

AN EXAMINATION OF UNCERTAINTY IN PERINATAL PALLIATIVE CARE

BY

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List of Abbreviations

AMA- American Medical Association

CCAM- Congenital Cystic Adenomatoid Malformation

CCFC- Comprehensive Center for Fetal Care

CHIP- Children's Health Insurance Program

C-Section- Caesarean Section

DNA- Deoxyribonucleic Acid

DNR- Do Not Resuscitate

MFM- Maternal Fetal Medicine

MRI- Magnetic Resonance Imaging

NCP- National Consensus Project

NICHD- National Institute of Child Health and Human Development

NICU- Neonatal (Newborn) Intensive Care Unit

NRN- Neonatal Research Network

OB- Obstetrician

PEC- Pediatric Enhanced Care

RVU- Relative Value Unit

WHO- World Health Organization

ABSTRACT

Medical ethics is a field that blends ethical theory with practice in a very concrete way. Many commonly discussed ethical issues derive specifically from addressing medical care at the end of life, and these issues become particularly complicated when the patient in question is a neonate or a woman carrying a fetus. Providing palliative and end-of-life care for these patients requires a complex interaction of clinical skills, communication skills, and ethical evaluation. This thesis is based on a practicum in which I observed discussions between health care professionals and parents about ethical issues in the care of perinatal and neonatal patients

The first chapter of this thesis provides background about palliative care in general, and more specifically pediatric and perinatal palliative care. The second chapter discusses my experience and observations at the three practicum observation sites and presents several patient cases. In the third chapter I describe uncertainty as a theme in perinatal palliative care, present two primary types of uncertainty I discerned, and analyze them as they apply to different aspects of a perinatal palliative care consult. The fourth and final chapter proposes the idea of “accompaniment medicine” as a means of responding to ambiguity in perinatal palliative care and further describes my conception of accompaniment medicine.

INTRODUCTION

I am a neonatologist who has been in practice for 6 years. In providing care for the smallest and sickest of infants, I frequently encounter ethical problems at both the beginning and the end of life. I have a particular passion for caring for infants with life-limiting illnesses and those who are dying. It is at the intersection of these two themes, bioethics and care for infants with life-limiting illness that the topic for this thesis originated. Perinatal palliative care is a relatively new subspecialty of neonatal medicine that provides dynamic and multidisciplinary care for mothers and their fetuses after the fetus has been diagnosed with a life-limiting illness. It is an evolving field with great opportunity to innovate and perform research. Perinatal palliative care programs are forming nationwide, but, like neonatal medicine in general, robust discussion of the associated ethical issues tends to lag behind new developments.

My goal for this practicum thesis was twofold. I hoped to experience the practice of pediatric palliative care with a focus on neonatal and perinatal palliative care and to analyze ethical issues arising from my observations. I found a multitude of ethical issues associated with perinatal palliative care, and with reflection, a common theme arose. Many ethical problems originate in the uncertainty involved in perinatal palliative care. This thesis will provide background information about perinatal palliative care, a description of and reflection on my practicum

experience, a discussion of the problem of uncertainty in perinatal palliative care, and my proposal for a new approach to perinatal palliative care. All of the patient cases I discuss are based on cases I encountered during the practicum. As I organized my reflections, observations, and thoughts, it became clear that full elucidation of the topic is beyond the scope of this short thesis. I hope that further investigation of these themes will be a foundation for my academic career.

The end product of this experience was much more than I planned or expected. Perhaps the most important result of this practicum thesis, however, is that it led to the creation of a perinatal palliative care program for patients in Winston-Salem. It has been my desire to create such a program, but it was the observation and time spent in this practicum that allowed me to create a model to serve our patients most effectively.

Armed with this information, my passion for perinatal palliative care, and the support of my colleagues, teachers and several parents of infants who received palliative care services, I obtained a grant and departmental support to create a perinatal and neonatal palliative care service at Forsyth Medical Center and Brenner Children's Hospital. The *Care Always Program for Perinatal and Neonatal Palliative Care* will begin serving patients in July, 2015.

CHAPTER 1: PALLIATIVE CARE

Clinical ethics blends ethics theory and practice in a concrete way. The practice of medicine requires ethical reflection in many situations; however, certain areas of medicine, by their very nature, involve discussion of ethical issues more frequently. Subspecialties involving critical care, reproductive technology, and transplantation tend to present clinical situations that raise ethical issues. Palliative care is a subspecialty that involves constant attention to ethics, and end-of-life care includes some of the most commonly discussed and controversial ethical issues in its daily practice. These ethics topics include withholding and withdrawing life-sustaining treatment, surrogate decision making, advance directives, physician-assisted suicide, and terminal sedation. Many of these ethical concerns have stimulated ongoing debate in the medical and ethical literature and have resulted in the formation of policies and statutes. There is sufficient overlap in many cases, such that both palliative care and ethics consultation seem appropriate.¹ Palliative care is a subspecialty that seeks to provide family-centered care. It focuses on relief and prevention of suffering for any patient affected by illness, and it seeks to provide the best quality of life possible for the patient and family when there is no chance of cure for a disease or death is near.²

Palliative care is often thought of as end-of-life care, and it is frequently used interchangeably with the term ‘hospice’. Palliative care

does not always involve hospice, but hospices always provide palliative care. While hospices provide palliative care near the end of life, palliative care has a broader scope and does not require that the patient be near death. It is active and involved care that addresses physical symptoms and spiritual, emotional, and psychosocial needs that occur throughout a patient's illness. While there is medical attention to the relief of physical pain, addressing the emotional and spiritual aspects of suffering is just as important, and the palliative care team is often composed of physicians, nurses, social workers and chaplains. The requirement of a multidisciplinary approach differentiates palliative care from medical care providing pain control.

The evolution of this branch of medicine has demonstrated that it is beneficial in many ways to patients, families, health care providers, and hospitals. Cancer has always been associated strongly with palliative care, but choosing palliative care is often viewed by patients as a "transition" from curative treatment of their cancer to comfort care only with no further chemotherapy. The perception that palliative care is only something for cancer patients who have "no hope of cure" and cannot be helped by chemotherapy is a commonly held misconception about palliative care. The mistaken view that palliative care is provided only when there is "nothing else to do" or when there is "no hope" left perpetuates misunderstanding about the true purpose of palliative care. Palliative care provides comfort and quality-of-life focused

multidisciplinary care throughout treatment of serious illness, and the general public perception that palliative care is synonymous with hospice care can cause strong negative reactions from patients and families when palliative care is recommended.

Past models of palliative care focused on beginning palliative measures when the decision is made to stop life-prolonging treatment; however, a more comprehensive model is the ideal practice. To be more effective, palliative care should begin at diagnosis and be an active part of care throughout further diagnostic testing and treatment. It should not be limited to those patients who have no hope of benefit from a curative treatment.³ With this approach, palliative care has become a rapidly growing aspect of care in United States hospitals over the past 30 years. Government funding, physician board certification, clinical practice guidelines, and insurance payment for palliative care and hospice services have solidified the place of palliative care in the practice of medicine in the United States. From 2001 to 2011, the number of hospice programs has increased by 47%, and non-hospice palliative care programs in hospitals with more than 50 beds have increased by 148%.⁴ Research on palliative care medicine has shown that it improves patient quality of life and decreases medical expenses.⁵

Pediatric Palliative Care

While palliative care has been provided to children for many years in conjunction with curative care, it was not until 2010, through the Patient Protection and Affordable Care Act, that funding from Medicaid and the Children's Health Insurance Program (CHIP) became available to patients who receive both palliative and curative care.⁶ Children's hospice and palliative care programs have been around for decades, but the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care only recently officially recognized "neonates, children, and adolescents with congenital injuries or conditions leading to dependence on life sustaining treatment and/or long term care" as potential populations to be served. At the same time, the guidelines also added pediatric and adult patients with "developmental and intellectual disabilities who develop serious or life threatening illness" to the group of patients served.⁵

Palliative care for children is expanding, but perinatal and neonatal palliative care services continue to lag behind services for older pediatric patients. Palliative care services for children follow many of the same conventions that adult palliative care uses, such as focus on comfort and quality of life for the patient. Family involvement is essential due to the pediatric patient's reliance on their family for primary support, care, and decision making. The approach to care for these children is similar to the approach for adults. That goal is to provide active, total care of the patient whose disease is not responsive to curative treatment and achievement of

the best quality of life for patients and their families.⁷ This description of patients who have disease that is not responsive to curative treatment therefore includes infants with genetic abnormalities, developmental and intellectual disabilities, certain cardiac, neurological and renal abnormalities, and multiple other congenital disorders that are treatable with palliative surgeries and medication or are fatal. While for many, “non-curable” illness may immediately bring to mind end-stage cancer, even in children, the focus is different in neonatal and perinatal palliative care. There is less focus on the “dying” patient. Instead, the focus is on care for infants who will not “get better.”⁸ The serious illnesses that neonatal and perinatal patients face often result in lifelong health needs and disability caused by medical problems that have no cure, but are not uniformly fatal. The focus is more on the patient and family living for a potentially long period of time with the illness rather than patients dying of the illness.

Perinatal Palliative Care

The perinatal period includes the months before and after the birth of a baby, and perinatal palliative care serves families who have received a life-threatening diagnosis for their fetus and choose to continue the pregnancy. This requires a shift in the framework of care which results in a different approach to the practice of palliative care for fetuses and their mothers. Perinatal palliative care differs from adult and pediatric

palliative care in that the patient is not a person, but rather, the family-fetus dyad. While there is important consideration of the family in adult and pediatric palliative care, the family is central in perinatal palliative care. Similar to adult and pediatric palliative care, there is emphasis on comfort and symptom control for both the mother and the infant in perinatal palliative care. The primary focus, however, in perinatal palliative care is a complex process involving the synthesis of information to help families understand decisions that they must make in order to form a plan for care during the prenatal, delivery, and neonatal periods. This occurs through multiple meetings in a short, intense period of time. Initially, perinatal palliative care addresses obstetrical issues of the mother with consideration of the mother-fetus dyad. The focus evolves into plans for birth and resuscitation of the infant that bridge the obstetrics and neonatology subspecialties and then transition into a medical care plan for the infant. There is no knowledge of the infant's preferences or desires, so all decisions are based on the family's values and what they believe is the best interest of the infant.

The process is further complicated by the uncertain outcomes of the pregnancy. There is uncertainty involved in the diagnosis and prognosis, there is vagueness in the concept of best interests for a child who may or may not even survive birth, and there is often lack of information about the actual lifespan that the fetus could experience. The maternal-fetal dyad is interdependent, and what is in the best interest of the child may

conflict with what is in the best interest of the mother. Often the family is asked to navigate this decision making with minimal guidance. For example, a fetus diagnosed with trisomy 18 may die during pregnancy, die in the initial neonatal period, or survive for years. Trisomy 18 is not curable, but some congenital defects associated with it are potentially treatable or surgically correctable. The decision to pursue life-prolonging care for infants with trisomy 18 creates a unique medical situation in which a life-limiting medical problem that will never improve underlies all future medical management decisions and considerations for therapy. Every medical decision made will also affect the mother and family.

Perinatal palliative care should begin when the pregnant woman receives prenatal testing that indicates the presence of an abnormality. Further testing is done to confirm this diagnosis and specify its implications. After the diagnosis and counseling about the potential condition, options for treatment are discussed, and the parents are asked to make decisions about care. Some of these diagnoses can be given with a very high degree of confidence, and the expected outcome is death of the fetus. More often, however, the diagnosis can be given with fairly high probability, but not complete certainty, and the outcome is known to be poor, with many affected individuals dying as fetuses or neonates, but some living with significant, life-limiting disabilities. Sometimes, extensive and invasive medical therapy is needed for the child to survive,

but it is not immediately known exactly what level of care will be necessary.

The goal of perinatal palliative care is to provide guidance during this difficult time in the form of information, support, and coordination of care. Many people who practice perinatal palliative care will describe what they do as “walking with the family” through this time of grief and difficult decisions by addressing physical, emotional, psychosocial, and spiritual suffering. The initial focus of perinatal palliative care is the mother and father who are making decisions regarding their fetus. Perinatal palliative care differs from neonatal, pediatric and adult palliative care in its primary focus on the family unit, inclusive of the fetus. The mother-fetus dyad is the patient, and the interests of both must be considered. While other forms of palliative care give attention to the needs of the family, it is primarily within the scope of care for the patient and the patient’s quality of life. The exception to this primary focus on the patient is grief counseling provided to family members after a patient’s death. The process of perinatal palliative care involves assisting with resources, providing grief and spiritual support, delineation of goals of care, discussion of values and priorities, creation of a birth plan that is essentially an advance directive for the baby, and a plan for medical care after birth. Frequently, the medical care plan is uncertain. It may involve assessment for aggressive treatment with consideration of transition to comfort care, or the family may decide that strictly comfort care is the best

plan of care for their baby. There is often planning for discharge home with hospice care, if the infant survives to discharge. Bereavement support throughout the entire process as well as after the death of the child is also a vital aspect of perinatal palliative care, because grieving for the loss of the “normal” child begins at the time of diagnosis.

The birth plan is one of the key processes in perinatal palliative care because it directs care in the perinatal and neonatal period, but it also incorporates aspects of maternal care. The mother will delineate the pregnancy care plan with her obstetrician, but the plan for labor and delivery is more complicated. When a mother is carrying a child with a life-limiting condition, it may be reasonable to forgo fetal monitoring during the labor and delivery process when there is no plan to intervene if the fetus develops distress in utero. For example, a family may decide that the plan for their infant is comfort care with a focus on time with their infant and pain control. Therefore, if the fetus begins to have distress or physical difficulties that may result in death, they would likely not want the mother to undergo a Cesarean section in order to deliver the child alive. In contrast a family may want fetal monitoring during labor simply to hear the fetal heart beat and potentially know the time of death if the baby expires in utero. Some families will choose to have fetal monitoring during labor with Cesarean section intervention for delivery if the fetus develops distress, with the goal of having a few precious minutes time with the child before death.

The family's approach to intervention on fetal behalf is a reasonable and important issue to address prior to labor because it will influence the entire process. It also helps families and medical providers discern the goals of care. Although it is an important aspect of care, it is often very difficult to discuss. The medical care provider will ask the pregnant woman, "If your baby develops distress in utero, do you want us to intervene on fetal behalf with a C-section?" This is a necessary question for the medical provider to ask, but it is also an emotionally loaded and complex question. To the mother, it may sound as if the medical provider is asking, "If your baby is going to die inside of you, do you want us to deliver the baby by C-section so she may live, or let her die inside of you?" This question, posed to every mother carrying a fetus diagnosed with a life-limiting condition, illustrates the complexity and emotional subtext of every aspect of care for these vulnerable patients.

Other aspects of the birth plan focus on medical interventions at the time of birth, such as provision or limitation of resuscitation measures like intubation and chest compressions. In this way, the birth plan is very similar to commonly used advance directives for adults, but perinatal palliative care birth plans incorporate much more than just these issues. A typical birth plan will express the parents' desires for the time with their infant and give directives about any important rituals, family traditions, basic infant care such as baths and dressing the child, restrictions on visitors, methods of infant feeding, and other significant but not directly

medical processes. For example, a birth plan may state that the infant should be wrapped in a blanket and placed on the mother's chest with the father to cut the umbilical cord. It may direct that the mother and father would like to give the child her first bath, dress her, and have minimal medical intervention interrupting their time with their child. It may also include instructions for photographs, handprints, footprints, molds, and other legacy-building activities. Directives for care after the infant's death are also a part of the birth plan. The family will often state whether they want an autopsy and to whom the body should be released. Overall, the birth plan prompts the family to think about all aspects of their baby's care in order to prepare and deliver care in a manner that the family wants. The birth plan itself is important, but the process it prompts is imperative to providing good perinatal and neonatal palliative care.

The creation of the birth plan begins when the family meets with a perinatal palliative care provider in consultation. The initial communication often focuses on the family's understanding of the medical issues that their fetus faces. Exploration of the family's wishes and desires for their child in the context of the illness is also important. With these factors in mind, the provider introduces the concept of the birth plan to ensure that the family's goals of care are known to the medical providers and that any requests by the family are honored if possible. Many organizations use standardized forms to guide the family in the creation of their birth plan. Ideally, a follow-up appointment is scheduled

for the perinatal palliative care provider to review the birth plan with the family and answer any further questions. Often, the families are gathering information from multiple physicians, and several appointments are needed to help the family synthesize the information and understand its meaning for them and their infant. Continuity and follow up are essential in the perinatal palliative care process.

Describing the role of perinatal palliative care with a case may be the easiest way to demonstrate how care is provided from fetal diagnosis through the neonatal period. The following case of Ms. M and her infant prenatally diagnosed with trisomy 18 illustrates the process of perinatal and neonatal palliative care.

The Case of Baby M

Ms. M is a 39-year-old single woman who has had multiple pregnancy losses in the past. She screened positive for fetal trisomy 18 risk factors and subsequently sought care with maternal-fetal medicine (MFM) specialists and perinatal palliative care counseling. Ms. M had cell free fetal DNA and ultrasound testing, and those tests determined that her female fetus had a >99% likelihood of having trisomy 18. A patient with trisomy 18 has 3 copies of the #18 chromosome; this genetic condition is associated with multiple congenital anomalies and significant physical and mental disability. Ms. M's fetus had a complex congenital heart defect, but no evidence of some of the other problems that infants with trisomy 18

often have. She declined an amniocentesis for confirmation based on the specificity of the tests already done, the advice of the MFM team, and her wish not to harm her baby or cause preterm labor. Ms. M was not interested in termination of the pregnancy. She also had a prenatal echocardiogram (echo) and an appointment with the pediatric cardiology group for evaluation and discussion of the congenital heart defect.

During the first palliative care visit with Ms. M, the perinatal palliative care specialist explained her baby's diagnosis and prognosis. Ms. M replied that she was following up regularly for fetal echoes with the cardiologist because at the initial echo, he diagnosed her fetus with a complex cardiac condition. Her impression of the plan with cardiology was that the cardiologist was going to speak with the surgical team to see if the baby was a candidate for surgery. During follow-up appointments with cardiology, the question of surgery would be further discussed. The palliative care provider asked Ms. M to explain her values, hopes, and desires for the pregnancy and the baby. Carrying her baby for as long as possible and doing whatever could be done so that the baby would be born alive were very important to Ms. M. Ms. M and the palliative care provider discussed intervention on fetal behalf and the implications of fetal monitoring and potential C-section. If her daughter had a chance for long-term survival, Ms. M wanted to do whatever could be done to try to achieve it. The palliative care specialist explained what this could possibly involve, including potential complicated heart surgeries and the

possible clinical course associated with this set of surgeries, leading to the need for a heart transplant as an older child. She was told that her baby would not be a candidate for a heart transplant due to her diagnosis of trisomy 18.

When asked what she would want for her daughter if surgery and longer-term survival was not possible, her primary goals were to have whatever time she could with her baby and to make sure that her daughter was not suffering. Time was then spent discussing the birth process and specific aspects of the birth plan. It was a long and complicated discussion due to the fetus's cardiac issue, uncertainty about the plan to address her cardiac condition, Ms. M's past medical history, and many other factors. After much discussion, a preliminary, rudimentary birth plan was created based on the presumption that Baby M would likely be delivered by C-section and comfort care would be provided. The palliative care provider and Ms. M discussed at length what this would "look like" and how it would occur.

Ms. M was encouraged to write out her birth plan more specifically with her goals of care and wishes so that she could solidify her thoughts, and to bring the expanded plan with her to her next appointment with palliative care. The palliative care nurse coordinator would contact Ms. M in a week to see if she had any questions. Ms. M had strong support from her parents and her church and declined follow up with the palliative care chaplain. When the birth plan was completed, it would be placed in her

chart and forwarded to the Labor and Delivery Unit and NICU of the hospital where the baby would be born. She was encouraged to bring a copy with her to the hospital if she went into preterm labor so that she could hand it to the hospital labor and delivery staff and everyone would know her wishes in an emergent situation. After meeting with the perinatal palliative care provider, the palliative care social worker met with Ms. M to assess her need for financial and social support and to provide information about grief counseling and parent support groups.

At Ms. M's next appointment with perinatal palliative care, there was some confusion about the plan to address the baby's heart condition. Ms. M relayed that the cardiologist recommended that her baby be admitted to the NICU for medicine to keep the heart functioning after she was born, and then they would see if she was a candidate for surgery. Ms. M wanted to proceed with this plan; if there was a chance her baby could have the surgery, she at least wanted to be able to discuss it. With this care plan, the baby would be taken from her mother immediately after birth, transferred to the NICU for central line placement and constant infusion of the medication. Baby M would likely need to be intubated and placed on a ventilator due to side effects of the medication, and Ms. M would be unable to visit the baby until she recovered from the C-section. Ms. M was not aware of these implications of starting "the medication" and waiting to see if Baby M was a candidate for surgery.

This was not the usual approach for an infant with a known diagnosis of trisomy 18 and such a complex cardiac problem, so the palliative care provider contacted the cardiologist. The cardiologist stated that an infant with confirmed trisomy 18 and such a complex cardiac defect would not be offered the heart surgery. After some discussion, the palliative care provider and the cardiologist recognized that the confusion resulted from his unfamiliarity with cell free fetal DNA testing. He was not aware of the high specificity of cell free fetal DNA testing and the very high probability that the fetus had trisomy 18, due to the ultrasound results combined with the cell free fetal DNA results. His impression was that because Ms. M had declined the amniocentesis, a genetic diagnosis would need to be done on the baby after birth to ensure that she truly had trisomy 18 before any decisions were made. He apologized for the confusion, and asked that the palliative care team inform Ms. M that a child with trisomy 18 would not be a candidate for heart surgery.

The palliative care provider relayed this to Ms. M, and she was distraught. Ms. M explained that this information “changed everything.” She was very confident that Baby M had trisomy 18, and she expressed that all she wanted was honest information so that she could make decisions for her baby. Ms. M was so upset that she could not proceed with discussion about her desires for her daughter after birth, and a meeting with the palliative care provider was scheduled for the next week. The follow up meeting was difficult, but productive, and Ms. M displayed

courage and strength through all of the confusion. In the end, she decided on full comfort care after birth with the focus on symptom control, quality time with family, and going home as soon as the baby was able, if she survived the immediate neonatal period. The revised birth plan was placed in her chart, circulated to the neonatology group who would be directing management of the infant, and forwarded to the labor and delivery unit and the NICU charge nurse.

Baby M was born at term by C-section. She survived the immediate post-birth period, and her birth plan was enacted. Special arrangements were made so that she could remain in the room with her mother and receive all care and evaluation there. Baby M did not leave her mother's side during her stay in the hospital. Lab tests and painful procedures were minimized, and she received special instruction for breastfeeding. Home hospice through a local organization was arranged, and Baby M was discharged home. She was followed after discharge by the palliative care team, her pediatrician, and hospice staff. After approximately a week, Baby M began to have difficulty feeding from the breast, and bottle feeding was started. When Baby M began having choking episodes with breast milk, the palliative care team spoke with Ms. M and the pediatrician and recommended thickening her feeds so that she could swallow them more easily. Ms. M was also given medication that she could administer in the event that Baby M had any pain or difficulty breathing. A hospice nurse regularly visited and spoke with Ms. M. The palliative care nurse

coordinator ensured communication among all involved care providers and spoke with Ms. M frequently. Baby M died peacefully in her mother's arms three weeks after she was born.

Ms. M's story demonstrates perinatal palliative care's distinctive approach to care. Care begins in the prenatal period shortly after fetal diagnosis with a life-limiting condition. Throughout several appointments and discussions with the multidisciplinary perinatal palliative care team, obstetrical issues and care plans are addressed and a birth plan is created that takes into account the medical information available and the patient's wishes for the baby. The palliative care team maintains communication with the patient's other medical providers to ensure continuity of care and contact with the patient to ensure that she is supported throughout the process. Perinatal palliative care provides guidance during the birth process and can follow the mother and child after discharge in order to ensure that the patient transitions to the appropriate level of care after discharge. This involves resource management, coordination of care providers, and attention to the special needs of the mother and infant after discharge that may not be addressed by other available services. There is not a standard model for a perinatal palliative care service. Each service must assess available resources and needs of the patients and community in order to design the best service for its institution, with the goal of providing excellent palliative care for this unique and vulnerable patient population.

CHAPTER 2: DESCRIPTION OF THE PRACTICUM

The primary goal of the practicum was to observe and participate in areas of medical practice that provide perinatal, neonatal, and pediatric palliative care in order to identify ethical issues pertinent to these areas of practice. In these settings, I was an observer at times and a participant at other times. My practicum took place at several sites, and my experience overall was greatly influenced by my role as a neonatologist with an interest in palliative care. This allowed a unique experience, and I had the opportunity to shift perspective when considering the ethical issues facing the care providers and the families. The result was a practicum that was different than initially expected, but that provided a rich, multifaceted exposure to the world of perinatal, neonatal, and pediatric palliative care.

Palliative and end-of-life care for infants and children is fraught with ethical issues. Perinatal palliative care involves particularly controversial issues. Many of these issues are frequently discussed in the literature, such as withholding and withdrawing life-prolonging therapies, the implications of prenatal genetic testing, and resuscitation at the margins of viability. During the practicum, my goal was to identify less common and more nuanced ethical issues that accompany these emotional and often controversial issues.

I was able to observe and participate in family meetings at the Genetic Counseling Clinic of the Comprehensive Center for Fetal Care (CCFC). I

observed the Pediatric Enhanced Care team (PEC) in its weekly multidisciplinary meetings discussing patient care, and I was able to accompany team members and observe while they conducted palliative care consults in the hospital. I attended on clinical service in the Newborn Intensive Care Unit (NICU) at both Brenner Children's Hospital and Forsyth Hospital. In addition, I conducted several family meetings for NICU families from both an ethics perspective and as a palliative care consultant. This chapter will describe my experiences in these venues.

Genetic Counselors at the Comprehensive Center for Fetal Care

The CCFC provides specialty and subspecialty care for pregnant women and their fetuses. It is a Wake Forest Baptist Health facility, and the Wake Forest Maternal Fetal Medicine (MFM) specialists provide care for women with high risk pregnancies, prenatally diagnosed fetal anomalies, and previous high risk pregnancies. While the clinic is staffed by MFM physicians and nurse practitioners, I focused on the genetic counseling section of the clinic. Genetic counselors help patients understand the fetal genetic diagnoses potentially complicating their pregnancies by meeting with families to record and interpret their family medical histories in relation to genetic medical issues, educating families about genetic inheritance, testing, management, and prevention, and promoting informed choices and adaptation to the risks or conditions in question.⁹ They provide personalized counseling about the diagnosis.

Genetic counselors are board certified and have completed a Masters of Science in Genetic Counseling. Their role in health care is not well known, but is incredibly important in fields such as obstetrics, pediatrics, and oncology.

In the MFM clinic, the genetic counselors meet with families whose fetuses are at high risk for genetic conditions. These conditions are complicated and often serious. They result from changes in the fetus's genome that are often quite difficult to explain. In the course of a counseling meeting with a family, the genetic counselors must explain human genetics in a way that families can understand, explain the abnormality their child is potentially facing, and describe the risks of associated anomalies and disabilities. They also discuss potential options for care, such as terminating or continuing the pregnancy, and support the families emotionally as they realize what this may mean for their unborn child.

Observing the genetic counselors as they met with families was a privilege. The two genetic counselors at the CCFC are patient, caring, master communicators. I learned a great deal about communication and patient/provider interaction from them. While their visits with families revolved around the potential diagnosis, the implications of this diagnosis, and options for decision making, ethical issues were woven throughout. The meeting with the genetic counselor often seemed to be the first time that the parents were able to truly understand the diagnosis that their child

was facing. Most had previously discussed the potential diagnosis with their physicians in the context of receiving lab results and determining the need to schedule an appointment with the genetic counselor, but the meeting with the genetic counselor was frequently when the potential diagnosis became more clear, and the parents were able to assimilate enough information to form an idea of what it would mean for their infant and for their family. In most cases, this information was devastating.

In my observations, the most difficult part of the process tended to be the explanation of the potential uncertainty complicating the diagnosis. Prenatal genetic testing often begins with screening tests. Other examinations such as ultrasounds and clinical exams are performed as well. Abnormal results on these screening exams lead to further, more specific, testing which can provide more information, but these more specific tests can often carry uncertainty as well. For example, one couple's fetus had multiple abnormalities on the prenatal ultrasound, and several of the general screening exams, commonly called the "quad screens," were abnormal. They were not interpretable, so the mother was offered cell free fetal DNA testing. This is a test that looks at the fetal DNA in maternal blood and assesses for amounts of certain genetic material that could indicate whether the fetus has too many or too few genes. The test sent on this mother returned as normal, but the physicians and genetic counselors were concerned that the test was a false negative. The mother was relieved to hear that the result was negative, and hope that

the fetus would be well was rekindled. The care providers offered the family a test for cell-free fetal DNA that is made by a different company and uses a slightly different quantification method. The family was hesitant, because they had the answer that they wanted, but agreed since the care providers were so concerned and since they wanted to be sure. This test showed that the fetus possessed 3 copies of every chromosome tested for, a condition called “complete triploidy.”

Complete triploidy is a condition that usually causes loss of the pregnancy in the first trimester. The care team and the family were unsure how to proceed. The mother was already in her third trimester, and the family had chosen to continue the pregnancy for moral and religious reasons, regardless of test results. The fact that the fetus had survived to the third trimester was already unexpected, and the level of uncertainty as to what would happen if she were born was incredibly high. No provider could predict with any reliability what the outcome of this pregnancy would be. In this case, the timing of the diagnosis and the decisions that the family had already made based on their values would dictate the direction of care. Unfortunately, there was no local perinatal palliative care program or bereavement program for the family. Most available services are for adult patients. There is not even a specialized pediatric hospice service available in Winston-Salem. The closest is 1.5 hours away.

This case demonstrates two issues that pervaded the cases I observed at the CCFC with the genetic counselors. The first is uncertainty and the difficulty of ethically approaching it from both the medical care provider and the patient point of view. The second is distributive justice and the limited availability of care for this vulnerable population. My earliest experiences in the practicum foreshadowed a consistent presence; these two issues would be prominent in the other practicum experiences as well.

Pediatric Enhanced Care

Pediatric Enhanced Care (PEC) is the official title of the pediatric palliative care team at Brenner Children's Hospital. The "Enhanced Care" title is congruent with emerging practices of calling palliative care programs "enhanced" or "supportive" care. In this case, however, it is not simply a different name to call palliative care because the service provides ongoing coordination of care for the most medically complex and fragile children. This is an aspect of pediatric palliative care that can differ from adult palliative care. While all palliative care focuses on quality of life for the patient, palliative care for infants and children can be ongoing for years due to the etiology of their medical problems. The PEC team provides this service. The team also consults on those children requiring palliative care for end-of-life issues, and the nurse coordinator works very closely with the local hospice centers to help arrange hospice care for

pediatric patients who need it. The PEC team does not provide hospice services.

I attended the PEC weekly meetings during which they discuss all hospitalized PEC patients and the patients who are having significant issues at home. The team is multidisciplinary and composed of a pediatric palliative care physician, a nurse coordinator, a bereavement coordinator, and several social workers who follow the children. Some meetings are attended by leaders from community organizations that work closely with the PEC team. Each social worker currently follows over 100 children. These social workers maintain personal contact with the parents and are a contact point for any questions, needs, or problems that the parents may have. The children that they serve are so medically complex that many have home health services, home ventilators and feeding machines, multiple subspecialists, and multiple hospital admissions each year.

In my observation of this team, it was clear that the service that they provide is imperative to the well-being of many of these families. Discussion often focused on the social rather than the medical aspects of their care, such as ensuring that patients follow up with their medical providers for needed medications and testing. Many of the medically fragile children also live in very tenuous social situations. Some are in foster care because their parents were unable to care for them appropriately. In some cases, it seemed that it took the PEC team, the local Medicaid worker, the school system, and multiple community

charity organizations to enable the parents to meet the child's needs. A recurrent issue was parental authority and responsibility. One particularly emotional case involved a child whose mother had a very difficult time caring for the child. The mother used many resources that were offered, but did not use the resources to help solve underlying problems that were barriers to her son's care. The social worker admitted that she was emotionally exhausted from constantly responding to the needs of the mother. The PEC team had gone above what is required of them and had even helped the family obtain housing and furniture. The mother would frequently call with demands on the PEC team members, miss appointments, misuse resources provided for the child, refuse recommended medical treatments, and alter her child's medications without discussing it with his physicians. The PEC team felt a responsibility to the child because the child was completely dependent and obviously not responsible for the barriers to care his mother created. However, several community physicians would no longer see the child because of the mother's behavior, and the family had exhausted their eligibility for all the community organizations that could help.

The team still felt a duty to help care for this child, and a potential recourse was child protective services. Since there was no outright neglect or abuse, a case was not opened, and yet their sense of duty remained. Every person in the room admitted to feeling that they still needed to try to help the family and not discharge the patient from the PEC service. There

was an exceptionally strong sense of duty to care for the medically fragile children who had no control over the actions of their parents, but were instead subject to them. There were many similar, though not quite as severe, cases discussed in the weekly meetings.

The PEC team had an overwhelming sense of duty to continue to care for the child regardless of the mother's actions, but rarely was the potential duty of the parent discussed. Does this parent have a duty to the PEC team that had supported the parent and child exhaustively? Does this duty require a certain amount of parental effort? Conversely, does the duty of the medical team include spending hours of time responding to the requests of the mother, when a clear pattern of behavior has emerged that the resources will not be used appropriately? Is there a point when the burden on the PEC team becomes so weighty that the duty to assist in the care of the child is limited or even negated? Is there a point when a family has used too many resources and support must end? These questions have no well-defined answer, but it was an insidious issue at nearly every meeting.

Much of the team discussion involved obtaining resources for the patients or assessing resources that the PEC team was able to provide. The patient population served by the team tends to have high resource utilization and minimal funding. The PEC team's services to these patients do not directly generate revenue for the hospital. The goal is to provide care coordination in an attempt to decrease resource utilization in

the form of hospital admissions and length of stay, but in this population, that can be difficult to achieve. Even in serving over 300 patients and their families, the PEC service cannot fund itself. The service is partially funded by the hospital and partially funded by grants which pay the salaries of several of the social workers. One social worker is funded by a state program as well. Grant funding is a struggle for the lead physician. She is an expert in her field, well published, loved by patients and families, and she works tirelessly, but grant funding is difficult to obtain and even more difficult to maintain. The team has actually lost members when particular grants were not refunded. In sum, the PEC team is overworked and under-funded. The local hospice center does not have any resources specifically for pediatric patients, so when hospice services are needed, the responsibility of coordination lies squarely on these already burdened providers. Again, the issue of distributive justice emerges, and resources for the most vulnerable and least-revenue generating patients are scarce.

Experience as NICU Attending

I am a neonatologist, and the daily practice of neonatology is what laid my path to bioethics. Practicing neonatologists face ethical issues every day, and decisions at the end of life for infants can be particularly divisive. As an attending physician in the NICU, I direct patient care. Because my role is necessarily active, I approached the ethical issues by reflecting on

my patients and the care I provided. I examined my own conversations with parents and my actions as a means of exploring the ethical issues. While self-reflection is always an important part of ongoing growth as a physician, retrospective consideration of my own actions specifically within the framework of ethics was instructive. Self-examination often reveals harsh truths that the demands of a hectic schedule can obscure.

In the past year, I have consulted with multiple families with prenatally diagnosed conditions to help develop birth plans and goals of care. I have also provided critical care to infants who were doing well and then within a short period of time died, leaving families shocked and shattered. There have been babies who spent months in critical but stable condition, teetering on the verge of medical decompensation, but somehow survived every complication and infection. I have had discussions with parents of NICU babies who have had complicated medical courses and need life-sustaining therapies such as surgical gastric tubes and tracheostomies.

In my past 6 years of practice, I have held dying infants whose parents were not in the room with them when they died, baptized a child because the chaplain could not make it in time and the parents desperately wanted the child baptized, and examined a dead infant's body in the morgue to obtain information that might give a grieving mother peace. I have removed breathing tubes, turned off ventilators, given medication that treats pain, but also slows breathing and hastens death. I have declared infants dead in the delivery room both shortly after birth and after long

meticulous resuscitations. Occasionally, I decided whether resuscitation should even be attempted. In essence, I was deciding if the infant would even have a chance to survive.

I have called a mother in the middle of the night to come in to the hospital to be with her baby because I did not think the child would survive the night, and then I have had that same child run into my arms two years later when the mother brought him up to the NICU to visit. I have told a family that their baby was not responding to therapy and was very likely to die, but we could try one more thing that would essentially be “grasping at straws,” and he then stabilized, weaned off of the ventilator and was discharged home 3 months later. I have escalated ventilator settings and vasopressor therapy to maximum levels while placing multiple chest tubes and thought to myself that my efforts were just torturing the baby because she was going to die. The child survived with significant disabilities, but is loved and cherished by her mother who is incredibly happy her daughter is alive.

In neonatology, there is rarely 100% certainty about anything, and the medical literature and experience do not always offer accurate predictions of what a particular infant will do at any time. There is still a responsibility to offer families medical opinions, however, and to help them with decision making. Uncertainty of prognosis and uncertainty of outcome are ever-present. How should a neonatologist approach this uncertainty? Should the one baby in 10,000 who survives support an

attitude of unbridled hope in the face of a devastating prognosis? How does a physician promote realistic expectations while supporting the family's hope? How does a neonatologist overcome her own bias and discomfort to support her patient medically and the parents emotionally? Is emotional support of the parents the duty of the physician? Where is the boundary between medical care and personal involvement? How does a physician balance the "miracle" cases with the ones that follow the expected course, and how does this affect communication?

As is common in the practice of medicine and medical ethics, observation has led to more questions than answers. Observation and reflection have allowed me to explore beyond the most common ethical issues, and to discern more obscure issues that are pervasive, but rarely addressed. In the following chapters, I will explore the concept of uncertainty that is more often present in perinatal palliative care than in pediatric or adult palliative care, and I will propose a means of addressing it in perinatal palliative care.

CHAPTER 3: UNCERTAINTY IN PERINATAL PALLIATIVE CARE

Neonatology is a relatively new subspecialty within the field of pediatrics that is devoted to intensive care for the smallest and sickest infants, beginning at birth. From its origins in the 1970s, neonatology has evolved into a highly technological field characterized by rapid advancement and constant research. In addition, neonatology is an emotionally loaded field in which physicians and surrogate decision-makers make high-stakes decisions every day. Historically, ethical discussion and legal guidance trails clinical practice and development of technology, making neonatology a crucible for bioethics.

Perinatal palliative care within neonatology provides care for mother-fetus dyads diagnosed with life-limiting conditions. It is an emerging subspecialty in which medicine and ethics are particularly tightly bound. This care occurs in the perinatal period that includes several months before birth up to several months after birth, and it involves many ethical problems because it simultaneously addresses care at both the beginning and the end of life for these neonates. Controversies such as resuscitation at the borders of viability, prenatal genetic testing, withholding and withdrawing life-prolonging measures, and the limits of parental authority abound.

In reflection on my practice as a neonatologist and my observations during my ethics practicum, a common theme emerged. While the

specifics of the ethics problems may differ, often, the problem of uncertainty in perinatal palliative care is nearly always at the root of those problems. I propose that uncertainty in perinatal palliative care can be usefully divided into two types, medical uncertainty and ethical uncertainty. Medical uncertainty is a function of the lack of clear or definitive factual information about the patient's diagnosis and prognosis, and ethical uncertainty is a function of ambiguous or conflicting moral guidance about communication and treatment decision-making.

In this chapter, I will use the process of a perinatal palliative care consult to analyze medical and ethical uncertainty. This framework begins with the initial diagnosis of the medical problem and the associated prognosis for the fetus. The provider communicates this information to the patient, and the patient attempts to understand the information and the implications for herself and her fetus. Finally, the medical provider and patient work to develop a treatment plan incorporating the patient's goals of care for her baby.

Diagnostic Uncertainty

In perinatal care, diagnostic uncertainty often begins with prenatal testing. The likelihood of a particular diagnosis is estimated based on consideration of contributing factors. For example, the report of a cell free fetal DNA test might include a statement that the fetus has a 5% chance of a particular genetic defect, or a 95% chance of the genetic defect.

Additional testing can be done, but rarely is there 100% confidence about a diagnosis. Diagnostics are further complicated by the fetus's location inside the uterus of the mother, preventing a full evaluation. Medical providers attempt to overcome this barrier by using technologies such as fetal MRI, cell free fetal DNA testing, fetal echocardiography, and 3 dimensional ultrasound, but even these highly specialized tests often indicate only the likelihood that a fetus has a particular anomaly, not a definitive diagnosis.

The case of Mrs. E and her fetus, Baby E, demonstrates how diagnostic uncertainty makes caring for these patients more complex. Mrs. E's first prenatal ultrasound showed that Baby E had limb abnormalities, growth restriction, a cardiac defect, and brain abnormalities. With multiple congenital anomalies, genetic testing was indicated, so Mrs. E underwent cell free fetal DNA testing. The fetal DNA present in her blood showed no abnormal amounts of genetic material. This result was perplexing, but fetal anomalies without easily identifiable genetic abnormalities occur, so the physician offered Mrs. E an amniocentesis to obtain intact fetal cells for a more specific analysis. An amniocentesis could provide more information, but it also carried a risk of pregnancy loss, injury to the fetus, and injury to the mother. Mrs. E and her husband had already chosen to continue the pregnancy despite the observed abnormalities and the possibility of a genetic condition, so they declined the amniocentesis because they did not want to put Baby E at risk.

With no further genetic testing to offer, Mrs. E was referred to pediatric cardiology for a prenatal cardiac echocardiogram to further characterize the fetal heart defect, to pediatric orthopedics for evaluation of the limb abnormalities, and to pediatric neurosurgery for a fetal MRI to investigate the brain abnormalities. Mrs. E and her husband were told by the MFM specialists that Baby E likely had a genetic abnormality, but further investigation would have to wait until after Baby E was born.

Prognostic Uncertainty

Perhaps more problematic than diagnostic uncertainty is the limited ability to predict or explain what the diagnosis means for the particular baby and family. Many genetic abnormalities and congenital defects do not produce one particular phenotype. Often, these conditions manifest as a spectrum of disorders. For example, all people with trisomy 21 have some level of intellectual disability, and there are certain unmistakable physical features that accompany the diagnosis; the severity of physical and intellectual disability varies greatly, however.

Medical providers attempt to prognosticate accurately by searching the medical literature and specialty databases for factual information that they can offer to parents. Valuable information is available, but it often does not address the considerable spectrum of problems associated with each illness. Also, in some instances data is limited due to lack of funding for research, or completely absent due to the rarity of the disease. To be

useful, the data must be up-to-date and applicable to the patient, but in many cases, the absence of data highlights the limits of medicine and offers little guidance to patients and providers.

Neonatologists attempt to address uncertainty associated with birth at the limits of viability with an online outcome tool based on empirical data that is available from the National Institutes of Health, National Institute of Child Health and Human Development (NICHD). This tool is the NICHD Neonatal Research Network (NRN) Extremely Preterm Birth Outcome Data Tool, and it is based on outcome data collected from 18 clinical neonatology centers involved in multiple areas of research.¹⁰ The database is the largest and most up-to-date widely accessible collection of survival data for neonates at the margins of viability. A medical provider enters information about the fetus' gestational age, sex, estimated weight, singleton/twin status, and whether the mother received prenatal steroids, and the tool uses that information to generate mortality and morbidity estimates for the infant at birth. Medical providers commonly use this information for counseling families facing decisions about resuscitation of their infant at the borders of viability (22-24 weeks). While the tool is accompanied by 2 paragraphs of text explaining that the "data are not intended to be predictive of individual infant outcomes" and should not be used as the "sole basis for care decisions," the numbers often play a major role in prenatal counseling, and the statistical estimates can be crucial in determining families' approach to care. It is helpful to be able to give

families an idea about their infant's chances of survival, but medical providers may not clearly understand the uncertainty involved in the application of the statistics, despite the disclaimer in the explanation of the tool, and therefore, may not convey that uncertainty to the families. Additionally, mortality and morbidity data can be confusing for families if providers do not give a clear explanation of the difference between morbidity and mortality and of the implications of the various morbidities.

Medical Provider Communication of Uncertainty

Information about diagnosis and prognosis for a mother-fetus dyad with a life-limiting condition is clearly important, but the way this information is presented may be even more important. There are several factors involved in the communication process. The medical provider must choose which information to offer and then present it in an effective manner. In the course of this communication process, the medical provider is developing a relationship with the family. The provider's goal is to give the family the information needed to help them make a decision, and this can involve explanation about the uncertainty in the data supporting the diagnosis and prognosis. This is also where ethical uncertainty enters. The provider will discuss information with the family in the hopes of offering guidance for decision making. The underlying ethical uncertainty influences moral aspects of the medical provider's communication with the family, and this in turn, can influence the

family's approach to the value-laden decisions that they are asked to make. For example, if there is ethical uncertainty about the appropriateness of withholding aggressive intervention, the provider may not include the option in the counseling discussion, thereby limiting the treatment choices for the family.

The information given to the family by the medical provider informs decisions about management of the mother in her OB care as well as treatment plans for the infant after the infant is born. Providers describe conditions and abnormalities, statistics and probabilities in an attempt to help families understand what is likely to happen when the baby is born. The medical provider gives the patient the information that the medical provider considers pertinent. This information can be based on data or evidence in the medical literature, but it can also stem from the provider's own experience and clinical judgment. The medical provider can introduce bias by the choice of information she presents as the factual basis for decision making. Introducing this bias may or may not be intentional and may or may not be detrimental to patient decision making, but regardless of intent, bias can influence decision making. A study of obstetricians' approach to resuscitation in prematurity revealed that obstetricians routinely underestimate neonatal survival at every gestational age less than 36 weeks.¹¹ Neonatologists within the same practice group can differ in their views about the minimum gestational age at which a baby should be resuscitated. There is no standard practice. The two

groups of physicians caring for the maternal-fetal dyad at this crucial time could seem to be at odds with each other, and the maternal choice for aggressive resuscitation could depend on who counseled her, the obstetrician or the neonatologist.

While the content of the information is important, in my observations and practice, it is clear that the manner in which the information is given is highly influential. How the provider relays the information to the patient may be the crux of the moral problem of communicating uncertainty. The term ‘framing’ is often used to describe the way in which person chooses to present information. For example, the person will choose to tell the best story to illustrate a concept or present the best scenario to encourage questions about important issues.

Consider the case of Ms. P, a 23 year old woman at 22 6/7 weeks gestation with her second child. She presented to the hospital with rupture of membranes (broken water) and preterm labor. She is admitted, and medication to try to slow her labor is given. The obstetrician needs to know whether or not to give her steroids to help mature the fetal lungs, and this decision hinges on whether the medical team will attempt resuscitation when the baby is delivered at 23 weeks. The neonatologist is asked to consult with Ms. P to help her make a decision regarding resuscitation.

The standard in situations involving the approach to care at the borders of viability is to take a non-directive approach to prenatal counseling. In

this approach, the counselor presents information about the infant's condition, prognosis, and options for treatment, but does not recommend a specific treatment. Using the NICHD NRN Outcome Data Tool, the neonatologist, Dr. B, explains to Ms. P that at 23 0/7 weeks her 500 gram male fetus without antenatal maternal steroids has a 5% chance of survival without profound neurodevelopmental impairment and a 10% chance of survival overall, if the baby is aggressively resuscitated. If she receives the prenatal steroids, the infant would have a 10% chance of survival without profound neurodevelopmental impairment, and an approximately 20% chance of survival overall.¹² Dr. B objectively explains the available empirical survival data in terms of survival and survival without profound disability. Research has shown that framing the prognostic information in terms of survival and survival without disability rather than in terms of mortality and morbidity makes parents more likely to choose aggressive resuscitation.¹³ Additionally, the order in which Dr. B presents the information may emphasize the seemingly large increase from 10% to 20% survival with prenatal steroids, and that emphasis may distract Ms. P from the primary question of whether she should choose aggressive resuscitation efforts for her 23 week infant.

Over the next 30 minutes, Dr. B offers more statistics about the varying neurodevelopmental disabilities and risks for other problems such as intraventricular hemorrhage, necrotizing enterocolitis, respiratory distress syndrome, and retinopathy of prematurity. Dr. B also discusses the

infant's expected length of stay and requirements for going home from the newborn intensive care unit. When asked if she has any questions, Ms. P asks, "So will he survive if I get the shots?" Dr. B reminds Ms. P of the 10% increase in overall survival with the maternal antenatal steroid injection. Ms. P states that she would like the injections in case her baby is born at 23 weeks, and since he has an increased chance of survival with the maternal steroid injections, she would like him to be aggressively resuscitated if he is born at 23 weeks.

Dr. B lets Ms. P know that her obstetrician will be in to discuss the steroids and potential intervention on fetal behalf in a few minutes. Ms. P asks Dr. B what intervention on fetal behalf means, and Dr. B explains that her obstetrician will need to know if she would like a Caesarean section (C-section) delivery of her infant if he does not tolerate labor. Ms. P indicates that if her baby develops distress she would, "not want them to just let him die inside of her." She would "want him delivered however is best for him so that he has the best shot." Dr. B states that intervention on fetal behalf at such early gestational ages is often discouraged because the risk it poses to the mother outweighs the potential benefit to the fetus. Ms. P replies that since her baby boy has a better chance at survival with the steroid shots, she "wants everything possible done," including a Caesarean section operation.

Dr. B conducted the consult by relaying information in what is considered to be a non-directive manner, but how she presented the

information likely greatly influenced Ms. P's understanding of the situation and, therefore, Ms. P's ultimate decisions. In this scenario, it seems that all of Ms. P's decisions are based on the increased possibility of her infant's survival with the antenatal maternal steroid injections. This information may have persuaded Ms. P that she must give her son the best chance at survival. For a rational, mentally healthy mother, the moral default position will always be to choose a reasonable chance of survival for her child. The "information dump" that ended with a description of the potential length of stay and qualifications for discharge from the NICU may have obscured the high probability of the infant's disability and death in this case. While all of the information that the physician gave Ms. P is correct and relevant, the way she framed it emphasized improved survival with antenatal steroids, which in turn, caused Ms. P to focus on this as well. It is almost as if the decision to resuscitate was predetermined, and that the question of administering antenatal steroids was the point of the consult. Actually, the question of whether or not the baby should be resuscitated was the primary question that would then determine steroid administration. If Ms. P was able to understand fully the implications of her son's potential preterm delivery and the low probability that the child would survive at all, she may have made a different decision.

Despite her best efforts to convey impartiality in order to respect Ms. P's autonomous decision-making, Dr. B's framing of the information probably significantly influenced Ms. P. Additionally, in her attempt to

decrease uncertainty with empirical data, Dr. B framed the discussion in a way that nearly denied the presence of uncertainty. Providers may unintentionally present information in a particular way because of their understanding of the data and their values, beliefs, and experiences.¹⁴ Framing, however, can also be intentional and crafted in a way to convey a certain bias without overtly stating the provider's preference. For example, using terms such as 'compassionate extubation' and 'transition to comfort care' conveys a much different sentiment than 'pulling the tube' or 'pulling the plug.' These examples are blatant, but even subtle choices of descriptive terms can change perspective.

In her commentary on neutral counseling in the American Medical Association (AMA) Journal of Ethics, Anne Drapkin Lyerly explains that non-directive counseling of women facing preterm birth at the edge of viability may actually undermine the woman's autonomy.¹⁵ She describes the case of a woman with no prenatal care who presents in premature labor. The woman's reported dates are consistent with a 25 week fetus, but fetal size and indicators are consistent with a 21 week fetus. Lyerly argues that presenting statistics of morbidity and mortality and discussing intervention on fetal behalf with a woman about to deliver a 21 week fetus implies that there is a genuine decision to be made, when in truth, at 21 weeks, there is not. In this case, she concludes that non-directive counseling describing vaginal delivery with expectant management (watchful waiting) as "withholding of care" for this pre-

viable fetus, creates a misleading impression that this mother is morally responsible for the death of her child. This undermines the purpose of non-directive counseling by conveying a false impression of uncertainty regarding the potential survival of the infant.

In consideration of the case that Lysterly uses to demonstrate that directive counseling is more appropriate in cases where there truly are no options, it should be noted that the presence of uncertainty in the case itself could actually make counseling more complicated. Most obstetric and neonatal providers would agree that aggressive resuscitation of a 21 week fetus is not appropriate. With the discrepancy between the fetal size of 21 weeks and the estimated dating placing the fetus at 25 weeks, however, the decision to present only non-aggressive intervention is more problematic. It is possible that the measurement of the pregnancy is not accurate, and the size consistent with 25 weeks is actually a better indicator of the potential maturity of an infant. Nearly all obstetric and neonatal providers would agree that aggressive resuscitation of a 25 week infant is appropriate. I agree with her premise that non-directive counseling is inappropriate in cases where there is no uncertainty. Additionally, I think that the discrepancy between the fetal size and dates that she describes in the scenario she uses to illustrate her point, while a realistic situation, may unintentionally complicate her discussion.

Framing in high-stakes, emotional situations requiring value-laden decisions from the patients, is complicated and nuanced. It is done

unconsciously at times and purposefully at times, but the moral issue for medical providers is recognizing that framing matters and a particular presentation will bias the information and potentially influence the patient's judgment. This bias can give the mother a false sense of confidence about the infant's diagnosis and prognosis. In the case of Ms. P, the uncertainty related to the spectrum of outcome at 23 weeks was overshadowed by the physician's focus on the improved survival with steroids and on the projected NICU course. In the case of the woman with the 21 week gestational age fetus described by Dr. Lyerly, clarifying that there is no prognostic uncertainty at that age, and that, given the lack of ambiguity, a decision for expectant management (waiting to see what happens) and vaginal delivery with comfort care is the morally sound decision. Using framing in discussing medical and ethical issues is not wrong; in fact, I would argue it is unavoidable because the information must be framed in some manner. The effect it has must be acknowledged, however, and the provider should ensure that it is being used for effective counseling and not coercion. The medical provider should also be aware of the potential effect of framing a situation in a certain way. For example, "good framing" could promote understanding of the situation and help guide the patient, while "bad framing" could cause confusion and unintended influence.

Parental Reception of Information and Consideration of Uncertainty

Many medical providers have conducted family meetings in which they meticulously explain diagnosis and care plans, and then the next day, the family will ask exactly the same question that the provider spent nearly an hour explaining during the prior meeting. It is also common for a mother to say “nobody ever told me that,” to the neonatologist taking care of her baby on Monday, when the neonatologist who cared for the baby the week before explained the issue in detail. A medical provider can communicate exceptionally well, but that is only half of the process. The emotional state, bias, and world view of the parents will influence how the information is perceived.

A pregnant woman who has just received a life-limiting diagnosis for her infant is undoubtedly upset, and this will certainly add to difficulty processing information. A study of parents who received the diagnosis of a fetal congenital cystic adenomatoid malformation (CCAM), a rare lung lesion that is usually benign but may require postnatal surgery, found that 66% of mothers and 74% of fathers felt disoriented after being given the diagnosis. Additionally, they found the time between diagnosis and meeting with the pediatric surgeon very stressful, and during this time they tended to focus most on the potential bad outcomes like in utero death and fetal distress.¹⁶ The authors concluded that the bad outcomes were likely “over-presented” or “over-perceived” by parents since other information was given at the same time. A stressed and disoriented parent will

probably not be able to process large amounts of information and fully attend to the high-stakes decisions they are being asked to make. When parents are considering their child, it is reasonable and even necessary that emotion influences medical decision making, but the dynamic nature of these emotions may make it difficult for the medical provider to address the family's informational needs fully.

Many other factors have been proven to influence a family's perception of medical information, but one that is prominent in empirical studies is religiousness. In surveys of parents who chose to continue pregnancies for a fetus with trisomy 18 or 13, 68% of respondents stated that personal moral beliefs such as their beliefs about abortion or a sense of fatalism were the primary reason, and 48% of respondents cited a specific religious belief as the factor guiding the decision.¹⁷ Studies have shown that religiousness confers a degree of resistance to the influence of framing¹³ and that strong religious convictions contribute to increased numbers of patients consenting to in-utero surgery for fetal spina bifida in the NICHD fetal surgery trials.¹⁸ In times of uncertainty, many who have strong religious affiliations turn to their faith for support and guidance. Religious beliefs about the sanctity of life, the redemptive value of suffering, and the role of technology can help families make confident decisions in uncertain situations. In his article evaluating hope when parents are faced with the uncertainty of fetal surgery, Mark Bliton notes that many turned to their god, religion and prayer.¹⁸ Many framed their

situation as a trial from their god, and Bliton noted that several families expressed that “there is a reason God chose us to have this child with spina bifida. He has a plan for us.”¹⁸ While Christianity tended to be a strong factor in many of the published studies, Catholicism, Orthodox Judaism, Pentecostal religions, and Islam all have nuanced and specific approaches to the ethical issues families face when they need perinatal palliative care. While there are certain commonly known religious beliefs that medical providers associate with specific approaches to medical care, such as those of Jehovah’s Witnesses and Christian Scientists, many others are not as well known, are not “official” beliefs of a religion, or are different interpretations of doctrine in different groups within the same religious tradition.

A case illustrating how strongly religious beliefs can influence the approach to uncertainty is the case of Baby L. Baby L was born with suspected life-limiting congenital anomalies associated with an unconfirmed chromosomal abnormality, and the mother’s religious and cultural beliefs decreased uncertainty about what to do. Prenatally, the mother received information about the suspected diagnosis and did not return for any further prenatal care. When she presented in preterm labor at 30 weeks, she refused all prenatal counseling. She was Muslim, from Afghanistan, and spoke only Pashto, the most common language of Afghanistan. She told the physicians through a translator telephone that she wanted her child to be resuscitated. The neonatologists agreed,

because there was diagnostic uncertainty, and there was no further discussion of a plan for treatment after the diagnostic information was obtained because Mrs. L was refusing all further communication. When Baby L was born, she was intubated and placed on the ventilator for respiratory distress, given central lines for monitoring and intravenous access, and underwent diagnostic testing. By the time all test results returned, Baby L was in critical but stable condition, her mother had left the hospital against medical advice, and the male members of her extended family were the identified decision-makers. After the test results confirming the diagnosis of trisomy 18 and confirming the other life-limiting congenital anomalies were conveyed to the father, he responded that he needed to speak with their religious advisor, not their Imam, before a decision could be made. Baby L continued on the ventilator, began to deteriorate clinically, and a DNR order with non-escalation of support and potential compassionate extubation was discussed with the family. Aware that the family had deeply held religious beliefs guiding their decisions, the neonatologist asked them through a translator if they had any specific beliefs about babies who die shortly after birth or after withholding or withdrawing of medical support. Baby L's uncle explained that they do not believe in interfering with death by interventions like chest compressions and medications to restart the heart, and so they agreed to the DNR order. The grandfather, and Imam, then explained that they would need to contact their religious advisor before they made any further

decisions. The neonatologist told the family that at the time, Baby L was actively dying, and that the machines and medications supporting her were essentially preventing her death. They expressed understanding.

The next day, the family returned, and in a family conference, they stated that their religious advisor told them that one more medical test to provide proof that the baby had not been cured should be done before they could agree to non-escalation of life-prolonging measures. They did not specify what the test should be, but that they would need to see the results of one more test before making a decision about treatment. After that step, and more time, they would consider compassionate extubation. The infant had received multiple tests, so the neonatologist chose the most noninvasive that would show the lung and gastrointestinal abnormalities. A chest and abdominal radiograph was done, and the neonatologist reviewed the film with the family. They agreed that the image had not changed from previous and again demonstrated her life-limiting condition, and they agreed not to escalate her treatment further. Over the next few days, her clinical condition deteriorated further, and the father agreed to removing her from the machines so that he could hold her when her heart rate began to fall and she was about to die.

The case of Baby L illustrates how religion, in this case Islam that was culturally related to Afghanistan, offered a clear process for decision-making. Reliance on faith and a belief that Allah was the one who “determined who lives and dies,” provided the first level of certainty.

When the uncle stated that they did not believe in interfering with death by means of cardiopulmonary resuscitation, he invoked their religious beliefs to justify the decision, even though the current treatment that Baby L was receiving could arguably fall into the same category. The family's relationship and reliance upon their religious advisor also reduced uncertainty by directing their decisions. The religious leader, who was not involved in any of the family meetings, sought to manage uncertainty related to the prognosis and clinical course by requesting "one more medical test" prior to altering the treatment plan, even though the test had no bearing on any medical decision that would be made by the neonatology team. The family did not explain their initial resistance to compassionate extubation, but perhaps the father's decision to "remove the machines" only as Baby L's heart rate was already decreasing, indicating an imminent demise, was based on his knowing that death was going to happen anyway, and so his decision would not be the immediate cause. It could also have been a compromise between his personal beliefs that his daughter's suffering should end and she should be allowed to die and the opinions of his religious leader that he should not remove the machine and thereby directly cause his daughter's death. Again, the reason for this request was not discussed, but throughout the process, the influence of their specific religious beliefs seemed to decrease uncertainty and guide decision making.

Addressing Uncertainty in the Birth Plan

As I explained in Chapter 2, the perinatal palliative care birth plan is an advance directive for the neonate, a description of the family's goals of care, and a treatment plan for the infant designed to achieve those goals. In essence, it is a document that attempts to decrease uncertainty about treatment surrounding the birth of the baby by clearly communicating the family's decisions after discussion with the medical providers. The process of creating the birth plan encourages the family to think about their baby's diagnosis, prognosis, and what approach to care they prefer, but in considering these issues, uncertainty requires that the family discuss several potential scenarios.

In his paper, "Harm and Uncertainty in Newborn Intensive Care," Kenneth Kipnis argues that neonatologists may not be obligated to override parental non-treatment decisions, even if there is a reasonable chance of a good outcome.¹⁹ Kipnis claims that there are three types of uncertainty that may limit neonatologists' obligations to treat severely ill neonates. He states that the boundary of what is an intolerable quality of life is vague, that there is uncertainty about whether aggressive intervention will result in a relatively healthy child or a devastated child, and that there is an inability to determine an acceptable ratio between the likelihood of those two outcomes. In his description, uncertainty about the outcome of aggressive intervention demonstrates medical uncertainty involving prognosis. Ethical uncertainty arises in the determination of a

tolerable quality of life and what is an acceptable ratio between the likelihood of a good and poor outcome. Kipnis argues against the obligation of a neonatologist to override a parental non-treatment decision, but his description of the three types of uncertainty can also be applied to creation of a birth plan and advance directive because much of the focus is on managing the uncertainty that accompanies discussions of quality of life.

After talking about the diagnosis and prognosis, the provider and the family will begin to discuss the plan for care. Often, this plan is based on the anticipated quality of life of the baby, and the acceptability of the quality of life to the family. It is unreasonable to expect each family to have the same idea about what is an acceptable quality of life, but it is important to realize that it is the family's determination of acceptability that is most important, not the medical providers. Medical providers may determine that specific medical treatments are not appropriate, and therefore not offer them, but the value judgment of what is an acceptable quality of life primarily results from the values of the family. Conversely, physicians may believe that an intervention is necessary, but the family may refuse on the grounds that the baby will not have an adequate quality of life. In this case, medical providers may offer the intervention as the only option, and if the family requests a non-aggressive approach, further discussions with the family might be necessary to ensure that all aspects of the case have been considered. The dialogue is dependent on both parties,

and it involves active participation by both parties. Eliciting the family's perception of quality of life and addressing it is imperative when considering treatment.

Research involving families of patients with trisomy 13 and 18 revealed that the quality of life that the medical provider portrayed for their infant was inaccurate and reflected the provider's evaluation of the child's life instead of an actual description of potential disabilities and how the disability would affect the child. Families reported being told that their infants would be a "vegetable" and that the child would "ruin their marriage."²⁰ They described that their experience of their children was very different from what had been presented, and that they believed that their children had excellent quality of life despite their significant disabilities.

Given the information available, each family uses its own beliefs, understanding, and reference point to determine an acceptable quality of life. Ms. A's fetus was diagnosed with multiple congenital anomalies associated with a rare, previously unreported genetic abnormality. The geneticists and genetic counselors could not provide any meaningful information about the infant's prognosis aside from the general prognosis associated with the congenital anomalies. Ms. A was told that her baby would definitely have disabilities, but that the extent of the disabilities could not be predicted. Ms. A told the medical providers that if Baby A would be like a child with Down syndrome, then she would consider her

to have a very good quality of life, but that if her child would never be able to “communicate or know what was going on around her,” that she would not “want her child to live that way. “ The medical providers could offer no prediction of the level of the infant’s disability, so Ms. A decided that a trial of therapy to assess the congenital anomalies and hopefully provide a more definite prognosis was what she wanted for her child. She had a very clear idea of what constituted a good quality of life for her child, but the ambiguity about the severity of the child’s disability precluded her from deciding that termination or non-aggressive initial intervention was morally correct. The resulting birth plan addressed her goals of care and the process she would like to occur if her baby was too ill to survive, but it would take many weeks and many more family meetings after Baby A was born to determine the final goals of care for Baby A.

Managing uncertainty with a predetermined plan in the face of such dynamic factors is challenging. The parents must consider that their baby may not survive to be born or may die during delivery. They are told that their child may survive several days in the hospital before death or may survive until discharge and then go home and die several weeks later. Rarely are families told that their child with a life-limiting condition may survive years, but this is also a possibility. As the medical condition of the infant evolves over time, initial aggressive treatment may give way to comfort care, and aggressive treatments may be necessary for palliative

purposes. The case of an infant born with hydranencephaly offers an example of how treatment plans may need to change with the needs of the patient. Hydranencephaly is a condition in which the fetal brain either does not form correctly or is damaged by an in-utero event and causes retention of only the brainstem. Often the infants appear to have no abnormalities at birth, but over time, they can develop severe hydrocephalus and seizures. The mother chose a DNR/comfort care plan for her child. Her birth plan was in place, and if the child survived, she planned to go home with hospice services until the child died. The baby was born, did well in the newborn nursery, and was discharged home with hospice care. Over time, the infant developed seizures that were treated with medication, and her head began to grow in size. The mother watched her child suffer the discomfort of hydrocephalus and severe seizures and asked the pediatric palliative care physicians what else could be done to relieve her child's suffering. The palliative care team explained that a surgically placed ventriculoperitoneal shunt to relieve the pressure of the increased cerebrospinal fluid in her brain would be reasonable. The mother found this confusing, because this procedure was what was portrayed as aggressive treatment during her prenatal discussions. While the goals of care for her daughter had not changed, what constituted palliative procedures had, and it was important for both the palliative care team and the mother to realize that flexibility and commitment to tailoring care to the needs of the patient are of utmost importance.

Conclusion

Medical uncertainty and ethical uncertainty permeate the perinatal palliative care process. The roots of many ethical issues that arise are found in these two types of uncertainty. Discussions about goals of care and treatment plans must consider the uncertainty associated with diagnosis and prognosis and the uncertainty associated with moral decisions about care at the end of life. Controversies associated with prenatal testing involve the confidence of the test results and decisions about what to do with the information. The goal of a birth plan in perinatal palliative care is to manage uncertainty while ensuring that the shared plan between the family and the providers is known, but uncertainty is woven throughout its creation.

While the medical provider guides the family through decision making, she attempts to manage uncertainty with data and experience. Mitigating ambiguity with presentation of facts, data, and experience without acknowledging that the uncertainty exists can influence the moral decision-making required of the family. What data the provider presents and how she frames the diagnosis, prognosis, and treatment options will influence the family's decision making as well. Additionally, the management of medical uncertainty by the medical providers may reflect personal beliefs of the provider and may conflict with the family's beliefs and medical providers' beliefs, thereby causing confusion and conflict.

Perinatal palliative care is fraught with high-stakes decisions that require focus on the moral beliefs and values of the family, and uncertainty is difficult to manage when a parent is faced with life or death decisions. The family's understanding of the information is the foundation for the delineation of goals of care, and there are many ways that attempts at mitigation of uncertainty can influence the understanding. Families will also seek to manage uncertainty in ways that resonate with them. Relying on religious beliefs and ideas about purposeful suffering may help them manage doubt when faced with decisions. The family should attempt to meet the challenge of decision making, and at times, moral beliefs and previously held values are challenged.

Uncertainty has always been present medical care, but advancements in perinatal and neonatal care push ethical problems related to uncertainty to the forefront. It is important to recognize when uncertainty is present, whether the origin is medical or ethical, and how it affects decision making and the provision of medical care. It is also valuable to realize when steps to manage uncertainty by the provider or the family influence decisions and outcomes. Tracing uncertainty through the process of a perinatal palliative care consult identifies some of the major ways that it affects care, but history suggests that it is possible that as technology advances, the moral problems associated with it will only increase in number. Addressing these issues with research into how providers communicate and how patients make decisions is important. Teaching

medical and advanced practice provider students to recognize, acknowledge, and develop a level of comfort with uncertainty is also needed, but with each consult I perform, it is clear to me that a more informed, collaborative, and complete approach to addressing uncertainty in perinatal palliative care is needed.

CHAPTER 4: MANAGING UNCERTAINTY WITH ACCOMPANIMENT MEDICINE

In this final chapter, I will draw on my observations and research to offer a strategy for managing uncertainty. Working on this practicum thesis gave me time to observe daily practice more thoughtfully and to research the issues that I encountered. This has been highly gratifying and a true privilege for me, since prior to this I was in private clinical practice where the focus was on seeing patients and billing. I admit that while I enjoy reading about and reflecting on these topics, my pragmatic tendencies compel me to apply them to improve care for our patients. In this practicum, I was submerged in the praxis of palliative care as an observer and then had the luxury of taking time to research and evaluate theoretical approaches to what I observed. To end my thesis, I would like to re-engage in consideration of praxis involving uncertainty in perinatal palliative care.

How Should Providers Approach Uncertainty in Perinatal Palliative Care?

Perinatal palliative care is more complex and carries more uncertainty than palliative care for children or adults, and I think that this necessitates a distinctive approach. Acknowledging uncertainty is the first and most important step to addressing it, and communicating it openly to patients with honesty and compassion is the next step. The role of the perinatal

palliative care provider goes beyond that of “provider of information,” because assisting families with decision-making, planning, and then re-evaluating the decisions and plans when new information arises is where much of the work of perinatal palliative care is done. My observations, reflections, and research have led me to believe that neither non-directive counseling nor paternalism is the best approach. I recommend an approach somewhere in the middle that includes the family’s wishes, beliefs, and priorities and allows for involved guidance by the medical care provider. Shared decision making is often explained as a means of accomplishing this, but in a medical culture that values patient autonomy, and by extension, parental authority, true shared decision making is difficult to achieve. In perinatal palliative care, where the decisions are often high-stakes and the amount of uncertainty is overwhelming, I propose that medical providers target “accompaniment” as the goal, not shared decision making. Research and education in communication and decision-making, formulation of protocols and novel tools for care, and providing special services for families will all be important, but all those efforts will not truly make a difference unless there is a change in the paradigm of how care is provided.

My proposal to use accompaniment to address uncertainty in perinatal palliative care has its origins in a very different discipline. One of my undergraduate degrees is in theology, and in my study of theology, I was particularly interested in Latin American Liberation Theology. The

concept of accompaniment is a tenet of Liberation Theology, a school of theology that arose during the 1960s in Latin America. It is a humanistic theology that grew out of the oppression by governments and the Catholic Church and out of widespread poverty in Latin America. It was considered heretical and controversial from the 1960s to recent times, and many of its leaders, like Archbishop Oscar Romero of El Salvador, were assassinated by government forces. Two of the primary tenets of Liberation Theology are recognizing the humanity of Christ and promoting a preferential option for the poor.²¹ These are in stark contrast to the practices of the Catholic Church at the time. Another important element is the concept of accompaniment. Accompaniment involves companionship, listening, and “walking with” a person through his or her struggles. It promotes, even requires, empathy and understanding through connection and solidarity. When Latin American Liberation Theology was first developed, this meant living with and becoming one of the poor in order to serve them spiritually and socially, instead of maintaining a convenient distance to ensure physical, emotional, and spiritual comfort. This concept has already extended into health care. US anthropologist and physician Paul Farmer, cofounder of the World Health Organization (WHO) “Partners in Health,” has worked to create an “accompaniment model” of international aid and health care delivery that uses a model of working with the people on a grassroots level instead of the traditional function of aid worker and aid recipient.²² Farmer’s understanding of

Latin American Liberation Theology informs his work and now influences how the WHO provides international health aid.²³

When I think about how we should approach uncertainty in perinatal palliative care, each approach I have reviewed within the current vocabulary of medicine just does not seem like enough. The model for these relationships needs to be more than shared decision-making, more than family-centered care, and more than good communication. In the palliative care literature, the phrase ‘walking with the family’ is often used. Truly “walking with” someone through suffering and joy is more than creating a plan over several consultation meetings and following up with a few hospital visits. It requires engagement on a deeper level. Despite its theological origins, the term that describes the best approach, in my estimation, is ‘accompaniment medicine’.

Accompaniment Medicine

Accompaniment medicine differs from traditional medicine in its approach to the physician/patient relationship. While medical culture is moving towards a more egalitarian physician-patient relationship through concepts such as shared decision-making, there can still be a substantial distance between the patient and the physician. The physician is providing a service for the patient and the model is medical care provider and medical care recipient. A physician practicing accompaniment medicine approaches the relationship as the formation of a partnership with a sense

of humility that allows her to “walk with” the family through the process of perinatal palliative care instead of just assuming the role of an advisor. The medical provider is a steward of the process. The central features of accompaniment medicine include partnership with families, the medical provider approaching the physician-patient relationship with humility and a sense of solidarity with the family, and commitment to the process of perinatal palliative care. The medical provider must also be willing to work with the family and tailor care within the bounds of the family’s worldview. Solidarity requires a willingness to enter more fully into the lives of the family through discussion and active listening. The concepts of shared decision-making and family centered care promote many of the same ideals, but accompaniment medicine requires a deeper involvement and commitment from both the provider and the patient.

Accompaniment medicine addresses uncertainty in perinatal palliative care, not by abating it, but by fostering a relationship between the medical provider and the patient that provides a “safe space” to address it. The relationship encourages the provider and patient to discuss uncertainty honestly and to formulate a plan without fear of judgment. There will always be uncertainty in perinatal palliative care, but without fear of abandonment and within the security of a strong medical provider/patient relationship, it will seem more manageable for both parties.

The challenge is finding a way to do this in the medicine’s current culture focused on productivity, relative value unit (RVU) generation,

length of stay, and quality measures that do not necessarily measure quality. Convincing hospitals and physicians to prioritize something that is not reimbursable is difficult. When I discussed the best approach to starting a perinatal palliative care service at Wake Forest with Brian Carter, a neonatologist, palliative care physician, and bioethicist, he told me to “expect that nobody will pay you for it because it does not reimburse well, and therefore holds very little value to those who provide funding.” This observation from a neonatologist who is a pioneer in the field of perinatal palliative care calls out for a culture change. Culture changes do not usually occur overnight, they occur over time as people’s views change. Therefore, committing to practice accompaniment medicine is committing to practice counter-cultural medicine and transform thinking until the time comes when those who fund medicine recognize its worth.

Additionally, committing to practicing accompaniment medicine requires personal reflection and dedication from the providers. Learning, researching, clinical innovations, and training are all important, but nurses, advanced practice providers, physicians, social workers, and chaplains who care for families requiring perinatal palliative care must commit to acknowledging the human side of this kind of medicine and the struggles that both patients and their health care providers face. Providers will make a more personal and emotional connection with their patients and families, and therefore, provider self-care and awareness of emotional

needs are imperative. The risk of emotional burn-out may seem higher, but accompaniment medicine may actually assuage provider burn-out because of the higher quality of the provider/patient relationship and the sense of partnership that is created. The medical provider will benefit from this model as well as the patient. All of this will also require changes to medical education and more focus on the interpersonal and humanistic factors in medical practice. Aspects of accompaniment medicine could be beneficial to all areas of medical care, but it is a method of practice that not all providers may find comfortable, and that is OK.

I recognize that this concept integrates medicine, ethics, and theology, but I have also learned that the field of bioethics ideally integrates all of these things as well. It is important to clarify that while the concept of accompaniment derives from theology, the practice of accompaniment medicine does not require any specific religious belief or practice. I also realize that this concept could be the topic of a thesis or a book in itself, and I hope to develop this idea further in the future.

The accompaniment approach to perinatal palliative care will not remove the uncertainty associated with the care of these patients, but practicing accompaniment medicine will change the relationship between the physician and family. That relationship will foster honest discussion of uncertainty and provide a safe space within which the physician and family can address how to approach it. It is unreasonable to expect families to be able to internalize information about the potential death of

their child and develop a plan in the course of one or even two out-patient consult visits. Similarly, it is unrealistic to expect a family to change their goal of care from aggressive treatment to comfort care in the course of a few days, when they have been “fighting” for their child’s life for months. The presence of a perinatal palliative care team or provider who has developed a relationship with the family over time would afford the family a trusted source of support and information. The key to this relationship, however, is often time.

In conclusion, this practicum thesis has been a remarkable opportunity for me. It has broadened the scope of my clinical and ethical practice, it has encouraged me to think carefully about how best to approach the practice of perinatal palliative care, it has provided me with the tools to form a perinatal palliative care service, and it has given me a direction for my future academic career. I hope to enter the evolving dialogue as a neonatologist, bioethicist, and palliative care provider and to increase knowledge within the field while working to improve patient care.

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PAST GRANTS:

AAP Resident Research Grant	IL-1 β and Glucocorticoid Affects on α -Epithelium Sodium Channel Protein Expression in Murine Lung Epithelial Cells. Investigator, 2004-2005
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Journal articles

1. Isaac J, DiGeronimo RJ, Henson BM, Dixon P, **Bishop CE**, Seidner SR, Mustafa SB. Mechanical stretch regulates alpha-epithelial Na⁺ channel

expression in murine lung epithelial cells: Role of MAPK pathways. Am J of Resp and Crit Care Med, 2004

2. **Bishop CE**, Blanco CL, Burney K, Waite LL, Petershack JA. Necrotizing enterocolitis in the era of increasing donor breast milk use in premature infants. 2007 Jan. p. s288. (Journal of Investigative Medicine; vol. 55, no. 1)
3. Sherburne KK, **Bishop CE**, Henson B, Blanco CL. Donor Breast Milk, is it the same as Mother's Own Milk? An in Vitro Study on Lactoferrin Levels 2008 Jan. p. 475-476. (Journal of Investigative Medicine; vol. 56, no. 1).
4. **Bishop CE**, Blanco CL, Burney K, Petershack JA. Does the use of donor breast milk in very low birth weight infants decrease the risk of necrotizing enterocolitis? 2008 Jan. p. 475. (Journal of Investigative Medicine; vol. 56, no. 1)
5. **Bishop CE**, Vasquez MM, Petershack JA, Blanco CL. Pasteurized Donor Human Milk for VLBW Infants: The Effects on Necrotizing Enterocolitis and Related Factors. Journal of Neonatal-Perinatal Medicine 2010 Jun;3(2)

Abstracts/Scientific exhibits/Presentations at national meetings

Regional

- | | |
|------|---|
| 2007 | Necrotizing Enterocolitis in the Era of Increasing Donor Breast Milk use in Premature Infants
Southern Society for Pediatric Research, New Orleans, Oral Presentation |
| 2007 | Necrotizing Enterocolitis Risk Factors and Related Morbidities in Very Low Birth Weight Infants
Central Conference on Perinatal Research, Austin, Oral Presentation |
| 2007 | Necrotizing Enterocolitis in the Era of Increasing Donor Breast Milk use in Premature Infants
Mead Johnson Perinatal and Developmental Medicine Symposium, Marco Island, Poster Symposium |
| 2008 | Does the Use of Donor Breast Milk in Very Low Birth Weight Infants Decrease the Risk of Necrotizing Enterocolitis?
Southern Society for Pediatric Research, New Orleans, Oral Presentation |

National

- | | |
|------|---|
| 2005 | Dexamethasone Restores GCR and α -ENAC protein levels in IL-1 β exposed MLE-12 Cells.
American Academy of Pediatrics Meeting, Washington DC, Poster symposium |
| 2008 | The Introduction of Donor Breast Milk Was Not Associated With a Decreased Incidence of Necrotizing Enterocolitis in Very Low Birth Weight Infants
Society for Pediatric Research National Meeting, Hawaii, Poster Presentation |
| 2014 | A Behavioral Approach to Behavioral Equipoise. American Society for Bioethics and Humanities National Meeting, San Diego, Poster Presentation |

INVITED PRESENTATIONS:

- 2/12/2015 Ebola: Clinical and Ethical Considerations. At Home and Abroad Symposium Wake Forest University Center for Bioethics, Winston Salem, NC
- 2/25/2015 Neonatal and Perinatal Palliative Care. Wake Forest University School of Medicine Department of Obstetrics and Gynecology Grand Rounds Winston Salem, NC
- 3/15/2015 Jaundice. Northwest AHEC, North Carolina Lactation Educator Training Program Forsyth Medical Center Winston Salem, NC
- 5/1/2015 Can We Do Nothing Better? Perinatal Palliative Care and the Changing Approach to Care of Infants with Trisomy 18. Wake Forest University College of Medicine Department of Pediatrics Grand Rounds Winston Salem, NC

GRADUATE STUDENTS/RESIDENTS/FELLOWS ADVISED:

- 2014-2015 Meghan Hall, Clinical Site Advisor for Independent and Thesis Study in the Brenner Children's Hospital NICU