

Oral feeding for “comfort” during the palliation of the infant with severe neurological impairment after the withdrawal of medically provided nutrition and hydration: An ethical analysis

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Abstract

Deciding that palliative care is in the best interests of a severely neurologically impaired infant is a very difficult and emotional decision for families and the medical team. It's generally accepted that there are circumstances where it is ethically and morally permissible to withdraw medically provided nutrition and hydration. While the logic and rationale surrounding this decision may be clear, the emotional reality of not feeding an infant can be very difficult.

This thesis uses a vignette to begin exploring the moral, ethical and legal issues around providing oral feeding for “comfort” after the withdrawal of medically provided nutrition and hydration. A palliative care model is chosen to explore the issues. I've argued that the palliative care model adds a secondary duty to care for the family and that decisions made during this time have the potential to cause lasting trauma to the family if they are not carefully considered.

Résumé

Décider que les soins palliatifs soient dans le meilleur intérêt d'un enfant atteint de dommages neurologiques sévères est une décision très difficile et émotive pour les familles et l'équipe médicale. Il est accepté qu'il y a des circonstances où il est éthiquement et moralement acceptable de retirer l'alimentation et l'hydratation artificielle. Bien que la logique et la rationnelle entourant cette décision soient claires, la réalité émotionnelle de ne pas nourrir un enfant peut être difficile.

Cette thèse présente une vignette pour initier l'exploration des enjeux moraux, éthiques et légaux entourant l'alimentation orale pour « le confort » après le retrait de l'alimentation et de l'hydratation artificielle. Je l'ai argumenté que le modèle des soins palliatifs ajoute un devoir secondaire de soins pour la famille et que les décisions prises durant cette période ont le potentiel de causer un dommage durable à la famille si elles ne sont pas considérées soigneusement.

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Vignette

Baby Jane is so upset that she is inconsolable. Her nurse struggles to hold her as her rigid body arches backward at an awkward angle. Her limbs are so stiff that they shake and cannot be bent. The nurse tries everything to comfort her. She cannot decide what is upsetting Jane and all her efforts to calm her seem to make Jane more irritable. Jane is so hard to hold that it feels like she is trying to push herself out of the nurse's arms. Saliva is collecting in Jane's mouth and is bubbling from her lips. Her nurse tries to wipe it away with no success. Jane begins to cough and choke. Her oxygen saturation begins to drop on her monitors. The monitor quickly begins alarming 'low sat'. The nurse gently places Jane in the crib and suctions saliva from her mouth and throat. Jane's oxygen saturations slowly return to an acceptable level.

The medical team enters the room on rounds. Jane continues to cry inconsolably. She is lying in her crib with her entire body rigidly extended and her neck twisted back in such a way that it looks like she is trying to look at the wall behind her. The Junior Resident summarizes the main issues of the day for the team. "Jane is a 3 month old baby who sustained a severe neurological insult at birth. The Neurology team discussed Jane's devastating neurological status and prognosis with the family yesterday. The family wanted to know whether Jane would have any quality of life. The neurologist described her as minimally conscious and said that she would likely be diagnosed with severe spastic cerebral palsy. They said that she has a complex seizure disorder, and is likely blind, deaf and will never walk or talk. She will be fed by tube, require suctioning of her secretions and will be completely dependent on her caregivers for life. The parents were distraught at the prospect of tube feeding. They feel that Jane is already being 'force fed' through the NG, and that she is in significant pain and distress with this type of feeding. The family asked what treatment options were available. Jane's parents and the medical team both agreed that she is suffering with little to no hope of a meaningful recovery or acceptable quality of life. The medical team is unanimous in their belief that aggressive medical intervention is not in Jane's best interest and the family agrees. Therefore, it is felt that the withdrawal of medically provided nutrition and hydration and palliative care are morally acceptable options in this case and were presented to the

family. There is another family meeting scheduled for this afternoon, but it seems like the family is very seriously considering withdrawal of tube feeding and IV fluids.”

Jane’s nurse reports that Jane’s NG feeds were turned off 4 hours ago at parents’ request. “They felt that Jane was in pain and needed a break from feeding. They are very frustrated that we insist on ‘pumping’ the food into her when she is obviously not able to tolerate it. They were asking why we can’t just feed her what she ‘asks’ for. Once the feeds were off and Jane’s fussiness continued, Mom started to ask if she could try to bottle feed her because she felt that Jane was ‘hungry’.”

“This baby will never be able to achieve full oral feeding. Therefore, don’t we need to make a clear decision regarding whether to feed her completely or not at all? It’s not right to give her only some of the nutrition that she requires. With partial and inadequate nutrition, she could exist in a malnourished state for a long time. That would potentially lead to many medical issues and risks prolonging Jane and her family’s suffering.” states one of the residents on the team.

“But if she is truly demonstrating hunger cues, how can we withhold bottle feeds from her?” asks her nurse. “She sometimes takes a pacifier - could we not at least try to bottle feed her?”

“Even if she isn’t really demonstrating hunger cues, this mother feels that she is and is struggling with being unable to respond to those cues. Being unable to try to bottle feed Jane is making these parents feel as though they are neglecting her and not meeting the most basic societal expectations of parents.” adds the social worker.

“Given her neurological status, isn’t she at high risk for aspiration? Bottle feeding her could be potentially dangerous and may risk hastening her death.” adds the medical student.

“We can assess if Jane is able to take small amounts of milk safely by bottle. This would help provide some comfort to her parents. If Jane is able to perceive hunger or enjoyment, this may then be a pleasant experience for her.” adds the OT. “But whose needs are we trying to meet?”

After observing this team discussion and the moral distress it was creating for the team the staff physician states, “If we are struggling with this, imagine how difficult this situation and these decisions are for her family. Based on yesterday’s discussion with Jane’s family it seems that this family may elect to withdraw medically provided nutrition and hydration. However, based on the parents’ interaction with nursing overnight, it seems that they continue to have a strong need or desire to attempt oral feeding. We can anticipate that this family may ask us to consider oral feeding for Jane after the withdrawal of medically provided nutrition and hydration. The discussion that we have just had illustrates that each of us have very strong and very different views on these issues. Obviously this is a complex situation and as a team, we need to explore the legal and ethical aspects so that we are able to best support Jane and her family.”

Chapter 1

Introduction

1.1 Introduction to the Problem

Giving birth to an infant with severe neurological impairment is something that no family plans for. The realization of the extent of neurological devastation combined with the fear that their infant is suffering, leads some families to the most difficult discussion of their lives; how much invasive medical support should be provided for their child? Is withholding aggressive medical intervention in favour of palliation and comfort care actually a more humane option?

The decision to palliate an infant with severe neurological impairment is a difficult choice that some families have to make. The decision is generally to maximize the infant's quality of life for whatever time she¹ has. Withholding and withdrawing medical treatments, such as ventilators and medically provided nutrition and hydration, may become part of the treatment plan for a medically fragile and neurologically devastated infant.

It is generally accepted that medically provided nutrition is a medical intervention. As such, there are circumstances where it is morally and ethically permissible to withhold or withdraw it. While the logic and rationale surrounding this decision may be clear, the emotional reality of not feeding an infant can be very difficult and disturbing. Likewise, the idea of feeding an infant who is unable to swallow safely or of possibly prolonging an infant's life and suffering, by allowing her to take small amounts of food orally after medically provided nutrition has been withdrawn, create anxiety and distress for caregivers.

This thesis aims to explore ethical issues that may arise when parents want to orally feed an infant with severe neurological impairment after withdrawing medically provided nutrition during palliation. This topic was chosen because it is an issue that has

¹ The feminine pronoun will be used to represent both male and female infants throughout this thesis.

caused me moral distress in my clinical practice as an occupational therapist (OT). The topic became more interesting after reading an article by Contro et al. In the article, the authors explore some of the small factors and events that negatively affected parents' perceptions and memories of a child's death. This article made me question what impact decisions regarding oral feeding for "comfort" may have on the family. As an OT working in a tertiary level, acute care paediatric facility, one of my primary roles is to assess whether infants are capable and safe to orally feed. This assessment usually involves assessing the infant's ability to swallow safely and her capacity to consistently eat sufficient quantities.

As the OT on the team, it is frequently my responsibility to tell families that their infant is not able to feed safely by mouth. The look of devastation and anguish on a parent's face when they receive this news is never forgotten. I watch as parents struggle to understand how not feeding their infant by mouth could be the best or right decision. Through working with these families I have begun to appreciate the incredible emotional aspects of oral feeding. I have also been able to understand the hope associated with oral feeding; if she is able to feed by mouth then there is a chance that she will get better. Parents seem to perceive an infant's inability to eat by mouth as one of the primary clinical signs of severe impairment and disability.

In my clinical practice, my initial introduction to these infants and families is when the infant is severely impaired, but generally stable and expected to survive in the short term. There are very rare cases however, where the infant is so severely neurologically impaired that the family and medical team feel that she is suffering. In these cases, the family and the medical team may agree that it is morally and ethically permissible to withdraw or withhold medically provided nutrition as part of palliative care. Oral feeding however is emotionally and ethically very different from medically provided nutrition and hydration. It is in contemplating the idea that parents might request oral feeding for comfort after the withdrawal of medically provided nutrition and hydration that highlight some of the ethical issues I find most difficult. I believe that

there is the potential for significant harm to both the infant and the family if this situation is not addressed carefully. My personal moral distress is related to two issues.

The first issue that I struggle with is watching parents face the reality that their infant is dying and having them ask me if they can feed her by bottle. I am concerned that families may feel as though they are not able to respond to what they perceive to be their infant's hunger cues, or feel as though they are withholding a potentially pleasurable experience by not trying to bottle feed her. Even though it may be unsafe to feed her by mouth, a family may feel strongly that the potential for pleasure is more important, as she is imminently dying. I understand my clinical duty and responsibility to the infant, but I struggle with my duty to the family. By restricting the family's ability to follow their parental instincts in the care of the infant, I worry that her death may be even more traumatic for them. In the context of a palliative and family centered model of care, I find that the interests of each group are sometimes hard to clearly identify. When interests are identified, I find that they have the potential to be competing, thus leading to my moral distress.

The other issue that creates personal distress to contemplate involves the infant with severe neurological impairment that is capable of drinking very small volumes of milk safely. If oral feeding is allowed as tolerated after medically provided nutrition and hydration is discontinued, I struggle with the thought that she could take small volumes of food by mouth each day, and question whether this would prolong her life and therefore increase suffering by sustaining her in a very malnourished state. I also wonder if this causes suffering for the family as they wait for her to die, or for siblings who are not participants in the decisions but significantly affected by the results.

This thesis will attempt to define and characterize a very specific group of infants characterized by the term "severely neurologically impaired infant with little to no expectation of meaningful recovery or quality of life". These infants share medical and social characteristics. This infant has never been healthy and by most definitions is in a minimally conscious state with a very guarded prognosis. It is acknowledged that her

very young developmental age and the brain plasticity that infants possess make it difficult to predict her prognosis with certainty following such a brain injury. Cases of infants who appear to be in a minimally conscious state demonstrating significant recovery do exist, but are exceedingly rare (Badawi, Felix et al. 2005; Rennie, Hagmann et al. 2007). While acknowledging these facts, this thesis will attempt to define this subset of infants in which a devastating brain injury has left them with an extremely guarded prognosis and little to no chance of any meaningful recovery.

The second goal of this thesis will explore the unique challenge of palliative care and the dual responsibility that the medical team has to the infant and the family. It will explore the unique moral status of the infant with severe neurological impairment. These infants have suffered such a severe brain injury at such a young age that their interests are hard to define. This will be described in the context of a palliative care model where the needs and interests of a loving and caring family also exist and may compete with the needs and interests of the infant. The resulting moral distress that is felt by the medical team and the family as they both struggle to act in the best interests of the infant with severe neurological impairment will be explored.

The thesis will refer to the vignette already present to highlight ethical issues throughout this thesis. The vignette has attempted to describe how the infant with severe neurological impairment can present clinically and the moral distress and confusion that can be felt among members of the medical team and the family. I have attempted to include some of the issues that I have found most morally distressing.

1.2 Importance of the Problem

The group of infants being described in this thesis is small and rare. While they are rare cases, the implications and outcomes of these cases are highly significant. The death of an infant is always a very emotional situation. The actions and decisions made before and during the palliation process have the ability to mediate this experience, allowing families to survive and go on or potentially destroying them (Contro, Larson et al. 2002; Knapp & Mulligan-Smith 2005; Miraie 1989; Truog 2007).

Watching families struggle with being unable to orally feed their infant has allowed me to appreciate how special the act of feeding an infant is for parents. Oral feeding is far more than a just a means to receive nutrition (Ersek 2003; Morin 2007). Understanding how important and difficult this is for parents whose infants are not palliative, has helped me appreciate how desperate parents can be to orally feed their infant during the palliation process.

The values and emotions associated with food and the act of feeding can be very powerful when families are making decisions about withdrawing medically provided nutrition and hydration in the palliation of an infant with severe neurological impairment and no hope of a meaningful recovery (Jacobs 2005). The decision to withdraw medically provided nutrition and hydration is often clearly understood by parents. Not offering the infant a bottle, even when it is deemed medically dangerous, may be far more difficult for a parent to resolve. It is important that these values and emotions around feeding be addressed with families. Everyone is working to maximize the infant's quality of life, but the perception of what is in her best interest may vary between people. If the situation is handled well, it is hoped that the family will grieve for her but have memories of her without feeling guilt or regret about how she died. If handled poorly, this can devastate and destroy a family forever (Contro, Larson et al. 2002; Truog 2007). They may feel as though she suffered unnecessarily or that they didn't protect her or fight for her rights.

1.3 Limitations of the Thesis

My interest in pursuing a Masters degree in ethics was due to the moral distress that I have encountered in my clinical practice as an Occupational Therapist. Over the 11 years that I have been practicing I have been searching for a way to work through my own ethical and moral distress as it relates to clinical cases. For this reason, I am approaching this Masters thesis as a clinician. I have chosen a pragmatic approach that attempts to explore a specific clinical case that could be found in the field. While a literature review was performed, specific clinical experience will also be relied on

throughout the thesis. This thesis will consider medical, legal, social and philosophical issues, but due to the inter-disciplinary nature of medical care and the fact that this thesis is being performed as a clinical ethics analysis, I will take an integrative approach to the analysis of the issues.

1.4 Outline of Chapters

Chapter 2, will provide a description of the clinical and physiological presentation of the “infant with severe neurological impairment with little to no hope of meaningful recovery” in order to facilitate an understanding of this small and rare group of infants and the devastating injury they have sustained. It also reviews some of the anticipated feeding options and challenges that are experienced by this population. Finally in order to situate the infant with severe neurological impairment within the medical literature and research, it reviews the terms persistent vegetative state and minimally conscious state and discusses which term most closely describes her.

Chapter 3 will define the ethical dilemma. It identifies the participants in the dilemma; the infant with severe neurological impairment, the family, and the medical team. It then explores the spectrum of presentations that I believe can exist for each of these groups.

A review of the law and jurisprudence is undertaken in Chapter 4. A review of the relevant law and statutes relating to the legal status of the infant with severe neurological impairment and parents’ responsibilities as surrogates was performed. A review of the professional guidelines and Codes of Ethics that the medical team is bound by was also performed. Finally, this chapter reviews jurisprudence relating to the boundaries of surrogacy and parental rights.

In order to better situate the ethical issues in the thesis, Chapter 5 explores the evolution of social norms related to feeding and nutrition and the withdrawal of medically provided nutrition and hydration. It also reviews some of the landmark historical cases that have helped shaped society’s views on these subjects.

Chapter 6 explores the changing health care relationship. It reviews some of the unique responsibilities and challenges involved in family-centered and palliative care models of care.

Finally Chapter 7 provides an analysis of the ethical issues. It analyzes the conceptual framework while using the vignette to emphasize and accentuate the issues as they manifest clinically. Chapter 8 then summarizes the issues and the discussion and provide recommendations for future considerations.

Chapter 2

The Infant with ‘Severe Neurological Impairment’

The infants being discussed in this thesis are a very specific group of infants who are “severely neurologically impaired and have little to no expectation of a meaningful recovery or quality of life”. This is a small and rare group of infants who represent the most extremely neurologically impaired infants that can be kept alive with significant medical intervention. This term was chosen as a descriptive term that represents this group of infants as it reflects the devastating nature of the brain injury they have sustained. It will describe any infant that has sustained a severe injury to their brain in utero, during or shortly after birth. It may manifest as complications of prolonged hypoxia in utero or during birth, a severe congenital brain malformation, complications of extreme prematurity, or sequelae of meningitis infections in the immediate neonatal period. It is only the most severe cases of these conditions that will result in an infant that fits the description of infant with severe neurological impairment. It is due to the sheer magnitude of the insult that these multiple etiologies can produce similar devastating neurological sequelae. While the etiology may vary, the resultant prognosis and clinical presentation of the infants in this group will be similar. The prognosis and clinical presentation will be discussed in this chapter.

It is recognized that neurological impairment occurs on a spectrum and that there will be infants that present with only slightly greater function and have a significantly better outcome than the infant with severe neurological impairment. This thesis will discuss only the worst cases of neurological impairment. The rest of the infants on the spectrum of neurological impairment would not fit within the category of the infant with severe neurological impairment with little to no expectation for meaningful recovery or quality of life and are therefore not being discussed in this thesis.

There are many similar terms in the literature that describe infants with neurological impairments. These include but are not limited to; critically ill, hopelessly ill, severely damaged, severely ill, and neurologically impaired (American Academy of

Pediatrics [AAP], Committee on Bioethics 1996; Gustaitis 1988; Miraie 1989). These terms were not chosen, as it was felt that they were often used to refer to children who were much more acutely ill and medically unstable, or that they did not reflect the devastating nature of the neurological injury.

In order to facilitate the discussion, the term “infant with a severe neurological impairment with little to no expectation for meaningful recovery or quality of life” will be shortened to the term “infant with severe neurological impairment”.

2.1 Typical Presentation of the Infant with a Severe Neurological Impairment

At the time when long term feeding plans in an infant with a severe neurological impairment are being discussed, she is usually a few weeks to months old. Medical technology (i.e. ventilators) and medication (i.e. inotropes) that were initiated in the minutes to days after her birth to maintain basic functions such as breathing and blood pressure are no longer required (West, Harding et al. 2005). These would have been initiated with the goal to stabilize her condition while the medical team began to understand the extent of her medical issues and assess whether or not they can be treated successfully (AAP, Committee on the Fetus and Newborn, 1995). These acute medical issues are now resolved as best as medically possible. The severity of the infant’s brain injury is now becoming obvious and decisions about further invasive medical treatment are required.

At this time, it is obvious that the infant has a severe disability. She will present with extreme hypertonicity throughout her entire body, observed as fisted hands, stiff or rigid extremities, and arching of the trunk (Drougia, Giapros et al. 2007; West, Harding et al. 2005). She will demonstrate severely delayed acquisition of motor milestones; decreased and poorly controlled spontaneous movement of the extremities, poor head control, and inability to roll (Drougia, Giapros et al. 2007; West, Harding et al. 2005). While her future functional abilities are impossible to predict with precision, it can be predicted with certainty that severe disability with minimal expectation of recovery will ensue. The exact level of “severe” disability however, will vary slightly from infant to

infant. While too young to diagnose, most medical professionals would expect that this infant will go on to develop severe spastic quadriplegic (spastic tetraplegic) cerebral palsy, require repeated hospitalizations, and have a shortened life expectancy due to complications related to her disability (Badawi, Felix et al. 2005; Carli, Reiger et al. 2004; deHaan, Wyatt et al. 2006; Drougia, Giapros et al. 2007; Rennie, Hagmann et al. 2007; Rutherford, Azzopardi et al 2005).

The infant will demonstrate periods of sleeping and wakefulness. When awake her eyes will be open and moving, however she does not appear to focus on faces and objects. Due to the diffuse nature of her brain injury the infant is likely severely visually impaired. While the structure of her eyes is normal, it is likely that the brain injury will impair her ability to process the visual input known as cortical blindness (Pugh 2000, pg 213). To an observer who does not know this infant, there will be no obvious response from her to people and actions in her environment. Caregivers familiar with the infant may report subtle changes in her behaviour or expression that they feel are in direct response to people or her environment (Stanley 2000).

Prolonged periods of irritability that are not relieved with traditional efforts to calm and console the infant are also demonstrated. The medical team will refer to this as neurologic irritability, where she is unable or has difficulty organizing and processing sensory information and is unable to regulate her behaviour. To the family, it looks like she is upset or possibly in pain. These periods of irritability may be completely unrelated to any actual external stimulus and may be a reflexive response generated by limbic and thalamic subcortical pathways (Schnakers & Zasler 2007). These periods of irritability can last for extended periods and be very stressful and exhausting for caregivers. There is no obvious cause for the infant's distress and often efforts to console her are futile or result in greater irritability.

2.2 Feeding the Infant with Severe Neurological Impairment

As discussed above, when the infant with severe neurological impairment is born, the acute, life threatening issues often related to respiratory distress, take precedence over

other issues such as feeding (Wolf & Glass 1992, pg 297-300). Initially, the infant will require mechanical ventilation to support and assist breathing function (Drougia, Giapros et al. 2007; West, Harding et al. 2005). She will generally require oral or nasal intubation, where an endotracheal tube (i.e. breathing tube) is passed through her nose or mouth and into her airway. A ventilator is then able to assist the infant's breathing by providing positive pressure with or without oxygen by way of the tube (Pugh 2000, pg 1952).

During this time the infant is generally too ill to feed orally. Even if she is able to suck on a pacifier, the presence of the endotracheal tube will preclude her from feeding safely. This is due to the fact that the tube maintains a patent airway, but prevents airway protection reactions that are required for safe swallowing. During this time where oral feeding is not possible, the infant can be fed in two ways. A nasogastric tube (NG tube) can be passed through her nose and into the stomach (Logemann 1998, pg 351). Nutrition can then be provided directly into the infant's stomach via this tube, bypassing the swallowing phase. Alternately, if the infant's digestive system is not able to handle breast milk or formula at this time, she can receive total parenteral nutrition (TPN). TPN is a solution containing water, electrolytes, lipids and fat that provides all her nutrition and calories, and is delivered intravenously, bypassing swallowing and the digestive system (Acra & Rollins 1999; American Society for Parental and Enteral Nutrition 2006).

A number of factors can affect and restrict the infant's ability to feed orally. With the resolution of the respiratory issues and removal of the endotracheal tube, the infant's ability to feed orally becomes a principle issue. When deciding whether an infant is able to feed orally, consideration is needed regarding her ability to eat enough to grow, as well as her risk of aspiration. Aspiration occurs when a foreign substance, in this case food, enters the airway (Pugh 2000, pg 156).

Infants with severe neurological impairment often demonstrate gastroesophageal reflux (or heartburn) with feeds. Hypertonicity can increase the incidence of gastroesophageal reflux, where stomach contents move back up the esophagus (Wolf &

Glass 1992, pg 336). This places the infant at risk of aspirating these stomach contents if her airway protection reactions are not intact. Aspiration can lead to the development of an aspiration pneumonia or respiratory compromise (Logemann 1998, pg 5; Wolf & Glass 1992, pg 336-337). If an infant with severe neurological impairment is demonstrating symptoms of reflux that are not able to be managed with medication, this may be an indicator that oral feeding is contraindicated. In these cases, the least invasive way to manage the reflux is with a nasojejunal tube (NJ tube) (Logemann 1998, pg 351-353; Wolf & Glass 1992, pg 269). This tube is inserted in the infant's nose, passes through the stomach and ends in the jejunum of the small intestines. Bypassing the stomach and delivering the formula into the jejunum reduces the likelihood that the formula will move backwards through the system and up the esophagus (Logemann 1998, pg 351-353; Wolf & Glass 1992, pg 269). Since the stomach needs to be bypassed in order to control the reflux, feeding by mouth (which delivers food into the stomach) may not be appropriate.

If the infant with severe neurological impairment is able to tolerate food in her stomach, her physical ability to eat sufficient quantities and her ability to swallow safely need to be assessed. In order to be able to eat, an infant needs to be able to achieve some level of alertness, have the oral motor skills to attempt to suck, and be able to coordinate breathing and swallowing (Wolf & Glass 1992, pg 93-146). The infant with severe neurological impairment often demonstrates weak or absent sucking. Some infants with severe neurological impairment present with a reflexive suck, however it is often disorganized, uncoordinated and ineffective for feeding by mouth (Wolf & Glass 1992, pg 233-256).

The infant with severe neurological impairment will often present with drooling and difficulty managing her saliva. She will often require suctioning to remove the saliva that builds up in her mouth. This inability to manage saliva may be due to poor oral motor skills, swallowing dysfunction or a combination of both. An inability to manage her own saliva suggests that the infant is not swallowing effectively or at all (Wolf & Glass 1992, pg 126-127). These difficulties may place the infant with severe

neurological impairment at increased risk of aspiration. Aspiration occurs when the infant is unable to control the food or saliva in her mouth and coordinate her breathing and swallowing. If milk or saliva passes into the infant's throat prematurely or unexpectedly, or if her swallow is ineffective, the saliva or milk can spill into her airway resulting in aspiration (Wolf & Glass 1992, pg 127). As discussed above, this puts the infant at risk of developing an aspiration pneumonia. If the infant demonstrates that she is unable to swallow safely, this also may preclude her ability to feed by mouth.

2.3 Literature Review; Persistent Vegetative State vs. Minimally Conscious State

There are two somewhat diagnostic terms emerging in the paediatric literature to describe infants with neurological impairment; persistent vegetative state (PVS) and minimally conscious state (MCS). These terms have originated with the adult population and literature. The term PVS or vegetative state (VS) has been recognized for some time. The American Academy of Neurology (AAN) defines PVS as being when,

- no evidence of awareness of self, or environment and the inability to interact with others.
- no evidence of sustained, reproducible, purposeful, or voluntary behavioural responses to visual, auditory, tactile, or noxious stimuli.
- no evidence of language comprehension or expression.
- intermittent wakefulness manifested by the presence of sleep-wake cycles.
- sufficiently preserved hypothalamic and brainstem autonomic function to permit survival with medical and nursing care.
- bladder and bowel incontinence. There are variably preserved nerve and spinal reflexes.
- PVS defined as a vegetative state present 1 month after injury, whereas permanent vegetative state was defined as an irreversible state. (Antommara & Bale 2002; Ashwal & Cranford 2002; Ashwal 2003; Yamamoto & Katayama 2005)

Minimally conscious state (MCS) is a concept that is more recent and was derived to capture those patients who were severely neurologically impaired, but appeared to demonstrate some basic evidence of consciousness. (Ashwal & Cranford 2002;

Yamamoto and Katayama 2005). There is much debate in the literature regarding the exact definition and criteria for MCS (Ashwal & Cranford 2002; Ashwal 2003). This seems to be largely related to attempting to define the highest level of MCS functioning, and is not relevant to this thesis.

MCS has been defined as “a condition of severely altered consciousness in which a person demonstrates minimal but definite behavioural evidence of self or environmental awareness”, by the Aspen Neurobehavioral Work Group on vegetative and minimally conscious states (Ashwal & Cranford 2002; Ashwal 2003; Strauss, Ashwal et al. 2000; Yamamoto & Katayama 2005). A patient must demonstrate awareness through reproducible responses to stimuli, such as “following commands, gestural or verbal yes/no, intelligible verbalizations, or purposeful behaviour (such as appropriate crying or smiling, reaching for objects, pursuit eye movements or sustained visual fixation)” (Ashwal & Cranford 2002; Ashwal 2003; Giacino, Ashwal et al. 2002).

The obvious problem in applying these criteria to children, and especially infants and neonates, is that developmentally these behavioural responses may be inappropriate expectations, for example verbalizing and reaching (Giacino, Ashwal et al. 2002). It is also unclear at which point these conditions are considered permanent (Ashwal & Cranford 2002; Ashwal 2003). There have been examples of adults emerging from VS or MCS after prolonged periods in these states (Ashwal & Cranford 2002). When discussing infants and children with the potential for recovery of function, predicting functional outcomes after a brain injury can be more difficult to do with certainty due to brain plasticity and natural central nervous system (CNS) maturation (Ashwal, Bale et al. 1992; Ashwal & Cranford 2002).

Studies have attempted to assess whether the prognosis differed for infants in VS vs. MCS. The literature suggests that the life expectancy of children in either VS or MCS is lower than the life expectancy for healthy children (Ashwal, Bale et al. 1992). One study attempted to evaluate the life expectancy of children (>3years of age) in VS and mobile and immobile MCS (Strauss, Ashwal et al. 2000). Strauss divided the MCS

group into mobile MCS and immobile MCS as in other populations mobility is a predictor of mortality risk. They defined 'mobile' as having "spontaneous movement of trunk or upper or lower extremities, specifically the ability to lift one's head or chest when lying on the stomach, roll..." (Strauss, Ashwal et al. 2000). The researchers found that survival rates for children in VS and immobile MCS were similar at 8 years of age (63 and 65%). They found that the children in the mobile MCS had significantly better survival rates at 8 years of age (81%) (Strauss, Ashwal et al. 2000).

In adults, and children, it has been proposed that the mechanism of injury may play an important role (i.e. poor recovery after non-traumatic injuries such as an anoxic-ischemic event) in determining the prognosis (Ashwal & Cranford 2002; Giacino & Kalmar 1997). The literature reports multiple etiologies to VS and MCS in infants and children, including traumatic and non traumatic brain injury, perinatal or genetic conditions and neurodegenerative processes (Antommara & Bale 2002; Ashwal & Cranford 2002; Ashwal 2003; Giacino, Ashwal et al. 2002; Strauss, Ashwal et al. 2000). Also, emergence from VS or MCS is usually to a state of severe disability with slightly increased level of awareness and not to a state of complete recovery (Ashwal & Cranford 2002). Generally in adults, it is felt that 3 months after a non traumatic acquired brain injury, that an individual that is not improving or emerging from a VS is likely in an irreversible state. The same is being proposed for the MCS (Ashwal & Cranford 2002). One article explored paediatric neurologists' comfort and use of the term VS in infants and children. They found that there was great caution among neurologists to apply the term VS to a child, especially under two years of age, and that most waited a minimum period of 5-6 months post injury before considering such a diagnosis (Ashwal, Bale et al. 1992).

The infant with severe neurological impairment being discussed in this thesis will most closely resemble the non-traumatic anoxic-ischemic population. In considering Strauss' study, she would also likely meet his 'mobile' MCS criteria.

The literature also stresses the importance of the management of children in MCS (Ashwal & Cranford 2002; Ashwal 2003; Strauss, Ashwal et al. 2000). One of the significant differences between children in VS and MCS is the presumption that due to some awareness of themselves or their environment, that the child in MCS has the potential to feel pain and to experience suffering (Ashwal & Cranford 2002; Ashwal 2003). This makes her medical management extremely important, in attempting to ensure that she is not suffering. This potentially differentiates aspects of her care from that of the child in VS who by definition is unable to experience pain and suffering (Ashwal & Cranford 2002; Ashwal 2003). The literature on children in MCS recommends discussion with caregivers and family around medical care and treatment, including limiting or withdrawal of treatment if it is felt that the child's pain and suffering is being prolonged with little hope of recovery. Issues such as 'Do Not Resuscitate' (DNR) orders, use or withdrawal of antibiotics, no further intensive care unit (ICU) admissions, and withdrawal of medically provided nutrition and hydration were listed as issues that potentially should be addressed with families when discussing the care of a child in MCS (Ashwal & Cranford 2002; Ashwal 2003).

2.4 Summary of the Infant with Severe Neurological Impairment

In summary, it is unclear whether the terms VS and MCS can and should be used with very young infants, and great care must be used if and when applying them (Giacino, Ashwal et al. 2002). The infant with severe neurological impairment being discussed in this thesis does not need to be defined as VS or MCS. What is important to note however is that she is profoundly impaired. However, family or hospital staff may believe that she is capable of demonstrating subtle signs of conscious awareness. Parents of infants with significant neurological impairment often report that they feel that their infant knows them and that they see changes in her face or eyes depending on her mood (Stanley 2000). This may be as simple as a change in facial expression or demeanour (i.e. sleeping more peacefully) with familiar caregivers or movement of extremities that appears somewhat purposeful. This demonstrates a basic ability to interact with others. If the infant with severe neurological impairment appears to be demonstrating even minimal conscious awareness of themselves or of the environment, then she will most

closely reflect a minimally conscious state. Given this, the possibility or likelihood that she is able to experience pain and suffering needs to be considered.

Due to the potential for suffering and the very poor prognosis of the infant with severe neurological impairment, the medical team and the family may decide that withdrawal of medically provided nutrition and hydration is a morally acceptable option that is in her best interest. This thesis will go on to discuss the potential issues that arise after the withdrawal of medically provided nutrition and hydration when the family wishes to provide oral feeding for comfort during the palliation process.

Chapter 3

Defining the Ethical Dilemma

While traditionally the medical relationship is between the patient and the medical team, with infants and children, there is an added and possibly complicating variable: the surrogate decision maker. Even the healthy infant is not able to express wishes and beliefs in order to direct her medical care, and requires a surrogate decision maker to act on her behalf (AAP, Committee on the Fetus and Newborn 1995; Beauchamp & Childress 2001, pg 102; Canadian Paediatric Society 2004). The surrogate decision maker is there to act in the infant's best interests and assist in directing her medical care (AAP, Committee on the Fetus and Newborn 1995; Beauchamp & Childress 2001, pg 102; Canadian Paediatric Society 2004; Street, Ashcroft et al. 2000). However, being autonomous adults, they have their own values, beliefs and interests (Beauchamp & Childress 2001, pg 154-155; Canadian Paediatric Society 2004; Stanley 2000). It may be difficult to separate the interests of the surrogate decision maker from those of the infant. When the surrogate decision maker is also the infant's primary caregiver, can or should the interests of the surrogate decision maker also be considered?

In the scenario being discussed in this thesis, there are three main parties involved, each having rights and responsibilities. They are the infant with severe neurological impairment, the parents and the medical team. While there is the potential for disagreement or conflict in any therapeutic relationship, the need for surrogate decision makers (i.e. parents) and the medical team to agree on the interests of a severely impaired infant can become complicated. The trend in paediatric care is to follow a family centered model of care that allows parents the ability to direct the medical care of their infant (Beauchamp & Childress 2001, pg 154-155; Canadian Paediatric Society 2004; Street, Ashcroft et al. 2000). This would include considering the physical, spiritual and emotional aspects of the infant and her family within the context of her medical care (AAP, Committee on Hospital Care 2003; Lundqvist & Nilstun 2007). The parents' rights as decisions makers however are not absolute, and can be challenged if the medical team believes their requests to be unduly burdensome or harmful to the infant (AAP,

Committee on Bioethics 1995; AAP, Committee on the Fetus and Newborn 1995; Canadian Paediatric Society 2004; Clark 1994).

While everyone believes that they are acting in the infant's best interests, it can be difficult to determine what her best interests are and when others' interest are complicating the medical decision making process. This chapter will go on to explore the three parties involved and the range of presentations of each of them.

3.1 The Participants in the Discussion

3.1.1 The Infant with Severe Neurological Impairment

The infant with severe neurological impairment is at the center of all care and treatment decisions and as such is one dimension of this discussion.

Any situation involving an infant and the need for medical treatment decisions is potentially difficult due in part to her inability to express wishes and values to assist in directing her care. The unique moral status of the infant will be discussed in more detail in the following chapters. At this point however, it must be noted that there are fundamental differences between an infant with a severe neurological impairment and an infant who has not sustained such an injury. In both cases, the parents and the medical team are making decisions based on what they feel the infant's best interests are. The interests of an infant with a severe neurological impairment are potentially very different from an infant without a severe brain injury (Beauchamp & Childress 2001, pg 138-139; Levi 2003).

The infant with severe neurological impairment being discussed in this thesis has never been a healthy infant with typical brain function. This infant sustained a devastating brain injury before or around the time of her birth, which essentially precludes her from ever developing into an independent, competent adult who is able to formulate and express values and beliefs. Therefore, while appearing as incompetent as any infant, she lacks the potential to develop into an autonomous being, which differentiates her from a typical, healthy infant in this regard.

There are cases in the literature that describe medical treatment of acutely ill infants where it is argued that the infant is too young to have developed their own values and beliefs, and that it can't be assumed that they will grow up to adopt the same beliefs as their families (Rosen 1996; Sheldon 1996; Wilson 2005). In these cases, where a family refuses medical care that could potentially save the infant's life, usually on religious grounds, it is argued that the infant has an interest in surviving and maturing into an autonomous adult (Sheldon 1996; Wilson 2005). Given the expectation that she will develop into an autonomous being, she should receive the proposed medical treatment so that she survives long enough to formulate her own values and beliefs (Sheldon 1996; Wilson 2005). Once she has become a competent and autonomous being, she will be free to express her own wishes, including the desire to forgo potentially life saving procedures based on religious or personal beliefs and values (Wilson 2005). This same argument is difficult to make for the infant with severe neurological impairment. Due to her extremely poor prognosis, it is very unlikely that she has the potential to develop into a person who is able to formulate and express independent values and wishes. Therefore, it is difficult to argue that she shares this interest with other healthy infants.

The exact interests of the infant with severe neurological impairment are difficult to establish. Arguments have been made that some neurologically devastated patients, generally diagnosed with PVS, are so devastated that they do not have interests and are not at risk of being harmed (Ashwal 2003; Levi 2003). As discussed in the previous chapter however, the infant with severe neurological impairment being discussed here, likely has minimal conscious awareness, and as such is at risk of feeling pain and suffering (Ashwal & Cranford 2002; Ashwal 2003). Therefore, this places her at risk of harm, makes her vulnerable and potentially exploitable and requires her to be protected.

Lynn and Childress have argued that conscious experience is required in order for interests to be developed (Levi 2003; Lynn & Childress 1983). By accepting that the infant with severe neurological impairment has some conscious awareness, by Lynn and

Childress' argument, she would also be capable of having interests. The degree and complexity of these interests is unclear (Hester 2007; Levi 2003). There are two obvious interests that can be attributed to the infant with severe neurological impairment. They have an interest in complete neurological recovery and an interest in experiencing minimal pain or suffering (Antommara & Bale 2002).

3.1.2 The Parents of the Infant with Severe Neurological Impairment

The parents of the infant with severe neurological impairment are the surrogate decision makers for the infant and as such represent another dimension of the discussion.

Parents are given the responsibilities of the surrogate decision maker, as it is believed that they are the ones who are best able to understand their infant's needs (AAP, Committee on Bioethics 1995; AAP, Committee on Bioethics 1996; AAP, Committee on the Fetus and Newborn 1995; Clark 1994; Street, Ashcroft et al. 2000). Parents are familiar with the family's religious and cultural beliefs as well as personal values and beliefs regarding the sanctity of life and quality of life. It is believed that they are best placed to make decisions for the infant that they love and planned to raise. It is believed that parents will generally act to protect their infant and her interests (AAP, Committee on Bioethics 1995; AAP, Committee on Bioethics 1996; AAP, Committee on the Fetus and Newborn 1995; Clark 1994; Street, Ashcroft et al. 2000).

After the birth of an infant with a severe neurological impairment however, the family will likely be in an acute state of grieving for the healthy child that they were expecting or hoping for (Carter 2004). In this state of grief, they are also being asked to understand and make decisions about the treatment of the infant with severe neurological impairment. These decisions may be required quickly and may have significant consequences that are very abstract and difficult for families to understand. Especially in a time of grief, the family may have difficulty conceptualizing and understanding the prognosis and long term consequences of the infant's severe neurological impairment and how this is likely to affect her quality of life (Ashwal & Cranford 2002).

While parents are charged with acting in their infant's best interests, they also have values, beliefs and interests of their own. At times, it may be difficult to separate the interests of the infant from the parents, or to know whose interests are being expressed (AAP, Committee on the Fetus and Newborn 1995; Beauchamp & Childress 2001, pg 103; Hester 2007). Relating specifically to their role as parents, parents presumably will have an interest in being a "good parent" and providing their infant with love and nurturing care. Society dictates clear parental roles and expectations, including feeding and properly caring for an infant. Parents may feel very strongly that certain things, for example oral feeding, are in their infant's best interest, even though this may be more of a parental interest in nurturing and providing for her in a socially acceptable or morally respectable manner. A parent is at risk of experiencing a difficult moral dilemma when the infant's best interest conflicts with their longstanding values and beliefs on parenting and being a good parent. A parent's perception of a good parent is based on their interpretation and understanding of society's expectations of parents (Ersek 2003; Franklin & Rodger 2003; Guerriere, McKeever et al 2003; Rollins 2006; Spalding & McKeever 1998). Society has legally defined parental roles and responsibilities as well as unwritten socially acceptable expectations of parents. Societal expectations and pressure can have a huge impact on parents' decisions, especially given the significant publicity and judgment that child abuse and neglect cases are given in the media. There may be even greater societal pressure on families of infants with severe neurological impairment given the added factor that their infant is recognized in society as being highly vulnerable and in need of special protection (Rollins 2006; Spalding & McKeever 1998).

Antommara and Bale have proposed that in the case of patients in PVS and MCS where the interests of the patient are either non-existent or reduced, that the interests of others (i.e caregivers) may become more "significant" (Antommara & Bale 2002). This is interesting to consider when looking at the family or caregivers of an infant with severe neurological impairment. The infant has rights and interests that the family is expected to acknowledge and respect. The parents are charged with identifying her best interest and directing her medical care to that end. Some models of care appear to consider the

infant's interests in an apparent vacuum. If the family must only consider the best interest of the infant with severe neurological impairment, they risk jeopardizing their own interests and those of other family members, or the family as a whole (Contro, Larson et al 2002; Monterosso, Kristjanson et al. 2007; Stanley 2000). The family of an infant with severe neurological impairment may have more than one child. Presumably, the parents have a responsibility to all the children in the family. If they chose to invest all their time and resources into the care of the infant with severe neurological impairment, this has the potential to negatively affect the other children in the family (Contro, Larson et al. 2002; Monterosso, Kristjanson et al. 2007; Paris & Fletcher 1987). Antommaria and Bale's comment becomes very interesting at this point. It appears to acknowledge the existence of competing interests of parents and the family and allows the interests of others who may be significantly affected by these decisions to be considered.

3.1.3 The Medical Team Responsible for the Infant with Severe Neurological Impairment

The medical team is ultimately responsible for the medical care of the infant with severe neurological impairment, and as such are the last dimension of this discussion.

Each member of the medical team is charged with practicing his profession in accordance with the profession's code of ethics. Codes of ethics generally have a strong focus on respecting the patient and her rights and autonomy, promoting healing/reducing suffering and preventing harm to the patient. For example, in the Canadian Medical Association's (CMA) Code of Ethics (2004) for physicians,

1. Consider first the well-being of the patient.
14. Take all reasonable steps to prevent harm to patients; should harm occur, disclose it to the patient.

Likewise, the Collège des Médecins du Québec in their Code of Ethics of physicians (2001) states,

3. A physician's paramount duty is to protect and promote the health and well-being of the persons he attends to, both individually and collectively.
4. A physician must practise his profession in a manner which respects the life, dignity and liberty of the individual.
58. A physician must, when the death of a patient appears to him to be inevitable, act so that the death occurs with dignity. He must also ensure that the patient obtains the appropriate support and relief.

Many of the Allied Health professions also explicitly outline the responsibility to the patient in their Code of Ethics. The Canadian Association of Occupational Therapists (2007) states that it,

expects its members to:

- Value and respect clients' rights to be self-directed in their decision making in accordance with their own needs, values and available resources;
- Value and respect clients' rights to be treated with respect and dignity within a safe and non-judgmental environment.

The Ontario College of Social Workers and Social Services Workers Code of Ethics (1994) highlight the profession's responsibility to patients in articles 1 and 2.

1. A social worker or social services worker shall maintain the best interest of the client as the primary professional obligation.
2. A social worker or social services worker shall respect the intrinsic worth of the persons she or he serves in her or his professional relationships with them.

The College of Nurses of Ontario's Professional Standards strongly reflects the importance of respect for the autonomy and rights of the patient. The "Indicators" used to evaluate whether a nurse has met their Professional Standards, states that nurses demonstrate the standards by:

- Providing, facilitating, advocating and promoting the best possible care for clients.
 - Taking action in situations where client safety and well-being are compromised.
 - Planning approaches to providing care/service with the client.
 - Creating plans of care that address client needs, preferences, wishes and hopes.
 - Collaborating with members of the health team to provide professional practice that respects the rights of clients.
 - Ensuring clients' needs remain the focus of nurse-client relationships.
- (College of Nurses of Ontario 2002)

Bound by the Codes of Ethics, the medical team will have an interest in practicing in accordance with these. They will have interests and a duty to treat the infant in what they believe to be her best interest and to prevent any harm or suffering to her. This is also in keeping with the duties of beneficence and non-maleficence as outlined in the Hippocratic Oath.

The same Codes of Ethics however, will also encourage the medical team to respect and collaborate with the family of patients they are treating. For example; CMA Code of Ethics (2004) for physicians Article 30 states, "Be considerate of the patient's family and significant others and cooperate with them in the patient's interest." Likewise, section 59 of the Collège des Médecins du Québec in their Code of Ethics of physicians (2001), states, "(a) physician must collaborate with the patient's relatives or any other person who shows a significant interest in the patient." The College of Nurses of Ontario states in their Professional Standards (2002) that nurses should demonstrate that they are, "developing collaborative partnerships with clients and families that respects their needs, wishes, knowledge, experience, values and beliefs." The International Council of Nurses also reflects this in article 1 of their Code of Ethics for Nurses (2006), stating that, "[i]n providing care, the nurse promotes an environment in which the human rights, values, customs and spiritual beliefs of the individual, family

and community are respected.” This interest in respecting the family’s values and beliefs, especially when practicing in a family centered model of care, may create some conflict for the medical team when the family of an infant is requesting a treatment plan that the medical team does not believe is in her best interest.

Like the other parties, the medical team has many identifiable interests. The duties of the profession may lead to competing interests and the medical team will have to prioritize them. In the case of an infant that is expected to recover with medical treatment, the medical team’s interests become very clear. The infant’s best interests are the top priority in that case. In the treatment of an infant with severe neurological impairment and little to no chance of recovery, the interests of the medical team become more complicated. In cases where the infant’s prognosis is very poor, the needs and grief of the family automatically increase. In these cases, the medical team must acknowledge both their interest in treating and respecting the infant, and their interest in the family’s needs and wishes at this time. The medical team may find that there are times when these will be competing interests. In attempting to respect the duties of beneficence and non-maleficence the medical team may find that fulfilling their duties to one party inadvertently causes harm to the other.

It is also recognized that the medical team may have an additional duty of justice related to resource allocation. For example, it can be difficult to justify using significant time, resources and hospital bed space on one infant with a very poor prognosis. There may be many other infants in need of medical care who are likely to have a better recovery, and who are left waiting in a fragile medical state due to lack of resources. I feel that issues of resource allocation should be dealt with at a policy or institutional level and should not impact the care of a specific patient. Therefore it will not be relevant to this discussion of the infant with severe neurological impairment.

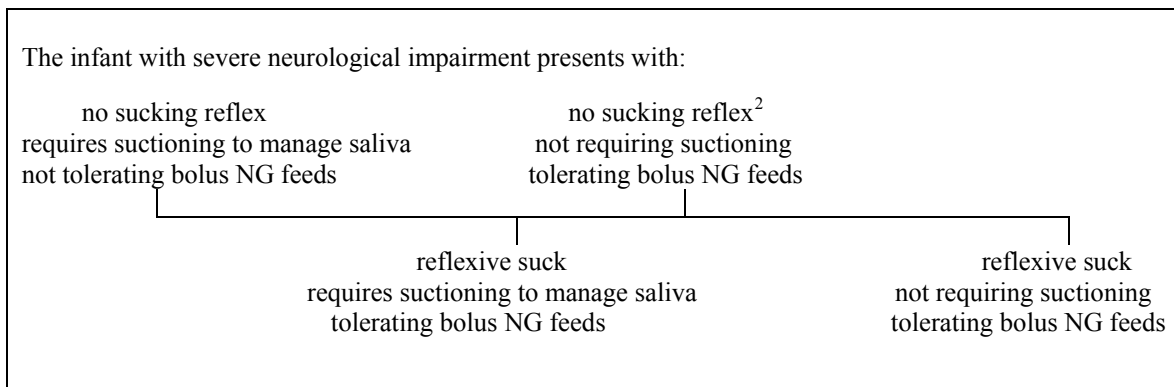
3.2 Spectrums of Presentation

Each of the three parties listed above correlates to one dimension of the dilemma being discussed. Within each of these however, I believe there exists a possible spectrum of presentations, values and beliefs, and I will attempt to outline this below.

3.2.1 The Infant with Severe Neurological Impairment

The infant with severe neurological impairment being discussed can present along a spectrum. All of the infants will present as severely neurologically impaired with very minimal level of consciousness as previously discussed, therefore typical infant hunger cues and behaviours are not demonstrated. This spectrum is illustrated below in Figure 1.

Figure 1 - Spectrum of Presentation of the Infant with Severe Neurological Impairment



At one extreme is the infant with severe neurological impairment that is not managing her secretions, and requires routine suctioning to remove built up saliva that she is not swallowing. This infant is also refluxing her bolus NG tube feeds, requiring continuous NJ tube feeding to reduce pain (from acid reflux) and the likelihood that she will aspirate refluxed material. This infant is not swallowing her saliva, and as such, she will likely have difficulty managing increased fluid (in the form of milk) in her mouth. The tube feedings are also by-passing the stomach due to feeding intolerance and reflux. By-passing the stomach is impossible to do with oral feeding. This infant is therefore demonstrating a number of issues that could make oral feeding attempts potentially more dangerous than it may be for other infants with severe neurological impairment.

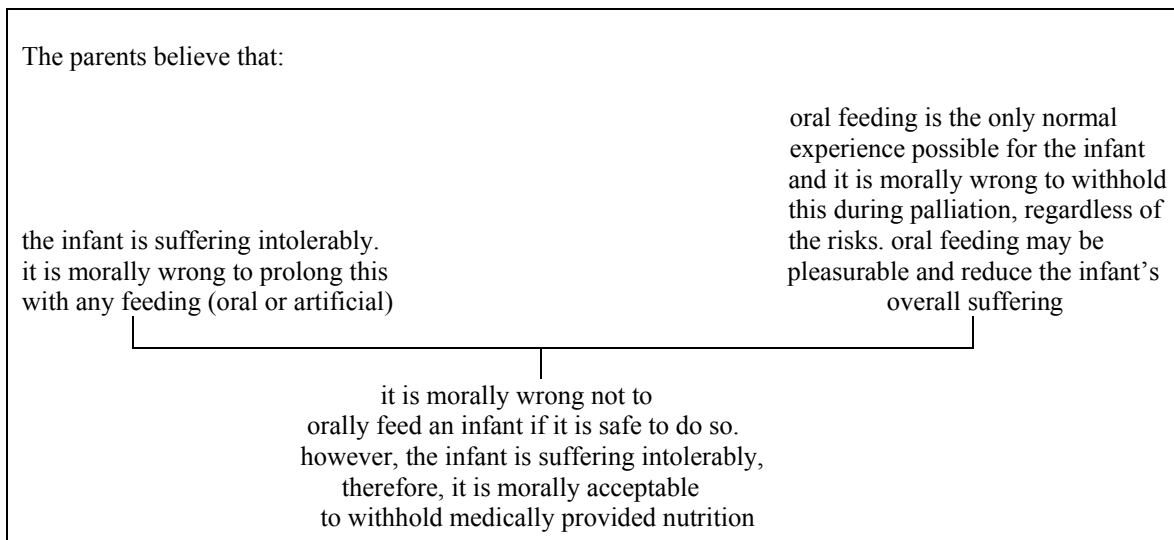
² I believe it is possible for an infant with no sucking reflex who is not requiring suctioning to manage her saliva to be higher on the spectrum than an infant with a reflexive suck that is unable to manage her saliva. This is because the infant's ability to manage her saliva implies that she is demonstrating some successful attempts at swallowing. Even if an infant is sucking reflexively, if she is unable to trigger a swallow, she will potentially have greater feeding difficulties and risks associated with oral feeding.

On the other end of the spectrum is the infant with severe neurological impairment that is tolerating bolus nasogastric tube feeding, is able to swallow her saliva and does not require a caregiver to suction her. This infant also demonstrates a reflexive suck when something is placed in her mouth, but does not cry or fuss to indicate hunger. This infant will have risks associated with oral feeding safety due to her severe neurological impairment, however she is presenting with other factors such as a reflexive suck and tolerance of tube feeds that could potentially allow her to feed partially or completely by mouth. If she is able to feed by mouth, it is recognized that this will be driven by her reflexive sucking response to a bottle placed in her mouth and is not volitional sucking driven by hunger cues, or other higher level cognitive function.

3.2.2 The Parents of the Infant with Severe Neurological Impairment

As with the infant, the parents also have the potential to present on a spectrum. While the infant's spectrum was based on her clinical presentation, the parents have the potential to present a spectrum of beliefs and values, and this is represented below in Figure 2.

Figure 2 – Spectrum of Presentation of the Parents



On one extreme will be the parents who believe that their infant is suffering intolerably and that to offer nutrition in any form will only serve to prolong this. They will believe that it is morally acceptable to withhold medically provided nutrition and that

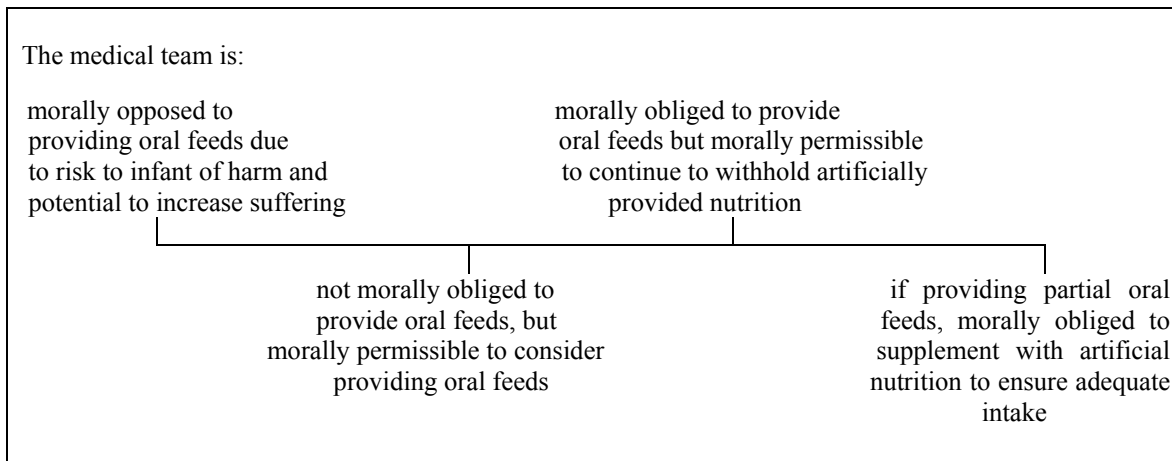
they are morally opposed to further evaluation of her ability to safely orally feed. On the other end of the spectrum will be the parents that believe that oral feeding is the only “normal” baby experience that their infant can experience, and that they, as caring and responsible parents, are not able to deprive them of this, regardless of the risks.

As discussed in the above section, the wishes expressed by the parents may reflect a combination of their values and beliefs and what they believe to be in their infant’s best interest. The spectrum described above reflects this, as well as how it can be difficult to understand whose interests are being served. For example, in the latter example, given the extent of the neurological insult, the infant with severe neurological impairment’s experience with bottle feeding will be significantly different than a healthy infant. Given the risk of swallowing dysfunction, the experience may be stressful and negative for the infant. It is also still unknown if the infant has the ability to perceive pleasure. Depending on the exact clinical presentation of the infant, it is possible that there is a significant component of parental interests here. While the competing interests that the parents may experience are not obvious in the descriptions above, they likely exist. The medical team may also feel that there are competing interests that the family has not identified. For example, the medical team may be concerned that the parents will feel guilty and likely be unable to cope with this infant’s death if they are not able to feed them by mouth, and this may then affect their ability to care for other children in the family. In this case the team may feel more pressure to allow the family to feed the infant in order to facilitate the parent’s grieving and allow them to continue to care for their other children.

3.2.3 The Medical Team Responsible for the Infant with Severe Neurological Impairment

The medical team also has the potential to have a range of presentations depending on their assessment of the infant. This is illustrated below in Figure 3.

Figure 3 – Spectrum of Presentation of the Medical Team



The medical team's belief about whether oral feeding is in the infant's best interest will depend on their assessment of the risks and benefits oral feeding poses to the infant. This will include weighing risks such as; causing an acute illness (pneumonia) that risks hastening death or prolonging suffering by providing partial nutrition against the possible pleasure and comfort of oral feeding for the infant and the family.

On one extreme, the medical team will feel that the risks associated with oral feeding are so great and obviously not in the infant's best interest that they are morally opposed to further assessing the infant's potential to feed by mouth. On the other extreme the medical team may believe that while there are risks associated with assessing oral feeding, the infant has demonstrated enough clinical signs that oral feeding may be possible that it would be contrary to her best interest not to assess it. The medical team would then provide even small amounts of oral feeding if she is able to swallow safely. While the goal of care has already been assessed and established to be palliation and maximizing quality of life, the infant's parents have expressed a desire to bond and care for her. Therefore, in the context of accepting the infant's prognosis and palliation and maximizing quality of life as goals of care, a decision must be made as to what constitutes appropriate palliative care. Providing the infant with the opportunity to orally feed will allow the parents (and possibly the infant) more chance for bonding and forming a relationship with their infant. This is due in part to the actual act of feeding that allows the parent to care for and nurture their infant. It is also due to the fact that on

a physiologic level, even the provision of minimal nutrition is liable to prolong the infant's life and the duration of the relationship with the family. If oral feeding is not assessed in this case it risks depriving the infant and the family of a possible pleasurable experience and bonding time.

Therefore, even though the "goal" of care has already been established and likely does not include further assessment and intervention, in this case, the assessment is appropriate and necessary and in keeping with the goals of care. This however leads to a further dilemma. If small amounts of oral feeding are being taken safely by the infant, the medical team must examine whether they feel that it is acceptable to allow an infant to sustain themselves with substantially inadequate intake. It is possible that the team will feel that if the infant is taking some nutrition by mouth that they are then morally obliged to supplement the oral intake, so as not to allow the infant to exist for an extended period in a state of malnutrition due to the additional burdens associated with malnutrition.

3.3 Summary of the Ethical Dilemma

These three spectrums do exist clinically. As discussed above, any case can fall anywhere on any spectrum. Given also that the parents and the medical team are parties with multiple individuals, there is also a potential for a variety of beliefs within these parties. This creates an almost infinite number of permutations and combinations of scenarios that can be anticipated. Obviously, if each group is cohesive in their beliefs and is representing one extreme, these issues, while still very emotional, are more easily defined. The greatest possibility and risk of conflict will arise when there is disagreement within a party or when each party is presenting in the grey zones of a spectrum. Any of these dilemmas can be potentially very emotional and difficult for families and the medical team. For the purposes of this discussion however, I have created a vignette which illustrates the most salient issues in this discussion.

The vignette highlights the issues that have created the most moral distress for me in clinical practice. As stated in the vignette, the infant (Jane) has a severe neurological

impairment and at best is in a minimally conscious state. The parents and medical team decide that Jane is suffering with little to no hope of a meaningful recovery or acceptable quality of life. The medical team is unanimous in their belief that aggressive medical intervention is not in Jane's best interest and the family agrees. It is felt that the withdrawal of medically provided nutrition and hydration and palliative care are morally acceptable options in this case. The family believes that withdrawal of medically provided nutrition and hydration is the best choice for Jane, but they continue to express a desire to orally feed her.

In this case, Baby Jane does not demonstrate a reflexive suck and requires suctioning to assist with secretion management. While she is not vomiting, she appears to have difficulty tolerating bolus NG feeds, and they are frequently stopped. The medical team feels that Jane is severely neurologically impaired, demonstrating no hunger cues, no ability to suck and is ineffective at swallowing her saliva. They believe that oral feeding is potentially very dangerous. They feel morally opposed, or at the very least not morally obligated to provide any further oral feeding for this infant during the palliation process. The parents feel that this is Jane's only opportunity for a normal infant experience and worry that she is hungry. They feel morally obligated to attempt to provide oral feeds. On further discussion, parents report having difficulty "allowing" their infant to starve and feel that they have a moral obligation to provide the oral feeds and allow her to refuse them.

Chapter 4

Review of the Law and Jurisprudence

In order to further discuss the issues involved in feeding an infant with severe neurological impairment orally, a review of the law is required. There are many nuances and possible issues that can be examined. This chapter will begin with a brief review of the legal rights of the infant with severe neurological impairment in Canadian society. Following that, I have specifically chosen to focus on the boundaries of surrogacy and parental rights as applied to medical treatment decisions. An understanding of the roles and responsibilities of the surrogate decision maker and the decision-making process is pivotal to this discussion.

Given the strong clinical context of this thesis, the discussion needs to be situated in a specific health care framework in order to continue. As an Occupational Therapist, I am familiar with both the Ontario and Quebec health care systems. As such, I have focused the law review on Canadian Federal law, Ontario and Quebec provincial law, professional health care Codes of Ethics and Canadian jurisprudence.

4.1 Laws and Statutes

4.1.1 Legal Status of the Infant with Severe Neurological Impairment

Before any discussion regarding an infant with severe neurological impairment can ensue, the legal status of that infant must be established. The legal status of the infant with severe neurological impairment is very clear within the Canadian legal system. The Criminal Code of Canada (1985), in Article 223 Section 1 states that,

A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother, whether or not

- a) it has breathed,
- b) it has an independent circulation; or
- c) the naval string is severed.

The infant with severe neurological impairment clearly meets these requirements, and as such is afforded full legal status and protection as a human being under Canadian law.

Even a healthy infant is considered to be part of a vulnerable population. They are warranted increased protection due to their complete dependence on others and their lack of personal values and beliefs. The United Nations' Declaration of the Rights of the Child (1959) recognizes that, "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth." In Canada, each province and territory has developed child protection acts specifically to ensure that its children are afforded this increased level of protection. For example, Ontario has established the Child and Family Services Act (1990) which states in Article 1, "the paramount purpose of this Act is to promote the best interests, protection and well-being of children." Similarly, Quebec has established the Youth Protection Act (1977) which states that it applies "to any child whose security or development is or may be considered to be in danger."

An infant who is ill or has a severe neurological impairment is arguably even more vulnerable than a healthy infant. This is due in part to the necessity for medical treatment that may potentially impose undue burdens on her. She requires protection to ensure that the medical decisions being made for her are likely to produce benefits to her health and quality of life, and are not imposing undue burdens at the request of, or for the benefit of others. In Canada, the presence of a disability, no matter how severe, does not reduce her legal rights as a person. Article 15 of the Canadian Charter of Rights and Freedoms (1982) states,

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. The Child and Family Services Act (1990) in Ontario specifically addresses the issue of children who require medical treatment. In Part III, Article 2 (e) when it identifies that, a child is in need of protection where: the child requires medical treatment to cure, prevent or alleviate physical harm or suffering and the child's parent...

does not provide, or refuses to....consent to the treatment.

Therefore, in Canada, the infant with severe neurological impairment is granted all rights as a human being regardless of her level of disability. She is also afforded special protection as a child and a person with a disability, because she is part of two vulnerable populations.

4.1.2 Parents' Responsibilities as Surrogate Decision Makers and the Boundaries of Surrogacy

Parents have a legal responsibility to care for their children, and in providing that care must consider their child's best interest. The Canadian Criminal Code (1985) in Article 215 (1) (a), charges the parents with the responsibility to provide their child with the "necessaries of life". Subsection 2 (a) (ii) states that an offence has been committed if failing to perform the above duty "endangers the life of the person to whom the duty was owed, or causes or is likely to cause the health of that person to be endangered permanently." The Civil Code (1991) of Quebec in Chapter 2 (32) states that "Every child has the right to the protection, security and attention that his parents...are able to give him." It goes further in Article 33 to state that "every decision concerning a child shall be taken in light of the child's interests and the respect of his rights."

It is generally believed that the parents of a child will make decisions that are in their infant's best interests, as they have an interest in protecting her from harm and undue burdens. Parents are assumed to be committed to their infants, and understand the family's values and religious and cultural beliefs within which the infant will be raised (Street, Ashcroft et al. 2000). This allows them to guide decisions regarding her best interests, as that infant's surrogate decision maker. The decisions made by the parents need not conform exactly to those of the medical team, as long as the child's rights are not being exploited and they are being treated with dignity and respect. Article 12 of the Civil Code (1991) of Quebec states,

[A] person who gives consent to or refuses care for another person is bound to act in the sole interest of that person, taking into account, as far as possible, any

wishes the latter may have expressed. If he gives his consent, he shall ensure that the care is beneficial notwithstanding the gravity and permanence of certain of its effects, that is advisable in the circumstances and that the risks incurred are not disproportionate to the anticipated benefit.

It is important to note that part of the right to medical care is the right that a competent being can refuse the recommended medical care (AAP, Committee on Bioethics 1995; Gustaitis 1988). This is supported in Canada by documents such as CMA Code of Ethics Article 24, and Canadian Health Care Consent Act Article 10.1(b). A lack of autonomy does not revoke this right or impose unduly burdensome care on an infant (Miraie & Mahowald 1988). It is generally accepted that an involved and informed caregiver is able to act as the infant's surrogate decision maker and exercise this right (Carter & Leuthner 2003). The medical team has a duty to the infant to work with the surrogate decision maker to establish the infant's best interest. While the medical team is encouraged to work with the families and to respect their values, beliefs and choices for their infants, they are in no way morally obliged to provide treatment that they believe is overly burdensome or not indicated.

There are clear procedures that parents, as surrogate decision maker, must adhere to when they give or refuse consent to health care treatment for their child. In Ontario for example, the Health Care Consent Act (1996) describes this process in Chapter 2, Schedule A, section 21 (1) and 21 (2). It states in 21 (1) that,

A person who is giving or refusing consent to a treatment on an incapable person's behalf, shall do so in accordance with the following procedures:

2. if the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests.

It goes on to describe in 21 (2) (c) that,

In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(c) the following factors:

1. whether treatment is likely to ,
 - i. improve the incapable person's condition or well-being
 - ii. prevent the incapable person's condition or well-being from deteriorating, or
 - iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.
3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.
4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

Parents' rights as surrogate decision makers for their children are not absolute. It is expected that parents are best placed within society to understand their family and their children. This should allow them to make decisions in their children's best interest in the context of their family and beliefs. A parent's capacity to make these decisions can be challenged however. There are clear procedures for acting as a surrogate decision maker. If it is felt that medical treatment decisions being made by parents are overly burdensome or not in the child's best interests, there are processes in place under which these decisions can be reviewed, such as with Ontario's Consent and Capacity Board.

4.2 Professional Guidelines and Codes of Ethics

It is also important in this discussion to consider the Codes of Ethics and Professional Guidelines that the members of the medical team are bound to practice by. These Codes of Ethics detail the core values of each profession. Rather than describing the minimum standards of practice, they describe the values and standards that each profession expects its members to exemplify and aspire to. Professional codes of ethics implemented by the respective regulatory bodies do not merely uphold the federal and

provincial laws. The expectations of these institutions are often much greater than the laws, and demand accountability to deliver best practices in one's respective discipline. Each regulated health care professional is bound to act in accordance with these.

As discussed in the previous chapter, all of these Codes of Ethics make reference to the primary responsibility that the medical professional has to their patient or client. The responsibility to the patient or client is the same for physicians as well as allied health professionals. For example, The Canadian Medical Association's Code of Ethics (2004) states in Article 1 that the physician must, "consider first the well-being of the patient." The Ontario College of Social Workers and Social Services Workers Code of Ethics (1994) states in Article 1 that, "a social worker....shall maintain the best interest of the client as the primary professional obligation."

These same Codes of Ethics also clearly state a responsibility to the family or caregivers of the patient. Again, as reviewed in Chapter 3, this is noted both with Codes of Ethics of physicians and allied health professionals. While most of the Codes of Ethics and Professional Standards that were reviewed acknowledge the role that family plays in medical care, responding to the family's needs and wishes is definitely not the first responsibility the medical professional is charged with. The Codes all identify a professional obligation to the patient as one of the first articles. The obligations to the family, while important, are generally detailed much later in these documents. Based on this, it is assumed that if there is a conflict between the patient and the family that the medical professional's responsibility to the patient takes precedence.

4.3 Jurisprudence and the Boundaries of Surrogacy and Parental Rights

The legal aspects of this issue requires a review of Canadian and provincial law as well as jurisprudence in similar cases. In reviewing the jurisprudence on this issue, there is little specific reference to paediatric and neonatal cases. This Chapter will have a focus on Canadian jurisprudence, given the clinical nature of the issue and the fact that it is occurring within the Canadian health care and legal systems. This is not an exhaustive

legal summary but rather a review of the most recent, relevant and salient Canadian cases.

4.3.1 Most Relevant and Recent Canadian Case – *EJG*

The most relevant and current case is that of EJG. The decision, “*E.J.G. (Re)*, 2007 CanLII 44704 (ON C.C.B.) — 2007-09-30”, is accessible through the Canadian Legal Information Institute. EJG’s case parallels the issues of this thesis. This case, involving an infant (EJG) who was in a neuro-vegetative state, was brought to Ontario’s Consent and Capacity Board in September 2007. At this time, the infant’s parents refused to consent to a medical plan that proposed weaning him from the ventilator, allowing him to die if he wasn’t able to breathe independently. The treating physicians questioned whether the parents’ refusal to consent to the proposed treatment plan violated the Health Care Consent Act’s principles of refusing consent.

According to the report of the hearing, ‘EJG’ was an 8 month old infant who sustained a devastating neurological injury at birth and was diagnosed to be in a persistent vegetative state (PVS). The report details that EJG sustained severe brain damage secondary to lack of oxygen to the brain during birth. The medical personnel quoted in the report described an infant with severe hypoxic ischemic encephalopathy (HIE) resulting in, “spastic quadriplegia, brainstem dysfunction..., exposure keratitis³, absent protective airway responses i.e. no cough, no gag and inability to handle oral secretions,recurrent episodes of respiratory arrest requiring at least 6 intubations and placement on mechanical ventilation, chronic lung disease...on home oxygen, history of deep vein thrombosis and urinary tract infections, gastro-esophageal reflux status post G-J tube insertion and bilateral dislocated hips secondary to chronic hypertonicity.” (*In the Matter of EJG*, 2007)

The physicians in the case reported that at 8 months of age, EJG did not demonstrate any voluntary or purposeful movements. They described him as hypertonic with limbs flexed “often in fixed positions”. They felt that all his “motor responses are

³ A painful inflammation of the cornea of the eye. (Pugh 2000, pg 943)

consistent with spinal reflexes” (*In the Matter of EJG*, 2007). EJG was reported to be blind and deaf. He was also unable to blink, requiring special eye care to prevent his eyes from drying out. EJG was fed through a G-J tube due to severe gastroesophageal reflux and an inability to feed orally, which placed him at risk of aspiration pneumonia. He was also described as having difficulty managing his oral secretions, which necessitated frequent oral suctioning. These were felt to be a factor in his repeated respiratory arrests. At the time of the hearing, EJG was ventilator dependent in a paediatric intensive care unit.

The treating medical team felt that EJG’s prognosis “is devastating and there is no hope for any improvement in his clinical condition. (*In the Matter of EJG*, 2007). The team also reported that they felt that EJG could not feel pain or discomfort due to the severity of his brain injury. They felt that he met all criteria for a diagnosis of PVS. The medical team was concerned that there was no cure for EJG’s condition, and that he would continue to require invasive and aggressive medical intervention to keep him alive. Although he could not feel pain, the medical team was reportedly concerned that EJG was suffering and that continued, invasive medical intervention with no hope of curing his underlying condition was not in his best interests.

The hearing report states that EJG’s parents understood and accepted their son’s condition. Their continued request for full medical intervention for their son was based in their faith that God would eventually miraculously cure him or provide the field of medicine with the knowledge to do so. The report states that EJG’s mother questioned how “anyone could think that they were in a better position to identify EJG’s needs than his mother” and “how letting him die could be in his best interests, especially since he could not feel pain or discomfort” (*In the Matter of EJG*, 2007). EJG’s mother requested that the members of the Consent and Capacity board travel to the hospital to meet her son and “observe their interactions”, which may imply that she felt that he could or did respond to her in subtle ways. Even if she did feel that EJG was responsive, this was not a focus of the hearing and the diagnosis of PVS was never questioned or debated.

In rendering the decision in this case, the Board first discussed the issue of EJG's values and beliefs. The Board stated in the hearing report that EJG had "no values and beliefs or previously expressed wishes" (*In the Matter of EJG*, 2007). They felt that this was due not only to his very young age, but also due to the fact that given his extensive brain damage, he had never been able to think, nor would he ever be able to "contemplate such abstract notions" (*In the Matter of EJG*, 2007).

Given EJG's lack of values and beliefs, decisions regarding EJG's care would have to be based on section 21(2)(c) of Ontario's Health Care Consent Act. As discussed in the previous chapter, this section details that a surrogate decision maker must consider the incapable person's well-being, and weigh the risks and benefits of the proposed treatment. In EJG's case, the Board felt that EJG's parents were making decisions based on their faith, and that they had not weighed the risks and benefits of the treatment for EJG. The Board felt that the family's strong religious beliefs could not be used to justify treatment for EJG, because EJG had no values and beliefs and therefore can not be said to share those of his family.

The Board then considered the scope of the words "well-being" as stated in section 21(2)(c) of the Health Care Consent Act. The Board had to decide how broadly this term could be applied to an infant that has no interests and is incapable of perceiving pain. Here they referred the British case of '*Anthony Bland*'⁴ that the medical team's lawyers had initially presented to the hearing. This case involved a man in PVS, whose family and medical team were requesting withdrawal of life support. The Board quoted Sir Thomas Bingham,

(3) Mere prolongation of the life of a PVS patient such as Mr. Bland, with no hope of any recovery, is not necessarily in his best interests, if indeed such prolongation is in his interests at all. (4) In making an objective judgment of Mr. Bland's best interests, account can be taken not only of any pain and suffering which prolonged feeding and medication might cause but also wider, less tangible considerations...It is of course true that pain and suffering, which may (if the

⁴ Airedale NHS v. Bland, [1993] 1 A11 ER 821

foregoing reasoning is sound) weigh in the balance against the presumption in favour of life, are here to be ignored because of Mr. Bland's insensible condition. But I accept the argument in step (4) that account may be taken of wider and less tangible considerations. (*In the Matter of EJG*, 2007)

Given that this was a British case, the Board was not obligated to follow these recommendations. The Board then, however, referred to another Ontario Consent and Capacity Board case⁵. In the original decision rendered on this case, the Board recognized that the term well-being "could include considerations of a person's dignity" (*In the Matter of EJG*, 2007). During the appeal process, Justice Cullity agreed with the Board's interpretation of 'well-being'. Given that, the Board felt that they could employ this broader definition of the term 'well-being' in their deliberations regarding EJG.

The Board's decision regarding EJG's case was that the parents were not refusing consent according to the policies set out in the Health Care Consent Act. They felt that it was appropriate to consider the "constant invasions and humiliations to which his inert body was subject. At some point those factors overrode the presumption in favour of continuing life and EJG had no countervailing values and beliefs to those factors" (*In the Matter of EJG*, 2007). The Board ruled that the family had approximately 24 hours to consent to the medical treatment plan that involved weaning the mechanical ventilation and not initiating any resuscitative measures. If they refused to consent another surrogate decision maker would be sought.

4.3.2 Other Relevant Canadian Paediatric Cases – L

In Aug of 2008, Ontario's Consent and Capacity Board rendered a decision in the case of "L". The decision, "*L (Re)*, 2008 CanLII 46902 (ON C.C.B) – 2008-08-26" is accessible through the Canadian Legal Information Institute. This case is similar to the *EJG* case listed above in the sense that the Board was being asked to review whether the parents' decision to refuse consent was in keeping with the Health Care Consent Act. The child in this case was neither an infant nor severely neurologically impaired. While

⁵ *Scardoni v. Hawryluck*, 69 O.R. (3d) 700, 12 Admin L.R. (4th) 67 (ON S.C. 2004)

the case deals with a previously healthy child who had the potential to develop into an autonomous being, it also explores the boundaries of parental decision making and as such has some relevance to this discussion.

L was a 2 year old previously healthy girl who sustained severe burns to 40% of her body. The case was brought to the Consent and Capacity Board after L's parents refused to consent to the treatment plan proposed by the medical team. The medical team brought a Form G application to the Board asking them to review whether this refusal of treatment was in keeping with the Health Care Consent Act. All parties in the case agreed that at two years of age, L was not competent to consent to her own medical care (*In the Matter of L*, 2008).

It is reported in the summary of the hearing that the medical team recommended a treatment plan that included pain medication, supplemental nutrition and fluids, wound debridement and skin grafting, all of which was in keeping with the current best practice standards. The team felt that without this treatment L would face profound scarring, and permanent deformity around joint areas, thereby increasing the likelihood of lifelong disability.

In the report, L's parents state that they wanted their daughter to recover, but that they feel that an alternative treatment was best for her. They requested that a member of their community treat L with a special cream and burdock leaves. This treatment did not involve wound debridement and grafting, and parents felt that it would spare their daughter the pain involved with these treatments. The family also proposed transferring L to a hospital in the US that was prepared to treat L with the treatment that they desired (*In the Matter of L*, 2008).

It is reported that the Board was told that the US hospital that was being discussed had a significantly higher than average mortality rate for patients with large burns. The report also states that it was eventually disclosed that L would be this hospital's first paediatric patient.

The family provided two examples of children and one adult with burns who were treated with the cream and burdock leaves, as evidence of the efficacy of the treatment. The court determined that these cases were significantly different to that of L, and therefore were not relevant to L's case and this decision (*In the Matter of L*, 2008).

The lawyer for L asked that the Board consider the risks and benefits of the medical treatment plan, and the parents' belief and faith in the treatment plan that they were requesting. She felt that due to L's young age, L did not have her own values and beliefs yet. Therefore she could not be said to share the beliefs of her parents nor share their faith in the cream and burdock leaf treatment. She cited the EJC decision which discussed that treatment decisions for the incapable infant/child can't be based solely on the faith and beliefs of the parents. She concluded that while L's parents could choose this treatment based on their faith for themselves, they could not do this for L, as L could not share their faith in this treatment (*In the Matter of L*, 2008).

As discussed above in the *EJC decision*, the court cited Ontario's Health Care Consent Act, Section 4 (1), 20 (1-5) and 21 (1-4). These sections detail the selection of a surrogate decision maker and the principles for providing treatment decisions on behalf of an incapable person. The court felt that L's parents' refusal to consent to the medical treatment plan was not in accordance with section 21 of this act. They subsequently directed the parents to consent to the medical treatment plan or an alternate surrogate decision maker would be sought (*In the Matter of L*, 2008).

4.3.3 Recent Canadian Cases involving Children of Jehovah's Witness Families

Many of the paediatric medical cases in Canadian jurisprudence are about Jehovah's Witness families who refuse to consent to blood transfusions for their children based on their religious beliefs. Much of the discussion in cases involving Jehovah's Witness families related to whether the parent's right to religious freedom, as described in the Charter of Rights and Freedoms, had been violated. These cases are slightly

different from *EJG* and *L*. The cases of *EJG* and *L* were brought to the Consent and Capacity Board in Ontario, and were based on whether the parents' refusal to consent for treatment was in keeping with Ontario's Health Care Consent Act. Religious or cultural beliefs were involved in the discussions, however the board was only ruling on whether parents had followed procedure as surrogate decisions makers.

The cases involving families of Jehovah's Witness faith does bear some relevance to the issues being discussed in this thesis, but it is important to note two significant differences of the cases. Firstly, the infants and children are not described as having any significant neurological impairment. Unlike *EJG*, it is anticipated that these infants have the potential to develop into autonomous beings and will develop independent values and beliefs. Secondly, these cases involve infants and children with treatable medical conditions with proposed medical treatment plans that had the potential to ameliorate their conditions. The proposed transfusions were to protect the infants' health and promote or facilitate recovery from an underlying illness. Thus, cases involving families of Jehovah's Witness faith are good illustrations of the influence and limits of religious beliefs, even though they differ because these children are assumed to have the potential to develop into autonomous beings. To illustrate this, two such cases have been chosen. These cases were chosen as they specifically involve very young infants.

In *V.M. v British Columbia*, Chief Justice Brenner had to rule on whether the seizure of 4 sextuplets born very prematurely for emergency blood transfusions was appropriate. The babies in this case were born at 25 weeks gestational age and within the first few weeks of life, blood transfusions were recommended by the medical team. The babies' parents were of the Jehovah's Witness faith, and as such refused to consent to the transfusion on the grounds that one of their religious tenets forbids blood transfusions. In the case, Chief Justice Brenner supported the lower court's decision to apprehend the babies for emergent medical treatment (*V.M. v British Columbia*, 2008).

Chief Justice Brenner concluded in the report of the hearing that the babies' health was "extremely compromised" and that the blood transfusions were necessary and

supported by the Child, Family and Community Services Act ss. 29(1), 30 and 32. The family argued that this violated their “liberty interest and security of the person” which are protected by s.7 of the Canadian Charter of Rights and Freedoms⁶. Chief Justice Brenner responded to this stating that based on current scientific knowledge and the medical testimony presented, the medical condition of the infants required medical intervention to attempt to preserve their life and health. He states that the infants’ right to life (and necessary medical treatment) as defined by s.7 of the Canadian Charter of Rights and Freedoms should take precedence in this situation. Chief Justice Brenner cited *B. (R.) v. Children’s Aid Society of Metropolitan Toronto* and *B. (S.J.) v. British Columbia*⁷ in his decision. These cases both stressed that a child’s best interest can take precedence over freedom of religion, which is not considered to be absolute (*V.M. v British Columbia*, 2008).

B. (R.) v. Children’s Aid Society of Metropolitan Toronto in 1995 is the second case that will be discussed in this chapter. *B. (R.) v. Children’s Aid Society of Metropolitan Toronto* is similar to the above case. It involves a baby girl born at 36 weeks gestational age to parents of Jehovah’s Witness faith in Ontario. During her hospitalization a blood transfusion was recommended and her parents refused to consent to it. In this case, the court was asked to rule on whether the parents’ right to liberty (s. 7) and religious freedom (s. 2a) were violated when the lower court apprehended the baby and consented to the blood transfusion (*B. (R.) v Children’s Aid Society of Metropolitan Toronto*, 1995).

In their ruling, the court discussed that the right to liberty does include the right to “nurture a child....and to make decisions for it in fundamental matters such as medical care.” The court acknowledged that parents are expected to act in their child’s best interest and are thought to be the people who are best able to appreciate how a decision is

⁶section 7 of the Canadian Charter of Rights and Freedoms states, “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice”.

⁷ *B. (S.J.) v British Columbia (Director of Child, Family and Community Service)*, 2005 BCSC 573

likely to affect their child (*B. (R.) v Children's Aid Society of Metropolitan Toronto*, 1995).

The Court continued by discussing that both children and parents have rights that are protected by the Canadian Charter of Rights and Freedoms. Children however, are unable to “assert” their rights. It is assumed that parents will exercise their rights and freedoms in such a way that also respects their child’s rights. The Court went on to state, “The exercise of parental beliefs that grossly invades those best interests (of the child) is not actively protected by the right to liberty in s. 7. There is simply no room within s. 7 for parents to override the child’s right to life and security of the person” (*B. (R.) v Children's Aid Society of Metropolitan Toronto*, 1995).

The court then discussed the parents’ freedom of religion. It stated that while the parents have a right to hold their own religious beliefs, that they do not have a right to act on these beliefs in such a way that violates another person’s rights. The Court discussed that this infant was too young to have expressed any religious beliefs. However, her right to freedom of consciousness would include her right to live long enough to formulate her own beliefs so that she can make decisions based on these beliefs. “‘Freedom of religion’ should not encompass activity that so categorically negates the ‘freedom of consciousness’ of another” (*B. (R.) v Children's Aid Society of Metropolitan Toronto*, 1995).

4.4 Historical References

There are two landmark US cases that are often cited in discussions about the boundaries of parental surrogacy in the context of medical futility. The cases of *Baby L* and *Baby K* are not exactly the same as the issues being discussed in this thesis, but both cases involve severely neurologically impaired children and parents requesting treatment that was not recommended by the medical team. Some of the issues discussed in these cases are relevant to this thesis and will assist with further discussion.

4.4.1 *Baby K*

Baby K was born in 1992 with anencephaly⁸ (Fletcher 1997; Romesberg 2003). Infants with anencephaly rarely survive for any length of time, and the standard of care in cases of anencephaly is palliation (Fletcher 1997). Baby K's mother requested aggressive medical treatment for her daughter, including intubation and ventilatory support, and refused the medical recommendation of a "do not resuscitate" order. The medical team experienced significant moral distress in being directed to pursue aggressive medical care that they felt was contrary to Baby K's best interests, and they attempted to transfer her care to another medical team. They were unable to find a team who would accept her care (Fletcher 1997; Romesberg 2003).

Baby K was eventually transferred to a nursing home but required frequent hospital admissions for respiratory distress that required intubation and ventilation. At approximately six months of age, a tracheostomy⁹ was inserted. At that time the hospital initiated legal action to request withholding further ventilatory support that it felt to be futile and overly burdensome for Baby K (Fletcher 1997; Romesberg 2003). The court ruled that the hospital was legally obligated to continue to provide aggressive medical intervention for Baby K's episodes of respiratory distress, as per the mother's request. The decision detailed that Baby K was presenting to hospital in respiratory distress, and that ventilatory support was appropriate and successful in ameliorating that issue. It was acknowledged that this intervention would not impact her anencephaly and overall prognosis, but anencephaly was not the reason that she was presenting to hospital. The court cited that the US law did not prevent other people with terminal diseases from seeking medical support, nor should it prevent this mother from requesting such support for her daughter. The case was appealed, and even though the moral distress of the medical team was acknowledged, the decision was upheld. Baby K died of a cardiac arrest at two and a half years of age (Fletcher 1997; Romesberg 2003).

⁸ Anencephaly is a neural tube defect that results in minimal brain development in utero. The babies are often born with only brainstem function and absent skull bones. In the most severe cases the rudimentary brain tissue is not covered by bone or skin (National Institute of Neurologic Disorders and Stroke 2009).

⁹ A tracheostomy is a breathing tube that is surgically inserted in the neck and trachea to maintain a patent airway. It is utilized for a variety of reasons, including in cases where long term mechanical ventilator support is required. (James 2009)

In some discussions of cases such as Baby K, it has been argued that the ongoing aggressive medical interventions were inhumane and simply prolong death. This argument is difficult to make in the case of Baby K due to her diagnosis of anencephaly. By definition, babies with anencephaly lack higher level brain function and consciousness, and do not experience pain (National Institute of Neurologic Disorders and Stroke 2009).

4.4.2 *Baby L*

Baby L was born in the late 1980s. She was born very small, and one month premature after a complicated delivery. She required aggressive medical intervention immediately after birth. In the days after birth she began experiencing seizures and it was felt that she was only responsive to painful stimuli. She required a g-tube for feeding and at seven months of age required a tracheostomy. She remained in hospital until she was over a year old. After her initial discharge, she was frequently readmitted for management of acute medical issues (Moore 1995).

The medical team responsible for Baby L's care felt that continued aggressive medical intervention was overly burdensome and painful for Baby L, and not in her best interests. The medical team was distressed by the mother's continued request for this level of intervention, as it was not improving her overall medical prognosis, which remained very poor. The medical team felt that continuing to provide aggressive medical intervention to Baby L violated their obligations of non-maleficence. Baby L's mother was distressed at the recommendations of the medical team and initiated legal action. A guardian ad litem was appointed by the courts. The guardian ad litem was able to find a different medical team who was willing to accept Baby L's care and agreed to provide the aggressive medical treatment that Baby L's mother requested (Moore 1995).

Discussions regarding Baby L often consider whether providing ongoing treatment was futile or inhumane (Moore 1995). As with the Baby K case, futility is difficult to argue. The humanity of providing continued aggressive intervention is at the center of this discussion. Contrary to Baby K, it was acknowledged that Baby L

responded to painful stimuli, therefore she was at risk of experiencing pain and suffering. This would have to be considered in a benefit burden analysis of proposed treatments for her. This case also highlights the subjective nature of the benefit-burden analysis and demonstrates that changing health care providers may be an acceptable solution to resolving conflicting situations.

4.5 Summary of the Legal Position

The legal picture is very clear on the issue of the legal status of the infant with severe neurological impairment as described in the vignette. The infant with severe neurological impairment is granted full legal rights and protection as a human being in Canada. Further to this, as an infant and a person with a disability, she is recognized to be a member of two vulnerable populations. This affords her increased protection to ensure that she is not exploited or unduly burdened by those who are making decisions on her behalf.

Both the law and the professional Codes of Ethics highlight the importance of families in the care and medical treatment of incapable patients. While the importance of the family is recognized and participation of the family is encouraged, the ultimate responsibility of the medical team and the legal system to the patient is without question. Recent jurisprudence also reflects this. The recent Canadian court cases that most closely resemble the vignette described in this thesis clearly highlight that there are limits to the rights of parents as surrogate decision makers. These cases demonstrate that in the Canadian health care system, when a surrogate decision maker's decision does not appear to reflect the interest of the infant, these decisions are not absolute and can be challenged. The landmark US cases however provide a different perspective. While all the cases discussed assessed the best interests of the infants in question, the issues on which the courts were being asked to rule were slightly different. In the two Ontario cases, the issue at hand was whether the parents' refusal to consent to treatment was in keeping with the provincial standards for refusing consent as a surrogate decision maker. By contrast, the US cases revolved around whether the treatment the parents requested was "futile".

Given this, it is difficult to decide whether the decisions are truly different or whether it was the nature of the questions that resulted in the differences in the decisions.

The lack of similar cases to the ones being discussed in this thesis and the paucity of cases that are even remotely related to it, make it difficult to speculate on future cases. Given the review of Canadian laws and recent court decisions however, it would seem that Canadian society as represented by the courts is not ready to allow parents' rights as surrogate decision makers to supersede the apparent best interests of the infant. A statement by Justice Abella of the Supreme Court of Canada from a July 2007 ruling also seems to support this premise. She stated in her ruling that "Families are the core social unit. At their best they offer guidance, nurture and protection, especially to their most vulnerable members – children." (*Syl Apps Secure Treatment Center v B.D.*, 2007) She goes on to state however that, "It is true that treating a child in need of protection can sometimes be done in a way that meets with the family's satisfaction in the long term. But it is not the family's satisfaction in the long term to which the statute gives primacy, it is the child's best interests" (*Syl Apps Secure Treatment Center v B.D.*, 2007).

Chapter 5

The Evolution of Social Norms

This discussion is not limited to the parameters of jurisprudence. Social values and the impact on the families of infants with severe neurological impairment also need to be explored. This chapter will review some history related to oral feeding and the withdrawal of medically provided nutrition and hydration. It will then review some landmark US cases that reflect challenges and society's anxiety around issues of nutrition and hydration in vulnerable populations.

5.1 Attitudes and Values Regarding Feeding and Hydration

In order for this discussion to evolve, it must be recognized that there are two issues regarding nutrition that need to be explored; the provision or withholding of *oral feeds* and the provision or withholding of *medically provided* nutrition. In my clinical experience, when an infant is clearly aspirating oral feeds and the goal of treatment is life sustaining, parents will stop oral feeds reluctantly. Paradoxically, when treatment moves to palliation and medically provided nutrition and hydration are withdrawn, I feel that the need or desire to provide oral feeds often becomes very strong. This chapter will explore some of the social norms and attitudes related to oral feeding and the withdrawal of medically provided nutrition and hydration.

Food and the act of eating hold significant emotional and social value in most cultures and are involved in many aspects of daily life. Food is far from simply a way to nourish and sustain the body; it is a form of nurturing and the center of family gatherings, celebrations, meetings and cultural traditions (Ersek 2003; Jacobs 2005; Morin 2007; Solomon, Sellers et al. 2005).

Feeding or nourishing an infant is one of the most tangible roles and responsibilities for new parents (Antommara & Bale 2002). As Miraie writes, "there is something very basic about food and babies. Our nurturing instincts tell us that infants ought to be fed" (Miraie & Mahowald 1988). In addition to a parent's instinct to feed an

infant, there is a social understanding that food is a basic human need and right (Carter and Leuthner 2003; Paris & Fletcher 1987; Winter 2000). Societal expectations are that parents will meet these basic human needs in order for the infant to survive, but also for her emotional development. The literature refers to feeding the newborn infant as an important time for bonding and for building and fostering trust and social development (Carter & Leuthner 2003; Ersek 2003; Morin 2007).

As an occupational therapist, I have watched many families struggle to provide their infant with oral feeding. In my experience, oral feeding is one of the most common goals that parents identify with therapy. The societal expectation that parents will feed and nourish their infant seems to place the locus of control of feeding on the parents. This is perhaps why parents feel additional stress, pressure and perhaps even failure, when an infant can't or doesn't eat well (Antommara & Bale 2002). Studies have investigated mothers' feelings when they have a child that has difficulty eating. They have shown that these mothers report that being unsuccessful with oral feeding can lead them to feel as though they are not "good mothers" and may impact their ability to bond with their infant (Franklin & Rodger 2003; Guerriere, McKeever et al. 2003).

Emily Miraie wrote an interesting article detailing her experience as a medical student who gives birth to a son with "serious brain damage caused by birth asphyxia" (Miraie & Mahowald 1988). In her article she very eloquently discusses her difficulty as a mother in viewing the provision of food without the emotional context. She writes, "Our nurturing instincts tell us that infants ought to be fed, even when one decides intellectually that feeding may not be in the infant's best interest....It is one matter to discuss theoretically the discontinuation of feeding; it is another to implement such a plan" (Miraie & Mahowald 1988). She goes on to state, "Ironically feeding an infant with no gag reflex can hasten rather than retard his death because of possible aspiration of secretions or food" (Miraie & Mahowald 1988). It is obvious in her writing the tremendous pain and difficulty her family had making these decisions.

As a therapist I have seen devastated families struggle, as Miraie describes, with being told that feeding is not safe for their infant, and try to comprehend how withholding such basic care as oral feeding can be in an infant's best interest. Over the years, in my mind, I have come to understand that there are issues about feeding that are intrinsic to the parents/family but also issues that are related to external influences such as societal pressures and expectations. This is reflected in the literature as well.

The issues that are intrinsic to the parents and the family unit are related to the responsibility parents feel that they have to orally feed their infant. They do not discuss the societal expectations related to feeding, but rather a 'need' to provide for and care for and protect their child (Antommara & Bale 2002). Parents often express significant fear that not feeding the infant will result in her suffering. These concerns are usually about feelings of "hunger". There is also a potential fear that parents may feel as though not offering oral feeds to the infant means that they *allowed* her to starve to death. In situations where parents are able to offer oral feeds and the infant is unable or "chooses" not to eat, it seems to relieve some of the feelings of responsibility, and fear of suffering (Carter & Leuthner 2003; Miraie & Mahowald 1988; Stanley 2000). The possibility that orally feeding the infant could have negative effects is rarely raised by parents.

In addition to the fears of suffering and feeling a responsibility to fulfill a duty as parents, other intrinsic issues have emerged. At times oral feeding is of such importance to families because it is the only way that they know to interact and engage with their infant who is minimally responsive. Similarly, oral feeding may be the only typical infant experience that a severely neurologically impaired infant can have, and families don't want to eliminate that potentially pleasurable experience (Guerriere, McKeever et al. 2003).

The external influences that have emerged in my mind are related to the parents' perceived societal views of the decision. When medically provided nutrition and hydration is withheld and oral feeding is not recommended, families may not share this decision with friends, or extended family. While the parents may be comfortable that this

is in the best interests of the infant, there can be fear and uncertainty about how other people will accept it. There may be concerns that society will feel that the infant starved to death, or that this decision was because she was disabled (Stanley 2000). At times there are fears that the decision to withhold medically provided nutrition and hydration will not be supported by their religion, and that families may be punished for this choice (Levi 2003).

The emotional response that parents fear from society is evident in public cases such as that of Terri Schiavo. Terri Schiavo's husband requested the withdrawal of medically provided nutrition for his wife, who was in PVS and had been for many years. He stated that he believed this was in keeping with her values and previously expressed wishes. Terri's parents objected to his request and disagreed with those statements (Colby 2006; Fine 2005; Hampson & Emanuel 2005). The case was given significant media attention in the US as well as Canada, and polarized the nation. The response from the public was very emotional. It demonstrates society's discomfort with the concept of withholding or withdrawing medically provided nutrition and hydration. It demonstrates that there is a significant part of the population that views the withdrawal of medically provided nutrition as unethical and tantamount to willingly starving a person to death. Cases like this also draw very powerful and influential individuals into the debate. For example, President George W. Bush and Governor Jeb Bush both publicly supported Terri's parents in recognition of the need to protect the weak and vulnerable (Colby 2006, Fine 2005). The public's expression of concern about Terri starving to death and suffering from hunger demonstrated a very strong emotional aspect regarding food and feeding a person who couldn't feed herself. While medically provided nutrition and hydration may be a medical intervention, society's strong emotional connection to "feeding" (i.e. medically or orally provided nutrition) and the belief that it is a basic human need seem to remain (Levi 2003). As Winter writes, "decisions about nutritional support at the end of life may be influenced by emotional associations and personal experiences that do not correspond well with the actual end-of-life experience" (Winter 2000). It is easy to see how a parent may have strong fears about how society's ability to

understand the decision to withhold medically provided nutrition and hydration and the resultant fear of criticism or judgement.

Having an appreciation of the deep emotional connection to oral feeding and the fears associated with withholding nutrition and hydration has allowed me to begin to develop an appreciation for the depth and multi-layered effect of this decision. Families who are able to put their infant's needs before their own, may remain fearful that even extended family will not understand their choice.

5.2 History of Withdrawal of Medically provided Nutrition and Hydration

It has long been recognized that medicine is not able to cure all patients and conditions. With the recent increases in medical technology however, it is now possible to sustain an infant's life even when there is no hope for a cure. It is generally accepted that there is no duty to provide invasive medical treatment or interventions for the sole purpose of sustaining an infant's biologic function (AAP, Committee on Bioethics 1983; AAP, Committee on Bioethics 1996; Carter & Leuthner 2003; Levi 2003; Paris & Fletcher 1987; Stanley 2000; Street, Ashcroft et al. 2000; Solomon, Sellars et al. 2005). As such, the concept of withdrawal or withholding of life-sustaining medical treatment has emerged.

The inclusion of medically provided nutrition and hydration in the category of 'life-sustaining medical treatment' has only recently been accepted. Due in part to society's emotional connection to food and our own experiences with hunger, it has been difficult to view nutrition as anything other than a basic human need and right (Levi 2003; McCann, Hall et al. 1994; Winter 2000).

The medical community's views on medically provided nutrition and hydration have evolved significantly in the last 25 years. There are two topics in the literature that assist in understanding how the medical community's attitudes and acceptance of withdrawal or withholding of medically provided nutrition and hydration have developed in North America.

The first are the Baby Doe regulations. In 1983, the Baby Doe regulations were passed in the United States. These regulations were initiated after an infant born with Down's Syndrome died at one week of age after his parents refused a routine and life saving surgery that would allow him to be fed. These regulations initially stated that, "the basic provision of nourishment, fluids and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment...no health care worker should take upon itself to cause death by dehydration or starvation" (Paris & Fletcher 1987). In 1985, these regulations were modified slightly to consider, "appropriate nutrition, hydration...which in the treating physician's reasonable medical judgment will be most likely to be effective in ameliorating or correcting the patient's condition" (Paris & Fletcher 1987). This slight amendment to the Baby Doe regulations allowed medical teams to ethically consider withholding medically provided nutrition and hydration that was felt to be burdensome or futile to the infant.

While the amendments to the Baby Doe regulations provided the medical team the ability to consider withholding or withdrawing medically provided nutrition and hydration, the beliefs about the possible burdens of providing medically provided nutrition needed to be explored. In the 1980's Yarborough began to challenge the medical community to consider the possible burdens and side effects that may accompany medically provided hydration and nutrition. He challenged that medically provided nutrition and hydration was similar to force-feeding. He proposed that medically provided nutrition should be administered with a specific therapeutic goal and not as a standard of care with little thought to negative side effects (Carter & Leuthner 2003; Yarborough 1989).

Since then, studies have begun to look at the provision of medically provided nutrition with a more objective focus, trying to minimize the emotional connection to feeding. There have been reports that the provision of medically provided nutrition in certain groups, specifically those that are terminally ill, can cause increased suffering in patients. The reported side effects include aspiration, infection, nausea, vomiting,

abdominal distension and pain (Andrews & Marian 2006; McCann, Hall et al. 1994; Winter 2000).

A study published in JAMA in 1994 attempted to document feelings of hunger and thirst in a group of terminally ill adults (McCann, Hall et al. 1994). The authors, McCann et al, reported that hunger and thirst in patients with significantly inadequate fluid and caloric intake were infrequently reported, and didn't persist after eating small amounts. Feelings of thirst and dry mouth were more frequently reported, but again were relieved with small amounts of food/water or mouth care. The study describes instances where patients ate at the insistence of family and subsequently reported pain and discomfort. They also reported an incidental finding of decreased oral secretions when nutrition is withheld, which correlates with positive effects such as decreased incidence of choking and decreased need for suctioning (McCann, Hall et al. 1994). Similar findings have been demonstrated in other studies (Andrews & Marian 2006; Ganzini, Goy et al. 2003; Smith & Andrews 2000; Viola, Wells et al. 1997). Research and anecdotal reports appear to be indicating that people in the end stages of disease do not perceive hunger and thirst in the same manner as healthy individuals. Applying nutritional supplementation in these cases without considering the patient's neurological status or advanced disease and the physiologic changes that accompany these, may actually create suffering rather than preventing or alleviating it.

Currently the medical literature indicates a consensus that medically provided nutrition and hydration constitutes a medical intervention. As with any medical intervention or treatment, it should be applied after an analysis of the benefits and burdens that it is liable to produce for the patient (AAP, Committee on Bioethics 1983; AAP, Committee on Bioethics 1996; Carter & Leuthner 2003; Levi 2003; Paris & Fletcher 1987; Stanley 2000; Street, Ashcroft et al. 2000; Solomon, Sellars et al. 2005). More specifically this requires an analysis of the benefits of providing medically provided nutrition and hydration versus the burdens of providing artificial hydration and nutrition. Given the potential for risks and harm, providing medically provided nutrition to medically fragile patients requires careful consideration by the treating medical team.

If the burdens clearly outweigh the benefits, such feeds can ethically be withheld or withdrawn.

There is very little in the literature detailing the medical community's attitudes towards allowing an infant to be *partially* nourished. A number of authors comment in their articles that while medically provided nutrition and hydration can be withheld, it is obviously unethical to withdraw or withhold any amount of oral feeding that an infant is able to *safely* consume (Carter & Leuthner 2003; Morin 2007; Solomon, Sellers et al. 2005).

5.3 Historical References Reflecting Societal Attitudes on Withdrawal of Artificially Provided Nutrition and Hydration

While not specific to the cases being discussed in this thesis, there are three US cases that have helped shape North America's views on the right to die and the withdrawal of medically provided nutrition and hydration. These are key cases in the literature and will assist with the framework of this discussion.

5.3.1 *Karen Ann Quinlan*

In 1975, Quinlan was a 21 year old woman who suffered a severe anoxic brain injury that left her in PVS and ventilator dependent. After the extent of her injuries was known, her parents requested that the ventilator be withdrawn and that Karen be allowed to die. The medical team refused this request stating that this would 'kill' her. Karen's parents took their case to the New Jersey Supreme Court. The court ruled in favour of Karen's parents and the ventilator was removed. Once the ventilator was removed, Karen began to breathe independently and survived in PVS for nine years. Throughout those years she continued to receive medically provided nutrition via a feeding tube. She eventually died from complications of pneumonia.

The *Karen Ann Quinlan case* is a hallmark case and is often referred to as one of the first right to die cases (Fine 2005; Hampson & Emanuel 2005). The verdict in this

case supported family members as substitute decision makers. It also allowed the concept of quality of life to be considered when considering medical decisions.

5.3.2 *Nancy Cruzan*

In 1983, Nancy Cruzan was left in PVS after a car accident. After a number of years in PVS, her parents began to believe that she would not recover from this injury and that she would not have liked to be kept alive in this state. They requested that the medical team remove Nancy's feeding tube, but their request was denied. The family embarked on a long and public court battle that eventually reached the U.S Supreme Court. The Supreme Court verdict was delivered in 1990 and delegated to the States the authority to determine the evidentiary standard required to respect a patient's prior wishes to refuse such care (Colby 2006; Fine 2005; Hampson & Emanuel 2005).

The verdict in this case supported the belief that life sustaining treatments (of which medically provided nutrition and hydration are an example) can be refused in certain circumstances. The verdict also discussed the burden of proof required to demonstrate that the refusal of treatment was consistent with the patient's wishes. This piece is not relevant to this thesis, as the infants being discussed have never had the capacity to develop or express interests.

5.3.3 *Terri Schiavo*

Terri Schiavo's case is the most recent of these very public and emotional cases. In 1990, Terri suffered a cardiac arrest which resulted in a severe anoxic brain injury. She was diagnosed in PVS and nutrition and hydration was provided artificially through a feeding tube. After her injury, her husband was appointed as her substitute decision maker. In the years after her cardiac arrest, Mr Schiavo pursued rehab and experimental therapies for his wife. There was no improvement in her neurologic status and she remained in PVS. Eight years later, Mr, Schiavo requested that Terri's feeding tube be withdrawn. Her parents strongly objected to this request. Mr. Schiavo took the case to court and on three separate occasions the medically provided nutrition and hydration was withdrawn. The medically provided nutrition was reinitiated after the first two decisions. The second time the artificial feedings were reinitiated was due to "Terri's Law" which

the Florida House and Senate passed. This allowed Governor Bush to request that Terri's feeding tube be reinserted. This case was very emotional and was more complicated than *Quinlan* and *Cruzan* because Terri's family was not unanimous in their interpretation of Terri's wishes, and by her parent's belief that she was not in a PVS state. Her parents even requested that Mr. Schiavo divorce their daughter and allow them to become Terri's substitute decision makers. Terri's feeding tube was removed permanently on March 18th 2005. Despite further appeals and government interventions, the decision to remove the tube was upheld and Terri died 13 days later (Colby 2006; Fine 2005; Hampson & Emanuel 2005).

The verdict in this case continued to support a patient's right to refuse life sustaining treatments. It demonstrated the difficulty in establishing proof that the wishes expressed by the substitute decision maker are in keeping with the patient's beliefs. It also highlighted how passionate the public can become and how the medical facts of the case can be ignored or distorted in public debates, thus further complicating the situation.

5.4 Summary of Consideration of Factors Beyond the Family

With the research and work done by the medical community, it seems that the withdrawal and withholding of medically provided nutrition and hydration can be argued to be ethical in some situations. It also seems that the medical community has generally accepted this as a treatment option in these cases. It is also clear however, that there is a significant emotional component to feeding that is strongly reflected in North American society, and that this can at least partially account for the significant resistance to this trend.

Society's attitudes and acceptance of these issues will significantly affect families as they are required to make these very difficult decisions. Parents' fears that family and friends will not understand their decision reflects the effect that these social attitudes have on them as they make these decisions. Therefore, while it may be ethical to withdraw medically provided hydration and nutrition, it is important that the medical team acknowledge the symbolic meaning of the provision of nutrition, specifically oral

feeding, to families and society. The fact that parents may have difficulty bonding with their infant or that they may feel as though they have failed in their role as parents when they are unable feed her need to be considered. During the palliation of the infant with severe neurological impairment, it will be necessary to consider the possible personal and societal consequences to these decisions. This may assist the medical team in understanding the context of the family's request to provide oral feeding after the withdrawal of medically provided hydration and nutrition. These factors can potentially cause further trauma to an already fragile and devastated family and will need to be acknowledged when considering parents' desires and need to provide oral nutrition to an infant that cannot tolerate them.

Chapter 6

Changing Health Care Relationship

Societal values influence the delivery of medical care. The once patriarchal, physician driven model of care has changed. Patients have become more informed and demand more involvement in medical care decisions. There is a shift from the physician deciding the “most appropriate” course of treatment to the informed patient choosing the treatment options they wish to pursue (AAP, Committee on Hospital Care 2003; Canadian Paediatric Society 2004). This paradigm shift has resulted in the emergence of issues surrounding best interests and the limits to a patient’s ability to demand or refuse care. These issues are most apparent in cases where the patient is unable to speak for themselves, such as in the case of the infant with severe neurological impairment. In these cases, typically parents and other family members, share the responsibility of decision-making. Therefore, the philosophies of family centered care and palliative care will be reviewed, in order to provide a context for the discussion.

6.1 Family-Centered Model of Care

Currently the most common philosophy of care in paediatrics is the family-centered model of care (AAP, Committee on Hospital Care 2003; Canadian Paediatric Society 2004; Cooper, Gooding et al. 2007). A family-centered model of care recognizes that children are situated within a family. This family unit is the main source of nurturing and support for the child (AAP, Committee on Hospital Care 2003; Cooper, Gooding et al. 2007; Jacobs 2005; Neal, Frost et al. 2007). This model recognizes that each family has unique values and beliefs that will impact medical decisions and choices. It recognizes the importance of the family unit to the child by acknowledging the added responsibility that the medical team has to the family unit (AAP, Committee on Hospital Care 2003; Jacobs 2005; Neal, Frost et al. 2007). The American Academy of Pediatrics (AAP) for example, lists “providing support for the child and the family” as a core principle of family-centered care in their policy statement on family-centered care (AAP, Committee on Hospital Care 2003).

One of the unique issues with the infant paediatric patient is the need for surrogate decision makers, as the infant is incompetent to direct her own care and has no previously expressed wishes (Beauchamp & Childress 2001, pg 102-103; Canadian Paediatric Society 2004; Jacobs 2005). As previously discussed, the law states that a surrogate decision maker must make decisions that are in the “best interest” of the patient. However, in clinical practice, the surrogate also has interests which may compete with the interests of the infant, adding complexity to medical decision making (Beauchamp & Childress 2001, pg 102-103; Canadian Paediatric Society 2004; Stanley 2000). It is also another relationship that requires consideration by the medical team and possibly adds an additional duty to care and the responsibilities associated with that.

The shift in health care to the informed patient being part of the “team” and making informed choices regarding medical treatment may have contributed to a consumerist approach to health care delivery. Patients expect to hear all of the available options and to be allowed to choose the best option for their unique situation. This expectation or attitude continues in paediatrics and family-centered care, only it is the surrogate decision maker and not the patient who is making the informed decisions (AAP, Committee on Hospital Care 2003; Canadian Paediatric Society 2004). The legal expectation that a surrogate decision maker is expected to make decisions based solely on the infant’s interests, takes the infant out of the context of the family unit. On a daily basis, parents must balance personal interests and responsibilities with the interests of each of their children and the interests of the family unit. Asking a parent who is acting as a surrogate to completely disregard competing interests when making medical decisions for an infant is unrealistic. The Canadian Paediatric Society (CPS) policy statement on “Treatment Decisions Regarding Infants, Children and Adolescents” acknowledges this. They state that the best interests of the child are the priority; however they acknowledge that “values, preferences, beliefs and expectations of the family also play an important role in decision making and should not be ignored when considering the best interests of the child” (Canadian Paediatric Society 2004). They propose a “standard of reasonableness” to assist in balancing competing interests. That is to say, choosing the option that, “most rational people of goodwill would choose after full

consideration of all factors that influence the situation” (Canadian Paediatric Society 2004). This is in keeping with the standards that parents are held to in other aspects of a child’s care. For example, parents are allowed to choose not to breast feed, refuse childhood immunizations, offer fast food and to forgo saving for a child’s university education. While it can be argued that these decisions may not be in a child’s ‘best’ interest, they are considered to be among a group of reasonable, and therefore acceptable choices.

It stands to reason that if it is this standard to which parents are held for other matters of child rearing, that it should apply for medical care as well. This means that there will be a number of acceptable options for each clinical case, and that the medical team and family need not necessarily agree on the ‘best’ choice. The risk with this standard in medical decision making with an acutely ill child is the increased potential for harm and undue burdens. To this end, the CPS policy states that, “surrogate decision makers must be able to balance the best interests of the child ... with competing interests to maximize benefits and minimize harms” (Canadian Paediatric Society 2004). As the legal cases previously discussed demonstrate, parental requests, while given latitude, are not absolute. However, if the treatment decisions a parent makes are among the acceptable options, then it should be respected. It is stated later in the document that “[a]lthough parental decisions may differ from the recommendations of the health care team, parental decision making ought to be accepted unless it is obvious to many that the decision is patently not in the best interest of the child...” (Canadian Paediatric Society 2004).

6.2 The Move to Palliation

When it is determined that medicine is no longer able to offer a curative treatment plan, or if it is felt that the burdens of the medical care outweigh the benefits, palliation may be considered. Palliation involves a switch from curative medical treatments to treatments that focus on the alleviation of symptoms and provision of comfort care while the natural progression of the condition or disease is allowed to occur (AAP, Committee on Bioethics 2000; Canadian Paediatric Society 2004; Carter 2004). Palliation can

include the withdrawal of treatments that are overly burdensome or that did not provide the curative benefit that they were initiated for (AAP, Committee on Bioethics 1994; Canadian Paediatric Society 2004; Paris & Fletcher 1987; Solomon, Sellers et al. 2005). This can include treatments and equipment such as ventilators and medically provided nutrition and hydration (AAP, Committee on Bioethics 1994; AAP, Committee on Bioethics 1996; Canadian Paediatric Society 2004; Levi 2003; Paris & Fletcher 1987; Solomon, Sellers et al. 2005; Winter 2000). Palliation can also include the provision of treatments such as medications or narcotics to decrease pain. Whether care is withdrawn or initiated, the goal of palliative care is to maintain comfort, control the symptoms of the condition and maximize the patient's quality of life during the dying process (AAP, Committee on Bioethics 2000; Canadian Paediatric Society 2004; Carter 2004).

6.3 Palliative Care Model

After the decision to pursue palliation has been made, delivery of care will move to a palliative care model. The palliative care field has emerged in response to medicine being unable to cure patients and yet still having a duty to care for them and reduce suffering. For example, the CMA Code of Ethics (2004) states in Article 3, that physicians should "provide for appropriate care for your patient, including physical comfort and spiritual and psychological support even when cure is no longer possible."

The palliative care philosophy continues to acknowledge the infant's place within a larger family unit. As with a family-centered care model, it also continues to acknowledge that competing interests within the family may exist and complicate treatment decisions for an infant (AAP, Committee on Bioethics 2000; Rushton 2005). One of the significant differences between the two philosophies, and the most relevant to this discussion, is the medical team's duty to the family. While the family-centered model of care implies some duty or responsibility to the family, the palliative care philosophy clearly states and defines this. The American Academy of Pediatrics (AAP)-Committee on Bioethics and the Committee on Hospital Care defines the goals of palliative care by stating it as, "the achievement of the best quality of life for the patients and their families, consistent with their values, regardless of the location of the patient"

(AAP, Committee on Bioethics 2000). They detail a responsibility to the family stating, “The needs of the family must be attended to both during the illness and after the child’s death to improve their ability to survive the ordeal intact” (AAP, Committee on Bioethics 2000). This duty to provide support and care to families throughout their child’s life and after their death, in an attempt to assist them in remaining a functional family unit, is not emphasized in the traditional medical ethic.

In most paediatric medical care, the family plays an important role, as the parents are called upon to act as surrogate decision makers for their children. The palliative care model recognizes that the infant is one part of a complex social family unit. It also recognizes the importance of family units within society and that the death of an infant will have a significant impact on the family unit (Contro, Larson et al. 2002; Knapp & Mulligan-Smith 2005; Lundqvist & Nilstun 2007). Therefore part of the goal of palliative care is to assist families in surviving a devastating loss and continue to function. The palliative care model appears to be challenging medical teams to recognize that each family is unique with their own values and beliefs, and that these will guide the choices and decisions that they make for themselves and their family. Miraie writes, “in situations of moral ambiguity, to impose one’s own moral values on relatives who are acting from pure motives is judgmental and condescending” (Miraie 1989). The principles of autonomy and self-determination recognize and respect that different people will judge the benefits and burdens of a situation differently (AAP, Committee on Bioethics 1994). It is important in a situation as emotionally challenging as the death of an infant, that the family’s right to autonomy and self-determination are not unreasonably violated because the values they express are different from those of the medical team (Contro, Larson et al. 2002; Lundqvist & Nilstun 2007). It should also be considered that it is the family that will have to bear the burden and consequences of the decisions for the rest of their lives, and that the death of the infant will change their lives forever (Contro, Larson et al. 2002; Knapp & Mulligan-Smith 2005; L’Ecuyer 1989; Miraie 1989; Stanley 2000). A family’s survival as a unit will depend on their ability cope with an infant’s death and to continue to survive and fulfill their responsibilities within their family and society.

6.4 The Evolving Medical Paradigm and Models of Care

In today's health care environment, most patients expect to be included in medical decisions and allowed the autonomy and self-determination to direct their own medical care. The expectation follows, that a loving family will be able have the same role in medical decisions for an infant who lacks the autonomy to direct her own care. Family units hold values and beliefs that are unique and individual to them. It is important to understand these values and beliefs to understand the value and context of life and illness in a family, and how they judge quality of life. While family-centered and palliative care models don't suggest that an infant's rights be disregarded, they recognize that the infant is placed with a family unit, and the complexities that this implies. They propose that while parents should not be allowed to act to the obvious detriment of the infant, that in cases of uncertainty, parents' request and rights to autonomy and self-determination, when motivated by a love and desire to care for their infant, should not be automatically disregarded because of conflicts with the medical team's values. Lantos writes,

I think it is morally appropriate, in some cases, to make decisions based on our assessment of the moral virtue of family members. This (Miraie) is such a case. It may or may not have been in the baby's best interest to receive nutrition, however it was clear that his parents wanted to act in a loving and nurturing way, as defined by their conceptions of what moral virtues were required by the responsibilities of parenthood. (Lantos 1989)

Stanley adds to this discussion when she discusses the experience of having a significantly impaired infant or having an infant that dies. She argues that the emotions and parental needs associated with these experiences are something that individuals on the medical team have likely never experienced directly (Stanley 2000). Without being able to understand the devastating effects on parents of not being able to respond and care for their infant, it is difficult to understand the symbolic and emotional needs behind their requests. These authors discuss the fact that it is the families that ultimately have to live with these decisions for the rest of their lives. If they feel that they were not able to adequately protect or care for their infant or that their dignity and beliefs have been

violated, they risk experiencing devastating guilt and experiencing her death even more traumatically. Given the secondary duty in palliative care, to care for the family, it seems imperative that these needs and the potential risks that they may pose to the functionality and unity of the family unit be acknowledged and considered.

Chapter 7

Ethical Analysis

Building on the discussion in the previous chapters, this chapter will go on to identify and analyse the specific ethical issues related to providing *or* withholding oral feeds *after* the withdrawal of medically provided hydration and nutrition in the infant with severe neurological injury. The intent of this thesis is to integrate normative concepts with the pragmatic challenges evident in the clinical context. Therefore, this chapter will consist of an analysis using a conceptual framework applied to the illustrative vignette.

7.1 Framework for a Duty of Care

As discussed in the previous chapter, the family-centered model of care generally adopted in paediatrics directs the medical team to engage the patient's family in medical care decisions (AAP, Committee on Hospital Care 2003). When a palliative care framework is added however, this expectation requires an additional duty to care for the family as well as the patient (AAP, Committee on Bioethics 2000). Looking at these two duties of care, there is significant potential for competing interests between the family and the infant with severe neurological impairment. While not reducing the importance of the interests of the infant, I believe that the potential for long-term, devastating effects to the family cannot, and should not be overlooked. I believe that there is a way to combine these two duties of care that highlights the most important duties to each party in order to maximize the overall benefit in such difficult situations. Conceptually and clinically, the medical team should balance a multitude of seemingly competing duties, primarily those of beneficence and non-maleficence towards the infant, to individual family members, as well as fairness towards all involved parties.

Typically, the medical team would be weighing the duties of beneficence and non-maleficence to the infant against the duty to respect parental autonomy. In a palliative care case, where death is expected and no treatment will be curative, it is important to understand the infant's interests in order to ascertain if a decision will likely

produce benefit or burden. In these situations, decisions are often related to issues of quality of life and suffering. These are complex concepts, and families will often measure and rate best interests and quality of life differently than the medical team.

As discussed in Chapter 3, the infant with severe neurological impairment has only minimal interests due to the devastating nature of her brain injury, coupled with her very young age. ‘Jane’ for example, is in a minimally conscious state (MCS, as opposed to PVS). She may have the potential to perceive some pleasure and pain. Thus, her first and most important interest is in not experiencing pain. As discussed in the *EJG* case in Chapter 4, the Ontario courts have accepted a broad definition of the term “well being” that allows for consideration of existential suffering, even in patients in PVS (*In the Matter of EJG*, 2007). Therefore, an interest in not suffering (physically or existentially) can be attributed to her.

Since Jane has a minimal capacity to experience external stimuli, she can also be considered to have an interest in experiencing, or not being deprived of, any potentially pleasurable experience. This is an “interest” that Jane’s family strongly advocates for. The family requests that Jane be offered oral feeds for comfort after medically provided hydration and nutrition have been withdrawn. They feel that this will mitigate potential hunger and will allow her to enjoy the only typical infant experience that she will likely ever have. The severe extent of the neurological injury and the apparent lack of any higher level cognitive awareness mean that she likely has only the most rudimentary ability to experience pleasure. While her body may be able to perceive some stimuli, it is nevertheless difficult to appreciate if her brain will process and interpret these stimuli in any meaningful manner. Jane’s responses are understood by many medical professionals as reflexive ones that do not require any cortical level neural processing. Also, Jane has never been healthy and has never fed orally. Therefore she has no prior experience of oral feeding and lacks the capacity to understand what is potentially being withheld.

Characterizing oral feeding as an “interest” for Jane is therefore potentially a source of conflict between the family and the medical team. The medical team may feel,

as in the case of *EJG*, that treatment or interventions with inherent risks and no curative possibilities are predominantly, or even exclusively, sources of significant suffering for Jane. The family however, believes that Jane deserves every opportunity to experience pleasure and typical infant experiences. Providing Jane with these opportunities is of the utmost importance to them.

In the absence of clear and easily interpreted responses from Jane to assist with this, the following is considered. The interpretation of experiences that Jane's parents assume would be *pleasurable* for her requires higher level cortical function than the reflexive perception of pain. For Jane, there is thus a significantly greater risk of experiencing pain than of being deprived of a potentially pleasurable experience. For this reason, Jane's interest in not experiencing pain should take precedence over any theoretical interest she may have in not being deprived of pleasure.

The family may attribute interests of survival, and in remaining with the family, to the infant with severe neurological impairment. This is where quality of life decisions become difficult. The medical team views the burdens of additional medical care to be excessive, while the family views the additional time with her family to be the ultimate reward that outweighs the perceived burdens. These decisions can be very difficult and emotional, as demonstrated by *EJG's* case. Continued hospitalization and burdensome medical procedures with no prospect of cure can be argued to constitute existential suffering, even for an infant in a vegetative state. Jane's devastating neurological impairment, combined with the unlikelihood of becoming an autonomous being or developing significant cognitive awareness and understanding, make any interests of survival and remaining with her family difficult to attribute directly to her. Rather, they are most reasonably conceptualized as a reflection of her family's wishes for her.

In summary, the infant with severe neurological impairment can only be argued to have some very basic interests due to a combination of her devastating neurological injury and her very young age. The interests that can be attributed to her are an interest in not suffering physically or existentially. She likely has some rudimentary ability to

perceive external stimuli given her minimally conscious state, and therefore a minimal interest in not being deprived of pleasurable experiences is also acknowledged. In order to ensure that the medical team is acting in a beneficent, or at the very least non-maleficent manner, they must be aware of these interests. They must then attempt to balance these interests with their duty to respect parental autonomy.

The duty to care for the family is similar, though not identical to the duty that the medical team has towards the infant. While there may not be a traditional fiduciary relationship between the medical team and the parents, the more progressive palliative care philosophy would clearly imply that the team has duties of beneficence and non-maleficence towards the family members. That is to say that the medical team should strive to help the family survive the infant's inevitable death intact and as a functional family unit. At the very least, the team should endeavour not to make her death any more traumatic to the family than necessary. They will have to balance these duties with the duty to respect parental autonomy as surrogate decision makers and the parents' right to self-determination.

The family typically consists of multiple individuals, including parents and siblings. Each of these individuals will have unique interests and roles within the family. These need to be acknowledged when considered when considering the medical team's responsibility and duty to the family. I believe that a duty of fairness in dealing with all family members is required to ensure that the burdens that medical decisions will have on each family member, as well as any conflicts of interest within the family are recognized. The burdens to other children in the family need to be acknowledged. The best interests of the infant with severe neurological impairment may conflict with the best interests of other children in the family. Parents have a duty to care for the infant with severe neurological injury, but also have a duty to care for any other children in the family. If parents focus all their resources (time, money, energy and emotional support) on the infant with severe neurological impairment, this will be potentially devastating to the other children's well-being, as they are at risk for emotional neglect.

Paradoxically, this focused attention will likely cause no significant improvement to the medical outcome of the infant with severe neurological impairment. Jane will mostly likely not be very aware of her parents' devotion to her. Her siblings however, who are very sensitive to their parents' attention, will likely be deprived of their parental care for a significant period of time. The medical team's duty to care for the entire family means they will have to consider the well-being of the other children in the family and how medical decisions are likely to produce benefits or burdens for them. When a family is unable to continue to function effectively as a family unit, providing love, nurturing and support to the other children in the family, it causes significant burdens for the surviving siblings.

In Jane's case, there are two aspects of fairness that need to be emphasized. Firstly, the immediate and long-term consequences of the request to provide oral feeding, such as demands on parents' time, financial repercussions, and the possibility that the infant's life will be prolonged, all need to be considered. Secondly, the team needs to be aware of how Jane's death and the decisions made in the palliation process are likely to affect Jane's parents. If Jane's parents are left with feelings of guilt as to their ability to perform their parent role throughout the process, this may have a significant impact on their ability to continue to function as effective parents for the siblings in the future.

The team must balance these duties with the parents' and family's right to autonomy and self-determination. This is extremely challenging, as each family experiences grief and the loss of an infant differently and has different needs and beliefs regarding the dying process. To ensure non-maleficence, the medical team must remain non-judgmental when considering oral feeding for Jane, and remain open to exploring each family's values and belief system regarding death and dying when considering allowing oral feeding for Jane.

I am not suggesting that Jane's rights or interests be violated in favour of the family's. I believe that the medical team's most important duty is that of non-maleficence to the infant. However, in situations where the benefit of treatment

requested by the family for the infant's comfort is unclear, the medical team's priority is to consider the potential burdens of this treatment. It is often impossible to establish the exact level of awareness and responsiveness of an infant like Jane. In the presence of differences of opinion regarding her quality of life, the most important duty that the medical team has to that infant is non-maleficence. They must ensure that they are not causing any additional harm or imposing further burdens than her current medical condition has already produced. Considering the devastating nature of her brain injury, her significantly diminished capacity to communicate pain and suffering, as well as the potentially competing interests between the infant and other family members, the medical team's duty of non-maleficence to Jane should be paramount.

With respect to the family, the medical team must ensure that at the very least, they are not making the death of the infant with severe neurological impairment any more difficult or threatening to the family unit. I argue however, that the medical team needs to aim for a duty of beneficence. Jane's family is requesting permission to feed her because they believe that she is hungry and suffering, and because they believe that this is part of their duty as parents. The request is rooted in love for Jane and a need to fulfill their role as her parents. Not allowing Jane's parents to respond to her "suffering", and preventing them from fulfilling their duty as parents has the potential to create long-lasting feelings of guilt and threatens Jane's parents' ability to effectively care for her siblings in the future.

I believe that in most instances, there is considerable possibility for planning and discussing care options with a family who is acting out of love and a need to parent, care for and nurture the infant with severe neurological impairment. The disagreements described in the court cases represent the most egregious examples of families and medical teams in disagreement. I don't believe this to be reflective of most cases. In my clinical experience, being proactive and implementing strategies to understand the family's beliefs and values, attempting to incorporate the family's wishes for the infant into the care plan, and empowering them to provide care and nurturing to a fragile and

very ill infant, would all contribute to helping the family cope with the infant's tragic condition and inevitable death.

Jane's parents feel as though they are unable to respond to her needs and nurture her the way that they would any other child. Her death is expected imminently, and the knowledge that they only have a short time left with her heightens their need to nurture and love and protect her. Being given permission to maintain an active and involved parental role towards Jane will allow the parents to feel successful in this role, and create lasting memories of Jane and her time with the family. Jane's parents' request to feed her may only be partly due to the concern that Jane is hungry and suffering. In addition, it most likely represents a symbolic caring activity that will allow the parents to feel as though they are demonstrating their concern for Jane as they would for any of her siblings.

The medical team can do a great deal to understand the motivations behind a family's treatment requests by engaging with family members in discussions regarding their beliefs and values, and actively listening to identify their hopes, preferences and wishes. This helps the team understand how an infant's death is liable to impact the family. It may assist the team in understanding how best to support the family in this difficult time. The discussions and planning sessions with a family will help the team to consider the parents' rights to self-determination and their autonomy in guiding their infant's medical care. As discussed earlier, the family's decisions for their infant need not match the medical team's recommendation. Parents have a right to make decisions for their infant and as long as these decisions are not violating her best interests. The medical team needs to carefully consider a family's request for the infant with severe neurological impairment before challenging the family's right to parental autonomy and self-determination. When an infant is dying, it can be expected that emotions will be very high and that the decisions being made will have the potential to profoundly affect the parents and family.

Lastly, I believe that a final consideration in framing a duty to care is that the medical team needs to be cognizant of fairness issues within the family. The reality of any family with more than one child is that in extreme situations such as this, parents must weigh the needs of one child versus the other(s). Is it fair to ask families to focus almost exclusively on the interests of a sick infant, neglecting the interests of the other children and the family unit? Given that there is a duty to care for the entire family, the idea of fairness becomes relevant and warrants careful consideration by the team.

7.2 Benefit and Burden Analysis for Oral Feeding

Jane's case represents the middle of the spectrum of the presentations of severe neurological impairment discussed in Chapter 3. She is not demonstrating any attempts at sucking, and requires suction to assist in managing oral secretions. She doesn't vomit, but her nasogastric feeds are frequently stopped due to signs of distress and discomfort as noted by the family. The medical team has not observed any consistent hunger cues from her, but the family is not in agreement with that observation. After the decision to palliate and to withdraw medically provided hydration and nutrition, the medical team feels morally opposed, or at the very least, do not feel morally obliged to provide oral feeds. The family on the other hand, feels a moral obligation to offer oral feeds as comfort care during the palliation process.

Having identified and described the interests of the affected infant and her, as well as the duties and responsibilities of the medical team, a benefit/burden analysis lies at the heart of this ethical analysis. In Jane's case, the specific medical intervention that is being requested and questioned is oral feeding. More specifically, oral feeding will be defined as the provision of very small amounts of oral feeding for "comfort" after the withdrawal of medically provided hydration and nutrition. There is an explicit understanding by everyone, including the parents, that such feeds will not provide any nutritional or medical benefit for Jane. This section will look at the benefits and burdens of providing or withholding such small amounts of oral feeding after medically provided hydration and nutrition has been withdrawn from an infant whose swallowing function is seriously impaired.

While the parents are prepared to withhold medically provided hydration and nutrition, they are nevertheless attributing significant value and meaning to oral feeding. Having a parent identify a “need” to feed the infant with severe neurological impairment identifies that they view this as one of the responsibilities and requirements for successfully fulfilling their parental role. This role has been integrated into their personal identity. Failing to respond to their infant’s needs or being prevented from being “successful” in this role has the potential to leave a significant and lasting psychological impact.

Jane has lived in the hospital since she was born. At the beginning, when she was in the NICU, she required invasive medical technology to keep her alive. To the parents she seemed “covered” in tubes, wires and lines. She was often sedated to help her body heal and to tolerate some of the medical procedures. Throughout this time, her parents had limited opportunities to hold her. They learned more about her complex medical care than basic baby care.

As she became more stable, some of the machines and tubes were removed. This made her easier to pick up and hold, however she was still attached to monitors and IVs that limited the distance that she could be moved from the crib. Her parent’s entire parenting experience to this point was dependent on asking “permission” from doctors and nurses. Very few of the family’s memories and photos didn’t reflect the amazingly fragile and complicated life that Jane had to date.

By this point, Jane’s parents grew to believe that she has suffered enough pain and trauma from medical procedures. They wished to provide her with love, nurturing and comfort for the short time that she has left. They wanted Jane and the family to be able to experience the briefest moments of normalcy in Jane’s final days. In this context, oral feeding opportunities became a priority for them. While this request may or may not have been in Jane’s best interest, it was motivated by love and a desire to care for and provide for Jane, as well as reduce her suffering.

Preventing Jane's parents from offering her oral feeds could have resulted in them experiencing feelings of guilt and lasting psychological trauma. At that point, the oral feeding experience was the most important goal they had for their daughter. The medical team needed to acknowledge that if the parents had been prevented from providing for her in this way, they may have ended up feeling as if they had not advocated for her strongly enough. Jane's parents had voiced concerns that she experienced hunger. They struggled with the belief that she may have been hungry or thirsty and that they had not done enough to respond to these needs.

Jane was not the only child in this family, and the other children needed their parents more than ever as they attempted to understand Jane's illness and death. Parents who feel that they have been unable to fulfill their responsibilities and commitments to one of their vulnerable and sick children risk carrying these self-doubts into their relationship with the surviving siblings. Thus, every child in the family was potentially at risk if Jane's parents were unable to cope adequately with her death and remain functional in their parental role.

Preventing the family from offering oral feeds to Jane could also contribute to an isolating effect for the family. The death of a child is an incredibly difficult time for a family, and members typically require support from their extended family and friends. When Jane's family considered taking her home to die surrounded by her extended family, they were aware that the decision to forgo any oral feeding could have caused significant isolation from the family's support network.

In my experience families are very careful who they speak to about their decisions to withhold medically provided hydration and nutrition for fear of judgment and condemnation about these choices. Friends and family members who realize that a dying child is never being fed may feel as though she is being neglected or treated inappropriately. Feeding children is a basic societal expectation, and there is potential that friends and extended family would not understand the related, complex medical

issues. Instead, they would likely react in shock and disbelief, and judge parents who are not attempting to feed their child negatively.

For this reason, Jane's family is liable to isolate itself from the very support networks it would need, for fear that it would be misunderstood and judged harshly. The other children in the family would be very sensitive to the need for secrecy. They would understand that there is secrecy surrounding the decision not to feed Jane, and this would risk causing them feelings of shame and guilt (Spinetta, Jankovic et al. 1999). These are significant risks that carry the potential for lasting psychological trauma. These risks will also threaten the stability of the marriage and the family unit if one or both parents are unable to continue to function in the roles of spouse and parent (Romesberg 2003; Carter 2004).

There are, however, risks to Jane and to the family that must also be considered if oral feeds *are* offered. Given Jane's clinical presentation, it is anticipated that she would suffer a significant degree of swallowing impairment or dysfunction. The biggest risk of offering Jane oral feeds are the complications that might arise. These complications can range from discomfort and pain to an adverse event that could actually hasten her death. Without question, it is expected that offering Jane oral feeds would result in an increased need for suctioning immediately following the feedings. This may be unpleasant for her; however, if she enjoys the taste of milk in her mouth, then this may be considered an acceptable trade-off. Suctioning is not a new burden for Jane, as she requires suctioning throughout the day to manage her secretions. Withholding oral feeds will not completely eliminate the need for suctioning. Therefore, if it is perceived that Jane experiences some pleasure from oral feeding, or that it reduces her hunger or thirst, then the burden of additional suction may be justifiable. Also, depending on what she is offered to eat, there may even be the potential to reduce pain. In NICUs, there is a common practice of providing a sucrose solution to neonates during painful procedures with the goal of reducing associated pain (Mitchell & Waltman 2003; Gaspardo, Miyase et al. 2008). If Jane perceives any pain, small amounts of oral feeding or tastes of a sucrose solution may

have a secondary benefit of reducing pain without the need for further medication or sedation.

If Jane aspirates during oral feeding attempts she would be at risk of developing an aspiration pneumonia. Jane is already at risk of developing an aspiration pneumonia by virtue of the difficulty in managing her secretions. Providing oral feeds would definitely increase this risk. An aspiration pneumonia could cause respiratory distress and would require additional and possibly burdensome oxygen and antibiotic therapy. Jane's family would now be required to deal with possible feelings of guilt for allowing or even causing this to happen to her. They would also be required to decide how the medical team would manage the pneumonia, i.e. with aggressive medical treatment or with comfort measures only. Whatever decision the parents would make with respect to her pneumonia, Jane would receive appropriate pain management so that events such as this would not cause her significant additional distress.

While unlikely, it is also possible that Jane could suffer a catastrophic event and stop breathing if oral feeds are offered. While Jane's inevitable death is relatively imminent, the quality of life leading up to her death and any suffering that she might experience are burdens that must be considered. At this time, it is expected that Jane would die peacefully surrounded by her family. If she has an apneic event or airway obstruction during an oral feed her death would be sudden, unexpected and distressing to watch. Her parents would likely experience guilt over the fact that their decision to offer oral feeds hastened her death in a very direct way. They would likely be stressed and upset that Jane didn't die peacefully.

Given Jane's neurological status it is unclear how she would experience such an event. It would likely cause her some pain and discomfort. However, Jane lacks the cognitive awareness and capacity to feel emotionally "scared" or stressed by the event. While this is an unlikely and extreme complication of the providing oral feeds, it represents risks to both Jane and her family and must be considered.

The other potential “side-effect” of offering small amounts of oral feeding to Jane is that even very small amounts may prolong her life, or, as some would conceive it, her dying process. When medically provided hydration and nutrition are withheld, there is a finite period of time within which Jane would be expected to die. Providing even small amounts of fluid or nutrition might extend her life (or dying process) for an unknown period of time. It would be difficult to quantify or characterize the extent of this prolongation. While some might consider the extension to be inconsequential, others might argue that it constitutes a significant time.

Depending on Jane’s health status during this time and the family’s perspective on her extended life, the situation can be characterized as either a benefit or a burden. If Jane does not appear to suffer from pneumonias and complications of her oral feeds, is able to tolerate the increased suctioning requirements and generally seems at peace, with her family can perceive this as a welcome extension of time. It would allow the family increased time to bond with her in a family context and to create special memories with her. It would give her siblings a chance to get to know her and increase the likelihood that they would have lasting memories of her as they grow up. If the family would be able to embrace and celebrate this time in Jane’s life, then it could ultimately be perceived as a direct benefit of oral feeding. If, on the other hand, the family is keeping vigil each additional day with their lives “on hold”, waiting for her to die, then this could be construed as a burden, especially for Jane’s siblings whose lives are “in limbo” while everyone waits for Jane to die.

In all likelihood, Jane’s life would be prolonged through minute amounts of oral feeding, but in a less than optimal state. She could suffer complications such as aspiration pneumonias and respiratory distress, but she would also be at risk for skin breakdown and subsequent infections as she continued to survive in a severely malnourished state. Watching Jane waste away and exist in such a state would likely be very difficult for the family to watch. These complications would increase the need for medical interventions and decrease opportunities for quality family bonding time.

If Jane is cared for in her home in her last days, the family could conceivably incur additional expenses to assist in managing Jane's increasing medical needs. Therefore, depending on the complications Jane suffers from the provision of oral feeds, and the family's ability to cope with and maximize the quality of any additional time with her, the fact that small amounts of oral feeding may prolong Jane's life can be either a benefit or a burden to both Jane and her family.

7.3 Summary

The benefits and burdens that an infant with severe neurological impairment is likely to experience if small amounts of oral feeding are provided or withheld, are multiple, complex and difficult to predict with confidence. This is due in part to the severity of the neurological damage itself, the uncertainty as to how aware she is, and the extent to which she is able to interact with her external environment. Also, it is unclear whether such minute amounts of feeding would reflect any of the changes in oral secretions and abdominal pain that have been noted in the adult studies.

It would be unethical to prevent Jane from taking food by mouth if she is able to do so safely. While it is unlikely that she will be able to *swallow* safely given her clinical presentation, it is also highly unlikely that she will be able to *ingest* any significant amount of food given her lack of sucking. If Jane appears to enjoy, or tolerate tastes or small amounts of oral feeding, I believe that the risks of her aspirating small amounts are acceptable because of these benefits.

The threshold at which aspiration causes significant complications such as pneumonia is different for every infant. Given her poor neurological status and impaired oral motor skills, Jane will only be taking very small volumes of food orally. Even if she is aspirating at times, her body may be able to tolerate this without serious complications (Wolf & Glass 1992, pg 228-229; Logemann 1998, pg 6). It is important to acknowledge that a serious complication or adverse event can occur because of oral feeds. I would argue however, that the likelihood of a serious complication for Jane can be reduced to an acceptable level with adequate preparation.

This includes a discussion with the family about what constitutes “feeding”. For some families, it means limiting the infant to tasting the food. For others, it is merely presenting the infant with food that it ultimately refuses because it is unable to suck. For others still, it can mean feeding the infant more substantial quantities regardless of the risks. Proceeding slowly and carefully with the provision of oral feeds (i.e. not force-feeding Jane) will reduce the risks associated with it. The less serious burdens associated with either the provision or withholding of oral feeds can be well managed medically as part of a more comprehensive palliative approach (e.g. provision on pain medication).

Therefore, I believe that the benefit of allowing small amounts of oral feeding, even if it is thought to be “unsafe”, requires serious consideration, as each infant may present a unique benefit/burden profile. Oral feeds can potentially reduce feelings of thirst or hunger. I believe that the potential benefits to the infant, as well as the family, warrant careful consideration. The presence of potential burdens associated with providing oral feeding should not automatically dictate that small amounts of oral feeding be withheld. There have been unique cases where the risks have been relatively well managed to allow for the benefits to be appreciated.

The analysis of the benefit/burden analysis for the family may be slightly more evident. In my experience, the psychological and emotional benefits to parents of providing oral feeding to any child, combined with the burdens of withholding it, make a compelling argument for allowing it. By allowing a family that feels compelled to feed the infant with severe neurological impairment to do so for “comfort” care during the palliation process, the traditional parental role is more obviously preserved. While some parents manage to understand the rational arguments in favour of foregoing oral feeding, many have great difficulty doing so. In my experience, even those who do reach this rational appreciation have great difficulty coping psychologically in their attempts to over-ride a cultural and emotionally conditioned default “reflex” in favour of feeding their child. Feeding will facilitate legacy building and the formation of more positive family memories. It will also be easier for other siblings to accept the inevitable outcome

and will not expose them to feelings of guilt or shame if secrecy is required (as when oral feeds are withheld). Allowing oral feeding will also allow the family to meet traditional societal norms and expectations, and will reduce the potential for outside scrutiny and judgement during a most difficult time.

In the case of baby Jane, I believe that the benefits of oral feeds to both her and her family outweigh the risks. In this case, the medical team acknowledged that they did not feel a moral obligation to provide oral feeds to Jane. I believe that despite this assertion, they have a moral obligation to *consider* oral feeds based on their duty to care for Jane's family. It may become obvious once oral feeding is attempted, that it should not be pursued, but refusing to consider such attempts on the grounds that there is no moral obligation to do so is inappropriate.

I am not arguing that the family's needs should be placed ahead of Jane's. I do believe however that *when it is still unclear* how a family's treatment request is liable to affect the infant with severe neurological impairment, the family's motivations and needs warrant careful consideration. I would argue that as long as there are no significant burdens to Jane, that oral feeding should continue in order to reduce the significant risks to the family unit if they are withheld.

Chapter 8

Conclusion

This thesis has explored some of the ethical issues that arise when a family wishes to orally feed their infant with severe neurological impairment in the context of “comfort” care after medically provided nutrition and hydration have been withdrawn. The topic reflects some of the issues that I have struggled with in my clinical practice as an occupational therapist. For this reason, I chose to frame the discussion and analysis by integrating normative concepts with pragmatic realities inherent in such a clinical setting.

These cases are exceedingly rare. However, they have the potential to cause significant moral distress. Decisions made in such situations may have a lasting effect on the parents and have the potential to threaten the integrity of the family unit. Such cases can have long-lasting and profound effects on members of the medical team caring for such children. As the acceptance of the concept of withdrawal of medically provided nutrition and fluid increases, the issues discussed in this thesis may become more common. Given the rarity of cases and the limited literature on this specific paradigm however, this thesis is clearly an initial exploration of a highly complex topic.

The thesis question was derived from my clinical experience. Being responsible for assessing whether infants are capable of feeding orally, I have begun to understand the incredibly complex emotional aspects associated with oral feeding and how important the act of feeding an infant is for parents. I wonder how the decision to forgo oral feeding for an infant with severe neurological impairment will ultimately affect a loving family that feels obliged to feed her. The study by Contro et al. describes the lasting pain and trauma that a single insensitive remark or inappropriate action can have on a family during a child’s dying process.

At first glance, there is an apparent paradox in caring for such children. In the initial stages of medical care, when the child’s prognosis is guarded but unclear, and the entire medical technology available in an NICU is used to maximize the child’s potential

recovery, the decisions around oral feeding are more clear. If the child does not suck adequately and appears to be unable to swallow safely, it would be safest to withhold oral feeding in order to reduce unnecessary risks associated with such oral feeds. The child's nutritional status is more effectively and more safely met through "medically" provided feeding by nasogastric tube. Arguably, if the child evolves neurologically and reaches a plateau where she has even a minimal suck reflex and begins swallowing her saliva but is still at significant risk for aspiration, the same benefit/burden calculus can be invoked. As the clinical course evolves and it becomes clear that there is no reasonable expectation of an acceptable long-term outcome, the goal of care switches to palliation. Now that the child's prognosis is accepted as an inevitable and relatively imminent death, the oral feeds which were previously too risky may now be appropriate.

Feeding is normally associated with growth and healing. Oral feeding for severely neurologically impaired infants is "dangerous" in the initial stages when the prognosis is still unclear, but potentially "appropriate" once the goal of care switches to palliation. This paradigm may be counter-intuitive and paradoxical for most, and thus ethically confusing. This thesis has attempted to explore some of the ethical issues around this.

The palliative care framework in this case not only allows the medical team to consider oral feeds for the infant's "comfort", but it implores the medical team to consider such feeding for the benefit of the family. Jane's parents are acting out of love. They are watching Jane cry and feel that she is suffering. They are interpreting her crying as a sign that she is hungry or in pain, and feel compelled to respond to her. By expressing a desire to attempt to feed her orally for comfort, they are expressing their family's beliefs as to what might be valuable and meaningful for Jane. If Jane's family is prevented from comforting her and responding to the cues that they believe she is demonstrating, they will be at risk of experiencing her death with regret and guilt. I have argued that given the negligible burdens of such feeding to the dying infant (if carefully titrated and medically managed), it should be an ethical duty of care for the medical team to give these risks due consideration.

While there is a duty of care to the family, this duty should not supersede Jane's rights and the medical team's duty of non-maleficence to her. A review of the relevant Canadian jurisprudence reveals that there are cases where parents request treatment that is contrary to the best interests of the infant and will likely cause unjustified suffering or be detrimental to the infant's health. The verdicts in these cases demonstrate that the courts are very clear on insisting that the infant's best interests be respected. The *decision in EJG* demonstrated that even when an infant cannot perceive pain, he can be at risk of existential suffering from living a life of repeated invasive medical interventions that will not significantly improve his underlying medical condition.

In Jane's case however, it is believed that she *is* able to perceive pain and possibly other stimuli at a very rudimentary level. Therefore, the medical team must always consider the possibility of her pain or suffering, both physically and existentially. Nevertheless, it is not obvious that providing small amounts of oral feeding in the palliative stages of her care is contrary to her best interests, even if there are risks associated with it.

The medical team does not feel that Jane's crying and irritability are due to hunger or pain. They also believe that appropriate analgesics are being provided in case any such pain is occurring. While the cause of her irritability is most likely neurological, hunger or thirst cannot be ruled out conclusively. As discussed in the Canadian Paediatric Society Position Statement, any such case likely has a number of contributing causes and potential treatment options (2004). Therefore the parents' request for oral feeding has some grounds to be considered.

The medical team need not agree with the family's judgement as to what constitutes the *ideal* choice for the infant's treatment, as long as it is among the ethically *acceptable* treatment options and not clearly contrary to her best interests. In the case of Jane, I believe that properly managed, the provision of small amounts of oral feeding

could be an acceptable option, even if it was not the treatment that the medical team felt was most appropriate.

In summary, this thesis has explored some of the challenging areas around the provision of small amounts of oral feeding to an infant with severe neurological impairment after medically provided nutrition and hydration have been withdrawn. I believe that there may be some unique cases where the arguments in favour of providing small amounts of oral feeding are ethically persuasive. The benefits to the infant may only be small, but the benefits to the family unit can be very significant. Even the team's transparent discussion with the family can be considered a benefit. In a palliative care framework, I believe that the medical team has a duty to explore these benefits. I agree with Lantos' statement, "I think that it is morally appropriate sometimes to make decisions based on our assessment of the moral virtue of family members" (Lantos 1989).

I believe that caution is required in cases where the medical team does not feel morally obligated to provide oral feeding on the grounds of non-maleficence. While the team may not be obligated to ultimately *provide* the oral feeding, I would argue that they should ethically be required to *consider* such a request as a potentially acceptable one. Each case would have to be evaluated individually, as the motivations, benefits and burdens attributed to the moral agents can vary significantly

The arguments in this thesis have challenged some of the traditional normative principles in medical ethics such as the fiduciary nature of a physician's duty to the patient, especially in the paediatric context where medical best interests and non-maleficence are of critical importance. However, I argue that the situation of the infant with severe neurological impairment who is in the palliative stages of her care constitutes a unique ethical paradigm that justifies reconceptualization of the traditional paradigm.

References

- Acra, S. A. and Rollins, C (1999). Principles and guidelines for parental nutrition in children. *Pediatric Annals*, 28(2): 113-120.
- American Academy of Pediatrics, Committee on Bioethics. (1983). Treatment of critically ill newborns. *Pediatrics*, 72(4): 565-566.
- American Academy of Pediatrics, Committee on Bioethics. (1994). Guidelines on forgoing life-sustaining medical treatment. *Pediatrics*, 93(3): 532-536.
- American Academy of Pediatrics, Committee on Bioethics (1995). Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*, 95(2): 314-317.
- American Academy of Pediatrics, Committee on Bioethics (1996). Ethics and the care of critically ill infants and children. *Pediatrics*, 98(1): 149-152.
- American Academy of Pediatrics, Committee on Bioethics, Committee on Hospital Care (2000). Palliative care for children. *Pediatrics*, 106(2): 351-357.
- American Academy of Pediatrics, Committee on Fetus And Newborn. (1995). The initiation or withdrawal of treatment for high-risk newborns. *Pediatrics*, 96(2): 362-363.
- American Academy of Pediatrics, Committee on Hospital Care. (2003). Institute for family-centered care policy statement: Family-centered care and the pediatrician's role. *Pediatrics*, 112(3): 691-696.
- American Society for Parental and Enteral Nutrition. (2006). *What is parental nutrition?* Retrieved April 20, 2009, from <http://www.nutritioncare.org/wcontent.aspx?id=270>.
- Andrews, M. and Marian, M (2006). Ethical framework for the registered dietitian in decisions regarding withholding/withdrawing medically assisted nutrition and hydration. *Journal of the American Dietetic Association*, 106(2): 206-208.
- Antommara, A. H. M. and Bale, J.F. (2002). Ethical issues in clinical pediatrics: Cases and analysis. *Seminars in Pediatric Neurology*, 9(1): 67-76.
- Ashwal, S. (2003). Medical aspects of the minimally conscious state in children. *Brain and Development*, 25: 535-545.

- Ashwal, S., Bale, J.F., Coulter, D.L., Eiben, R., Garg, B.P., Hill, A., *et al.* (1992). The persistent vegetative state in children: Report of the child neurology society ethics committee. *Annals of Neurology*, 32: 570-576.
- Ashwal, S. and Cranford, R. (2002). The minimally conscious state in children. *Seminars in Pediatric Neurology*, 9(1): 19-34.
- Badawi, N., Felix, J.F., Kurinczuk, J.J., Dixon, G., Watson, L., Keogh, J. M., *et al.* (2005). Cerebral palsy following term newborn encephalopathy: A population based study. *Developmental Medicine and Child Neurology*, 47(293-298).
- Beauchamp, T. L. and Childress, J. F. (2001). *Principles of biomedical ethics*. New York, Oxford University Press.
- B. (R.) v. Children's Aid Society of Metropolitan Toronto*, 1 S.C.R. 315, 21 O.R. (3d) 479 (Ont. Ct. App. 1995). Retrieved July 15, 2008, from the Canadian Legal Information Institute Web site: <http://www.canlii.org/en/ca/scc/doc/1995/1995canlii115/1995canlii115.html>
- Canadian Association of Occupational Therapists. (2007). Code of ethics. Retrieved March 30, 2008, from the Canadian Association of Occupational Therapists Web site: <http://www.caot.ca/default.asp?pageid=35>
- Canadian Charter of Rights and Freedoms. (1982). Retrieved March 30, 2008, from the Government of Canada, Department of Justice Canada Web site: http://laws.justice.gc.ca/en/charter/const_en.html#charte
- Canadian Medical Association. (2004). Code of ethics. Retrieved March 30, 2008, from the Canadian Medical Association Web site: <http://policybase.cma.ca/PolicyPDF/PD04-06.pdf>
- Canadian Paediatric Society. (2004). Position statement: Treatment decisions regarding infants, children and adolescents. *Paediatric Child Health*, 9(2): 99-103.
- Carli, G., Reiger, I., Evans, N. (2004). One-year neurodevelopmental outcome after moderate newborn hypoxic ischaemic encephalopathy. *Journal of Paediatric Child Health*, 40: 217-220.
- Carter, B. S. (2004). Providing palliative care for newborns. *Pediatric Annals*, 33(11): 770-778.

- Carter, B. S. and S. R. Leuthner (2003). The ethics of withholding/withdrawing nutrition in the newborn. *Seminars in Perinatology*, 27(6): 480-487.
- Child and Family Services Act (R.S.O 1990, Chapter C.11).(1990). Retrieved March 30, 2008, from ServiceOntario e-Laws Web site: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90c11_e.htm
- Civil Code (S.Q., 1991, c.64.).(1991). Retrieved April 1, 2008, from Justice Québec Web site:
http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/CCQ/CCQ_A.html
- Clark, F. I. (1994). Intensive care treatment decisions: The roots of our confusion. *Pediatrics*, 94(1): 98-101.
- Colby, W. H. (2006). From Quinlan to Cruzan to Schiavo: What have we learned? *Loyola University Chicago Law Journal*, 37: 279-296.
- Collège Des Médecins Du Québec. (2001). Code of ethics of physicians (R.S.Q., c.C-26, S. 87; 2001, c. 78, s. 6). Retrieved March 30, 2008, from the College Des Medecins Du Quebec Web site:
<http://www.cmq.org/~media/132E0C657730482DBEE837D7473D439D.ashx>
- College of Nurses of Ontario. (2002). Professional standards. Retrieved March 30, 2008, from the College of Nurses of Ontario Web site:
http://www.cno.org/docs/prac/41006_ProfStds.pdf
- Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatric and Adolescent Medicine*, 156: 14-19.
- Cooper, L., Gooding, J.S., Gallagher, J., Sternesky, L., Ledsky, R., Berns, S.D. (2007). Impact of a family-centered care initiative on NICU care, staff and families. *Journal of Perinatology*, 27: S32-S37.
- Criminal Code of Canada (R.S., 1985, c. C.-46).(1985). Retrieved March 30, 2008, from the Government of Canada, Department of Justice Canada Web site:
<http://laws.justice.gc.ca/en/C-46/>

- Declaration of the Rights of the Child. (1959). Retrieved March 30, 2008, from the United Nations Web site: <http://www.un.org/cyberschoolbus/humanrights/resources/child.asp>
- deHaan, M., Wyatt, J.S., Roth, S., Vargha-Khadem, F., Gadian, D., Mishkin, D. (2006). Brain and cognitive-behavioural development after asphyxia at term birth. *Developmental Science*, 9(4): 350-358.
- Drougia, A., Giapros, V., Krallis, N., Theocharis, P., Nikaki, A., Tzoufi, M., *et al.* (2007). Incidence and risk factors for cerebral palsy in infants with perinatal problems: A 15 year review. *Early Human Development*, 83: 541-547.
- Ersek, M. (2003). Artificial nutrition and hydration: Clinical issues. *Journal of Hospice and Palliative Nursing*, 5(4): 221-230.
- Fine, R. L. (2005). From Quinlan to Schiavo: Medical, ethical and legal issues in severe brain injury. *Baylor University Medical Center Proceedings*, 18(4): 303-310.
- Fletcher, J. C. (1997). Bioethics in a legal forum: Confessions of an "expert" witness. *The Journal of Medicine and Philosophy*, 22: 297-324.
- Franklin, L. and Rodger, S. (2003). Parents' perspectives on feeding medically compromised children: Implications for occupational therapy. *Australian Occupational Therapy Journal*, 50: 137-147.
- Ganzini, L., Goy, E.R., Miller, L.L., Harvath, T.A., Jackson, A., Delroit, M.A. (2003). Nurses' experience with hospice patients who refuse food and fluids to hasten death. *New England Journal of Medicine*, 349: 359-365.
- Gaspardo, C., Miyase, C., Chimello, J.T., Martinez, F.E., Linhares, M.B.M. (2008). Is pain relief equally efficacious and free of side effects with repeated doses of oral sucrose in preterm neonates? *Pain*, 137(1): 16-25.
- Giacino, J. T., Ashwal, S., Childs, N., Cranford, R., Jennette, B., Katz, D.I., *et al.* (2002). The minimally conscious state - definition and diagnostic criteria. *Neurology*, 58: 349-353.
- Giacino, J. T. and Kalmar, K. (1997). The vegetative and minimally conscious states: A comparison of clinical features and functional outcome. *Journal of Head Trauma Rehabilitation*, 12(4): 36-51.

- Guerriere, D. N., McKeever, P., Llewellyn-Thomas, H., Berall, G. (2003). Mothers' decisions about gastrostomy tube insertion in children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, 45: 470-476.
- Gustaitis, R. (1988). Right to refuse life-sustaining treatment. *Pediatrics*, 81(2): 317-321.
- Hampson, L. A. and Emanuel, E.J. (2005). The prognosis for changes in end-of-life care after the Schiavo case. *Health Affairs*, 24(4): 972-975.
- Health Care Consent Act (S.O.1996, c.2, Sch. A). (1996). Retrieved March 30, 2008, from ServiceOntario e-Laws Web site: <http://www.search.e-laws.gov.on.ca/en/isysquery/2fb16e84-282b-411a-bf9b-fa8f02194bd2/7/frame/?search=browseStatutes&context=>
- Hester, D. M. (2007). Interests and neonates: There is more to the story than we explicitly acknowledge. *Theoretical Medicine and Bioethics*, 28: 357-372.
- In the Matter of E.J.G.* A Patient at the Hamilton Health Sciences - McMaster Children's Hospital. (Ontario Consent and Capacity Board, 2007). Retrieved July 15, 2008, from the Canadian Legal Information Institute Web site: <http://www.canlii.org/en/on/oncccb/doc/2007/2007canlii44704/2007canlii44704.html>
- In the Matter of L.* A Patient at London Health Science Center - Children's Hospital. (Ontario Consent and Capacity Board. 2008). Retrieved October 1, 2008, from the Canadian Legal Information Institute Web site: <http://www.canlii.org/en/on/oncccb/doc/2008/2008canlii46902/2008canlii46902.html>
- International Council of Nurses. (2006). Code of ethics for nurses. Retrieved March 30, 2008, from the International Council of Nurses Web site: <http://www.icn.ch/icncode.pdf>
- Jacobs, H. H. (2005). Ethics in pediatric end-of-life care: A nursing perspective. *Journal of Pediatric Nursing*, 20(5): 360-369.
- James, A. (2009). *About kids health - trusted answers from The Hospital For Sick Children: Health A-Z - tracheostomy*. Retrieved April 19, 2009, from <http://www.aboutkidshealth.ca/HealthAZ/Tracheostomy.aspx?articleID=9056&categoryID=>

- Knapp, J. and Mulligan-Smith, D. (2005). Committee on pediatric emergency medicine: Death of a child in the emergency department. *Pediatrics*, 115(5): 1432-1437.
- L'Ecuyer, J. L. (1989). Withholding nutrition from hopelessly ill infants. *The Journal of Pediatrics*, 114(2): 339.
- Lantos, J. (1989). Withholding nutrition from newborn infants. *The Journal of Pediatrics*, 114(1): 165-166.
- Levi, B. H. (2003). Withdrawing nutrition and hydration from children: Legal, ethical and professional issues. *Clinical Pediatrics*, 42: 139-145.
- Logemann, J. A. (1998). *Evaluation and treatment of swallowing disorders - 2nd edition*. Austin, Pro-Ed.
- Lundqvist, A. and Nilstun, T. (2007). Human dignity in paediatrics: The effects of health care. *Nursing Ethics*, 14(2): 215-228.
- Lynn, J. and Childress, J.F. (1983). Must patients always be given food and water? *The Hastings Center Report*, 13(2): 17-21.
- McCann, R. M., Hall, W.J., Groth-Juncker, A. (1994). Comfort care for terminally ill patients. *Journal of the American Medical Association*, 272(16): 1263-1266.
- Miraie, E. (1989). Reply to withholding nutrition from hopelessly ill infants. *The Journal of Pediatrics*, 114(2): 339-340.
- Miraie, E. D. and Mahowald, M.B. (1988). Withholding nutrition from seriously ill newborn infants: A parent's perspective. *The Journal of Pediatrics*, 113(2): 262-265.
- Mitchell, A. and Waltman, P.A. (2003). Oral sucrose and pain relief for preterm infants. *Pain Management Nursing*, 4(2): 62-69.
- Monterosso, L., Kristjanson, L.J., Aoun, S., Phillips, M.B. (2007). Supportive and palliative care needs of families of children with life-threatening illnesses in western Australia: Evidence to guide the development of a palliative care service. *Palliative Medicine*, 21: 689-696.
- Moore, D. L. (1995). Challenging parental decisions to overtreat children. *Health Matrix*, 5(2): 311-323.
- Morin, K. H. (2007). Infant nutrition during palliative care. *The American Journal of Maternal/Child Nursing*, 32(5): 320.

- National Institute of Neurologic Disorders and Stroke. (2009, March 9). *Anencephaly information page*. Retrieved April 18, 2009, from <http://www.ninds.nih.gov/disorders/anencephaly/anencephaly.htm>.
- Neal, A., Frost, M., Kuhn, J., Green, A., Gance-Cleveland, B., Kersten, R. (2007). Family centered care within an infant-toddler unit. *Pediatric Nursing*, 33(6): 481-487.
- Ontario College of Social Workers and Social Services Workers. (1994). Code of ethics. Retrieved March 30, 2008, from http://www.ocswssw.org/sections/membership_info/current_members/ethicsandpractice.html
- Paris, J. J. and Fletcher, A.B. (1987). Withholding of nutrition and fluids in the hopelessly ill patient. *Clinics in Perinatology*, 14(2): 367-376.
- Pugh, M. B. (Ed.). (2000). *Stedman's medical dictionary - 27th edition*. Baltimore: Lippincott Williams & Wilkins.
- Rennie, J. M., Hagmann, C.F., Robertson, N.J. (2007). Outcome after intrapartum hypoxic ischaemia at term. *Seminars in Fetal and Neonatal Medicine*, 12: 398-407.
- Rollins, H. (2006). The psychosocial aspect on parents of tube feeding their child. *Paediatric Nursing*, 18(4): 19-22.
- Romesberg, T. L. (2003). Futile care and the neonate. *Advances in Neonatal Care*, 3(5): 213-219.
- Rosen, P. (1996). Religious freedom and the forced transfusion of Jehovah's Witness children. *The Journal of Emergency Medicine*, 14(2): 241-243.
- Rushton, C. H. (2005). A framework for integrated pediatric palliative care: Being with dying. *Journal of Pediatric Nursing*, 20(5): 311-325.
- Rutherford, M. A., Azzopardi, D., Whitelaw, A., Cowan, F., Renowden, S., Edwards, D.A., et al. (2005). Mild hypothermia and the distribution of lesions in neonates with hypoxic-ischemic encephalopathy. *Pediatrics*, 116: 1001-1006.
- Schnakers, C. and Zasler, N.D. (2007). Pain assessment and management in disorders of consciousness. *Current Opinion in Neurology*, 20: 620-626.
- Sheldon, M. (1996). Ethical issues in the forced transfusion of Jehovah's Witness children. *The Journal of Emergency Medicine*, 14(2): 251-257.

- Smith, S. and Andrews, M. (2000). Artificial nutrition and hydration at the end of life. *Med Surg Nursing*, 9: 233-246.
- Solomon, M. Z., Sellers, D.E., Heller, K.S., Dokken, D.L., Levetown, M., Rushton, C, *et al.* (2005). New and lingering controversies in pediatric end-of-life care. *Pediatrics*, 116(4): 872-883.
- Spalding, K. and McKeever, P. (1998). Mother's experiences caring for children with disabilities who require gastrostomy tube. *Journal of Pediatric Nursing*, 13(4): 234-243.
- Spinetta, J. J., Jankovic, M., Eden, T., Green, D., Martins, A.G., Wandzura, C., *et al.* (1999). Guidelines for assistance to siblings of children with cancer: Report of the SIOP working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology*, 33: 395-398.
- Stanley, A. L. (2000). Withholding artificially provided nutrition and hydration from disabled children - Assessing their quality of life. *Clinical Pediatrics*, 39(10): 575-579.
- Strauss, D. J., Ashwal, S., Day, S.M., Shavelle, R.M. (2000). Life expectancy of children in vegetative and minimally conscious states. *Pediatric Neurology*, 23(4): 312-319.
- Street, K., Ashcroft, R., Henderson, J., Campbell, A.V. (2000). The decision making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital. *Journal of Medical Ethics* 26: 346-352.
- Syl Apps Secure Treatment Center v B.D.*, 3 S.C.R. 83, S.C.C. 38. (S.C.C. 2007). Retrieved July 15, 2008 from the Canadian Legal Information Institute Web site: <http://www.canlii.org/en/ca/scc/doc/2007/2007scc38/2007scc38.html>
- Truog, R. D. (2007). Tackling medical futility in Texas. *New England Journal of Medicine*, 357(1): 1-3.
- Viola, R., Wells, G., Peterson, J. (1997). The effects of fluid status therapy on the dying: A systematic review. *Journal of Palliative Care* 13: 41-52.
- V.M. v British Columbia (The Director of Child, Family and Community Service)*. 12 W.W.R 102, R.F.L. (6th) 187 (B.C.S.C. 2008). Retrieved July 15, 2008 from the

- Canadian Legal Information Institute Web site:
<http://www.canlii.org/en/bc/bcsc/doc/2008/2008bcsc449/2008bcsc449.html>
- West, C. R., Harding, J.E., Knight, D.B., Battin, M.R. (2005). Demographic characteristics and clinical course in infants with moderate or severe neonatal encephalopathy. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 45(151-154).
- Wilson, P. (2005). Jehovah's Witness children: When religion and the law collide. *Paediatric Nursing*, 17(3): 34-37.
- Winter, S. M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *The American Journal of Medicine*, 109: 723-726.
- Wolf, L. S. and Glass, R.P. (1992). *Feeding and swallowing disorders in infancy: Assessment and management*. Therapy Skill Builders.
- Yamamoto, T. and Katayama, Y. (2005). Deep brain stimulation therapy for the vegetative state. *Neuropsychological Rehabilitation*, 15(3&4): 406-413.
- Yarborough, M. (1989). Why physicians must not give food and water to every patient. *Journal of Family Practice*, 29: 683-684.
- Youth Protection Act (R.S.Q., c. P-34.1). (1977). Retrieved March 30, 2008, from Justice Québec Web site:
http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/P_34_1/P34_1_A.HTM