the ethical and moral dilemmas faced by physicians and nurses at EOL in the NICU. They reviewed 299 consecutive deaths at Yale, 14% of which were related to decisions to withhold or withdraw life-sustaining treatment (Duff & Campbell, 1973). Currently, WLST precedes 40-90% of deaths in the NICU (Roy, Aladangady, Costeloe, & Larcher, 2004; Wall & Partridge, 1997; Barton & Hodgman, 2005; Verhagen, van der Hoeven, van Meerveld, & Sauer, 2007; Schulz-Baldes, Huseman, Loui, Dudenhausen, & Obladen, 2007). The frequency of WLST is increasing over time as is the active role of parents in decision-making at EOL (Eventov-Friedman, Kanevsky, & Bar-Oz, 2013). Over a 10 year period in one US centre there was an increase in the frequency of do not resuscitate orders from 39% to 56% in the NICU (Singh, Lantos, & Meadow, 2004). In addition, the traditional ICU “disease oriented” approach which focuses on ensuring survival at any cost and views death as the ultimate failure, is being replaced with a more flexible “person-oriented” philosophy, which takes into account quality-of-life (QOL) considerations in EOL decision-making (Duff & Campbell, 1976). With this shifting paradigm, some clinicians are beginning to distinguish between WLST from
moribund infants versus those with morbid neurologic prognoses on a both a clinical and moral level (Janvier, Barrington, & Farlow, 2014). It often feels contrary to the role of parents and clinicians to let an infant die, much less withdraw life-sustaining treatment based upon predicted QOL and despite its legal and moral permissibility, living with the choice can be a struggle (Carnevale, 2007).

EOL care for the newborn must take into account the thick ethical issues facing clinicians and families and the context of the unit culture. In the NICU, unit policies and guidelines are often driven by technological progress and parent/family expectations. Lantos and Meadow suggest that societal attitudes towards newborns and their medical care may be shaped by technological developments in neonatal practice or the stimulus to develop new neonatal technologies and legal policies (Lantos & Meadow, 2006). How a unit shapes its practices and policies around these emerging experimental technologies and expectations, contributes to the overall unit ethos.

The way a group functions, its shared values or beliefs, its hierarchal elements, behaviours and standards, associations with power, and its moral climate have all been used to describe the culture of a clinical unit (Brown, Ohlinger, Rusk, Delmore, & Ittmann, 2003; Baker, King, MacDonald, & Horbar, 2003; Goodenough, 1971; Rodney, Doane, Storch, & Varcoe, 2006; Savage, 2000). In an individual NICU, local culture is made up of meanings attributed to relationships, styles of decision-making, aspects of patient care, and team functioning. In the adult ICU literature, the characteristics of team culture including communication, collaboration, and interprofessional relationships affect team performance (Cole & Crichton, 2006). In addition to challenging clinical cases with ethical dimensions, teams may encounter problems with ineffective leadership, poor communication, mistrust, conflicting values and beliefs, and interdisciplinary rivalry (Hawley, 2007; McNair, 2005). The nature of interprofessional interactions in other contexts changes as teams move through different temporal periods and medical crises, suggesting a dynamic process (Piquette, Reeves, & Leblanc, 2009). In the development of a common moral language, it is necessary to understand and build team capacity to deal with these issues which are often embedded in a unit’s hidden curriculum (Hafferty, 1998).

Over the last 25 years, the literature has begun to describe how parents of critically ill infants fit into NICU culture. In the NICU, ‘the patient experience’ is subsumed in the concept of Family-
Centered Care (FCC). Three key principles of FCC were first identified by Helen Harrison, the parent of a surviving premature infant. She identified from her experiences: the value of open communication, the practice of shared decision-making, and the need for compassion (Harrison H., 1993). A consensus definition of FCC has not been achieved to date, but there is agreement on some general principles including: i) open, objective, and unbiased information sharing; ii) respecting and honoring differences; iii) partnerships and collaboration between HCPs and families; iv) negotiation of medical care plans; and v) providing care in context of family and community (Kuo, et al., 2012). FCC is considered the standard of care at pediatric centres and the adoption of the principles of FCC has transformed how parents are integrated into the care team.

2.2 Defining and measuring quality end-of-life care

EOL care is often described as one component of palliative care, focusing on managing the end stages of the medical condition while preparing for death (Field & Behrman, 2003). In the NICU, Epstein defines EOL not as a discrete concept or a particular moment, but rather a combination of multiple continuous factors including decision-making, communication, symptom relief, family support, and continuity of care (Gingell Epstein, 2010). For the purpose of this dissertation, it is in this latter context that the term EOL is applied.

In the newborn population, palliative care describes:

Holistic and extensive care for an infant who is not going to ‘get better’... [it] is an entire milieu of care to prevent and relieve the infant’s suffering and improve the conditions of the infant’s living and dying... [it] focuses on the prevention and relief of physical pain... for the infant and on relief of existential suffering of the family. (Catlin & Carter, 2002, pp. 184-185)

In 2001, Catlin and Carter created one of the first neonatal palliative care protocols, incorporating the experience and expertise of a 101-member international Delphi panel (Catlin & Carter, 2001). From American data, most children who die do not receive palliative care as defined above (Carter B. S., 2004; Pierucci, Kirby, & Leuthner, 2001). The Canadian Hospice Palliative Care Association affirms that infants and families have a right to receive palliative care from caregivers who understand their perspectives on their notion of QOL for themselves and their child. (Canadian Hospice Palliative Care Association, 2014)
In 1996, the EURONIC group began a large, international study examining the opinions and experiences of medical and nursing staff concerning ethical decisions and parental involvement at EOL in European NICUs (Cuttini, et al., 2000). In the initial phase of the study, 7 countries were included, but over time the group expanded to include a total of 144 NICUs, more than 1400 physicians and 3400 nurses, with a response rate of >85% (Cuttini, Kaminski, Saracci, & de Vonderweid, 1997). Over the following 15 year period, the study group continued to expand to include other countries and performed follow-up analyses to examine changes in practice over time.

Variations in practice were found across a spectrum of EOL decisions including non-escalation of intensive treatments, WLST, and pain management with the risk of hastening death. WLST was most frequently discussed in regards to the treatment of extremely premature “non-viable” infants, infants with congenital defects incompatible with short term and medium term survival, and infants with longer term lethal prognoses or predicted poor QOL (Orzalesi & Cuttini, 2011). Physicians’ clinical practices were related to their own personal values. Country of practice which was felt to involve historical, social, cultural and legal influences, remained the most important predictor of whether physicians were more likely to value ‘quality’ or ‘sanctity’ of life. Barr suggests that in addition to culture, religion, and country of origin, personal attitudes and fears associated with death also influence physicians’ EOL decisions (Barr, 2007). In the years following the initial EURONIC study, follow up surveys continued to demonstrate variation in practices regarding limiting life-sustaining treatment at EOL, furthermore, centres also reported an increasing involvement of parents in EOL decision-making (Samaan, Cuttini, Casotto, & Ryan, 2008; Garel, Caeumaex, Goffinet, Cuttini, & Kaminski, 2011).

In addition to variation in practice existing across different NICUs, there may also be variation in practice amongst professionals within one NICU. In a recent survey of 80 nurses and 24 physicians in four NICUs in Taiwan, neonatologists were significantly more likely than nurses to agree with the practice of WLST or non-escalation of care (Huang, et al., 2013) This and other studies highlight the importance of understanding the views of individual members of the care team in order to improve practice (Chambliss, 1996; Oberle & Hughes, 2001; Shannon, 1997).

The most challenging aspect of palliative care in the NICU is the decision to initiate it. In the NICU clinicians are often unprepared to engage parents in EOL decision-making (Boss, Hutton,
Donohue, & Arnold, 2009). Following a review of the literature, Kain devised a questionnaire to survey neonatal nurses about the barriers to providing palliative care to infants. Barriers that were identified included: the sense of failure associated with the death of a baby, the difficulty in transitioning from curative to palliative models of care, difficulties communicating with families about death and dying, previous stressful experiences, frequent exposure to death, conflicting opinions on the healthcare team, lack of organizational support for nursing staff, and lack of formal training in EOL care (Kain, 2006). In emotionally weighted situations, the literature describes nurses distancing themselves from patients/families in order to avoid the discomfort of witnessing patient/family emotions (Paterson & Zderad, 2007). In addition, nurses’ abilities to care for bereaved families are affected by their own attitudes toward EOL. The literature identifies other barriers as well, including: i) lack of familiarity with a family’s cultural customs and language barriers (Engler, et al., 2004), ii) the expectation of “medical miracles” within the ICU culture (Paris, DeLisser, & Savani, 2000);(Carter, Hubble, & Weise, 2006), and finally, iii) lack of consistency of care (Carnevale, et al., 2007) and difficulties with collaboration and interprofessional communication (Epstein, 2008). A recent case study by Martin identified similar barriers to providing palliative care in the NICU with the addition of fear of respiratory depression surrounding opiate use, conflict among members of the care team leading to moral distress, and inadequate training and support for staff (Martin, 2013).

A ‘good death’ has been described as one which is timely, peaceful, and involves rational decision-making (DelVecchio Good, et al., 2004). In the adult literature, factors important to quality of care at EOL differ by professional role and by individual patient (Steinhauser, et al., 2000). For example, when assessing the perception of quality of death and dying in adults, caregivers at the front lines (nurses and residents) have ranked quality of care less favorably than attending physicians and families (Levy, et al., 2005).

In 2005 Walther developed a practice guideline on withholding and WLST, specifically addressing what the needs of the nonviable or dying infant, family, and neonatal staff might be. Walther described a 5-step process of: i) diagnosis and prognosis, ii) decision-making on the basis of futility of treatment or QOL issues and counseling of parents, iii) perinatal audits and v) after-care of the family to complete the process. Addressing issues of language, he also suggested that in the NICU withholding and WLST should be synonymous with palliative care (Walther, 2005). Epstein interviewed 21 nurses and 11 physicians regarding EOL experiences
with a specific set of infants. Professionals described their roles, experiences and ‘obligations’ to the infants and families. Overall they felt families’ needs included creating the best possible experience for parents, building relationships, preparing for EOL, and creating memories (Epstein, 2008). A review of the literature echoes similar themes, identifying the process of EOL care in the newborn to involve several aspects, including: (1) clear and consistent communication delivered with compassion; (2) shared decision-making; (3) physical and emotional support at the time of death; and (4) follow-up medical, psychological and social care (Williams, Munson, Zupancic, & Kirpalani, 2008).

A clear understanding of what parents and HCPs view as important at EOL is key to the success of improving care for dying patients. In one qualitative approach exploring parents’ perceptions of staff competency in an NICU, parents judged competency in professionals, not solely on skills and tasks, but rather on caring behaviours (Cescutti-Butler & Galvin, 2003). In the context of FCC in the NICU, the quality of EOL care includes the extent to which parents’ preferences and values are honored. In pediatric ICU and oncology, interviews with families and surveys have been used to assess parents’ perspectives on EOL symptom management and quality of life, as well as describing the characteristics of decision-making, death, and dying (Meyer, Burns, Griffith, & Truog, 2002; Meert, Thurston, & Sarnaik, 2000; Hechler, et al., 2008). Current parental grief models demonstrate benefit in parents building and preserving relationships with their dying children (Davies R., 2004). In addition, bereaved parents in the Pediatric ICU often highlight the contributions of different disciplines or professions (Macnab, Northway, Ryall, Scott, & Straw, 2003), suggesting different roles in EOL decision-making and care.

Groundbreaking work exploring the parent experience in EOL in the NICU was performed by McHaffie in Scotland over a decade ago. She interviewed 108 parents of 62 babies at 3 months and 13 months into their bereavement. She explored themes around limitations on treatment and treatment withdrawal, decision-making, the dying process, autopsy, time after death, and follow-up care. Parents in her sample valued the following aspects of EOL and bereavement care: full and frank information given sensitively, timely scheduled follow-up with a physician, efforts to find out how they were coping, and providing reassurances where possible (McHaffie, Laing, & Lloyd, 2001). Similar themes have emerged from other qualitative and survey work with bereaved parents (Brinchmann, Forde, & Nortvedt, 2002; Pector, 2004; Wocial, 2000). Recent studies exploring parental involvement in ethical decision-making through ethnographic
observation; open-ended, semi-structured and structured interviews; and case study also reveal similar themes (Payot, Gendron, Lefebvre, & Doucet, 2007; Einarsdóttir, 2009; Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; Orfali & Gordon, 2004).

From a survey of neonatal caregivers from 125 hospitals, Engler et al reported that 82% had an existing bereavement protocol in their unit and most NICUs had packages listing support numbers, community groups, and media information to help families through the grieving process (Engler, et al., 2004). However, the impact of bereavement protocols or interventions in this population has not been extensively studied. One randomized control trial on perinatal bereavement in 1982 randomly allocated families to receive a new counseling support group or routine hospital care. Families were assessed at six and 14 months after the death using a semi-structured interview and two self-reporting scales. There was no significant difference between the two groups at 14 months in regards to psychiatric symptoms; however, support and counseling in the early months shortened the duration of bereavement reaction for the mothers in the supported group (Forrest, Standish, & Baum, 1982). Subsequent descriptive studies also report positive experiences related to caregiver interventions (Koopmans, Wilson, Cacciatore, & Flenady, 2013). Brosig et al interviewed 12 parents and reported aspects of care that assisted with coping, these included: honesty, empowered decision-making, parental care, the environment, faith and trust in nursing care, physicians bearing witness, and support from other hospital care providers (Brosig, Pierucci, Kupst, & Leuthner, 2007).

In palliative care, Currow et al. suggest that the translation of evidence to practice at EOL lags behind due to the heterogeneity of the patient population and the lack of consensus on definitions in service provision, which challenge concepts of validity and generalizability (Currow, Wheeler, Glare, Kaasa, & Abernethy, 2009). In order to address the specific concerns related to the newborn population at EOL, the first phase of this ‘With Care’ project focused on developing and pilot testing a survey tool to assess care and practices based on the experiences of bereaved parents (Williams, et al., 2009).
2.3 Ethical issues at end-of-life in the neonatal intensive care unit

Ten years after the original EURONIC surveys of EOL practice, the authors identified four ethical values underlying clinician attitudes and practices, these were: protecting the sanctity of biological life, respect for parental authority, infant best interest, and the dignity of a human being (Orzalesi & Cuttini, 2011). In a review of the ethical and legal aspects of newborn care, Messner and Gentili described the ethical underpinnings of quality EOL care as questions to guide clinical practice, including: What is the “best interest” for the newborn? What are the limits between a good standard of care and aggressive treatment? When should we stop? What survival percentage counts as sufficiently futile or hopeful? What kind of morbidity counts as sufficiently worthless? Who should have the right to decide? (Messner & Gentili, 2011) These are the ethical questions that continue to challenge clinicians and parents.

In 2007, a special issue of *Theoretical Medicine and Bioethics* included seven articles from authors in the US and Canada who were asked to consider whether there are morally relevant features of newborns that distinguish them from other children, and what implications these might have for clinical decision-making (Ross, 2007). They were invited to write a manuscript on a current issue in neonatal ethics. Selected topics fell into three areas of ethical focus that are prominent in neonatal ethics:

i) parental involvement in decision-making

ii) the best interest standard

iii) care at the end-of-life

The first two areas of ethical focus have to do with ethical decision-making for newborns, including both the agents or decision-makers and the standard at which decisions regarding non-competent children are to be made. The third area of ethical focus involves the clinical and moral spectrum of EOL practices from non-escalation of life-sustaining treatment to euthanasia. Underlying the three areas of ethical focus is the unique moral status of the newborn, who was very recently a fetus, and will not be for many years, a ‘full’ person. Another ethical component not captured by these three areas of ethical focus, are the consequences arising from ethical conflicts in the NICU. These consequences include moral distress in caregivers and both
individual and organizational moral residue affecting health care team function and the quality of EOL care.

Figure 2 illustrates a schematic of the relationships between the underlying special moral status of the newborn, the common areas of ethical focus and conflict in neonatal ethics arising from the literature, and the resulting consequences. These ethical issues challenge good quality EOL decision-making and care and will each be explored in the following sections.

**Figure 2: Ethical issues at end-of-life in the neonatal intensive care unit**

### 2.3.1 Special moral status of the newborn

According to Beauchamp and Childress, an individual is a moral agent if she or he is capable of making moral judgments about the rightness and wrongness of actions and she or he has motives that can be judged morally (Beauchamp & Childress, 2009, p. 74). Critically ill newborns are not (nor ever have been) competent and thus lack moral agency. However, by possessing biological human properties, the potential for cognition and the formation of future relationship, they are accorded a certain degree of moral status (Beauchamp & Childress, 2009, p. 83). Children are entitled to welfare rights, rights of evolving liberties (United Nations, 1989) and the right to an open future (Feinberg, 1980). In addition, newborns have relational worth to families and families in turn are their social conduit for culture, emotional enrichment, sense of identity, and moral character (Hyun, 2002). Parents are accorded the right and responsibility for surrogate decision-making on their behalf (Baines, 2008). In clinical care and decision-making, newborns
are worthy of ethical regard, which includes respect for their intrinsic value and care that is in their best interest and provided with dignity.

2.3.2 Ethical issues

2.3.2.1 Parental involvement in shared decision-making

During EOL decision-making, parents often must reconcile the infant's well-being with their own emotions, ranging from attachment and separation to guilt, anger, and grief. Experiences of grief may differ and parents may struggle with issues of mental health and relationship difficulties (Najman, et al., 1993). In interviews, parents have referred to themselves as ‘emotional experts’ who must live with the outcome of decision-making regarding their extremely-low-birth weight infants in the NICU (Einarsdóttir, 2009). They have special knowledge of the culture and value system in which the child would be raised, thus it is expected that they are in the best position to make QOL judgments for their child in the context they would be living (Sade, 2011). The respect for parental authority in decision-making is based on a relationship of concern, obligation, responsibility, and intimacy (Hester, 2007). However, narrative interviews with bereaved parents in France found that, though parents found it valuable to be involved in shared decision-making, they needed continuous emotional support and explicit sharing of responsibility with HCPs for the decision (Caeymaex, et al., 2011). In the NICU, parents are called upon to make difficult choices and though most wish to be involved in decision-making, not all of them want the responsibility (Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; Wocial, 2000). Physicians' and nurses' perceptions of parental involvement in decision-making are often inaccurate as are their abilities to predict which parents wish to cede decision-making (McHaffie, Laing, Parker, & McMillan, 2001; Zupancic, et al., 2002). The ‘optimal’ degree of parental involvement in decision-making is currently contested in the literature. Some clinicians and ethicists question whether in this emotionally charged situation, where there is often no ‘right answer’, the final responsibility of the decision should rest on the parents or fall on the health care team (Gillam & Sullivan, 2011; Orzalesi & Cuttini, 2011).

Professional guidelines in pediatrics as well of the views of individual practitioners broadly support a shared decision-making approach with active involvement of parents in EOL decisions (Gillam & Sullivan, 2011; Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006). Within this model of shared decision-making, because the values and beliefs of the providers may differ
from those of the family, providers must be careful to ensure it is the family’s beliefs, values, and preferences that guide decision-making (Kon, 2010). Moulton and King suggest that while clinicians, health services researchers, and ethicists have advocated shared decision-making as a model, because of these challenges, few physicians have successfully integrated the process into their practice (Moulton & King, 2010).

In the adult literature, Charles et al have contrasted ‘shared’ versus ‘informed’ decision-making by describing its four necessary characteristics:

1. At a minimum, both the physician and patient are involved in the treatment decision-making process.
2. Both the physician and patient share information with each other.
3. Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
4. A treatment decision is made and both the physician and patient agree on the treatment to implement. (Charles, Gafni, & Whelan, 1999, p. 652)

While studying parental involvement in shared ethical decision-making in the NICU, Rosenthal and Nolan synthesized the results of ten primary qualitative studies. They identified seven key themes in their work (Rosenthal & Nolan, 2013):

i. variability in parent involvement in decision-making
ii. parents’ perception of their role
iii. the necessity of good information
iv. the need for good communication for decision-making
v. satisfaction with decision-making
vi. the desire for both hope and compassion from caregivers
vii. trust in the caregiving team facilitates decision-making

As Rosenthal and Nolan suggest, in the NICU there is a variation in the degree to which parents are and wish to be involved in decision-making. Through interviews, Orfali and Gordon performed a cross-cultural study of bereaved parents’ experiences in NICUs in France and the United States. They found that French parents expressed overall higher satisfaction with the care of their babies and were better able to cope with the loss of their child than American parents. They highlighted that the French parents’ perception of autonomy and their sense of satisfaction
were related to the strong doctor-patient relationship, the emphasis on medical certainty versus uncertainty, and the “sentimental work” provided by the health care team. In the American setting, respect for parent autonomy was described as a limitation to the rapport between doctors and parents and contributed to parental isolation (Orfali & Gordon, 2004). Similarly, Montello and Lantos point out, many patients and families do not want the responsibility of autonomous decision-making at EOL thrust upon them (Montello & Lantos, 2002).

Clark, Potter and McKinlay suggest that decision-making is accomplished through and influenced by patterns of social interaction and communication between clinicians and patients. These involve their respective values, interests, expectations and orientations to health, illness and the particular clinical problem (Clark, Potter, & McKinlay, 1991). In the ideal situation, shared decision-making in perinatal medicine is a multidisciplinary process involving parents, physicians, nurses, and other allied health professionals (Leuthner, 2004; Pector, 2004). There is little literature however about the role of allied health team members in EOL decision-making (Epstein, 2008).

In interviews with parents regarding decision-making at EOL in the NICU, parent highlight the importance of relationships rather than ethical principles (Wocial, 2000). The literature suggests that relationships with parents differ according to professional roles. The parent-nurse relationship in the NICU context is one of closeness and emotional involvement which though integrally important, can become an emotional burden to both parents and nurses (Fegran & Helseth, 2009). From physicians, parents prioritize communication and trust in order to foster confidence (Wocial, 2000). Gillis describes the goals of communication in pediatric decision-making as fostering understanding and demonstrating caring (Gillis, 2008). Ward suggests that when Baby Doe legislation in the US began dictating treatment for seriously ill and/or disabled newborns, parents described frustration with communication practices, i.e. vocalizing the need to control content and flow of information, and the need for trust in care providers (Ward, 2005).

In summary, in the context of neonatal EOL decision-making, these empirical findings suggest that parent-provider relationships are most effective when they are characterized by patient trust in caregivers, shared responsibility for decision-making by parents and HCPs, respect for parental autonomy, and good communication particularly with physicians. How these relationships are realized in practice across health care teams is not well studied. However,
within this context, shared norms are thought to include at the very minimum, considerations of what is in the ‘best interest’ of the newborn.

### 2.3.2.2 Best interest standards

With the evolution of treatment possibilities for imperiled newborns, (i.e. the extremely low birth weight infant, the fetus affected with severe congenital anomalies, or the infant with hypoxic-ischemic brain injury) HCPs and parents may face decisions regarding initiating, limiting, withholding or withdrawing life-sustaining treatment. The Canadian Pediatric Society and the American Academy of Pediatrics (AAP) recommend that within a model of shared decision-making, medical decisions regarding children should be based on balancing the benefits and burdens of possible treatments as perceived and agreed upon by parents and physicians (American Academy of Pediatrics, 1996; Canadian Paediatric Society, 2012). For surrogate decision-making, this standard of ‘best interests’ is based on the estimate of what reasonable persons would consider the highest net benefit among available options (Beauchamp & Childress, 2009, p. 172). However, the determination of best interests is contentious. On the one hand, some authors suggest that there can be no a priori determination of best interest for newborns as benefit and harm can only be assessed relative to the newborn’s unique clinical and social circumstances (Rasmussen & Den Uyl, 2005). On the other hand, other authors have argued that parents and physicians may be poor judges of the subjective experiences of infants and therefore can never determine with certainty whether death is in the infant’s best interest; arguing that some sort of objective standard is needed (Kon, 2007). Empirical uncertainty about what constitutes the newborn’s best interests can therefore lead clinicians seeking moral prudence down two paths, the first intent on promoting life and the other intent on preventing suffering.

Conflicting personal and professional values underlie debates surrounding quality vs. sanctity of life, utility vs. futility of treatment, palliative care vs. ‘aggressive intervention’, and the notion of “too much health care” (Evans & Stoddart, 1990). Issues of justice and cost-effectiveness surface in debates that are sometimes grounded in values and beliefs rather than data. For example, several cost-effectiveness analyses in North American have illustrated that NICU costs are well-targeted to patients who will survive, particularly in contrast to resource allocation in adult ICUs (Buchh, et al., 2007; Caughey & Burchfield, 2014; Meadow, et al., 2012). In these analyses,
NICU care is broadly cost-effective in life years and quality adjusted life years in that, the sickest of infants die early, and those that leave the NICU survive in society for a proportionally long period of time. Debates such as those above have moved from the bedside to the policy level polarizing the notion of the ‘value of the newborn’. On one end of the values spectrum, with the increasing use of artificial reproductive technology, is the concept of the ‘precious pregnancy’, i.e. the 3rd, 4th, even 8th gestation for a woman, that has yet to result in a live-born infant. On the other end of the values spectrum is the perceived devaluation of the newborn, i.e. where newborns are ‘replaceable’, and parents of newborns are allowed a wider discretion for decision-making than surrogate decision-makers for older children, or non-competent adults (Janvier, Bauer, & Lantos, 2007).

The AAP Committee on Bioethics acknowledges that judging what is in a child’s best interests is highly value-laden and thus for reasons explored above, the family’s values should guide decision-making (Kon, 2011). In the perfect steward relationship, the clinician entirely adopts the patient’s point of view, acting as if he or she was the patient and all choices would be made to maximize the patient’s wellbeing (Maynard & Bloor, 2003). This is complicated by several factors in the NICU. Decisions are always made ‘for’ newborns not ‘with’ them. In practice, as vulnerable potential persons, dependent on relationships, the infants’ interests can be difficult to separate from those of parents and other family.

In a review of the literature, Truog and Sayeed suggest that neonatologists are more willing to consider family-centered interests in decision-making than are physicians who care for older children and adults (Truog & Sayeed, 2011). Clinicians often advocate for including the interests of and effects on families in discussions of best interest regarding the infant (Fowlie & McHaffie, 2004). Moreover, the literature often highlights negative effects on families, for example, psychological illness and marital discord (Harrison H., 2008; Raina, et al., 2005). Hester argues for a robust consideration of the interests surrounding newborns, including interests “of” a newborn and the interest “in” a newborn. These include the medical interests of achieving cure, avoiding pain, suffering, and harm; as well as future potential interests (what might be imagined for the child and what the child him or herself might want). Finally, there are communally imposed beliefs about values (of disability, respect, and dignity), separate family interests, and state interests of protection that may factor into decisions (Hester, 2007).
Other authors suggest developing a practical approach to analyzing best interest standards, using a defined threshold for acceptable care. There is ongoing debate however in the literature about where that threshold should be set. Views on acceptable thresholds themselves are morally contentious involving value-laden language regarding what is an acceptable QOL or a ‘life worth living’ (Wilkinson D. J., 2011). Diekema suggests thresholds for interference with parental decision-making should be set at the level of avoiding harm (Diekema, 2011). Kopelman suggests choices should be made at a standard where they are consistent and compatible with the moral and legal duties to all incompetent individuals (Kopelman, 2009). Wilkinson argues for a change in language, to consider a ‘life worth starting’ or a ‘life worth continuing’, identifying ‘restricted lives’ below a certain threshold of net well-being that defines the upper permissibility of treatment withdrawal (Wilkinson D. J., 2011).

To complicate matters, balancing benefits and risks in decision-making depends on certainty of diagnoses, prognoses, and the decision-makers’ understanding of these (Summer, Kavanaugh, & Moro, 2006). Ruger debates the nature of the struggle in the distribution of health care services: what we ‘can’ offer vs. what we ‘should’ offer. She suggests a goal of ‘health capability’, defined as a person’s ability to function (what individuals are able to do and be; their freedom to pursue the lives they have reason to value), rather than the quest for ultimate happiness or equality of opportunity (Ruger, 2004). The challenge in counseling parents is the prediction of which individual infants will survive and with what degree of long term capability (Meadow, et al., 2008). Kipnis describes three types of uncertainty that undercut decision-making in the NICU, these include: the vagueness of the boundary at which an infant’s deficits become so intolerable that death could be ‘reasonably preferred’, the uncertainty about whether aggressive treatment will result in the survival of a reasonably healthy child or one with ‘intolerable deficits’, and the inability to determine an acceptable ratio between these two (Kipnis, 2007). Clinicians (and parents) struggle with both prognostic uncertainty, related to the plasticity of the newborn brain, individual resilience, the influence of environment, and limitations in clinical assessment and prognostic tests; and experiential uncertainty, understanding how much pain or pleasure the child may experience (Wilkinson D. J., 2011). This may result in an overall moral uncertainty around the initiation and/or withdrawal of life-sustaining treatment in the NICU.
2.3.2.3 The moral weight of end-of-life practices

As explored in the previous sections, there is variability in attitudes and practice amongst clinicians regarding management at EOL in the NICU related to values. Though the literature suggests the spectrum of options available to limit life-sustaining treatment are not different at a moral level, in clinical practical, different degrees of moral residue and discomfort are associated with different EOL practices in the NICU. This is particularly apparent in relation to withdrawal of artificial nutrition and hydration (Porta & Frader, 2007). Of particular challenge are issues of intent and responsibility in relation to the final cause of death. Ethics texts devote pages to the debate between ‘killing’ versus ‘letting die’ (Beauchamp & Childress, 2009, pp. 172-185), bioethics journals dedicate special volumes to the controversies regarding the link between abortion and infanticide in relation to the special moral status of the newborn (Savulescu, 2013), and euthanasia protocols for newborns continue to be debated at yearly conferences by neonatal ethicists and clinicians (Willems, van Wijlick, & Verhagen, 2014). All of these add to the complexity of the moral situation.

2.3.3 Moral distress and moral residue in the neonatal intensive care unit

2.3.3.1 Moral distress and moral residue: concepts and origins

Moral distress refers to the psychological disequilibrium associated with ‘knowing’ the morally right course of action, but failing to follow through with that action because of internal or external constraints (Bell & Breslin, 2008). In health care, external constraints often come from hospital administration, policies, colleagues, and the law. Internal constraints include lack of courage, self-doubt, socialization to follow orders, fear of job loss, and the futility of past action (Wilkinson J. M., 1988). Moral residue generally refers to the remnant stress resulting from unresolved moral issues or from the realization there are few moral dilemmas with only one solution (Moral distress and moral residue, 2014). Often moral distress and moral residue are confused with one another or erroneously used interchangeably. Moral residue, though less studied in the literature, is anecdotally far more common in the NICU particularly surrounding ethical issues at EOL. Moral distress, which is better understood in the literature, is described below.
Concepts of moral distress date back to Aristotle, who wrote about the ‘weakness of will’ (internal constraints) preventing morally right action (Aristotle, 2009, p. 1145b). Jameton and Wilkinson advanced the notion of moral distress in the nursing literature, distinguishing between concepts of moral uncertainty (not knowing the right thing to do) and moral distress (knowing, but unable to do it) (Jameton, 1984; Wilkinson J. M., 1988). They published the first studies on the effects of moral distress on nurses and patients. The impact of moral distress has since been measured through qualitative studies and by validated instruments, including the first Moral Distress Scale for nurses (Corley, Elswick, Gorman, & Clor, 2001).

Moral distress experienced by health care providers affects relationships with patients and the quality of patient care (Bell & Breslin, 2008). It leads to feelings of frustration, anger, guilt, resentment and powerlessness (Sundin-Huard & Fahy, 1999). The two most common professional effects are reluctance to care for patients and withdrawal from others (Gutierrez, 2005). Self-worth, personal relationships, and job satisfaction can suffer (Bell & Breslin, 2008). Somatic symptoms such as sleep disturbance, appetite suppression, and social isolation may also result (Kingsley, 1992). Though moral distress is frequently described in the nursing literature, evidence identifying moral distress in other professions including medicine, respiratory therapy, pharmacy and social work is emerging (Bell & Breslin, 2008). At an institutional level, moral distress influences both the cost and effectiveness of palliative care (Bruner, 1998) and results in increased staff turnover (Schluter, Winch, Holzhauser, & Henderson, 2008).

2.3.3.2 Moral distress in end-of-life care

Studies on moral distress in the pediatric intensive care soon followed Jameton’s and Wilkinson’s original work with nurses caring for adult patients. In 1996 Davies et al developed a substantive theory about ethical dilemmas involving nurses’ experiences caring for dying children. Moral distress began in these instances when the death of the child was perceived as inevitable and thus all subsequent aggressive treatment regimens were incongruent (Davies, et al., 1996). Studies in moral distress in the pediatric and adult ICU settings share similar themes regarding distress associated with the provision of aggressive care to patients not expected to benefit (Elpern, Covert, & Klempell, 2005; Maeve, 1998; McClendon & Buckner, 2007). A common untenable situation is the perception of pain and suffering as a result of a medical
decision which the nurse has little influence over (Davies, et al., 1996; Huffman & Rittenmeyer, 2012).

Toward the end of the last decade, there has been an increasing amount of work, predominantly among nurses, identifying issues causing and consequences of, moral distress in the NICU. Using a framework based on Corley’s original work, Cavaliere et al, 2010, defined moral distress in neonatal nursing by linking it to moral concepts. They identified the psychological pain and disturbed personal relationships resulting from patient care situations where the nurse is aware of the moral problem, accepts the moral responsibility, and makes a moral judgment regarding the correct course of action; however because of perceived or actual constraints, participates by act or omission in a manner that is perceived to be morally wrong (Cavaliere, Daly, Dowling, & Montgomery, 2010). Using this definition, they adapted the Moral Distress Scale for the NICU and measured the top 10 items causing moral distress in NICU nurses. Seven out of ten of these items were related to EOL care and all were related to what they perceived to be the infant’s ‘best interest’. Examples included: following the family’s wishes to continue life support, even though it is not in the best interest of the child; participating in the care of a ventilator-dependent infant when no one will decide to stop; and to carry out physician’s orders for unnecessary tests and treatments for a terminally ill infant (Cavaliere, Daly, Dowling, & Montgomery, 2010). A review of the literature by Kain identified similar themes relating moral distress in the NICU to perceived futility and to associations with interprofessional conflicts (Kain, 2007).

In 2008, Catlin et al completed a survey of 66 NICU and PICU nurses proposing conscientious objection as a response to the moral distress expressed by nurses related to following orders in cases of perceived futility. These nurses described feelings of helplessness, powerlessness, anger, frustration, sadness, and the feeling they were torturing the child. They expressed the wish to object to aggressive interventions that don’t change outcomes; moreover, some acted in a way that displayed their objection without ‘formally’ objecting. Finally they identified external barriers to moral action such as physicians’ orders, administrative policies, legal consequences, and the influence or pressure from parents (Catlin, et al., 2008).

Though the majority of moral distress in the NICU has been reported in nurses, Epstein recently interviewed 21 nurses and 11 physicians, and demonstrated that though more frequently encountered among nurses, moral distress was identified in physicians as well. All incidences of
moral distress in that study arose as a result of prolonged aggressive treatment that was perceived to be futile (Epstein, 2008).

Parents’ responses to the death of their newborn are profoundly affected by their interaction with HCPs; therefore, how HCPs deal with moral distress is important (Engler & Lasker, 2000). In addition, moral distress affects the ethical climate and function of an institution. Strategies to improve moral distress in the NICU are emerging, but most have focused on interventions occurring after the fact (Rogers, Babgi, & Gomez, 2008). In a post-implementation survey of 116 HCPs after the introduction of a comprehensive care round hoping to alleviate moral distress, the program best served those who were already comfortable talking about moral issues (Okah, Wolff, Boos, Haney, & Oshodi, 2012).

Despite the work done in identifying moral distress in the NICU, there are still important areas open for study. Kain has argued that moral distress in the area of EOL in the NICU is under-theorized and the discourse regarding moral distress in general lacks conceptual clarity (Kain, 2007). McCarthy and Deady suggest that there is too much attention focused on the psychological distress and not enough on the moral character and professional identity of the clinician (McCarthy & Deady, 2008). In addition, moral distress in the context of professionals working on interprofessional teams has not been explored. In this way, there is a need for an interprofessional understanding of the experiences of HCPs who make difficult moral judgments and decisions in complex situations and how professionals interact to deal with the moral residue. This project aims to design an ethical framework based on the experiences of parents and members of interprofessional teams, in order to facilitate effective and compassionate EOL care and decision-making, and to reduce clinician moral distress and moral residue.

2.4 The need for an ethical framework for end-of-life care in the neonatal intensive care unit

This dissertation aims to explore interprofessional ethical competencies and develop an ethical framework for EOL care in the NICU. Such a framework would:

i) facilitate shared decision-making between parents and the health care team,

ii) contribute to enhancing interprofessional team function at EOL, and
iii) reduce moral distress and moral residue surrounding EOL decision-making in the NICU.

The application of existing ethical theories to difficult cases involving newborns by clinicians working on interprofessional teams, poses contextual challenges. Contextual considerations include: providing effective and compassionate decision-making support, dealing with uncertainty of prognoses, predicting quality of life, negotiating conflicting views of best interests, balancing risks and benefits, and ensuring effective team communication, consistency and consensus (Williams, Munson, Zupancic, & Kirpalani, 2008). As illustrated above, when caregivers are prevented from translating moral choices into actions, resentment, guilt, frustration, and a sense of powerlessness may result (Kain, 2007).

The traditional approach of moral principles, the oversimplification of issues, and the neglect of emotional and personal factors, leaves clinicians ill-equipped to deal with families facing tragic ethical dilemmas (Arras, Steinbock, & London, 1999; Campbell, 2003). The challenge of attempting to create precise guidelines based on ‘imprecise data’ (Dupont-Thibodeau, Barrington, Farlow, & Janvier, 2014) with little consensus on which neonatal outcomes should be considered beneficial and which potentially detrimental challenges concepts of beneficence and non-maleficence. For some, the nature of non-maleficence has QOL implications that cause moral conflict (Wilkinson D. J., 2011). Furthermore, balancing the right amount of parental autonomy versus isolation requires ‘emotional work’ (Orfali & Gordon, 2004) involving a more nuanced approach grounded in caring relationships and shared accountability. Sade suggests decision-making for newborns cannot just be about thresholds because these change but rather about the process, the context, the agents, and the reasons (Sade, 2011). Similarly, if within this context, the newborn has a special moral status, then these implicit valuations need careful situational analysis and justification (Janvier, Bauer, & Lantos, 2007). The ethics of responsibility in these situations is complex, (Paris, Graham, Schreiber, & Goodwin, 2006) and begs for a different moral approach.

Given the variation in ethical practice observed in the literature, explicit consensus on issues of decision-making appears unrealistic particularly in the context of uncertainty and relative values. Following the EURONIC experience, those authors suggested that rather than guidelines, interprofessional frameworks should aim at achieving ethically correct methodologies for addressing these issues in clinical practice (Orzalesi & Cuttini, 2011). In the absence of a shared
moral approach, clinicians on NICU teams will otherwise defer to their own professional codes of ethics and personal values when facing moral dilemmas.

Accreditation Canada defines an ethical framework as an analytical tool designed to help staff identify and respond to ethical issues appropriately and guide decision-making (Accreditation Canada, 2009). Different from a code of ethics, frameworks are tools that enable staff to work through dilemmas and develop ethical competencies. In practice, there are examples of ethical frameworks in bioethics education and pandemic planning (Robichaux, 2012; Thompson, Faith, Gibson, & Upshur, 2006; Manson, 2012). In their review on the ethical and legal aspects of NICU care, Messner and Gentili suggest that an ethical framework for this practice should consider the duties and obligations incumbent on all those involved in the care of the newborn (Messner & Gentili, 2011).

Epstein explored through interviews, the moral obligations of nurses and physicians providing EOL care to newborns (Gingell Epstein, 2010). Learners were under-represented in her sample, and her work did not include the perspectives of parents and other allied health members of the team, however she highlighted that roles in decision-making were complex and needed further study. Importantly, she found a gap in interprofessional communication and collaboration related to a lack of understanding across nurses and physicians regarding the meaning of EOL care for each profession. She suggested that this gap exists because professionals on teams lack common moral language. This dissertation addresses this concern by grounding this ethical framework for EOL care in the NICU in a common language of interprofessional virtues.
Chapter 3
Virtue Theory

This chapter introduces the virtue theory at the foundation of this dissertation. First, the works of theorists informing the understanding and application of modern virtues are summarized. Second, the need for a framework based in context and in virtue is explored in relation to quality EOL care and decision-making in the NICU. Next, the challenges and common criticisms related to the practical application of virtues as an ethical theory are discussed. Finally, the application of virtue theory in the context of this project is outlined.

3.1 Virtue theory informing this dissertation

Aristotle’s works highlight three components of Virtue Ethics: virtues, phronesis (practical reasoning) and eudaimon (the quest for happiness). He defines virtues as habitual traits, acquired over a lifetime, which could not be captured in rules or universal principles (Aristotle, 2009, p. 1103a.15). Virtues such as courage are situated on a mean between extremes. In this way, moral agents have feelings and responses that are appropriate and proportional, avoiding excess and defect (Aristotle, 2009, p. 1106b.15). Moral agents employ practical wisdom in order to determine where their state of character (virtue) should lie along the mean. A virtuous act is also determined by practical wisdom; through the practice of intellectual virtues of thinking and reasoning. For Aristotle, right action and human good are related to happiness. This refers not to a state of mind but rather to human flourishing or the good life achieved through the practice of virtues (Aristotle, 2009, p. 1177a.5).

Modern virtues continue to be defined as traits of character manifested in habitual action. Over time, though, most modern virtue theorists have abandoned the doctrine of the mean and the concept of the quest for the good life has moved from the individual to the social context i.e. within the context of shared community values (Hursthouse, 2006; MacIntyre, 2007). In addition, there is a new emphasis by virtue theorists such as MacIntyre on the rightness of an act itself, resulting from the habitual practice of virtues and practical reasoning, separate from Aristotle’s concept of the quest for happiness. (MacIntyre, 2007).
In healthcare, Pellegrino sought to restore virtues particularly related to professional ethics (Pellegrino E., 1995). Professional codes of medical ethics emphasize the moral agency of the physician and the cultivation of certain virtues. Pellegrino and Thomasma define virtues in medicine as related to the physician-patient relationship underlying professional ethics. These include: fidelity to trust and promise, benevolence, effacement of self-interest, intellectual honesty, justice, prudence, compassion, and caring (Pellegrino & Thomasma, 1993). In their text, they recommend the resuscitation of virtues in order to: restore moral force; balance altruism, beneficence and self-interest; and focus on moral character rather than on the resolution of dilemmas. In this way, virtues may supplement principles by taking into account moral agency. Pellegrino highlights professional ethics as the domain of duties, obligations and virtues entailed in the clinician’s role as healer (Pellegrino E., 1995). The moral agency of the physician is exemplified not simply in possessing personal or professional virtues but in developing the capacity to know when and how to exhibit them (Gardiner, 2003; Larkin, et al., 2009; Tsai, 2005). In this way, practical wisdom continues to play an important role. Pellegrino suggests that ethical frameworks in healthcare should be based on moral reasoning because these link the character, motivations, and experiences of HCPs to the determinants of moral actions (Pellegrino E., 1995).

Negotiating decision-making around EOL in the NICU involves establishing a relationship for moral deliberation with the aim of minimizing moral residue. By applying Pellegrino’s theories regarding moral reasoning to the NICU context, components of ethical decision-making would include:

   i) the moral agents themselves (here, parents and the interprofessional team),
   ii) the ‘act’/decision (ex. decisions regarding EOL options and practices),
   iii) the consequences (ex. avoiding moral distress and moral residue), and
   iv) the context of the decision (Pellegrino & Thomasma, 1993).

Pellegrino and Thomasma’s list of professional virtues are meant to increase moral sensitivity and responsibility and define aspects of the therapeutic relationship. However, they do not clearly illustrate how agents might approach specific moral dilemmas i.e. the content ethics (ex. conflict in decision-making regarding WLST or the administration of blood products in the case of a practicing Jehovah’s Witness). Gardiner illustrates how this can be done by clinicians
reflecting on the virtues that might be helpful in resolving particular moral dilemmas. He highlights the contextual and flexible nature of a virtue-based approach (Gardiner, 2003).

In his text, Marcum supports an expansive and comprehensive definition of virtues, based on the works of McKinnon, Swanton and other modern virtue theorists (Marcum, 2012). Like Pellegrino and Thomasma, he highlights the erosion of morality in medicine and proposes a framework based in virtue as a solution not only to the professionalism crises but also to the crisis in quality of care. In earlier work, he spoke to the importance of the ‘epistemically virtuous clinician’ (Marcum, 2009), highlighting the significance of the intellectual virtues. Later, with a more comprehensive analysis of the virtues important in medicine, he explains while describing a Virtuous Physician, “to think, requires intellectual virtues; to feel, theological or transcendental virtues; and to act, moral or ethical virtues” (Marcum, 2012, p. 40). Through case study, he describes the intellectual (prudence), ethical/moral (courage, temperance, justice) and transcendental (faith, hope, and love) virtues and their application in clinical medicine. In addition, he identifies caring as the chief virtue, and uncaring as the main vice.

Slote describes a Virtue Ethics of Caring, which grounds reasoning in the phenomenon of empathy. Building on the works of Hume more than Aristotle, he argues that empathy forms the basis not only for moral action but also for understanding what we are doing when making judgments (Slote, 2010). A framework grounded in virtue, in addition to focusing on moral sensitivity, perception, and responsibility (Sherwin, 2001), offers a contextual blend of reason and emotion (Campbell, 2003). In medicine, Halpern highlights the role of clinical empathy in facilitating trust in the physician-patient relationship, making the experience of caring for the patient [family] more meaningful (Halpern, 2003). In Benner’s dialogue between Virtue Ethics and Care Ethics, like Pellegrino, she supports the restoration of virtue ethics, but not only for medicine, for nursing as well. She emphasizes that both are lodged in social practices and communities and moreover, she recommends the combining of care and virtue ethics for clinical and moral reasoning. Her dialogue highlights health care as a caring practice carried out by practitioners of trustworthy character (Benner, 1997). Ethical behavior in this context arises from a combination of moral sensitivity (the ability to recognize a moral problem), moral motivation (prioritizing moral values over other values or desires), and moral character (ex. displaying courage) (Duckett, et al., 1992; Rest, 1994). Informing this theory of virtues is also the ethics of
caring’s assumption that connections to others (relationships) are central to what it means to be human (Noddings, 1984).

3.2 The need for a framework grounded in context and in virtue

The purpose of this virtue-based framework, informed by the EOL experiences of parents and professionals in the NICU, is to provide tools for individual HCPs and teams to navigate ethical dilemmas. It, in and of itself, is not meant to resolve dilemmas by providing ‘the answer’.

There exists a need for an interprofessional model for ethical decision-making where the views of all team members are considered (Monterosso, et al., 2005). Moreover, clinicians and ethicists suggest that ethical empirical studies should reflect a more nuanced approach to withholding or withdrawing NICU interventions, to provide a more accurate reflection of the circumstances of death and dying in the NICU (Singh, Lantos, & Meadow, 2004). It is not just about the decision itself, but rather the shared process of decision-making. As discussed, the traditional approach of moral principles or the evaluation and summation of consequences are not sufficient to explore the thick ethical context surrounding these discussions. Principles emphasize parents’ duty to separate their interest in being a parent (love and commitment to that relationship) from the objective interests of their child (Baines, 2008). Virtue theory argues the opposite, embracing the role of emotions in recognizing the morally pertinent aspects of the situation, sensitizing parents to circumstances, illuminating perceptions, and informing choices (MacIntyre, 2007).

Another important and unique component of virtue theory is that of moral reflection. Pediatric professional bodies indicate the importance of the ‘reflective practitioner’ i.e. to be aware of her or his own personal values (Canadian Pediatric Society, 2004). Professional values and personal identity may be in conflict in decision-making around issues of meaning and quality of life and death. Unlike deontological, consequentialist or principle based frameworks, virtue theory encourages moral agents to acknowledge and express the pain and regret they may experience when negotiating tragic dilemmas (Gardiner, 2003). Finally, frameworks and programs that incorporate reflective practice and mindfulness strategies are emerging in the adult palliative care literature as methods that may facilitate the compassionate care of dying patients, families and professional caregivers (Rushton, et al., 2009).
This virtues-based framework brings virtues to the forefront. As habitual traits of character, they are instrumentally important to the ‘good’ or ‘virtuous’ clinician, but are also in and of themselves important as an outcome ex. achieving a shared common language of ‘hope’ on the interprofessional team. In this way, virtues may engage team members in values clarification and promote better interaction. In this framework, virtues are associated with HCPs as individual agents but are also essential traits that assist teams to navigate ethical dilemmas.

In addition to a definition of virtues, this framework emphasizes ‘reason’ in their application. Putnam highlights the problems inherent in the facts/values dichotomy which view ‘facts’ as completely objective and ‘value judgments’ as completely subjective (Putnam, 2002). In today’s language of ‘best evidence’, objectively and fully informing parents would make them aware of the statistical risks associated with possible outcomes with little understanding of their meaning (Cole F. S., 2000). In this way, when facts are treated as value-neutral, clinicians practice a form of moral distancing or moral disengagement, such that their own moral agency becomes uncertain. A virtue-based model of shared decision-making is a deliberative one, as described by Emanuel and Emanuel (Emanuel & Emanuel, 1992). The physician acts as a friend and guide toward recommended interventions that incorporate the values of parents. It is through exercising this moral agency, with active regard for others’ welfare (compassion) use of astute judgment and sensitive insight (discernment), integration of their own moral character (integrity) and the motivation to do what is right because it is right (conscientiousness) (Beauchamp & Childress, 2009, pp. 38-45); that communication and trust are fostered, and parents’ values are respected. In this way virtue theory focuses on the moral behaviours, attitudes, and motivations of clinicians, which is aligned with goals of professionalism and interprofessionalism in health care.

3.3 Criticisms of virtue theory as an ethical framework

Attempts to operationalize virtues within ethical frameworks have been met with criticism from health care practitioners seeking answers to moral dilemmas. Following Aristotle’s reasoning a moral agent seeks to answer: what kind of person should I be? What is the best life for a person to lead? In this way, an act is right, because virtuous individuals leading a ‘good life’ would choose it. (Arras, Steinbock, & London, 1999) For some, this circular logic fails to provide structured answers to moral dilemmas (Arras, Steinbock, & London, 1999).
Hursthouse outlines six objections to virtue ethics as a normative theory. These are: i) the application problem, ii) the justification problem, iii) the ‘situationalist’ challenge that questions the existence of habitual character traits (virtues), iv) the conflict problem, v) the charge of cultural relativity, and vi) that of being self-effacing (Hursthouse, Virtue Ethics, 2012).

### 3.3.1 Objections related to the definition, application, and justification of virtues

The first four objections are related to claims that virtue ethics first, lacks ethical principles, and second, lacks sufficient grounding of definitions, i.e. identification of which character traits constitute important virtues. Central is the argument that the definition, nature, and priority of virtues lack the precision required to put them into practice (Donovan & Pellegrino, 2009). Without a set of universal rules or principles, how is a moral agent to select the right action (application and justification problems)? What is a moral agent to do when facing dilemmas in which the requirements of different virtues are in conflict (application, justification, and conflict problems)? Critics interpret the virtuous agent’s question “what sort of person should I be?” as agent-centred rather than act-centred i.e. “what should I do?” and thus conclude virtue ethics is unable to provide action-guidance (application, justification, and conflict problems; situationalist challenge) (Hursthouse, 2012).

However, the critics’ perceptions that the practice of virtues lacks ethical principles, that deliberation leads to variation in decisions where definitive action is too open-ended, and that virtue theorists are not able to define the ‘right action’ is not in fact true. Firstly, in modern practice, virtues are linked to corresponding duties and obligations. Beauchamp and Childress, for example, argue that the principle of respect for autonomy can be linked coherently to the virtue of respectfulness (courteous regard for other people’s feelings) and the principle of beneficence to the virtue of benevolence (a disposition to do good or show kindness) (Beauchamp & Childress, 2009, p. 45). Secondly, Hursthouse suggests, guidance can be found in the application of “v-rules”, employing the virtue and vice terms, such as “do what is honest; do not do what is dishonest” (Hursthouse, 1999). Finally, moral justification can be provided both by inductive reasoning based on emotions, relationships, and context; and deduction, by asking, what would a virtuous person do? Moreover, in regards to criticism that this form of justification remains abstract and not specific enough for clinicians, Beauchamp and Childress suggest that
ethical theories or frameworks are more plausible if they are applied only to some limited range of morality rather than to all of it (Beauchamp & Childress, 2009). To address this within this project, the practical application of virtues will be situated within a contextual framework aiming to achieve quality EOL care and decision-making in the NICU based on the experiences of bereaved parents and HCPs.

3.3.2 Objections related to cultural relativity, egoism, and the moral ideal

Cultural relativity is a challenge not only to virtue based theories, but also to ethical theories based in principles, rules, or consequences. Cultural variations in the understanding of character traits which are regarded as virtues exist, as do cultural variations in rules of conduct and in what constitutes happiness or welfare. For virtue theorists, this raises the question that, if different cultures exemplify different virtues, will the v-rules choose actions as right or wrong relative only to particular cultures (MacIntyre, 1985)? Virtue theorists respond that cultural variation is in fact less of a problem in virtue based theories than in others. They explain that though the local language and understanding of individual virtues may differ across cultures, the concept of contrasting virtues and vices as a basis for right or wrong moral action can be universal (Nussbaum, 1993). Carnevale further contends that theoretical frameworks grounded in virtue have an advantage in dealing with personal and cultural diversity because contextual understanding plays an important role in virtue-based frameworks (Carnevale, 2005).

Although virtue based theories are agent-centred, in that there is a strong focus on the moral character and moral agency of the individual, agent-centeredness ought not to be confused with egocentrism. Given that humans live in social contexts, modern virtue theories identify virtues not as self-regarding but rather of benefit to both possessors and others. For some, the concept of the ‘virtuous agent’ brings to mind a saintly individual on the quest for moral excellence or the achievement of the moral ideal. A common misconception regarding the application of virtue as a moral theory in clinical practice is the notion that in order to achieve excellence of moral character, a moral agent must achieve this moral ideal. Moral ideals do not in fact have associated obligations (Beauchamp & Childress, 2009). Aristotle infers that what is important is the quest for excellence rather than its achievement (Hursthouse, 2012). Agents who misunderstand this concept may live in fear of making ethical errors. Moreover, patterns of
failure to discharge these ill-perceived moral obligations of perfection could be interpreted as defects in moral character (Beauchamp & Childress, 2009, p. 34). The virtuous agent is, as described by Hursthouse, just “the agent with the virtues” (Hursthouse, 2012). In this application of virtue theory, virtues are the essential features of a HCP or a health care team who has the character to tackle ethical dilemmas.

3.4 Application of virtue theory

The virtue theory at the foundation of this dissertation involves two aspects: first, the instrumental use of virtues as lenses for analysis and second, the intrinsic goal of virtue, as an outcome, in the development of a framework for approaching EOL decision-making and the provision of good quality EOL care. The inspiration for the application of virtue as a theory evolved during the analysis of the first phase of inquiry of the With Care project, interviews with bereaved parents. Throughout their accounts they highlighted in conjunction with aspects of good (and poor) quality EOL care the corresponding virtues and vices observed in HCPs.

It is the intent of this study to establish an understanding of roles, attitudes, and experiences across professional team members in the NICU, such that a shared concept of interprofessional virtue-based team ethics will emerge. In the specific context of EOL decision-making and care, this dissertation intends to develop a framework that approaches both the issues related to professional ethics (communication, interprofessional team function, trust and the HCP-family relationship, consequences of moral distress and moral residue) as well as issues of content ethics (negotiation of the best interests of the infant, EOL practices, and issues related to shared decision-making).

Virtue theory in the context of this dissertation is informed by the normative aspects of Pellegrino’s work. It is expected that this framework will utilize a broad and composite definition of virtues. Supplementing Pellegrino’s concept of professional virtues, this theory includes the classification of virtues in healthcare advanced by Marcum, the additional primacy of empathy as illustrated by Slote, and the grounding of virtue in relationships from an ethics of caring approach described by Benner (described above).
3.4.1 Constructing a framework based in virtue

Pellegrino suggests that a normative framework grounded in virtue theory should include three components (Pellegrino E., 1995):

i. a definition of the theory of medicine, i.e. the telos or the ‘good’ of medicine and healing as a practice;

ii. a definition of what constitutes a virtue coherent with this theory of medicine; and

iii. an enumerated set of virtues connected to the theory which characterize the “good” health professional

These three components are the starting point for the development of a conceptual moral framework for the approach to EOL decision-making and care in the NICU.

3.4.1.1 A definition of the good of medicine

Pellegrino suggests the telos of medicine is situated within the healing relationship itself, and the primary end is the good of the patient (Pellegrino E., 1995). Pellegrino’s theory is grounded within the therapeutic practitioner-patient relationship and is specific to each clinical encounter, and to each patient. He outlines three phenomena grounding this relationship. These include i) the fact of illness (when patients acknowledge that they are sufficiently concerned over a symptom to believe they need help), ii) the act of profession (the implicit promise that the HCP possesses the knowledge needed to help and intends to use it in the interests of the patient), and iii) the act of healing (directing the knowledge, techniques, and personal commitment of the HCP to help the patient to a “technically correct and morally good decision and action”) (Pellegrino E., 1995, p. 267). These concepts can be adapted to the NICU recognizing that the good of the patient lays within the context the family. In this project, the first objective of study explores the attitudes and experiences of HCPs caring for families and negotiating moral events at EOL thus exploring the act of the profession and the act of healing. The second objective of the study compares the experiences of parents and professionals, further contextualizing the fact of illness and the act of healing.
3.4.1.2 A definition of virtue

The second objective of the study compares the experiences of parents and professionals using virtues as lenses for analysis. In the second component of Pellegrino’s normative theory of virtues, he defines a virtue as:

A trait of character that disposes its possessor habitually to excellence of intent and performance with respect to the telos specific to a human activity. Virtue gives to reason the power to discern and to will the motivation asymptotically to accomplish a moral end with perfection. For any profession, there will be a specific activity that, if executed well, makes the professional good or virtuous. Healing is the activity specific to nursing and medicine. (Pellegrino E., 1995, p. 268)

In this study, a virtue is an essential trait of an individual HCP’s character or an essential trait attributed to an interprofessional team that enables them to navigate ethical dilemmas at EOL. When practiced habitually, a virtue predisposes the HCP and/or the interprofessional team to excellence of intent and performance with respect to the provision of good quality EOL care.

3.4.1.3 Enumerating a set of virtues characterizing good quality end-of-life care

In the development of his theory, Pellegrino expresses that lists of virtues are “notoriously difficult to compose” (Pellegrino E., 1995, p. 268). The list of virtues is meant to define the ‘good’ HCP (or this case, also, the ‘good’ interprofessional team). Though Pellegrino states that virtues themselves are essential for achieving the good of medicine, lists of virtues are not all-inclusive, nor are they organized in any particular order of preference. Lists can be reduced or supplemented, the number and nature being less important than the agreed notion of the good and the shared concept amongst HCPs of a common language of virtues to sustain that notion. The virtue lenses used in this study to enumerate the virtues important to an interprofessional approach to EOL care in the NICU will be described in the next chapter. These involved the traditional intellectual, ethical, and transcendental virtues discussed above, in addition to relational virtues (of attunement, openness, and responsiveness) representing the primacy of the clinician-patient/parent relationship. Finally, drawing together Pellegrino’s three posits, linking the good of medicine (good quality EOL care in the NICU) with the definition and enumeration of traits essential to individuals and teams in achieving this end, a stepwise framework for approaching dilemmas at EOL can be created.
Chapter 4
Research design and methods

This chapter describes the dissertation research design and methods. First, the underlying research questions and objectives of the study are reviewed. Next, the study design and setting are described. Third, follows a justification of the mixed research paradigm which addresses both the descriptive and normative aspects of this empirical ethics work. Finally, a detailed description of the study methods as they pertain to the study objectives is provided including a final section discussing ethical considerations.

4.1 Study goal and objectives

The overall purpose of the ‘With Care’ project was to study EOL practices and shared decision-making in the NICU in order to improve care for families and support practitioners. The overall goal of this dissertation is to develop evidence-informed, ethically sound guidance for NICU practice around decisions and care at EOL involving parents and the interprofessional team. The specific research questions addressed by this study were:

- What are the attitudes and experiences of HCPs concerning good quality EOL care in the NICU, including how these are similar or different across health professions?
- How are the attitudes and experiences of parents and professionals regarding good quality EOL care and its challenges similar or different?
- How might virtue theory provide an appropriate ethical foundation to improve understanding of and practice in good quality EOL care within the interprofessional team and with parents?

To address these questions, the objectives of this dissertation were:

1. To describe professional perspectives on EOL care and decision-making in the NICU
2. To compare and contrast these perspectives with the identified needs and perspectives of parents whose infants died following WLST (from Phase 1) using a virtue theory lens
3. To construct an ethical framework based on i) and ii), grounded in virtue theory, to aid health care professionals in the approach to EOL care and decision-making in the NICU
4.2 Description of the research paradigm

Empirical ethics aims to be both descriptive and normative, with an overall objective of improving the context-sensitivity of ethics (Musschenga, 2005). In the case of this dissertation, empirical research and philosophical bioethics were integrated in a way that utilized empirically gathered experiences as a foundation for ethical reasoning while satisfying the demands of theory, in this case virtue theory (Ives & Draper, 2009). Obtaining the answers to the research questions above involved two styles of inquiry including qualitative and normative description and interpretative explanation (discovering relationships, associations, and patterns) (Crabtree & Miller, 1999).

The descriptive phase of the study, exploring the attitudes and experiences of HCPs, employed a constructivist paradigm as described by Patton which holds that the world of human perception is not real in an absolute sense but is made up and shaped by social constructs. Empirical work based in constructivism focuses on the meaning-making activity of the individual mind and the unique experiences of participants (Patton, 2002, pp. 96-103). Foundational questions underlying this paradigm explore how participants have constructed reality, their reported perceptions, “truths”, explanations, and beliefs; as well the consequences of their constructions for their behaviours and for those with whom they interact (Patton, 2002, p. 96). Patton describes relevance and validity related to this form of inquiry as substantive significance, i.e. solid, coherent, and consistent evidence which increases and deepens the understanding of phenomena; which is consistent with other knowledge: either confirmatory or innovative; and is useful for an intended purpose (Patton, 2002, p. 467). The constructivist evaluator attempts therefore to capture different perspectives through open-ended interviews and examines implications from multiple perceptions, with no single or more frequently held view being ‘more right’ or ‘more true’. In this application, the ‘truth’ or ‘facts’ related to the experiences of HCPs providing EOL care and taking part in shared decision-making is understood within their described context and within their described value framework.

Next was adopted, for the comparison of HCP and parent experiences through the analysis lens of virtues, the transcendental realism approach of Miles and Huberman which holds that “social phenomenon exist not only in the mind but in the real world” and aims to “register and transcend” the constructivist meaning-making processes by “building theories to account for a
real world that is both bounded and perceptually laden, and to test these theories in various disciplines” (Miles & Huberman, 1994, p. 4). This approach involves a different form of meaning making, including both the social and historical construction of knowledge by stakeholders in partnership with investigators using inductive methods; and deductive attempts to provide explanation, causation, and hypothesis testing to phenomenon under study (Miles & Huberman, 1994).

Combining these two paradigms which are situated along the epistemological spectrum is commensurate with an empirical ethics approach. The empirical ethics approach seeks to provide both descriptive understanding of phenomena under study as well as evidence-informed guidance for clinical practice. There is however debate in the literature regarding the congruence of mixed paradigms. Purists feel that both the logic and internal consistency of each approach are contrary to methodological mixing. A moderate view holds that the paradigms cannot be merged for cross-analysis or triangulation due to epistemological differences, but they may provide complimentary information about phenomena (Sale, Lohfeld, & Brazil, 2002). A third view highlights the strengths of mixed methods, that is, enhancing meaning with precision; supplementing description with theory development and testing; and the ability to overcome individual paradigm weaknesses (Johnson & Onwuegbuzie, 2004). For the reasons described above, it is this third view that informs this research.

4.3 Study design and setting

To answer the research questions, how parents and professionals in this setting construct reality must be understood through their reported perceptions, explanations, and beliefs. This includes the perceived consequences of their constructions for their own actions and for those with whom they interact. With the goal of improving EOL care based on the values and experiences of parents and HCPs, a qualitative methodology was therefore adopted. Qualitative methods encourage inquiry into issues at great depth, attention to detail, context, and nuance (Patton, 2002, p. 227).

In addition to the principal investigator (C. Williams), an interprofessional research team (1 senior physician, 1 neonatal nurse, 3 social workers, 1 anthropologist, and 2 parent advocates)
informed and oversaw the design, data collection, and analysis of Phase 1. Phase 2 was led by the principal investigator (C. Williams) and a PhD dissertation committee comprised of two physician researchers and one bioethics researcher. However, as was done in Phase 1 of the study involving interviews with parents, members of the original interprofessional team were involved in triangulation of the thematic analysis of the HCP interviews.

The setting for this study was the NICU at McMaster University Medical Centre in 2005. At the time, McMaster was a tertiary care, perinatal centre with 47 level III beds supporting 1500 births per year. As a referral centre, they serviced 22 regional hospitals with a catchment of 25,000 births per year. The infant population in the NICU consisted mainly of infants with diagnoses of prematurity, surgical anomalies, brain injury, and other critically ill neonates. Babies were looked after by an interprofessional team of nurses, nurse practitioners, medical housestaff (residents and fellows), and a staff neonatologist; who were supported by respiratory therapists, pharmacists, social workers and a dietician. The unit was also supported by a regional neonatal transport team and a follow-up clinic. There was no bereavement coordinator or palliative care program and they had two ethicists supporting the hospital at the time of the study.

4.4 Study methods

The methods will be outlined according to the three objectives related to this phase of inquiry.

Objective 1: Describing HCP perspectives on EOL in the NICU;
Objective 2: Comparing parent and HCP perspectives using virtue theory analysis; and
Objective 3: Developing a conceptual framework for EOL care.

4.4.1 Objective 1: Describing health professional perspectives on end-of-life in the neonatal intensive care unit

4.4.1.1 Study Sample

Stratified purposeful sampling (by profession) was employed for the professional interviews in order to capture variations in attitudes and experiences (Patton, 2002, p. 240). In addition, snowball or chain sampling, was used, asking participants to suggest colleagues who may act as information-rich key informants (Patton, 2002, p. 237). At the time of enrollment, the NICU had
on staff approximately 200 nurses, 7 staff neonatologists, 8 neonatal fellows, 20 pediatric residents (in rotation), 20 clinical nurse specialists (full and part time), 4 social workers, 3 chaplains, 1 dietician and hospital respiratory therapists in rotation through adult, pediatric and newborn services. Eligible HCPs were invited through electronic invitations, information rounds, and postings in the NICU. Eligible HCPs were those who had been working in the NICU for at least 2 months. Those with more experience in EOL decision-making and care were encouraged to participate. Following enrollment, the sample included 43 HCPs: 18 bedside nurses, 12 physicians (5 staff neonatologists, 5 pediatric resident trainees, and 2 neonatal fellows), 5 transport nurses (who have experience working at the bedside), 3 social workers, 2 clinical nurse specialists (nurse practitioners, with prior experience as bedside nurses), 2 chaplains and 1 dietician. Though all staff training or working in the NICU were invited, no respiratory therapists participated in interviews. Table 1 describes the demographic characteristics of the HCP sample. HCPs that took part in interviews were members of the various professional groups providing care to families in the NICU. Within the NICU, there was a wide range in years of experience and ages of HCPs. Almost half had worked in another NICU prior to McMaster, more than half were married and had children, and a majority of HCPs identified with a specific organized religion.

Table 1: Demographic characteristics of health care professionals taking part in interviews

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age, in years (range)</td>
<td>44.5 (23 – 61)</td>
</tr>
<tr>
<td>Median years in current unit (range)</td>
<td>13 (0 – 31)</td>
</tr>
<tr>
<td>Median years in any neonatal unit (range)</td>
<td>16 (0 – 33)</td>
</tr>
<tr>
<td>Worked in another neonatal unit, No. (%)</td>
<td>20 (47%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>No. (%) single</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>No. (%) married or common-law</td>
<td>26 (60%)</td>
</tr>
<tr>
<td>No. (%) divorced</td>
<td>6 (14%)</td>
</tr>
<tr>
<td>No. (%) widowed</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Have children, No. (%)</td>
<td>25 (58%)</td>
</tr>
<tr>
<td>Identify with religious affiliation, No. (%)</td>
<td>33 (77%)</td>
</tr>
</tbody>
</table>
4.4.1.2 Data collection

In-depth interviews in the ‘depth interviewing’ style of Crabtree and Miller were undertaken (Crabtree & Miller, 1999). The depth interview “concentrates on the figure at the expense of the ground” and uses “open, direct, verbal questions that elicit stories and case-oriented narratives” (Crabtree & Miller, 1999, p. 93). This approach to in-depth interviews is well suited when the focus of inquiry is narrow (such as EOL decision-making and care in newborns), when respondents represent a clearly defined unit within a known context (professionals in the NICU); when they are familiar and comfortable with interview as a means of communication (as in health care), and when the goal is to generate themes and narratives (Crabtree & Miller, 1999). Such interviews form the data collection method of choice for personal inquiry, gathering intimate details, emphasizing depth, detail, vividness, and nuance (Rubin & Rubin, 1995, p. 76).

Interviews were semi-structured using open-ended questions within an interview guide (illustrated below). While enrolling for interviews, certain HCPs expressed a preference to be interviewed in pairs or as a group, these requests were accommodated. In total there were 33 individual interviews, one group interview involving two transport nurses, one group interview involving five pediatric residents and one group interview involving three social workers. Interviews occurred at a single point in time and lasted from 30 minutes to 2 hours. Interviews with health care professionals occurred in a concurrent time period, but separately, from parent interviews.

Sample size was determined by the purpose of the inquiry, i.e. exploring, documenting diversity, and understanding variation in the health professionals. The intended sample size was to include a depth and breadth of experiences from all invited professions, and aim for saturation of ideas/redundancy of themes within professions (Patton, 2002, p. 244). Due to the limitation and variation in numbers participating from each profession, from 1 (dietician) to 18 (bedside nurses), saturation of themes and ideas across or within professions was not achieved. Interviews continued until no further participants volunteered to take part.

4.4.1.3 The interview guide

A semi-structured interview design with interview guide was selected in order to focus the interviewer on a subject area but allow the freedom to explore, probe, and ask questions to
elucidate and illuminate the subject. The advantages of this format include a more systematic, comprehensive, and efficient use of time, while still allowing the opportunity for new perspectives and experiences to emerge (Patton, 2002, p. 349). The HCP interview guide was developed through literature review and based on the experiences of the 7-member interprofessional research team. It was then refined with a set of ‘expert’ bereaved parents. These steps conferred credibility and legitimacy to the data collection (Crabtree & Miller, 1999). Professionals were probed about their experiences, preparedness and training in EOL; challenges working with families; how they evaluated their own practice; their involvement with parent follow-up; and suggestions on how to improve care and training. Appendix 1 contains the interview guide for professional interviews.

4.4.1.4 Data analysis

The interpretative process was modeled after the 5 steps of the iterative cycle outlined by Crabtree and Miller: describing, organizing, connecting, corroborating/legitimating, and representing the account (Crabtree & Miller, 1999). The choice of organizing style was fluid, dynamic, and evolved over the project. It was based on researcher self-analysis, the research question and aims, emerging knowledge about the policy and practice of EOL in newborns, and the potential audience who will benefit from an ethical framework for decision-making.

HCP interviews were tape-recorded, transcribed, and all names and descriptors were removed. Modified thematic analysis of the interviews was performed by the primary investigator in the editing style of Crabtree and Miller (Crabtree & Miller, 1999). The analyst searched for “meaningful units/segments that both stand alone and relate to the purpose of the study. Once identified, these units are sorted and organized into categories or codes. It is these categories that are explored for patterns and themes in the connecting phase of analysis.” (Crabtree & Miller, 1999, p. 23) Primary documents, codes, memos, and families were managed using the qualitative research software ATLAS.ti 7 (atlas.ti, 2014). Finally, under the supervision of the thesis committee, modified open and axial coding was performed by the primary investigator, with triangulation of codes and themes with at least one other inter-professional team member enhancing the reliability of the analysis (Denzin, 1977). The primary investigator worked back and forth between the data and categories to verify meaning and accuracy (Patton, 2002, p. 465).
Following the generation of items, themes and domains above, these were ordered by professional role using ATLAS.ti 7 in the style of Miles and Huberman (Miles & Huberman, 1994, p. 122). The role-ordered matrix sorted data reflecting the complex motivations and perceptions of HCPs around the topics of inquiry (ex. parent needs, challenges, and quality of care). Comparisons across and within professions on salient themes and domains was made.

Figure 3 depicts the concurrent processes of analysis, linking objectives 1 and 2, and resulting in the empirical data informing the ethical framework for approaching EOL issues in the NICU. The next section explains the comparative analysis using virtue theory of the parent and professional perspectives.

Figure 3: Process of thematic analysis and analysis using a virtue theory lens of health care professional and parent interviews
4.4.2 Objective 2: Comparing parent and health professional perspectives using a virtue theory lens

4.4.2.1 Background: Parent study sample and data collection

In the next section, background will be provided on the first phase of the ‘With Care’ project, involving interviews with parents whose infants died following WLST. The results of this first phase informed the comparison of parent and HCP attitudes and experiences. (Williams, et al., 2009) and (Williams, Munson, Zupancic, & Kirpalani, 2008) contain further background regarding Phase 1 of the ‘With Care’ project).

4.4.2.1.1 Objectives of Phase 1 – Parent interviews

- To explore parents’ experiences in WLST and EOL in the NICU
- To determine parents’ needs in this setting
- To develop a tool to assess whether HCPs are meeting parents’ needs

4.4.2.1.2 Parent Sample

A modified intensity and criterion based method was used for the parent sample in order to understand the phenomenon of interest (Patton, 2002, p. 238). Seventy-nine parents of infants who had undergone WLST from 2003 to 2005 at the NICU of McMaster University Medical Centre were identified from a bereavement list and invited via mail to participate. Eleven parents took part in eight in-depth interviews. They were predominantly English speaking, Christian, married, and nonimmigrant. Completed education level varied from high school to university, as did size of household and presence of other children. Their infants were representative of the most common diagnoses that contribute to North American perinatal mortality: congenital malformations, genetic syndromes, and prematurity. Infants died after non-initiation of life-sustaining treatment or WLST at ages 1 day to 2 months of life. There was 1 set of twins and 1 family had a history of 2 neonatal deaths. Because of Canadian privacy legislation and the sensitive nature of the subject, we collected no data on non-responders upon ruling by the institutional REB.

4.4.2.1.3 Parent interviews and results

Interviews were tape-recorded and transcribed, and all names and descriptors were removed. A full print copy was independently analyzed by 7 members of the research team on the basis of
the editing style of Crabtree and Miller (Crabtree & Miller, 1999). Meanings emerged from the data and were interpreted as the essence of what interviewees reported. After consensus on themes was reached, the primary investigator worked back and forth between the data and categories to verify meaning and accuracy. Items of importance to parents were organized into the following six domains (Williams, et al., 2009):

a) **Communication:**
   i. encourage parents to ask questions
   ii. allow parents time to digest the details of diagnosis and prognosis
   iii. adequately explain the likely outcomes in words that parents understand

b) **Quality of care:**
   i. support parents through their anger, fear, and guilt
   ii. be respectful
   iii. avoid intimidating parents with medical knowledge
   iv. use the child's first name
   v. maintain consistency of care

c) **Quality of life:**
   i. explain the child's future ability to interact, see, and hear
   ii. balance pain and suffering in life with long-term outcomes
   iii. respect parents' view about their child's quality of life

d) **Shared decision-making:**
   i. support parents whatever their decision
   ii. respect when parents do not want to make a decision
   iii. make parents feel that the right decision has been made

e) **WLST process:**
   i. treat the child with dignity
   ii. encourage parents to hold the child
   iii. acknowledge that timing of death may be uncertain
   iv. prepare parents for the physical changes that occur with death
   v. ensure that the child does not suffer
   vi. provide keepsakes (foot/hand prints, memory boxes)
vii. respect parents' religious beliefs at the time of death and during discussion of autopsy

f) Bereavement care:
  i. provide appropriate medical and psychosocial follow-up, including counseling about marital stress and sibling grief
  ii. ensure that autopsy results are reviewed in a timely manner
  iii. attend the child's funeral when appropriate
  iv. provide a grief package with information regarding funeral arrangements, emergency contact numbers, and group supports

Informing many of these practical items from families were the virtues of caregivers providing care. Parents spoke about honesty, compassion, empathy, caring, advocacy for their infant, patience, and temperance in decision-making displayed by different health care professionals on the team. Parent accounts of decision-making and EOL experiences were complex and rich in emotional context.

4.4.2.2 Comparing the perspectives of parents and professionals: Data analysis

Sandelowski examined levels of theory used in qualitative research and highlighted both its implicit and explicit importance in study design and analysis (Sandelowski, 1993). The virtue theory applied in the comparative analysis of the parent and professional virtues was based on Pellegrino’s three posits. As discussed in Chapter 3, in relation to the good of medicine in this context, a virtue was defined as an essential trait of an individual HCP’s character or an essential trait attributed to an interprofessional team that enabled them to navigate ethical dilemmas at EOL. When practiced habitually, a virtue predisposed the HCP and/or the interprofessional team to excellence of intent and performance with respect to the provision of quality EOL care.

Virtues were enumerated using a modified classification system based on the work of Marcum (Marcum, 2012). In his book he identifies virtues under the classical headings of intellectual (ex. insightfulness and wisdom), ethical (ex. courage and justice), and transcendental (ex. faith, hope and love). For this analysis, an additional category of virtues, inspired from an ethics of caring, was added in order to capture the virtues important in the clinician-parent relationships, specifically, relational virtues such as attunement, openness and responsiveness.
The steps of the virtue theory analysis were as follows. First, the traits, attitudes, and behaviours exemplifying the virtuous HCP were explored across the thematic data from the HCP perspective. Experiences highlighting the practice of virtues within the clinical context were then compared across the professional and parent interviews in similar clinical situations ex. involving communication, shared decision-making, and care provided at EOL. Using triangulation of data sources (parent and professional) and theory (virtue), the traits, attitudes, and behaviours exemplifying the virtuous HCP from the parent perspective were explored, highlighting areas of congruence, contrast, and silence between parent and professional perspectives. The virtues important in EOL decision-making and providing good quality care, as endpoints themselves, also emerged from the data. Finally, during more complex clinical and ethical contexts, composite virtues relating to “good practice” were also identified. Composite virtues were defined as combinations of virtues across intellectual, ethical, transcendental, and relational categories. These emerged when parents and/or HCPs described HCPs practicing multiple related virtues in order to negotiate dilemmas or provide good quality care. Finally some individual and composite virtues were attributed not to single HCPs but rather were important to the health care team as a whole in the provision of good quality EOL care. These were defined as ‘team virtues’ and examples in clinical practice were illustrated by both parents and HCPs.

4.4.3 Objective 3: Developing a conceptual framework for end-of-life care

The aim of this phase of the project was to integrate the attitudes, perceptions, and experiences of parents and professionals into a new interprofessional conceptual framework for approaching EOL decision-making and care in the NICU. Based on Pellegrino’s components, building the framework involved:

i) Developing the theory of the good of medicine in relation to interprofessional EOL care and decision-making in the NICU;

ii) Defining virtues in relation to (i) that characterize the “good” health professional or health care team, from both the parent and professional perspectives and situating this specific set of virtues within the clinical context and within the interprofessional relationships in the NICU
iii) Illustrating how to apply both this theory of quality of care and set of virtues to reconciling moral events at EOL

The conceptual framework was also developed in accordance with the criteria from Beauchamp and Childress for theory adequacy (Beauchamp & Childress, 2009, pp. 334-336). In defining the components of the framework, attention was paid to ensure that in the application of the framework as a whole, it could meet the following criteria: clarity (taken as a whole or in its parts), coherence (lacking conceptual inconsistencies or contradictory statements), comprehensiveness (accounting for justifiable norms and judgments), simplicity (both theoretical parsimony and practical simplicity), explanatory power (relating relevant meta-ethical questions to its normative system), justificatory power (providing grounds for beliefs), output power (producing new judgments, not in the original database used for construction), and practicability (requirements not be so demanding or extraordinary that they cannot be satisfied) (Beauchamp & Childress, 2009). Simplicity, clarity, and explanatory grounding were achieved through the definition of the virtues important to providing good quality EOL care from the perspective of parents and professionals. With the additional triangulation of virtues important to parents at EOL described in the literature, coherence of the theory was enhanced. Finally, the stepwise illustration of how the framework is applied in chapter 6, Figure 9, depicts its comprehensiveness, practicability, justificatory and output power.

4.4.4 Ethical considerations

Ethical considerations shape the design, execution, and reporting of a study. This study involved three main areas for reflection: first the respect and protection of parent and professional participants, second, the moral weight of the data, and third, the potential impact of the process and results on hospital personnel and patients. Information regarding bereavement support services was provided and boundaries for privacy were respected. Personal interviews were used to build trust and support, with assurances of confidentiality of the data. In the analysis, there was no direct link made between specific health care providers and specific patients. Final consideration involved the question: were the results likely to be interpreted in such a way as to be harmful to anyone? The construction of a conceptual framework to aid and improve EOL care and decision-making addressed this issue at both the individual clinical and organizational level.
Due to the sensitive nature of the subject, and the first time such a study was performed at the institution, approval from the Hamilton Health Sciences Research Ethics Board was predicated on the interviewer being ‘outside’ of the clinical team. Interviews therefore were conducted by a graduate student in the social sciences and trained by an anthropologist member of the research team. There were both advantages and disadvantages to an interviewer who was not known to participants, or part of the clinical team. Participants may have felt more comfortable with the degree of anonymity and confidentiality provided. Conversely, the interviewer may not have recognized significant information when given if they were not knowledgeable about the clinical context. In order to overcome this, the principle investigator was involved in interview training (for learning and experience), with the post-interview data quality (Crabtree & Miller, 1999, p. 106), and during the transcription phase, but did not interact with participants.
Chapter 5
Results

As outlined in Chapter 4, data collection, analysis, and theory development proceeded along three objectives: i) describing the perspectives of HCPs providing EOL care in the NICU, including how such perspectives may differ by role within interprofessional teams, ii) comparing the perspectives of parents and HCPs using a virtue theory lens, and iii) developing a conceptual framework which makes operational the results of i) and ii). This chapter reports the outcomes of the first two objectives. (The resulting virtue-based framework will be discussed in Chapter 6).

In the first section of this chapter, HCP perspectives on the roles and challenges involved in providing good quality EOL care in the NICU are described. In the second section, relevant differences in perspective by professional role within the interprofessional team are illustrated. The final section compares parent and HCP perspectives on the components of good quality EOL care and its associated professional virtues.

5.1 Health care professional perspectives on good quality end-of-life care

5.1.1 General findings

HCPs in our sample described NICU care as interprofessional and recognized that in addition to being patient-centred, care was family-centred. As one Nurse explained:

You come to realize when you start working here how important communication is with the families… they are going through stressful, challenging times and we are not just taking care of a baby we are actually the nurse for that whole family and they are an important part of it as well. {PRIW21 RN; 37}

HCPs perceived their roles at EOL based on their anticipation and understanding of the needs of both the baby and parents in their care. Across professions, participants acknowledged that families’ needs differed; they highlighted the importance of understanding where parents are “coming from” and being sensitive to individual family situations. One Nurse Practitioner suggested that the only way to know what parents needed was to ask: “I think number one is for us to ask them what their needs are… for somebody to say what do you need right now, instead
of making assumptions of what they need.” {PRIW10 ACNP; 263} She then spoke of her experience in recognizing and anticipating parents’ needs:

If I was to make an assumption of what they need I think that… every parent is different, some parents I look at and I think they need a lot of support right now and they need us around, you see the fear, you know they are holding you and they don’t want to let you go… they’re holding their baby and they’re squeezing your hand… so maybe what I should do right now is just sit down and be with them… you have to take their cues. Whereas other families I feel need to be left alone… sometimes we hover too much… be around too much and we… So I think it’s really what the parents need… for you to take their cue on what they need at that time. {PRIW10 ACNP; 265}

Participants were often unsure of what was ‘best for parents’. The challenge was how to assess how parents were coping and how to meet their needs. As above, they recommended following parents’ cues, learning about what was meaningful to them at EOL, and tailoring care including discussions, decision-making, and EOL rituals to their individual needs. As one Nurse explained:

Just being there for them, letting them know …. giving them permission to take a break, to leave for a little while, to ask questions, trying to sort of get a sense of where they were… if they were looking like they wanted to say something sort of encouraging that, or if they were quiet and didn’t want to talk… then that was fine too…. supporting them in any way that’s appropriate for them and that’s a challenge I think for us to figure how best to do that. {PRIW21 RN; 57}

Participants were concerned with ‘getting it right’ and worried that the care families received at EOL for their newborns may affect them forever. One Nurse observed that HCPs often overestimated how well parents were coping:

The thing that has opened my eyes up recently… a little guy that I had… he died in March and his mum has been in contact with me via e-mail and I think you know, March, a long time ago and she should be doing better and although she is, she does not perceive herself as doing better… I don’t think we realize how long that grieving takes for some families… when I look at this woman who was very together, good support with her family and husband… she’s doing great but she doesn’t perceive herself as doing better and she feels that she’s still stuck… back at the beginning when she first lost him… we think in our brain that they are much better than they are… they are still really suffering and grieving much longer than we realize. {PRIW25 RN; 119}

One Social Worker suggested why it may be difficult for HCPs who experience death and dying in their day to day work, to understand what families are experiencing:

I think because we deal with so much sadness… that we deal with so much that it’s highly charged all the time we can almost forget in a way how exceptional this is
for a family. You know it’s almost, not ordinary for us, but it’s a weekly event so what’s ordinary for us is extraordinary for them. {PRIW35 SW; 152}

HCPs attempted to ‘put themselves in parents’ shoes’ in order to better anticipate their needs, but recognized the difficulty of ever really ‘knowing’ what they are going through. One Nurse recounted:

I will try and think of how I would feel if that were my baby or it were my family member and I think it’s a privilege for families to let us in, to be a part of that, to work with them and to be at such a difficult moment in their lives… to support them… I find it hard sometimes too. I try to put myself in their shoes… you can never really understand what they are going through. {PRIW21 RN; 41}

Despite the inherent challenges, the ability to meet families’ needs at EOL during care and decision-making was a marker of ‘quality of care’ as one Neonatologists suggested: “Part of what we need to be doing is learning how to read the parents… carrying out a discussion with them in a way that we are meeting their needs, but we are not forcing ourselves beyond what they need from us, that’s really tricky.” {PRIW19 NeoMD; 93}

In order to provide care tailored to individual families’ needs, participants identified specific roles as team members and individuals providing care. These roles fell into the following categories:

a) Clinical expertise and moral sensitivity

b) Communication

c) Guidance, support, and relationships

d) Shared decision-making and planning EOL care

Figure 4 lists the categories and themes which emerged from interviews with HCPs regarding their perception of parents’ needs. The following sections explore each of these, highlighting the perceived roles and challenges of HCPs as well as their markers of good quality EOL decision-making and care. Finally, individual clinician and organizational responsibilities associated with meeting families’ needs are outlined.
Figure 4: Themes summarizing HCP perceptions of parents' needs at EOL in the NICU.

5.1.2 Clinical expertise and moral sensitivity

Participants suggested that expertise was required in EOL decision-making and care in the NICU due to the inherent difficulty of the work. Their message was: babies are different, death is a challenge, and the moral weight of decisions is a burden to both caregivers and parents.

5.1.2.1 Babies are different

For many participants, looking after babies who were critically ill was different than looking after adults. Even with years of experience in EOL care, some described how ill prepared they were for their role, including one chaplain who recounted:

> I know at that time, the very first time, not only was I shocked at how tiny this baby was but … I feel quite certain my shock like my feeling of oh my goodness, was that apparent to the group…when I left afterwards I just thought what just happened in there because no one had prepared me. {PRIW Chaplain; 36}

A number of participants spoke of the difficulties of dealing with death at the ‘beginning of life’ for both parents and caregivers. A different Chaplain interpreted:

> For [parents] the loss of a child is harder than say the loss of a parent or other family member. It’s a life that never was allowed to begin and so when the child dies not only does the child die but all the hopes and dreams that each parent had for their child. {PRIW7 Chaplain; 120}

In a similar way, this change in perception and transition to a palliative role was a challenge for HCPs, as one Nurse explained:

> It’s something that was a very difficult thing to do initially because babies are about beginning life … they are a start of life not an end of life so it’s a hard thing to sort of get your head around… once you can, you know, resolve that within yourself, you can help the families deal better with the fact that their child is not going to survive. {PRIW14 RN; 27}

One aspect that challenged HCPs, particularly physicians in training, was breaking the initial news to parents that their baby was critically ill, would not survive, or would survive with significant deficits as a result of their illness or injury. One Resident compared breaking bad news to adults regarding conditions affecting their own health versus breaking bad news to parents regarding serious illness in their children:

> I don’t know for you but [my training] focused around breaking bad news to adults that are going to accept information about themselves not about a parent who has carried this child … had these ideas that their child is going to you know be Baryshnikov and Dali or whatever, and then they have this child and you are
breaking every hope and dream and anything that they have ever had when they thought about having children. You are asking them to put all of that aside, to think of beyond that to put themselves in that position, and then to say that’s enough. So you learn you know how to say to the 80 year old man… you have colon cancer sir and there is nothing we can do. You don’t learn how to say: your brand new little person isn’t going to live beyond today, and it’s a very different discussion. {PRIW12 Residents; 83}

In order to provide quality care for families in these circumstances one Neonatologist described recognizing the evolution of shock and preparedness that families experience and meeting them where they are on the spectrum:

Well among the biggest challenges is the fact that they are usually in a shock situation when trying to talk to them about these things… they discover they’re pregnant and so a whole set of expectations falls into place and they start to make preparations for a term baby who is going to live and it takes a variable amount of time for people to adjust to the fact that that’s not going to unfold in that way. So one of the challenges is you’re meeting people at various points along the spectrum in their preparedness to deal with the death of a child. {PRIW19 NeoMD; 49}

In addition to understanding the depth of potential meaning around a parent’s loss and the bleak certainty of death at the beginning of life, other aspects of the NICU culture that challenged good quality EOL care and decision-making are explored below.

5.1.2.2 Death in the neonatal intensive care unit

In the NICU, participants described variability in the types of patients who receive EOL care. Timing was unpredictable as illustrated by this Nurse:

Sometimes it can happen very quickly, sometimes it happens very slowly depending upon the situation and how critical the baby is at the time. Then sometimes it’s a very startling and surprising thing for the parents and other times it’s something that everybody has been waiting for a long time. {PRIW1 RN; 25}

Some HCPs stressed that this variability in timing and anticipation necessitates an individualized approach to families. One Transport Nurse explained this difference, contrasting unexpected deaths versus those that were anticipated:

[A baby] suddenly has a massive pulmonary hemorrhage and dies, there was nothing wrong with him like 3 hours ago, and that’s a sudden neonatal death. Those parents need to be treated differently… [as opposed] to when a parent that has been treated up till now that you know really there is probably nothing we can do. Since the baby has been born, he’s been very sick, there really wasn’t anything we could do in the first place but we felt we would give these 2 things a try. Those
people are in a different mindset because those other people are at home thinking their baby’s all okay and suddenly they are calling them to race them here because their baby is dying. These people have known from the beginning that their baby has been very unwell and dying … I think it’s important that there is different groups of people and they need to be treated differently, it’s not just all clumped into one thing. {PRIW6 TN RN; 327}

Analogously, for some HCPs certain deaths were ‘easier’ for HCPs to accept than others. The most common comparison made was between the death of an extremely premature infant and that of a full term infant. For example, this Nurse explained: “if it’s a preterm baby, they are not supposed to be here yet so it’s a little bit easier to deal with … so when it’s a term baby and you expect a happy baby, that’s hard to deal with sometimes.” {PRIW32 RN; 58} One reason for the difference, as articulated by this Transport Nurse, is the perception of time and the suffering a premature infant may spend in the NICU before dying:

In some instances I feel actually it is very much for the best, the ones that are very difficult are the term that should be healthy… it’s usually something that’s happened like a birth trauma… those are the hardest ones I have to deal with. The premature ones although it is sad and you feel very bad for the families, seeing what we put these babies through sometimes, sometimes you’re actually happier when they have passed without that suffering. {PRIW20 TN RN; 125}

HCPs reveal that the majority of deaths in the NICU occur after everything has been done, with most babies dying shortly after life-sustaining technology is withdrawn. When asked about their attitudes toward death in the NICU, caregivers’ perceptions were influenced both by their prior experiences and by their own religious beliefs. Participants described four attitudes regarding death which were not mutually exclusive, these were:

i. Death is natural and inevitable
ii. Death is hard
iii. Death is better than the alternative
iv. Death is our failure

Death is natural and inevitable. Caregivers, who expressed this belief, spoke of death as a natural part of life, not to be feared, and inevitable in a unit providing critical care. One Neonatologist explained:

It’s not necessarily something that’s to be fought… sometimes you hear physicians saying… you have to fight death to the end. I think what we do, a good deal of what we do, is struggle against the natural order of things. In other words, if we weren’t here, a lot of the babies that are born, who fall under our care would have
died very quickly… in that sense we are always fighting against nature, but I guess my attitude is nature ultimately wins and so our job is to work with and sometimes struggle against nature but not at all costs… I don’t feel that as a defeat unless my sense is that we really could have done a better job. {PRIW19 NeoMD; 45}

**Death is hard.** Some of the participants who believed death to be inevitable in the NICU also shared the attitude of other HCPs that death was hard to deal with, particularly for those left behind. Some HCPs, such as this Neonatologist described the intimate nature of death:

> Being present at death is an even more intimate experience than being present at the birth … it’s the point at which a health professional is most intimately connected to the patients that they look after and as such places them in an extraordinarily privileged position… nobody else in the world other than chaplains, pastors, priests, ministers ever gets put in that position except almost by accident. {PRIW24 NeoMD; 41}

The responsibility of this close intimacy and bearing witness with the family was uncomfortable for some of the caregivers in our sample, particularly when past experiences or personal feelings become a factor, as this Nurse confided:

> Well I have had a lot of [death] in my family which is why I don’t want to be around it. In the unit I don’t know… I don’t like to watch it but I know… it’s necessary, it’s better to have that than continuing on… but I have a lot of family death and I have had my fill. {PRIW30 RN; 53}

HCPs sharing this attitude described death as sad, uncomfortable, and scary. However self-awareness and reflection helped caregivers to overcome past experiences and build resilience which enabled them to support families. This Resident reflected on supporting a family at EOL, while dealing with their own sense of grief:

> As much as one would like to believe that they’re there to support the parents… you always reflect back on yourself… somehow you’re grieving for yourself or what you know or who you know or you’re grieving just because a life has passed whether that life has passed to a better place… you’re grieving for your own pain and I think you have to honor that… acknowledging that you know I didn’t really believe it the way they did but I supported them and I can be proud that I supported them with what they needed. {PRIW12 Resident; 169}

**Death is better than the alternative.** A common attitude in the NICU viewed death as a release from suffering, often the ‘only best outcome’ where survival could be worse, as vividly described by this Resident:

> Death still scares me to death, just me personally, but then I see babies in the NICU… not a chance that these babies were going to survive and for hours I watch them having 50 chest tubes put in and intubated and re-intubated and lines and and at the couple hour mark somebody says oh well maybe we should start a morphine
infusion and then they went ‘this is hopeless’ and withdrew and you think what was the point of that? … why didn’t you give the baby to the mom, have it gasp a little bit in mom’s arms and then die as opposed to cutting it and stabbing it and giving very little consideration to pain control and then withdrawing care and having it die? … I mean although it scares me to death, I can see… death was a blessing for that baby in particular… {PRIW12 Resident; 157}

The attitude that death is a release was based not only on the acute suffering of the infant as described above but also in consideration of the long term morbidity in NICU survivors, as described by one Nurse Practitioner: “I think that in my own opinion, death is something that is very sad, it’s very difficult to go through but at the same time I think the alternative of having a severely poor quality of life is also not fair and potentially could be worse than death.” {PRIW10 ACNP; 162}

As illustrated by the resident above, HCPs sharing this attitude toward death, express frustration at the underlying NICU culture, where technology can often ‘keep babies going’, arguing that perhaps ‘can’ does not equal ‘should’. As this Nurse points out: “I think we are very good at what we do, I don’t think we are very good at stopping what we do, in fact I think we are really bad at that.” {PRIW31 RN; 170}

This transition from curative to palliative care is a challenge to NICU teams, as described by one Social Worker detailing her observations of the technological imperative and its effects on families:

Technology gets better and better and pushes things back further and further… what point do we stand up and say enough… So I think we do all the heroics and the baby survives for a week and then all of a sudden it becomes the parent’s decision to discontinue care. So they have connected with this baby over that week and then we are sitting them down saying well this, this, and this has happened, what do you want to do? … We have intervened and we have done everything we could and here we are… then we are saying to the parents now you have to decide… that’s an awful lot to ask of any parent. {PRIW35 SW; 128-132}

Dealing with death is our failure. Some HCPs described a pressure on their practice from the medical community, parents, and society, that views death as a form of professional failure. One Chaplain recounted her observation of staff failing to meet parents’ expectations:

Parents place a lot of hope and a lot of expectation on staff there and when staff have to break the news to them that their child is not going to live… it’s also traumatizing for the staff as well, especially if it’s been a baby who has been on the unit for a considerable amount of time. {PRIW7 Chaplain; 55}
There are instances from our sample, where HCPs described the death of a patient as an agonizing failure, and as is evidenced by this Nurse, they may take these failures personally:

I used to be on the transport team …and I went out for a baby… 34-36 weeker… we walked in and they were resuscitating and it was just myself and another nurse and we worked on that baby for hours and that baby died and it was my role to go and talk to the parents to tell them first off that you know we weren’t having much success … then it was my job to go and tell the parents that the baby had died … As I was driving home I guess the reality of the situation set in and I sobbed, I mean uncontrollably, and I actually went down on my knees praying I hadn’t killed that baby. I was so upset I was honestly so upset…” {PRIW31 RN; 88-110}

One Neonatologist normalized this sense of failure but highlighted the importance of dealing with it, as he detailed:

I don’t think that that’s always a bad thing. It’s usually considered to be bad but in fact if doctors and nurses didn’t feel some sense of failure … sense of regret, then they probably wouldn’t be very healthy. So dealing with that sense of failure, regret, loss, amongst staff I think is a major challenge. {PRIW24 NeoMD; 45}

These four attitudes regarding death in the NICU were present across professions (medical, nursing, and allied health). Similarly, though the specific experiences surrounding death in the NICU varied, other common themes emerged. Inexperience with death and dying made trainees and new staff of all professions uncomfortable. In addition, several caregivers felt that insight into their own personal feelings and values improved their ability to support and counsel families.

5.1.2.3 Moral weight of decisions

The third notion contributing to the special circumstance of EOL care in the NICU as illustrated by HCPs in our sample involved understanding the moral weight of EOL decisions and decision-making. The challenge as described by some HCPs lay ‘not in the dying but in the decision’.
Two factors contributed to this view:

i) the difficulty in making decisions based on QOL when looking at a newborn, and

ii) appreciating that though there is no moral difference between non-initiation of life-sustaining treatment and withdrawal of life-sustaining treatment in its various forms, there is a definite emotional and practical difference for both HCPs and families.
As mentioned previously, patients died under different circumstances in the NICU. HCPs in our sample drew distinctions between babies who were acutely dying, those who were likely to die, and those who could potentially survive with a poor predicted QOL. Though caring for dying babies required specific skills (as will be described in the next sections examining aspects of quality EOL care) EOL decision-making was facilitated in these situations by the inevitability of the outcome. For patients requiring the more decisive transition from curative to palliative care, the common underlying principle amongst caregivers, driving this deliberation, was balancing the short and long-term QOL of the infant. The characteristics and challenges of shared decision-making as perceived by HCPs will be explored in more detail in the next sections. However, the special circumstance of understanding and weighing QOL in newborns is examined here.

One question which surfaced in our HCP interviews was who should decide what an acceptable QOL is for a baby in the NICU? One Social Worker drew upon her own personal experiences and values in her approach to involving parents in discussions about their baby’s QOL:

We have a nephew who is profoundly handicapped … huge heroic efforts to save that child … I have seen the cost to his parents… for them a huge psychological cost … he’s well-loved but I can see how it’s changed how the family works together, their expectations on their older son as well… when his parents die, he will be responsible for this young man…. I guess I don’t believe life at any cost… Who decides what quality of life is? Quality of life needs to include the parents, the siblings, as well as the child so I think when we are having discussions that sometimes [parents] are scared to talk about it {PRIW 35 SW; 112}

Having an understanding of what was an acceptable QOL in the short and long-term for a patient in the NICU was important. In our sample, this was what most often influenced the decision to offer the option of palliative care. One Neonatologist shared his thought process:

If you’re asking about my beliefs then coming from a medical background much as it is a difficult thing for me, I put myself in the position of trying to appreciate truly the quality of life of a particular given infant, recognizing the severity of the underlying condition and the prognosis and its impact that it will have on the family. If in my opinion, based on the information I have, that this is truly going to compromise the child in terms of both suffering and its quality of life… if I feel that death is inevitable… and it’s just going to prolong suffering then my approach would be… to accept the death as something which is acceptable to both me and hopefully to the family. {PRIW 23 NeoMD; 49}

Understanding of long term QOL was often difficult when looking at a baby, particularly for those who on the outside appeared ‘normal’ but had sustained significant internal injuries. For
these infants, the long term effects were not apparent for months or years to come as one Nurse Practitioner explained:

Sometimes the decision is being made on likely outcomes further down the road for the baby and to look at the baby and the baby looks perfectly fine… that’s a big challenge… overcome your own or the family’s concern that you know how could you possibly “just give up” on a baby that looks so cute so. That’s a big challenge to sort of get over that emotional hurdle... {PRIW11 ACNP; 45}

This underlying preoccupation with ensuring parents understand how devastating the potential prognosis for their infant might be, appeared in our sample to originate from a fear that babies would survive the ‘heroics’ of the NICU and endure as HCPs envision, a fate worse than death. This conflict of values was described by this Social Worker:

Part of our role is working with staff to not beat the hope out of families because I think there’s a very fine line between making sure they understand that there are severe quality of life issues if this child survives and imposing your own values on what you could cope with… sometimes what I struggle with is that some of the staff feels so strongly quality of life focused, as I do personally, but they are not able to separate out that’s what I feel and that’s what I would want for my child… as long as we really help this family get as good an appreciation you can have what it might be like for this child, if they are choosing to stop or to continue, that’s their decision, you got to respect . That’s something that I have struggled with. {PRIW35 SW; 118}

The concept of WLST is in and of itself laden with value. Language associated with WLST varied within our sample, being described as a ‘brave and loving choice’, ‘playing God’, ‘giving up’, or ‘killing their child’. HCPs identified the importance of clarifying not only language but motives and intent particularly when misunderstandings could create significant distress for families. One Fellow explained why it was important that parents understood that WLST was not ‘withdrawal of caring’:

I think that [parents] need to know that this isn’t a withdrawal of care, it’s a withdrawal of intensive care measures, because I can’t think of anything worse than thinking that nobody was going to care about my baby or look after my baby… you have to have to be very clear about that. {PRIW5 Fellow; 51-54}

In addition, a particular moral challenge to HCPs was the spectrum of WLST practices. HCPs acknowledged both an emotional and practical difference between non-initiation of life-sustaining treatment, withdrawal of ventilator support, and withdrawal of artificial nutrition and hydration (WANH) in babies who didn’t die once the ventilator was withdrawn. One
Neonatologist illustrated the difficulty of WLST after a decision for initiation of intensive care was made:

> The waters get muddied by the fact that the parents have in the initial phase… agreed to having everything done for their child… we may have embarked and it is their request, but to draw the fine line in terms of when do we stop… we tend to lose the forest for the trees… I just had this meeting today … on a 400 gram [baby] who if you were standing away from the situation is very easy to say well let’s just look at our statistics… we have few or no survivals under 500 grams. The parents would like us to start resuscitating the baby because they [are] indecisive at that point in time… so you embark on this strategy … but is now developing numerous ventilator complications and although the baby looks “relatively well” by his vital signs, how do we make that decision? … say okay we have started on this route but… the long term outcome of this baby is really relatively poor… trying to get them, when they are looking at this infant who is moving around, to think to withdraw is extremely difficult. {PRIW23 NeoMD; 57}

Another challenge as described by participants, for both caregivers and families, which contributed to the moral weight of the WLST decision, was when babies did not die after ventilator support was withdrawn. One Neonatal Fellow described witnessing the struggle parents endured:

> We had a baby with a hypoxic ischemic encephalopathy, that means the baby is basically comatose… the decision was made by the medical team, which means the staff and the other subspecialties, that the baby has poor prognosis in the future … the decision was made that this baby needed to be withdrawn from the care and I wouldn’t say it was difficult because the perception from the parents was easy to be taken because they are quite educated … we were expecting that the baby was going to die within a few hours but the baby is alive now. We struggled with the parents that the baby is still alive. What we should do? Parents now stated they wanted the baby to die; they didn’t want to commit to the baby anymore because that would prolong their suffering… {PRIW13 Fellow; 21}

For babies that survive after withdrawal of respiratory support, HCPs described the next challenging step, withdrawal of artificial nutrition and hydration. As this Dietician described, anticipatory planning regarding WANH was often missing, and there was variability as to when the medical team may address feeding with families which resulted in distress.

> Most of the time I am more in the background kind of waiting to see what the plan is for feeding and sometimes it’s really difficult because they are talking about withdrawing care but the feeding is sort of one of the last issues to be addressed… and it’s really an issue of whether they are going to feed or not feed… it’s kind of difficult because from my perspective I need to provide full nutrition support until I know that they aren’t going to continue to feed. So if the baby is on IV then I tend to optimize their IV feeding orders or if they are on enteral feeds then I try to optimize their nutritional support... it’s difficult because we have had cases
where… they have been withdrawing care and we sort of stop their feeds and then the baby doesn’t die… they decide that they are going to continue… then it’s difficult because… you have missed a couple of days where you could have been feeding but you weren’t feeding. {PRIW 26 Dietician; 21}

The special circumstance of WANH in the NICU, requiring a holistic and multidisciplinary approach, was illustrated by this Neonatologist:

The baby was not able to feed naturally and so there was a long period of working through with the parents about in what way would nutrition support or hydration support be provided… and working through with the relevant nurses what we are going to do and their comfort level with that… in the end the decision was not to feed… then the issue was expecting that the baby would die over a rather long period of time, weeks rather than days and making sure that all parties involved were still comfortable with that as it unfolded… what sometimes happens is people agree or acknowledge that it may take a couple of weeks for the baby to die and then as time is going on, they get more and more anxious about the fact that it’s not happening and so you have to review the situation, make sure people are still comfortable. {PRIW19 NeoMD; 13}

In summary, the clinical expertise and moral sensitivity associated with caring for newborns making the transition from curative to palliative care involved understanding the special circumstances surrounding ‘the newborn’ i.e. its ‘value’ on a relational level to families and on an intrinsic level to society; the special challenges of death at the beginning of life; the nuances of intent and outcome involved in limiting ‘heroics’ in the NICU; and finally ensuring good communication with families.

5.1.3 Communication

A particular expertise regarding communication during decision-making and around EOL in the NICU was important to HCPs. In describing communication, HCPs identified themes related to parent needs, challenges facing caregivers, and markers or indices useful in evaluating quality of care.

5.1.3.1 Parents’ needs: a morally contoured approach to communication

HCPs identified communication with families as essential for family-centred care. They highlighted the importance of a multidisciplinary approach to discussions and viewed EOL discussions as necessary. Regarding discussions around prognosis, decision-making, and EOL care, HCPs identified these parent needs regarding information:

i) parents need access to information;
ii) this information should be frank, clear, and consistent amongst team members;

iii) parents need assistance in understanding the specific information;

iv) parents need assistance in reaching acceptance of the ‘overall message’

These items defined a ‘morally contoured approach’ to communication in this setting.

5.1.3.1.1 Access to information

HCPs perceived that parents needed information in order to make treatment decisions regarding their infants. As described by this Nurse Practitioner, access to information, even if achieving access ‘slows down the process’ was essential for families:

I have never felt that withdrawal of care has been a hasty decision it has always been in my opinion been very well thought out and discussed… sometimes I have felt that it’s been discussed too much, that it’s almost dragged out, but also understanding that it is … one of the biggest decisions that parents have to make… [HCPs] have to give them all the information possible in order to make that decision. Sometimes that takes a long time and that could be getting the neurologist involved, can be getting the geneticist involved, could be consulting another neonatologist, can be waiting to receive records from another hospital… prior to withdrawal there has been a lot of thought that has gone behind, to make sure that the parents do know all the information in order to make that choice. {PRIW10 ACNP; 74-86}

5.1.3.1.2 Frank, clear, and consistent information

When dealing with multiple sources of information, as happens with an interprofessional NICU team, with staff changeover and the involvement of outside consultants, HCPs in our sample stressed the importance of information being frank, clearly delivered, and consistent across HCPs. In order to avoid miscommunication or misunderstanding, HCPs recommended a direct and frank approach when providing parents with information. This required preparation and time as indicated by this Neonatologist: “You can’t do it as a 5 minute communication thing you can’t afford to be disorganized in your approach, you can’t afford to give a lot of jargon, and information which is tentative and not coming across in a constant fashion.” {PRIW23 NeoMD; 113} One Nurse tells of an observation where information given to a family was left to too much interpretation:

I think the biggest challenge is… back to giving them direct information instead of … vague information…. you hear oh well your baby may have a limp but it may have severe CP. I mean those are 2 huge spectrums… often the parents are not told the extent of it and we as bedside nurses know and you sit in the meetings and you
listen to the information that the parents are being given and knowing that they come out of that meeting without a true picture of what the outcome is going to be. {PRIW29 RN; 53}

She continued to recount complaints from parents about the ambiguity of prognostic information:

Anger and frustration, and I have heard parents say that nobody told us, nobody told us it was going to be this bad… I don’t know if that’s because maybe they weren’t hearing what they were being told… I think it also relates to the person who’s providing the information… is it again a vague kind of information or are they being quite honest? I have seen both sides where there are some physicians who are very direct and I respect them for that and then others don’t give the same kind of direct information. {PRIW29 RN; 65}

In addition to being direct, this Transport Nurse recommended ensuring that information was clearly laid out:

There will be the doctor who goes in … review the care of that baby from day 1, all the problems… and we have done this… and now there is no longer anything else we can do … we have had this consultant … and this is where we are at. Her chances of survival if we carry on are 0 to 1% … or her chances of severe … outcomes, handicaps … are 99% if we continue… it is our opinion that we should now discontinue treatment … for the well-being of this baby we don’t want to prolong suffering… are you in agreement with that? … it’s quite easy then for that parent to say … they have done this, they have laid it all out, it’s very clear to me now … and hopefully they have been getting this information all along but it’s kind of a summary of everything that’s happened .{PRIW6 TN RN; 87}

As important as directness and clarity of information, was consistency of information from caregivers. This Nurse, drawing on her experience, linked these qualities together with emotional support for families and the combined efforts of the whole interprofessional team:

Well in the cases that I have seen I think it is important to be consistent with the parents, give them a clear message but a message that tells them what reality will be and at the same time give those parents the emotional support that they need so that they can make that decision and I don’t think one person can do that, it has to be the whole team on the same page. {PRIW22 RN; 124}

5.1.3.1.3 Parents need: assistance in understanding

While directness, clarity, and consistency of information aimed to assist parental understanding, HCPs also suggested preparing families early for the potential of bad news. This was particularly important if HCPs anticipated a medical deterioration which would place parents in a crisis situation during discussions. One Transport Nurse described a warning tone during discussions, which prepared parents for bad news: “Some foreboding or something with the parents during
discussions that there may be a bad outcome in the end and so that there is a bit of preparation there so that when that complication occurs it doesn’t totally blow them away.” {PRIW9 TN RN; 95} One Neonatologist described a process of “simultaneously starting to prepare [the family] for the possibility the baby’s not going to survive” as part of the “therapeutic package”, in order to “manage the death as well as manage the living period.” {PRIW19 NeoMD; 45}

HCPs highlighted one advantage to providing care using an interprofessional team model, that is, the availability of team members in different roles who could help clarify information for families. One Social Worker explained her role in ensuring parental understanding of information:

> Often a physician will meet with them and sort of go over everything and of course it’s so overwhelming and we will stay back then and meet with the family and … go over the things that the physician has said sometimes in a bit more simplified terms… just to make sure that they really do have a clear understanding… if what they feed back to us doesn’t seem like they are really getting it, we will get the physician again and make sure that we sort of revisit things. {PRIW35 SW; 40}

The importance of consistency of information as highlighted above may also be influenced by parents’ abilities to understand and interpret the information provided. This is elaborated on by one Social Worker:

> We know that 2 people can say the same thing in a different way and it can be interpreted into completely different information and there’s a lot of that, the nurse before said this, the nurse this time said this, the doctor before said this… Who am I supposed to believe? You’re saying, isn’t that the same information? But parents don’t necessarily perceive it that way {PRIW35 SW; 192}

HCPs suggested that parental understanding could also be facilitated by giving parents time to take in all the information, holding multiple meetings, providing notes or written information for them to review, and finally, fully answering their questions.

### 5.1.3.1.4 Parents need: assistance reaching acceptance

HCPs identified a difference between understanding the details of the information at hand and accepting the overall message being conveyed. A commonly held opinion across all professions was that parents needed assistance in coming to a realization of the long-term outcome for their child. This ability to gauge parent understanding and acceptance was challenging. Parent understanding and acceptance was a dynamic process that changed over time. HCPs may not have intuitively recognized parents’ perceptions and had difficulty predicting parents’ future
feelings, attitudes, and even memories of discussions or events that occurred while their infant was critically ill in the NICU. One Nurse Practitioner reflected on a troubling past experience:

I can recall one situation that really struck home with me … I had been in many discussions with the family and with the physicians who had recommended withdrawal of care and the family refused … and this child survived and was discharged and he has since been seen in pediatrics… one of the comments the mother made to another practitioner in pediatrics was: ‘I wished they would have told me how bad he was going to be because I would have withdrawn care’… I remember clear, clear conversations with this mom as if it was yesterday. I remember these conversations and how hard it was for the staff to continue on caring for this baby even though they felt that we were doing the child a disservice and then you hear this is what this mother had said. {PRIW10 ACNP; 279-292}

Sentinel cases such as these shaped attitudes and beliefs. A common related belief amongst the HCPs was that parents simply did not understand counseling about neonatal outcomes particularly using statistics and population data. There existed therefore a conflict between wanting parents to ‘know’ the outcomes as stated above but feeling that parents couldn’t really understand them. One nurse described ways she felt HCPs should try to get their messages across:

The parents can’t grasp what’s mild, moderate and severe cerebral palsy… sometimes seeing pictures, a pamphlet or even maybe a video, I’m not sure if that would be helpful. I don’t know if that’s tacky… but I think sometimes parents need an example… we assume they understand it but do they really understand? … I think in premature infants… just because they are still growing … they perceive some degree of hope that the brain will heal… the doctors always say you know 80% chance of being severe … so then the parents [grasp] on that 20% and so what does that mean 20%? What does that really mean in terms of handicap? {PRIW2 RN; 22}

Another reason HCPs observed that parents didn’t fully understand outcomes counseling was related to the physicians not wanting to be the bearers of bad news and therefore sugar-coating the prognosis. One Chaplain recalled:

Parents really didn’t know how serious this was or parents didn’t understand what has been said to them… I think that is a reflection in some cases of physicians in particular not wanting to be the bearer of bad news and I have noticed this not only in the neonatal unit but elsewhere throughout this facility and other hospitals. {PRIW7 Chaplain; 103-107}

Finally, there were times when HCPs’ perceptions of parents not understanding outcomes was related more to their own desire for WLST to have occurred rather than a true lack of understanding on the part of parents regarding the prognosis. One Nurse described one occasion:
Sometimes we want to take advantage of that small window of opportunity to withdraw treatment especially if they are really sick… there’s been comments where people have said that these parents should have withdrawn treatment because their baby now has been here like six months and you know they are still on a ventilator … and can’t see, can’t hear, can’t do this … so I think because we have been with the baby for a long time and have seen what it’s gone through we wish that maybe parents would have withdrawn treatment. {PRIW22 RN; 68}

Helping parents achieve an understanding and acceptance of the potential devastating outcome for their critically ill infant was a complex process, and as evidenced by the HCPs in our sample a source of distress for both HCPs and families. One Nurse highlighted the importance of recognizing where parents were emotionally and discussed her role: “To support them, to recognize their grief, and answer their questions, and understand that this is obviously a very bad time for them… there are issues that they are not really taking in… to be patient about that”. {PRIW31 RN; 9-15}

Similarly, one Neonatologist described a family’s acceptance as a dynamic process:

The parents had agreed with withdrawal on Wednesday … I was at the bedside, the nurse was at the bedside and then they came… we gave morphine for the baby but the baby was pink, active, moving, it was very good looking… they said you know can’t we wait until tomorrow morning to see how she does… you can’t push them … So sometimes you’re moving to a decision but because they are humans and [they] watch [their] daughter and she’s fine … so we stepped back… in the next 48 hours … I gave [parents] more numbers and in that specific situation that outcome for her … [parents] felt more strong to make the decision. So it’s really dynamic. {PRIW28 NeoMD; 145}

5.1.3.2 Content of discussions: what caregivers think parents need to know

As mentioned, the most common thing that HCPs felt parents should understand from EOL decision-making discussions was what the short and long-term prognosis meant for the infant and their family, that is, specific outcomes that were pertinent to them and their values. The first step involved understanding what information was pertinent to that particular family, and then to ensure that the information provided was as accurate and consistent as possible. One Neonatologist described his approach to eliciting parent values regarding weighing QOL and EOL decisions:

Firstly obtaining a clear understanding that the outcome for their child is, and here I am talking about quality of life for that child, is going to be poor … it’s their comprehension of the factual knowledge given the situation that they are placed in
… Viewpoints about disability and long term prognosis are very different, just ask the parents, and to me that does sometimes factor into the equation in terms of withdrawal i.e. [willing to] take home any child with any degree of disability. {PRIW23 NeoMD; 57}

In addition to understanding parents’ values, the Social Workers in our sample indicated that some parents who may be reluctant, may need to be given ‘permission’ to make decisions based on those values. One Social Worker explained:

I think in the discussions we have with families it’s important to give them permission to say…I’m scared to have to have this child … I don’t know what it’s going to mean to all of us and reframing it for them… they are often very worried about that particular child and what’s this going to mean. {PRIW35 SW; 114}

HCPs expressed that parents needed to hear about their options for decision-making. Some HCPs emphasized that WLST was not an all or none process, that care plans needed to be developed that addressed the goals of care for that particular infant and that particular family. One Social Worker described:

I think the whole idea of withdrawal is not all or nothing. Sometimes I think that we get into the mindset that withdrawal means stop all active treatment… but maybe for a family who’s not ready to go there, maybe it means okay we won’t do an intense resuscitation on this child if this child arrests as opposed to physically pulling the tube and maybe that’s a way to see what happens and let nature take its course, which I think is somehow easier for families, that again it’s not that they made the decision to stop but that nature did. {PRIW35 SW; 366}

HCPs in our sample also suggested that another matter that should be covered in EOL decision-making discussions was practical information about death and dying. One Neonatologist explained that few, if any, parents had ever been in this situation, and even their overall experience with death may be limited:

They need purely practical information about what to do… when the child dies… never having seen that they haven’t a clue… information about where to go, who to talk to… as well as supportive information about how they may feel, how other people may feel… they need some sort of preventative interventions that they may not hear at the time but hopefully they will sort of remember it or at least remember some of it. {PRIW 24 NeoMD; 53}

In addition to options regarding medical and comfort interventions, parents also need to be made aware of options around EOL, including timing, setting, and whether they would like to take their baby home to die. One Nurse Practitioner described the need to individualize care:

It’s not the same for every baby in every situation… identifying with them what their priorities were and what they felt was going to be important for them and
their family… palliative care in the NICU doesn’t always stay here sometimes the families are ready to go out to the community, to go home with their baby… It’s really multifaceted, the planning, the negotiating with the families, putting their resources in place, it’s really complex, it’s a complex role and it’s different every time. {PRIW11 ACNP; 13}

5.1.3.3 Communication challenges

While recognizing the importance of communication with families around diagnosis, prognosis, and EOL options, HCPs also identified barriers and challenges to achieving ‘good quality’ communication. These barriers were both intrinsic to HCPs (including communicator skill, ability to gauge parents’ understanding, and personal fears or discomfort associated with EOL discussions) as well as extrinsic to HCPs (the medical uncertainty of prognosis and varying perceptions or disagreement amongst members of the interprofessional team).

5.1.3.3.1 Skills of communication, caregiver discomfort, fears, and emotions

One recommendation from HCPs was that the physicians needed to be comfortable conveying bad news. Other HCPs acknowledged that physicians had different communication styles, and levels of skill. HCPs observing physician-parent interactions felt communication was good when it was comfortable, open, and honest. Learners in particular were concerned about ‘getting it right’ and identified throughout their training, good and bad role models. This Resident described her observations and her worries:

A situation where somebody who’s done this before… says the things that they need to say to the parents and they say it in such an amazing way… something that’s kind of comfortable… and sounds really honest and open and just rolls really well off their tongue… this is something that you are going to have to… practice saying, something that’s going to sound right coming out of your mouth and isn’t going to be all jilted and awkward… [I] don’t mean… practice in front of the next parent whose child is unfortunately not going to make it but… practice in a situation… with residents. {PRIW12 Resident; 59}

Some HCPs had received training in communication during their professional training; fewer had training specifically in EOL or WLST discussions, and none specifically tailored to EOL in newborns. Most of the training was on the job and included observation of role models or other experienced staff. Residents in the group interview candidly spoke of their fears, wishing they were taught what to cover in conversations with families, and worried that lack of experience would cause harm to families:
Resident 1: Even to know the things that you’re supposed to cover, like not having one of those moments of walking out of the room and saying... I really couldn’t tell them about that ... the staff people have watched the babies die so they can actually honestly say to the parents this is what they are going to look like...

Resident 2: We don’t know what they look like.

Resident 1: It’s probably one of the biggest fears to think it’s going to be a horror show movie you know awful death-ness, blood, blue, and gasping, seizing... and just to be able to hear people have those honest discussions and be able to say that and you think oh okay that’s what I need to say but that’s also how I need to say it-

Resident 1: and how much of this should be you know saying statistics and how much of it should be compassionate conversation, as opposed to medicalized discussion

{PRIW12 Resident; 61-67}

Challenges in communication were not only described at the level of the learners, HCPs described variation in communication skills in experienced physicians delivering news to families. HCPs analogously identified varying levels of comfort accepting death and dying in the NICU and as a result, a varying level of comfort discussing it. As one Chaplain described, this variation influenced the ability for clinicians to effectively communicate with families:

Well, there are some physicians that are better able to talk about death than others for any number of reasons and I think the more comfortable physicians are themselves with that as an end point, the better ... able to communicate... I think in part it also entails a physician’s acceptance of his or her own mortality and also recognition even given the advances within ... medicine over the past 100 years that there are still limits. {PRIW7 Chaplain; 111-116}

Social Workers in a group interview described this variability in physician skill and how as members of the team, they tried to help physicians who struggled in EOL discussions:

Social Worker 1: I think one of my biggest hopes for this whole project is ... more consistency. Over and over again it’s such a difference from which neonatologist is on ... there is such a variation in the care that families get-

Social Worker 2: And how to present the whole withdrawal of care discussions. Some are very straight forward and sometimes- so it’s yeah consistency again

Social Worker 3: That’s a big point because in a crisis [parents want] answers or they can’t read between the lines... I don’t think anyone’s comfortable when talking about withdrawing care but if that’s what we are talking about it needs to be said in a way that the family can understand it and sometimes it just feels like it’s so vague or [read] between the lines. I think we as social workers... say you
know doctor so and so is what your saying is this?... trying to give them some words that they can also use. \{PRIW 35 SW; 48-52\}

One Neonatologist acknowledged that EOL discussions with families in the NCIU were difficult and required practice and experience, beyond a HCP’s initial professional training. He described integrating learning from ‘protocolized’ training along with real-life experience. He also acknowledged an interdisciplinary approach to discussions:

I think you can learn the essential elements of that package, to actually do it in an effective way the only way in my opinion is to glean exposure, repetitive exposure to the situations because each situation is entirely different… learning a protocol for breaking bad news isn’t it… very good communication and learning how to work in an interdisciplinary fashion which in fact pulls in the key stakeholders apart from the parents so that there is a clear comprehension of the various factors that interplay to help in that final decision-making process … I think we can teach it don’t get me wrong, I think we can teach the elements of that and I wish I had actually learned at least the fundamentals through attending a course but I think so many factors interplay in this that you know that unless you are exposed… you develop your own style, truly you develop your own style… where I think that is important is you know learning what to say, what not to say, that in fact may jeopardize the situation. \{PRIW23 NeoMD; 101\}

The importance of experience and practice in communication was therefore highlighted by our sample. Learners mentioned the importance of learning from role models (good or bad) and wished for opportunities for practice and to receive feedback/debriefing after challenging conversations. Interestingly this practice of feedback was not described by experienced clinicians. One Resident recounted an experience where she and another resident observed a staff person at a family meeting, but were reluctant to offer feedback:

Huge amount of clinical information given and very wishy-washy initially … then it took a really, really long time to get to the point of saying look… we are really sorry but there is nothing more we can offer… just from witnessing it, it was really stressful on the parents and on the support person for the parents ‘cause they were sitting there… waiting for the ball to drop… they know something’s coming but … nobody’s coming round and just saying it… the two of us afterwards were kind of talking about it in terms of what we didn’t like about what was said but… there’s no way that we could have had that discussion with the staff… In terms of for our own learning it was just kind of us sitting back and going um yeah I didn’t think that went over very well… but I don’t know… how many times people afterwards come out of those meetings and … actually sit down and debrief on how they went. \{PRIW12 Resident; 101\}

Finally, HCPs highlighted the specific skills of good communication, including: avoiding jargon or complicated medical language; engaging in active listening (allowing parents to talk and ask
questions); the use of appropriate tone; understanding and employing empathic body language; and finally, following parents’ cues. These will be further elaborated in a subsequent section examining the virtues of good communication.

5.1.3.3.2 Dealing with uncertainty and inconsistency

As previously discussed, HCPs felt it important that parents have access to frank, clear, and accurate information in order to make decisions. It was generally understood that the most responsible physician on the team was the one who provided this medical information to families. This posed a challenge in some cases, where uncertainty regarding prognosis existed. In addition, it was difficult for HCPs to identify what outcome or risk percentage was meaningful to families and for their baby, how certain, was certain ‘enough’. Similarly, the degree of ‘meaningful certainty’ varied amongst team members and affected team function. Individual clinician acceptance or ‘tolerance’ of uncertainty affected which patients were offered palliative care. This variation also influenced team discussions and consistency of care. One Nurse Practitioner described the dynamic:

I think also when there is uncertainty amongst staff members when everyone’s not on the same page that can be a challenge... if you have nursing and medicine who are thinking totally different things, that’s a challenge to overcome. In the position that I am in as a practitioner I am sort of like that middle man between nursing and medicine and so I have been in situations where I understand where medicine is coming from and what they are thinking and in order to offer withdrawal of care you need to be 100% sure in some case and in some cases you don’t, but it’s all dependent of the physician... in the nursing world... there’s in some sense there’s the empathy, the compassion, the more emotional gray zone and so you understand how nursing is feeling as well that’s it very difficult to sit and watch a baby suffer when you know that it’s unlikely that there’s going to be a good outcome but the key word is unlikely, where the physicians are always thinking there’s always that chance. So there is a little bit of a conflict there. {PRIW10 ACNP; 219-232}

The art of truthfully acknowledging uncertainty while also providing consistent and ‘useful’ information to families, in a manner that is in accordance with their values will be explored further in the sections highlighting virtues important at EOL.

5.1.3.4 Consequences of breakdown in communication

The challenges in communication illustrated above were found by participants to have consequences to both families and HCPs. Some of these consequences influenced decision-making, caused harm to families, and affected interprofessional team function.
5.1.3.4.1 Communication influencing decision-making

HCPs identified parents’ need for information in order to make decisions, and decision-making appeared easier for parents when they were able to have their questions answered during discussions. In addition to providing consistent answers, HCPs perceived that the way in which they answered parents’ questions and framed information, also appeared to influence parents’ ability to make decisions. One Nurse described the compounding effects of inconsistency of caregivers, inconsistency of information, and different framing, on families:

I think an acute problem that we have here is … whether they have their own personal beliefs… we find that the attendings are being inconsistent in the whole approach to families. So one physician may come and say to a family you know there’s not much we can do for your baby and we have done the best we can and paint sort of a grim picture and the next one will come and say oh well you know there’s probably a 50%, 60% chance of survival... and they change every two weeks… I think if we had sort of one attending that deals with the family as far as information, so that their opinion or the way they explain things is consistent for the families, then they don’t feel they are getting mixed messages… you find a lot of anger from some of these parents where they will say well you know doctor so and so told us this and you get the next one who is saying well you know this is what I believe… when you are getting to the really difficult cases… and you have to make a decision it’s difficult for the parents. {PRIW20 TN RN; 236}

5.1.3.4.2 Harm to parents

In addition to confusion or frustration that families may feel facing inconsistency in communication, HCPs worried that the communication challenges described above would leave some families feeling mistreated, as expressed by one Chaplain:

Physicians in particular need to recognize that they first and foremost are human beings and that I think a lot of what transpires, that these parents feeling mistreated, has to do not only with communication, but connected with communication is the physicians’ discomfort with death… particularly with the death of baby. {PRIW7 Chaplain; 277-281}

The right balance of content, skill, timing, and caring necessary for effective, morally contoured communication with families will be discussed with the development of the ethical framework, in subsequent sections, and will include strategies to decrease avoidable harms to families.

5.1.3.4.3 Effect on team function

Though the emphasis for HCPs was patient and family centred, there were analogous effects of poor communication practices on the function and comfort level of the health care team. Several
HCPs on the interprofessional team highlighted the primacy of the physician’s approach to WLST decisions and discussions for team dynamics and function. One Chaplain stated plainly:

I don’t have it in for physicians but they often set the tone. The extent, to which the physician is comfortable with the issue, explaining to the parents, often determines the extent to which the rest of the staff involved in the patient’s care is comfortable. {PRIW7 Chaplain; 321-325}

In summary, effective communication with families around diagnoses, prognoses, and EOL issues was felt to be a large component of EOL care and decision-making. Moreover, improvement in communication was believed, by the HCPs in our sample, to lead to improvement in overall quality of EOL care.

5.1.4 Parents’ needs: guidance, support, and relationships with caregivers

In addition to expertise in understanding the special circumstances of critically ill newborns in the NICU and expertise in communication, HCPs identified families’ needs for guidance and support throughout the entire EOL process. For many HCPs guidance and support first involved establishing relationships with infants and families, followed by the ability to engage in shared decision-making, the development of comprehensive palliative care plans, and finally, physical, emotional, and spiritual support through the dying process and bereavement period.

5.1.4.1 Consistency of care

In addition to the importance of consistency with communication, consistency of caregivers was perceived as critical to families in the EOL process. Not only did the inconsistency of physicians risk families receiving mixed messages as illustrated above, but rotation of other HCPs on the team presented challenges in understanding the decision-making process and the ability to carry out care plans. One Nurse Practitioner described:

I think one of the challenges is the inconsistency of care… if I am on one day with one set of families and the next day I move over to another patient’s family and I have not been part of that whole discussion that’s happened… it’s difficult to document an entire conversation and get the feel… for the visual cues and the tones… the exact words… So when you come sort of in the middle of that decision sometimes that can be very difficult because you don’t have a very clear understanding of how things came to be and you have to trust that the process was honored and that the decisions are being made for the right reasons. {PRIW10 ACNP; 202-211}
In the same way, one Fellow reflected on how difficult it must be for families lacking continuity of caregivers, worried that they may feel bereft or abandoned when caregivers switch over:

To me the most important thing is the continuity of being able to follow this through or at least feel that you have made satisfactory arrangements and the parents aren’t going to be left high and dry with somebody they have never met before or that they can’t relate to. {PRIW5 Fellow; 164-168}

Finally, HCPs suggested that ensuring continuity of caregivers was the first step in establishing supportive relationships with families.

5.1.4.2 Relationships

Nurses in particular perceived themselves to be in a supportive role for families during the decision-making and EOL processes. An important component of the ability to provide this support and guidance lay in the relationships HCPs developed with families. One Nurse Practitioner described the importance of these relationships:

Often they want … somebody that they know, so it’s always good when you’re making that plan that the nursing staff or the medical staff are people that they have already built a little bit of a relationship with, they usually want those people to be around. {PRIW11 ACNP; 21}

HCPs reported that supportive relationships with families:

i) facilitated decision-making and bereavement

ii) could be rewarding for caregivers themselves and

iii) allowed caregivers to provide better care

In addition, HCPs described challenges that arose when these supportive relationships were lacking. Nevertheless, it was also apparent that, though supportive relationships with families were vital, relationship boundaries between HCPs and families sometimes became blurred. In these cases, there was resulting harm to both families and HCPs.

5.1.4.2.1 Relationships facilitate decision-making and bereavement for parents

HCPs reported that ongoing supportive relationships with caregivers in the NICU facilitated parents’ acceptance of prognoses, assisted discussions and decision-making regarding the transition from curative to palliative care, and allowed parents to begin a journey of supported
bereavement in the NICU. This process and the importance of ongoing relationships were beautifully illustrated by one Chaplain’s experience:

Here’s an example… twins born at 25 weeks, one appeared to be much stronger than the other… I sat in the neonatologist’s meeting with them where one twin was doing very well and the other one was deteriorating … we baptized both of the boys and we did it in a service in which wonderfully the nurses took part and sometimes the physicians even do… the parents had tried for a long time to have a child… and so giving up the one was very, very, difficult for them… after a long and very tearful process they came to the conclusion that they had to let this baby go. The process from my point of view was done so professionally I was impressed… [the doctor] had met with the parents almost on a daily basis as this one child deteriorated, had always included all of the disciplines in the meetings which made us all very aware of what was happening… when we met with them individually we were all coming from the same [page] and when it came time for that meeting … to tell them this is as far probably as we can go with your one son… losing any child is horrendous, the fact that they now felt strong affiliation with the doctor, with the primary care nurse, with the social worker, and with the chaplain they were so supported in the process… I had done a prayer prior to the removal of life support at their request and then we placed the baby in this little bassinet and the nurse had dressed him beautifully, all these little touches that seem so superfluous to new people, are so important…I did subsequently do the grave side service after that so it was continuity for them right through … we were able to provide them with the support to let the child go and to say good bye in a manner that was so respectful and so mindful… everyone involved with that particular case had so much awareness. {PRIW3 Chaplain; 23-24}

As highlighted by the experience above, EOL care is an intimate process. Ongoing relationships, allowed HCPs to prepare families for the potential outcomes that may occur, i.e. eased families into the understanding and acceptance that their critically ill newborn may not survive or that difficult decisions may need to be made. HCPs perceived that parents needed close support during death and dying, and this support was best provided by an interprofessional team who had already established a relationship with the family. In the same way, at parents’ request HCP attendance at baby’s funeral was not an uncommon occurrence and allowed some closure for both HCPs and families.

5.1.4.2.2 Relationships can be rewarding for caregivers

As evident from the Chaplain’s experience above, HCPs described a strong sense of personal reward stemming from engaging in supportive relationships with families. One Neonatologist tried to describe the privilege of working with families at EOL:
There is simple reward in being as close or as involved with parents under those circumstances… it’s sort of hard to explain the rewards, it’s very personal. It stems in part from the belief that I mentioned earlier about the sort of the privilege of being involved with a family of a dying patient. {PRIW24 NeoMD; 85}

These rewards were evidenced when families invited HCPs to attend memorials for their baby, when they returned to share future happy moments with the team or when they stayed in contact beyond their bereavement period with the primary caregivers they interacted with.

### 5.1.4.2.3 Relationships allow caregivers to provide ‘better’ care

Beyond the personal sense of reward, HCPs attested that establishing consistent, ongoing, supportive relationships with families, allowed them to ‘know’ the family, to ‘understand’ the baby, and to provide better quality care. One Nurse explained:

> A primary nurse with a patient, for however length of time… seems easier to me… you understand the baby much more clearly… you know everything that’s gone on and you also know the family. I find it’s hard if you come in and … [the baby] has died and you haven’t really had a chance to get to know the family… you don’t really know where the parents are coming from… it’s harder to try and get them involved … you don’t know what they are comfortable with and what they are not comfortable with… it’s sort of a rush, rush, affair… it’s sort of a, ‘oh he’s dying, okay lets go… here, quick hold him’… it’s not as nice as when it’s been a long term child and you can sort of [work] up to that possibility… that one day this may happen. {PRIW15 RN; 17}

After the death of the baby, some HCPs recognized the sense of loss parents may feel when suddenly, they return to their life outside of hospital without their familiar health care team surrounding them. The social workers in our sample recommended that staff remain mindful of the effect of the loss of these important caregiver-parent relationships.

Some HCPs drew on their own personal experiences in establishing these relationships, enabling them to share in the sadness and grief that families were experiencing, in a supportive way. One experienced Nurse reflected:

> I have many years of experience in the unit so I actually couldn’t even count how many babies I probably have been involved in directly for [WLST]. I think personally … I was a better person after I had my children because I could relate to that pain of losing a child, not that I have personally lost a child… what that feeling is of having a baby … I think that that understanding was stronger… I don’t think I did a bad job before but I think that compassion, caring was stronger I think as I have grown older. I used to cry on my own, I would leave the unit and cry, but now I cry with the family. {PRIW25, RN; 21}
Achieving the right balance of intimacy and professional support in caregiver-parent relationships in the NICU can be a challenge however. The next sections explore the harms that may occur when the important professional boundaries in relationships become blurred.

5.1.4.2.4 Importance of relationship boundaries: harm when caregivers become ‘too attached’

HCPs described forming deep attachments to families and in particular to the babies themselves. This was particularly common for babies who spent months in the NICU. One Nurse contrasted how deaths could be emotionally different for staff:

> As a nurse I become emotionally involved not only with the family but with the child as well especially if you have had that child for a long time. Sometimes we have them eight months... you are emotionally involved with... your thoughts for the baby and your feelings for the family and doing what is best. I think that it’s always a very sad and traumatic event but... how long you have been involved with the family does make a difference. Sometimes if you have only known them for a very short period of time it’s sometimes a little easier emotionally on you... Whereas if you have had them for a really long time and you are emotionally involved in both family and baby, it’s much harder. {PRIW17 RN; 29}

This closeness of nurses to families and babies, related to proximity and to time they spend at the bedside, was common amongst several nurses. Some staff even viewed themselves in the role of primary caregiver, as in the case of this Nurse, who was distraught when she was not present for the death of one of her primary patients that she had cared for, for six months:

> I heard about it but I wasn’t here and I wasn’t really informed... being one of his primary nurses no one ever called me to say this was the game plan and I couldn’t say my last good byes to him, that was kind of hard... she said I couldn’t get a hold of you but I said they could have left me a message... [I would have ] wanted to... visit with the parents... that last minute of support and give them the feeling they made the right choice and just say good bye... because I was the caregiver. {PRIW2 RN; 51-59}

HCPs who felt invested in the relationships with babies under their care often continued to follow their clinical course even once they left the NICU, and for the long-term NICU residents, when their death occurred in other parts of the hospital, some staff continued to be affected. One Transport Nurse described a few such cases:

> Those babies died generally not here but down in PICU but a lot of the nurses still kept in contact... and would go down and see the baby and see how they were doing... if you were working and if you had time to zip down there for a minute... and then those babies died. I think some of the nurses were... pretty devastatted. {PRIW6 TN RN; 221}
Finally, clear blurring of the relationship boundaries occurred when HCPs were so invested in the caregiver relationship with the infant that they began to press families to make decisions or became morally distressed when decisions were not made in the way they wished them to be. This will be further explored in the next section on shared decision-making.

In summary, achieving the ideal supportive relationship between caregivers and families in the NICU at EOL was challenging for HCPs, but when achieved, it improved the family experience around EOL and was professionally and personally rewarding for staff.

5.1.5 Shared decision-making

Decision-making around EOL in the NICU was described by HCPs as an intimate and complex process, and HCPs recognized that parents had the right to make decisions affecting the future of their family. In trying to understand the concept of discussing WLST and obtaining consent from families, one Resident suggested that the role of the physician in these discussions was different from consent discussions for other procedures:

> When you’re counseling parents you want to get informed consent for other things … you give them you know the risks, benefit, blah, blah, blah… you ask them to make an informed decision… in those circumstances… you’re not just a dispenser of information… they are looking to you for your wisdom and your guidance… how much of that overlaps to withdrawal of care decisions? How much do they look to you for what your decision would be in that circumstance? Is that something that we should be even offering or implying? ... because certainly in the treatment realm you know 99% of parents regardless of the information that you give them will do what you as a physician would recommend. So is the circumstance the same in this situation? … They would do what you feel is the best thing and is that right? I have no idea… Is it appropriate to be suggesting or implying or even full out saying you know what we would suggest in such a situation? {PRIW12 Resident; 203}

The next sections will explore components of shared decision-making and potential quality indicators as perceived by HCPs, as well as some inherent challenges faced by both HCPs and parents.

5.1.5.1 Quality of care in decision-making

As previously described, it was sometimes difficult for HCPs to transition from curative to palliative care. HCPs themselves were at different stages of understanding and acceptance of the diagnosis and prognosis. Some HCPs suggested that undertaking WLST should be a consensus
decision by the multidisciplinary team. Most HCPs described a lack of structure and great variability in practice when approaching palliative care decisions in the unit. One Neonatologist described his previous experience which included team meetings and obtaining the opinion of palliative care specialists before meeting with parents. This Neonatologist compared undertaking EOL decisions here versus places he had trained in in the past:

It felt lonely because there is not a structure here… when I was training in another place they had better structure for this kind of decision, they had a group of people called palliative care people so every time a doctor was faced with that kind of situation we called this group of people, we presented the case and they had very different professionals in the group… and we come up as a group with decisions. Here my own experience was I tried to collect opinions from different people working here but I felt that basically I had to go for that decision by myself. {PRIW28 NeoMD; 17}

The concept of a dedicated expert team for consultation around palliative care decisions including ethicists and other multi-disciplinary members was also suggested by other HCPs in the sample. One Nurse described the expertise she perceived that families needed and what might be missing in order to provide quality care:

Most doctors are uncomfortable… patients’ families look to the physician because they are the all-knowing and that’s what I do when I had family members passing away, you know look at the doctor for the answers and so maybe… some are very good and some are just as uncomfortable as I would be. So I think it’s better, I’m not saying a 24 hour call group, but a group that you can at least get some info off of because right now we only have social workers who obviously are very good at it but I think a team approach…. What are we going to do? How are we going to do it?... What is the time frame? What are we saying to the parents? Let’s all say the same thing or have one person be a spokesperson. {PRIW30 RN; 113}

Providing quality of care to families during decision-making (whether direct from the NICU team or a specialized group of palliative consultants) involved the skills in communication, access to information, and concepts of support and guidance outlined above. Two components of good quality decision-making at EOL that were apparent from our interviews were:

i) Decisions were shared between parents and caregivers; and

ii) Parents felt supported in having made the ‘right’ decision.

HCPs indicated that parents needed to be guided into decision-making. HCPs felt that parents wanted to understand all of their options and the reasons why a decision needed to be made. Multiple meetings were sometimes required and timing for families varied. Different professions described different roles in shared decision-making with families which will be illustrated later
sections examining team identity and team function. There was also disagreement across professional groups about where the locus of control should be in decision-making, and about how directive medical personal should be in counseling families. These professional differences and the effect on families and team function will also be explored later.

All professionals felt that parents needed support in decision-making. Some HCPs felt it was important that parents did not feel alone. They also highlighted the importance of support that parents received from their own family members. Finally, there was a clear message from some HCPs that parents must feel supported no matter what their decision. One Transport Nurse identified parents’ greatest needs during WLST decision-making to be:

Information, so that they can make whatever decision they need to make whether it be to discontinue or not and then support that regardless of how we feel, their decision is what it is, what we are respecting, and that we are supporting them for however it goes. {PRIW20 TN RN; 155}

In this way, a good quality decision at EOL for parents was the ‘right’ decision for them. As one Nurse described, parents sought reassurances, “you have fabulous social workers, [but parents] look to the doctor for guidance for the right decisions, have they made the right decision?” {PRIW30 RN; 69} Participants recommended that HCPs provide reassurances to parents that the right decision has been made. One Dietician imagined being in that situation: “I think I would be constantly questioning what I was doing and whether I was doing the right thing and [parents] probably need lots of support and reassurance and follow-up after the fact after the baby has died.” {PRIW26 Diet; 61} One particular challenge to feeling that parents have made the right decision is when the baby does not die immediately after WLST. One Chaplain described situations such as these that required close parental support and reassurance:

When support is withdrawn and then the child doesn’t die immediately that’s very difficult for parents… and when a child continues to breathe you know for several hours afterwards it can be very agonizing and sometimes parents need help reframing what they remember … parents will sometimes second guess themselves in: did we do the right thing? Could he or she have actually lived if we hadn’t you know agreed to withdraw support? {PRIW7 Chaplain; 159-172}

HCPs were asked, what tells them that they and other professionals have done a good job meeting parents’ needs when making WLST decisions. One Nurse answered: “Obviously the parents are going to be upset but I guess that they seem in some way at peace with the decision that they have made.” {PRIW31 RN; 204-208} The most common answers were indeed, that
parents felt supported, they felt the right decision has been made, and they were able to move on through their bereavement period.

5.1.5.2 Challenges in decision-making

HCPs worried about the level of stress EOL decisions placed on parents. Often they perceived parents were not ready to or could not possibly make ‘informed’ decisions given the tragic and emotional circumstances. HCPs acknowledged the weight of these decisions, describing them as the biggest parents would ever make, that would affect them for the rest of their lives, and stated that parents would have to live with the consequences in both the short and long term. HCPs felt it was their responsibility then to ensure that parents did not have any regrets. One Transport Nurse explained:

You don’t want them to live the rest of their lives thinking did we do everything we should have done? Maybe we should have waited another week, maybe we should have waited another couple of days, maybe if we had only done this it would have been different. It’s our job to make sure that they don’t walk away with those feelings… Because it’s very difficult to live with yourself after knowing that you have had to make that decision on your own. {PRIW6 TN RN; 133,291}

There was sometimes an underlying struggle that HCPs faced, not wanting the baby to ‘suffer’ given what they perceived to be an inevitable end, while decisions were being made, but also not wanting parents to feel they were being rushed to make a decision. One Nurse recalled a baby she looked after and how difficult it was for family and staff:

He was a very bright, sweet little baby… it was pressure from the grandparents… they watched TV and looked on the internet… for a heart lung transplant [that] just wasn’t going to be. At one point there was just no options for [CHILD]… that was just kind of prolonging the inevitable I thought… as nurses we were getting destroyed because we felt it wasn’t fair to [CHILD]… he was having these events… and his parents didn’t want withdrawal of care they still wanted a code, there was always going to be code no matter what… ultimately he was going to die anyway and in the end we eventually convinced the parents that [CHILD] was going to die no matter what and that it would be kinder for [CHILD] if he would just have withdrawal of care. {PRIW2 RN; 42-49}

The ‘optimal timing’ of discussions and decision-making was often difficult to achieve. HCPs described it as somewhere between not too hasty and not too dragged out. One Neonatologist described working with parents along their timeline:

So [the team’s] expectations are out of sync with … where the parents are and sometimes the parents just need a couple more days… [parents were] not prepared
to make the decision… day after day the story was dragging out and all of a sudden something clicked for them and they made the decision and the baby was taken off life support and some of the staff expressed surprise and wanted to know what had happened that suddenly the parents changed their minds… it is that the parents evolved to a point where they were ready to make the decision and maybe they weren’t voicing that evolution in a way that everybody would see it but if you spend enough time with them you can see that evolution in their thinking… so it’s not a change in mind, it’s giving them time to unfold. {PRIW19 NeoMD; 49}

Related to timing, another challenge to decision-making was when parents were not on the same page or disagreed about what the decision should be. One Nurse described a scenario she faced:

The only problem was this family, I don’t think that they were all sort of on the same page when it came to decision-making. They did seem to be united and you know made the decision together but at the same time we sensed a little bit of conflict between the mother and the father so that made it a little more difficult… they were going through the whole gamut of emotions, grief, shock, anger … any of us didn’t know what to say or what to do to make it better for them… just trying to read you know the best way we could support them without being too over bearing on them … because you know you sort of need to find a happy medium. {PRIW 21 RN; 49}

A further challenge for HCPs involved supporting parents during decision-making while not imposing their own values. HCPs spoke of reconciling their own beliefs with those of families and the difficulties of trying to be objective in order to provide care and guidance. One Social Worker reflected on when the values of HCPs and parents did not align:

I think again personal values, people just can’t understand how a family would decide not to withdraw care… so it’s those personal values that come across… sometimes you hear that a lot, ‘they are just not getting it’ when very clearly our assessment is that yeah they clearly understand, they are just choosing not to and that is their choice. {PRIW 35; 152}

HCPs suggested being mindful of the influence of faith beliefs and cultural norms on the decision-making process. One Resident described struggles that can arise when these beliefs are not known or understood by HCPs: “It’s always a bit difficult as well when the parents have a different idea in terms of goals of care… and the team is in a different position…”, she continued to recommend that HCPs become aware of different beliefs regarding WLST practices: “as much as you can, inform people different belief systems are such that they require that absolutely everything’s done until the very last breath whether that be now or years from now.” {PRIW12 Resident; 209}
Respecting parents’ choices and values sometimes challenged HCPs particularly when having to interact with families after WLST was offered but declined, as these Transport Nurses described:

Nurse1: We have had some parents where discontinuing care has been recommended and the parents have become very adamant that they don’t even want to consider that … what the long term effects will be-

Nurse2: - and usually those parents get very, very difficult … usually the ones that are the hardest to deal [with]… the ones that you know you put so much into and they leave feeling so angry and you understand that but it’s so hard to take when they … take it on you and you feel so bad for them. {PRIW20 TN RN; 161-164}

Achieving ‘quality’ in EOL decision-making is therefore challenged both by aspects pertaining to parents’ understanding, acceptance, and values, as well as by the values of the HCPs themselves.

5.1.6 End-of-life planning and care

Although there was no specific palliative care team at their centre, HCPs stressed the importance of pulling together an interprofessional team not only for EOL discussions but also to provide EOL care itself. The first step in providing EOL care involved HCPs understanding the infant’s needs and parents’ wishes. Once these were identified HCPs aimed to provide care according to the values and beliefs of families, incorporating parents’ wishes into babies’ care, and facilitating meeting their needs during the WLST process. One Nurse described the role of the bedside nurse in this process:

The bedside nurse participates in the meetings with the parents where it’s discussed and then supports the parents… facilitate them in getting family involved… being with them throughout the whole process, explaining to them exactly what will happen, and staying with them… if that’s what they want or just allowing them the time to be together as a family… knowing that you are right there for them. {PRIW29 RN; 17}

The concept of tailoring EOL care for each individual baby and family was paramount to all of the HCPs in our sample. In addition, from their experiences, HCPs identified five common needs of babies and families. These were:

i) It is important to relieve and prevent suffering at EOL;

ii) Parents and babies need a good EOL care plan;

iii) Parents and babies need caregivers who are skilled in EOL care;

iv) Parents need their own ‘culturally appropriate’ spiritual and emotional support;
v) Parents need to experience the ‘role of parent’ before the death of their baby.

5.1.6.1 Important at end-of-life: relieve and prevent suffering

There was a solid consensus amongst HCPs that babies should not suffer at EOL. HCPs, particularly nurses, felt it was important for parents to be reassured that their baby was, and always appeared to be, safe, calm and comfortable. One Nurse practitioner described how WLST could be ‘messy’ and appear unpleasant:

I certainly am always concerned that the baby is going to you know struggle or look like it’s suffering or in pain… we try to have sort of a plan for how we are going to manage the baby’s sedation or pain prior to withdrawal of care… so the baby can be in sort of a calm state… the actual withdrawing of care is a little bit messy because there’s machines and it’s noisy and it takes a few people and so we try to do it as nicely as we can… sometimes we can take the baby off the machine in a noisy place and the parents are sort of waiting somewhere where it’s nice and you can take the baby to them. {PRIW11 ACNP; 21}

For one Neonatologist in our sample, the ability to objectively assess suffering in a baby was a challenge, and he wished for a more consistent, objective approach in his unit. He spoke specifically to prescribing the right amount of comfort medications and how to monitor their effectiveness particularly in cases where WANH was undertaken. He also suggested the perception of suffering in babies may reflect the suffering of parents or those of the HCPs, in response to the situation:

We don’t know what the newborn is perceiving… the nurses worry that if we stop feeding the baby, it would be in distress and if the baby starts to fidget a little bit after a day or two, [nurses] say the baby is hungry cause that’s what they can relate [to]… or they say the baby is in pain and they come ask for morphine… it creates a dilemma because we don’t want to be giving the kid a lot of morphine and be seen contributing to the death of the baby… people in the age group where we can evaluate their perception… they get dehydrated, they actually get less aware of their discomfort and it’s not an issue for the pain. It might be an issue of anxiety or other things… we are so accustomed to thinking that fidgeting and restlessness in terms of pain because so much of what we do can cause pain…we need to learn more about what, what actually is going on there… {PRIW19 NeoMD; 97}

Related to managing the overall ‘suffering’ inherent in the situation, three concepts arose from the HCP interviews:

i) babies should receive optimal comfort care and symptom management, if there is pain, treat it;
ii) ongoing or prolonged suffering needs to be dealt with by earlier decision-making and balancing the risks of current suffering and long term benefits. (HCPs perception of prolonging suffering differed across professions, and will be explored later); and

iii) the aim of EOL care and a way to prevent further guilt and suffering in families, is to ensure the baby has a ‘good death’.

The definition of a ‘good death’ in babies, like suffering, was not easily or objectively described. Nor could it be easily measured. However, the notion was identified as a marker of good quality EOL care according to the HCPs in our sample. HCPs associated a ‘good death’ with one that was gentle and peaceful; in which babies died with dignity. One Chaplain described the exceptional way babies are treated at EOL by nurses:

> Watching a nurse get a baby ready for this was one of the most powerful experiences I have had in this hospital. The way she bathed that baby and dressed that baby… I would believe if I were its mom or dad and I was holding it, that it definitely went directly from my arms to God’s arms because the baby looked like an angel. The way that she did it with so much loving care… all disciplines should be required to spend some sessions with nurses when they actually prepare a child for this. {PRIW3 Chaplain; 96}

A Nurse described her role in ensuring families have a ‘good death’ for their infants as “you are there to make that the best possible bad experience”. {PRIW14 RN; 13} This theme of making a terrible experience as positive as possible was common across caregivers, and a key marker for HCPs in our sample, that they have provided good quality EOL care.

Because a good quality death was important for babies and families, Residents worried about being able to one day provide families with this, given their lack of training and experience:

> Resident 1: End-of-life care is something that is very important for those that are involved in the child’s care and the family of that child. It’s something that you don’t learn how to do formally, we pick it up on the fly, it’s something that we have seen done well and it’s something that we have seen done very badly and it would be nice to have the opportunity to evaluate ourselves and to be taught some of those skills because it is something we want to be able to do well.

> Resident 2: I totally agree with what you just said… I recognize that death is something that we can all expect and that even the youngest of children can have that happen to them… I may not be able to do anything… despite my best intentions as a physician, but at the very least I expect myself to be able to give the parents a good experience as much as they could possibly have… it’s a horrible experience for them regardless but I can make things many times worse… I think I
would have a hard time... accepting my failure if I did that badly. {PRIW12 Residents; 301-303}

In order to avoid doing it badly, HCPs detailed some of the components involved in providing good quality EOL care. The first was a good EOL care plan.

5.1.6.2 Parents need a good quality end-of-life care plan

According to the HCPs in our sample, a quality EOL care plan should be individualized, well organized, and seamlessly executed. Consensus across staff was important not only for creating individualized and organized care plans but also to ensure that implementation was integrated and consistent. One Nurse complained: “I find that not all medical staff is on the same page. What one will do one day, the next people come in even hours later and change everything, which is very frustrating for parents and nursing staff.” {PRIW1 RN; 48-51} This was not only an issue of inconsistent care, but of professionalism, i.e. in respecting the care plans developed by colleagues. For some HCPs frustrated with inconsistencies in care, a solution proposed was the development of a unifying unit policy based on the literature, expert opinion, current laws, and understandings of ethics; while still respecting individual family’s wishes.

For HCPs, it was essential that the development of a quality EOL care plan include input from parents. Parents however could not be expected to ‘drive’ the process, as they had no prior experience or preparation for this role. HCPs in our sample stressed that parents needed guidance and to be made aware of their EOL options. One Nurse described it from the parent perspective:

A lot of times it just comes right out of the blue, they don’t know what to expect, they don’t know what is going to happen, they don’t know what the procedure is, they are not aware that they can take the baby to a private room… afterwards [parents say] I wish I had had this done and this. They are not given enough time to really think things through and I think that’s just the nature of the situation but I think sometimes if they have a little bit more time to think about how they would like things to go… {PRIW1 RN;129-136}

Other HCPs echoed this sentiment of needing to slow things down, particularly at moments of crisis for parents, to enable them to take part in the process. In this way, parents needed the time to plan how they would like to spend time with their baby. By letting parents know what to expect, HCPs could guide parents slowly and stepwise through the process of WLST and EOL care. This degree of anticipation and preparation (of potential scenarios and outcomes) allowed parents to understand their options for example: choice of setting of WLST, at the incubator, in a
private room, or even at home. By respecting their practical wishes, HCPs assisted them in coming to terms with their pending loss. HCPs also highlighted that parents need reassurance as discussed previously, that their baby will not suffer, and comfort measures including medications should be pre-ordered and ready for administration as needed. In this way, HCPs aim to organize supports and resources ahead of time, attempt to ensure that families have a comfortable setting in which to say goodbye to their infant, allow time for extended family and friends to arrive, remain available to answer the questions and concerns from extended family (as per parents’ wishes), and finally provide just the right amount of ‘supportive privacy’ for their baby’s final moments. One Nurse described her experience of gauging the degree of privacy or support parents need and how she provided it:

I came on and spent time with them in the morning and then stayed with them when the withdrawal happened because they didn’t feel they wanted to be alone… At one point the mom just felt she couldn’t cope, she didn’t want to hold the baby anymore, so I held the baby for her and when she was ready to take him back, because the baby didn’t die… he actually lasted longer than we thought he would… it was just being there the whole time with the parents. Some parents choose in other situations… that once the withdrawal happens… they just want to stay by themselves and we just come back and forth to check the heart rate and see how they are getting on. {PRIW29 RN; 21}

A particular challenge for both parents and caregivers, and what was often unpredictable, as highlighted above, was how long a baby survived after WLST. One Neonatologist described a situation in which a baby was not anticipated to survive and the anxiety and stress that resulted:

The baby was quite severely preterm, severely asphyxiated and had a chromosomal abnormality that normally results in the death of the child within the first couple of weeks of life… that baby we sent home and put into place a palliative plan with a pediatrician… with the expectation the baby wouldn’t live more than a couple of days… the baby ended up living for three months… When the baby didn’t die after the first couple of days there wasn’t a renegotiation of what to do, how much of an intervention to provide… On discharging the baby I wasn’t really thinking that far ahead ‘cause I thought the baby wasn’t going to live beyond the weekend and so the parents were very unhappy… then came back to me complaining that I hadn’t adequately planned for those things when I thought at the time the baby was discharged it was clear to all parties involved that we weren’t expecting the baby to live more than three days. {PRIW19 NeoMD; 61}

HCPs suggested preparing parents ahead of time that dying is a process, and the timing of death is unpredictable. If it is uncertain whether a baby will survive after WLST, this should be disclosed to parents ahead of time. The practical aspects of WLST, dying, and the events that occur after death including questions regarding organ donation, post mortem examinations,
storage of the body, and funeral arrangements, should also be discussed with families while developing the EOL care plan.

In order to achieve consistency of implementation of the individualized care plan developed with families, EOL care required ongoing monitoring by all members of the team, with discussions with families and adjustments made to the plan if needed. Finally HCPs recommended that if families were transitioning home with the baby to receive palliative care in the community, comprehensive handover to the receiving caregivers needs to take place, as well as mobilization of resources in that family’s community before they are discharged.

5.1.6.3 Parents need skilled caregivers at end-of-life

In addition to good quality care plans at EOL, parents need skilled HCPs to carry out these plans. HCPs often referred to individuals within the unit who were particularly skilled at providing EOL care, and suggested that these individuals often gravitated toward these cases, just as those with less comfort or experience, tended to shy away. One Nurse described the unofficial way this process evolved and the informal mentoring system present in the NICU nursing culture:

The ones that are the chosen are people with a real sensitivity… to families and what they are going through… there are certain people who are very in tune… what we tend to do is if there’s a… younger nurse, newer, less experienced, quite often we will say to them are you up to participating in this and quite often they are nervous and afraid… then we will get one of the other nurses who has had this experience of helping families to kind of mentor them along… so I guess we have our own little mentoring… but it’s informal, there is nothing spoken or written or anything… you just know who the people are… then you get these younger folks and you walk them through … {PRIW14 RN; 41}

For most HCPs, the ability to provide good quality EOL care was influenced by time on the job and experience. In some cases however, even experienced HCPs were not comfortable. One Nurse honestly described her discomfort:

I don’t do a lot to tell you the truth, that’s not my expertise. I am uncomfortable with it. Probably in the 22 years I have been there I have had two babies die on me which probably is pretty rare…. it’s very emotional, I don’t enjoy it at all. I don’t know what to say to people. I don’t really know the right words. {PRIW30 RN; 9, 21}

In contrast, a new staff member is hopeful that providing EOL care will get easier over time:

I have been here for a year and coming in as a… new staff member it was scary… it was really my first direct experience and I think that I was feeling a little
overwhelmed, but as I worked with the family and worked with the team I did feel more comfortable and felt that I was able to better support them… I think it’s just experience… I don’t know if it will get any easier but maybe I will feel better equipped because I will have more experience under my belt. {PRIW21 RN; 109}

In addition to skilled individuals in EOL care, the team needs to be skilled at anticipating the needs of the frontline caregivers providing direct support to the family. HCPs described at a team and organizational level, peer support in providing care, recognizing when colleagues needed help, or an extra set of hands, covering nursing assignments so primary nurses could focus on the EOL tasks, and finally the importance of ‘working together’. One Nurse illustrated the benefits of this team approach in supporting families and each other:

When it happened it was very silent and the parents were at the bedside and the nurse was a very experienced nurse… she drew the curtain and she turned the lights down and she was in there… just talking to the parents… I would say for at least two hours. So that nurse just kind of let go of whatever was happening within the pod and was there, and the rest of us in the pod we just knew that that was happening so we all kind of supported her in that role and we took the rest of the babies on and whatever else had to be done for that day… we made sure to keep it down in the rest of the pod and let them have their time… {PRIW22 RN; 17}

During the dying process, HCPs recommended that caregivers skilled in EOL care closely support parents through all the stages, provide physical comfort to baby and families, ensure that parents do not feel alone or abandoned while their baby is dying, and try to protect parents from unpleasantness by turning off alarms and monitors. For HCPs, finding the right balance of support versus ‘smothering’ was a skill learned with experience.

5.1.6.4 Parents need their own ‘culturally appropriate’ spiritual and emotional support

5.1.6.4.1 Understanding and facilitating spiritual support

Facilitating spiritual support for families involved understanding their beliefs and cultural customs; the meaning of rites, symbols and ceremonies; and recognizing the comfort and tangible memories families may derive from these. One Nurse described how sometimes she struggled to facilitate what was important to families at EOL:

They wanted to have a ceremony that they have where they burn grass… they weren’t allowed to obviously set a light in the ICU and that was really disturbing for them. So there must be room to do that… I don’t think we think outside the box in terms of trying. I mean at that point that child was going to die and the only
thing that we can do is make it better for the family… I think we need to be… more creative in trying to meet those needs. {PRIW33 RN; 124-134}

In order to understand what was important to families, HCPs emphasized the need to ask families directly. Some HCPs believed that a family’s faith influenced how well they were able to cope and noted that EOL was often a time that families turned to their faith or religion. More challenging for HCPs than asking about a family’s spiritual or cultural customs was tailoring care in a way that respected and honoured these while not feeling disingenuous. Residents spoke of this during their interview:

Resident 1: I believe there is a creator… that there’s a heaven and a hell afterwards and that children are especially treasured souls… I know the parents sometimes don’t believe… so it’s hard to comfort them in that way…

Resident 2: Because I don’t necessarily believe that personally so I find it difficult to know how to support somebody who does just purely … in terms of my own beliefs but … I do want to support the parents … because that’s what gives them the comfort at that time and what my values [are] don’t really matter per say.

Resident 3: perhaps that would be a helpful thing that somewhere in the beginning of like a discussion about end-of-life to say … what are your thoughts about death… what do you believe happens at the end of life… so you’re not being in-genuine, [you say]: this is what you believe… maybe this is where your baby’s going … like if they say I believe in heaven then you know maybe the baby’s going to a better place.

Resident 2: It just feels just a little bit disingenuous on my part just because that’s not how my, how I personally feel, but at that point it doesn’t matter because all you’re doing is giving comfort… not for you to express how you feel about it per say. {PRIW12 Residents; 159-167}

The struggle between faith beliefs, technology, medical prognoses, and WLST recommendations sometimes posed a challenge at EOL in the NICU. One Chaplain recalled the stress placed on families and her own inner struggle:

So often families are struggling… they might have a child who has severe brain damage, cerebral palsy, blindness, deafness, some people of some faiths feel it’s not their right to end a life that could be saved no matter what and I think my biggest challenge is as a religious caregiver to let them know that it’s machines that are doing this, they are not making the decision, they are just removing a machine and to provide them with the spiritual strength to say it’s not God’s will that they would live on a machine indefinitely… It’s because of all the interventions that we can do… you have to be trained in multi-faiths so that you can make meaning for these people so that letting go does not mean that they have abdicated their right as parents but rather used their rights as parents to do what a
loving God would do for this child… Make it okay to make a good decision… it’s a huge challenge because in a way you feel like you’re playing God. {PRIW3 Chaplain; 40}

Another challenge HCPs identified involved cultural misunderstandings and HCPs making assumptions about individual families based on cultural biases. One Neonatologist described one such experience:

We made the mistake; I think we assumed that it was related to the culture. [The chaplain] said don’t worry about it, I come from the same country, I know what these people are thinking and charged in with all kinds of assumptions in mind based on the fact they came from the same country, same cultural group and made a complete hash of situation, got the parents very angry because in fact the assumptions he made were entirely incorrect. So all I’m asking for is how do I get the discussion started? … What kinds of things might be on their minds, their perceptions, not only about the death of an infant but also about the role of the physician in the whole dynamic… I want to know what are the possibilities… part of the problem is for some cultural groups, I don’t know what’s on the menu. {PRIW19 NeoMD; 97}

HCPs therefore acknowledged the importance of understanding and supporting spiritual and cultural practices; though at times these posed a challenge. Practical recommendations from the HCPs in our sample included: problem solving about how to facilitate the timing and involvement of families in religious rites; inviting religious support in for families early in discussions; and taking part in the rites and rituals with families if invited and HCPs feel comfortable.

5.1.6.4.2 Helping parents to navigate the “emotional roller-coaster”

Multiple HCPs perceived parents in the NICU to be on a type of emotional roller-coaster. They described witnessing the overwhelming and paralyzing grief, anger, fear, guilt, shock, and denial. They recalled parents asking “why me?” and noted that couples may not always be on the same emotional page. During their interview, two Social Workers discussed the difficulties some staff encountered facing parents’ emotions:

Social Worker 1: Of course parents are going to cry and some [HCPs] are so uncomfortable with that… you know they want them to stop crying-

Social Worker 2: Or they just want to get out of the room… ‘I will just leave you now with the social worker and I will come back if you need me’. You see us tearing down the hall after [the physician, asking]: ‘Can you come on back?’ … we just need to be comfortable with the full spectrum of emotions…
Social Worker 1: - and coping I think ways that people cope is an important part of that because people cope in so many different ways… you know a baby that’s extremely, extremely sick and all the mum wants to know is, is he peeing? … it really doesn’t mean anything but to her it gives her that hope for him… it’s a practical thing that she can understand, she can focus on, and that’s it. You know that’s a way to cope and help her through this. {PRIW35 SW; 310-314}

HCPs acknowledged that everyone reacts differently to death and dying, and different families have different ways of coping. In regards to navigating parent emotions, HCPs recommended:

i) give parents the permission to feel and express their emotions;
ii) know both that parents can ask for help but not to wait for them to do so;
iii) offer counselling and professional support if needed, particularly in cases where there may be co-morbid issues of depressions and/or anxiety;
iv) prevent further suffering and stress by giving parents emotional breaks; and
v) help parents to take care of other practical ‘life-matters’ (dealing with bureaucracy / insurance / work / extended families) that often compounds the stress they are under.

5.1.6.5 Parents need to be ‘parents’

HCPs recognized that EOL care in the NICU was tragically unique in that parents had not had any opportunity to ‘parent’ their babies before they became critically ill. Part of their loss involves the loss of their identity as parents. The care and dignity provided to babies at EOL helps parents to experience their role as parent, as this Chaplain described a sad case where a baby’s father was not able to arrive in time to meet his child: “What they are going to remember is that they really did have a little baby. It was only 24 weeks old but it’s their baby and it’s their child for forever. You have made it real for them even though the father didn’t see it.” {PRIW3 Chaplain; 96}

In this way, respecting babies, preserving their identity and memory for families was of utmost importance. Nurses described taking great care to ensure a baby’s appearance was a comfort to families. In the same way, mementos were a standard of care. One Nurse even recommended involving parents in these aspects of tangible memory making:

We have certain things that we do with babies that are dying… what we do is make memories for families, we do certain things that they can remember that are … warm and comfortable and pleasant… we tend to take a lot of pictures so it makes the experience real to them and they have something to look back on when in fact they have nothing and that helps them with the grieving process. We really
encourage families to hold and touch and participate as much as possible... because they are the parents and they are the family... we do things like foot prints, little baby foot prints, hand prints, we cut a little lock of their hair, put it in a little bag with a little poem, and we make little arm band you know out of the beads. {PRIW14 RN; 45}

If parents were not emotionally ready for these experiences or for the memory boxes, HCPs would store these at the hospital during the aftercare period until parents were ready to have them.

In addition to preserving the memory of their baby, HCPs felt it was important that parents have the opportunity for normal parenting experiences. They emphasized treating the baby ‘like a normal baby’, encouraging holding, bonding, and concrete baby care. One Nurse described how she supported a family’s grief by gently encouraging these experiences:

However they want to grieve... do they want to hold their baby, do they want to bath their baby? I would let them do what they were comfortable with. Parents that don’t want to hold their babies I encourage them to do that, ‘cause parents in the past have said that they were sorry they didn’t... you can gently encourage them... do it gently and supportive, not pushy... can I make their baby more presentable, more baby-like and less hospital-like... dressing them, cover up things...try and make their baby look like a baby and not a patient. {PRIW25 RN; 9}

Finally, as illustrated in earlier scenarios, a special circumstance for parents arises in the case of twins or multiples. HCPs mentioned that it was important to be mindful of the need for memory making with both/all the babies for the parents and for the surviving twin/multiples in the future.

### 5.2 Comparison of health care professional roles and perspectives within the interprofessional team

As mentioned, care in the NICU is provided by interprofessional teams. For HCPs, the challenges inherent in decision-making around EOL and providing good quality EOL care affected the function of the interprofessional team, which in turn affected the quality of EOL care provided. In addition, HCPs described feelings of moral distress and occupational stress associated with EOL decision-making, team dysfunction, and witnessing the suffering of babies and families. This chapter compares and contrasts these challenges and their consequences across different professional roles on the interprofessional team.
Understanding and valuing the roles of different team members was the first step to improving team function and quality of care for families, as one Chaplain illustrated:

All new people to the profession whether they come on as a fully trained chaplain or fully trained nurse or a fully trained doctor but new to neonatal… walk in the nurse’s shoes, walk in the chaplain’s shoes, walk in the neonatologist’s shoes, walk in all the different sets of shoes and understand what everyone’s role is. I think understanding what everyone else’s role is gives value to all the team members and when all the team members are valued the parents get a sense of that and they feel more cared for. {PRIW3 Chaplain; 96}

5.2.1 Professional roles and challenges within the interprofessional team

The three main professional groups involved in EOL decision-making were the Neonatologists, the bedside Nurses, and the Social Workers (with the addition of chaplaincy for families who requested it). The Neonatologists in our sample self-identified and were recognized by team members to be the initiators of EOL discussions with families. Neonatologists described their role as ‘instigator’, ‘coordinator’, and ‘organizer’ of palliative care. Their first important responsibility was the identification of patients for whom WLST or palliative care would be offered. One Neonatologist described this role:

It’s usually the attending who identifies the fact that survival is unlikely and therefore initiating some degree of palliative care either in patients who are dying or patients who are so ill that they are likely to die at some point later… and as part of that identifying what constitutes appropriate palliative care… enabling appropriate nursing care, parental support, staff support… it’s virtually always the attending who is present for the majority of that discussion… as a consequence it maybe tends to be the attending who sort of starts to put together the bits and pieces that constitute palliative care … whether or not feeding is going to be provided… what analgesia or sedation is appropriate.{PRIW24 NeoMD; 13,21}

In addition to initiating discussions, the Neonatologist was seen to guide decision-making.

The bedside nurse was also important in the decision-making process. Nurses described a supportive role in decision-making; helping families to come to the realization of prognosis and making parents feel comfortable with their decision once it had been made. However, some nurses described variability in being invited to attend the actual discussions and found it challenging then to provide support to families afterward. In particularly difficult cases when Nurses were excluded from decision-making discussions, some Nurses described frustration when they were left to ‘pick up the pieces’. One Nurse explained being left out of the process:
Nursing is one of the major areas that’s involved in palliative care... because you probably have more intimate contact with the family and siblings involved... [Nurses] are not there often times when the decision is made and we are the ones that are left at the bedside. {PRIW17 RN; 13}

As the caregivers who spent the most time at the bedside with the baby and family, nurses described having to bear the emotional and psychological burden of caring for families as they navigated through their loss.

Social Workers in turn described their roles as interpreters and mediators for both parents and the medical and nursing members of the interprofessional team. They were involved in slowing the process down for families and seeing the ‘big picture’. One Social Worker described her role:

There’s a lot of crisis intervention, try to slow the process down to give families a time to think... try to liaise with the medical team... to say yes, can this be deferred for half an hour or helping the medical team sometimes to go over what they are saying in a more simplified way, provide some buffer between the team and the families so that the family then have a chance to think. {PRIW35 SW; 34}

Social Workers described the role of ‘middle man’, a liaison between families and HCPs, interpreting parent needs for the team and facilitating discussions. They helped Nurses and Doctors find the right language to use around EOL. One Social Worker described the role she played when the team and parents may disagree:

The parents can sometimes pick up on that... they will sometimes say, ‘I know that, you know, the nurses or the doctors think I’m doing the wrong thing’... and our role is to help support what they want to do... sometimes it is a little bit of a buffer between those vibes that they are picking up... and helping them understand on their own time. {PRIW35 SW; 46}

Finally, Social Workers also helped parents to understand what they could cope with regarding diagnosis, prognosis, and long term outcomes including QOL.

The role of learners including pediatric residents and neonatal fellows varied in our sample. Some felt like part of the team in EOL discussions, delivering the message. Others felt they played an important role at the bedside during WLST. There were a few however who were unsure of their role, and described feeling like ‘silent observers’.

Once the decision to initiate palliative care was made, members of the team continued to have unique roles. The Neonatologist described ongoing assessment of the plan, ensuring that it was being followed, and enabling staff to do so. At the bedside Nurse Practitioners described a role in
planning the details of care, including fluid and pain management. The Social Workers provided holistic and practical support, booking bunk rooms for family, organizing professional photography for memory making, inviting clergy/spiritual support as per families’ wishes, and providing information regarding funeral, burial, and aftercare. Finally it was the Nurses spending twelve hours a day/night at the bedside that provided intimate care for families and babies at EOL. One Nurse identified this key role:

I would venture to say as the nurse at the bedside we probably have the biggest role even more so than the physicians. They come around, they have a discussion … and the nurse at the bedside will go in, will meet with the family to sort of outline what we anticipate… and for the most part the nurse is the one providing the ongoing support and ensuring that the plan is executed. {PRIW14 RN; 13}

The effectiveness of EOL care provided to families was influenced by how well members of the interprofessional team functioned in their roles. According to HCPs, team function was affected by the awareness that HCPs on the team had of each other’s roles, individual member’s attitudes and assumptions, and the level of comfort of team members regarding death, dying and EOL care. There were a number of commonly held attitudes and shared experiences amongst the different professional members of the NICU team. Physicians, nurses, and allied health team members highlighted the importance of respecting parents’ wishes regarding their baby’s care and relieving suffering. They also highlighted the importance of the interprofessional nature of EOL care and the importance of team consensus. Each profession described minimal training in EOL care and approaches to decision-making. Attitudes regarding death in the NICU and the futility of technology varied amongst professionals in all disciplines. Another area of commonality to HCPs was the feeling of privilege of working with families and the rewarding nature of the work.

HCPs identified challenges to team function, these included: consistent communication and a consistent approach to WLST, achieving consensus amongst and across professions, trusting in one’s colleagues intentions, avoiding assumptions and judgments of other team members, and lapses in professionalism. These lapses in professionalism involving value judgments made to colleagues while EOL decision-making was ongoing, was described by multiple members of the team. One Neonatologist described the scenario in which this occurs:

I sometimes spend as much time dealing with the anxiety of the caregivers around the situation as I am dealing with the parents. That’s for me a huge distraction. For the nursing staff who are most directly involved in the care of the baby it can be a
very distressing situation when their colleagues are criticizing them for continuing to be involved in a case… I think it wouldn’t hurt to have some education for people about if you see something that’s happening that you’re not happy with and you’re not directly involved in the case, what are appropriate channels for expressing that discomfort? {PRIW19 NeoMD; 81}

These lapses in team professionalism significantly affect the team culture and the HCP’s ability to provide direct emotional and physical support to families. This Nurse described her feelings in this situation:

I can tell you one thing when you are looking after children who are critically ill, that a lot of times… staff people sometimes are very hard in saying, what are you doing? This is cruel. We shouldn’t be doing this kind of thing… not supporting you in the role of being the caregiver of this person which makes it hard ‘cause we are not given the emotional support. {PRIW15 RN; 57}

When there was team dysfunction affecting HCPs’ ability to effectively perform their role, there was moral distress described by caregivers in our sample. Moral distress was related to HCPs’ sense of responsibility to the patient and family, the intimacy of the relationship they had established, the witnessing of suffering in the NICU, and finally, the locus of control or responsibility of decision-makers taking part in EOL decisions. The origin of moral distress was perceived differently amongst the Nursing and Medical professionals in our sample and will be explored in the next section.

5.2.2 Moral distress in caregivers across professions

In going through the described steps of EOL communication, decision-making, and care, the first area of distress reported by HCPs involved identifying patients who should be offered the transition from curative to palliative care. This Neonatologist had contrasting opinions of the medical and nursing approach:

The thing that I think … distinguishes different groups though, is that the medical staff tend to be more analytical in their approach to things… the way that [nursing staff] express themselves is almost as if it’s coming from a gut reaction. I don’t like what is going on therefore you should stop, whereas the medical staff will be analyzing and trying to work through what are the probabilities of this or that, what are the parents actually saying, and I think are somewhat more tolerant of variations in parent responses than I think many of the nursing staff are. So I think the strongest reactions that I have encountered have come from the non-physicians. {PRIW19 NeoMD; 53}
In his opinion, Physicians are analytical, and thinking of the future, while Nurses are emotionally enmeshed in the present. Another Neonatologist described this challenge of perspectives influencing the ability to provide consensus-based interprofessional EOL care:

That everyone feels comfortable about withdrawal is not easy and the imbalance they are in sometimes poses a major difficulty. Where on the one hand it is clear that the nursing staff for example may say, you know, how much more are you going to put this baby through? While on the other hand the physicians might say but wait a minute… we perceive… no major issues in terms of long term compromise… and so may have what the nurses perceive as you know very intensive neonatal care being eked out to the limit… the discrepancy and comfort levels within the health care team in fact continues to be a problem in terms of making the ultimate decision for withdrawal. {PRIW23 NeoMD; 57}

Team disagreements regarding EOL decision-making often arose from similar differences in perceptions. A common aspect of decision-making related to moral distress in HCPs in our sample, was related to the spectrum of control or responsibility of the decision-makers. All professions described a concept of shared decision-making involving parents and physicians but there was disagreement amongst nurses and physicians about who should have ‘control’ over the final decision. Social Workers illustrated the variability in physicians’ approaches:

I think the way you phrase it is so important. I have been with some physicians who direct the conversation… are so good about saying we would strongly recommend that this is not in the best interest of your child and I have been with other physicians who might frame it as, well this is your decision… what parent ever wants to stop treating their child? How do you ever say yes to that? … you’re setting the parents up to go with continuing the treatment whether they really want to or not. {PRIW35 SW; 134}

For the most part, nurses felt that physicians were not consistent or directive enough in counseling and that physicians should be making stronger recommendations for WLST or more definitive declarations of when no further escalation of treatment should be offered:

Medicine should be directing the withdrawal process a little bit more… I don’t mean taking it fully away from the parents but being a little bit more up front and direct… a lot of the times we give this wishy-washy… we are not, blunt is really not the word I want to use but not totally honest with the parents… I don’t know if it’s from previous litigation or they feel that the parents need to make the ultimate decision but I think that medicine needs to have a different approach… saying to them we as medical professionals do not think that your baby will survive this or once they have consulted other teams should say we really cannot do any more for your baby so we feel we need to discontinue care, instead of saying to a parent well you have the choice of discontinuing care. I don’t think we should present it as a choice to the parents because they are not in an emotional position to make that choice at the end of the day. {PRIW29 RN; 29}
Physicians however, discussed the need for parental involvement and engagement in decision-making; for a more formal sharing of responsibility. Some stated they could not make the decision for parents and expressed discomfort when they alone were guiding the decision. Of particular difficulty were cases in which parents did not want to make a decision, as this Neonatologist described:

I will be giving them the facts, asking them to think about things and saying I don’t need a decision today but I want you to be thinking about the following things… and their response is whatever you decide doctor and it’s very difficult sometimes to get them engaged in participating in the decision… seemingly wanting to hand the decision over to the physician to make… that’s difficult because that is counter to what our Canadian expectations are about the role of the parents and decision-making… the most problematic ones… don’t want to have any part of the decision or they want the baby somehow to magically die without us doing anything or they want the sole decision to be made by me and that’s uncomfortable because that’s so different from what my expectations are… It’s not a necessarily wrong thing to do that, I just like to feel that when I’m writing my notes in the chart about how the decision was made that there’s more evidence of support from the parents with the decision rather than me just making the decision and doing it and them passively standing by… maybe that’s an okay thing to do, but it’s not a comfortable thing to do. {PRIW19 NeoMD; 57}

According to some nurses in our sample, the above case should not pose a problem, medical recommendations for WLST and EOL care should be easily forthcoming. In our interviews, nurses’ opinions on directive counselling in EOL discussions stemmed from four sources:

i) the intimate relationship they had developed with the child under their care;

ii) their wish to end the perceived suffering that the child was enduring in the NICU;

iii) the feeling that parents were being ‘tortured’ having to make a decision that effectively ends the life of their child; and

iv) the feeling that parents should be protected from long term guilt once this decision is made.

5.2.2.1 Suffering caused by health care professionals

Suffering that is perceived to be caused by HCPs was a common source of moral distress for our nursing participants. The described life of a baby receiving intensive care in the NICU included multiple painful procedures each day, and when the outcome as perceived by HCPs was poor, nurses in particular felt distress about the pain they inflicted upon their patients. One Nurse described it:
We see what we are doing to these babies whether it’s putting in chest tubes or putting in lines… sometimes the parents come in and they see the baby just lying there and sedated and not doing anything, but we are the ones that have to do it, and I think that’s hard for us sometimes. {PRIW32 RN; 84-88}

Moral distress in these scenarios was related to nurses working in close proximity to the infant, witnessing their struggles over time, and their perceptions about the baby’s poor long term outcome. In stark contrast to the peaceful dying process illustrating a ‘good death’ mentioned above, dying on the ventilator after aggressive medical therapy was described by nurses as a form of torture. The word torture was used by many nurses in this context: “it is cruel that some people have to suffer so long. I think here lots of time we torture these babies until they die when it’s almost inevitable from the get go.” {PRIW31 RN; 139-141} Another Nurse described the feeling of continuing intensive care for babies when she felt WLST was in their best interest but physicians did not agree:

    We are torturing the babies. What are we thinking? Why are we doing this? A feeling of helplessness…because the parents have been told one thing in a meeting and then discussing it at the bedside with the bedside nurse you have to, it’s almost like you’re skirting around the subject because as a nurse we often feel that we can’t contradict what they have been told in a meeting with medicine. {PRIW29 RN; 57}

HCPs described this perceived prolongation of suffering as causing tension between physicians, nurses, and parents. As mentioned, it was also a challenge for HCPs to care for babies when WLST was offered but parents, who were put in the position of having to ‘decide’, were unable to stop treatment or when WLST was declined by families. One Nurse described what it was like caring for a baby in that circumstance:

    You have instances where … care has been recommended to be discontinued and you know that what you are doing is beyond what the baby can handle but we are doing it anyway because the parents are insistent on it and I find those instances are probably more stressful on staff than … when care is discontinued. I can think of one particular instance where even the fellows were so upset at what we were doing for this child at the parents insistence, that they woke the parents up and got them in to look at x-rays… she was horribly distressed… the parents just you know they would be in for 5 or 10 minutes… like okay keep going… nursing didn’t want to take of this baby because they felt so badly about what we were doing, the fellows were getting very upset because they were just so frustrated… and they felt we were torturing this child at the parents’ insistence. {PRIW 20 TN RN; 166-168}
In this scenario, HCPs experienced moral distress while continuing to provide aggressive care for a baby at parents’ request and adding to their distress was that the parents themselves were not present to ‘witness’ the baby’s suffering.

Many nurses were under the impression that there is a window of opportunity to WLST particularly, artificial ventilation, during which time the baby is assured to die. One Nurse illustrated:

There’s a period of time in which if you withdraw, the baby will die, but if you continue for a few more days... there is a chance that they will withdraw and the baby will have a very bad period of time but won’t die on their own and then you risk possibly more brain damage than was already present... parents need to be aware that this is our opportunity now, if this is the decision we are making...

{PRIW6 RN; 91}

HCPs described families’ increasing levels of distress when babies didn’t die after WLST, sometimes interpreting lingering on as further suffering, or that the wrong decision had been made. Missing this window, when decision-making took longer than anticipated, was therefore a source of distress or anxiety for team members. Other members of the team also felt distressed when decision-making was ‘dragged out’. One Nurse Practitioner described the relief that the team felt once the decision was ‘finally’ made:

People who are saying oh thank God this is finally happening, it should have happened six months ago... or this should have happened last week... we have dragged it out until now. You hear more of that than you hear of, oh my God why are you withdrawing? {PRIW10 ACNP; 247-257}

Ultimately in these scenarios, team function was eroded, influencing quality of care and potentially causing harm to families.

5.2.2.2 Too much pressure on parents for decision-making

The above conflicts could be avoided, according to nurses in our sample, if the responsibility to ‘say stop’ were not solely placed on parents. These nurses felt that there was too much stress and responsibility placed on parents in decision-making. Moreover, that it was unfair to expect them to be able to make this decision. This Nurse described how impossible it was for families:

[Doctors] are trying to provide the information without directing them into making a decision... they hope that the family will then say to them this is what we would like to do, we would like to withdraw care... many families I have found over time don’t want to be put in that position of having to make the decision of saying stop everything because it then becomes them choosing death as opposed to the
physician saying there is nothing more that we can do… we recommend stopping treatment… It’s very few families that will come forward and say that’s enough or I don’t feel that this is in the best interest of our child’s life… it’s rare that families will do that because they don’t want to make that decision… they want it to be somebody else. It’s like the death sentence; they do not want to feel like they are the ones pulling the plug. {PRIW14 RN; 21}

These strong words were echoed by one Social Worker who recalled a family saying “I can’t decide to kill my child.” {PRIW35 SW; 164} One Nurse had the opinion, that we harm parents, and even “torture them with guilt, trying to make that decision”. {PRIW 33 RN; 154} It was important to Nurses, that parents were protected from long-term guilt surrounding the death of their child. Moreover, in addition to parents not feeling guilty, nurses felt it especially important that they not feel judged: “I think they need no judgment… they need to know that you’re not judging them and thinking they’re bad people, and/or that they are making a wrong decision or that they are too eager to make that decision…” {PRIW16 RN; 81} In contrast, physicians were generally silent on the topic of parental guilt, however one Neonatologist did suggest that parents’ guilt “needs to be assuaged… they need to be told it wasn’t their fault, yet it wasn’t other peoples fault either.” {PRIW24 NeoMD; 24}

5.2.3 Resilience in caregivers: dealing with emotions, compassion fatigue, and vicarious trauma

How caregivers dealt with the emotional toll associated with EOL work in the NICU also influenced team function and the quality of care provided to babies and families. Caregivers described witnessing the suffering of not only the babies but also the parents. One Nurse Practitioner described her own reaction to families: “I think the other difficulty that I have is in a sense feeling the pain for the families, the sadness that they feel… when you see the sorrow in their face… to hold in my own emotional sadness for them.” {PRIW10 ACNP; 214-219} Some nurses reported needing time between cases to recuperate and also described symptoms of compassion fatigue. One Nurse told how she felt detached after years of working in the NICU:

I detach myself, that’s important for me to do that… telling you I’m detached, tells you right there that’s my experience. It’s very uncomfortable a situation to be in. I prefer to, but you can’t totally withdraw from it, you have to be there for the parents you have to be there for them, they need your support. {PRIW30 RN; 25}
Finally, Nurses described episodes of vicarious trauma, revisiting the same situations over and over, especially after the death of an infant they were particularly close to.

For physicians, they were also bothered by cases, but often not because of the emotions involved but rather with how the management unfolded. One Neonatologist recalled:

I think the most challenging thing is just revisiting the situation again and again… it’s the imagery and the recall especially the amount of work that went into trying to do everything and the outcome was inevitable or in fact I find it even more challenging when we don’t sometimes have a medical explanation as to why the child has died and meeting with the parents in my opinion then can be even more challenging because the parents are always seeking answers… but it’s just not there… we don’t have a likely and a plausible explanation for the child dying it is very, very difficult, I find that is the most challenging. The other part of the challenge I think is when you know they have not accepted or continued to deny the death and you are trying to get them to recognize that offering the amount of medical care that was offered was beyond… there was nothing else that we could provide in support of the baby. {PRIW23 NeoMD; 93}

Emotions, such as sadness, grief, and frustration around providing EOL care in the NICU were most often expressed by nurses on the interprofessional team. For some, these emotions were uncomfortable, and for this Nurse affected the care she provided:

Basically I don’t like it because I cry really easy… I don’t like doing that in front of people. So even if it’s going to emotionally make me unstable, even if it’s for 5 minutes I don’t like that, nobody here has seen that in me and I don’t want them to see that… I have this thing about my space, I don’t like people coming into it and I’m not that hands on like some nurses… to put their arms around somebody and say it’s okay. {PRIW30 RN; 61}

Another problem arose when a HCP’s sadness or grief caused them to feel helpless or began to exceed the grief and emotions of parents. One Neonatologist described the range of emotions that he had observed in team members:

Going home and being upset, crying, not sleeping, wondering how things should have been differently. But the other group of comments… about how the process went, frequently a lot of anger… guilt and going home and sort of wondering what could have been done better sort of thing… not sleeping. Anger is common and it’s commonly expressed against families, against other staff, perhaps other staff even more so, you know: ‘why the decision was left until it was?’… emotions that patients and families undergo in bad situations is the sort of classic… guilt, anger and denial and acceptance etc. You see the same thing amongst professional staff when they are dealing with a baby who dies and at the same time I have seen a lot of staff who have been incredibly caring and compassionate particularly nursing staff around dying infants, more so than physicians. Physicians don’t talk about it
as much, nurses will talk about it more and of course people like social workers even more so. {PRIW24 NeoMD; 49}

Physicians in our sample were less likely to share their emotions or take part in debriefing. There was a perception from some team members that they simply moved on to the next case or patient. Trainee physicians however, identified this lack of emotional / psychological support for the medical members of the team and wished they had the same amount of support that they perceived to exist amongst the nurses.

HCPs in the NICU were often personally affected by the work. For some HCPs, workplace emotional stress affected them physically and at home. One of the most difficult emotions that challenged caregivers, and was described across professions, was a sense of failure. For some HCPs, including nurses and residents, this occurred when caregivers were unable to meet a family’s needs at EOL and when they could not give babies a ‘good death’. For Neonatologists, some spoke of the death of babies, the inability to ‘cure them for families’ or meet parents’ expectations, as failure. In either profession, both nursing and medical, caregivers often took those failures personally.

The ability therefore for HCPs to deal with their own emotions and build resilience was important both professionally and personally. Experienced staff explained how coming to terms with their own emotions helped HCPs care for families. Caregivers described a need for emotional support from colleagues/peers and from their institutions through more formal programs. In addition, resilience could be role modeled by experienced staff for all members of the interprofessional team.

In summary, the challenges and the consequences of EOL work in the NICU were present across all members of the interprofessional team providing care. Individual team members performing their roles, team function, quality of care for families, and the ability for HCPs to build resilience, were all interrelated. Differences identified across professions related to attitudes and experiences, challenged team function. These included: the lack of awareness of the roles, ideas, and attitudes of other team members; inconsistent communication or difficulties reaching consensus; disagreement about the locus of responsibility of EOL decision-making; and the
suffering caused, witnessed, and endured by HCPs. In turn, these influenced the ability of HCPs to provide babies with ‘a good death’ and families with good quality EOL care.

5.3 Parent and health care professional perspectives on good quality end-of-life care and its associated professional virtues

By applying a virtue theory lens to the interviews with parents and HCPs, the virtues important to providing good quality end-of-life care were identified. In the next sections, these virtues are defined and categorized. Next their practical application as ‘composite virtues’ is illustrated within the context of good communication, enabling shared ethical decision-making, providing families with the ‘right amount of hope’, and dealing with vices and threats to team function.

5.3.1 Types of virtues

The following sections illustrate the perspectives of both parents and HCPs on good quality EOL care and its associated individual professional and team virtues. As outlined in Chapter 4, virtues were first classified as intellectual, ethical, transcendental, and relational.

5.3.1.1 Intellectual virtues

There were three intellectual virtues, highlighted by both parents and HCPs, important in anticipating and meeting parents’ and babies’ needs in decision-making at EOL. These were: insightfulness, wisdom, and thoughtfulness. HCPs displayed insight when they put themselves in parents’ shoes, attempted to understand their perspective, and recognized the importance of identifying ‘what page they were on’. They practiced insight when they anticipated potential scenarios ahead of time and prepared families for these. Parents themselves highlighted the importance of anticipatory guidance for decision-making as well as what to expect at EOL. One parent described how she was prepared for the physical changes that would occur in her infant after WLST:

[NEONATOLOGIST] earlier that day had talked to me about… what happens when you die… they take these gasps, gasping breaths and they are very strong breaths… his whole body would move when he gasped so she prepared me for that and how the colour would change like in his face… and I’m glad she did that
because I had never, I had never seen anybody die in front of me. So I was prepared for that. {IW7 Mother; 107}

In addition to awareness of parents’ needs, HCPs must also have an understanding of the infant’s needs as well. Wisdom encompasses the ability to reason, knowledgeably and judiciously, in order to determine what therapeutic options are available, which are in the best interest of the infant and their family. Balancing the risks of intensive care therapies in the context of long term outcomes was a challenge for HCPs and families. Though physicians and nurses differed on their assessment and understanding of suffering in the newborn, both groups felt it was important as a concept to prevent and alleviate a baby’s suffering. Parents were even more attuned to the suffering of their infants in the NICU, as one mother worried:

I always remember looking at [CHILD] and seeing all the interventions that we had and thinking there is nobody that can tell me that he is not hurting, that he’s not scared, that he’s not in pain, and just to know that he was going through all of that… I just wanted that to stop for him. {IW4 Mother; 917-925}

In addition to insight and wisdom, there is a thoughtfulness, that is, an ability for self-reflection that is required of caregivers in order to offer choices and recommendations to families and to ‘give them permission’ to make decisions based on the short and long term QOL of their infants. One Nurse Practitioner reflected that decisions for WLST were well thought out, evaluated QOL issues, and often came after all else had been done:

Death doesn’t just come by people throwing up their hands and saying oh well why bother trying anymore… it comes after lots of thought has gone into it. So I can’t ever say that I have thought that baby shouldn’t have died. Yes in a sensitive sense or empathy sense… how horrible that is for the families, but at the same time I know that there is a lot of thought that goes into that… if there is a death in this unit it’s usually because there was not another alternative and if there was another alternative then it didn’t necessarily reflect a good quality of life for that patient. {PRIW10 ACNP; 156-166}

Parents highlighted the importance of outcomes counseling, of understanding the practical dimensions of QOL (to see, to hear, to walk, to interact) and wished that their views about what was an ‘acceptable’ QOL for their child be respected. As the family below recounted:

Mother: At the same time when we were reading these stories… of exactly what they thought, ‘cause we thought, we don’t want that for him… I don’t want him to suffer his entire life. I don’t want that at all.

Father: I mean you’re hearing this story… baby X is 5 years old but baby X is blind, can’t eat on his own, has to have 24 hour nursing…
Mother: …I just look at the story like that and think how awful, that’s not life to me… but I guess it’s all what you believe… so we have that initial belief to begin with so that did, that guided us quite a bit…

Father: We sat there every night holding him saying they’re wrong, we did, we sat there every night and we knew when we came back to quality of life his wasn’t there… and when we sat in that room, we made the decision, we had made it probably the day before, it was just a matter of saying it. {IW4 parents; 424-439; 927-941}

Balancing insight, wisdom, and thoughtfulness, in order to prudently enter into EOL discussions with families is one step in ensuring parents’ values and wishes as surrogate decision makers are respected. In order to exercise these intellectual virtues in the NICU, team members often drew upon ethical virtues to guide their approach to discussions with families and enable them to develop consistent care plans.

5.3.1.2 Ethical virtues

In addition to ‘knowing what is right’ through the intellectual virtues above, HCPs and parents highlighted several ethical virtues that allowed clinicians to ‘do what is right’. These ethical or moral virtues were evident as individual HCPs practiced and health care teams were ascribed, the virtues of courage, temperance, and the cognate virtues of justice.

In interviews, HCPs commented on the bravery of parents in making EOL decisions for their infants. In turn, families also highlighted the courage required of caregivers to continue to do the work that they do, looking after critically ill babies in the NICU. Trainees described needing to overcome their own fear of doing things ‘wrong’ and HCPs often blamed themselves for bad outcomes. One mother graciously acknowledged the difficulty of the work:

I feel bad for the nurse… she was changing his air tube she was very nervous I could tell, she was obviously in training… but I felt very bad for her because she took it really hard… she felt it was her fault, it’s not her fault, it could have been a doctor with 20 years’ experience changing an air tube and the same darn thing would have happened… so another thing to make note for the nurses who are taking care of the babies, you know you can only do so much, you can only do so much, not to blame themselves because I know she was blaming herself and I wish I could of told her not to and I hope she doesn’t feel like I do blame her cause I don’t. {IW8 Mother; 588}

As highlighted, working with babies who are dying in the NICU required a special ‘expertise’. A part of this expertise was grounded in the courage to overcome one’s own discomfort, not to run
from the overwhelming emotions of families, and to continue to ‘want’ to do the work. Related to courage, is temperance which involves discipline and self-control, and being able to recognize when to refrain from ‘heroics’. Building on the wisdom necessary to recognize the needs of infants and parents, the interprofessional team practiced temperance when they recognized when the transition from intensive care to palliative care was an option that should be presented to families. The challenge in making this transition for HCPs and families, related to the technological imperative and the fear of ‘admitting defeat’ was illustrated by this nurse:

A baby with APGAR scores of 0, 0, 2… I think that nobody wants to say that’s it… we’ve gone 6 minutes or 7 minutes or 8 minutes with no respirations and no heart rate we have to stop. I think nobody wants to be the one to say that… just get through the shift and pass this on to somebody else. Those are tough decisions and I don’t think we are very good at making them. {PRIW31 RN; 172-180}

In our interviews, parents suggested that they were waiting for a signal and a recommendation from HCPs for this transition of care. What varied in their experiences was how HCPs approached the transition and how the critical course of their infants’ illness unfolded. One mother recounted visiting her baby once her husband had gone home when her baby suddenly developed a pneumothorax (lung collapse) spurring a cascade of events she felt unprepared for:

I was there unfortunately I had to see it… the noise, the panic, calling of the doctor and I’m sitting there going I’m in the way, I need to get out of the way and I’m trying to hang on as best as I can emotionally at that point… the nurse just told me to sit over there away from the incubator while they figured out how to handle the situation and the doctor and a few more nurses came rushing in… the doctor kicked me out at that point, said you have to go back to your room we have to deal with this… so I just sort of sat on my bed… so maybe an hour or so later… they told me to come on down… the doctor sat with me and he said it’s not looking too good, we’ve had to put an air tube into his chest, we want to know how far do you want us to go and that’s when they discussed with us how far. I was by myself which was really not the best thing… the emotional state that I was in, it wasn’t sinking in, what do you mean? I had to get him to explain it to me again, what do you mean? What are you trying to say? … I tried to absorb it as best as I could… How far do you want us to go? … And I asked him, is he suffering? Yes he’s suffering… Is it going to work? We don’t know. Is he dying? We don’t know. These are questions they couldn’t answer for me. They said right now the first tube is taking, more likely we will have to put in a 2nd one… how many more do you want us to go? We can keep going until there’s no little chest left… I just want him to go as far as he can go until there is nothing left, but at the same time… I wanted to try within reasonable parameters. {IW8 mother; 354-362}

In the NICU, lack of time, related to the rapid deterioration of a baby’s status or because of competing patient demands, was sometimes a barrier to being able to effectively support families
through EOL discussions, decision-making, and developing an EOL care plan that took into account all of their wishes and values. Other barriers identified to providing good quality EOL care involved achieving consensus and consistency of both communication and care plans. From interviews with parents and HCPs, these barriers could be overcome if HCPs and teams practiced virtues related to justice. The cognate virtues of justice important in EOL discussions, decision-making, and the development and enactment of care plans for families in the NICU include:

i) fairness i.e. the equal opportunity for parent participation in decision-making and planning;

ii) honesty rooted in the integrity of the individual HCP;

iii) team virtues of trustworthiness, reliability, and dependability, in order to achieve interprofessional team consensus and consistency.

There were some HCPs who observed variability in who was offered transition to palliative care depending on which physician was making the decision. In addition, some HCPs identified that all families may not be given the same rights and opportunities for engagement in discussions and decision-making. One nurse perceived families were treated differently based on culture, ethnicity, education level, and/or socioeconomic standing:

So how come you can do that for one… I have been here for 23 years nearly and I have seen… some of the decisions were made according to … cultural background, educational background, it was absurd to me to see that… this one couple… professionals living in Burlington… the decision was withdrawal of care and we did it … and then another mother who wants her baby to have [WLST]… is going to be severely compromised and that physician, that attending said no, we are not going to, and six months later the baby is in our level 2 nursery and she has Swiss cheese for brains and she is going to be severe CP and that mother [says] I am going to have to take care of her for the rest of my life… and that woman was black. What difference did it make that she should be denied… her power of decision-making?... when it comes to disability… ultimately it’s the family that takes care of that child and can they care for a child?… Are we being fair to the society as a whole? I don’t know. {PRIW2 RN; 131-168}

Ensuring fairness and equal opportunity for parent engagement in the decisions affecting their infants was related to the integrity of the caregiver as well as the practice of honesty and trustworthiness regarding discussions of diagnosis, prognosis, and options for management.

All of the parents in our sample valued frank honesty regarding the medical status and predicted outcome for their child. One mother explained it clearly:
We appreciate that he is being so open and forward with us in telling us because we needed to know, good or bad, exactly what was going on and we could tell that they were presenting us with you know the entire worst case saying this is exactly how it is... We didn’t seem to feel that they weren’t telling us anything... they didn’t sugar coat anything because we told them not to. We told them we want it straight up front... that’s how we need to deal with things... {IW3 Mother; 195}

In addition to directness and honesty, it was important to parents, to understand that prognostic information and therapeutic decisions reflected the consensus of the entire health care team. It was not enough for parents to trust or respect individual HCPs but they needed to know that there was trustworthiness, reliability and dependability on the interprofessional team as a whole. This was reflected in practice when information was consistently presented to families, when messages from different caregivers did not cause confusion, and team function was not eroded by inconsistent approaches to WLST. One parent recounted her experience with rotating physicians and the challenge this presented, when her baby took a turn for the worse:

They told us that they have a thing where the doctor that’s in charge of the entire thing is there for two weeks and then somebody else comes in for two weeks. That we didn’t like at all. She was doing well and I’m not saying oh because this doctor came in you know she wasn’t getting the care that she should have been getting or anything. For the first doctor, things were looking good and when she switched over to the next one it went straight downhill... {IW3 Mother; 107}

Similarly, parents were also concerned about continuity and consistency of nursing caregivers and handover of care plans. One Mother recounted having an unfamiliar nurse looking after her baby who was not aware of the previous care plan:

I don’t quite know how to say this but maybe if...the nurses talk amongst themselves about what the parents like or what the parents know... there was one instance where there was a new nurse caring for the boys... [CHILD2] was just starting to start to breast feed... so he didn’t nurse very well and then he was going to be topped up with milk... I knew how to hold him, I knew how to be still, not rock the chair while they gavage feed him... and I said well can I just hold him you for while you gavage him... and she was rather adamant about, no... if they weren’t left alone they won’t grow... later on I cried... it was the only time I cried... because it seemed so mean to me. I think it was the first time that I figured out... I’m in this hospital and somebody just told me I can’t hold my baby... I wanted to say I am an experienced NICU mom and I know what to do... I wanted to say that but I knew I couldn’t. {IW7 Mother; 283-287}

In addition to the problems related to continuity and consistency, this mother described the vulnerability she faced as a parent in the NICU, needing to be empowered to speak up for herself and her child. By practicing team virtues of reliability and dependability, HCPs build parents’
trust in the health care team as a whole which is of paramount importance not only when parents are present but especially when they are away from their infants’ bedside. This establishment of trust, enhances the faith that parents have in caregivers, and also reinforces HCPs own faith in the abilities and performance of the interprofessional team.

### 5.3.1.3 Transcendental virtues

In addition to knowing what is right, and doing what is right, a third set of virtues, the transcendental virtues, refer to the concept of HCPs ‘being’ what is right for families (i.e. the type of caregiver that families ‘need’). Faith, in its secular sense, was the first of the transcendental virtues that was important in HCP interactions with families. From the interviews, this referred to the certainty, assurance, and conviction of HCPs. HCPs and parents described the challenges of decision-making and team function when faced with the uncertainty of diagnosis and prognosis. A lack of certainty, assurance, or conviction on the part of HCPs risked eroding a family’s faith and trust in caregivers. On the other hand, ‘too much’ conviction on the part of caregivers for what they perceived was the ‘right’ decision, could also corrupt relationships within the interprofessional team and with families. Section 5.3.2 illustrates the role of faith in decision-making and dealing with uncertainty when exploring composite virtues in clinical practice.

An equally complex transcendental virtue that challenged HCPs and was vitally important to parents was hope. For parents, hope encompassed two aspects. The first was the aspiration that a good outcome may still be possible. One Mother described it not as denial but holding on to the positives:

> You want to believe so much that everything is okay and everything’s going to be okay… you overlook the things you don’t want to see… and take on that little positive spark. Oh, he had a great day today, and you know he opened his eyes… so you do tend to look for that. {IW4 Mother; 149-154}

The second aspect of hope was the reassurance from the health care team that everything possible had been done, that no one was ‘giving up’, and their baby (and they as parents) were not being abandoned. The challenge for HCPs was that parents wished for them not to remove all hope, but also not to provide false hope either. This balance is explored in the practical application of virtues in the section 5.3.2.
The third transcendental virtue, love, and the related virtues of empathy, sympathy and compassion featured as the most common virtues highlighted by both parents and caregivers. In addition to these caring virtues, though not named as such, but illustrated by the experiences of the parents in our sample, it was important that members of the interprofessional team also practiced the virtues of loyalty, forgiveness, and humility. Without these, HCPs and parents described how other virtues can be undermined.

Compassion was described as an instinctual response by some HCPs and learned or developed by others. For parents, it was important that HCPs displayed true empathy, and that they were sincere in their compassion for each and every family. One mother hoped caregivers would continue to provide the compassionate care she received despite the difficulty of the work: “Carry that empathy and compassion for every single parent, every single time, that would be wonderful… if they do this 100 times a day, they need to keep that compassion and that empathy for those people because it’s tough, it’s tough.” {IW8 Mother; 660}

One way in which HCPs displayed empathy and compassion, was by making the family feel that their child wasn’t just any patient; that the loss of a child was not a routine experience in the NICU; and that caregivers shared and were sympathetic to parents’ grief. Parents expressed that it was important to them that HCPs genuinely care for their infant. In particular they described HCPs going above and beyond to support them:

He was the doctor that was working on [CHILD] at the time and he was absolutely phenomenal and even went so far as to call us at home afterwards to make sure we were doing okay… he definitely made the horrible situation a little bit easier to handle … Just being so supportive and so empathetic… he seemed equally upset as we were about what was happening… and again the nurses… in particular [NURSE2] … she actually came in, she had been off the day that he got sick and then the day that he passed away she was back on and as soon as she came in… she was like what happened? … you could see it, she really, really cared about what was going on and it really made me feel sort of like family because you spent so much time with them. {IW6 Parents; 90-102}

In addition to HCPs genuinely caring about their baby, parents commented that it was helpful when caregivers openly expressed their own sadness or grief. One family described how seeing how much their infant had touched his caregivers, left them with a deep feeling of trust and peace after his passing:

Father: we came out and we were getting ready to leave… and [Nurse] came through with [CHILD’s body] at the same time so we kind of crossed and I think
the one thing that I will never forget is she had been crying. So it was kind of surprising just how many people he had touched…

Mother: they allowed you to see that… it wasn’t all clinical… you could tell they were touched by it… that they were devastated by it just as much as we were and they didn’t try to hide that… it helped us because we could see they were humans and they were doing everything possible to help out… even if it doesn’t help you so much at the time, later on when you are on your own and you are going through this and thinking things through… over and over… it does help because you know that he was treated the best possible way… {IW4 Parents; 741-765}

Parents valued relationships with caregivers that were based in empathy and compassion. These relationships were also built upon loyalty, that is, HCPs were devoted to promoting the baby’s best interest and the family’s wishes. Loyalty was displayed when HCPs respected parents as surrogate decision-makers and also when they understood and accepted parents’ values and choices. One Mother described the parent’s role as advocate and her advice to other parents:

Realize how important you are… even though that little baby is depending on these tubes and IV’s… you may feel like you, you’re of no use to them, but just to realize how important you are… as an advocate for that baby, for your baby… and realizing that that you are part of the health care team. {IW7 Mother; 303}

Similarly, parents also wished loyal caregivers to act as advocates for their child in their absence. This same mother described the importance of the many relationships:

[NURSE3] his other primary nurse… she was very good at answering my questions… all of them cared so much for [CHILD1]… I really saw [NURSE2] as… caring for [FATHER] and I and then I saw [NURSE3]… she was [CHILD1]’s cheerleader and you know like she was rooting this boy on… they are the ones there caring for your baby when you can’t be there… just knowing that they are there and they care for that baby and they are really being an advocate for him and going to the doctors… it’s priceless when you’re in this situation. {IW7 Mother; 69}

In addition to advocating for the baby’s interests, part of being loyal agents to families involved HCPs displaying the virtue of forgiveness in the face of strong parental emotions, i.e. to resist reacting emotionally themselves to parents’ anger or emotional outbursts. HCPs suggested that parents were going through a difficult time and that their anger was often not directed toward them but rather at the situation. Nevertheless, HCPs were challenged to find the right words and actions to help parents with these emotions. One Nurse struggled with feeling she had not given parents the support they needed:

It hurts when things end on such a bad note. People leave here feeling that maybe the best hasn’t been given to them or their child… You take a lot of negative from
parents because you know they are going through a difficult time and you accept that as part of the course but when they actually leave and they feel that the best hasn’t been done… that’s hard to deal with. {PRIW20; 186-190}

It was an equally worrisome situation for parents, as one Mother described some HCPs’ reactions to parents’ emotional suffering:

I know you have to stand back in order to deal with this stuff ‘cause it is so hard and I know if you do it often enough you build up a wall but not to make the wall too thick or too distant from the parents… we had great nurses for the most part but you still have to respect [parents] and allow them to deal with it how they have to deal with it. I mean some may yell and scream at you and whatever else but that’s their mechanism for doing it and I know that can make the staff put up a wall and get angry back or whatever else. Some of them, going back to that one doctor and a couple of other people… what they do is great [but] they still can’t lose the point… that you can’t lose your humanity, they can’t lose that, and some of them do. {IW3 Mother; 353}

Overall, HCPs and parents felt it was important that parent emotions such as fear and anger were acknowledged and validated by all members of the care team in a compassionate manner.

Thus far, the virtues associated with good quality EOL care in the NICU were not specific for individual professions on the interprofessional care team. Rather as members of the interprofessional team providing care during decision-making and at EOL, the practice of these virtues by all members was viewed as important for team function, consistency, and quality of the experience for babies and families. Parents and HCPs valued a multidisciplinary approach to EOL care and decision-making. However, parents sometimes perceived the number of HCPs and the imbalance of knowledge as intimidating. They suggest that all members of the team and their function be explained to parents, including any learners.

As discussed previously, different roles, and different strengths existed among team members providing EOL care and parents appreciated these. Here the virtue of humility on the interprofessional team was important. Not only was it important for caregivers to recognize their medical limitations, as illustrated above, but also to recognize when their skill in one area may be limited and others on the team may be more expert. One example frequently cited by parents was the importance that information from the physician could be re-discussed with members of the health care team. Another source of ‘expert support’ for parents that HCPs could not approximate was other parents in the NICU. A number of parents described being “in the same boat”, a “connection… kind of supporting each other”, of someone knowing “what you’re going
through”. {IW5 Parents; 475-479} One Mother described the comfort that was derived from relationships with other parents in the NICU:

There was a lady on my floor… her little boy and my boys were born on the same day so I had seen her briefly like when you’re up in the middle of the night… our boys were right beside each other in the pods and… we were on the same schedule pumping so we spent some time you know talking … when you come here every day for a long period of time and seeing those parents who are going through the same thing… they are the same as you… I don’t know, maybe knowing that you’re not the only person in the world that’s going through this, that was nice… {IW7 Mother; 89}

It was important therefore to recognize parents’ unique needs and for team members to draw from within and outside the strengths of the team to meet these needs.

5.3.1.4 Relational virtues

Due to the emotional and intimate nature of EOL care, the intellectual, ethical, and transcendental virtues defined above were often described by HCPs and parents in the context of relationships. These therapeutic relationships had their own associated virtues that enabled good quality care. As defined in Chapter 3 these relational virtues represent the primacy of the clinician-patient/parent relationship. The central relational virtue as described through examples by both parents and HCPs was that of attunement, that is, the ability to understand what is needed by parents, involving both an openness and responsiveness on the part of HCPs. HCPs practiced these virtues when they respected parents’ wishes for information, did not avoid answering parents’ questions, and actively listened to parents during discussions. These Parents described the importance of HCPs being open, responsive, and empowering toward parents’ needs:

Mother: We could ask whatever we wanted. I mean it was all on our terms…

Father: They had their team and they let us… have our team… they let us bring some people in on our side… they were telling me things that I couldn’t repeat the next hour, that my brother could repeat it, he knew exactly what they had said. [MOTHER]’s aunt was there and my brother and separately they went home and checked the stuff on the internet to see what they could find and which was something again I would never have thought to do…

Mother: It was eyes and ears for us and there was no problems being able to do that, so that was kind of nice that we could do that. {IW4 Parents; 220-246}
From the interviews with parents and HCPs, the intellectual, moral, transcendental, and relational virtues associated with good quality EOL care and decision-making were defined and are summarized in Table 2. These included the insight, wisdom, and thoughtfulness to know what is right, the tempered courage and tenets of justice including fairness, honesty, and dependability to do what is right, and finally the balance of faith, hope, compassion, and loyalty to be what is right for families; within the context of an open and responsive therapeutic relationship.

Table 2: Virtues associated with good quality end-of-life care with examples obtained from interviews with bereaved parents and health care professionals

<table>
<thead>
<tr>
<th>Category</th>
<th>Virtues</th>
<th>Examples in practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>Insightfulness</td>
<td>Awareness of parents’ needs, anticipatory guidance in discussions and EOL care</td>
</tr>
<tr>
<td></td>
<td>Wisdom</td>
<td>Ability to reason, knowledgeably and judiciously Determine medical options in best interest of infant &amp; family</td>
</tr>
<tr>
<td></td>
<td>Thoughtfulness</td>
<td>Ability for self-reflection and introspection</td>
</tr>
<tr>
<td>Ethical</td>
<td>Courage</td>
<td>To engage, to do the work</td>
</tr>
<tr>
<td></td>
<td>Temperance</td>
<td>Competence not overconfidence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recognizing the transition from intensive to palliative care</td>
</tr>
<tr>
<td></td>
<td>Justice</td>
<td>Fairness of opportunity for parent participation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Honesty, integrity, trustworthiness in discussions and guidance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reliability and dependability in the form of consistency and consensus from the team</td>
</tr>
<tr>
<td>Transcendental</td>
<td>Faith</td>
<td>HCW certainty, providing assurance, and conviction</td>
</tr>
<tr>
<td></td>
<td>Hope</td>
<td>Parent needs: aspiration and reassurance</td>
</tr>
<tr>
<td></td>
<td>Love</td>
<td>The caring virtues: compassion, sympathy, and empathy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loyalty to relationships, respecting parents’ wishes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Forgiveness: dealing with parent emotions, balancing own values</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Team humility: recognizing expertise of members and their roles</td>
</tr>
<tr>
<td>Relational</td>
<td>Attunement</td>
<td>Openness and responsiveness: understand what parents need, respect parents’ wishes</td>
</tr>
</tbody>
</table>
Within the context of the HCP-family relationship, virtues were practiced in combinations in order to provide good quality EOL care. The next section illustrates how HCPs providing quality EOL care and support during decision-making employed combinations of these virtues, termed ‘composite virtues’, to address the challenges of this work.

5.3.2 Combinations of virtues in practice

5.3.2.1 Composite virtues

In section 5.1 and 5.2 of this chapter, the roles and challenges associated with providing good quality EOL care and decision-making in the NICU were identified from HCP interviews. The consequences related to the patient experience, team function, and moral distress, were also explored. In section 5.3.1 the virtues associated with good quality EOL care and decision-making in the NICU from the perspectives of parents and HCPs were defined and categorized. This section illustrates, from the perspectives of parents and HCPs, the practice of combining these virtues in order to address some of the challenges and consequences identified above. Labelled as ‘composite virtues’, these combinations of virtues are the foundation for the interprofessional framework for approaching issues at EOL in the NICU. Table 3 summarizes the composite virtues in practice obtained from the analysis of the parent and HCP interviews.

The first step to approaching the challenging moral and clinical situations associated with providing good quality EOL care involved situating the intellectual, ethical and transcendental virtues within the important relational virtues. In the practice of composite virtues at EOL in the NICU, some virtues were ascribed to individual HCPs, and some were ascribed to the interprofessional team as a whole. Composite virtues were essential for morally contoured communication, for enabling shared decision-making, and in providing the right amount of hope to families. The next sections will explore in more detail these combinations of virtues in these three contexts of clinical practice and will illustrate the consequences of the practice of vices at EOL in the NICU.
Table 3: Combination of virtues in practice illustrating the composite virtues important in good quality end-of-life care from the perspectives of parents and health care professionals

<table>
<thead>
<tr>
<th>Virtues of good communication</th>
<th>Composite virtues in practice</th>
<th>Intellectual</th>
<th>Ethical</th>
<th>Transcendental</th>
<th>Relational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morally contoured sensitivity</td>
<td>Insight</td>
<td>Honesty</td>
<td>Compassion Loyalty</td>
<td>Openness Responsiveness</td>
<td></td>
</tr>
<tr>
<td>Dealing with uncertainty</td>
<td>Thoughtful</td>
<td>Honesty</td>
<td>Faith Humility</td>
<td>Responsiveness</td>
<td></td>
</tr>
<tr>
<td>Ensuring understanding</td>
<td>Thoughtful</td>
<td>Temperance</td>
<td>Responsiveness</td>
<td>Responsiveness</td>
<td></td>
</tr>
<tr>
<td>Facilitating acceptance</td>
<td>Insight</td>
<td>Temperance (patience)</td>
<td>Faith (certainty)</td>
<td>Responsiveness</td>
<td></td>
</tr>
<tr>
<td>Enabling shared decision-making</td>
<td>Initiating decision-making</td>
<td>Wisdom</td>
<td>Courage Loyalty</td>
<td>Attunement</td>
<td></td>
</tr>
<tr>
<td>‘Right’ decision for family</td>
<td>Insight</td>
<td>Justice</td>
<td>Compassion Faith Loyalty</td>
<td>Attunement</td>
<td></td>
</tr>
<tr>
<td>Right amount of hope</td>
<td>Therapeutic hope</td>
<td>Thoughtful</td>
<td>Honesty</td>
<td>Compassion Openness Responsiveness</td>
<td></td>
</tr>
</tbody>
</table>

5.3.2.2 Virtues of good communication

As illustrated in sections 5.1 and 5.2 of this chapter, there was variability in the level of HCPs’ comfort in approaching EOL discussions with families. In addition, according to HCPs, the comfort level of the physician facing these discussions often set the tone for the interprofessional team’s comfort level when moral or ethical issues arose. The composite virtue described by both parents and HCPs associated with skillful EOL communication was compassionate honesty. Parents appreciated that while being blunt and direct, discussions were still done “very caringly”. {IW5 Mother; 113}
Practicing morally contoured communication also required a level of sensitivity displayed at the interprofessional team level. HCPs and parents described the need for individual practitioners to practice compassionate honesty, but also for the team have:

i) the collective insight in order to anticipate what parents may need without relying on them to ask the questions; and

ii) the openness to empower family to ask questions and not have them feel embarrassed

One mother described the context of when EOL discussions occurred, her experience of being told that she was going to deliver an extremely preterm infant who was not going to make it, and her wish for a clearer explanation:

[The discussion] occurred when they checked my cervix… I remember [the doctor] saying oh my gosh that’s not good… she’s not going to make it… I mean we were hysterical… I never thought once on the way to the hospital that I was having her that night… that was it, that was the only discussion and it wasn’t in-depth or anything and we didn’t know what questions to ask… I think it would have been helpful if she would have explained… she could have said her lungs weren’t developed enough, like we know that, but it would have been good to hear it from her… none of that was discussed it was just no, she’s not going to make it, there is zero percent chance… I mean it was good the doctor was really up front about that… we would have maybe felt worse ‘cause we knew we didn’t want to put her on life support and have her suffer… it was good that she said there was really zero percent chance of her living but it would have been nice to know if there was something like a policy… it seemed like she made this decision on her own. {IW2 Mother; 126-152}

This Mother appreciated the frank honesty of the physician, but believed that the caring and relational aspects of the discussion were lacking. One particular challenge for HCPs was relaying information by phone. One Mother described the sensitivity required to convey difficult messages, recalling receiving information unexpectedly by phone while separated from her baby:

That was the only bad experience we had… I phoned in to check on him and the doctor came on the line… she wanted to set up a meeting for the next day just to go over [CHILD]’s diagnosis and I said well what’s wrong with him?… she suspected he had an illness affecting multiple organs and it was very bad and she said I could tell you the name but it wouldn’t mean anything to you. Well that was very devastating at the time… we didn’t know what was going on and to just hear that over the phone… I guess she was trying to be open and honest but over the phone like that… it was very hard. I think I would have preferred to just know that there was a meeting and that would have been enough… {IW4 Mother; 21-22}

In this case, though this Mother had asked what was wrong with her son on the phone, it required a degree of insight on the part of the physician to recognize the weight of the diagnostic
information as well as empathy to recognize what this Mother would be feeling upon receipt of this information. Related to this was the practice of loyalty in being available to families for what they require, when their needs require it.

As illustrated by these examples, the team virtues of good communication are built on:

i) the relational virtues including openness and responsiveness to parents’ needs,

ii) the transcendental virtue of loyalty, of placing the best interests of the baby and family above those of the individual team members,

iii) the intellectual virtue of insight in order to anticipate parents’ needs for truthful information, delivered with,

iv) the caring virtue of compassion, in a supportive setting, which all together build faith and trust in the health care team.

Finally, related to communication and supporting families, an aspect of justice arose in the parent interviews that was not a prominent theme in the interviews with HCPs, which was, the importance for HCPs to provide support for fathers as well as mothers. At the end of his interview, when asked if there was anything else he would like to add, one Father described his feelings:

I think in the whole spectrum of everything … I don’t find that there is support for the dad… there are all these support groups for the mothers, there’s all this help for the mothers, but there is nothing really for the fathers… Well it just naturally happens they already feel more empathy…. for the mother automatically, I think it’s just our society in the way we all think. {IW5 Father; 637-653}

This Father went on to state that he felt his wife needed more support than he did, however he wanted caregivers to recognize the unique needs of parents in these circumstances.

In the next sections, three of the challenges of EOL communication are explored highlighting the utility of composite team virtues. These scenarios include:

    i) Dealing with medical or prognostic uncertainty;
    ii) Ensuring parental understanding; and
    iii) Assisting parental acceptance

HCPs described the challenge of balancing being decisive for families and disclosing uncertainty. Physicians reported difficulties in dealing with circumstances when they are wrong about prognoses or when they failed to determine a ‘medical explanation’ for events. Parents in
turn, asserted that it was important for HCPs to frankly acknowledge their uncertainty, particularly when the alternative was to receive conflicting or inconsistent information from different members of the care team as evidenced by this Mother:

> You have different doctors looking after everything, which I know you can’t be on seven days a week constantly because you get burned out… and they said it’s kind of good then you get another perspective of another doctor, well it is, but it isn’t… you have this doctor saying okay she has this, this is going on… then you have some other guy come in and say no it’s not that and that… It was just too much, too much information and nobody had a clue what was going on with her… I would have felt better if they had said and I don’t think they did… I don’t think they ever said, we don’t have any idea what is going on with her and we don’t know what to do for her. {IW3 Mother; 118}

The team virtues important in acknowledging uncertainty and recognizing the limitations of medical knowledge or technology in the NICU included thoughtfulness (self-reflection) in order to balance the right amount of faith (certainty or assurance), humility, and truthfulness in a way that was consistent amongst all caregivers. Figure 5 conceptually illustrates the practical application of a combination of virtues for acknowledging uncertainty. In this way, practicing these virtues of communication may enable HCPs to be comfortable saying “I don’t know” while still providing support and reassurance to families.

Figure 5: The practical combination of virtues important in acknowledging medical and prognostic uncertainty
HCPs recognized their role in both ensuring that parents understood the medical and prognostic information related to their child’s illness as well as facilitating their acceptance of what this information meant to the child and their family in the long-term. From a practical level, ensuring parent understanding involved recognizing how much time parents needed to take in all the information, accepting that they may need multiple discussions, and using ancillary aids to facilitate comprehension. One set of parents described how they received information regarding their critically ill infant in the NICU and their ability to take it all in:

Mother: We would have meetings with doctors and certainly we could ask them any questions but they are so busy… I would say between the social worker and the nurses that’s probably where a lot of our day to day information came from. If you ask for specifics and the prognosis… that kind of thing came from the doctors.

Interviewer: Did you feel that you understood everything that was being said?

Father: Me personally no, so it probably took some repeating only because I was in a situation where I didn’t hear… they would say it… and some people had to repeat it to me.

Mother: It was laid out for us as best as they could… it was simplified for us. And again we were allowed to ask whatever questions… they may have been the stupidest questions but we are not doctors, we don’t know, and we weren’t ever made to feel stupid for asking anything, ever. {IW4 Parents; 351-378}

As seen above, ensuring parent understanding required a team approach and composite virtues when exercised by the team, facilitated parent understanding. Two important virtues included responsiveness and thoughtfulness. Two abilities to harness these virtues were: first, to recognize parents’ cues when they might or might not be able to grasp the details of prognosis and diagnosis due to medical jargon, complexity of illness, or overwhelming context of emotions; and second, to reflect upon one’s own communication style, skills, and approach. These were the first steps to tailoring discussions to meet parents’ needs. Next there was a degree of temperance that was required to moderate the flow and amount of information presented to parents, recognizing how much parents could absorb at once. One neonatal fellow described how approaching EOL discussions with families was challenging, particularly when in addition to providing information, decisions needed to be made:

Amidst all the technical terminology, the emotion… How much time do these parents need? How much do they want me to go into details? Some parents almost sort of say you know tell me what to do and that’s a very difficult thing… likewise
I don’t want to put the burden of the decision of terminating a baby’s life on their shoulders alone so I sort of like to regard it as a partnership, and to try to convey that is quite a challenge. {PRIW5 Fellow; 31-39}

In order to transition to decision-making, in addition to understanding information, parents must also achieve an acceptance of the meaning of that information for their baby and their family. From both parents’ and HCPs’ interviews, it was suggested that, like facilitating understanding, supporting acceptance required a unified team approach. The composite team virtues involved in helping parents to come to a realization of baby’s state, included: temperance (patience) and responsiveness; HCP faith i.e. certainty and assurance regarding the diagnosis and prognosis; loyalty to upholding what was in the best interest of the baby and family; and finally, insight in order to gauge parents’ degree of acceptance and anticipate what they may need from HCPs to help make the transition. Figure 6 conceptually illustrates the practical combination of the virtues of good communication important in enabling parent understanding and facilitating parental acceptance.

Figure 6: The practical combination of virtues important to enabling parental understanding and acceptance at end-of-life
From the perspective of HCPs ‘best interests’ often involved discussions of both baby’s direct
interests (immediate medical needs, assessment of suffering, and long-term QOL) as well as the
interests of families (as a relational interest to the baby). Parents however spoke to the direct
interests of their baby and only peripherally acknowledged the rest of the family’s interests.

One mother described the roller coaster they endured during the course of her son’s illness in the
NICU. Her son had recurrent episodes of renal failure, infections, and shock requiring ventilation
support and intermittent episodes of dialysis. HCPs had engaged parents in discussions regarding
the potential for a transition to palliative care, but for parents, they felt they had not yet gotten
the ‘official word’ saying this was the end. Over her son’s course, she described the evolving
depth understanding of her child’s illness, her acculturation to the NICU, and finally the
acceptance that nothing more could be done:

It was always cautious optimism… then he got septic again with a staph
infection… he got lethargic and the kidneys just weren’t working the same… he
started to get sores on his body, he started to have trouble breathing, and he would
have really bad bradycardias… we just were hoping… it wasn’t beyond him that
he could fight this because he fought and got through so much… We still hadn’t
got the official word from the doctor saying you know there is no more, this is bad,
this is the end. There was not a talk like that yet. So that morning I was watching
[NURSE1] change his diaper and it was full of blood… I knew at that point that
this was really bad and I remember asking her is that what I think it was? … I
forget what she said… but I knew when she left the room with the diaper that she
was going to find somebody to say, ‘hey come here’… everyone was cool around
me but I had been around the NICU long enough to know this is it, you know this
is bad, something’s wrong… I guess that’s when I really, I knew it was over, there
was no more hope and everybody was good… they set up a care by parent room…
you know we were pretty calm… I think we were just so beaten down at that
point… so I held him and talked to him… and around 9:15 he took his last breath
and I was prepared for that kind of gasping breath cause they had told me what it
would be like and so he died while I was holding him. {IW7 Mother; 17-21}

For this mother, witnessing the evolution of her child’s illness was the prompt for consideration
of EOL care. She was also waiting on the guidance of the team for the ‘official word’ that
nothing more could be done. In these circumstances, HCPs need to display insight, a balance of
certainty, patience, and responsiveness in guiding families through EOL discussions. If HCPs are
not attuned to parents’ readiness and their need for guidance, there could be confusion with
regard to how HCPs frame the information and how parents understand and accept it.
Variability in framing caused tension on the interprofessional team and was felt to alter how parents were able to make decisions. As noted in section 5.2 of this chapter, nurses and physicians had differing views on how directive physicians should be regarding counseling for WLST. This was particularly related to how information and choices were presented. In one interview, these Transport Nurses discussed their opinions on how choices should be framed for families:

Nurse1: I think if a medical decision has been made that no other treatment is available or there’s nothing else we can do for this baby, it really shouldn’t be presented to the parents as a decision for them to make, only something that they should agree or disagree with... You could say... it is our opinion that we can no longer do any more, are you in agreement with that? You know it’s a subtle difference but I think there’s a lot of guilt... a lot of responsibility placed on the parents that I don’t think should be on them. The opportunity is there for them to say no I don’t agree if that’s how they feel...

Nurse2: I agree with her 100%... no matter what kind of baby you have, you are never going to get a parent to say, ‘okay then I guess if that’s the best thing’... to know that they made that choice... later on for people to say, ‘well I made that decision to stop treating my baby and just let them die’-

Nurse1: Did I make that decision too soon? Should I have made them continue treatment longer?

Nurse2: Whereas if somebody sort of makes that decision for you and says this is all we can do there is nothing more we can do... You don’t have to make that choice because that choice has been made for you. {PRIW6 RNs; 75-81}

As highlighted, from the perspective of HCPs there was worry amongst team members about how framing of information and choices may influence parents’ decision-making, may give them a false sense hope, and erode consistency of care plans and communication. The next two sections will explore the virtues that help to overcome these challenges in shared decision-making and the composite virtues that enable HCPs to offer parents the ‘right amount of hope’.

5.3.2.3 Enabling shared decision-making at EOL without moral residue

Parents in our sample often described being in a state of shock, or not in the right frame of mind, to understand and be receptive during EOL discussions. The first step to shared decision-making therefore involved HCPs recognizing parents’ emotional readiness to engage in discussions. This required insight on the part of HCPs in the context of attunement, i.e. establishing a relationship...
with a family that is open and responsive to their needs and recognizing or anticipating what else they may need from the team.

Decision-making was described by HCPs as a partnership. Parents themselves felt that it was important that decisions reflected the health care team’s consensus. It was challenging for HCPs to balance their own opinions and values, to reconcile their own beliefs with those of families, to be objective in order to provide families with support, and to advocate for what was in the best interest of the infant. Initiating shared decision-making on the part of HCPs required therefore the practice of a composite set of virtues including the wisdom (to grasp the importance of the events involved in decision-making, and to reason reliably and judiciously), the attunement (to recognize the needs of the baby and parents) and the loyalty (to represent these by providing options to families that align with their goals and values). Reconciling one’s own values in clinical practice also required a degree of thoughtfulness (reflection and introspection). There were some parents who did not wish to participate in decision-making or who did not want to make ‘the decision’. Temperance (or patience) was required in this instance as well as forgiveness when parents did not act as HCPs expected them to, or did not agree with suggested care plans.

One of the challenges of shared decision-making at EOL in the NICU involved the locus of responsibility for the decision to WLST. Nurses worried that too much pressure was placed on parents and physicians did not wish to shoulder this burden alone, needing some degree of assent on the part of parents to move forward with palliative care plans. All eight parents described a range of experiences; from not having been offered clear options prior to initiating life-support or WLST to feeling they alone made the decision. One mother described not being offered a choice when her child was born at the threshold of viability. She expressed that she would have liked an explanation as to why they had not been given any options, for example, a consensus from other doctors or a unit policy on resuscitation at the their baby’s particular gestational age. She was left feeling the decision to withhold life-sustaining treatment was more of a value judgment:

Mother: We were never offered life support because I was only 22.5 weeks pregnant, but they never explained things… I think the hospital has a policy that they won't perform any lifesaving treatment, like they won’t do anything unless the baby is 24 weeks but we didn’t know that… we just kinda felt like… oh your baby’s not good enough… we’re not going to save her… it would have been nice to know… why there weren’t any options.
Interviewer: Okay your child was not put on life support system and the doctor if I am hearing you correctly made that decision and you did not have a choice

Mother: Oh yeah, definitely. We did not have a choice.

Interviewer: Do you think it was the right decision?

Mother: Yes, yes, yes, yeah definitely... we went through this with our friends, with their baby on life support for 4 or 5 months and then ended up dying... he was in an incubator and tons of needles and wires and tubes... we wouldn’t do that to our baby so, so it was the best decision, yes.

Interviewer: Do you feel that the right person made that decision?

Mother: Yes, if she would have like backed it up with something... it would have been nice to just know if the hospital has a policy or you know the doctors all agree... and we don’t try and save a baby before 24 weeks that would have helped.

Interviewer: Do you think you should have had a part in making that decision?

Mother: No.

Interviewer: No, why not?

Mother: Because it would have been too difficult... it would have made us second-guess everything... the doctor came back and said you know there’s zero chance, if she had said ‘what do you want to do?’ then maybe we would have gone back on that and we would have went through even more heartache and not enjoyed the time that we had with her. I think yeah, it would have made it worse in the long run to just always [be] guessing. {IW2 Mother; 11-257}

Although this Mother felt no choice was given, she would not have wanted one, i.e. she would not have wanted to have to make a decision. Moreover, though this Mother did not feel that she took part in making the decision, she did feel the right decision had been made.

Some families that felt that they made the decision, described scenarios where due to the severity of their baby’s illness, there was no real decision to be made. These parents explained:

Mother: His intestines were so affected by the infection that there was no hope that he would have recovered, and short of you know having a bowel transplant but that was obviously not going to ever happen in his situation and we just couldn’t even think about putting him through the pain and having to continue on ... it would have been just too much.

Interviewer: So who do you feel made that decision?
Mother: We did totally, do you agree with that?

Father: Um hum... but there was no decision to be made really.

Mother: we didn’t feel like there was any hidden information… maybe that was part of what it made it so clear cut for us at the end was that everybody was so up front and honest and supportive through everything else.

Interviewer: Okay. Do you feel the right person made the decision?

Father: Yeah. {IW6 Parents; 66-86}

The idea of there being no other choice, was a common theme for parents when making EOL decisions, and when asked whose decision it was in the end for WLST, the most common answer from parents was that the baby him or herself had decided. This Mother described who had the final responsibility of ‘calling it’ in the end and how she herself had not recognized in the moment that she was making a decision to WLST for her daughter:

Interviewer: Okay, tell me about the decision to withdraw or not withdraw [CHILD] from life support. Who do you feel made that decision?

Mother: She did.

Interviewer: She did?

Mother: Yeah, she did. Her lung had collapsed again… and from what the doctor had said previously there was no way we would have made them you know fix the lung again and put her through that and plus when we saw her, like we just knew, we got that, we just knew. She called it.

Interviewer: So you think she was the right person to decide -

Mother: We said that from day one to all the doctors... she will let us know and she did. I mean the doctor may have said you know things are getting worse, I don’t expect her to survive… but he didn’t say you know we have to pull the plug or we didn’t say don’t pull the plug… It was a month or two after the fact and another woman I had talked to… they had to take their child off life support, to make that decision. To me we never made that choice but I said that to my husband… and he said to me we did the same thing. I didn’t realize that… she had said that’s enough, that’s enough so just get rid of all the apparatus… I didn’t see it as pulling the plug… So that got me extremely upset again when he said that to me because I didn’t realize that’s what we did. But no she’s the one… she called it, and I knew she would. {IW3 Mother; 201-212}

The variability of parents’ perceptions, experiences, and needs during decision-making highlighted that there can be no one policy on the locus of control or responsibility in shared
decision-making. Rather each situation required HCPs to exercise the virtues explored above as well as insight and the virtues of justice (fairness, honesty, integrity and fidelity) to ensure that the ‘right decision’ was made for each baby, and each family. It was here where commonly parents and HCPs agreed, that in the end, they wanted to feel that the right decision had been made. These parents described how they were treated after they made their decision:

Mother: We made the decision and I said … we just want to be sure we are doing the right thing here. I mean we have to live with this forever and [GENETICIST] said something that totally brought it into perspective for us and she said you know you’re just letting nature takes its course... [Medicine] intervened with that and put him on life support, so you are just letting nature take its course. So from that moment on we were at peace with it… {IW4 Parents; 109-115}

Parents then described the decision-making process:

Father: they just worked around our schedule… they laid out all our options… we could continue care for as long as we wanted to, the second choice was continue care but not aggressively… if he should start to fail they wouldn’t resuscitate him-

Mother: I mean we just asked questions and I guess we were fortunate in that [FATHER] and I both felt that it wouldn’t be fair to [CHILD] to continue life support and nobody swayed us at all, nobody-

Father: whether they felt they liked it or not… they were going to support [our decision]… they made us well aware there is no right answer… we decided our decision to pull life support was based on us

Mother: and once we had made the decision… we were amazed to feel like, ‘you made the right choice here’ and they supported us 100%... it was like ‘okay you are doing the right thing and we will support you and however you want to go about this when you are ready we can do it however you want it done’…

Father: they actually let us decide the time too… they gave us time to build up to prepare ourselves which was nice. {IW4 Parents; 265-341}

For this family, though it was difficult, it was important that they made the decision:

Mother: There were days when it would have been easier for someone to make the decision but I think looking back now it would be very difficult now if someone else had made that decision… there would have been a lot of anger there and resentment… if someone had made that choice for us I think that would have just grown bigger… until it was like oh yeah they could have done this and they could have done that, whereas this was our decision, we knew there was no hope, so it’s closure. {IW4 Mother; 525-532}

As these and other parents expressed, they felt the right decision was made if they were supported by HCPs, i) whatever their decision and ii) regardless who they felt (themselves, the
doctors, or ‘the baby’) made the decision. In order then to help HCPs share the responsibility of decision-making with families, HCPs as a unified team derived courage from their compassion and projected a faith (certainty and assurance for families that they were doing the right thing) that was grounded in loyalty. Figure 7 illustrates the practical application of composite virtues to enable shared decision-making while minimizing moral residue.

![Composite Virtues Diagram](image)

**Figure 7: Applying the composite virtues enabling shared decision-making at end-of-life**

It was important that HCPs help parents to not feel guilty. One mother illustrated how she continued to have doubts or questions even months after the death of her baby, about what they could have known or done differently:

> I was in emotional pain and feeling pretty down about myself unfortunately… I should have known, is what I felt, I should have known but this was my first pregnancy ever. That’s something I have to emotionally go through and I still feel… I know it’s not my fault but at the same time I feel deep down I really maybe should have known… {IW8 Mother; 146-150}

Later in the interview she and her husband reflected on their decision for WLST in their infant:

Mother: We took turns holding him and he died in our arms. I would say maybe a month later I came home from work and I said to [FATHER] did we do the right
thing? Did I? I don’t believe in euthanasia, I don’t believe in that, so… I said, did we do the right thing? Have we murdered our baby?… and he’s like no-

Father: no-

Mother: and after a year and a half I think we did the right thing-

Father: he’s not in any pain. {IW8 Parents; 388-394}

By practicing both the virtues of good communication and drawing upon the composite virtues important in shared decision-making with families, parents could be made to feel the right decision was made, without feeling the burden of responsibility. Drawing upon similar composite virtues, HCPs may also achieve another milestone of great importance, that is, providing families with ‘the right amount of hope’ to sustain them through their tragic experience and enable them to begin the next stage of healing.

5.3.2.4 The right amount of hope

The transcendental virtue of hope is at the foundation of health care yet, it is complex in both its nature and practice. It is both a trait of character as well as an aspired outcome in compassionate EOL care and decision-making. As mentioned, parents needed both the aspiration that a good outcome may be possible and the reassurance that everything was being done (or attempted) in order to achieve this. Transitioning parents from the hope for cure or survival to the hope for meaning, comfort, and reassurance was a unique and individual process for families. The right amount of hope involved a composite of virtues grounded in the relationships with caregivers and the identity of the parent, i.e. as ‘Mother’ or ‘Father’.

Providing the right amount of ‘compassionate hope’ required self-reflection on the part of the caregiver, as well as openness and responsiveness to what parents needed in order to cope with the tragedy before them. Parents and some HCPs recognized that in order to remain in control, to cope with visiting (and leaving) their child day to day, they needed hope. One social worker described it:

Some of these families are there for weeks and months and their child ends up dying. How do we expect anybody to cope on a day to day basis if they don’t have some hope? … how do you come in here every day, wash your hands, go see your baby, talk to the nurses, and then leave, if you have no hope, like how do you even get out of bed in the morning if you don’t have hope? {PRIW35 Social worker; 186}
Though some HCPs struggled to provide hope to families, nurses in our interviews often worried that inconsistent messages regarding prognosis from different physicians, and different ways of framing information, risked leaving families with ‘false hope’. Families identified a balance of the right amount of hope and realism, situated within the relationship with the health care team. Through thoughtful reflection and being attuned (open and responsive) to parents’ needs, HCPs could be both truthful and compassionate in providing therapeutic hope. Parents described how the health care team managed to do this:

Father: They never faltered from anything they had originally said. There was never a moment where they gave us false hope... they were compassionate in everything they did but at the same time they never told you, you know, tomorrow’s going to be a brilliant day.

Mother: Just celebrating his little triumphs… he was a great eater…we were kind of hopeful from those sort of things but… we never felt like we were being led down the wrong path… it felt like we were always being dealt with honestly… yet at the same time nobody ever made it like you know completely morbid either.

Father: The nurses had a very unique way of letting you know that, when you start to get a little high… they would always say let’s wait… they always had a way of bringing you back into reality… and it wasn’t like they were being mean… They did it in a manner where nobody was upset. You knew they were right, you just kind of lived for the moment and that’s what we did. {IW4 Parents; 451-486}

Once parents had made the transition of understanding that care had shifted from the curative to the palliative, there was one last ‘right amount of compassionate hope’ they could be left with. This involved the ‘meaning’ of experiencing the role of parents for their infant, for however short a time that may be. This experience was common to most families, and the Father above summarized those bittersweet feelings:

We got to do everything parents get to do… We got to change his diaper and we could bathe him and we could hold him. Granted all within the restrictions of the neonatal unit, but we could do everything that we would do at home. Except for take him home, we couldn’t do that. {IW4 Father; 49-52}

Enabling parents to be parents, was also linked to honoring the life of the baby, recognizing his/her identity as a person by using his/her name, sharing in memento-making, and allowing him/her to die peacefully with dignity. All of these were highlighted in interviews as important to both HCPs and especially to parents as one mother described:

We actually got to meet her… I mean it was still extremely hard don’t get me wrong but because we had met her it helped resolve some things, it gave me more of a peace, [an] upsetting peace but still… I said the best gift she gave us was
letting us meet her… Remember that the child is a human being, a living person and deserves every ounce of respect… One thing I did appreciate, they also referred to her by her name which was good… {IW3 Mother; 349-353}

Therefore therapeutic hope for families may not be hope for cure or survival but hope for peace, closure, and the opportunity for memory making and meaning. Robbing parents of this hope, or providing unrealistic hope were two examples of the harm associated with the failure to practice virtues during discussions, decision-making, and at EOL with families. Figure 8 illustrates the application of composite virtues associated with providing therapeutic hope.

![Composite Virtues](image)

**Figure 8: Applying the composite virtues associated with therapeutic hope**

The next section explores one other source of harm, related to human vices, which affected both families and team function.

5.3.2.5 Dealing with vices: improving team function and avoiding harm to families

The most common complaint from both parents and HCPs around WLST and EOL decisions in the NICU involved HCPs passing value judgments on the decisions that parents made, and
subsequently not providing support to colleagues who must continue providing care to families who are not ready to or don’t wish to make a WLST decision. Section 5.2 of this chapter explored the erosion of team function associated with the latter. Here, one mother described value judgments and criticism of her decision to continue life-sustaining treatment:

   We had one major concern about one doctor… you know how they have a group of them and they all kind of go around and look… She basically said to us you’re wasting our time and our money, just turn off the machine and let her die…We were both extremely upset… she walked away after talking to us… and we both looked at each other and said, did she say what we just thought she said? We just couldn’t believe it… we had the head of the department… talk to us a couple of times and you know he said most doctors here would give her 0%, he says I am going to… have a bit of hope here for you and give her 5… He said the same thing but how he said it, he didn’t say… you’re wasting [our time], you know just pull off the vent just let her go. {IW3 Mother; 108-117}

In this instance and in the situations previously described, HCPs displayed an imprudence that undermined team function and were practicing the vice of lovelessness, that is, a lack of compassion, loyalty and forgiveness which caused harm to families by eroding both their faith and hope.

5.3.2.6 Concluding remarks regarding professional virtues at end-of-life

By applying a virtue theory analysis to interviews with parents and HCPs, important virtues were defined. By relating these virtues to specific clinical encounters, composite virtues emerged illustrating how HCPs may approach the challenges and barriers to providing good quality care. By the habitual practice of these virtues on the part of the interprofessional team as a whole, the consequences of the work, including moral distress in caregivers, team dysfunction, and harm to families, may be avoided. The next chapter evaluates the characteristics of this virtue-based approach and discusses its application and limitations in clinical and ethical practice.
Chapter 6
Discussion: a virtue-based framework for end-of-life care in the neonatal intensive care unit

This study has i) examined the clinical and ethical challenges surrounding EOL care from the perspective of HCPs; and ii) explored the perspectives of parents and HCPs on good quality EOL care and its associated virtues. In this chapter, the clinical and ethical challenges of meeting families’ needs at EOL are examined in the context of the current literature. Second, the professional virtues associated with good quality EOL care are reviewed and they are situated within an interprofessional framework for approaching EOL care in the NICU. Third, the characteristics of this virtue-based interprofessional framework are examined. Fourth, the limitations of the study are discussed and finally, study applications and future considerations are explored.

6.1 The challenge of meeting families’ needs at end-of-life

6.1.1 Clinical considerations

In the previous chapter, the experiences of professionals in EOL decision-making and care were explored. HCPs identified their perceptions of parents’ needs which included: special expertise in dealing with the moral weight of decisions in the NICU, skills in communication, therapeutic relationships between parents and the health care team, and support and guidance during decision-making and EOL planning. HCPs also described indicators of good quality care including the sense of reward and satisfaction derived from the work as well as feedback and appreciation from parents. This section discusses key thematic findings related to the challenges in providing quality care at EOL in the context of the current literature and the experiences of parents.

6.1.1.1 Challenges in communication

Both HCPs and parents identified the value of frank and honest communication. HCPs described challenges in understanding what was meaningful to families and the required skill to read parents’ cues. It was important to parents to be empowered to ask questions and respect their
wishes for information. This study was unique in that the perspectives of medical residents and neonatal fellows regarding EOL communication were prominent. Learners were concerned with getting the content of conversations right, i.e. being able to identify and provide the required information for parents. The need for learners to ‘get it right’ and the fear of failure in communication with families were important themes emerging from the interviews that have not been explored in the literature.

HCPs from all professions identified the need to assist parents in understanding the diagnosis and prognosis as well as the need to facilitate their acceptance of the meaning of this information for their baby within the context of their family. The complexity of parent understanding and its influence on decision-making has been explored. In a review of the research literature pertaining to neonatal EOL, Moro et al found that parents’ abilities to make EOL decisions were influenced by their interactions with care providers (Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006). Moreover, in Wocial’s interviews with parents, parents reported that they were unable to make decisions until they could accept that the infant was critically ill (Wocial, 2000). For the parents in our sample, understanding took time, repetition, multiple discussions, and at times the use of ancillary aids to enhance explanations. As found by Kavanaugh et al, timing for parent understanding varies. Ultimately parents must balance the medical information regarding prognosis with their own values (Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005).

In addition to an element of timing from the viewpoint of the parents, Ward identified another effect of timing, this time controlled by HCPs. A ‘temporal gap’ for parent understanding of prognosis developed when HCPs waited to present information until they had achieved a ‘unified certainty’ of prognosis. This led to parents having less time than staff to absorb information and reconcile its implications, which resulted in an unrealistic expectation of parents on the part of staff (Ward, 2005). Interestingly, King also identified that the amount of communication between parents and caregivers decreased the longer prognostic uncertainty persisted, which affected the ability for parents to engage in decision-making (King, 1992).

This temporal gap phenomena, where HCPs are ‘ahead’ of parents in understanding and acceptance may have contributed to the attitude, mostly amongst nurses in our sample, that parents ‘don’t get it’ regarding discussions of prognosis. This was described particularly in the case of parents who have been counseled regarding poor outcomes but have declined WLST.
From interviews with NICU nurses and physicians regarding their obligations to patients and families at end-of-life, Epstein described the approach of physicians: to start gently to inform parents regarding prognoses. Then if parents didn’t ‘get it’; become more direct (Epstein, 2008). Similar to the HCPs in our sample, there were HCPs in Epstein’s study who thought parents in situations of medical futility, wished to continue aggressive treatment because they carried ‘false hope’ based on their ‘lack of understanding’ (Gingell Epstein, 2010). Hope as described by one social worker in our sample was not ‘false’, arguing that in order to cope with their tragic circumstances, often parents who do ‘get’ the long term prognosis choose to focus on the positives, or the day to day. The important virtue of hope is discussed further in section 6.2 of this chapter exploring the virtues important to good quality EOL care.

Finally, the contrasting perspectives of the nurses and physicians in our sample echoed those in Epstein’s study regarding time for families to arrive at a realization of prognosis. Where the physicians were more apt to approach the process slowly, nurses often recognized the inevitability of the infant’s death or poor prognosis sooner, and used two strategies to prepare for EOL: first, they attempted to push the physicians to talk to families earlier in order to prevent suffering in the infant; and second, some discussed options with parents directly (Gingell Epstein, 2010). The nurses in our interviews attempted the first strategy on occasion and expressed a wish to do the second.

6.1.1.2 Therapeutic relationships in the neonatal intensive care unit

HCPs and parents were in agreement regarding the importance of therapeutic relationships in the NICU. Relationships facilitated decision-making and allowed caregivers to provide better care to families. In the literature, therapeutic relationships are aligned with good continuity of care and were related to lower instances of decisional conflict (Epstein, 2008). From the perspective of parents in our sample, relationships with HCPs were grounded in advocacy and genuine caring for their baby. Parents described themselves as, and hoped caregivers to be, advocates for their infants. Advocacy was identified by parents when they felt their child was regarded as special, that caregivers genuinely cared about them, and treated them as a person due moral regard. The desire for ethical advocacy for babies is described by Spence who proposed the concept to be related to the virtue of caring and the rights of the vulnerable (Spence, 2011).
Though both physician and nursing groups spoke of the importance of continuity of caregivers at EOL, the nature of therapeutic relationships for physicians and nurses differed. Our findings coincide with the current literature that grounds nurses’ relationships in proximity and intimacy particularly in the moments around EOL whereas strong therapeutic relationships (such as those defined by Pellegrino in chapter 3) for physicians are particularly crucial in shared decision-making (Epstein, 2008). Finally, in addition to contributing to the quality of patient/family-centred care in the NICU, therapeutic relationships were also described by our HCP sample as an intrinsically rewarding aspect of their work.

In contrast, there were instances however when relationships were no longer therapeutic for families and HCPs. When relationship boundaries were blurred, nurses described, and other HCPs observed, situations where nurses as primary caregivers were ‘too attached’ to infants and struggled to manage their own emotions and values. These situations contributed to episodes of moral distress regarding the witnessing of ‘suffering’ and may have led to value judgments being passed regarding family wishes. Issues of proximity and closeness in nursing are well described in the literature. One exploratory qualitative study of NICU nurses and parents found that closeness increased the emotional involvement of nurses. However when a balance between closeness and distance could not be struck, relationships became an emotional burden to both nurses and parents (Fegran & Helseth, 2009). Balancing therapeutic relationships with families and babies therefore requires insight, reflection, and practical reasoning on the part of caregivers.

6.1.1.3 Shared decision-making between parents and HCPs

HCPs and parents described decision-making as an interprofessional process. The literature suggests however, that shared decision-making is not as interprofessional as often described. The nursing role in EOL has been centred on patient care and family support during death and dying; whereas decision-making has been the sphere of the physician (Gingell Epstein, 2010; van Zuuren & van Manen, 2006). Interestingly, parents in our sample highlighted the necessity that information, options, and recommendations during EOL decision-making represent a consensus from the interprofessional team. For parents, it was important that shared decision-making be shared not only with the physicians but with all the members of their baby’s care team.

What emerged from our sample was the interprofessional involvement of caregivers in decision-making along specific (though implicit) roles. Across all professions, role categories were
defined through examples of decision-making with families, resulting in the following designations:

a) physicians as initiators (identifying patients where palliative care is appropriate and determining the time when EOL discussions should be undertaken),

b) nurses as supporters (of families specifically, and the process in general), and

c) allied health team members, specifically social workers (and in some cases chaplaincy) as mediators and moderators (acting as a buffer at times between the ‘team’ and the family)

This classification of roles, particularly the involvement of allied health has not been specifically explored in the literature. In addition, there is little published regarding the role of learners in this process. There was variability of resident and fellow experiences in our sample, from being at the periphery with no role; to playing a role as ‘initiator’, intimately involved in palliative care discussions; or a role as ‘supporter’, akin to learners at the beside.

In our study, engaging in EOL decision-making with families required an internal motivation (exercising moral agency on the part of HCPs), an external collaboration amongst HCPs to achieve consensus, and ‘enough time’. Parents often described themselves to be in a state of shock and not in the state of mind to engage in decision-making discussions. The literature describes the experiences of similar parents, emphasizing that information sharing and EOL discussions should occur only when parents are ready (Brinchmann, Førde, & Nortvedt, 2002; Walwork & Ellison, 1985).

The ability to gauge the emotional readiness in families however was challenging for HCPs. Parents in our sample described waiting for a signal from caregivers on when to transition from curative to palliative care. In addition to anticipating parent readiness, it was important for HCPs to guide parents through the steps of both EOL decision-making and the EOL process. Some parents and HCPs in our sample expressed that there was a lack of time to effectively engage in EOL discussions and decision-making. This was likely related to the variety and acuity of critically ill patients and the pace of the NICU. In one review of parent experiences in decision-making, the amount of time allowed for decision-making was of critical importance to parents’ satisfaction with care (Ward, 2005).

Kon suggests that when challenged with dilemmas involving decision-making at EOL in the NICU, it is about “the best decision for this child and this family at this time” (Kon, 2011). We
agree, since when HCPs and parents in our sample described ensuring the ‘right decision’ was made, it was described in this context. For parents the right decision involved being supported by the entire health care team. This attitude echoes the perspectives of parents in the literature (Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006; Pector, 2004). In this way the process of shared decision-making does not ‘end’ with the decision.

6.1.1.4 Quality of care at end-of-life

Similar to the process of decision-making, care at EOL was described as interprofessional by parents and HCPs. A review of neonatal family-centred EOL care by Harris and Douma found that the knowledge and communication skills of the interdisciplinary team influenced the ability for parents to cope with the loss of their child (Harris & Douma, 2010). For our parents and HCPs, quality of care at EOL involved both skilled caregivers and a good quality EOL care plan. Skilled nurses in our sample appeared to gravitate toward the work involved. In addition, experienced nurses were seen to mentor new staff or more junior colleagues. The importance of the work was recognized even by those caregivers who sought to avoid it for reasons of personal discomfort or lack of experience. In contrast, the notion of mentoring physician learners in EOL decision-making or the concept that certain physicians had greater aptitude toward this aspect of the work was not present in the accounts of senior physicians. Interestingly, medical trainees, particularly the residents in our sample expressed clear desire for this mentorship.

The goal of quality EOL care for families, as described by HCPs from all professions, was to create the best possible experience for families given the circumstances. This included relieving and prevention suffering (of both baby and family), providing spiritual and emotional support, and finally enabling parents to experience the role of parents. Epstein’s sample of NICU nurses and physicians described the same primary theme. For them creating the best possible experience for families included providing families with options, preparing parents for events at EOL, providing comfort to infants, and advocating for and creating peace and normalcy for families (Epstein, 2008).

In their review, Moro et al identified that while analgesia was a key component of EOL care, pain and symptom management was still not well understood in neonates nor was it reliably delivered (Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006). This view was consistent with
our sample, with some physicians wishing to have better tools for assessing pain and suffering in newborns in order to optimize comfort care.

HCPs also felt that skilled caregivers were able to acknowledge and validate parents’ emotions. In turn, parents in our sample stated that they needed their emotions acknowledged and supported. Though HCPs described ways in which they could guide parents through the emotional roller coaster, the literature suggests that many caregivers are often not experts at understanding and supporting parent emotions. A survey of parents’ experiences of communication with nurses and physicians in an NICU (not exclusively at EOL) showed that while parents were satisfied with communication in general only half felt that the clinicians understood their emotional situation (Wigert, Dellenmark, & Bry, 2013).

In addition to emotional support, HCPs attempted to provide culturally appropriate spiritual support for families. Learners shared an interesting challenge, that of wishing to provide comfort to families by acknowledging and reinforcing their spiritual beliefs regarding death and dying, but feeling disingenuous in doing so when they did not share those beliefs. There is only limited literature regarding cultural considerations at EOL in the NICU specifically addressing the needs of parents. In one study, 58 HCPs were interviewed regarding perceived care-related experiences of newly immigrated parents and found the needs of parents in ethical decision-making (information, communication, trust, compassion, hope, and patient satisfaction) were the same across ethnicities (Nicholas, Hendson, & Reis, 2014). In that study, barriers to quality engagement of parents in ethical decision-making included communication misunderstandings with staff, lack of ‘fit’ in therapeutic relationships, and conflict between family and the health care team.

From our sample of parents, there were very few examples of conflict with the interprofessional team around EOL decision-making. This is in part due to the fact that interviews were conducted with parents whose infant had WLST or non-initiation of life-sustaining treatment resulting in the death of their infant, rather than a sampling of all parents who engaged in EOL decision-making where some parents would have declined WLST when offered. From the perspective of HCPs, disagreements with parents occurred around continuing therapies that appeared to have no benefit, a theme that is common in the neonatal EOL and moral distress literature and will be explored in subsequent sections.
Similar to the concept of creating the best possible experience for families was the notion that parents needed to be given the opportunity to experience the role of ‘parent’ before the death of their baby. In Wocial’s interviews with 20 parents of infants who died, parents similarly described the importance of their involvement in planning EOL care, giving them a sense of control, allowing them to share physical and emotional bonding experiences with the infant, and the chance to be a parent (Wocial, 2000). HCPs in our sample operationalized this by involving parents in the routine daily care of infants, in memory making rituals, in treating the baby with dignity and respect, and finally in acknowledging the baby’s ‘identity’.

Harris and Douma, described quality EOL care as a process that requires clear and consistent communication delivered by a compassionate multidisciplinary team within a framework of shared decision-making (Harris & Douma, 2010). Each of these themes resonated with both our parent and HCP samples. HCPs associated a ‘job well done’ with their own sense of satisfaction and reward. Similar themes regarding the privilege of being a health care provider in these circumstances were present in Epstein’s sample of NICU nurses and physicians. Additionally, our sample of HCPs appreciated positive feedback from families, and identified parents’ ability to ‘move on’ and find peace, as a sign that they had done their job well.

Our HCP sample reported very little training in EOL communication, WLST discussions, and grief counseling. This is congruent with the literature. Catlin and Carter cite lack of formal training in palliative care skills as one of the greatest challenges in adopting consistent palliative care in the NICU (Catlin & Carter, 2002). Some HCPs suggested creating a specialized palliative care team to provide support, guidance, and care. The literature does suggest that the use of palliative care services may help pain management, continuity of care, assisting parents in understanding and accepting their infant’s condition (Moro, Kavanaugh, Okuno-Hones, & Vankleef, 2006). However, work needs to be done in order to evaluate individual program efficacy. Finally, at an organizational level, Martin suggests a need for interprofessional education and programs to cover the tenets of palliative care, including symptom management, communication skills, and debriefings to improve neonatal EOL care (Martin, 2013).

### 6.1.2 Ethical considerations

In Chapter 5 the challenges and consequences of decision-making around EOL were described from the HCP perspective. Ethical issues illustrated by HCPs were congruent with those
currently being debated in the literature. The special moral status of the preterm infant, the moral weight of decisions at EOL, the struggle with uncertainty, best interests, and definitions of QOL, and the ‘optimal’ involvement of parents in shared decision-making were at the forefront of dilemmas involving ‘content ethics’ i.e. difficult cases requiring decision-making. Another sphere of ethical conflicts contributing to moral distress involved issues related to ‘interprofessional ethics’. Here HCPs described moral residue associated with professional roles, attitudes, consistency of communication, and overall team function.

6.1.2.1 Dilemmas involving content ethics at end-of-life

As discussed in Chapter 2, the context of discussions regarding resuscitation of extremely low birth weight newborns, and the ‘aggressiveness’ of therapies offered to other imperiled newborns has begun to shift from purely statistical outcomes based counseling to more nuanced, family centred discussions incorporating values and contexts. Given that parents often look to caregivers for direction, this shifting paradigm necessitates a review of the moral agency of caregivers who initiate discussions, frame information, and make recommendations.

How HCPs in our sample characterized the ‘value of the newborn’ was similar to concepts emerging in the literature. For some HCPs, degrees of moral status were attributed along the gestational age continuum, with deaths of extremely preterm infants described as ‘easier’ than those of term infants. A concept of relational worth of the newborn was also described in context of the ‘preciousness’ of the pregnancy (i.e. the value of a baby’s life determined in part by the family context into which the child is born) which was congruent with the language used by other health professionals in the literature (Janvier, Bauer, & Lantos, 2007).

HCP’s views of death in the NICU reflected both their personal values and professional experiences. There were contrasting sentiments regarding neonatal death. One concept was neonatal death was unnatural, and as described in the literature, this belief extends to parents who as a result often have unrealistic expectations about medical interventions (Papadatou, 1997). In contrast, neonatal deaths were often described as inevitable or as better than the alternative. Kipnis describes a similar value-ordering of neonatal outcomes, with the ‘worst’ end of the spectrum being survival with intolerable deficits, followed by death, then survival with tolerable or no deficits (Kipnis, 2007). Finally was the concept of death as a ‘failure’ which was a view of some professionals. This sentiment was described in neonatal nursing as long as 30 years
ago, when most of training was geared toward rescue and HCPs were found to be prone to distress caused by grief and the perception of death as failure (McIntosh & Eldridge, 1984).

Just as there were perceptions of value attributed to different lives and deaths in the NICU, there was moral weight attributed to the different options available at EOL. HCP experiences suggested a difference between withdrawal of ventilator support and invasive procedures like chest tubes versus withdrawal of artificial nutrition and hydration (WANH), with the latter requiring a greater degree of moral sensitivity. Similarly, while the sum of the literature states there is no moral, ethical or legal difference between practices, the latter decision is harder to take (Messner & Gentili, 2011). McHaffie found that when babies lived longer, parental doubts arose, while a quicker death confirmed the wisdom of the decision (McHaffie, Lyon, & Fowlie, 2001). There were no parents in our sample whose infants ‘lingered on’ following withdrawal of ventilator support or who died due to WANH therefore those parent experiences are not captured in this study. It is unknown whether parents attributed different moral weight to the ‘degree’ of support their children required. Certainly parents were acutely aware of the perception of pain in their infants and used language that highlighted the invasiveness of tubes, lines, and machines. From other studies of parents of children who underwent WANH, parents identified artificial feeding as a form of life sustaining treatment that ethically and compassionately could be withdrawn (Hellmann, Williams, Ives-Baine, & Shah, 2013).

Parental involvement in decision-making in our study echoed the complexity of roles, perceptions, and relationships described in the literature over the last 20 years. There was no consensus within or across professions regarding the ‘locus’ of control or responsibility for decision-making. A review in the literature of 16 key studies of parents of infants/young children in which WLST decisions were made also found a mix of decision-makers, including models where some parents were sole-decision-makers, others with shared approaches, and finally others with doctors as decision-maker (Gillam & Sullivan, 2011). Parents in our sample described different decision-making experiences and even between parents of the same infant, interpreted events, roles, and responsibility i.e. who made the decision and what exactly was the decision, differently. Perhaps it is as suggested by Dostoevsky, that once there is agreement on a goal, the focus is not on identifying a specific decision maker and assigning responsibility, “rather it is to disguise the decision and to diffuse and submerge responsibility for it” (Paris, Graham, Schreiber, & Goodwin, 2006, p. 149).
Despite or perhaps because there was no clear ‘ideal’ decision-making model amongst our sample, one of the most common conflicts amongst the attitudes of nurses and physicians involved the degree of sharing of responsibility for decision-making between families and HCPs. As mentioned, several nurses wished physicians to be more directive in their counseling to families, advocating for models involving medical recommendations for WLST with assent from families rather than models of informed consent which were described as forcing parents to ‘choose’ that their baby should die. Physicians on the other hand were reluctant to shoulder the full responsibility for decision-making in cases where parents did not wish to or were unable to make a decision. Physicians were silent on the issue of how directive they felt their counseling ought to be, or how it was perceived by other members of the team. A related challenge for physicians, also explored in the literature, was that of medical and prognostic uncertainty during this process.

For parents, it was important that HCPs honestly acknowledge uncertainty, both their own, and in the collective professional field. For physicians there are several challenges. The first is recognizing that uncertainty exists in the first place; there are instances in the literature indicating that clinicians are not always aware of the uncertainty of their own prognoses (Saposnik, et al., 2013). The second is to reconcile how to counsel families, make recommendations, and develop care plans while accounting for the degree of certainty. Some authors suggest that when uncertainty exists, more weight should be placed on parents’ wishes in decision-making (Kipnis, 2007). Others argue a change in language; rather than ‘clear and convincing evidence’ (measures of risks and benefits required to meet some pre-defined ‘threshold’), a balance of probabilities should inform decision-making (Wilkinson D. J., 2011). Though it was suggested by McIntyre and Popper back in 1983, the following adapted sentiment is still pertinent: In the realm of EOL decision-making for the newborn, clinicians must, while living with doubt and uncertainty, embrace the merits of compromise, consider the possibility of making imperfect or even fallible solutions, admit the possibility of erring, and be capable as moral agents of learning from their mistakes and continuing to strive for quality improvement (McIntyre & Popper, 1983).

Another belief that differed amongst physicians and nurses in our sample was the degree to which HCPs ought to ‘protect parents’ from the emotional toll (grief, guilt, ‘torture’, and responsibility) of having to make EOL decisions. In Einarsdottir’s interviews with NICU parents regarding the possibility of having to make EOL decisions for their infants, parents wanted to be
involved in decision-making but did not want to suffer the adverse psychological consequences (guilt and remorse) from their involvement (Einarsdóttir, 2009). Similar ambivalence is described in other studies of parent involvement in decision-making (Orfali & Gordon, 2004). In the literature, the desire to protect parents from having to make decisions is not exclusive to nursing. In fact a number of studies report physicians professing doubts that parents should make treatment decisions with complex ethical components, citing reasons of lack of medical expert knowledge, lack of understanding of the ‘complexities’ of the decision, and a desire to protect them from guilt and regret (Cuttini, et al., 1999; van der Heide, et al., 1997).

Interestingly, the literature is inconclusive regarding guilt and regret and the degree of autonomy amongst parents engaging in ethical decision-making on behalf of their children. McHaffie et al.’s sample of parents found no guilt associated with having made the decision, with 83% and 98% at 3 and 13 months thinking that the decision was right (McHaffie, Laing, & Lloyd, 2001); whereas Carnevale et al identified both guilt and regret in parents with no apparent relationships between parental decisional responsibilities and subsequent guilt experiences (Carnevale, et al., 2007). Perhaps this is explained by the degree of support parents received for their decision-making approach rather than the actual decision-making approach that was utilized. From their interviews with bereaved parents, Brosig et al found that it was important for parents to feel supported by the team and reported feelings of anger and abandonment if they experienced a lack of respect for their decisions (Brosig, Pierucci, Kupst, & Leuthner, 2007). Brinchmann et al suggest a different language for the role of parents in decision-making, referring to parents ‘participating’ rather than ‘deciding’ (Brinchmann, Førde, & Nortvedt, 2002). This may protect parents from the ‘ultimate’ responsibility while still supporting their role as advocate for their child. Finally, similar to the parents in our study, in studies that did not find guilt or regret in parents related to making EOL decisions, parents described the positive effects of, after having made the decision, being able to engage in bonding with the child, solidifying their place as a family member, and creating memories (Armentrout, 2007).

A final consideration influencing the complexity of EOL decision-making for newborns involved the ‘standard’ upon which decisions for WLST were made. These standards frequently involved weighing best interests of the newborn and concepts of QOL. Parents in our sample wanted to understand the practical dimensions of QOL and what that would mean for their baby in the short and long term. An interesting observation was made in the comparison of parent and professional
experiences that related to best interest considerations. Where the parents in our sample were concretely focused on the direct interests of their infant, HCPs were more apt to consider both the direct (medical and long-term) interests of the newborn, and the indirect family interests related to the baby in their discussions and recommendations.

Given the contextual complexities surrounding EOL decision-making for newborns, these nuanced approaches cannot be detailed in protocols but rather must be individualized for families. Additionally, HCPs working on teams looking after these infants need tools in order to approach these decisions.

6.1.2.2 Dilemmas involving interprofessional ethics

For parents in our sample, consistency (of providers, of communication, and of care plans) and consensus amongst team members were essential for decision-making and facilitating acceptance of medical diagnoses and prognoses. The importance of consistency and frustration associated with inconsistency are echoed in the neonatal, pediatric, and adult EOL literature (Carnevale, et al., 2007; Meyer, Ritholz, Burns, & Truog, 2006; Heyland, et al., 2006). From Epstein’s sample of nurses and physicians, the involvement of ‘too many cooks’ contributed to inconsistency, which in turn caused prolongation of what was perceived as ineffective treatment before decisions could be made (Epstein, 2008).

For HCPs in our sample, the identified challenges affecting their own professional roles and interprofessional team function included: consistent communication, a consistent approach to WLST, avoiding value judgments, and lapses in professionalism. Differences in attitudes and experiences across professions challenged overall team function. Specifically, these attitudes consisted of a lack of awareness of the roles, ideas, and attitudes of other team members; inconsistent communication or difficulties reaching consensus; disagreement about the locus of responsibility of EOL decision-making; and, insensitivity to the ‘suffering’ caused, witnessed, and endured by HCPs. In turn, these influenced the ability of HCPs as a collective team to provide babies with ‘a good death’ and families with good quality EOL care.

Families valued the roles of individual professional members of the health care team and described harm when criticism or value judgments were made regarding their choices. While some physicians suggested negatively that nurses were ‘emotional’ in their reasoning; parents
appreciated when caregivers openly expressed their emotions. Team members commented that the tone regarding death and dying at any particular time seemed to be set by the skill and comfort level of the most responsible physician on the team. Physicians in our sample did not describe an awareness of the primacy of their role related to the overall team climate. While there was a direct statement from some HCPs that EOL care was an ‘interprofessional process’ there was not a clear expression of how the team collaborated in practice to achieve a common interprofessional team approach or goal.

The day-to-day moral residue therefore for HCPs was related both to the individual challenging cases and moral decisions that needed to be made, but even more so to the tensions pervading the ethical climate in which teams function while providing EOL care in the NICU.

6.1.2.3 Moral distress and moral residue

Moral distress and moral residue as a consequence of EOL work, was experienced across professions, and was related to i) the identification of patients for whom WLST was offered, ii) the pain and ‘suffering’ caused by physicians who embark upon ‘ineffective’ therapies, iii) the challenges of shared decision-making related to roles and responsibilities, iv) the burden of guilt, and v) ‘dysfunction’ on the interprofessional team. There was a variable level of resiliency amongst HCPs and a number of HCPs shared experiences illustrating compassion fatigue and vicarious trauma.

Moral distress in nurses was related to both their proximity at the bedside and their perceived lack of control or voice in decision-making. The same proximity inherent in the nurse-patient-family relationship and valued by the families in our sample could contribute to moral distress. Peter and Liaschenko suggest that proximity is a paradoxical thing, that may propel nurses to act but can also propel some nurses to abandon or ignore as evident in compassion fatigue (Peter & Liaschenko, 2004). Frustration and moral distress amongst nurses regarding the EOL decision-making process is well described in the literature (Corley, 1995; Elpem, Covert, & Kleinpell, 2005; Kain, 2007). In Epstein’s sample, moral distress was associated with prolonged, aggressive treatment that was perceived to be futile. Prolonging the inevitable was connected with what they defined as ‘false hope’. ‘False hope’ was sometimes related to the fluctuating clinical status of the baby (Gingell Epstein, 2010).
In interviews with 25 pediatric nurses at EOL, Davies et al found both grief and moral distress occurring within the context of nurse-patient relationships but found moral distress to be decreased if nurses were able to have some control in decision-making (Davies, et al., 1996). In Kain’s review of moral distress in neonatal nurses, she found that if nurses were not able to provide palliative comfort care when warranted and an infant was perceived to die a protracted death, the nurses’ ability to grieve may be inhibited (Kain, 2007). In addition to wishing to protect their infant patients, nurses in our sample reported distress when unable to protect parents from the ‘guilt’ or ‘torture’ involved in EOL decision-making.

The concept of suffering as described by the HCPs in our sample was complex. Some HCPs particularly nurses and residents, used ‘suffering’ interchangeably with ‘pain’, when describing the course of an infant who was felt to have an inevitably poor outcome. Attributing suffering to the newborn propelled nurses to advocate for more directive counseling on the part of physicians regarding WLST. The perceived suffering of parents also played a role. The concepts of ‘suffering caused by us’ and medically-induced handicaps made HCPs uncomfortable and contributed to significant moral distress and moral residue. These themes have been identified in the literature as moral dilemmas in neonatology (van Zuuren & van Manen, 2006). Though the suggested solution from nurses in our sample was to engage in EOL discussions earlier and with more direction, physicians spoke to different degrees of timing and certainty. Likewise, in vanZuuren and vanManen’s qualitative study on the moral dilemmas in neonatology, nurses underlined the suffering of the newborn as a stressor, whereas physicians stressed the uncertainty in treatment outcomes (van Zuuren & van Manen, 2006). In our sample, this difference in perspectives seemed to find no clear resolution amongst professionals on the team and contributed to instances of inconsistent EOL care.

vanZuuren and vanManen found that nurses focused on their caring tasks in order to ‘make the best of it’ whereas physicians hoped that future research would lead to more predictable outcomes (van Zuuren & van Manen, 2006). For some of the HCPs in our sample, self-reflection and insight into their own experiences promoted resilience. Resilience in our sample, as depicted by the descriptions of the consequences of the work, was variable. A few HCPs described scenarios where a lack of resilience contributed to experiences of vicarious trauma and subsequent post-traumatic stress. The literature identifies analogous cumulative effects of repeated loss and death exposure in nurses (Kain, 2007).
6.2 Virtues important to good quality end-of-life care

This is the first study to explicitly employ a virtue theory analysis to the descriptive EOL experiences of parents and practitioners. The intellectual, ethical, transcendental, and relational virtues important to the delivery of quality EOL care in the NICU were defined in Chapter 5 and listed in Tables 2 and 3. In addition, the application of virtues to challenging scenarios involving communication, shared decision-making, and supporting parents through the death of an infant were illustrated in Figures 6-8.

The clinical and ethical challenges of EOL communication, shared decision-making, and EOL care were explored above. From the perspective of parents and HCPs the practice of virtues in these contexts facilitated good quality of care and the absence of virtues or practice of vices contributed to harm or interprofessional team dysfunction. Generally the EOL literature does not speak specifically to virtues as a foundation for decision-making. However, some studies examining the parent and HCP perspectives at EOL discuss similar concepts of virtues in similar contexts. In a review of communication and ethical decision-making between parents and HCPs in the NICU, Ward found that collaborative decision-making depended on time, trust, and a dedication to the best interest standard for both the neonate and parents (Ward, 2005). Similarly, parents needed their providers to be truthful as a foundation for trust, and associated truth with direct and frank information delivery. Some centres have begun focusing on communication programs and the use of expert consultants to improve quality of care and communication in the NICU. Coscia et al describe a program aimed at developing a common communicative style in their NICU by helping practitioners decide what to say and how better to understand parents (Coscia, et al., 2010). Other groups have developed approaches that integrate emotions and reasoning using mnemonics into EOL conversations, but outcomes using these heuristics have not yet been measured (Janvier, Barrington, & Farlow, 2014).

From the experiences of the parents in our sample, it was not sufficient for parents to trust individual HCPs but rather parents wanted to have faith in the interprofessional team as a whole. Parents identified the individual strengths of team members, they also highlighted synergy in team function when it occurred, and likewise, they remarked upon the harms associated with team dysfunction.
The virtues of insight, wisdom, thoughtfulness, courage, honesty, and caring were associated with the individual HCP achieving aspects of good quality communication, shared decision-making and end-of-life care. There were some virtues that were found to be both important at the level of the individual HCP or moral agent as well as important at the level of shared virtues of the interprofessional team, these included temperance, loyalty, faith, and humility. Finally, virtues reflected by parents and professionals to be important in achieving consistency of communication, care, and consensus, and thus enabling team function were specifically identified. These ‘team virtues’ included sensitivity (collective insight and openness), fairness, trustworthiness, reliability, and dependability.

By practicing these ‘individual’ and ‘team’ virtues in the context of communication, decision-making, and EOL care, HCPs engaged and reinforced parents’ trust. In situations of uncertainty of diagnoses and prognoses, trust is an active and essential part of the decision-making relationship. If the relationship between trust, moral motivation, and uncertainty is neglected, Harrison and Smith suggest that practitioners become morally indifferent (Harrison & Smith, 2004). In this way, the moral nature of trust derives from risk, vulnerability, individual agency, discretion, and the absence of regulatory mechanisms of control. Gilson describes different types of trust, from calculative or cognitive trust that is based on risk / benefit analyses, and rooted in judgment and circumstance; to affective trust, which is grounded in emotional bonds, obligations, empathy, and identification (Gilson, 2003). Both of these are important to the principal-steward relationship i.e. the therapeutic relationship between HCPs and babies/parents during EOL decision-making. In the context of this relationship, trust includes four key features: it is relational, voluntary, it involves a degree of vulnerability and risk, and it is rooted in the expectation that the steward (HCP) will have concern for the principal’s (newborn in the context of the family) interests (Gilson, 2006). In their meta-ethnography on parental ethical decision-making in the NICU, Rosenthal and Nolan similarly found that hope and compassion facilitated trust and reflected parents’ confidence in the competence and dependability of the health care team; these in turn facilitated decision-making (Rosenthal & Nolan, 2013).

For our sample of parents and HCPs, hope and hopefulness had many meanings. For parents, reassurance, comfort, and finding meaning were important. For HCPs it was sometimes a challenge to remain hopeful after ‘having done everything’, while supporting parents with compassionate but honest discussions. For the parents in our sample the perception of whether or
not the team had ‘done everything’ was related to their hope and was also necessary for some parents for the transition to EOL care. The concept of parents feeling that ‘everything has been done’ is explored in the literature. vanZuuren and vanManen suggest that defining ‘trying everything’ is difficult. They found that HCPs felt parents were better able to consent to WLST when treatment had taken place, but they worried that the medical possibilities available may be endless (van Zuuren & van Manen, 2006). Some authors suggest that it is about language and caring, rather than an exhaustive list of available therapies. Gillis suggests that when parents say “we want everything done”, he takes it to mean: “Care about us and our child. Care for us and our child. Don’t abandon us and our child” (Gillis, 2008, p. 192). For the parents in our sample, recognizing that ‘everything had been done’ was related both to the appearance and illness severity of their baby as well as an indication from HCPs that the ‘everything’ point had come.

6.3 An interprofessional virtue-based framework

In virtue theory, the existence of virtues is not sufficient for moral action; rather, the moral agent must employ practical reasoning in their application. Chapter 5 illustrated clinical contexts where agents practiced a combination of virtues in order to enact moral action. As suggested by Pellegrino, the process of developing a framework based in virtue involves defining the specific virtues important to the agents, context, and moral consequences of the particular situation, in this case, EOL care in the NICU. In the areas of communication, shared decision-making, and end-of-life care, the list of virtues described in Chapter 5 is not an exhaustive list for all virtues in all contexts at EOL, rather it illustrates the process of applying virtues in action.

In a stepwise fashion, Figure 9 illustrates the application of the virtue-based framework derived from this study to ethical issues at EOL in the NICU. These steps include: i) defining the components of the moral event(s); ii) identifying the characteristics of a virtuous clinician and the important team virtues; iii) applying combinations of virtues to address the context and potential consequences of the moral event(s); iv) performing the ethical action(s) with the aim of the ‘good of medicine’; finally, v) reflecting on the process.
Figure 9: Stepwise application of a virtue-based framework for approaching ethical issues at end-of-life in the newborn intensive care unit

1. Define the components of the moral event(s)

![Diagram](image)

2. Identify the characteristics of a virtuous clinician and the important team virtues

<table>
<thead>
<tr>
<th>Category</th>
<th>Virtues</th>
<th>Examples in practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>Insightfulness</td>
<td>Awareness of parents’ needs, anticipatory guidance in discussions and EOL care</td>
</tr>
<tr>
<td></td>
<td>Wisdom</td>
<td>Ability to reason, knowledgeably and judiciously Determine medical options in best interest of infant &amp; family</td>
</tr>
<tr>
<td></td>
<td>Thoughtfulness</td>
<td>Ability for self-reflection and introspection</td>
</tr>
<tr>
<td>Ethical</td>
<td>Courage</td>
<td>To engage, to do the work</td>
</tr>
<tr>
<td></td>
<td>Temperance</td>
<td>Competence not overconfidence Recognizing the transition from intensive to palliative care</td>
</tr>
<tr>
<td></td>
<td>Justice</td>
<td>Fairness of opportunity for parent participation Honesty, integrity, trustworthiness in discussions Reliability and dependability in the form of consistency and consensus from the team</td>
</tr>
<tr>
<td>Transcendental</td>
<td>Faith</td>
<td>HCW certainty, providing assurance, and conviction</td>
</tr>
<tr>
<td></td>
<td>Hope</td>
<td>Parent needs: aspiration and reassurance</td>
</tr>
<tr>
<td></td>
<td>Love</td>
<td>The caring virtues: compassion, sympathy, and empathy Loyalty to relationships, respecting parents’ wishes Forgiveness: dealing with parent emotions, balancing values Team humility: recognize expertise of members/roles</td>
</tr>
<tr>
<td>Relational</td>
<td>Attunement</td>
<td>Openness and responsiveness: understand what parents need, respect parents’ wishes</td>
</tr>
</tbody>
</table>
3. Apply combinations of virtues to address the context and potential consequences of the moral event(s)

4. Perform the ethical action(s) with the aim of the good of medicine

5. Reflection on the process
In Chapter 4, Beauchamp and Childress’ criteria for theory adequacy of an ethical framework were described. These included clarity, coherence, comprehensiveness, simplicity, explanatory power, justificatory power, output power and practicability (Beauchamp & Childress, 2009, pp. 334-336). The virtue-based framework resulting from this analysis is characterized in this section, according to these criteria.

Simplicity, clarity, and explanatory grounding were achieved by defining the virtues important to providing good quality EOL care from the perspective of parents and professionals. The practice of virtues was linked to the data, in real clinical contexts, with face value to both parents and practitioners. Composite and team virtues made sense as a whole in dealing with the complex situations involving EOL communication, decision-making, and ensuring team consistency and function. In this way, the virtues were operationalized through context, thus enabling the philosophical theory of virtue to become normative (explanatory power). In the case of EOL care in the NICU, this framework provides an empirically found set of virtues that are important to parents and clinicians to act as a starting point. These virtues were coherent in that the ‘benefit’ of virtues and the ‘harm’ of vices were consistent across accounts from parents and HCPs. Justificatory power is achieved through the stepwise application of the framework involving defining the important components of the moral event(s), defining virtues important to the context, identifying the combination of individual and team virtues required to effect moral action, and reflection on the process.

The list of virtues highlighted from the HCPs and parents in our sample is unlikely to be an exhaustive list of virtues important at EOL in all contexts of NICU care. Though the list of virtues is not comprehensive on its own, the stepwise application of the framework as illustrated above is simple, practicable, and may apply to settings beyond the context of our sample of HCPs, parents, or NICU environment. As an output therefore, this framework offers a template for teams to enable developing a common moral language around their approach to ethical issues within their context of care.
6.4 Limitations of the study

Procedural rigor in this study can be examined through scrutiny of the sampling and data collection methods, as well as the conceptual interpretation of the data through analysis and the resultant linkage to new and existing theories. The procedural limitations related to the interviews with parents are discussed elsewhere [(Williams, et al., 2009)] but in short were related to sampling, and particularly to the cultural and ethnic homogeneity of the parent sample. The next sections discuss the limitations in the dissertation phase of the study.

6.4.1 Potential for selection bias

The limitations inherent in our sampling techniques were related to selectivity and convenience of sampling. There was a limitation of accessibility in the HCPs sampled related to time period (when on their shift) and who was available to leave the bedside for interviews. Time and geographical flexibility differed across profession and NICU roles. This may have lost unique perspectives and data from potential informants (Crabtree & Miller, 1999, pp. 84-85). The goal of sampling was to represent the different HCPs that work together in the NICU. Unfortunately, because no respiratory therapists (RTs) volunteered for interviews, the resulting framework was not inclusive of their views. At the time of the project, RTs were a shared resource across the hospital (with adult and pediatric services) and not dedicated to the NICU per se. This may have influenced their involvement. There is little literature regarding the views of RTs and their role at EOL; therefore this is a perspective that is currently lacking. The framework could be strengthened in the future with the addition of a measured RT perspective. Another problem involved achieving saturation of items across professions. Sampling included all HCPs who were willing to participate in interviews and continued until no further participants could be recruited. The resultant virtues therefore may not represent an exhaustive list of virtues associated with EOL care as mentioned above.

6.4.2 Potential limitation of generalizability

Interviews took place at a single institution and though many of the themes and concepts from the interviews echoed the experiences of parents and HCPs in the literature, there was a risk that the themes and concepts important to HCPs and parents from one NICU may not be transferable to other NICU contexts. Similarly, the age of the data, i.e. interviews having taken place in 2005
may threaten the face validity of the results. The literature suggests that even as far back as the last 20 years, the same themes and concepts in ethical decision-making in the NICU continue to resonate today (Ward, 2005). Even so, generalizability of experiences was not the primary goal of the project; rather the importance lay in the rich contextual narrative informing a process of theory development and framework construction. The principles of the theory and framework could then be utilized as a template or adapted for other contexts as applicable.

### 6.4.3 Potential for investigator driven bias

In qualitative interviewing, questions and interpretations may be driven by researchers’ own assumptions or traditions, and could be influenced by our professional and personal experiences in the NICU (Crabtree & Miller, 1999, p. 84). In attempting to overcome this, an interview guide was used to introduce some structure and comprehensiveness to the data collection. However, this format introduced another potential problem, risking missing important salient topics. In order to minimize individual personal and professional biases, an interprofessional research team (including expert parents) oversaw the design and implementation of the study. The rigor of the study depends not on the objectivity of researchers but rather their credibility. Patton describes the criteria for a credible voice, that of authenticity and trustworthiness (Patton, 2002, pp. 541-588). Research questions and the development of the underlying virtue theory arose from perceptions, attitudes, and experiences. In the case of the primary investigator, these were accrued over the last 10 years; first as a physician trainee and then as a member of the interprofessional team looking after imperiled newborns in the NICU. Eakin and Mykhalovskiy acknowledged that health professionals bring an orientation from training and their work environment to their investigations (Eakin & E, 2003), and Patton emphasized the reporting of personal and professional information that may affect data collection, analysis, and interpretation (Patton, 2002, p. 566). These assumptions and ethical sensibilities were reflected upon during the preparation of this dissertation and may have in fact improved the congruence between the experiences of HCPs and the theory of virtues informing the ethical framework.

### 6.4.4 The analytical framework

There were two traditions of analysis employed, qualitative exploration of themes and ethical analysis using virtue theory. The trustworthiness of the analysis of the qualitative themes was achieved with the triangulation of themes with at least one other member of the interprofessional
research team. The virtue theory was informed by both the literature and through external critiques (during the dissertation proposal process and presentation of work in progress). In addition, the face validity and credibility of the themes and theory were explored through the presentation of the work in various forums, including rounds and education sessions with health professionals at the original study centre, as well as during posters, platform sessions, and workshops at national medical and bioethics conferences.

6.5 Study applications and future considerations

This dissertation informs three areas of study, these include, interprofessional education, further empirical work to broaden the breadth and depth of virtues, and facilitating health policy by suggesting enabling conditions for supporting the shared moral work. Consensus guidelines and policy statements are difficult to apply to the moral and clinical dilemmas facing parents and practitioners at EOL in the NICU. Case by case evaluation is always required to achieve shared decision-making. The ethical framework developed in this work, emphasizes, i) the exploration of individual professional and team virtues; ii) the development of moral reasoning; and iii) the strength of moral courage and moral agency. Pellegrino and Begley illustrate in the medical professionalism literature the benefits of several strands that this dissertation has covered: how and why virtues should be taught; and how repeated performances of right and good acts, modeling good examples, and making moral choices, raises sensitivities and enhances critical reflection on personal values. All of these facilitate moral development, practical wisdom, and sound ethical judgments in practice (Pellegrino E. D., 1989; Begley, 2006).

This framework, based in the common language of interprofessional virtues, aims to meet babies’ and parents’ needs while navigating issues of best interest and responsibility in decision-making. It does not define who should be the decision-maker, nor the thresholds for decisions or ‘acceptable’ QOL. Rather it informs the process of achieving good communication, consensus, and consistency in decision-making, while minimizing moral residue and alleviating moral distress. This virtue-based framework reflects that quality of care is not about the deciding, but about the caring; the skills and relationships that humanize caregivers and help families cope with tragic dilemmas. The next phase involves measuring the utility of this framework within and outside the site of its development, by adapting and implementing it in multiple NICU contexts.
Bibliography


Savulescu, J. (2013). Abortion, infanticide and allowing babies to die, forty years on. *Journal of Medical Ethics, 39*(5).


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


Appendix 1: Interview guide for professional interviews

INTRODUCTION
Thank you for joining us in this study. We are hoping to learn from professionals like yourselves about the challenges you face when in the difficult situation of having to withdraw life-support from infants in the NICU.

Review consent form
Answer Professionals’ questions
Obtain signature
Provide parents with copy
TEST TAPE RECORDER (DO SOUND CHECK!!!)

OPENING QUESTION
1. Describe your role in providing neonatal palliative care at the MUMC NICU.
   [PROBES]:
   Can you describe particular experiences in this area?
   Have you had much experience in the area of withdrawal of life-sustaining treatment in the NICU?

PREPAREDNESS AND TRAINING
2. Describe any formal or informal training you have had around providing neonatal palliative care.
   [PROBES]
   Did your training involve withdrawal of care discussions?
   Did your training involve grief counseling?

WITHDRAWAL OF LIFE-SUSTAINING TREATMENT
3. What are the biggest challenges you face when working with families who are being asked to consider making withdrawal of care decisions for their infants?
   [PROBES]
   Can you recall any complaints you hear from colleagues in these situations?
   What do you feel are the parents’ greatest needs at these times?
   Can you recall complaints from parents in these situations?

4. How do you know if you and other professionals have done a good job meeting parents’ needs when dealing with withdrawal-of-care issues?

BEREAVEMENT AND FOLLOW-UP
5. Are you involved in bereavement care for families whose newborns were cared for at the MUMC NICU?
   [PROBES – IF YES]
In what setting?
What have you found challenging?
What have you found rewarding?
[PROBES – IF NO]
Why not? What are some potential barriers?

6. Are you involved in follow-up care once infants are discharge from hospital or for families who have lost an infant in the NICU?
[PROBES – IF YES]
Who initiates follow-up?
What is the timing and duration of this follow-up?
Have you received any feedback regarding follow-up care

[PROBES – IF NO]
What other follow-up is arranged?
What are barriers to providing follow-up care?

IMPROVING CARE

7. We’re working to design training material to help you and other professionals better meet the needs of families involved in withdrawal-of-care decisions and bereavement after the death of the newborns. What do you think we should include in that material?
[PROBES]
How do you think that material should be organized or presented?

PROFESSIONALS FEEDBACK

8. Thinking back on everything we’ve talked about today, if you could summarize your thoughts and ideas about this for the whole research team, what message would you like me to bring them?

9. We will be interviewing other professionals who work with families facing withdrawal-of-care decisions in the NICU and bereavement. Is there anything that I should be sure to ask in those future interviews that we didn’t cover today?

10. Are there any colleagues of yours that you feel we should interview, either because they do a wonderful job of working with parents of terminally ill newborns or because they’re so important to the structure and functioning of the NICU here that we should be sure to talk to them?

11. If we had a training program for professionals to help them more consistently and easily provide good pediatric palliative care and follow-up bereavement and grief work for families, what would be some of the indicators that you think could be used to tell us if that program is working well?
CLOSING QUESTIONS

12. Thank you for your time today. Would you be interested in reviewing a summary of our findings from this and other interviews? That way we can be sure that your story is still in our summary of findings by groups of professionals.
   [IF ‘YES’, GET CONTACT INFORMATION FOR SENDING SUMMARY TO BE REVIEWED.]

13. If you have any additional thoughts you’d like to share after today, you can reach me at [CONTACT INFORMATION] and I will add that to the written summary of today’s interview.

CLOSING REMARKS

Thank you once again for taking part in our study. We know that your answers will help us in providing compassionate end-of-life care to newborns in our NICU.

Please take the time to fill out our anonymous questionnaire so we can better understand your professional experience.