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End of Life Decisions in the NICU: The Value of New Life and the Degree to Which Religion Plays a Role in These Ethical Decisions

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**END OF LIFE DECISIONS IN THE NICU: THE VALUE OF NEW LIFE AND
THE DEGREE TO WHICH RELIGION PLAYS A ROLE IN THESE ETHICAL
DECISIONS**

**BY
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Submitted in Partial Fulfillment
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ABSTRACT

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This thesis explored the role of religion as a social variable affecting end of life decisions in the NICU. The existing literature has studied many factors that are a part of the tough ethical decisions made in the NICU with some reference to religion. However, there is not adequate attention given to religion specifically.

In order to further expand upon religion, various members composing the medical teams of two hospitals were interviewed. The interviewees included neonatologists, nurses, chaplains, and a social worker. This thesis found that religion is a variable that matters more than the existing literature has claimed. Often, it is the undercurrent of religion, or a religious persuasion, that does not get put in the forefront but most definitely has strong and undeniable effects. It would be most effective to conduct further research on this topic, notably the concept of miracle seeking parents. Also, adding interviews with parents would be an integral component, which analyzes religion from the perspective of the parents as opposed to solely the medical team.

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CHAPTER 1: INTRODUCTION

The neonatal intensive care unit is the central location for neonatology and a subspecialty of pediatrics, focusing on caring for critically ill newborn babies (Cadge and Caitlin 2006). People have been saving babies for a long period of time, but neonatology as a field has only emerged in the mid 1960's. Since this time, the NICU has been the focus of a variety of studies. In my eyes, it is one of the most fascinating and interesting places both in and out of medicine. Over the past three years, I have been inside multiple NICUs to gain insight and wisdom on the inner workings of such an important yet controversial unit. It is here where critically ill or premature newborns spend time until they are healthy enough to be cared for by their parents alone. The majority of my time was spent shadowing neonatologists as they did their rounds, discussing each baby extensively and the plan for care moving forward. One reoccurring theme that connected all of the NICUs across different hospitals was that there were always notable cases I was told about certain newborns. There have been numerous stories that were considered particularly difficult and worth mentioning to someone hopeful and eager to enter the profession in the future. These cases were ethically challenging and religion often played a role, whether it was the religion of a member of the medical team or the parents.

There is something to be said about new life that draws people's attentions and gets everyone talking. New life is unique in that it has the greatest amount of potential. This makes it more likely for physicians and families to fight for a newborn to live, where they may not have made such a choice with an older patient. Newborns are also unique among patients, as they cannot voice their opinion or wishes with regards to their

care and the choices made about their health. As a result, the NICU is an environment where serious ethical considerations come into play when decisions need to be made.

With the increase in medical technology that has occurred over the past 50 years, physicians in the NICU are now able to save lives where in the past technology would have prevented this option. However, these methods for saving or keeping a newborn alive can often conflict with existing religious views on life; in particular, the value of new life. How do these decisions get made, and who gets to make them? How important of a variable is religion in deciding the fate of a newborn too young to contribute any answers or input in their own future?

The NICU is an incredible unit that can be studied from a sociological perspective, as it is composed of many social dimensions. In such an ethically charged environment, lines are blurred, as what is “right” and “wrong” becomes a matter of debate. Religion is one variable that is often an important determinant in decisions that are made. There is uncertainty not only regarding who has a right to make these decisions, but also the degree to which religion should influence them. Both the religion of the family and the medical team are relevant and have their own unique effects on the circumstances surrounding the patient. This project examined religion and its potential effects on decisions made in the NICU when an infant is nearing the end of life. The literature will shed light on what has been proposed thus far with regards to these complex decisions, expanding upon where religion comes in as a variable, and look at to what degree its influence is seen in the end results of the choices that are made.

CHAPTER 2: LITERATURE REVIEW

Before going into the details of my research, it is important to explain what is known so far about this topic. The first section of this chapter will discuss the ideas of ethics and its relevance to NICU decisions. The second section provides an introduction to religion as a variable in making these ethical decisions, starting with how religion is viewed in sociology and then showing how it can be applied to medical decision-making in the NICU. The third and fourth sections look at the two main stakeholders, the medical team followed by the family of the newborn, and the challenges faced by both. This brings the entire body of literature full circle, as the overall basis of ethics in the NICU is based upon balancing the rights and wishes of medical team and the patient (or in this case, the family of the patient).

A. The Ethics of NICU Decisions

Decisions made in the NICU are never simple or easy; there are different ethical perspectives that all illustrate seemingly legitimate answers to the most difficult questions. Often, the family and health care providers will have opposing ideas as to what is in the best interest of the newborn (Stutts and Schloemann 2002). Ethics tells us that health care professionals have a commitment to beneficence and nonmaleficence, which often conflict with the principle of autonomy, which guides a family in the care of their newborn. Beneficence is the principle of acting to do good for the patient (Veatch 2003), and nonmaleficence is the principle of not intentionally inflicting harm (Purdy and Wadhvani 2006). On the other hand, with the family autonomy is an important aspect of

ethics that should always be preserved. These two components represent a delicate balance that is the origin of nearly all of the ethical dilemmas presented in the NICU.

Typically, the process by which decisions are made regarding newborns varies between units, but overall will require a number of carefully considered steps. Conway and Mooney-Harmon (2004) outline a model entitled the “Seven-Step Path to Better Decisions” which is a clear plan to approach an ethical dilemma and ultimately seek resolution with a decision. The first step is to stop and think, as thinking ahead is necessary to prepare and avoid poor choices for the future. The second step is to clarify both short-term and long-term goals. Third is to determine the facts, so that adequate information can support the right choice. Next, developing options allows for potential to broaden perspectives. Following this step is a careful consideration of the consequences of choosing those options. Conway and Mooney-Harmon’s six pillars of character are helpful here, which are trustworthiness, respect, responsibility, fairness, caring, and citizenship. If an action violates any of these core ethical principles, it is most likely unethical and should be eliminated. Next is to choose, where a decision is actually made. The last step is to monitor and modify, as decisions may need updating over time. This is one example of many models that exist.

A number of studies have been done both with and outside of the United States that examine various aspects of ethics in the NICU. Cross-cultural research is useful, as it allows for a more comprehensive analysis of patterns in ethics. Verhagen et al. (2010) define more explicitly the process of end-of-life decision-making in the United States, Canada, and the Netherlands, finding that the causes of deaths differ between countries. Another study recognizes the variance in decision-making practices by country, and

focuses on one hospital in Switzerland and the circumstances surrounding neonatal deaths (Berger and Hofer 2009). The researchers acknowledge there is an increase in the practice of withdrawing life-sustaining therapies from infants whose situations are categorized as futile cases. Also, parents had a strong presence in the NICU and their involvement was generally consistent throughout the process. Miljeteig et al. (2009) conducted a similar study in an Indian NICU, where they expand upon the understanding that there are certain external factors, which are not purely clinical, that influence decisions about treatment. These include complex, interrelated socioeconomic reasons. Also, providers were sensitive to local, culturally established intrafamilial dynamics. Ultimately, there is a good deal of information that has been gathered, even outside of the United States, that acknowledges the ethical difficulties involved in a NICU setting.

In discussing the balance that exists ethically between the medical team and parents, McHaffie et al. (2001) has conducted empirical research that illuminates the importance of open discussion and involvement by both of these stakeholders. This study was composed of face-to-face interviews of neonatologists as well as parent interviews in six large NICUs throughout Scotland. The question investigated, which is the basis of the ethics discussion, is who really gets to make the decisions on behalf of the newborns when it comes to treatment withdrawal. Medical ethicists agree that it is ideal for both the medical team and parents to have input. McHaffie's research, however, discovered that it was instead more complex than this. What was found was that the actual and ultimate decision is going to be made by the medical team, even though 56% of parents perceived the ultimate decision was theirs. So it is clear that the shared-decision making process, or dual involvement of the medical team and parents, is not acted out in all NICUS. Instead,

the perceptions of decision-making differ between the medical team and parents.

Decisions made specifically about treatment withdrawal are acknowledged here as some of the most difficult; regardless, judgments have to be made to learn from all the experiences and make progress in a quickly advancing field.

Ethics has really changed for medical professionals over the past 50 years. Medical technology has advanced considerably; now doctors can “play God” through drugs, machines, and other types of interventions (Lantos and Meadow 2006). Although they are able to use these new technologies to keep the patient alive in any situation, ethics would guide a medical team as to what should be done instead. More recently, physicians have been making efforts to avoid “futile treatments” (Purdy 2006). This may be seen as an effort to create an environment where decisions are fair, and treatments are as logical and sensible as possible. Again, ethics reveals that this idea of fair is subject to disagreements due to natural subjectivities that intervene in the treatment process; in other words, futility means different things to different people in certain situations. A case may be considered futile if treatment is merely keeping a patient alive without improving the health outcome, or treatment, which does not guarantee a meaningful quality of life.

The medical team has a number of components, including physicians, nurses, and residents. Anspach (1987) expands upon the differences between members of the medical team in terms of their roles in making decisions, and the fact that they all bring something uniquely different to the table. Due to their varying experiences in the NICU, their views of infant prognoses will naturally be different as their backgrounds and contexts are not the same.

Principles of ethics also come into play for the family of a critically ill newborn. With growing attention to the importance of autonomy and consent, parents feel strongly that they are the ones who must always fight for their child. Manzar et al. (2005) stress the dilemma presented when the care given to infants is categorized as “futile care”. Though it was not found to have a huge impact on cost containment, it did prove to be ethically challenging to continue care in such scenarios. On one side, parents can express their willingness to move forward with aggressive care to treat their newborn. However, when it comes time to accept a devastating prognosis, parents are often in denial and face many internal issues as a result of a situation, the life of their newborn, which becomes out of their hands (Einarsdottir 2009). Veatch (2003) stresses that with a never-competent patient, such as a newborn, the parents are the next of kin and if they are willing, should speak on behalf of that newborn unless they prove themselves to not be competent themselves. This would mean that parents may be foolish, malicious, or not serving the best interest of the patient. Ultimately, situations become ethically complex when what competent parents believe is in the best interest of their newborn is not what the medical team has recommended.

Conway and Moloney-Harmon (2004) show how a true ethical dilemma results, when stakeholders disagree on the fate of a newborn. This involves both the medical team and family directly, and such dilemmas are both stressful and emotional for all who are involved. Even with numerous ethics consults, there are going to be questions that are left unanswered or unclear due to the nature of the difficulties in even defining what ethics is, as no single individual has the right to decide what “should” be done since it will never be a strictly objective claim. In the face of such a dilemma, Conway and

Moloney-Harmon (2004) describe in detail a specific case of triplets to shed light on ethical issues in the NICU. One triplet specifically was born with anomalies that complicated the mother's requests for treatments, which were mainly based on her religious faith. Over the course of a few weeks, there were several meetings with the family and the ethics committee, as the mother used religion to explain how she wanted her baby to be allowed to die, but the medical team said it was not time to discontinue treatment. There were attempts to get the infant to a state where it was possible for discharge to occur, but surgeons disagreed and eventually the baby was transferred to a hospital willing to do the specific procedure necessary to be brought home. However, she had a significant respiratory event and had expired after a short life filled with many ethical dilemmas. Using what was learned from this case, the researchers propose five different approaches developed by philosophers to deal with these kinds of issues. These approaches are the utilitarian, rights, fairness of justice, common good, and virtue approach; combinations are often used in addressing ethical issues.

A discussion follows consisting of common but specific dilemmas seen in NICUs, which include congenital anomalies, borderline viability, and postnatal complications. Last, a protocol is proposed for ethical dilemmas unique for NICU infants. The protocol lays out steps in the following order: recognize that a dilemma exists or is fast approaching, educate the staff on their personal responsibilities, develop a "Parents' Bill of Rights" distinct from that for the patient, establish an ethics committee of members who are expert in infant ethical issues, provide support for both the family and staff, and establish the protocol and place it where everyone is able to have access to it. Overall, this study is comprehensive in its analysis of ethical dilemmas in the NICU, using both a

specific case and universal guidelines for dealing with such scenarios when they arise. Also, it acts as an instructive example of the NICU's tough and complex environment.

What makes these ethical decisions stand out is the aspect that is purely sociological; namely, that life and death decisions are complicated by the fact that physician's decisions, and family's decisions as well, are only partially objective (Anspach 1987). In other words, there is a social context and there are key variables that may have an important place in making decisions. In an area where it is already incredibly challenging to deduce sound solutions to problems as they arise, the ethics that support what goes on are even more actively debated and reconsidered. The NICU remains an experimental unit, representing a field that is constantly developing yet has the ability to set the stage for remarkable debates and inquiries.

B. Religion as a Variable: Christianity, Judaism, and Islam

Religion is claimed to have important social functions, and is composed of a number of attributes (Southwold 1978). These include the relationship between men and a godlike being, concern with the sacred, ideas of salvation, ritual practice, a body of scriptures, priesthood, association with a moral community and similar group, beliefs held on the basis of faith, an ethical code supported by such beliefs, and sanctions on infringements of the code. What is most notable here is the ethical code and beliefs that are not restricted by ideas of logic. So within religion there is an ethical code or system of some kind, which guides the way in which followers of that religion believe things to be ethical or moral. A connection can now be seen between religion and its function in having the potential to alter perspectives on ethics and issues that have ethical

components. For many people, religion can therefore be used to explain things that might not be explicitly described by science or any kind of concrete, widely accepted knowledge. Religion is going to have a play, and potentially a very strong one, in how one thinks about ethics and also provides a definition for life.

1. Sociology of Religion

There are a number of sociological perspectives that examine religion and its important role in society. Weber, Marx, and Durkheim are three notable sociologists who have significantly contributed to sociology and ideas have influenced the discipline as a whole. Weber (1993) sees variation in the influence of ideas on action, and the concept of ideas guiding action. He believes that the effects of religion on behavior may differ by both culture and classes. In addition, religion can provide the tools for stability as well as social change. Marx (1904) criticizes religion as preventing man from being able to have a grasp on his own reality. He also explains, though, that the alienation religion describes between humans and god represents the alienation individuals feel from their own existence. More so than Marx, Durkheim (1912) sees religion as having a close relationship to power in society, and even influencing the direction of society and having true social functionality. He aims to show how religion can stabilize society and unify members of the community. All of these sociologists generally see a declining influence of religion in a society as it modernizes and conflicts with many of their rational ideas.

Even within Marx's beliefs, there is no denial of the strong presence of religion in society and the fact that it is a determinant of the way people react and make decisions. Reminiscent of Weber's ideals, religion is known to have an important function in

helping people deal with the difficulties of life. Whenever there is something that humans don't understand, religion can be expected to come in and form the basis of understanding or justification. An understanding of these views on the basis of sociology and religion from Weber, Marx, and Durkheim can be applicable to the present day conflicts and how religion functions within society. Berger (1969) sees religion as a tool for legitimizing opinions and actions in the world. This means religion offers a kind of knowledge that explains or interprets events. So the canopy is an image he creates, and religion is that buffer between humans and certain things in life that cause them distress and trouble.

In ethics, both religious and secular ideas influence decisions that are made in the NICU. Religion is a variable that is able to have a dual influence on both members of the medical team and family. Medical ethics frequently uses religious claims, history, and tradition to support their arguments and actions (Sugarman and Sulmasy 2010). Therefore, it is worth considering religion in an area where attention to ethics is so stressed. More specifically, the extent to which religion affects both the recommendations that members of the medical team make to the family and beliefs that the parents have on behalf of their newborn. Caitlin et al. (2001) conducted a survey both showing that spirituality and religiosity exist in the NICU and providing the framework for how providers and families approach issues. They realize that this approach is not purely secular, but instead has religious undercurrents. Within this study, it was found that more than 80% of healthcare providers said they use religion or spirituality to privately pray for infants at some point during treatment. This emphasizes the importance of religion as well as the more qualitative aspects of how different members of the medical team

construct their own meanings for events in the NICU (Cadge and Caitlin 2006). Many people find it easy to describe their world through religion, including both members of the medical team and the patient's family.

One specific aspect of all religions that is a key predictor of their effect on NICU decisions is views on life, or how a god-like being relates to that life. Different religions have their own ideas of how they view life and death decisions. Within each religion, there is a range and degree to which those followers are religious, which has to be taken into consideration as well. The discussion below focuses on only distinctive contributions from religions traditions to end of life care, as it would be impossible to discuss all aspects of every religious faith. The major religions that will be examined include Christianity, Judaism, and Islam. After discussing the relevant beliefs of each religion, I will review a variety of studies that have explored how these specific beliefs have played a role in the ethical decision-making process.

2. Christianity

Christianity is an extremely complex monotheistic religion, consisting of Catholicism, Protestantism, and Orthodox faiths (Rahner and Dych 1982). Most followers believe that there is one holy, true, and omnipresent God who is powerful and all knowing. Christians use and practice the Bible as the Word of God, and believe in both heaven and hell after death. In medicine, it is believed that there is a duty to preserve our life and use it for the glory of God, but it is not absolute (McCabe 2001). The use of life-sustaining technology, for example, must be judged in the light of the meaning of life, suffering, and death. One branch of Christianity McCabe examined in particular is

Catholicism, which holds that the ideas of faith, human reason, and individual conscious should work together to interpret the word of God (Clarfield 2003). This variant of Christianity is fundamentally rooted in the moral tradition of the ordinary versus extraordinary means distinction (Clark 2007). This is not a new concept, and refers to the idea that when caring for a patient, only ordinary means of treatment are appropriate. In a NICU setting, this means that keeping an infant alive through ordinary means is appropriate, and not extraordinary means (McCabe 2001). Ordinary means are all which offer hope of benefit and do not involve excessive pain or inconvenience to an individual. Extraordinary methods, on the contrary, are all which cannot be used without excessive pain or inconvenience, or would not offer a reasonable hope of benefit. So, Catholics would consider medical intervention to be morally mandatory if it was judged ordinary; if extraordinary, it is morally optional. Hospitals are called to embrace Christ's healing mission, so they must only offer treatments to patients that will be beneficial to them. This gives physicians the ethical justification to refuse medical treatments if they consider them burdensome or medically futile for the patient (McCabe 2001). The recognition is key here, though, that the distinction between ordinary and extraordinary means is often extremely subjective and ambiguous. Typically, this means there will be a reliance on one viewpoint as opposed to a comprehensive decision on what the patient would actually want. The skewed nature of these views appears inevitable, as what could be considered "excessive pain" means different things to different people.

Jehovah's Witnesses, though they claim to be a specific group of Protestants, have a set of beliefs that have made them controversial and the source of many ethical issues. They have beliefs that are inconsistent with many other Christians as they believe that

God is a single person who is not all knowing or powerful; however they still consider themselves to be serving the true and living God (Macklin 1988). Unlike many religious groups, Jehovah's Witnesses are very specific in their practice and rules, especially with regards to medical treatment. These members have strong religious convictions against accepting whole blood, red or white blood cells, and platelets, and will only accept non-blood replacement fluids (Dixon and Smalley 1981). They believe that the Bible tells them to abstain from blood, which becomes a very significant claim at the end of life. Murray (1980) provides different cases of Jehovah's Witnesses refusing treatment and the way ethics committees handle such instances. What complicates these issues is the addition of a fetus or newborn, as their moral status is questioned. If the adult Jehovah's Witness refuses treatment for their unborn or newly born child, there were major discrepancies on what should be done. With a specific case of a newborn, there was final agreement that if their life or health was severely threatened, and parents did not wish to continue recommended medical treatment, the hospital should seek court approval of the transfusion. Committee members who struggled with this were considering patient autonomy, religiously based belief in the sacredness of the individual, political consequences, and respect for legal tradition. Regardless, all members agreed that cases should be taken on an individual basis and that when a competent Jehovah's Witness is refusing blood for themselves and not another fetus or newborn, their decision should always be respected.

3. Judaism

Judaism is a monotheistic religion, centered on the concept of Jewish Law, which literally translates to “the way” (Clarfield 2003). Reform, Conservative, and Orthodox, the three main branches, only differ in the degree of observance and essentially have the same system of law and belief. This religion holds some very strong fundamental convictions (Dorff 2005). Those specifically relevant to end of life include that the body belongs to God, human beings have the permission and obligation to heal, and that human beings are mortal. In Judaism, the physician has strong obligations with respect to the duty to heal. The patient, on the other hand, has less autonomy than in secular ethics and is encouraged to follow medical advice (Clarfield 2003). Sanctity of life is a paramount principle here, and although illness and death are considered natural, there is a general duty to make efforts to save a life whenever possible. Weiner’s (2009) research observed medical professionals and held interviews in an Israeli NICU. What is noted from the beginning is the fact that Jewish and Israeli laws confer personhood at birth, showing how religion has a role here in establishing moral status. The focus is on the way subjectivities are socially produced by moral practices, specifically of the neonatal intensivists. Weiner found that at times this fact is not taken into consideration, and the question of “quality of life” overwhelms any thoughts regarding moral status. Dorff (2005) looked at Judaism’s positions on a number of medical subjects. With respect to death and dying, Jews believe that every person’s body belongs to God. Therefore, like Catholicism, Judaism asserts that we should seek to cure and may not do anything to hasten death, but at the same time should not prolong the dying process. Also, decisions on medical questions have to have the patient’s benefit as the fundamental goal.

4. Islam

Islam is a monotheistic religion whose followers look to the Qur'an as their holy text (Gatrad et al. 2008). The Qur'an asserts life is wholly and altogether an examination, or test. Muslims have duties toward the Creator and fellow human beings, and there is reciprocity of rights and duties that exists with Muslims and all around them (Clarfield 2003). This means that even though Muslims believe all healing comes from God, they may seek medical attention when they feel appropriate. Traditional Muslims, when discussing death, believe destiny is in God's hands or predetermined. Even encouraging patients to discuss their imminent death could be viewed as wrong (Stutts and Schloemann 2002). One principle that is of utmost importance medically is sanctity of life, that every moment in an individual's life is precious. Again, like the other monotheistic religions, there is recognition that death is inevitable and natural in human existence. Treatment does not necessarily have to be provided if it merely prolongs the final stages of an illness as opposed to treating a condition. There is a strong emphasis on the individual patient, and beneficence and nonmaleficence are major goals.

Gatrad et al. (2008) provide a Muslim perspective to end-of-life issues in the NICU. This perspective is unique, as the loss of a child, according to Islam, does not have to be a completely negative experience. Instead, it can represent a time to reflect on the meaning of life, and social and spiritual relationships that exist. Muslims believe that sharing tough decisions with families can aid them during difficult times, as these are people they trust and look to for guidance. As much as the family can provide support, they can also negatively interact with the process when many relatives wish to get involved with these discussions and instill their views on the medical team. Veatch

(2003) describes a case in which Muslim parents, who firmly believed in the power of Allah, insisted that Allah would intervene if it were his will and that the physicians must keep their son alive to give Allah that opportunity. Such a dilemma is made even more difficult when religious beliefs get brought up and are the primary basis by which the parents are outwardly expressing their subjective wishes, which are opposing the medical team's recommendations.

5. Religion in Medicine

Religion has been shown to have an undeniable effect on care outcomes in medicine (King et al. 1994). Results showed that better obstetric outcome was associated with Christians and other religions as opposed to those with no religious preference. Though it is limited by the use of only one site, this research draws attention to religion and its relationship to medicine. List (2005) explores the faith-health connection and concept of religion and spirituality pervading health and medicine. Donohue et al. (2010) conducts a study using an internet-based survey, which evaluated the potential for religion to have a strong but unrecognized impact on care in the NICU. They found that religion cannot definitively be linked to all decisions made by neonatologists. However, it was found that religion does play a role and is a large component of the decision-making process for some physicians. Barrett (2001) stresses the importance of caregivers to be "culturally competent" as religion is considered to be a legitimate cultural characteristic worthy of consideration in medicine. The religions previously described all have belief systems that could have a significant effect on ideas and perspectives regarding the NICU and treatment for newborns.

Though there are many things that religions share, there are also major differing aspects that set them apart. In order to make the best possible decisions, it is vital for the religions of both the medical professionals and patient to be understood and respected in an increasingly multicultural society (Clarfield 2003). Reaching agreement would require each stakeholder to understand the impact of spirituality on coping or decision-making strategies. So in the end it is crucial to have a grasp on these key religious rituals and social norms that undoubtedly exist, and also know how to integrate them into the end-of-life decision making process.

C. The Medical Team and the Challenges They Face

Medical professionals face serious challenges in caring for infants in the NICU. Such challenges broadly can be categorized into clinical, purely ethical, and more complex, subjective challenges. When all these components are taken as a whole in the process of making decisions, there is a multitude of considerations that often overwhelm even the most experienced professionals.

1. Clinical Challenges

Clinical innovation and intervention has changed NICU medicine radically compared to where it was decades ago (Lantos 2006). Technology has progressed at a rapid pace, making it possible to sustain life when years ago it would have never even been contemplated. In fact, concerns of over-treatment now exist (Cadge and Catlin 2006). However, when dealing with newborns, their inability to contribute to the process means it is up to the medical team to use appropriate treatments with no verbal input from

the patient. Instead, they have only biased cues or danger signs which may be deduced upon examination, such as refusal to feed, drowsiness, fever, rapid breathing, jaundice, and abdominal distension (Kavita et al. 2010). Miljeteig (2009) classifies the reasons and ways in which providers decide to support treatment. These classifications are clinical, protective, structural, procedural, compassionate, formal, and indirect. Clinically, a large concern is the risk for disability later on in life. “Intact survival” is defined as the absence of neurologic disability as well as costly treatment in the future. These considerations become more complex with increasing resource constraints, as was seen in the Indian NICU which Miljeteig performed his study. Verhagen et al. (2007) conducted a study to examine the considerations of physicians in a less developed health care setting. The findings first emphasized the importance of quality of life as a predictor of continuing treatment. However, what is notable is the fact that in a less developed setting, where resources are scarce, decisions made by physicians were not influenced by legal or economic considerations. Instead, the decision-making process and considerations were similar to more developed health care settings.

2. Ethical Challenges

In spite of all the clinical advancements that have taken place, the job of medical professionals is never as easy or simple as using new technologies or techniques for all infants that enter the unit. This is where ethical challenges come into play, and their role is an important and ever-present one in the NICU. Here, the evolution of ethical analysis has almost paralleled the evolution of technology and scientific knowledge (Lantos 2006). Lantos describes the first meeting in 1968 where doctors debated what are now

considered ethical dilemmas, but was not yet thought to be ethics at the time. At this meeting were two philosophers, Joseph Fletcher and Robert Veatch. They represented the two opposing positions that could be taken by doctors. On one hand, Fletcher argued for a principle-based utilitarian consistency by which the end might justify the means. In other words, the real decision to be made is whether the life of the infant was worth preserving; if not, practitioners should have the moral courage to both acknowledge and act accordingly. Veatch challenged this and instead claimed that the parents were the ones who should have the right to make decisions. This sets the stage for questions regarding the degree to which physicians should have control over decisions as well as how they decide what is in the best interest of the patient. McHaffie (2001) conducts a series of interviews in six large NICUs and investigates medical authority; specifically, how vital the experience and authority of the medical team are in the process of making decisions. It was found that the medical team does typically have the final say in the decisions that are made; however, the study illuminates the importance of understanding the reality that the parents' input is a necessary component as well. Ultimately, from the perspective of a physician, there is a balance that exists ethically between helping an infant and withholding a treatment or procedure due to futility (Manzar et al. 2005). So, while having the ability to fight for an infant, there is also a time when there may be a realization that enough medical intervention has taken place, and nothing more can effectively be done to help the infant. Bosk (2004) discussed what happens when medical professionals actually wind up making the wrong decision, and the consequences and aftereffects that result. Ultimately, medical failure has been found to have two meanings. First, there is a failure to apply theoretic knowledge to professional action. Second, there

is a failure to follow codes of conduct regarding professional action, which can be considered moral failure. The moral errors stemming from moral failure were considered more serious and found to be more conspicuous than technical errors, as well as arise a stronger response. This is due mainly to the fact that professionals rest on a primarily moral foundation, despite the fact that medicine is becoming more specialized and technologically advanced.

3. Additional Challenges

Looking away from the more objective ideas presented, there are also complex, subjective, and personal types of challenges and stresses that exist. Cadge and Catlin (2006) hypothesized that there might be specific patterns by which health care providers make sense and construct meaning from their work. They found that there was a range of religious, spiritual, existential, and other meaning-making systems for how these individuals understand difficult scenarios and define their own purpose and role in carrying out this work. In fact, caregivers have not only recognized the presence of religion and spirituality in the NICU, but often pray themselves for the babies as well (Cadge 2006). So there is a spiritual and religious framework, which has been found to aid in providing better support and care in some of the most desperate situations. Rebagliato et al. (2000) studied physicians' attitudes in 10 European countries, showing variation in opinion and beliefs. Specifically, it was found that some physicians were more likely to agree with statements regarding preserving life at any cost, whereas other physicians were more likely to agree with statements that took quality of life into account. In addition, being female, having no children, being Protestant, not having

religious background, considering religion as not important, and working in a NICU with many low-birth-weight newborns were associated with views which considered quality of life more than other physician qualities.

Many believe that all of the challenges rest predominantly on the physician, who feels the greatest effects and pressures. However, physicians are not the only members of the medical team who are affected and have a distinctive role in the decision-making process. There are a number of personal challenges and pressures faced by NICU nurses, who are often at the front line of a variety of ethical issues while treating critically ill infants. Cavaliere (2010) looked more closely at the problem of moral distress that is often not recognized by other members of the medical team. This descriptive study shed light on the concept, frequency, and intensity of moral distress, which is a significant problem for nurses. These NICU nurses confront ethically and morally challenging situations regularly, yet this fact is often overlooked. What was found showed there was large variation between nurses individual experiences, but that moral distress does exist and is an issue worthy of attention. Chambliss (1996) expands on the frustration and disappointments that many nurses feel and the moral premises that explain these feelings. He explains that nurses are encouraged, simultaneously, to be a “caring person, a committed professional, and loyal subordinate”. These three components of their role frequently and naturally conflict with each other. The reality of life for nurses is one of high demands and often too little recognition for the amount of stress they must endure on a daily basis. Physicians are frequently viewed as the authoritative, all-knowing figures in medicine, so the role of nurses should not be understated, as they are a vital part of the medical team. All members of the medical team bring something uniquely

different to the table, and all are going to have opinions that should be respected and considered in establishing a strong NICU that makes fair ethical decisions.

D. Families and the Challenges They Face

Families, more specifically parents, have many considerations and pressures when their infant is in the NICU. These can be categorized in the same way as medical professionals, into clinical, purely ethical, and more complex, subjective challenges. However, they are not defined equally and affect parents and families in much different ways than members of the medical team.

1. Clinical Challenges

Parents of the patient are going to have their own preferences and often will face a choice between either continuing and withholding or withdrawing treatment (Lantos 2006). There are many aspects of this that are going to be objective and scientific. If a negative health outcome, such as a disability or disease, is debilitating to the point where quality of life is going to be compromised to a certain degree, then the choice may be made to stop fighting. More often than not, however, most parents choose treatment over non-treatment. Although parents do not have the same background or medical expertise to be making clinical recommendations, with the exception of parents who work in the NICU, they possess a special kind of knowledge, simply due to the fact that they are the parents of this sick infant.

McHaffie et al. (2001) carried out a project to expand upon the struggles parents face in the NICU. Both the medical and nursing staff as well as parents were interviewed

through in-depth interviews. The results show that while there is agreement that parents should be involved in treatment decisions, there is dispute over who should have the final decision. While many doctors and nurses consider that responsibility too overwhelming for families, the majority of parents do not agree and would like to make the final decision themselves. There is also description of the variation in experience and authority that parents bring to the decision making process. With experience comes a lot of personal suffering, and parents acknowledge this fact. At the same time, there is not always an increased understanding that results from this experience. Therefore parental autonomy is not an illusion, but parents do have to rely on the medical team for facts, and a mutual respect must exist while making decisions. Pinch (1990) described the views of five families on ethical decision-making in the NICU. These families were chosen due to their varying characteristics in relation to age, religion, sex, ethnic origin, marital status, and socioeconomic level. There was not an indication as to how these variables may affect parental experience, but it was recognized that families were purposively chosen to represent these differing characteristics. In depth, qualitative results supported the idea that parents experience an overwhelming amount of stress when they have a child admitted and fighting for their life in the NICU, and these experiences have a formidable impact on parents and families.

2. Ethical Challenges

In examining the ethical challenges, autonomy is the main, most visible moral principle that is relevant for parents. Autonomy holds that one has a duty to respect the self-determined choices of autonomous individuals (Veatch 2003). Therefore, it is

assumed that these individuals would have to be considered independent and competent by members of the medical team for autonomy to be respected. During discussion of newborns in the NICU, these patients do not have the ability to voice their own concerns, wishes, or demands, so the parents are the surrogates so long as they themselves are deemed competent. Veatch takes a strong stance at the first real ethics meeting in 1968, where he made a radical claim defending the autonomy of parents with regard to decisions about end of life care for their babies (Lantos 2006). From this point forward, growing attention to autonomy remained a part of nearly all ethical discussions.

Stutts and Schloemann (2002) present a neonatal case study highlighting the role of family support in the care for Baby S. The study addresses the extent to which parental autonomy should influence treatment decisions. The fact that there was a large degree of uncertainty surrounding Baby S's long-term prognosis and quality of life only added to the complications and differing ideas between the medical team and patient's family. Findings have shown the existence of strong medical, legal, and moral precedents for recognizing that parents should be the ones making choices on behalf of their infants, and courts have supported this to a large extent due to the assumption that parents will try to act in the best interest of their child. Courts have ruled that if there is disagreement between parents, there should be support for the parent who is in favor of life. The medical community, on the other hand, is more neutral with regards to parental autonomy. Conway (2004) also acknowledges family choice as a factor requiring balance in the NICU as well as autonomy as a key principle.

3. Additional Challenges

Parents face many complex, subjective challenges that often involve countless variables. This is natural when recognizing the relationship that exists between parents and their child. The entire decision-making process can be influenced by personal values, past experiences, culture, and spirituality (Stutts and Schloemann (2002). Williams et al. (2009) constructed a parent-derived questionnaire to measure end-of-life care after withdrawal of life-sustaining treatment to better assess the practice of withdrawing treatment on the basis of experiences of parents. It shows that health care workers are concerned about how to support parents, and wish to do this effectively. The study found that parents are generally well supported through the process. So, though they are not purely clinical and objective in nature, the alternative challenges faced by parents are valuable and taken into consideration. Catlin et al. (2001) designed an anonymous questionnaire to see if spiritual distress appeared in NICU settings. Results supported the fact that there exists a strong undercurrent of spirituality and religiosity in the NICU, and highlighted the strength of sacred themes in a secular setting.

Haward et al. (2008) revealed an aspect of this undercurrent of spirituality and religiosity through an analysis of how information framing affects decisions regarding infants, specifically resuscitation. Message framing can be defined as subtle aspects of communication, specifically concentrating on the information transferred to the parents from the physician. There is an understanding and acceptance that the information transferred should ideally be without bias to assure parental choice is not altered in any way. A confidential survey was administered via the internet to parents to explore possible factors associated with these difficult treatment decisions. Religion was a main focus of the survey, and results proved religiousness modifies the effect of framing on

resuscitation decisions. Participants who were not highly religious were significantly more likely to be influenced to opt for resuscitation by a positive frame compared to participants who were highly religious. So, framing has a significant effect on resuscitation decisions and the effect was modified by religiousness. One possible reason is the fact that framing may have a greater impact on people whose beliefs are more ambiguous; on the other hand, people with predetermined preferences are less likely to conceptualize the problem as a choice and therefore less susceptible to framing. Overall, there is acknowledgement that there are biases, such as religion, that affect decision-making and present challenges to parents, and efforts should always be made to avoid letting biases alter judgments.

Einarsdottir (2009) examined the views of parents in the only NICU in Iceland, shedding light on both their experiences and concerns. Parents were interviewed and spoke openly about their experiences. There was agreement that there is an inseparable bond between a child and their parents that gives them the strength to continue fighting, even in unfavorable situations. These decisions were acknowledged to be even more difficult for children than the elderly. They expressed concerns over communication and its importance during hard times. In addition, there was a discussion of how feelings of guilt or repentance could cloud judgments, but completely omitting parents from decisions was not the answer. In the end, a fundamental issue was found to be establishing reliable information for all who are involved. Parents expressed confidence in the knowledge held by the medical team, but at the same time sought alternative wisdom when they felt they were not adequately involved in the decision-making process. It is at this point where they may bring in more subjective concepts and ideas to

justify their experiences, current situation, and outlook on future action. In the end, parents were still found to be experts in their own rights and an integral part of the process.

York (1987) discussed concepts of death, religious-based denial, and the role of social workers as potential advocates for families. Death has always been viewed as an extremely sensitive subject that families often refuse to even discuss. With children, this fact is only magnified and stressed even further. Children, infants in particular, have not lived out their lives or experienced the world; as a result, it is natural to expect an even greater level of denial from parents faced with the death of their newborn. When this denial is reinforced by religious concepts, parents often will rely on and attempt to convince the medical team that a miracle is going to happen. Over time, they actually will focus their energy more on the miracle than their infant, and their physical and emotional fatigue actually increases their inability to see reality and reduces their ability to make the right decisions. Two specific case examples demonstrated how social work could be beneficial, but also detrimental if introduced too late. The role of the social worker is already difficult, and when religion is introduced, it complicates their role even further. For families, social workers can be successful advocates and provide emotional support and support for their belief system. When parents have trouble understanding something, the social worker can be available to clarify information from an unbiased, neutral standpoint. When parents feel isolation from medical staff, the social worker has the ability to establish a relationship with them. Prayer is recommended as a therapeutic tool that is generally effective when opening lines of communication and empathizing with parents. Ultimately, religion is a controversial but often necessary part of the process. The

role of the social worker is complex, but can include providing valuable support to families as well as recognize and integrate religious beliefs into decision-making models.

E. Summary

Research has shed light on the broader topic of ethics of NICU decisions when infants are at the end of life. This work has stressed the balance that exists between the medical team and family of a newborn in the NICU, and the challenges that develop as a result.

The ethics involved in NICU decision-making at end of life have proven to be complex, and in addition the ideas surrounding religion and belief systems are complex and difficult. When these two concepts are combined, what is left is insufficient research focusing on religion specifically as a variable in these decisions. Some literature goes further, pulling in religion and alludes to religious concepts as potential variables. There is not enough information that puts religion at the forefront and concentrates on this idea in relation to ethical decisions in the NICU.

After review of this literature, it is clear that it would be beneficial to further investigate religion as a specific variable with the capability of affecting NICU decisions. It can be hypothesized that religion is going to be a social variable that has important, underlying effects on decisions made at the end of life for an infant. Once there is a better understanding and interpretation of these effects that religion may have, then there will be an increased ability to improve the way in which decisions are made in this unit. Last, there may be an increased knowledge of the implications of religion and an appreciation for religion as a powerful social force in medicine.

CHAPTER 3: METHODS

The literature provided information on the overall concept of religion as one of multiple social variables; however, there was not much found that focused on religion and investigated the potential effects of religion more thoroughly. In order to further explore the role that religion may play in making these tough ethical decisions, face-to-face interviews were conducted in two hospitals between December 2011 and January 2012. I chose to interview numerous members of the medical teams, which included neonatologists, nurses, chaplains, and social workers, to gain a more well rounded perspective, in addition to the fact that they are all important components of the decision-making process. This is an exploratory study, and so open-ended face-to-face interviews were conducted to gain the best possible understanding of all the issues at hand. One clear limitation that I faced in this process, though, is the number of interviews I could conduct for the study. Although the data is qualitative, this was still a limitation due to the small time frame that interviews had to be conducted within prior to the start of the data analysis. Before collecting any of this data, approval was gained from the human subjects committee at Union College, Schenectady NY.

Securing a Sample

To set up the interviews, I used two kinds of approaches. First, I used a snowball method of securing my sample by contacting neonatologists I knew, asking for their help in my data collection and in turn obtaining more contacts in their hospital they believed would also be interested in being interviewed. Second, I reached out to a department in both hospitals myself, specifically pastoral care, for the chaplain interviews. Before interviewing any participants, I explained to them the purpose of my study and then

asked them if they would be interested in taking some time to be interviewed. Essentially, my goal was to have different medical team members spread the word and make their colleagues aware of my study in an effort to obtain more and more participants. I was very successful in accomplishing this, and as a result interviewed a total of 17 medical team members.

Interview Procedure

The majority of the interviews were conducted inside the hospital; however, some were conducted in the participant's own home. Regardless, the time and location was set to be convenient for both the participant and myself. Before the interviews were actually conducted, I explained a bit about myself as well as the study. I then gave an informed consent form, which all participants read and signed. This informed consent form explained that they were voluntary participants, there would be no negative consequences of not choosing to participate, and that all information was going to be kept confidential. Last, since I was going to be using a digital recorder in order to later transcribe the interview, I verbally explained this to obtain permission, explaining that no part of the recording was to be used in my study. I discussed the fact that it was much easier for me to later transcribe the interview myself than attempt to take notes simultaneously while the participant was speaking. There were no issues with this at all that I faced from any participants. This method has given me the most precise and accurate results, and prevented me from becoming overwhelmed taking notes. If overwhelmed, I was possibly running the risk of misinterpreting or misrepresenting what was said during the interview. The participants' names were not recorded on tape; instead, designations such as "Nurse 2" or "Chaplain 4" were used to protect the privacy of the participants. Immediately after

collecting the data, I transcribed the interviews. I was the only person who had access to these files, and they were deleted from the recorder as soon as the transcription was finished.

The Interview Questions

Since all of the participants have very busy schedules, I made a conscious effort to create questions that were short, to the point, and not repetitive. First, there was a set of objective questions asking gender, age, religion, time serving the NICU, and a brief description of how they see their role in the NICU for end-of-life decisions. Then, they answered two questions with a range of answers from strongly disagree to strongly agree, which can be found in the appendix. Next, I recorded a set of five open-ended questions, followed by closing questions that varied depending on which medical team member was being interviewed. The duration of the interviews ranged between 15 and 45 minutes. These five open-ended questions covered the presence of religion in the NICU, the role these individuals felt that they played in the decision-making process, a discussion of notable cases where religion was involved, as well as variables other than religion that may also have important effects on these end-of-life decisions. In terms of the questions targeted to specific members of the medical team, neonatologists were asked about where they stand between physician beneficence and patient autonomy when there is an ethical dilemma on who should have control of decisions in the NICU. In addition, they were asked whether the fact that the patients are infants who do not have competency, and cannot speak for themselves, changes anything about their stance. Nurses were asked about the concept of moral distress, and how religion may be a part of that distress. Also, they were asked about whether they see their potential emotional connection with an

infant providing a different perspective than other members of the medical team. Last, the nurses were asked whether they have ever prayed for an infant, and if so the motivations behind that action. The questions for social workers asked if they believed that social workers can act as advocates for the families and help integrate religious beliefs into decision-making models, as they are seen by many as potential mediators to bridge the gaps between parents and NICU staff. Chaplains were asked to what extent they see their own religious commitments influencing the advice they give, and whether they would like to see religion discussed more between staff and family. In addition, they were asked if they feel the medical team always acknowledges religion as a part of making these decisions. Last, they were asked if they have seen parents hesitant to express their religious concerns to staff out of some sort of fears that they have.

Sample Overview

I interviewed a total of four chaplains, six neonatologists, six nurses, and one social worker. A set of basic information was collected in order to gain an understanding of where their point of views may stem from, or to observe patterns in certain responses to questions.

Chaplain 1 is a 58-year old male who has been serving the NICU for 3 years. He is Catholic/Christian and describes his role in the NICU as being the one to comfort the family and staff, baptize the child, and pray with the family if they are Catholic or Christian. *Chaplain 2* is a 50-year old female who has been serving the NICU for 1 year. She is Roman Catholic, and describes her role in the NICU as a part of the NICU team, sometimes more than others, who is mostly called at the end of life for Baptisms and for support for parents and other family members. *Chaplain 3* is a 60-year old female who

has been serving the NICU for 2 ½ years. She is Quaker, and describes her role as working with parents, siblings, or other family members both spiritually and emotionally as they are challenged by the context and events of their baby's life. *Chaplain 4* is a 73-year old male who has served the NICU for 15 years. He is Protestant Christian, and sees his role as supervising the chaplains who work in the NICU.

Neonatologist 1 is a 59-year old male who has been serving the NICU for 25 years. He is currently part of the Reformed Church, and sees his role as supervising and directing patient care interaction with parents in the decision-making process.

Neonatologist 2 is a 50-year old female who has been serving the NICU for 25 years. She is Jewish, and describes her role as directing medical care and family centered medicine, incorporating parental decision and ethical concerns. *Neonatologist 3* is a 39-year old male who has been serving the NICU for 7 years. He is Agnostic, and sees his role as one who speaks directly to the family regarding whether to discontinue support, but also provides support as time leads up to the end of life. *Neonatologist 4* is a 53-year old female who has been serving the NICU for 23 years. She is Catholic and describes her role as helping babies to get better. If that is not possible, she helps them to live their lives with dignity, with as little suffering as possible, trying to maximize comforting times with their families. *Neonatologist 5* is a 57-year old female who has been serving the NICU for 26 years. She sees her role as one who communicates with parents regarding the infant's condition and the futility and/or inappropriateness of continuing or discontinuing life support. *Neonatologist 6* is a 53-year old male who has been serving the NICU for 26 years. He is Catholic, and describes his role as assessing and making decisions, coordinating staff, and communicating with family.

Nurse 1 is a 54-year old female who has been serving the NICU for 25 years. She is Catholic and sees her role as providing information, support, and empathy for the infant and family. *Nurse 2* is a 56-year old female who has been serving the NICU for 12 years. She is an atheist, and describes her role as being an advocate for the patient and their family. She feels that parents need to have their choices validated concerning tests and procedures, and that her patients deserve to have the least traumatic and painless deaths possible. *Nurse 3* is a 65-year old female who has been serving the NICU for 10 years. She is Agnostic, and her role in the NICU is to be an ethics consultant when decisions need to be made. *Nurse 4* is a 59-year old female who has served the NICU for over 36 years. She is Catholic, and sees her role as one who is at the bedside tending to infant's monitors, meds, and vital signs, as well as supporting parents directly. In addition, she often is the one who takes infants off of life support for parents to hold until death. *Nurse 5* is a 50-year old female who has been serving the NICU for 14 years. She is Christian, and describes her role as being part of the nurse staff and medical team. *Nurse 6* is a 56-year old female who has been serving the NICU for 35 years. She was raised Methodist and currently is Catholic, describing her role as a case manager and supportive role to family and staff.

Social Worker 1 is a 41-year old female, who has been serving the NICU intermittently. She is Protestant, and sees her role as providing emotional support to parents or guardians and sometimes contacting outside agencies for reporting or assisting with burial arrangements of infants.

Analysis Strategy

In order to analyze the data, I first grouped the interviews by the participant's role in the NICU (chaplain, neonatologist, nurse, social worker) and compared each of the answers to questions by role. Then, I looked more comprehensively at themes and interesting responses regardless of the roles that I initially used to categorize and group the participants. Both of these methods for analysis compose my results and discussion chapter.

CHAPTER 4: RESULTS AND DISCUSSION

Thus far, I have established the setting of the NICU as being an ethically charged and often controversial unit. Through the 17 interviews conducted with neonatologists, nurses, chaplains, and a social worker, it is evident that religion is only one of the many variables that have an effect on decisions made in the NICU. More specifically, it is one that deserves increased attention from this point forward. The interview data supports the point that religion is frequently overlooked and not given the appropriate degree of consideration by the medical team. Religion has effects on both the medical team and family, with specific focus placed on ethical decision-making. In this analysis, I begin by noting general patterns in characteristics of those who were interviewed, followed by patterns in responses for each role (neonatologist, nurse, chaplain, social worker). Last, I will present themes more generally across all members of the medical team, which will include interesting responses, common answers to questions, or points which were truly surprising or going against what I would have predicted.

The responses begin with neonatologists, followed by nurses, chaplains, and social workers. The majority of individuals who were interviewed had at least 10 years of experience in the NICU. All 17 interviewees agreed or strongly agreed that religion has the ability to influence decisions made in the NICU. All but 3 of the 17 interviewees agreed or strongly agreed that religion can become a source of conflict between parents and the medical team. In addition, all but one claimed to have some religious belief.

When discussing the responses, the gender of those interviewed was randomly assigned.¹

¹ The role of gender is not being examined, so the genders may or may not be accurate. Whether the interviewee is male or female was not a focus of any part of this study, and randomly assigning gender also helped preserve anonymity.

Neonatologist Interviews

The six neonatologist interviews revealed many significant patterns. Every neonatologist agreed that religion should be considered in the decision making process, but that when it comes to their own religion, they would not want it to be a barrier or change the course of treatment for that infant. In terms of the role that they saw themselves playing, many believed they hold a major role, but at the same time are joint decision-makers with the parents. In addition, advising, supporting, and acting as advocates for the newborn were all frequently stressed. With respect to loyalty, one neonatologist mentioned the importance of being a liaison between the family and other medical team members. Others stressed protecting the baby's rights, whereas some felt they were often on the fence between parents and the medical team.

Among the neonatologists, some portrayed religion as being a helpful tool to deal with difficult situations, and yet others saw religion as the cause of many problems when making difficult decisions. When asked to discuss notable cases some did not have a lot of personal experiences to draw from, yet others had many stories to tell. Neonatologist 1 discussed a case where a religious mother, when presented with the fact that this was a futile case, used her religion and belief in miracles to justify continuing to keep that baby alive. This neonatologist felt very frustrated due to the fact that this mother was incapable of making sound decisions, and yet her beliefs on what proper care was continued to be driven by this feeling that a miracle would save the baby. There was an incredible amount of pain that the baby went through, even though pain medication was administered to make the end of life as comfortable as possible. However, this was a terrible situation medically, where religious persuasions, namely her general beliefs in a higher power and

miracles, extended the life of a newborn who could have had a much less painful course at the end of life. Neonatologist 2 also addressed the fact that there have been cases where religion has played a role; specifically, “people of extreme faith, despite a devastating prognosis for their child, wanted absolutely everything to be done.”

Neonatologist 3 notes more broadly the fact that religion can make it more difficult for a family to make a decision about terminating care. There was one specific case where the parents insisted that they were going to bring in their pastor, and the pastor never came. This made it seem as though religion was being used to alter the direction of care, or in this case postpone the end of life. Last, the neonatologist discussed some cases where parents would bring back information from the pastor, claiming that they were praying for the infant and felt that this was not the right time to terminate care. In many ways, it was seen as a kind of way to provide very basic, generic means of support to persuade the medical team to continue treatment, even in situations where care is considered futile.

Neonatologist 4 began by stressing the high number of “miracle-seeking families”, who “knew that medical data did not expect this baby was going to survive, yet they thought there was a chance that a miracle might happen for their baby.” There was then discussion of specific religious groups. First were Jehovah’s Witnesses, who often have a lot of medical controversy surrounding them. This neonatologist had experienced cases where the patients are usually not expected to die if they receive a blood transfusion, but these parents of infants will claim that their child will go to hell if transfused. Here, religion is a very serious barrier, as the infant would not be nearing end-of-life so long as they receive the necessary transfusions. For Jehovah’s Witnesses,

however, there is serious legal precedence given to medical team members who wish to give a transfusion in order to save an infant's life when parents insist that it is not what the baby would want. According to this neonatologist, a lot of the justification from the medical team's perspective for this is due to the fact that we really don't know what religion the infant will grow up to have- it may be the religion of the parents, but it may not be, which means that it would not be in the infant's best interest to follow the parent's very harsh and strict beliefs against blood transfusions. One baby in particular had a blood group incompatibility with his mother, who was a Jehovah's Witness, and she would not allow him to get an intrauterine transfusion as this technically would mean the blood must also go through her. Once the baby was born, the medical team had legal authority to give him blood, but there were many efforts made to respect the religious preferences of the mother without compromising the health of the infant. This was given as a specific example of how religion has the ability to cause serious conflicts with health care providers. There were also a few cases of Orthodox Jewish families where parents were unable to make the decision themselves, and had to first go through their rabbi. In many instances, the rabbi would live far away and everyone involved would have to wait for the rabbi to arrive before making any important decisions regarding care. Last, the ritual of baptism appears over and over as very important in dying infants, mainly as an acknowledgement that the family understands that this may be their only chance to do so. There were even times where pronouncing a baby dead has been delayed waiting for the person to arrive and do the baptism.

Neonatologist 5 mentioned only one case where Islamic parents held a belief that the child was communicating pain as a good sign, and therefore anytime the infant was

screaming she refused to give the child morphine. This meant that the medical team actually had to bypass her in order to give the necessary medications due to a promise to the child that they would not die in pain. This neonatologist did admit, though, that not many babies stay in the facility who are very sick; instead, they are typically transferred to another facility. This reduced the number of cases experienced that were specifically geared towards infants in critical condition, or nearing the end of life.

Neonatologist 6 talked more generally of the many difficulties in distinguishing religion from the rest of culture in the cases that he has seen. Jehovah's Witnesses may be an example where it is clear that their religious beliefs are driving their decisions. They then concluded,

“There have been a number of different cases over the years where either religion or other strong social beliefs have made for interesting, unusual situations where we've gone out of our way to try and support the families and the babies.”

Looking outside of religion, neonatologists were asked to recall other potential variables that have affected end-of-life decisions in the NICU, and there was universal agreement that besides religion, specifically past experiences of the staff stands out as important in the decision-making process. Neonatologist 1 considered past experience of the staff as another major factor, as “the longer you are in the business...the more experience and time you have to recognize how much you can do for a baby, and when it becomes futile.” Neonatologist 2 admitted there are a lot of factors that go into end of life decisions, including cultural values, station in life, age, and familial structure.

Neonatologist 3 also considered past experiences of staff as guiding the choices that are

made. They described the importance of having a neonatologist be comfortable talking about a baby dying, with the understanding that these words are never truly easy to come by in any situation. Neonatologist 4 agreed that not only past experiences, but also values and culture of the family, could have an important impact on decisions. Specifically, they have encountered a family who believed that they were being discriminated against due to the color of the skin once told that there was no way their baby was going to survive in the long term. Here, there was a cultural difference where the family felt they were being prejudiced due to their appearance. Neonatologist 5 answered that the parent's understanding of the situation is the most important variable and potential obstacle.

“Sometimes the parent's don't really understand what you are saying, the implications of the prognosis... there also may be some disagreement between the parents, one parent may be having more difficulty dealing with ending the life of the child or not starting to support the child who otherwise would die. So I think that would be the main obstacle, trying to make sure that both parents are on the same page, and help them if they have different understandings.”

In addition, it was noted that past experiences of the staff could also be an issue, specifically when a baby is born too early and there has to be a decision made about whether or not to provide life support. Neonatologist 6 considered past experience as well as cultural belief to have a strong influence:

“Poor minorities tend to have an approach to end of life where they wish to have everything done, which usually means ‘I don't want you to withhold anything from me because I'm poor’. So there is this fear that somehow, they

won't get the best care because of their social position and I think that unfortunately that often overrides considerations of the baby's best interest...you can't profile people and make judgments about their underlying reasons for thinking certain things."

The last question was aimed at the struggle that frequently occurs between physician's beneficence and patient's autonomy, asking who should have ultimate control when presented with an ethical dilemma, and there was stress placed on the mutual, joint nature of making decisions. There was also acknowledgement here of the fact that the patient in this case is an infant, who is not capable of speaking for themselves. Neonatologist 1 leaned more towards the side of physician medical view as coming first in making a decision, but it still has to be a cooperative process. This does not change when considering the fact that the patient is an infant. Neonatologist 2 instead stated it is the parent's decision to make, unless they are not capable of making that decision, and their stance also remains the same when taking into consideration that patient is an infant. Neonatologist 3 felt strongly that it should be a joint decision, but primarily more paternalism with the trust and understanding from the parents that the right decision is being made. Neonatologist 4 agreed that the decision should be mutual. The patient's family should have some, but not 100 percent say with regards to what is being done. They mentioned how in the past, parents had to sign DNR forms, and discussed the emotional difficulties that put on a family. Instead, it may be better to have a shared burden between the family and the doctors all coming together and agreeing as opposed to forcing the family to sign a physical form. When thinking of the fact that the patient is an infant, this neonatologist believes that the parents are best qualified to speak on their

behalf more so than the health care professionals. This was because the health care professionals are going to be taking care of this baby for a few days, or weeks, or maybe even several months, but ultimately if the baby survives he is going to be with his family. If he dies, on the other hand, the health care professionals are not going to be emotionally connected to the child it is really the family who is going to be connected to the child. Neonatologist 5 explained that so long as the parents seemed to be competent, then they should be the ones ultimately making decisions. Like Neonatologist 4, Neonatologist 5 believes that in the end, the parents are the ones who have to live with their decision. They placed stress on being respectful to the belief system or religion of the parents, as you can affect how they feel about themselves and their child forever. Neonatologist 6 claimed that control of medical decisions should be with the patient, but since this patient is an infant, there is by default primary responsibility to make those decisions belongs to the parents. It is the job of the medical staff, though, to take some of that burden from the families, not through taking control but instead by supporting them while simultaneously giving them control. Again, they noted that the parents are going to be living with this decision their whole lives.

Once the formal interview was concluded, some of the neonatologists had more to say, which was telling of the importance of this topic and the fact that there is a lot that they have been thinking about with regards to religion. Despite their busy schedules, these neonatologists wished to make extra time to continue conveying their views on this important topic in greater depth. Some of the neonatologists concluded the interview with their own interpretation of my work on a larger scale, information they felt remained unsaid, or just opinions of a previous idea discussed. One neonatologist noted the

importance of taking the time to understand where people are coming from- whether it is their religious background or something else, people come into the NICU with a lot of things and it is a very busy place where factors can often get overlooked. Nonetheless, it is crucial for the family to be understood in order to get better communication, and care for the child is ameliorated significantly when everybody understands this family structure, religion, and what makes the family tick. With regards to the concept of miracle seeking, which has been a reoccurring concept throughout all of the neonatologist interviews, one neonatologist explained that miracle seeking is a type of wishful thinking that there are a lot of irrational behaviors that take place within the realm of medical miracles and unreasonable expectations.

Last, one ending note in particular did a good job summarizing the nature of the NICU atmosphere. The neonatologist noted that with elders, everybody has a certain expectation that they are going to soon pass, but nobody wants it to be today. Infants, on the other hand, are surrounded by this hope about them and the future, and if you are a parent you have all these notions of what they could be and are going to be. It's really hard to give up all of that hope, there's just a lot of hope to give up on infants, and that's a very different and unique issue we are faced with. Overall, all of the neonatologists agreed that if religion was important to parents or members of the medical team, that was often reflected through how they approached making decisions, giving input on a treatment course, or deciding that care was truly reaching the point of futility.

Nurse Interviews

The six nurses who were interviewed all appeared to be compassionate, understanding, and devoted to their jobs in the NICU. Every nurse saw religion as something that if present, should be considered in the decision making process for an infant at the end of life. There are going to be differences in the interpretations of the medical data, often in the context of religion, and so it is important to have as concrete of an understanding as possible. According to one nurse, her own religion only enters so far as to support families and respect life more generally. One nurse was actually an atheist, and provided some of the most telling responses.

When questioned about their role in the decision making process, the nurses had many similar descriptions of how they saw their role in the NICU. Nurse 1 explained her role as being at the front line, where the doctors actually back up a lot of what they say. Their responsibilities include maintaining continuity of care with the babies, as nurses are the ones who establish these relationships with patients and families. The role is supportive as well, but not ever trying to impact personal beliefs on anybody else. Nurse 2 also focused her role on the idea of support, and really giving the families all of the information so that they can come to their own conclusions. There is no textbook right and wrong, and they are the ones who have to live with those decisions. Issues would not likely arise, so long as the baby is not being unnecessarily tortured because of their decision. A lot of times, the doctors have the attitude of doing everything they can, and can not see the big picture that what they are doing is not going to be helpful for the baby or family. A nurse would be able to step in and help them see the big picture, and make everyone realize that the baby should not be suffering if it is not beneficial at all to them. Nurse 3 stated her role is one of ethics consulting and therefore not to make

decisions herself, but to get a handle on the family's values system. They believe that there are occasionally absolute rights and wrongs, but these are rare and instead everyone should be looking at the considerations that are being weighed and support the family through the process. Nurse 4 saw the role as being between the parents and the doctor, similar to the mediating role discussed by Nurse 2, as often times the doctors will be holding out and do not want to make any decisions of terminating care, but the nurse has the ability to shed light on the fact that the baby is suffering and encourage discussion of how we are making these decisions. Nurse 5 admitted that families are often in denial and are not realizing their baby is at the end of life, and so the nurses have to be very honest with them. Often, this process will involve referring the families to someone in pastoral care of the hospital, or a religious advocate outside of the hospital's own pastoral care if needed. This religious advocate could be an individual who is from the parents' own place of worship, or simply an individual who is close to the family and provides them with advice and guidance. Nurse 6 saw her role as being a combination of getting the medical team together and then the family together, getting a good sense of the dynamic and what is important to both parties.

The next question asked about loyalty, and where the nurses felt that they stood, be it on the side of supporting autonomy of the family or defending the team and medical knowledge more generally for decisions. It was clear that their loyalty was primarily with the infant or parents. Nurse 1 felt it was mostly to support the parents and be an advocate for the baby and the parent's beliefs, and Nurse 2 agreed by stating simply, it is with the parents. Nurse 3 felt the parents and medical team should not be in conflict. Most times, issues will arise when some of the staff disagree with what's happening or are just

uncomfortable about something. Nurse 4 was also clear that advocating for the baby was key, with the parents being next and the medical team having the ability to be pushed one way or the other depending on what the parents want. This nurse explained that there have been babies whose parents didn't want to take them off life support, even though they were told there's nothing that can be done, but then they turn around and survive, so they don't like giving up hope until the very last second, because it has happened several times this way. She concludes, "It's actually cool, the miracle thing." Nurse 5 saw her loyalty as being with the parents, admitting that situations can get very sticky quickly. There are times when they will have to do something against the parent's wishes because of ethical standards that must also be carried out in the hospital. An example was given where parents do not expect a baby to be a stillborn and conclude that they do not want anything done afterwards, but the baby surprises everyone by showing signs of life, and in that situation they will not just let the baby die regardless of what the parents had said beforehand. Nurse 6 appeared to have loyalty for both sides, stating there was inherent support for the medical team's medical judgment at the end of life, but also support for the family in whatever decision they make once it has been determined they have received all of the information they can to make the best possible decision.

When considering notable cases, all but one of the nurses had a lot to share from their experiences. Nurse 1 told a story of an Irish Catholic family who had their 7th baby, Baby X, born into the NICU. This nurse had cared for another child of theirs and because of this had a previous relationship with the family. The family felt very strongly that they wanted Baby X to make it home, and the nurse believed that their strong faith influenced

decisions that were made regarding care. Nurse 2 spoke not on one particular case, but still had a very strong response to cases more generally:

“I think every baby that I have taken care of that has died and the parents have been involved in the end of life, I think all of them have had some sort of religious belief system that played into it...treatment has been pursued that may not have necessarily been pursued, which makes me feel a little bit uncomfortable because I don't think it's in the baby's best interest.”

Nurse 3 began with a legendary case, and then spoke on religion and how it affects many NICU cases. The baby was neurologically devastated at birth, but the parents, based on their strong Fundamentalist beliefs, felt that any life was worth preserving regardless of the quality. The staff struggled with the case because they felt that they were doing harm and no good for the baby. Nurse 4 explained the case of a very sick baby whose parents did a lot of praying. No one on the medical team thought that this baby was going to survive, and yet the baby is still alive today.

“Is this a miracle? Did we do wrong? The parents thought that this was where the miracle part comes in...the parents were Baptist, and the mother mentioned the word miracle and would read to the baby and pray every single day...I think that had a lot to do with why they didn't give up, her heart kept telling her to keep fighting and her religious beliefs, she just believed there was going to be a miracle and she actually turned out to be right, because in the medical profession this baby had no chance.”

Nurse 6 talked about the fact that there have been quite a number of cases that can be considered notable for discussion. There have been families who they know are very faith based because they profess it when they come.

“Families have asked me to step away from a window because angels are coming...I’ve certainly had Jewish families who have gotten on the phone with their rabies to help them direct them completely and they leave all the decision making up to that rabbi...Catholic families have come with their priest for direction as well.”

When asked to look outside of religion towards other things that may have significant effects on decisions, all of the nurses made a variety of claims. Nurse 1 considered culture as playing a big role in decisions. Nurse 2 on the other hand spoke about money as being a variable that does not drive decisions. She describes the movement towards health care rationing, and how that has never been an issue in the NICU when at times she believes that it should be. Quality of life can often be overlooked due to the focus on survival and life at any cost. When parents expect miracles, they will always want everything done. Nurse 3 talked about the fact that there is so much that goes into decision-making in the NICU, but experience is something that can truly create a divide between staff members when a decision has to be made. So Dr. A might say “Your baby is stable”, Dr. B might say “things are looking terrible”, and then Dr. C might say “We’re not really quite sure.” This seeming inconsistency may also have something to do with personal comfort levels with delivering bad news. Nurse 4 focused on new staff members and herself in a particular situation where an infant was dying. The new staff members were visibly upset and hugging each other when the infant

passed, and she was actually viewed as being the cold one in the group. However, this was a situation where she was not being cold but instead helping attend to funeral arrangements. This occurrence demonstrates the differences in reactions when medical team members have varying degrees of experience. As a result, some may get very emotional whereas others will be able to filter that out and use their energy to focus on other things that have to do with the infant, such as funeral arrangements and providing support for the parents and family. Nurse 5 stressed the multi-faceted nature of decisions, and that each individual case is going to be different. She describes protecting the baby's rights, making sure everyone is on the same page, and respecting parents' wishes as more general variables that are important to consider in all cases. Overall, she thinks each case is going to be very different, and no two cases are ever the same. Nurse 6 listed culture as a large variable, in addition to the family dynamic, support system around the family, and the parents own experience with death in the past.

The next set of questions was directed only towards nurses, and referred to Cavaliere's (2010) study that examined moral distress among nurses. They were asked about how religion is a part of the many conflicts and internal issues encountered when infants are in end of life situations. Nurse 1 gave a specific case example where she personally felt a great deal of moral distress. There was a family with a very strong Catholic background, where a father was insisting that everything be done for their extremely premature set of triplets. She considered this a very tough instance of moral distress, where she truly felt that these babies were being tortured. Nurse 2 discussed the fact that she is an atheist in an environment where there is so much emphasis put on God as far as making some of the decisions that is distressing. When looking from the

perspective of the baby, she does not believe that God wants babies to be early or even has a plan, and expressed that this was very hard for her, as she keeps this to herself and would never say anything to the parents. There are situations in which she wishes to offer a family comfort, but because a lot of people find comfort in religion it is distressing to not be able to see the meaning in that. Nurse 3 saw moral distress as being prevalent and even rampant in the NICU.

The nurses were then asked if they felt that the amount of time or potential emotional connection they have with an infant gives them a different perspective than other members of the medical team. All of the nurses unanimously agreed that they do have a different perspective than others. Nurse 1 referred back to the beginning of the interview, and the fact that the nurses are usually the closest with the patients in the NICU. Especially if the baby is admitted for any length of time, more than a few days, an emotional connection or bond develops. Nurse 2 agreed that it does give them a different perspective. Not only do you get attached to the babies, but you also feel for the parents.

“Doctors can come in, come out, they do a quick exam and leave but when you are at the bedside for hours, especially if you take care of the baby a lot as a primary nurse, then you have a lot more at stake. Most doctors tend to not make connections with the families because I think that they think it gets in the way of making decisions, and it’s just too painful. But I definitely think nurses have a big stake. You get attached to babies that are 24 weeks and they are only a week old, but you see all the things in them that the parents see, the potential, but you also see the potential for the suffering and bad outcomes. It is

very hard...you don't want to be negative, you want to support the parents, but you have to be realistic too in some ways.”

Nurse 3 agreed as well that because nurses are at the bedside for such long stretches, they are going to develop a relationship. This may be through watching this child as he starts to smile or interact to some level, and she recognizes that this is often problematic if the child is experiencing a lot of pain. Nurse 4 declared that she most definitely has a different perspective. The nurses are the ones who are ripping the tube out, turning off a vent, taking the infant into the mother's arms and sending it to the morgue, and so they have the most emotional and physical involvement. She then continued, explaining that the doctors come in, say a few words and walk out; the nurses are there for the whole process. Nurse 5 thought that in situations of turmoil and distress due to their infant's condition, parents will take it out more on the nurse but also engage more with the nurse, simply because they had that opportunity to build up more of a rapport so they'll open up more to you. On the other hand, the doctor comes in and they will ask more pure medical questions, but they won't necessarily open up with more personal issues. Nurse 6 discussed the fact that they are the ones spending the bulk of time with that infant. In nursing, the difficulty is that the family either is not where you are, or not where you want them to be in terms of an understanding. You want them to be able to see what you see, and when they can't then the moral dilemma for the nurse surfaces. Often, the nurse sees the terrible outcome and is trying to get a family to understand that reality, but at the same time the job is still always to support the family where they are and help bring them to a place where they are able to understand.

The final question for nurses referred to a study on prayer, which noted that nurses in particular were praying for their infants (Caitlin et. al 2001 and Cadge 2006). The nurses were asked if they have ever prayed for an infant, and if so, what their motivation was for doing this. Most of the nurses admitted to praying, and even if they did not, these nurses nonetheless expressed a respect for the parents wishing to do so, and even a willingness to participate if asked to do so by the parents. Nurse 1 has prayed on more than one occasion, in addition to being present at several baptisms of babies at the bedside. There was one specific case where there was a very large family, possibly Baptist, and everyone held hands, prayed, and sang. She mentions how parents' will frequently ask the nurses if they are comfortable with that and they do take part. Nurse 2, because she does not believe in God, has not prayed. She did mention, though, that when doctors are doing procedures they will ask her to "Say a Hail Mary" and she does, and sometimes it works and it makes them all feel good. Nurse 3 admitted that she personally does not pray, but would be happy to bow her head or do whatever a family would want if they asked. Typically, pastoral care will come in at a certain point and carry out prayers and things of that nature. This nurse cited a specific case on point, where a patient was actively dying and a nurse kept reminding the family to pray to God, and things would be okay. In this situation, her personal belief system appears to have intruded onto the patient and family, which this nurse considered a disservice to them. Nurse 4 simply stated she always and frequently prays for infants, and is motivated both by her own religion as well as the religion of the patient and family. Nurse 5 has prayed for infants, and describes that what motivated her was her own belief. Being Christian, she prays for friends and even people who she has conflict with, but in the NICU she is praying for

babies all the time. Nurse 6 said that she absolutely prays for infants, and is motivated by her own religion with an understanding on the part of the family that they shared the same religion or wouldn't find it offensive. If unsure, she would instead pray silently.

Some of the nurses concluded their interviews with interesting comments, which were not prompted by any particular questions. Just as the neonatologists took time out of their schedules to extend their talk with me, the nurses did the same and were willing to genuinely open up and make comments regarding concepts of ethics and religion more generally. One nurse went into a detail with a case of a baby who was with them for almost a year, and the incredible amount of moral distress that one nurse was feeling. In another case, there was a 23-week baby that was born, and because such extreme prematurity typically results in bad outcomes the medical team wasn't planning on doing anything. However, once everyone got there the baby took a breath, and so he was admitted and lived for a week. This experience was torture, while at the same time appeared to be helpful for the mother because she got to spend some time with him. The nurse then explained that she does things rationally and realistically in order to make everyone's lives better. Personally, she understands how the mothers feel in terms of struggling and potentially losing their baby. In some ways, she believes that it is good that people have religion to help them. However, what is not good is when those beliefs steer you to do things that are not going to help the baby, as miracles don't happen 99.99 percent of the time, but you can't argue with someone's faith. Another nurse explained the guilt that is felt by many working in the NICU, as people will often ask themselves if they missed something or could have done anything more. This guilt, unfortunately, is carried around almost forever in many cases. The last nurse explained how the decisions

that get made in the NICU usually have to happen over some period of time, and their job really is to be as supportive to the family as possible through the entirety of the process, because it is not her child and personally she would not want anyone making that decision for her.

Chaplain Interviews

All of the four chaplains interviewed worked directly through pastoral care in the hospital, and had at least a year of experience with NICU cases. As one might expect, all of these chaplains recognized that religion has an important place in the NICU, especially at the end of life, and that when making decisions it is very important to consider and take care of the religious beliefs of the family.

When asked about their role in the NICU, none of the chaplains claimed to be the ones who make any decisions themselves. Instead, they all agreed that they were there to support and assist all parties involved in whatever way possible. This often involved requests for baptism, prayer, or blessings of some kind. The chaplains were then asked about whether their loyalty is to be there for the parents, medical staff, both, or somewhere in the middle. All answered that they were somewhere in between, and to a degree appeared torn when responding to the question. Chaplain 1 sees his loyalty as being with everyone, as nothing can be done if the parents are not on board and the staff always takes on that supportive role for the parents. Chaplain 2 considers himself a part of the medical team when he is asked to come onto a case, and so there has to be some loyalty and respect to the medical team. At the same time, support primarily should go to the parents as long as they are well informed and have been listening to what the medical

team has to say. Chaplain 3 sees his loyalty as being with both the parents and the medical staff, and that he walks the line in between. He fully supports what the parents are trying to do for themselves and for their child, as well as supporting the staff for what they understand and their medical knowledge. Chaplain 4 thinks he is there for the patient primarily, and does not know whether there should ever be conflict between the parents and medical staff. This is because the medical staff is supposed to support the family, and he considers himself to be part of that staff and therefore fulfilling that supportive role as well.

The next question asked the chaplains to describe any notable cases they remember, and the majority of these cases involved conflict due to religion rather than religion helping to alleviate parents' feelings or solve problems. Chaplain 1 discussed more generally a couple of his experiences. He sees that for parents of Christian faith, it is often very important that their child to be baptized and they take this very seriously. Sometimes, he admits that conflicts arise when the parents have different religions and can't decide on what is best for their child. On other occasions, the grandparents will come into the scene and conflict arises there because they may have strong religious beliefs that influence their decisions. Chaplain 2 gave two specific cases that he could recall. In one case, there was a couple that did not think that they could have children, but by a miracle they had a girl. This was a Jewish couple very grounded in their faith; their baby was very premature, but they were extremely attentive to her needs. The baby had a lot of anomalies, and as she grew older the medical staff discovered even more. Through all of this, nothing ever threw the parents, they believed their daughter was a gift from God and they wanted to have her as long as they could. There was conflict here because

the medical team thought that the parents did not understand their daughter's prognosis. However, they did know what was going on, it was just their strong faith that was guiding them in their decisions. The second case involved very young, unmarried parents and their sick infant. There was a point where the parents realized they were not going to be able to deal with her special needs if she ever left the hospital. They asked this chaplain to baptize the baby, which he did because the baby was about to go through a procedure. However, in this case he believes that religion played a detrimental part in the child's life as only a few days later, the parents decided to withdraw her life support. He believes that this decision was based solely on the fact that since now she could go to God, the parents did not have to deal with her medical complications anymore and felt permitted to let her go. Prior, the chaplain knew that the medical staff were honoring the parents' wishes in treating their child as a Christian, but had no idea that the parents would use the baptism as a door to allow their child to expire. Chaplain 3 spoke regarding the Amish more generally. He describes their sense of community and elders, which comes with a tendency to make decisions as a group rather than say, strictly the parents making a decision for their infant. He has seen conflicts happen relating to religion, more often with young families, but whenever this happens the staff typically turns to the ethics department to work things out among the parents and staff so that everyone's concerns are understood. Chaplain 4 did not discuss a specific case, but explained that there are many instances where he thinks the family's spiritual understandings and religious practices played a great role in their decision. Religion will be taken into consideration in the baby's last few days in the form of a baptism or prayer of some kind, as well as in death when parents have to cope and deal with the grief and sadness of losing their child.

He has also seen cases where one member of the family wants the child baptized and the other one does not, and the chaplains will try to have them come to some compromise based upon what is ultimately meaningful to them. Last, another struggle that parents sometimes have is the ability to accept a very poor prognosis for their infant. They become so convinced that God will do a miracle at the last moment, and want to hold off for that miracle. When it does not happen, they really sometimes become bereaved, angry, or frustrated that God did not come through with this miracle for them.

The chaplains were asked to look away from religion and consider other variables that may be at play in the NICU, and their answers were as a whole divergent but fully explained. Chaplain 1 looked to culture as being a variable that can cause conflict when decisions have to be made. Chaplain 2 thought that the parents respect for the knowledge of the medical team weighs in on their decisions at the end of life. He also mentioned consideration for quality of life that the child would have as an adult. Chaplain 3 thought that there could be other variables on the parents' side of things, notably their own maturity, experience, and values. He gives an example of a father who is devastated and even feels ashamed of his child who has been born with Down Syndrome:

“Some parents love regardless, other parents love with condition, and maturity has a great deal to do with it. And if a parent doesn't have the capacity... they're kind of setting themselves up for a great deal of heartache later on. There's nothing you can do about that either, that's just simply the way people are.”

Chaplain 4 agreed that there are a number of other important variables in addition to religion. A consideration that is often very persuasive to a family is perception that the

child is suffering, and that is not always a strictly religious decision it is more a suffering decision. The values of their respective communities might also be reflected, in addition to family members who are very persuasive and aggressive in terms of what they want to happen.

The last four questions were directed specifically towards chaplains. First, they were asked to what extent their own religious commitments influence the advice that is given. All of the chaplains agreed that their own religion should not influence the advice that they give, but instead they should work with the parents and their own beliefs. However, Chaplain 2 recognized that it is difficult because your own belief system is going to color what you say even if you try to hold back, and the best thing to do in that case is to try and reflect the parents' belief system as best as possible.

The next question asked if the chaplains would like to see religion as something that is more talked about towards the end of life among the medical staff and the family. Two of the chaplains agreed, as at the end of life people all somewhat rely on the higher power they believe in, and like to follow religious support. The other two chaplains did not necessarily think that religion needs to be discussed more, and one felt that there was nothing they could actually do about the medical staff and family talking more to each other about religion.

Subsequently, the chaplains were asked if they felt that the medical team acknowledges religion always, or is it instead pushed aside. Chaplain 1 explained that the medical staff are not religious workers, but that the staff always try to provide support and guidance to the family according to their own belief. Chaplain 2 considered there to be a range, where some members of the team are very comfortable talking religion,

whereas others don't put it into the equation at all. He wishes that the medical staff could be more open about talking to parents about faith and not just science. Chaplain 3 saw the staff as being generally good at suggesting a chaplain when the time is right. Chaplain 4 thought that it's acknowledged a lot, and staff are generally respectful and will do everything they can to honor that.

The final question focused on the parents, and whether the chaplains found parents sometimes hesitant to express their religious concerns to medical staff out of some kind of fear. Chaplain 1 answered that parents sometimes do have fears that they might not be understood, but the hospital makes an effort to alleviate any of their fears or concerns. Chaplain 2 could not recall parents who were afraid to mention their belief structure. Chaplain 3 saw this as being dependent on the case, as some parents will be very clear about what they believe, and others will not be. Chaplain 4 suspected that people will at times feel a little inadequate to talk about their religious beliefs with medical staff.

At the end of these chaplain interviews, there were some significant unprompted closing remarks. One chaplain discussed the work that he does, and the fact that he can maintain the connection with the families and watch some of them mature over time. He considers it a privilege to watch this evolve, and as they become more capable their faith grows and they become more secure in this faith. Another chaplain described the NICU as a very tender place with fragile beginnings. This environment has the capability of bringing out the best and the worst in people, because you are in shock at how fragile life is, and there is also room here for a real spiritual growth to take place. If parents do lose a

child, this loss will indubitably impact their lives forever, and add a shape to their lives that they never counted on having.

Social Worker Interview

There was only one interview conducted with a social worker, and her responses were interesting and insightful. However, the lack of representation of social workers and difficulty getting willing representation here may be telling of the interactions between social workers and medical staff. It appeared that the medical team members all had a degree of reservation in recommending social workers who would be interested in being interviewed. This was partially due to the fact that there were not many, and the ones that were around simply were unwilling to speak regarding their roles in the NICU. Similar to responses from the chaplains, this social worker did not see her religion as being a part of the decision-making process but instead considered her role to be primarily a supportive one. She wants parents to feel they have an advocate. When asked about loyalty, she answered that the first loyalty should be to the baby, which is a hard thing to keep separated because the parents are the ones talking on the behalf of the baby. The parents usually want what's best for their baby, but may be making decisions that don't uphold that. Due to the small amount of experience in the NICU, there were no notable cases that were mentioned. In terms of other variables, Social Worker 1 explained that support systems, for the parents, play a big role in how much involvement they need from the staff. The last question, directed specifically towards social workers, referred to a study that looked at religious-based denial in the NICU (York 1987). Within this study, social workers were highlighted as having the ability to be potential advocates for the families,

providing emotional support and support for their religion. Social Worker 1 hoped that she has been an advocate for families through her work thus far, and believes that it is their professional obligation to do so and actually intervene when necessary on behalf of the parents.

Discussion

Looking at all of these interviews, there are a number of central themes that have emerged which are not limited or separated by the interviewee's role in the NICU. One theme that resonated across all roles was the concept of miracles; more specifically, miracle-seeking parents. This spans across many religions, so long as within that religion there is some belief in the idea of miracles. Cases have revealed that the majority of the time, a belief in miracles actually winds up becoming a barrier for doing what is in the best interest of the infant. In terms of the source of the miracles, it appeared that this may come from either a divine intervention or even the control which parents feel they have in the fate of their child. There was only one case that stood out where the infant's condition was medically hopeless, and yet by what appeared to be a "miracle" the infant got better due to the parents' persistence and claims that the infant was still fighting to survive. In most cases, parents are going to expect miracles but farther down the road, if the baby does survive, they are going to have a compromised quality of life because decisions were made to appease these parents. Instead of valuing quality of life, life in general is valued at almost any cost. Therefore, when parents claim that they believe in miracles or are waiting for a miracle to happen, it is most likely going to hurt the infant. This is an extremely deep issue, as many people who believe that it is up to God to determine what

happens to a sick infant will never admit that it is an appropriate time to discontinue care. So deciding at what point life should no longer be prolonged in these scenarios is one of the hardest questions to answer in the NICU.

Moving beyond miracles, some other specific religions or components of religions were also repeatedly mentioned in the interviews. Most notably were the Jehovah's Witnesses and the ritual of baptism. Most frequently, the Jehovah's Witnesses were brought up either when individuals were asked to discuss notable cases or after the completion of the formal interview as a part of their closing statement. This religious community can arguably be one of the most controversial religious groups discussed. Their opposition to blood transfusion, which is so often a life-saving intervention, is so strong that in a NICU setting it may be the difference between life and death for a sick infant. Luckily, as one neonatologist stressed, there is strong legal precedence given to medical team members in cases where Jehovah's Witness parents attempt to prevent a necessary transfusion for an infant. The reasoning for this is as a child, no one is certain what religion the infant will grow up to have, and so it would not be in the infant's best interest to assume that they will take on the religion of their parents.

Lastly, the ritual of baptism among Christians has appeared over and over again in interviews in numerous contexts, whether it be in discussion of notable cases, the chaplain's descriptions of their roles, nurses interpretation of their connection with infants, or in closing remarks made by the interviewees. One neonatologist considered baptism to be, in many ways, an acknowledgement of the family's understanding that this may be their infant's only chance to be baptized. On the other side of things, one chaplain described a case where the baptism was actually detrimental to the infant's care, and a

means by which the parents allowed themselves to withdraw treatment with less guilt. So it appears that the ritual of baptism is common in the NICU when infants are at the end of life. While it can be an important way for parents to cope and deal with their impending situation, it can also potentially be abused as a means by which parents allow themselves to let their infant go too soon.

Another theme that appeared throughout the interviews was the idea of protecting the baby, primarily from undue harm, with acknowledgement of the difficulties that endeavoring to provide such protection presents during the course of treatment. Due to the characteristics of the NICU, the patient will never hold the competency to speak for themselves. As a result, everyone is essentially using their own judgment to determine what the newborn infant would want, likely imposing their own values on this helpless patient. In addition, there is often more than one of these individuals who wind up advocating for the infant and speaking on their behalf. When asked about their role in the decision making process when an infant is at the end of life, individuals from every role had placed importance on supporting, advocating, and representing the baby first. Some expanded, though, on the fact that because the baby cannot indicate its desires for treatment, conflict results from any member of the medical team having a view or thought which opposes one or both of the parents. This is a struggle that frequently presents itself in the NICU, and religion often plays a role in this conflict to some degree.

Another theme, which came as a surprise throughout the interviews, was the nurses' perceptions of the doctors as being somewhat narrow minded, or limited in their ability to step back and see the big picture when a tough decision needs to be made. When describing the role that the nurses play in the NICU, there was discussion of the

ability of a nurse to step in and help the doctors see the big picture, making everyone realize that the baby should not be unnecessarily tortured. In the eyes of the nurses, the doctors often have the attitude of doing anything and everything to try and save the baby, when there are times where nothing more actually can be done. One nurse discussed how most doctors tend to avoid making connections with families because they believe it gets in the way, whereas the nurses have a big stake in these decisions. A number of the nurses interviewed stressed the fact that the doctors essentially will come in, say a few words and walk out, as opposed to the nurses, who are there for the whole process.

Although the analysis was twofold, looking at the religion of the medical team as well as the parents, the data was heavily concentrated on the religion of the parents. This may be due to the fact that the interviews were one-sided, from the medical team members' point of view. Perhaps if parents or family members were interviewed, they may have had more to say about the religion of members of the medical team having an effect on decisions.

Nonetheless, one interview in particular truly stood out as highlighting the religion of the staff and its importance. This interview really concentrated on some very key aspects of this project and came at religion from a very unconventional viewpoint. The interview was with Nurse 2, who openly stated that she was an atheist. This interview, in its entirety, reminds us that the medical team is composed of human beings with backgrounds that are not all the same. This nurse in particular, had a background that set her apart completely and showed how regardless of what some may say, one's religion and other components of one's life make up who you are, and even as a professional you are going to go into situations leading with who you are as a person.

Who we are as people can be explained as reflections of our experiences, beliefs, and values. In the case of this nurse, her atheist beliefs have made her very rational and realistic when tough decisions present themselves, but at the same time she maintains a respect for other individuals' religions despite not holding any of these beliefs. She was extremely open in admitting to the difficulties faced when parents have a religious belief system that plays into their decisions at the end of life. The point where this nurse begins to feel uncomfortable is when decisions are made that she believes are not in the baby's best interest. Instead, they are making decisions based on their own best interest due to what their religion is telling them.

Overall, the nurse's lack of religious beliefs colored her values and opinions, but at the same time allowed her to take a step back and see how religion played into the decision making process from an outside point of view. Finally, on the topic of moral distress, she explained that in an environment where there is so much emphasis on God, it is very distressing for her. She declared that a lot of people can find comfort in religion and assign a meaning to things because of these religious beliefs, but that she does not have the ability to see this meaning other than random unfairness when an infant is gravely sick. Religion is that means or way in which people do come together and bond, but it is clear now that religion can be both a barrier to care and a mechanism by which parents understand, cope, and learn to accept their infant's situation.

The existing literature has revealed a wealth of information on the topics of ethics and NICU decision-making, religion as it applies to sociology and medicine, as well as challenges faced by the medical team and family members. The findings of this study are generally consistent with the considerable amount of research that has already been

conducted on this topic. Following is a summary of how the results from the interviews compare to what is already known on these topics that were previously discussed in the literature review.

Ethics of NICU Decision-Making

As previously discussed in the Literature Review section of this paper, Stutts and Schloemann (2002) introduced the conflict that can exist between the family and health care providers. Veatch (2003) discussed the principles that underlie the ethics behind such conflicts. Through the interviews in the present study, it is apparent that these conflicts do in fact exist. Berge and Hoffer (2009) discussed the increase in the practice of withdrawing care that is futile, and parents having a strong presence in the NICU and consistent involvement in the entire process. Manzar et al. (2005) also stressed the dilemma with futile care, and parents wanting to move forward with aggressive care regardless. Neonatologists 1, 3, and 6 all mentioned these concepts. Notably, Neonatologist 1 explained the idea of futility, and how the role of a neonatologist is to often help parents see that continuing care is not going to help their newborn. In other words, Neonatologist 1 stressed keeping them involved as mentioned by Berger and Hoffer (2009), but guiding and helping them to make the right decisions. A previously conducted study expanded upon the external factors, not purely clinical, that influence decisions about NICU treatment (Miljeteig et al. 2009). Some of these factors include complex, socioeconomic reasons. Neonatologist 6 shed more light on these external factors, and gives a scenario where parents of lower social position will say that they want everything done, when the reality is they do not want the medical team to withhold

anything from them because of their lower social position. So a fear is instilled in these parents, and as a result their decisions are affected which often override more objective considerations of the baby's best interest. In addition, Nurse 2 talked about another external factor, money, as being something that does not drive decisions in terms of rationing health care. In the NICU, she believes that quality of life is often not given the appropriate degree of consideration, and life is frequently favored over quality of life. Her perceptions may come as a result of her atheism, with regards to the stress that she places on individuals in the NICU overemphasizing survival and prolonging life. This is due to the fact that those who are not religious are not apt to believe in miracles or higher powers, which is much more characteristic of religious individuals.

McHaffie et al. (2001) illuminated the importance of having open discussion and involvement by both the medical team and parents. The results of the current study fully support this statement, as it was repeatedly mentioned that it is vital for the medical team and parents to feel comfortable discussing their concerns with one another. However, within McHaffie's study was an interesting realization that the medical team ultimately makes the decisions, even though the majority of parents perceive that they are the ones making these decisions. This held true in the interviews as well. All neonatologists, but notably Neonatologist 3, stressed that although the control should go to the patient, or in this case the parents, it is key to make the parents feel as though the decision was fully and completely theirs. The parents, not the medical team, will be living with this decision for the rest of their lives as it is their child so it is important to be extremely respectful. On the other hand, as much as parents want to have the best interest of the baby in mind they are not capable of understanding all of the things that neonatologists see. Lantos and

Meadow (2006) talked about the advancements in medical technology over the past 50 years. This has allowed for doctors, without the guidance of ethical principles, to keep a patient alive in any situation. Neonatologist 4 provided examples of situations where colleagues may lean towards trying to preserve life at all costs, even if it means having the patient suffer.

The literature also contained discussion of the differences between members of the medical team (Anspach 1987). The results of this study revealed some interesting differences among the various members of the medical team. The chaplains focused more on the individual religions than other members of the medical team, who instead discussed the role of religion in a more abstract sense. All of the nurses, especially Nurse 2, thought that doctors focus too much on pure survival, whereas the nurses are better at considering quality of life. Nurses also were more likely to mention taking the time to talk to parents as a way of getting everyone on the same page. Neonatologists primarily stressed more so than others that there should be more trust placed in medical knowledge when making decisions.

Conway and Moloney-Harmon (2004) were comprehensive in detailing a specific scenario that dealt with religion and showed how a true ethical dilemma can result when stakeholders disagree on the fate of a newborn. A description of this scenario was followed by an analysis of the dilemmas that can occur in the NICU from a variety of standpoints, just as the interviews of this study were composed of a number of different cases that illustrated some of these dilemmas. One such case came from Chaplain 2, who recalled a Jewish family with a strong faith, and a resulting conflict due to the fact that the medical team did not believe the parents understood what was going on with their

newborn. The reality of the situation, according to the chaplain, was that the parents fully grasped what was happening, and yet they were guided by their religious beliefs to push for their child to live as long as possible.

Anspach (1987) explained the purely sociological aspect to these ethical decisions. Mainly, the literature focuses on the idea that these decisions are only partially objective, and a number of other social variables, including religion, come into play here. Overall, both the literature and the results are in agreement when elaborating and exploring the complex ethical difficulties in a NICU setting, and that there is a component to these decisions that is sociological in nature.

Religion in Sociology and Medicine

From the sociological perspectives of Weber, Marx, Durkheim, and Berger, the literature has presented religion as having an important role in society. Religion is explained as a known determinant of the way people react and make decisions. Berger (1969) sees religion as a tool for legitimizing options and actions in the world. Nurse 3 considered how someone interprets medical data as often happening in the context of religion, and therefore it has to be considered when making decisions. All who were interviewed agreed that religion is important, and in the NICU setting, if it is present, then it must be considered. The literature then detailed Christianity, discussing the views of Jehovah's Witnesses, Judaism, and Islam on life or end of life care. All of these religions, including Jehovah's Witnesses, were mentioned in a number of cases and examples, and their beliefs through the literature generally coincided with what was explained in the interviews. However, one example that was not in agreement with what

was in the literature dealt with the Islamic faith. Neonatologist 5 detailed a case where Islamic parents had a belief that their child had to communicate pain as a good sign, and so as their child was screaming in pain, the mother refused to allow the child to have morphine. So this was a case where traditional Islamic beliefs may or may not have been depicted, but instead related to the parents own interpretations of their religion and what it meant to them.

King et al. (1994) has shown religion to have an undeniable effect on medical outcomes, along with a discussion of the faith-health connection (List 2005). There is a lot of power associated with prayer, hope, beliefs, and convictions. The current results have shown that religion is indeed a very powerful source by which individuals can come together, whether it is to make decisions or simply to be comforted and have a means by which to understand their difficult situation. All members of the medical team reported a great deal of discussion about miracles. Nurse 4 has illustrated a case where the religious-driven persistence on behalf of the parents has actually resulted in a kind of medical miracle, and a newborn beat all of the odds and survived. In this situation, it appears that religion had an incredible effect on the medical outcome for this extremely sick newborn. Nurse 1, when asked about her motivation for praying for infants, partially attributed the motivation to her own religious beliefs, whether this was the same or different religion as the family. More than the actual religion, simply the fact that she believes in prayer or overall faith is meaningful for a family. Nurse 2, who does not have a religious faith, expanded on the comfort a lot of people find in religion because they can assign meaning to something. Clarfield (2003) explained that in order to make the best decisions, the religions of both the medical professionals and patient must be understood and respected,

as these religions will have certain aspects that set them apart. This idea resonated throughout the results of the interviews, as interviewees put emphasis on a mutual understanding and respect that is essential to making the best possible decisions in the NICU.

Challenges faced by the Medical Team and Family

When considering clinical challenges, the literature classified many reasons and ways health care providers decide to support treatment in the NICU (Miljeteig 2009). Neonatologist 2 explained one of these major clinical concerns, a risk for disability later on in life, through a case of a very premature baby. The Christian parents, due to their belief that “it was in God’s hands”, insisted that absolutely everything be done despite the almost certain likelihood of severe disability. Ethically, Lantos (2006) described the two opposing positions that can be taken by doctors. These positions are physician beneficence and patient (or in this case parental) autonomy, and the results from this study have shown that there are in fact varying viewpoints among the neonatologists. Neonatologist 1 sided with the physician’s own medical judgments primarily, Neonatologist 3 and 4 hoped it would be a joint decision, whereas Neonatologists 2, 5, and 6 believed it is the parents who have the authority to make the final decision.

Cadge and Caitlin (2006) hypothesized on some of the additional challenges faced by medical team members, focusing on the religious or meaning-making systems for how they understand difficult scenarios. More specifically, caregivers were found to pray for babies as well in the NICU. All but one of the nurses interviewed did admit to praying for their babies in the NICU when asked. In addition, Neonatologist 3 believes that one’s

religious beliefs guide choices that are made in addition to personal comfort levels dealing with difficult situations. When concentrating on moral distress, Cavaliere (2010) looked more closely at this problem and the idea that other members of the medical team do not acknowledge moral distress. The results of the interviews confirmed what was found in the literature, which was variation between individual experiences but an overall agreement that moral distress exists and is a problem in the NICU. Nurse 4 explained the tremendous amount of guilt that nurses experience on a daily basis, which can be very distressing. There was also mention by the nurses of their role being understated. Nurse 5 discussed the role of the nurse in the NICU as sometimes just being able to sit and talk to the parents, providing them with advice and comfort. Although some may not see this as being most important, it is in many ways invaluable to the families to have someone around to fulfill this role.

The challenges faced by parents in the NICU can be placed into the same broad categories as the medical team: clinical, ethical, and subjective. Lantos (2006) studied the clinical judgments of parents, and how they are going to have their own preferences despite not having the same expertise or knowledge as the medical team. Neonatologist 2 acknowledged the clinical experience held by the medical team that allows them to know what is going on, and that parents do not have such experience but are still making the bulk of decisions. Ethically, Lantos (2006) stressed autonomy as a general principle in the NICU, while Stutts and Schloemann (2002) presented a specific case study that highlights and recognizes that parents should be the ones making the ultimate choices for their infants. Neonatologist 2 mentioned there is a certain degree of autonomy that parents have for their own baby, but at the same time there is a role that physicians must

play in emergent situations. Other neonatologists reacted in a similar fashion, explaining that parental autonomy is important but is not the overriding principle for decisions. Instead, they claimed that acting in the best interest of the baby is the ultimate goal.

Additional challenges faced by parents included personal values, past experiences, culture, and spirituality (Stutts and Schloemann 2002). All members of the medical team discussed these challenges. Williams et al. (2009) constructed a questionnaire that showed health care workers are concerned about how to support parents, and generally they do a good job of providing support. Nurse 5 stressed the importance of being honest with families and treating each situation as being unique and individual, as different parents are going to perceive and react to situations differently. Nurse 6 noted that culture is a large challenge, as well as the past experience of the parents with death or end of life that they are going to bring to the table when making decisions.

The undercurrent of spirituality and religiosity was revealed through an analysis of framing and its effect on decisions (Haward et al. 2008). Chaplain 2 admitted it would be beneficial for the medical team to share in open discussion with the family of faith more broadly, as opposed to specific religious beliefs. York (1987) provided a discussion of the role of social workers; because this current study only interviewed one social worker, it is difficult to speak definitively regarding York's study. However, Social Worker 1 agreed with the role of social workers as being advocates for the baby and parents, who can provide a great deal of emotional support for parents and their belief system.

Through an examination of the literature as well as the interview data collected, it is clear the data has confirmed the majority of existing sources. Religion is a variable that sparks a lot of discussion among neonatologists, nurses, chaplains, and social workers. There are many issues on which these individuals do not agree upon, or view differently as a result of their own personal biases or perspectives. Religion provides comfort and meaning for individuals who hold those beliefs, and as stated simply in one interview, “you can’t argue with faith”. In addition, it appears that it is faith more generally and not one’s specific religious principles that matter in the grand scheme of things. In other words what is more important is the fact that parents hold religious beliefs and have a faith that is a strong guiding force in their life as opposed to the details of one’s religion.

CHAPTER 5: CONCLUSION

Existing literature has discussed religion as being important from a sociological perspective, having a presence in the NICU decision-making process. This thesis aimed to further explore the concept of religion and the degree to which it is capable of influencing decisions in the NICU. This was a twofold analysis, looking from the sides of both the medical team and the parents. Results from face-to-face interviews revealed that religion in fact does hold a very important, yet complex place in the NICU when an infant is at the end of life. This thesis provided a more thorough examination of religion specifically as a social variable, aiming to present a twofold analysis of the perspectives of the medical team and parents on how religion affects decisions made in the NICU.

The information found in the results reveals a great deal about the underlying presence that religion may have in the NICU. Although the literature acknowledges religion as a potential variable for consideration, the results of my interviews demonstrates that the role of religion may be undermined to an extent, and in fact be a much more significant component of the decision-making process for both the medical team and parents. Through the interviews, it was revealed that the life of these newborns is a very important priority in such an ethically charged environment. Religion has the ability to make the process of decision-making much more difficult and complex, as individuals who look to religion in their own lives are going to bring that with them into discussion in the NICU. Whether explicitly admitted or not, it became apparent that the majority of interviewees did let religious beliefs influence decisions made in the NICU.

There were a number of limitations of this study. The results may be biased to an extent, since the sample for the interviews came from only two specific hospitals in New

York. There was also an obstacle in interviewing social workers. This was not strictly because of the time frame, although with more time I am sure I could have obtained more interviews from social workers. The main reason for this obstacle was the perception from other members of the medical team that there was a lack of representation of social workers who were enthusiastic and willing to be interviewed. At times, I would simply be steered away from approaching certain individuals as well due to their lack of participation in the process of decision-making in the NICU. Last, the sample size was relatively small, and so this did not allow for generalizing about what goes on in all NICUs. As a result, the conclusions drawn are going to be relatively speculative.

The research conducted was successful in shedding more light on religion, but further research should be done on this sensitive, unique topic of religion and its effects on end of life decisions in the NICU. For future research, it would be beneficial to conduct interviews with parents to provide more information on the parents' side of things. This analysis was aimed at being two-fold, so by interviewing parents who have been through these things in the NICU, it may shed more light on their views as well as reveal information about the religion of the medical staff. The medical staff's religious beliefs were not discussed nearly as much as the religion of the parents or families.

Interviewing parents may provide more information on how the religion of the medical staff affects medical decision-making. In addition, the concepts of miracles in the NICU may be a narrower topic to explore further due to the amount of discussion it brought throughout the interviews. In addition, further research should explore the potential differences between secular and religious hospital NICUs, as this may be relevant on a larger scale when able to include more hospitals in a study.

This study has some implications based upon the findings. Primarily, it would be most beneficial to be open regarding religion and its role in each specific case in the NICU. If religion is in fact present, and it is a part of the lives of those involved, instead of overlooking these beliefs they should be integrated into the decision-making process in the best, most effective way possible. Religion is such a powerful social force that it would be impractical to pretend that it does not come in the way of decisions that are made in certain cases. Therefore, both medical team members and parents should be more attentive to religion and beliefs more generally in order to have a concrete understanding of some perceptions that may not make sense objectively. It is important to look at the bigger picture, as the reality is that despite claims that decisions are becoming increasingly secular, this is a highly subjective world, and not only does this hold true for the NICU, but it is just one great exemplification of this fact. Although there is pressure to never let religion matter considerably, religion does appear to matter and therefore is deserving of attention.

The principles that Berger (1969) addresses are most relevant to the NICU. When you are dealing with infants, death is not the normal course of events and therefore there is going to be more controversy and in the minds of parents, more legitimization of decisions that are made here. Considering the stress regarding miracles, there is now question as to who really decides the fate of these sick infants. Many people will fall back on religious and faith issues, and Berger sees religion as a tool for explaining, interpreting, or validating events that occur. Whether it is the medical team or the parents, religion has the ability to be that means by which people in the NICU can deal with

situations that are challenging to accept or come to agreement on. Berger ultimately provides the most relevant sociological theory to the issues that appear in the NICU.

The lives of these newborns admitted into the NICU are wholly affected by the decisions made by parents and medical team members- such patients will never have the ability to contribute or have a say with regards to their own fate. These patients are the most innocent, sensitive, and fragile, and these factors underscore the importance of this topic and the need for the further research suggested. These interviews helped to illuminate and substantiate very important points with regards to religion as a social variable, and more broadly religion in decision-making as a sociological topic. Advances in medical science will not address the issues that come up in the NICU, as technology only enables us to do more to sustain life. This potentially will only serve to further complicate things from an ethical standpoint. So, these incredibly important lessons learned should be analyzed and built upon in the future.

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APPENDIX A: SET OF OBJECTIVE QUESTIONS FOR INTERVIEWEES

OBJECTIVE QUESTIONS (to be handed and completed in the beginning of the interview, after the consent form is filled out).

What is your gender?

What is your age?

What is your personal religion or belief system?

How long have you been serving/had served the NICU?

What is your profession, and how would you describe your role in the NICU, specifically when infants are at the end of life?

For the following statements, please tell me whether you agree or disagree with the statement.

Generally, religious perspectives have the ability to influence decisions that are made in the NICU.

→Strongly Disagree-Disagree-Neutral-Agree-Strongly Agree←

Religious commitments can become a source of conflict between parents and the medical team.

→Strongly Disagree-Disagree-Neutral-Agree-Strongly Agree←

APPENDIX B: INTERVIEW GUIDE FOR NEONATOLOGISTS

Do you believe that religion or belief systems should be considered in the decision making process when an infant is at the end of life?

If you answered yes to the previous question, how do you feel that your own religion or belief system belongs or is a part of the decision making process?

If you answered no to the previous question, what is your reasoning for not considering religion in the medical decision making process for an infant in the NICU?

What kind of role do you believe you play specifically in the decision making process when an infant is at the end of life? For example, do you wish to make the decision yourself, advise the parents, support the parents, or something else?

Neonatologists/Nurses: Do you feel that your loyalty is to be there for the parents, supporting their autonomy, or to defend the medical team and medical knowledge more generally for decisions and outcomes?

Are there notable cases that you felt religion played an important or interesting role at the end of life? This can be either the religion of the infant/family, medical team, or both?

If so, would you like to discuss one or some of these case(s) with the trust and understanding that I will not reveal any identifying features which may be traced back to any patients?

(If not, would you like to expand on why you think religion does not influence decisions in the NICU for infants who are at the end of life)?

Within these cases:

Did you feel that religion influenced any members in the decision making process?

When or if conflicts did arise with regards to religion, how did you handle it and what did you feel was important?

Is there something other than religion that you feel has an effect on end-of-life decisions in the NICU? This can be from either the medical team, the patient or family, or both. (values, past experiences, culture).

*For Neonatologists:

More generally, the heart of nearly all ethical dilemmas boils down to physician's beneficence versus patient autonomy. Where do you personally stand on this spectrum of potential viewpoints on who should have control, ultimately, of decisions?

In the NICU, the patient is an infant who cannot voice their own opinions and this typically results in the parents speaking on their behalf. Does this change how you feel about who should control such decisions?

APPENDIX C: INTERVIEW GUIDE FOR NURSES

Do you believe that religion or belief systems should be considered in the decision making process when an infant is at the end of life?

If you answered yes to the previous question, how do you feel that your own religion or belief system belongs or is a part of the decision making process?

If you answered no to the previous question, what is your reasoning for not considering religion in the medical decision making process for an infant in the NICU?

What kind of role do you believe you play specifically in the decision making process when an infant is at the end of life? For example, do you wish to make the decision yourself, advise the parents, support the parents, or something else?

Neonatologists/Nurses: Do you feel that your loyalty is to be there for the parents, supporting their autonomy, or to defend the medical team and medical knowledge more generally for decisions and outcomes?

Are there notable cases that you felt religion played an important or interesting role at the end of life? This can be either the religion of the infant/family, medical team, or both?

If so, would you like to discuss one or some of these case(s) with the trust and understanding that I will not reveal any identifying features which may be traced back to any patients?

(If not, would you like to expand on why you think religion does not influence decisions in the NICU for infants who are at the end of life)?

Within these cases:

Did you feel that religion influenced any members in the decision making process?

When or if conflicts did arise with regards to religion, how did you handle it and what did you feel was important?

Is there something other than religion that you feel has an effect on end-of-life decisions in the NICU? This can be from either the medical team, the patient or family, or both. (values, past experiences, culture).

*For Nurses

Nurses are unique members of the medical team, as they are frequently the ones spending the most time at the bedside with the infant.

There was a study done last year that looked at moral distress among nurses, which is often not acknowledged properly or overlooked. How do you see religion as a part of the many conflicts and internal issues you encounter when infants are at the end of life?

Do you believe that the amount of time or potential emotional connection you have with an infant gives you a different perspective than other members of the medical team? If so, can you explain it a little more?

A past study revealed that nurses in particular were praying for their infants. Have you ever prayed for an infant? What motivated you to do this? For example, was it your own religion, their religion, or something else?

APPENDIX D: INTERVIEW GUIDE FOR CHAPLAINS

Do you believe that religion or belief systems should be considered in the decision making process when an infant is at the end of life?

If you answered yes to the previous question, how do you feel that your own religion or belief system belongs or is a part of the decision making process?

If you answered no to the previous question, what is your reasoning for not considering religion in the medical decision making process for an infant in the NICU?

What kind of role do you believe you play specifically in the decision making process when an infant is at the end of life? For example, do you wish to make the decision yourself, advise the parents, support the parents, or something else?

Social Workers/Chaplains: Do you feel that your loyalty is to be there for the parents, medical staff, both, or somewhere in the middle?

Are there notable cases that you felt religion played an important or interesting role at the end of life? This can be either the religion of the infant/family, medical team, or both?

If so, would you like to discuss one or some of these case(s) with the trust and understanding that I will not reveal any identifying features which may be traced back to any patients?

(If not, would you like to expand on why you think religion does not influence decisions in the NICU for infants who are at the end of life)?

Within these cases:

Did you feel that religion influenced any members in the decision making process?

When or if conflicts did arise with regards to religion, how did you handle it and what did you feel was important?

Is there something other than religion that you feel has an effect on end-of-life decisions in the NICU? This can be from either the medical team, the patient or family, or both. (values, past experiences, culture).

*For Chaplains:

To what extent do your own religious commitments influence the advice that you give to parents and physicians of a different religious persuasion? Do you speak on behalf of your own belief system, their belief system, or somewhere in the middle?

People frequently look to religion to provide them with advice, or the answers to life's most difficult questions.

1-Would you like to see religion as something that is more talked about towards the end of life among the medical staff and family? Please explain.

2-Do you feel that the medical team acknowledges religion always? Is it often not mentioned or thought about? Please explain.

3-Do you find parents at times hesitant to express their religious concerns to medical staff out of some kind of fear-that they won't understand, won't listen, or these concerns will be dismissed. Please explain.

APPENDIX E: INTERVIEW GUIDE FOR SOCIAL WORKERS

Do you believe that religion or belief systems should be considered in the decision making process when an infant is at the end of life?

If you answered yes to the previous question, how do you feel that your own religion or belief system belongs or is a part of the decision making process?

If you answered no to the previous question, what is your reasoning for not considering religion in the medical decision making process for an infant in the NICU?

What kind of role do you believe you play specifically in the decision making process when an infant is at the end of life? For example, do you wish to make the decision yourself, advise the parents, support the parents, or something else?

Social Workers/Chaplains: Do you feel that your loyalty is to be there for the parents, medical staff, both, or somewhere in the middle?

Are there notable cases that you felt religion played an important or interesting role at the end of life? This can be either the religion of the infant/family, medical team, or both?

If so, would you like to discuss one or some of these case(s) with the trust and understanding that I will not reveal any identifying features which may be traced back to any patients?

(If not, would you like to expand on why you think religion does not influence decisions in the NICU for infants who are at the end of life)?

Within these cases:

Did you feel that religion influenced any members in the decision making process?

When or if conflicts did arise with regards to religion, how did you handle it and what did you feel was important?

Is there something other than religion that you feel has an effect on end-of-life decisions in the NICU? This can be from either the medical team, the patient or family, or both. (values, past experiences, culture).

For Social Workers:

A past study looked at religious-based denial in the NICU and how social workers could be advocates for families, providing emotional support and support for their belief system, helping to integrate religious beliefs into decision-making models. In many ways, they can be a mediator and middle point to bridge communication gaps between the parents and NICU staff.

Do you believe this is true of social workers, and have you personally accomplished integrating or even acknowledging religion in any NICU cases?

APPENDIX F: INFORMED CONSENT FORM

My name is Maria Battaglia, and I am a student at Union College. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. A description of the study is written below.

I am interested in learning more about religion as a variable in NICU end of life decisions. You will be asked to answer a series of questions that relate to this topic. This will take approximately 30-60 minutes. The risk of participating in this study is that information provided is not accurately restated in my thesis. These risks will be minimized by assurance that I will accurately report what I learn and also preserve confidential information, including the name of you, your institution, and other identifying characteristics. If you no longer wish to continue, you have the right to withdraw from the study, without penalty, at any time.

Again, all information will be kept confidential.

I understand that even though all aspects of the interview may not be explained to me beforehand (e.g., the entire purpose), during the debriefing session I will be given further information and have the opportunity to ask questions.

All of my questions have been answered and I wish to participate in this research study.

Signature of participant

Date

Print name of participant

Name of investigator

Date

APPENDIX G: WRITTEN DEBRIEFING FORM

My name is Maria Battaglia- I am a senior at Union College in the Leadership in Medicine Program, an 8-year combined degree program with Albany Medical College. I am doing my thesis on end-of-life decisions in the NICU, and the degree to which religion may play a role in making these decisions. For part of my research, I wish to conduct interviews of neonatologists, nurses, social workers, and chaplains. I will do my best to accurately report any information you give me so that I do not misrepresent things that were said during the interview.

All identifying characteristics in my notes that can potentially go into my thesis will be kept confidential and not disclosed in the final paper; this includes the name of the medical institution, your name, as well as the names of all individuals who could be the topic of discussion. The only features which would be mentioned are the fact that it is in a NICU setting, your role in the NICU, and any patient's medical condition, gender, age, and religion and *only* where relevant. This is because the central focus of my thesis is on religion as a social variable, and these are some characteristics that may prove to be important and beneficial in my analysis. It is very important to me that I respect my interviewees' HIPAA obligations.

If you have any questions, please do not hesitate to ask or discuss these with me now.

Thank you for participating in my study.