

DECODING MIRACLES: THE ETHICS OF ENGAGING RELIGIOUS AND
SPIRITUAL PERSPECTIVES IN THE NEONATAL INTENSIVE CARE UNIT

BY

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“Should you shield the canyons from the windstorms, you would never see the beauty of their carvings.” –Elisabeth Kübler-Ross, *On Children and Death*

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LIST OF ABBREVIATIONS

NICU Neonatal Intensive Care Unit

PBUH Peace Be Upon Him

ABSTRACT

There are few places in a hospital that have as rich a bed of ethical, moral, and religious issues as the NICU. Physicians and staff of the NICU find themselves on the cusp of life and death caring for tiny lives wracked with illness. A conglomerate of ethical issues makes communication paramount for parents and practitioners in ascertaining best outcomes for babies. In this thesis I focus on religious and spiritual perspectives introduced to neonatal care by parents and families in statements and questions such as “We are praying for a miracle”; “We believe there will be a miracle”; “We believe you/God will perform a miracle”; and “Do you believe in miracles?” I examine the miracle teachings of Abrahamic religions Judaism, Christianity, and Islam to better understand what miracles are and when and why they have been recorded as happening. To understand the physician/patient relationship and shared decision making process, I recount the history of the physician/patient relationship. Finally, I examine what potential responses from physicians and care team members hinder or facilitate the therapeutic alliance. I propose that if properly addressed, miracle language can be a miracle for the NICU practitioners and support staff in helping the therapeutic alliance.

INTRODUCTION

There is no better way to discuss ethics and theology than enlisting the example of suffering or dying babies. It is the quintessential example given to philosophy undergraduates when examining utilitarianism, or to Divinity School students considering the problem of evil (theodicy or Providence). The real life scenario faces practitioners and families every day in the neonatal intensive care unit (NICU) and, truthfully, there are few places in a hospital that have as rich a bed of ethical, moral and religious issues as the NICU. Physicians and staff of the NICU find themselves on the cusp of life and death, tiny lives wracked with illness (suffering) every second of the day. Care team members are engaged in saving lives through technologies, pharmaceuticals, surgeries and methods that are innovative and ever changing. There are evolving and established treatments and diagnostic methods that at one time or another were impossible, and targeted diagnoses that are extraordinarily rare. The field of neonatology is young, not yet 50 years old (Phillips, 2005), and not globally accessible, making many of the medical options and ethical issues unique to the First World. Additionally, the patients are not able to speak or advocate for themselves, so their assent cannot be obtained, and their preferences cannot be discerned.

This conglomerate of ethical issues exists in the daily functioning of the unit, making communication paramount among practitioners and between practitioners and parents. Parents and practitioners strive to meet on the common ground of best outcomes for their babies, but the means for effective communication are not neatly afforded in the NICU. A NICU parent can be anyone, with any combination of medical experience, language, socioeconomic situation, religious affinity, educational background and

psychological coping abilities. Care team members too, approach the NICU with their own set of experiences and personal perspectives. When so much is at stake and with so many different people involved, objectives, perceptions, understanding and discussion can become strained. I argue that moments of opportunity for effective communication into the NICU world are presented when parents discuss treatment or their understanding of pathology in terms of religious or spiritual perspectives. In this thesis, I focus on religious and spiritual perspectives that are introduced to neonatal care by parents and family in statements and questions such as “We are praying for a miracle,” “We believe there will be a miracle,” “We believe you/God will perform a miracle,” and “Do you believe in miracles?” What do these invocations mean? What problems can they cause or address? What solutions do religious petitions from parents offer for communication?

Have We Tried to Change God?

It is nearly impossible for a spiritual or religious person to escape the issues of theodicy (the problem of evil, Providence or when bad things happen to good people) one encounters in the NICU. In conjunction with the suffering of tiny babies, medical interventions and therapies have been developed in rapid succession and now enable first world countries to sustain life that 20 to 40 years ago was impossible. The presence of so many new and advanced medical technologies to help neonates survive is an astounding testimony to the powers of science. Have members of both the medical and patient worlds shifted their understanding of God and suffering in light of the advances of modern medicine? As one author notes, “[t]he advances in medical care brought about in part by modern technology reinforces our ‘living forever’ fantasy” (York, 1987, p. 33). We have constructed these neonatal intensive care units to “protect our children from

death” (Hauerwas, 1975/1987, as cited in York, 1987, p. 31), and thereby furthered our fear of death: “We are in an age of abnormal fear of dying. When we were born at home and died at home, death was often looked upon as a release from suffering, a deliverance to be welcomed, a friend to be accepted, if not loved” (Stahlman, 1979/1981, as cited in York, 1987, p. 33). In my discussions with a rabbi I asked the question, “Have we changed our understanding of suffering and Yahweh because we are now able to do so much in medicine and technology? Do we now think suffering is an archaic concept, and that when a baby dies or suffers, it completely uproots our constructed perceptions of the world, suffering and God?” We agreed that we have:

The fact that modern medicine gives us hope for survival has positive implications for society. However, when this hope leads to an unhealthy fear of death or denial of death, we are confronted with serious problems in making treatment decisions. (York, 1987, p. 34)

We now have more control over things we were at the mercy of 20 to 40 years ago: extreme prematurity, lung and respiratory dysfunction, cardio-vascular disorders, and a number of birth defects that can now be corrected with relatively low risk interventions. Suffering can be intervened upon, *we* can offset death, and for religious persons, this ability has been imparted by God. Our “powers” have increased by divine design. Therefore, the experience of suffering the death of a child or infant is particularly shocking. There is a bit of magical thinking in how we regard our command over disease and illness. Maybe there’s been a false mounting of confidence to believe that we can change God’s mind or that we are in closer communion with Him and His work in the world. When malignant illness happens and we find ourselves at the mercy of its

prognosis, it shatters our world of meaning (Hyde, 2006). What have we failed to do? Why did God fail us? Why does suffering keep happening?

This process, I think, is exemplified in the media and social media. Television and mass media report on miracle births and miracle medicine. Parents and their supporters rally “prayer warriors” and the “power of prayer” on blog posts and group pages. Our society’s perceived control and expectation of success with modern medicine and science has shifted our appreciation of human beings’ ultimate vulnerability to suffering. For the religious person, all the knowledge and ability of modern medicine is bestowed by God, so perhaps suffering is now outmoded by God. In fact, nothing about our vulnerability has changed. While science has made many advances, there is still a limit to what it can do. We, as members of the human species, at some point will encounter the vulnerability to suffering, to entropy, that shows no favoritism or justice. My thesis seeks to explore the struggle of families and physicians when confronting the suffering of innocents, and the difficulty they have with coming to terms with problem of evil (theodicy). I will investigate how religion and spirituality allow a better physician-family relationship in the NICU when both physicians and families encounter innocents suffering and are willing to engage each other over the resultant emotional and spiritual issues.

Steps to Decoding Miracles

My research into theology and the genesis of the patient-doctor relationship uncovered several key issues for my thesis. There is a deeply held theological, philosophical and psychological aversion to the experience of suffering, especially the suffering of innocents. This angst also affects the physician/patient relationship. For physicians and families, the experience of the innocents suffering can affect the ways in

which communication and trust are achieved, and thus greatly influence how care and pathology are perceived. In this thesis I review aspects of the emergence of religious language in the NICU setting and examine how it can help or hinder the therapeutic alliance.

My thesis also draws on a literature review and conversations I was able to have with various NICU/PICU practitioners on the topic of religious or spiritual discussions in medical care. I address communication in the NICU, what current issues exist, and how religious language can either damage or strengthen the therapeutic alliance. I also show how communication offers a unique tool for facilitating a physician-family care alliance, in particular in response to certain “cues” from families, via the miracle language they use. I asked practitioners how religious perspectives on care have arisen in their experience, how they have addressed religious and spiritual language, and what issues it raises for the team in the NICU. Additionally I had discussions with the Chaplain team as well as other hospital consultation teams—ethics, social work and nursing—to understand more about what religious perspectives on care mean to them and how they believe religion should be addressed or has been a problem. Community resources (ministers, imams and rabbis, other scholars on communication, theology and medicine) also provided important insight into the opportunities and challenges of medicine and religion, therapeutic alliance and coping.

My first chapter delves into the relationship between miracles, magic and medicine from the theological perspectives of Judaism, Christianity and Islam. This chapter reviews literature on miracles in the practical sense: When have miracles occurred? Why have they occurred (for what purpose)? What makes them different from

magic? When they are seen as medical miracles (changes in a person's pathology that result in healing), what do these religious traditions teach about these divine interventions? I also include insights I gained from non-clinical members of the medical team (chaplains, psychologists, and social workers), as well as community religious leaders on their understanding of miracles and how families expecting miracles should be addressed. Because they lack knowledge of or experience with their baby's medical condition and face grim prognoses, faith may be all that some of these families have. Parents can have an ambitious expectation of miracles. This may be coupled with an unrealistic expectation of the ability of medicine; parents may believe that advances in medicine can do more than medicine is actually able to do. In such cases, how does addressing or not addressing miracles affect these families? How should these invocations for miracles be handled? What do practitioners need to understand about miracle language? How and when can the medical and support teams speak to their understandings of miracles?

The second chapter navigates the history of the patient/physician relationship. What beliefs about how physicians should interact with their patients have been carried over throughout the history of medicine? There is a deep-seated and longstanding history and psychology of physicians' assuming the role that Percival charged them with as "minsters of hope" (Katz, 1984, p. 18). Does this role give rise to inner conflict in the physician and consequently create conflict in the patient/physician relationship? Must physicians examine their own religious or spiritual beliefs in order to come to terms with in order to be effective in their practice and communications with parents? What does the history of the physician/patient relationship mean for understanding the psychology of

physicians confronting their own issues with Providence, theodicy or perceived unfairness (when bad things happen to good, or innocent, people)? How do physicians' perspectives on these issues affect communication and trust between physician and patient?

My third chapter focuses on developing the relationship between scholarly understanding and practical application, based on discussions with neonatologists and pediatric surgeons. I examine different approaches that can be taken by physicians, and identify what seems to be effective in engaging families in these religious discussions and what seems to be less effective. I also review the problems that not being able to engage in these discussion has caused for physicians and families.

I conclude in my fourth chapter with ideas on how to use miracle language as an opportunity for better communication. Here I posit that despite radical variations in personal religious, spiritual, and mystical perspectives, when the opportunities for such discussions arise meaningful conversations can occur and improve the relationship between physicians and families in the NICU. I also assert that physicians should develop their own meaningful understandings of the purpose and function of suffering in order to avoid burnout. Their confidence in this perspective can form the foundation for positive communication and empathetic engagement with parents when religious language is used. I propose that if properly addressed, miracle language can be a miracle for the NICU practitioners and support staff in helping the therapeutic alliance.

CHAPTER 1. THE DISTRESSFUL MAGIC OF MIRACLES

Forewarning

The purpose of this thesis is not to provide means of discrediting deeply held values and convictions. As Kee (1986) notes, “It would be a serious historical error to assume . . . that the medical approach to health was the province of the intellectuals, while religion and magic were left to the ignorant, or that intellectuals universally respected the medical profession and shared its basic outlook” (p. 5). The hope for this work is to provide meaningful insight for better communication. I find it beneficial to discuss the genesis of the topics at hand, from a very basic and scholarly and historical position. Granting that there is substantial emotional value to religious constructs for those with religious and spiritual beliefs, I want to provide an understanding of the concepts of miracles, magic and medicine from various religious perspectives at a very simple and fundamental level.

This chapter covers only the three major Abrahamic monotheistic religions: Judaism, Christianity and Islam. This limitation is exclusively for the logistical purpose of fitting the extensive discussion on the intersection of religion and medicine into a manageable length. However, this work should provide a starting point for the intended goal of better facilitating medical discussion from any religious perspective.

My overview of the religious texts/principles is also necessarily limited. Much has been written on these theological touchstones and many points can be well disputed. My goal in this thesis is to focus on commonalities that can be found by a meaningful review of certain features of these religious texts and practices. This is not to say that variant positions are neither important nor meaningful. However, the attempt of this thesis is to

posit hope for engaged communication and relationships between practitioners, patients, and families, not to discuss differences in theological doctrine.

On a personal note, through the detailed and engrossed journey I took through each of these traditions, I am further assured of the deep human commonality towards compassion and peace. The importance of this thesis is to advance the argument that whether based in the demands of ethics or religious morality, the human experience of suffering and illness can and ought to be meaningfully engaged in by all parties involved in medical care.

The Evolution of Miracles

Religious traditions, similar to scientific inquiry, have roots in man's attempt to understand the world around him. Kierkegaard (1843/1983) states, "It is true that science and scholarship consider and interpret life and man's relationship to God in this life" (p. 209). How did this earth, humans and animals come to be? Distinctly for religion, what are our purposes? Why is there suffering? Why do the righteous suffer? Religious texts attempt to unravel the mysteries of the natural world and perceived injustices through stories and parables while positing morality and hope. As the Jewish, Christian and Islamic faiths began to emerge, there were intersections between these religions and the growing body of science. Religion and science were fumbling toward similar ends:

The fundamental aim of primitive religion was to safeguard life, which was achieved by certain simple mechanical procedures based on rational inference, but often upon false premises. Primitive medicine sought to achieve the same end, and not unnaturally used the same means. Hence in the beginning religion and

medicine were parts of the same discipline, of which magic was merely a department. (G.E. Smith, as cited in Kee, 1986, p. 5)

While the modes were different, at the outset, the journeys of religion and medical science were on similar paths, to understand and thwart human suffering.

In an interview, Desmond Tutu states that “[m]ost of the Bible is written either out of or into situations of suffering” (Trenoweth, 1995, p. 12). The difficulty for religion is to explain why suffering happens to the innocent or seems to be without justice or cause. For Judaism and Christianity, God does not intervene in suffering for one of two reasons: Either (a) God is limited in His ability to intercede against real evil, or (b) God does not meddle with the mechanisms He has set in motion here on Earth (Edwards, 2010; Kushner, 1981; Hunter, 1990). According to an imam and an Islamic scholar I conferred with about Islam, there is no reason to question the happenings of this world. Allah is ultimately in control and we are to submit to his plan, which we could not possibly understand. Our human history includes much suffering: the suffering and genocide of Native Americans in the U.S., the ongoing struggles of the African nations, the Holocaust, countless violent wars, slavery, racism, sexism, disease, and, important to this thesis, miscarriages, and the suffering and death of the newly born. Senseless suffering provokes pleas for reprieve from people across the world. Biblical books of the Abrahamic traditions include the Books of Job and Habakkuk. These stories are filled with the pleas of prophets in despair, looking for divine justice and absolution from what seems to be unjust suffering. When relief mysteriously or unbelievably happens, humanity has often referred to this as a “miracle.”

So what is a miracle and when does it happen? Dr. Greg Schmidt Goering, Th.D., with whom I discussed the topic, remarked that it would be best to discuss the root of the word, from Latin, *miraculum*, a wonder, marvel, or from *mirari*, to wonder at (personal communication, January, 13, 2015). Edwards (2010) discusses Aquinas's take on miracles, noting that the "word miracle comes from the Latin word *admiratio*, suggesting the wonder that accompanies the experience of something whose cause is hidden from us" (p. 83). An incident, thing, or achievement is said to be a miracle when it supersedes our understanding of the natural order, or of what we have come to know about the world. When something happens that exceeds our understanding, these experiences put us in a state of wonderment. As I discussed with Dr. Goering and with physicians, we experience wonderment sometimes by everyday miracles: looking up at the right time to avoid a collision on the interstate, watching the birth of a baby, or when your laptop works even after your small child dumps a Coke into it. "It was a miracle!" we often gasp. This understanding is helpful for several reasons. Miracles are often identified as such by the observer. What one person may view as a miracle can be more easily explained by someone else—the computer tech who repairs my computer from the Coke incident does not consider himself to have divine powers. Neither does the obstetrician who delivered my children. Yet the experiences can put one in positions of genuine *mirari*. That the event deemed "miraculous" can be explained does not diminish the experience of wonderment for other observers.

Dr. Goering observed that miracles are often events and accomplishments noted for two features: first, miracles seem to be important for the element of *faith* that is involved; and second, these events seem to be so profound because they somehow

interfere with what is expected of the “natural order” or “natural law.” Natural order and natural law are debatable terms that I will not address here. However, I will state that for definition purposes, a miracle from both religious and nonreligious perspectives is an event that was not anticipated, based on either experience or what is known or expected. Erhman (2004) states that “it is probably better to think of miracles not as supernatural violations of natural laws, but as events that contradict the normal workings of nature in such a way as to be virtually beyond belief and to require an acknowledgement that supernatural forces have been at work” (p. 226).

Miracles also have an element of faith that is important to their value. In *Fear and Trembling*, Kierkegaard (1843/1983) notes miracles follow endurance through *ordeal* (pp. 19, 22), in which faith in God’s will plays a particularly important role. He emphasizes this in the story of Abraham, Isaac and the ram. Readers of the story typically know the outcome, or once they know the outcome (miracle), then the process—the *ordeal*—may not be appreciated (pp. 52–53). Kierkegaard remarks how the ordeal of Abraham spending three days journeying and preparing to kill his own son should not be lost in how the story ends; Abraham was prepared to follow God’s command until the end, faithfully. This could extend to any number of the stories in the Jewish text. Moses and Aaron clearly had an extensive “ordeal” (or suffering) with the Pharaoh, and never once knew that God would part the Red Sea. Yet their *faith* called them to *action* and led them through an *ordeal*. The miracle was never promised or indicated, nor was it “owed” to them because of their faithfulness. The prophets in these stories have *faith* that whatever the end result is the will of God, so they *act* as called, and endure the *ordeal* without expectation or knowledge of a coming miracle.

Often, miracles are grouped with “signs and wonders” and noted to happen when God acts on behalf of His people, for “redemptive purposes for his covenant people, and to bear testimony to his control of the events of history” and to confirm “prophetic call” (Kee, 1986, p. 11). Signs and wonders are referred to in the Hebrew Bible, New Testament, and the Qur’an, and these three texts share many of the same stories, such as Noah and the flood, and Moses and the parting of the Red Sea. In the New Testament, miracles (or signs and wonders) happen with exorcisms, walking on water, and healing acts performed by Jesus, and in the Qur’an the miracle (or signs and wonder) is the revelations of the Holy Book to the Prophet Mohammad (Peace Be Upon Him or PBUH).

What is true about miracles? What is their purpose theologically and how do they differ from magic? To be clear, we cannot historically “*show* that [miracles] have ever happened” (Erhman, 2004, p. 226). It is important then to understand *when* they happened in the sacred texts, and what theologically Yahweh, God, or Allah intended by them. The insight will hopefully allow a better understanding of the intersection of medicine and religion in a family’s hope for a miracle. These sections will provide some theological understanding of the role and purpose of miracles.

Religion and Medicine: A Brief History

I believe there has not been much of change in how ancient and modern religious people view the function of science. Erhman (2004) states that

[f]or people in Greco-Roman times, the universe was made up of the material world, divine beings, humans, and animals, with everyone and everything having a place and a sphere of authorship . . . a person, like Jesus or Apollonius, stood in special relation to the gods. For someone like this to heal the sick or raise the dead

was not a miracle in the sense that it violated the natural order; rather it was “spectacular” in the sense that such things did not happen very often . . . [a]nd when they did happen they were a marvel to behold. (p. 226)

This world view has not changed much for religious people today. Because medical knowledge is the privilege of trained physicians, the everyday miracles of medicine affect members of modern society much as they did the ancients. Cures and interventions are spectacular to those who behold them from outside this skill and knowledge set.

Additionally, followers of Judaism, Christianity, or Islam believe that God is at work in our lives (to some degree): our medical knowledge, why illness happens, and when we suffer is the will of God or a part of the workings of God. Physicians are believed to have their unique skills and ability due to the will of God and God-given talents; in Chapter 2, I explore this special relationship further.

Kee traces the roots of ancient medical history through Pliny, Alcmaeon, Hippocrates, Celsus, Dioscorides, Rufus of Ephesus and Galen, who were starting to lay “the very foundation of science, for the distinction between the permanent and the transient, between cause and effect, natural or normal and accidental, health and disease” (Heidel as cited by Kee, 1986, p. 30). Medical science was beginning to understand the phenomena of health and disease from observation and experimentation: “Medicine in this period relied heavily on the accumulation of information through casebooks, records of plagues, and the reports of new species of plants and animals” (Kee, 1986, p. 29). Nonetheless, many of the ancient Hippocratic physicians attributed their knowledge and prayed to Asklepios, the son of Apollo and god of healing. Asklepios’s serpent staff is still used as the symbol of medicine to this day. “[T]here was no cleft between medicine

and the ministrations of the gods” (Kee, 1986, p. 28). Knowledge of medicine and its successful practice was granted and bestowed by the gods.

Where science lacked the understanding, religious perspectives filled the gaps—a phenomena we still witness in theists today. When healing is achieved (or not achieved) beyond what is scientifically known, the explanation for these events has often been filled in by theology (the belief that a miracle has occurred, or that illness has been caused by sin or transgression). When the scientific knowledge of healing or disease is not widely understood or accessible, people find their own understandings of these experiences based on their theological perspectives. Explaining these gaps in understanding using miracles or divine justice is referred to as God in the gaps (Bonhoeffer, 1953, pp. 311–312). Illness and suffering have a purpose denoted by the justice of the gods or God and reprieve comes by performing the right acts, rituals, or prayers, and demonstrating the correct faith.

Yet why do some receive divine intervention—a miracle—and some do not?

Miracles and the Holy Texts

Truthfully, there are volumes and volumes on miracles, signs, and wonders, and their function and purpose in the holy texts. My focus in this thesis is “miracle” in the context of improving health care communication. The purpose of my work is to strive for an understanding of the commonalities to sufficiently provide a means for a meaningful conversation in the face of much suffering.

Jewish tradition. What is striking about instances of miracles in the Hebrew Bible is the outlandish circumstances on which the miracle is premised. For example, Genesis 6:11 starts the story of Noah, commanded by Yahweh to build a large boat over

the course of many years to save two “of all living creatures, male and female” to survive the flood sent to “put an end to all people for the earth is filled with violence because of them” (Genesis 6:11-7:24). Noah was 600 years old when the ark was finished, and loaded his family and the animals as directed by Yahweh onto the ark. If we grant this story to be true, it is not far-fetched to believe that those witnessing Noah piecing this massive ship together thought this old man to be out of his mind. Yet Noah completes the task, loads his family and animals on the boat and the flood waters rush in.

Moses receives a sequence of bizarre requests from Yahweh. Several observations are important: (a) there is clear evidence that what God is asking is unbelievable even to the prophets (Moses and Aaron) themselves, (b) while God instructs the prophets to perform the actions, the resulting miracles are attributed to God in a way that is clearly different from the work of sorcerers and magicians, and (c) God’s decision to perform a miracle is not necessitated by the faithfulness or particular action of the prophets.

This delineation is important when discussing the difference between magic and miracles. Moses is instructed in Exodus 6:2-12 by the God of Abraham and Isaac to tell the Israelites that God would lead them from the “yoke of the Egyptians.” Aaron is to take a staff and throw it upon the ground and it will turn into a snake in front of the Pharaoh. This miracle would verify Moses’s communion with God. At court, the wise men, sorcerers, and magicians did the same when instructed by the Pharaoh to match the miracle, yet Aaron’s staff swallowed up the others. Yahweh next tells Aaron and Moses to turn the waters of the Nile into blood; the magicians match the act. It is important to note to whom the act is attributed: Exodus 7:25 states that “Seven days passed after *the Lord* struck the Nile” (emphasis added).

After more plagues, Pharaoh finally tells Moses and Aaron “Up! Leave my people, you and the Israelites!” (Ex 12:31) Yet God still commands Moses to act seemingly senselessly, having him double the Israelites back toward Egypt so that the Pharaoh may think “The Israelites are wandering around the land in confusion” (Ex 14:3). In this time the Pharaoh and his court change their minds, upset at losing the Israelites’ service, and pursue Moses to the Red Sea. God commands Moses to spread his hand over the sea and it will part, allowing the Israelites to pass through. As the Pharaoh’s horses and chariots follow the Israelites through the sea, God tells Moses to stretch his hand back out so that the sea will close over the pursuing Egyptians (Ex 14:12-29). Yet Moses neither turns back to the Red Sea expecting that God will part it, just as Abraham does not know that God will intervene to prevent him from sacrificing Isaac, nor do either prophet’s faithfulness to God’s plan require God to intervene. These miracles are performed in the context of God’s will and God’s sovereignty.

These two stories of Noah and Moses are shared in the Jewish, Christian, and Islamic traditions. It is clear in their textual accounts that one of God’s purposes for miracles is to test the faithfulness of His prophets. If God can part the sea and raise the flood waters, God does not need Moses to spread his hands, Aaron to throw a staff, or Noah to build an ark. So why make use of these prophets? I believe it is to examine the role of faith—both God’s faithfulness (be it by coming alongside His people, or alleviating suffering) and the prophet’s faithfulness to God’s will. God calls people to do outrageous things, and when they step forward and do as directed, God comes through: through an *ordeal*, the prophets *act*, and have *faith* that what will be is the will of God.

When discussing the role of miracles in the Jewish faith, a progressive rabbi said candidly that the Jewish faith calls its followers to petition earnestly for God's intervention in suffering, but to act as if there will not be a miracle. Moses and Aaron had no way of knowing that when they turned back to throw off the Pharaoh, God would also part the Sea; it was their *faith* that was as much a miracle as the sea parting. Pray and believe that God can act in a miracle to relieve suffering, but the question and response of the petitioners should be "how are *we* going to handle this?" Jewish faith, according to this Rabbi's perspective, has come to terms with the nature of suffering on this earth and in this life. Bad things happen without necessary intention from God; for example, there is no clear reason why Moses's Israelites are in bondage to begin with. Their role is to accept, not wonder if the lack of divine intervention is indicative of guilt or sin. Rabbi Saul Berman emphatically addressed this during his plenary (Mohrmann, Arozullah, & Berman, 2015a). Berman stated that it is a Jewish law that Jews *should not* judge a person's suffering or illness to be caused by sin or guilt. Bad things happen in the world, and it is our job to accept that they happen and find out what our next steps need to be.

Christian tradition. In the New Testament, miracles function in a different manner. Ehrman (2004) states that miracles can be perceived in several different ways through their accounts in the various Gospels (signs being performed privately in the Gospel of Mark versus more publicly in the Gospel of John). The Gospel of John asserts that miracles do not *solely* function to prove that Jesus is God's son and divine. In John 4:45-48, Jesus is welcomed by the Galileans, who were interested only in his miracles: "They were not welcoming the Messiah who could save them, but only a miracle worker who could amaze them" (Footnote, John 4:45, NIV Zondervan, p. 1636, 2002). Jesus

speaks in John 4:48 and says “Unless you people see miraculous signs and wonders . . . you will never believe.” His annoyance (Matthew 12:38) with this sort of expectation and belief is clear. He repeats this in John 20:28 when he says, “Because you have seen me, you have believed; blessed are those who have not seen and yet have believed.” From these passages it can be posited that a true believer would not need these sorts of displays as proof (Erhman, 2004, p. 161). These signs were meant to teach a deeper lesson on the nature of God and how humanity should act.

The intention of the sign is not just to validate who Jesus is (Son of God) but to reveal the nature of God. The Hebrew Bible is filled with God’s covenant to a chosen people, God protecting and helping the Israelites, demonstrating His faithfulness to them. In the New Testament, we see God (through his Son) healing anyone, not just the Israelites; God’s mercy and care is to extend to all people. The greater function of the signs in the New Testament is that God is accessible and loves all, and *acts* for others as well. Further, Jesus demonstrates these signs of God’s nature even when “some people could benefit from Jesus’ miracles and yet still not understand what they signified” (Erhman, 2004, p. 161). God’s movement through the world (through Jesus) is to bring healing to the afflicted and hope for a better life after this one (Hunter, 1990, p. 498). This is why God acts through Jesus to heal. Miracles are a show of God’s charge to all people: heal the sick, condemn evil and encourage everyone to know eternal life after death.

In the New Testament, evil is not necessarily the wrongdoing of the individual, but a freely existing force on the earth. Where the God in the Hebrew Bible may afflict those who are sinful with disease and illness,

Jesus and his followers believed that sickness and disease resulted from demon possession rather than from divine punishment of personal or corporate sin.

Illness and disease were regarded as forms of bondage to evil forces, taking place in the depths of a personal being apart from personal choice or control. (Hunter, 1990, p. 498)

In my discussions with religious physicians as well as chaplains and Christian scholars, it became clear that they believe miracles are limited by the sovereignty of God. These individuals discussed at length the power of God, but more importantly, the wisdom of His movements. As I mentioned before, Christ would not indulge the request of the Pharisees for the sake of “performance,” leading one to understand that God’s intention in interceding fulfills a different purpose than just exhibiting His power and ability. These religious scholars all observed that “healing” comes in many forms—and not necessarily the forms we hope for—yet all forms of healing are overseen by God.

Islamic tradition. There is some complication yet veritable simplicity when discussing signs, miracles and suffering in the Islamic tradition. The complication comes from the diversity in the Hadith tradition. The text that is agreed to be holy for Islamic scholars is the Holy Qur’an, which was revealed over the course of 23 years by the angel Gabriel (Jibreel) to the illiterate Prophet Mohammad (PBUH) (Ali, 1978, p. 1). However, there are also collections of over 700,000 Hadith, the various teachings of Prophet Mohammad, which fall outside of the revelations of the Qur’an. Many of these are rejected by Islamic scholars (Ali, 1978, p. v), but most agree on the selected 42 called the *Arba’in* and about 7,000 others collected by Al-Bukhari (Ali, 1979, p. vii). The debate over Hadith is not too dissimilar to debates about the Apocrypha and various books

outside of the “agreed” Biblical canon. The Qur’an proclaims to be complete “Nothing have We omitted From the Book . . .” (Surah, 6:38, 114) in its intended purpose. Allah in the Qur’an is a highly Holy God, whose complexities are beyond human capacity to understand. Many references are made to the teachings of Mohammad (PBUH) in the Hadith, but those teachings are not direct revelations from Allah through Gabriel to Mohammad as is the Qur’an (Ali, 1978). There are the signs (miracles), then, in the Qur’an, and the signs in the Hadith. For my purposes, I paid attention to signs in the Qur’an. My discussions with an imam and another Islamic scholar reference a few Hadith as illustrations of the intentions of the word of Allah.

The Qur’an references the signs and miracles of the Hebrew Bible, for example, Moses, Noah, and Abraham, expanding upon Allah’s intentions with these signs. Suffering is a result of the evil of man, good things come from Allah. For example, Surah 7:94 speaks on how Allah has saved the people of the prophets, but their arrogance corrupts them and Surah 4:79 states, “Whatever good, (O man!) Happens to thee, is from Allah; But whatever evil happens to thee, is from thyself . . .” Suffering is also the result of being imperfect and operating in an imperfect world remote from the Holiness of Allah (Surah 13:26). Allah “means no injustice to any of His creatures . . .” (Surah 3:108) and God’s mystery and purposes are veiled from his people in the Qur’an (Surah 42:51; Ali, 1978, p. 1).

The imam I spoke with says that Allah is like a parent, who knows that when the children in the next room are suspiciously quiet they are up to no good, but who has not necessarily planned it to be so. Humans still have the element of choice, but Allah knows.

The imam cited Hadith Sahih al-Bukhari 5652, saying that suffering is an opportunity to slough off sin:

Shall I show you a woman of the people of Paradise? . . . This black lady came to the Prophet (PBUH) and said, ‘I get attacks of epilepsy and my body becomes uncovered; please invoke Allah for me.’ The Prophet (PBUH) said (to her), ‘If you wish, be patient and you will have (enter) Paradise; and if you wish, I will invoke Allah to cure you.’ She said, ‘I will remain patient,’ and added, ‘but I become uncovered, so please invoke Allah for me that I may not become uncovered.’ So he invoked Allah for her.

In this case the woman was not cured of her epilepsy as it was an opportunity for her to slough off sin, but the Prophet (PBUH) petitioned Allah that she not become uncovered during her episodes. The Imam explained two things: that modesty is a crucial component of the Islamic practice and that there is an implicit understanding that Allah could cure her of her epilepsy very easily. However, Allah knew better what this woman needed, which was not to be cured, but to be able to preserve her modesty to use these episodes, her suffering, as a religious experience to be more worthy of Allah’s favor.

In the Qur’an, miracles are not instances of the Divine interfering with the natural order. These *miracula* are actually naturally explainable, but supersede our understanding. This puts the observer in a position of *mirari*, harkening back to the observations of Dr. Goering and the opening of this chapter. The Imam referenced a Hadith, Sahih al-Bukhari Book 76 Hadith 1: “The Prophet (PBUH) said, ‘There is no disease that Allah has created, except that He also has created its treatment.’” By Allah’s will we come to understand these diseases and their treatments, but they are not beyond

the comprehension of Allah. When medical interventions defy all expectations, it is not because Allah has inserted himself into the natural order of things, what has happened is simply beyond our own current limited understanding. By the Will of Allah (Insh'Allah) we come to have medical knowledge, a knowledge that is pre-existing in Allah. So medical miracles are not a sign of Allah's meddling with the natural order, but more a reflection of how little we understand, how much we have to learn, and how much Allah knows.

Miracles, in Islamic traditions, are proof of Allah's supreme omnipotence and our lowliness. They put us in positions of wonderment because we cannot possibly understand all that Allah does and is able to do. One Islamic scholar I talked with stated that Islam encourages Muslims to be "realists." The scholar also referred to the story from the Hadith tradition of Hagar and Ishmael being led into the desert by Ibrahim (Abraham), explaining that "belief in a miracle should be accompanied by a healthy dose of reality of our situation, and we should strive to help ourselves through our efforts while having an unshakable belief that the Help of Allah is always nearby" (Zeba Anwar, MD, personal communication, October, 29–30, 2014). In the Hadith tradition, when Ibrahim was directed by Allah to lead Hagar and her child, Ishmael, to the desert, Hagar had faith that Allah would sustain them. Unable to bear her infant son starving to death, once they had no more water she left him as she ran from one mountain peak to the other seven times to see if she could find someone or something to help her. When she returned for the last time, a voice directed her to an angel digging up the waters of the Zam Zam. The Islamic conclusion on miracles is nearly identical to the Jewish understanding, that God can perform a miracle but that one's duty is to determine one's next action when

confronted with a difficult situation: one must have *faith* through an *ordeal* that whatever the end result is, is the will of God, and *act* as called.

The commonalities. The understanding of miracles in each of the Abrahamic faiths came together for me in this question: Can we expect, hope, ask, or petition in prayer for a miracle when we are suffering? Every religious scholar with whom I discussed this question mentioned in some way Harry Emerson Fosdick's quote: "God is not a cosmic bellboy for whom we can press a button to get things" (Harry Emerson Fosdick, n.d., para. 1). The imam I spoke with mentioned Martin Luther King Jr.'s version. In a 1948-1954 paper titled "The Misuse of Prayer," King writes, "Although prayer is natural to man, there is the danger that he will misuse it. Although it is a natural outpouring of his spirit, there is the danger that he will use it in an unnatural way." One of these ways is when we use prayer to "make God a cosmic bell hop a universal errand boy" (p. 1).

When we look at these three faiths there is a commonality in the perceived purpose of miracles on several different levels: (a) Miracles are subject to the sovereignty of Yahweh, God, Allah; (b) Miracles may not be outside Yahweh's, God's, or Allah's natural ability but may be perceived as miraculous; (c) No miracle has been done simply for the sake of performing a miracle nor solely to prove Yahweh's, God's, or Allah's divinity.

Is there then no reason to hope for a miracle? Should no one pray or seek that Yahweh, God, Allah may interject His power into our suffering and provide reprieve? Again these three Abrahamic religions center on the same theme: have Faith in God. Suffering is agreed to be a natural occurrence anyone is subject to in this life, regardless

of an individual's devotion and piety. Miracles can and do occur, but one should not expect a "cosmic bellhop." Additionally, anyone can experience wonderment at something that supersedes their understanding of the individual or even of the scientific community. It is not unreasonable to have faith that a powerful God can perform and has performed miracles, events that supersede our understanding and expectations, but He has done so within the context of His own Divine purpose.

Magic versus Miracle, and Potential Issues

Kee traces the study of magic through Pliny, the six tribes of the Medes or *magoi* (from which the name is derived) to the magical papyri, and through Greek/Roman times. The distinguishing feature of magic versus miracle is that "the purpose of the formulae [magic] is to coerce the desired results by means of repeating the appropriate words or acts. What is sought is not to learn the will of the deity, but to shape the deity's will to do the bidding of the one making the demand or to defeat the aims of evil powers" (Kee, 1986, p. 112). Dr. Greg Goering, Th.D. (personal communication, January, 13, 2015) commented that magic is distinguishable from miracles in that in magic, the performer seeks to control the situation, the outcome. Exodus 15:11-12 clearly emphasizes this difference. Moses and Aaron did not attribute the plagues and signs to their own powers; they merely served as conduits to the workings of Yahweh. Similarly, Jesus does not act independently of the will of his Father. In John 6:38, Jesus says, "For I have come down from heaven not to do my will but to do the will of him who sent me." The signs and miracles he performs do not stand for Jesus's power, but the power and will of God. Interestingly, Kee (1986) notes that "magic regularly involves some kind of ritual pronouncement or action, and . . . there is none reported in connection with Jesus

commissioning his followers to perform baptisms, healings and exorcisms in Mark” (p. 116).

It is important to note the difference between miracles and magic with regard to petitioning for miracles in prayer. As mentioned, magic “is to coerce the desired results by means of repeating the appropriate words or acts . . . to shape the deity’s will to do the bidding of the one making the demand” (Kee, 1986, p. 112). Clearly, there is a fine line between petitioning for God’s intervention and seeking to control God’s will. For physicians, this issue may arise when families state, “We believe you will perform a miracle.” The cultural phenomenon of “Power of Prayer” seems to align itself more with magic than with faith. In my observations, I have noticed parents telling their communities: “Keep praying! Prayers are really working!” Is there a belief that prayer is coercing the desired result? If left unaddressed, these expressed beliefs may be problematic to a family’s coping.

King’s (1948-54) “The Misuse of Prayer” states the three ways in which one should not pray:

- (I) Never make prayer a substitute for work and intelligence
 - (1) (a) . . . prayer must be a supplement and not a substitute [e.g., calling a Doctor when sick] . . .
 - (2) Prayer is no substitute for intelligence . . .
 - (3) [When] [w]e make God a cosmic bell hop, a universal errand boy . . .
- (II) Never pray for anything which if done would injure somebody else . . .
- (III) Never pray for God to change the fixed laws of the universe. (pp. 1-2)

King's direction here is in keeping with the sovereignty of God, the Ten Commandments, and the teachings of the Bible. It is also in keeping with the Islamic teachings on prayer. For example, a footnote in the first Surah of The Holy Qur'an (Mushaf Al-Madinah An-Nabawiyah) states, "Allah needs no praise, for He is above all praise: He needs no petition, for He knows our needs better than we do ourselves. . . . The prayer is *primarily* for our own spiritual education, consolation, and confirmation."

A fourth point that could be added to King's three could be, "Never pray for God to justify the problem of evil." When asked "Why then tolerate the treacherous? Why are you silent while the wicked swallow up those more righteous than themselves?" (Habakkuk 1:13), God does not respond directly. Job (31:35) pleads that he should know what he has done to be guilty of his suffering: "Oh that I had someone to hear me! I sign now my defense—let the Almighty answer me; my accuser put his indictment in writing." In response, God questions *Job* back; God lists out what He has done since the beginning of time and is capable of, but never answers why Job suffers. The three Holy texts state that the wicked will suffer while also acknowledging that the suffering of the innocent is part of the world. There is no divine statement about why suffering is allowed, God says that the world is full of imperfections (Edwards, 2010, pp. 84–89; Hunter, 1990, p. 968; Kushner, 1981, pp. 66–67) that can afflict the innocent as easily as the wicked. The imperfections of this world are why it is separate from the Kingdom of God and why there is hope for a better world in the afterlife.

Is there hope for a miracle then? If one understands the power of God, of course there is. However, this understanding has to be within the context of the knowledge of God's sovereignty and divine will. Kushner (1981) states, "We can't pray that He will

make our lives free of problems . . . People who pray for miracles usually don't actually get miracles" (p. 138). So what sorts of prayers seem to be in keeping with what can be understood about the nature of God in times of suffering? Kushner lays out two different sorts of prayer in his book; one is prayers that "bribe" God to make things work out," citing Jacob's vow (Gen 26:20): "His attitude, much like that of so many people today facing illness or misfortune, is expressed in this way: 'Please God, make this work out well and I'll do whatever you want' . . . It is not immoral to think that way, but it is inaccurate. God's blessings are not for sale" (Kushner, 1981, p. 136). Later in Jacob's life (Gen 32:9-12), his prayer changes; Jacob asks "God only to make him less afraid, by letting him know that He is at his side, so that whatever the next day might bring, he will be able to handle it because he won't have to face it alone" (Kushner, 1981, p. 138). With knowledge of sovereignty and the "natural order," a prayer for the strength to endure is true to the fundamental teachings of the three holy texts. Kushner (1981) says, "Prayer, when it is offered in the right way, redeems people from isolation" (p. 134).

The Ultimate Truth about Miracles

What is decidedly true about those who say: "We are praying for a miracle" or "We are hoping for a miracle" is the position in which they find themselves. Petitions for God's intervention in suffering in Biblical texts come when people are dying, stricken with illness, enslaved, or besieged. They are overwhelmed and feel helpless, and no one is able to intervene in the situation. They are out of options and resources and their only hope rests in divine intervention. Clearly, the position and experience of those petitioning for a miracle has not changed in modern times. What can be said is that those who are

hoping for a miracle are in positions of great suffering and distress, and feel they are out of options.

I have traced some of the role of suffering throughout the chapter so far. However, I wish to conclude with some key points. In Kushner's (1981) book, *When Bad things Happen to Good People*, he references extensively the story of Job. Kushner concedes God's omnipotence, stating: "Laws of nature treat everyone alike" (p. 66). Kushner believes that God has set into motion the world, and He cannot intercede: "Laws of nature do not make exceptions for nice people." This point is harmonious with the last tenet of King's "The Misuse of Prayer" (1948-54): not to ask God to change the laws of the universe. God has set the world in motion and suffering and illness are part of it; there is no changing that. For these scholars and many others (Desmond Tutu, John Seed, Elisabeth Kübler-Ross, Paul Davies, Barbara Thiering, and Michael Fox among them) in Samantha Trenoweth's (1995) *The Future of God*, whether it is called the Problem of Evil, or theodicy or Providence, the suffering innocent is established to be a difficult issue to reconcile with the conception of a benevolent God. As set forth in the first stories of Genesis about the fall of man, evil and suffering have been part of the world as humans have come to know it. The age-old question remains: How does a loving, just and wise God allow for it? How do we make sense of suffering?

The Essential Problem

The only thing necessary for the triumph of evil is for good men to do nothing.

—Edmund Burke

Clearly there are many perspectives on this matter. Whether God's power is limited, whether God will not meddle, whether suffering is a purposeful lesson for God's

creation to learn will not be debated in this thesis. What is most important at this juncture is the recognition that (a) suffering is a real, pervasive human experience; (b) when the innocent suffer it challenges the sense of justice and hope a person may have; and (c) the suffering innocent is a difficult theological question. Anyone confronting this experience is in a very distressing position. Others who are party to this experience may also be coping with the same internal struggles. How do we come to meaningfully understand suffering?

Divine Will was explored by the imam as Allah understands the nature of the individuals He has created as parents know the personalities of their children. He can guess what our choices might be, but leaves the choice up to us: “God has set Himself the limit that He will not intervene to take away our freedom, including our freedom to hurt ourselves and others around us. He has already let Man evolve morally free, and there is no turning back the evolutionary clock” (Kushner, 1981, p. 90). This also applies to placing us in an imperfect world that exists in a state of entropy and randomness (pp. 60–61). When suffering happens, it is not that God caused it (p. 91). Kushner states (as cited in Trenoweth, 1995):

[T]he question is not, “Why does God permit this?” Ultimately, the real question is the one the psalmist asked: “I lift my eyes unto the hills. From here does my help come?” [Psalm 121] He doesn’t say, “From where does my malignant tumor come?” He doesn’t say, “From where does my Alzheimer’s disease come?” He doesn’t say, “From where does my heart condition come?” *It doesn’t matter where they come from. They’re there and he’s got to deal with that.* The real

question is, “From where does my help come? How will I manage to get through this?” (p. 159)

Senseless suffering and evil are “an offense to God’s moral code” (Kushner, 1981, p. 91). “God is always opposed to evil” (Hunter, 1990, p. 968). Where is God in suffering? In both an interview with Kushner discussed in Trenoweth’s book and in Kushner’s own book he references the responses of a German Lutheran theologian, Dorothy Soelle, to the question of where God was during Auschwitz: “God was at the side of the victims, suffering and grieving with them . . . to suggest, by word or hint, that what the Nazis did to Jewish men, women and children could possibly have been the will of God is to offer us a God so cruel that no decent person should ever worship him” (Trenoweth, 1995, pp. 148–149). The truth is that suffering happens in a human context, which is a social one. Kushner quotes 19th Century Hassidic rabbi Menahem Mendel of Rymanov, “human beings are God’s language” (Kushner, 1981, p. 154), meaning that when one is suffering, there are people who have decided to dedicate to healing (doctors and nurses) and friends and family who come around to “sit at your bedside through the night” (Trenoweth, 1995, p. 151). For Kushner, religion and religious ritual are “not to put people in touch with God, but to put them in touch with one another” (Kushner, 1981, p. 132).

Kushner states, “We need people. We need to know that we are cared about” (as cited in Trenoweth, 1995, p. 151). For healers such as Kübler-Ross and leaders such as Desmond Tutu, suffering provides an opportunity for humans to engage the most powerful capacity we have—compassion. Specifically, this comes through *acknowledgment*. Michael Hyde provides a body of work on this: “Acknowledgment provides an opening out of such a distressful situation, for the act of acknowledging is a

way of attuning consciousness toward others in order to make room for them in our lives” (Hyde, 2005, p. 25).

We know that individuals petitioning for miracles are in positions of great distress. We also know that from a scriptural standpoint, miracles are subject to God’s sovereignty (His will) and are different from magic (our bidding). Regardless of what the person petitioning for a miracle may theologically believe and what the other person in the discussion may theologically believe in (or not), both parties are confronting distress and suffering. The petition allows both parties an opportunity for human engagement; the people petitioning for a miracle are offering religious engagement and asking for their suffering to be acknowledged by those around them. When a family says “We’re praying for a miracle,” what they may be asking is “Where is God? Why is He allowing this to happen? Will He forsake me? Have I been abandoned?” These unspoken questions are a call for us as humans to be “the language of God” by sitting with those who are distressed and suffering and abiding with them in their suffering. This grants us the opportunity to be part of God’s intervention in suffering, or the opportunity to heal through our presence, to not abandon fellow human beings in their moment of suffering. In Job (31:35), the prophet cries out in his affliction and suffering for a mediator to weigh his condition and his innocence fairly for God. We seek mediators and lawyers when we feel we have been dealt with wrongly, to have our suffering *acknowledged* and to validate that what has happened is unjust. Petitions for miracles or the interjection of faith in the NICU/PICU setting is an opportunity to meaningfully engage in the suffering and distress being presented. It is an opportunity to *acknowledge* the fear, distress and injustice of watching the innocent suffer. This position requires the physician to sit, without any

agenda other than being present and bearing witness, *acknowledging* the family's suffering.

In conclusion, I believe there is great hope in the commonalities of these three major religious perspectives with regard to suffering and miracles. The current fear is that when patients and families communicate in this way, it puts up a barrier to communication. Understanding miracles as *mirari*, or points of wonderment, broadens the experience of miracle beyond being just a religious or spiritual experience. Anyone is capable of being in a position of wonderment, where what they had anticipated, understood or expected did not occur. Further, miracles in their theistic tradition are not necessarily miraculous to the producer, but are to the perceiver. I believe this allows for the genuine witness of "miracles" in any person's life, embracing an understanding of *mirari* that all forms of spirituality and religion can appreciate. Authentic appreciation of miracles is important when engaging with families in the NICU who may be discussing miracles.

Additionally, in the Abrahamic traditions, miracles occurred when individual were in positions of great suffering and their own abilities to alleviate their afflictions were limited. They had faith in the power of God, but no foreknowledge of His next steps or whether a miracle would be part of that. This position of suffering and limited foreseeable outcomes is also true of the parent's position in the NICU when discussing miracles. Thus, when a patient or family is petitioning for a miracle, there is a critical opportunity for the physician to *acknowledge* their position of existential and physical suffering. The job of the physician in these moments is to hear these petitions for what they are: a family suffering through the grieving process facing the loss of a child or of a

“normal” childhood, hopes diminishing, coming to terms with the limited outcomes of their child. The opportunity for the physician is to abide with the family through this process, to acknowledge the difficult position the family is in, and to be present without an agenda for the family’s suffering. Authenticity, again, is important in these moments, and comes from a physician’s personal examination of suffering and the problem of evil.

My hope for this chapter has been to lay a strong foundation from the scriptures and their interpreters that provides relevant insight to physicians engaged in this sort of conversation. In Chapter 2, I show how this capacity to *acknowledge* and engage patients and families in their suffering has been wrongfully avoided in medicine.

Chapter 2. The Lost Emissaries of Hope—A Twisted History

Spend any time with attending physicians in the NICU/PICU and you will hear phrases like these: “The family is not ready for that information yet”; “We’re not at that point yet”; “this news would destroy them” or “We are too invested at this point to discuss limiting care.” These sorts of responses come when what appears on the patient’s horizon is bleak or invasive. While appearing on the surface to be compassionate to the patient and family, this reservation is an ethically problematic mentality and response. In this chapter I discuss why there is a history of avoiding discussing bad news in medicine and perhaps why there is an aversion to truth telling in the medical world. I also discuss why telling the truth in a timely manner is morally necessary. In this chapter I also discuss the proper means of attending to bad news. I believe the aversion to bad news interplays with an aversion to being present to suffering, especially with suffering that seems unjust or tangled with notions of theodicy. I believe that a physician’s own personal understanding of suffering will help them not only deliver bad news but be present for the aftershock of delivering bad news.

History of Silence

As mentioned in Chapter 1, from ancient to modern times, physicians have been perceived to be appointed by the gods/God and endowed with God-given talents. For ancients, “there was no cleft between medicine and the ministrations of the gods” (Kee, 1984, p. 28) and much of this perspective remains true for many theistic traditions today. Katz (1984) thoroughly examines this perceived relationship between the divine and physicians and how it historically operated in the physician/patient relationship in the opening chapters of his book, *The Silent World of Doctor and Patient*. Katz describes the

relationship during the medieval period as one where “[p]atients must honor physicians, for they have received their authority from God; patients must have faith in their doctors; and patients must promise obedience” (pp. 7–8). He notes a quote from a third century Jewish physician, Bin Sira, “My son, should you fall sick, place yourself in the hands of a doctor, for this is his calling and God has given him of His wisdom” (p. 8). In both the ancient polytheistic tradition and the emerging theistic traditions,

The postulated intimate relationship between physician, patients, and their God made any critical questioning of doctors’ practices by patients difficult. During the Age of Faith such an encounter came close to blasphemy. Thus, not only would patients find it difficult to question their Aesculapian physicians but the latter, being anointed by God, also would disdain explaining themselves and their practices. (p. 9)

The demand for obedience revealed ultimate faith in God and “the importance of faith for cure that authority and obedience could only strengthen” (p. 9). The physician was instructed: “Reassure the patient and declare his safety even though you may not be certain of it, for by this you will strengthen his Nature” (ninth century Jewish physician Isaac Israeli, cited by Katz, 1984, p. 9). The foundation of the patient-physician relationship was established in the obedience of the patient to the physician, the supreme and consecrated authority of the physician, and limited dialogue between the physician and patient (p. 4). The revered Hippocrates is quoted by Katz as admonishing physicians to

[p]erform [these duties] calmly and adroitly, *concealing most things from the patient* while you are attending to him. Give necessary orders with cheerfulness

and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, *revealing nothing of the patient's future or present condition.* (p. 4, emphasis added)

Patients, no matter their class, were not to be engaged in discussion on their care; physicians were to “convince” the “free and rich” of their treatment protocol, but the poor had “no time to be ill” and discussion was futile due to their lack of understanding (Katz, discussing Plato, 1984, pp. 6–7). Plato and the ancients believed that physicians and their patients were “united through *philia*, friendship, which made their objectives one and the same” (p. 6), so there was no reason for back and forth conversation or question about what the physician recommended to the patient. Nineteenth century medicine and Percival declared that a “physician should be the minister of hope and comfort to the sick.” Physicians should uphold this position, “by urging restraint in making ‘gloomy prognostications,’ except ‘on proper occasions [when a physician should] give the friends of the patient, timely notice of danger” (p. 18). Percival’s ideal physicians should be bearers of health and hope at all costs, to the point where they are not even allowed to impart bad news.

Why the aversion to truth-telling when confronted by limited ability to intervene on suffering? Was it to avoid the questions of ability, to avoid admitting that God’s power through a physician was limited? Maybe God is not powerful enough or the physician not godly enough when illness cannot be overcome. Was it reflective of how mysterious the workings of God are despite the revelations of the Holy texts, and thus responsive to some of the same mystery in the workings of a physician? I believe it

more likely that this aversion simply reflects the natural human aversion to being powerless and the bearer of bad news. Katz states as much:

I had been engaged with other physicians in a heated debate over the question of whether to disclose to patients their hopeless prognoses. All the doctors who spoke up asserted that patients . . . could not tolerate an awareness of impending death. Late in the discussion, the patriarch leaned over and whispered into my ear, “It is not the patient who cannot tolerate hearing the truth. I could not tolerate telling my patients the truth.” (p. 19)

Medicine is sought to restore to health, to alleviate suffering. There is an entrenched belief that a physician fails when that end is not achieved. This failure is then either a shortcoming in the physician’s own abilities, or reflective of God’s will. Imparting bad news is an uncomfortable position to be placed in regardless of profession, but in the context of the art of medicine, it appears as a failing. The problem of responsibility or the inability of medicine to cure all illness and disease poses questions about the problem of evil and the ability of both God and the physician. The fathers of modern medicine naturally avoided the problem, and this aversion to disclosing bad news was maintained as a professional stance that lingers today. The first AMA code of ethics states: “It is . . . a sacred duty [for a physician] to guard himself carefully [in his action and words] . . . and to avoid all things which have a tendency to discourage the patient and to depress his spirits” (AMA Code of Ethics, Act 1§4, 1847, p. 94).

Changing tides. The mid-19th century ushered in the “age of science in medicine” (Katz, 1984, p. 40) in its triumph over the charlatans and “quacks” of the eighteenth century. But medicine’s pedestal was shaken when it started to confront a

change in the burgeoning twentieth century. Starting in 1905 with *Pratt v. Davis*, the legal world did its best to reframe the paternalistic construct of the physician-patient relationship. The term “informed consent” was coined in a court ruling by Justice Bray on October 22, 1957 following a string of lawsuits. (pp. 50–60). The term was ambitious, broadly encompassing autonomy and “self-determination,” a term coined by Justice Cardozo in 1914 (p. 51), but lacked precise definition and steps for application in the medical world. Katz foreshadows the challenge of moving to informed consent in the evolution of the medical world early in his discussion: “Physicians of ancient Greece were keenly aware of the importance of confidence and faith in treatment of disease. A call for shared decision making would have puzzled them” (p. 6). Informed consent proved to be a puzzle to twentieth century physicians and schools of medicine too, because they were steeped in a tradition of paternalistic medicine. Informed consent was established as a right, but exactly how it affected the century’s old relationship between physician and patient was not clear.

In 1903 a revolutionary paper by Dr. Richard C. Cabot was published in *American Medicine*. Dr. Cabot asserts that patients confirmed the “astounding *innocuousness of the truth* when all reason and all experience would lead one to believe it must do harm” (p. 347). The long held belief that sharing bad news with patients would utterly destroy them and pose added risk to their health was not true in his own “experiments” on the issue. This idea was still revolutionary nearly 80 years later when Katz wrote his book, in which he references Dr. Cabot’s findings. Clearly, centuries old notions of paternalistic medicine were having a hard time coming to terms with the new

patient/physician relationship. In my own observations, this long held belief is still very present in current medical traditions.

In the modern context of truth telling, we have further convoluted the issue through the metaphors and similes used to describe disease and health care (E. Lee, Ellis, Blanke, & Roach, 2015). Terms like “warrior,” “fighting,” and “battle” only further complicate the perceived role of doctors as “miracle workers” and make a dim or poor prognosis even more of a “failure.” This language undermines the willingness of the physician, patient and family to come to terms with bad news. Death already causes loss; when a patient “loses” a “battle,” the families are left with not only the *physical* loss of a family member, but also the *perceived* loss of a battle. This failure is not unique to the family’s position; it also complicates the physician’s view of the situation, and increases avoidance of bad news, because no one wants to admit or be viewed as responsible for failure.

Shared decision making or mind games? Recent studies have shown that models of shared decision making are still often viewed as on the fringes of the paternalistic traditions of medicine. A study by Karnieli-Miller and Eisikovits (2009), a paper by Harrison (2008), and a book by Forman (2009) show clearly that what information is shared and the manner in which it is shared is colored greatly by the “sales-man” physician. Karnieli-Miller and Eisikovits categorize the salesman approach into seven different ways of presenting information to parents/patients such as dramatizing the evil, using others as examples, or presenting treatment as an authorized “we” decision. This article shows how these seven ways of presenting the information do

not encourage a mutual decision making process, but rather, effectively convince the patient to accept the suggested intervention.

This manipulation is reflected in research on physician-patient communication. In his keynote lecture, Arthur Kleinman (2015) stated that on average a patient has 19 seconds before being interrupted by a physician. Cleave et al. (2014) show that on average in a family meeting a physician or the physician team talks for more than double the time the family speaks and Karnieli-Miller and Eisikovits found in their research, when physicians informed patients, that “[m]uch of the conversation and energy was focused on achieving adherence to the recommended treatments” (p. 3).

Of course the motivation behind the salesman physician is regarded as beneficent, and is grounded substantially in the physician’s experience and education. However, these tactics are one sided: “The suggested treatment is based only on medical concerns and benefits, and not on lifestyle, values and patient’s preferences” (Karnieli-Miller & Eisikovits, 2009, p. 5). The effects of these sorts of discussions can be felt tremendously by parents, as recounted in Lantos’s *The Lazarus Case* (2007) and Forman’s *This Lovely Life* (2009). Parents in both books were dissuaded from withdrawing life support from or convinced to resuscitate their extremely premature babies, with lifelong repercussions for the families. In both books, families go through what Harrison (2008) lists as

months or years of grueling hospitalizations with associated gastrostomy tubes, jejunostomy tubes, and funduplications; the tracheostomies, shunts, and orthopedic, eye and brain surgeries; hyperalimintation, oxygen tanks, and ventilators . . . bankruptcies, divorces, mental and physical breakdowns, deaths in late childhood, neglected siblings and suicides caused by the extreme burdens of

caring for medically and developmentally compromised children. (Harrison, 2008, p. 310)

For Harrison (and others) the offer of treatment (or resuscitation) is “far too often, one parents literally can’t refuse” (p. 311). Forman also eloquently notes this “turf war” (Harrison, 2008) in her book. An educated daughter of a child psychiatrist, she was well aware of the lifelong issues confronting a severely brain-damaged child when she had her twins at 23 weeks gestation. Insisting on a DNR elicited the following responses from her physicians:

“There are various things that can happen when a baby is on a respirator,” Dr. Lamb explained. “He could pull the tube out and have to be reintubated. He could have a pneumothorax, which is when the lung develops a hole in it due to high-frequency ventilation. In themselves, neither of these situations is life threatening. But if there is a DNR in the chart, I would not be able to intervene, and the babies, who might survive, would die.” He stopped for a moment and let this news sink in . . . “The same is true for withholding nutritional support or antibiotics. All of these measures do indeed keep a baby alive who might otherwise not survive. But they are all part of a typical plan of care for babies like yours and it is our policy at this hospital to provide care for twenty-three-week babies and not withhold unless there is a catastrophic event.”

“So no DNR,” I said.

“I would prefer not to,” Dr. Lamb said. “For all the reasons I have just stated.”

(Forman, 2009, p. 24)

Forman (2009) observes that “there was a difference between living, existing, and surviving. To the doctors, survival was all that mattered. To the parent, “living was what you wanted for your child; pure existence would never do” (p. 20). To be sure, not all physicians or parents would view interventions this way. The point should not be determining what medicine makes possible, but addressing how medical intervention functions in a broader perspective, namely in the context of a patient/family’s life. If the “shared decision making” research is true, then physicians are still spending more time and efforts asserting their best medical opinion and less time accounting for their patients’ views: “suggested treatment is based only on medical concerns and benefits, and not on lifestyles, values and patient’s preferences. These preferences are not explored, and even when they are known they are not actually included in the decision” (Karnieli-Miller & Eisikovits, 2009, p. 5).

So have informed consent and shared decision making done their part in systematically breaking down the patriarchal relationship between a physician and patient? It is clear from my own observations and in the research literature that “*shared decision making*” is still up against a long held relationship and belief system. It has a long way to go. In tracing its origins, my hope is to provide an analysis as to why.

How to Handle Truth and Bad News

The aversion to death, failure and uncertainty is not unique to the medical profession. Michael Hyde (2005, 2006) discusses the jarring interruption anyone experiences after arising from a fall, setback or breakdown, which makes one vulnerable, shifts one’s world of meaning, disrupts one’s home or “dwelling place” and creates uncertainty and anxiety. Evidence of the natural aversion to telling bad news can be seen

in our turns of phrase: “Do you want the bad news or the good news first?” “Don’t shoot the messenger!” “I hate to be the bearer of bad news” and even in the common business management concepts of providing “constructive criticism” with the “sandwich”: good thing, bad thing, good thing. Bad news, illness, and suffering create a loss of comfort and exposure to vulnerability and initiate the stages of grief. Because bad news can engender both grief and loss of hope, anticipating these reactions makes us less willing to impart bad news.

Any physician who readily sought to create these turbulences without an awareness of the potential devastation caused by bad news would be acting against ethically established principles of non-maleficence and beneficence (Beauchamp & Childress, 2008). Physicians are not always mistaken in thinking that revealing a poor prognosis or clear and complete information will send a patient/family into shock, disbelief and even panic (Black, 2011; Cabot, 1903; Lipson, 2005; Moskop, 2014; Rockwell, 2007). Yet at the same time, the timely delivery of truthfulness is a moral requirement for a physician acting in accordance with non-maleficence and beneficence. Physicians must allow the patient to move through the Kübler-Ross (1969) processes of grief (shock, denial, anger, bargaining, acceptance, and adaptation). This is not a linear process; it can take time, change, regress and progress (Kaldjian, 2010). Timely, meaningful disclosure of the truth is ethically required, despite the discomfort these discussions may cause (Rockwell, 2007). There are many better and worse ways to share bad news, depending on the relationship a physician has with a patient and/or family.

The Moral “Ought”

Lipson (2005) states, “The patient’s truth is worthy of endorsement” (p. 307). In avoiding giving clear and complete information, “we are denying the reality of the person who is before us in that moment” (p. 307). The Greek root of *prognosis* roughly translates to “what is before known.” In his discussion of the *living truth* Mill (1863) states, “The truth of an opinion is part of its utility” (p. 24). Regular discussion of the truth is necessary, for “if it is not fully, frequently and fearlessly discussed, [an opinion] will be held as a dead dogma, not a living truth” (p. 24). In *diagnosis* and *prognosis*, we are dealing with informed medical opinions, forecasts about the medical nature of the situation at hand. Providing the patient and families with the relevant details of their current situation as understood by doctors establishes the context of their symptoms and care. Without the clear and complete information, “the perilous roller-coaster ride [of the illness] that bends and turns with mortality at every twist will be darker and more terrifying” for the patient (Rockwell, 2007). The failure to fully disclose diagnosis and prognosis in the context of recommendations for treatment risks creating a fantasy world, because “[t]ruth or falsehood consists in an agreement or disagreement either to the *real* relation of ideas, or to *real* existence and matter of fact” (Hume, 1739, p. 251). In my observations sometimes physicians decided to delay telling a family they believed that their baby “would never make it out of the unit,” believing such news “would crush them.” As a result, when a baby had a “good day,” this could be seen by parents as one more good day on the road home. I argue in Chapter 3 that problematic views like this can create “miracle cycles.”

Teaching the Truth

Establishing a truthful relationship. The Latin root meaning of “doctor” helps to convey the role a physician can have with his/her patient that is preferable to the former paternalistic role. As Rockwell (2007) notes, “The Latin root of the word ‘doctor’ is teacher” (p. 455). Bonhoeffer states that telling the truth “depend[s] on the nature of the relationship between two persons, and so, ‘telling the truth’ requires a correct appreciation of one’s relationship with another” (as cited in Moskop, 2015, chapter 4). Bonhoeffer (1955) explores how this relationship changes through the maturation of a child into an adult, illustrating how truth telling “mean[s] something different according to the particular situation in which one stands” (p. 326). The physician who takes the role of teacher seriously should examine how particular patients or families interact with the physician and how they “learn” their pathology and prognosis. The physician in this model is more like a grade school teacher, or an engaged academic mentor, than a lecturing professor. “To teach is to present the truth with all its variables, known and unknown . . . The task of a teacher, a doctor, is to reveal the unknown and chart a course through it, to ask questions, and guide the course of answers” (Rockwell, 2007, p. 455). Some patients will need multiple meetings repeating the same information; others may require some materials or diagrams. It is also important to understand the unique relationship a physician has with each individual family and patient. Just as an effective teacher assesses each student for his or her learning style and achievement level, physicians have to learn their patients/families well enough to know how to engage with them and “teach” the patients their medical diagnosis and prognosis.

In the video *Breaking Bad News* (Pediatric Community Alliance Hospice and Palliative Care Center, 2006) a mother states,

[Doctors need to] talk to people, explain what's going on. Truth is, I don't understand a lot of things they say, um and I write some things down so I can research it, if they can break it down to a different level . . . at the same time tell the truth though, if it's not a good sign or a good thing, let them know.

The mother does not ask physicians to delay portions of the bad news or deny it, but to take the time to discuss the medical terms in a way that she can understand. She is looking for a process that involves her. The psychologist and client relationship provides an analogy there “helping is not something that helpers do to clients; rather, it is a process that helpers and clients work through together” (Egan, 2010, p. 38). Although Egan is referring to the rapport between a psychologist and a client, the foundation remains true for the physician/patient relationship.

Physicians should want their patients to appreciate the circumstances of their illness and interventions, and most patients and families will want help to understand bad news. Patients will come to understand their pathology and treatment in their own unique way and learning style, and physicians must be engaged in understanding the unique relationship they have with an individual patient, and how to relate information in a meaningful way in this relationship. As Bonhoeffer (1955) states, “[t]elling the truth is . . . something that must be learnt” (p. 327). Physicians have to “learn” their patients and families to know how best to truthfully communicate with them.

Ultimately, physicians are seeking to act with *phronesis*, or with practical wisdom, in this model of the physician/patient and/or family relationship. A good

physician does not just disclose the truth, but also seeks to understand *in what manner* to disclose bad news, and, most importantly, what to do in the aftermath of sharing bad news. The physician guided by practical wisdom possesses the “virtuous quality enabling one to judge the right means to the good end” (Black, 2011, p. 19). Phronesis is “developed through practice . . . it functions as a disposition that motivates and enables a person to make good choices by responding realistically to a problem through clear perception and deliberation concerning a given set of circumstances” (Kaldjian, 2010, p. 558).

In other words, truth telling includes how the physician presents the “truth,” and both anticipates and is involved in addressing the effects on the patient of confronting bad news. Kaldjian states that for Pellegrino and Thomasma, clinical judgment, or “the basic skill of the physician that solves a medical problem through data collection, development and testing of explanatory hypotheses, and formulation of recommendations for therapy based on those hypotheses” (Kaldjian, 2010, p. 560) *requires* practical wisdom. Kaldjian goes on to assert that clinical judgment is a form of practical wisdom: a moral physician must integrate goals of care and ethical reasoning with clinical judgment, to look “at problems truthfully and then decid[e] how best to respond on the basis of the ends in view, the means best suited to achieve those ends, and an appreciation of the moral principles and virtues necessary to guide and motivate action” (Kaldjian, 2010, 560). A physician guided by practical wisdom does not avoid telling the truth, but is able “to tell a patient upsetting news as a function of valuing veracity . . . [and] mediate[s] the distressful truth by being compassionate; being fully present to the patient in the aftermath of the news, responding to questions, allowing the patient time and space to

grieve or be angry” (Black, 2011, p. 19). The truth-telling is not the problem; the difficulty comes in the process of coming to terms with bad news and the willingness to be present with that.

A concept from psychology called *verbal tracking* is the first helpful step to being able to speak with a patient and family about difficult news. Verbal tracking is a method employed by psychologists in which they

repeat key words and phrases back to their client to ensure the client that they have been accurately heard. [Psychologists] don’t do this in a mechanical way; instead they weave the clients’ language into their own. In addition . . .

[they] monitor the train of thought . . . and are able to shift topics smoothly rather than abruptly. (Pomerantz, 2011, p. 151)

Like a psychologist, a good physician understands and is able to use the terms families or patients are already comfortable with; this helps to accurately communicate pathology and prognoses to them. In this way physicians can help avoid the pitfalls Cabot (1903) warns of, such as snowing patients with information or “cramming information down peoples’ throats or trying to tell them what they cannot understand properly” (p. 347). Cabot also advises to avoid “button-holing” (p. 347) every detail or prognosticating to a degree of detail that cannot be promised. Bonhoeffer and Cabot would both agree that truth-telling requires the physician to provide the information necessary for the patient to understand his or her care, and to give a straight answer as opposed to the “blunt truth” or the “naked truth” (Cabot, 1903, p. 347). Cabot recommends, “A straight answer to a straight question . . . not an unasked presentation of the facts of the patient’s case” (p. 347).

The process of teaching a patient and family depends on a physician's ability to use modifications (metaphors, translating technical and medical terminologies, etc.), visual aids (diagrams, pictures, charts, etc.) and interventions (asking for understanding, asking the family to repeat back what they know or heard, allowing for questions, etc.). Physicians who have been attentively present in conversations with families and patients will be able to "orient the outcome of all reasoning [clinical judgment, ethical reasoning and patient preferences] to the patient's good" (Kaldjian, 2010, p. 560). Sensitive physicians are better able to ask the right questions and evaluate the responses of the parent or patient for the degree of detail parents/patients would like to know.

Avoiding difficult discussions and failing to break bad news does not help physicians understand what patients may need in the context of a healing relationship. Discussion is an important component of understanding someone else. In a webinar (Kogan, 2015), Dr. Kogan notes that not only do physicians have to be comfortable sitting with difficult circumstances, they also have to be able to ask the right questions, but not necessarily to have the right answers. As Bonhoeffer (1955) states, "[t]elling the truth . . . is not solely a matter of moral character; it is also a matter of correct appreciation of real situations and of serious reflection upon them" (p. 327). Questions and discussions allow the physician to impart difficult truths, but more importantly to know how to help the grieving process.

Truth, denial and time. As mentioned, denial is part of the grief process (Kübler-Ross, 1969). It can be a frustrating reaction to deal with in the context of medical decision making and the physician-patient and physician-family relationship. Yet as a mom in *Breaking Bad News* (Pediatric Community Alliance Hospice and Palliative Care

Center, 2006) states, “Denial is your friend. Denial allows you to survive a trauma [like the loss of a child]. Denial lets in just as much as you’re ready to deal with.” Denial and working through the accompanying stages of grief to get to acceptance and adaptation is contingent on having the information to process. When a family is thought to be in “denial” they may be perceived by physicians as not comprehending the truth, or pretending the truth is different. I believe, however, that denial stems from *knowing* the truth (to either a complete or partial degree) and not being able to or wanting to come to terms with the truth. One cannot be in denial of something if one does not know what that something is. Shock, anger, denial and bargaining are key opportunities for *discussion*. Yet being able to sort through denial, shock, anger and bargaining are contingent on *having been told* the truth. Deliberation, questions, and processing are subject to having adequate time to do so. When the physician teacher is present through these steps, this allows for the patient, family and physician to arrive at a meaningful conclusion. Delay in giving patients clear and complete information, owing to the negative nature of shock, anger, and denial is not necessary, and does not allow the family adequate time to process through their reactions to bad news. The physician needs the ability to be present and handle those reactions meaningfully.

The Meaningful End

Breaking bad news is difficult for any compassionate member of humanity. Yet without the common ground that truth-telling establishes, physicians, patients and families cannot have effective care discussions. When truth telling is delayed or avoided, these conversations are based on a lopsided relationship, with the physician withholding relevant information and limiting patients’ and families’ ability to contextualize their

experiences and their illness. The truth becomes, as Mill (1863) states, *dead dogma* (p. 24), or useless, because the people it applies to the most do not have access to it, which then limits their ability to exercise self-determination. How can they express goals or preferences if they do not know what those may realistically be? Delaying bad news compresses the time allowed for the process of coming to terms with it. Some studies have shown that patient families need around four days to assimilate to bad news (Prendergast & Luce, 1997) underscoring the need for time and the physicians' presence.

Truth telling and bad news usher in the problem of evil to the patient, family and physician. Bad news introduces the questions, "Why is this suffering happening to me?" "Why has God allowed this to happen?" "Where is God in my care?" My intentions in this chapter are to show how this history of physicians withholding information from patients has complicated communication. What has been avoided is coming to terms with suffering, vulnerability and perceived failure. When God is perceived as the one who ultimately imparts ability to a physician to intervene medically in suffering, and a physician cannot succeed, there is not just a perceived *failure* of the physician, but also of God, to intervene in death and suffering.

Bad news begs the difficult questions: *Why* is there bad news? *Why* is there suffering? In a spiritual care workshop (Puchalski, 2015), Dr. Christina Puchalski warned of the physicians' tendency to try and "fix things." Delivering bad news well requires physicians to have meaningfully addressed their own existential difficulties with suffering, and to be able to *sit with*, be present to, the existential suffering of the patient and family. Physicians need not rush and try to "fix" this existential suffering, nor hide behind futile attempts to "fix" the physical suffering. Bad news and truth telling will

bring up existential suffering for patients and families, and these explanations will not be meaningfully engaged by discussions of risks, benefits and prognosis alone.

For anyone who makes a career of taking care of sick children, being confronted by the theological quagmire of the injustice of the innocent suffering happens daily. How we come to understand it for ourselves and *acknowledge* it in others is critical. It should not be surprising that when parents are confronting critical illness/suffering in their children, they then turn to divine intervention. It is not unreasonable for a distressed parent to petition for a miracle. It is dangerous to dismiss these religious inquiries and responses on the grounds that they are professionally problematic to engage in by the NICU/PICU medical team. The underlying problem being presented is an individual in deep distress. The members of a NICU/PICU team should also be acutely aware of their systematic exposure to suffering innocents and willfully wrestle with their understanding of suffering. In a webinar (Kogan, 2015), Dr. Kogan cautioned that if practitioners themselves have not attempted reflection on the spiritual, religious, or existential dimensions of illness and suffering, then responding to religious pleas or discussions can only come from a superficial level. The lack of authenticity in a physician's response is clear to patients and families, and physicians may thus lose an opportunity to foster trust and a deeper connection with patients and families.

Avoiding religious conversations can also create an awkward environment; for effective communication, physicians must be able to sit with a problem that is not medically related, listen without being action oriented or focused on an agenda, and not respond with data, but human empathy for the parent's position and suffering. In Chapter 3, I hope to show how practitioners who are comfortable with their personal religious or

spiritual beliefs are able to handle this systematic confrontation *and* sympathize with their patients, families, and colleagues as well. K. Lee and Dupree (2008) and Vohra (2014) discuss the problem of physician burnout when physicians continually dehumanize their experiences of adverse outcomes in the NICU. This happens when they are not afforded the opportunity to react in a human way to a tragedy, for example cry, or take time to process through a negative outcome or prognosis. In both accounts, when a child or infant passes away, the physicians and trainees are “taught” to muscle through, disengage, and not emotionally process the experience. The purpose of *acknowledging* this problem first in oneself and then in others is (a) to recognize that the suffering of innocent infants and children is an essential truth experienced by all parties in the NICU, and (b) to learn that being a part of the experience of innocent infants and children suffering provides a crucial sympathetic commonality in which to meaningfully communicate.

Acknowledgment.

*Acknowledgment . . . is a capacity of consciousness that enables us to be open to the world of people, places, and things so that we can “admit” (Middle English: *acknow*) its wonders into our minds and then “admit” (Middle English: *knowlechen*) to others the understanding we have gained and that we believe is worth sharing.*

—Michael Hyde, 2005, p. 23

Suffering, especially innocent suffering, is not a new phenomenon. Suffering and the innocent suffering have been documented across human history. It is well noted as equally afflicting both the most pious of prophets and the most tyrannical of human beings. I believe that suffering is a function of being in the world; being vulnerable to

suffering is a human capacity and has little to do with purpose or justice. It just is. To reiterate Kushner (1981), “Laws of nature do not make exceptions for nice people” (p. 66). Additionally, laws of nature do not make exceptions for the innocent.

In the webinar (Kogan, 2015), Dr. Kogan noted that spirituality and religion are not check boxes on a form and not just about finding the answers. It is about asking the right questions to help come alongside a patient or family, through the religious and spiritual aspects of their health and understanding, or as another physician said to me, the opportunity when patients and families present these moments through religious petitions are to *abide* with a patient and family.

I have tried to show that not just the delivery of bad news but also the timeliness of clear and complete information for families is crucial to the initial processes of grief, to enable acceptance and adaptation. Being present as *teacher*, coming alongside parents who have religious convictions, means that physicians may have discussions on the role of God in care and suffering. In Broyard’s (1992) novel *Intoxicated by my Illness*, he discusses a physician who is part poet, part priest, part scientist. This physician engages his patient from within the patient’s reality. Broyard asks the question, “How can a doctor presume to cure a patient if he knows nothing about his soul, his personality, his character disorders? It’s all part of it” (p. 47). Being present, *acknowledging* both the suffering and the process of acclimating to the truth, and engaging in these discussions will help the working alliance (Mohrmann, Arozullah, & Berman, 2015b). This means a physician must be open to becoming the physician modeled in Broyard’s novel—part poet, priest, and scientist. Opening up the conversation in this way will help physicians to accurately understand a family’s preferences for care. Ultimately if clinical judgment is

seen as a form of practical wisdom (Kaldjian, 2010), then the issues that may currently exist in shared decision making, physicians talking more than the parents (Cleave et al., 2014) or using various methods to convince the patient and family to accept the physician's decisions (Karnieli-Miller & Eisikovits, 2009), will not be as problematic.

Another aversion to confronting the issue of suffering is demonstrated when more time is spent with technical discussions than the “why me?” Jobian query. Physicians avoid uncomfortable bad news not just by silence, but by active avoidance: “Countless opportunities . . . had been abandoned by his doctors, hurriedly dismissed, as another priority conveniently emerged, and a too time-consuming, too-intimate conversation, was, again, postponed” (Rockwell, 2007, p. 454). Physicians must be mindful of the historical, cultural, and personal aversion to truth telling as well as the theological underpinnings of their endeavors to address illness and suffering. Kübler-Ross cautioned that “with every decision that faces us, we can ask ourselves if we’re making a choice from a basis of love or from the clutches of fear” (Trenoweth, 1995, p. 45). I believe that aversions to being present to bad news are rooted in fear—fear of perceived failure, fear of suffering, fear of inducing grief. Ultimately the physician has to come to terms with suffering, to engage in appropriate truth telling. Percival's role for physicians as “miracle workers” ensured that physicians “found it safer to hide behind our roles of nurturing and optimism” (Lipson, 2005, p. 307). But that role should be replaced with the role of the loving *teacher*. Truth then becomes something that is taught and learned by both parties to the relationship. Because all people approach their lives differently, allowing a patient and family the time to process medical bad news is the first crucial component of a

meaningfully engaged religious discussion on medical care. As Broyard (1992) says, “The important thing is the patient, not the treatment” (p. 68).

Chapter 3. Care Team Members and Miracles

To this point, I have been discussing the *position* a family is in when they are petitioning for a miracle. From Chapter 1 the real question that emerges is not about whether miracles happen or can happen, but about what is being communicated when there are petitions for miracles and the need for *acknowledgment*. Chapter 2 discusses the barriers to truth-telling and breaking bad news in medicine from a historical perspective. What we should now understand is the history behind this aversion and the moral impetus for presenting clear and complete information to patients and family. In this chapter, I discuss the convergence of miracles and physician communication. I attempt to illustrate how health care team members (including health practitioners, chaplains, and social workers) identify, engage and respond to religious or spiritual discussions from parents using practical wisdom (Black, 2011; Kaldjian, 2010), and what happens when they are unable to do so effectively.

In addition to researching the literature, I talked with some NICU/PICU team members about their experiences with miracles and miracle language in the context of care and the therapeutic alliance. I have consolidated my observations and recollections of these conversations on the subject of miracle language, and I present them here as paraphrased “discussions” in italicized extracts. There were a few things I noted in reflecting on team members’ insights on instances of miracle language in care. On most NICU teams, there are some people who are known as “good communicators.” These team members are recognized by their colleagues as *being able to talk with parents*, e.g., “Parents always open up to her,” and “She spends a lot of time talking to parents.” They may also be recognized as able to engage parents on their religious or spiritual

perspectives on care. Some may have some *theological training* or express their faith as important to their work. Team members who believe that they do not meet this high standard (feeling comfortable engaging parents' theological perspectives, able to talk with parents, having a strong theological perspective *or* theological training) may demonstrate significant distress when describing these discussions with families: for instance, having tears in their eyes when recounting stories, some being visibly shaken by memories, or wishing openly that they had some sort of training on how to handle these sorts of issues. I hope to examine in this chapter how one becomes a "good communicator" and to ask whether it is possible to train "good communicators," exploring certain phrases and ideas drawn from my conversations that I consider problematic or helpful for acknowledging the family's position.

Practitioners who do not feel comfortable talking *with* parents from a religious or spiritual perspective, and do not demonstrate a strong personal theological perspective, may believe that it is not professionally appropriate to do so, or may prefer to rely on other people in the unit who are viewed as better suited to handle these sorts of responses. On the surface their responses may seem to accommodate the family's religion and needs. However, they do not actively engage the family's level of distress or take the opportunity to abide with the family. For example, one of the most common responses from care team members was an automatic "reframing the miracle" response. Even team members with some theological training may practice reframing: *When families tell me "We're praying for a miracle," I reframe the miracle. If I know it's not a good outcome, I might say things like "Maybe the miracle will come in a different way." Or "I am praying for your peace with whatever does happen."* What team members who "reframe

the miracle” do not acknowledge is that families do not want alternate miracles. A family praying for the health and life of a child just wants the health and life of the child. All other “miracles” are secondary and cannot fill that primary hope. To a mother and father who are desperately hoping for their child to make it through their illness, directing their attention instead to how their family or community has come together or how they were able to have a child for a given amount of time is dismissive to their position of distress and hope. Kushner (1981) states:

[W]hen Job said “Why is God doing this to me?” . . . Job’s words were not a theological question at all, but a cry of pain . . . what he was really asking for . . . was not theology, but sympathy . . . He wanted [to be told] that he was in fact a good person, and that the things that were happening to him were terribly tragic and unfair. (p. 98)

Further, when talking to an individual struck by tragedy, Kushner lists things to avoid saying:

Anything critical of the mourner (“Don’t take it so hard,” “Try to hold back your tears, you’re upsetting people”) is wrong. Anything which tries to minimize the mourner’s pain (“It’s probably for the best,” “It could be a lot worse,” “She’s better off now”) is likely to be misguided and unappreciated. Anything which asks the mourner to disguise or reject his feelings (“We have no right to question God,” “God must love you to have selected you for this burden”) is wrong as well. (p. 99)

For Kushner, people in the presence of those who are suffering should validate their anger, “permit [them] to be angry, to cry and to scream” (p. 100), and listen. Reframing

the miracle neither allows for the physician to acknowledge the parents' immediate position of suffering, nor does provide an opening for engaging the parent. Reframing a miracle is analogous to telling someone with a broken leg "Well, at least your finger is not broken." Neither does it validate the pain and suffering that distressed parents are currently facing, nor does it provide a way for them to handle their crisis. While a family may have experienced lovely things in the illness of their child, like the coming together of their community or the meeting of new friends or reunion of family, they are still suffering because their child's health and life are impaired.

In my interactions with practitioners I learned that certain rote prepared responses that are often considered culturally sensitive and politically or socially correct are commonplace; *I am praying for your peace with whatever happens* or *Perhaps a miracle has already occurred* or *I hope you are right*. I gathered that these responses are given when a team member feels restricted by a lack of personal comfort with religious expression or holds the professional belief that it is better to avoid religious discussion with patients and families. Justification for them may include statements like: *I try to go there only with families I feel comfortable with* or *I might not think it's appropriate to discuss how I feel or my experiences on the issues* or *We are not trained on how to handle those sorts of things*. While on the surface these rote responses seem safe, they do not fulfill the ethical obligations of the responder to the eliciting parent. While initially many responders may feel religious discussion with parents to be "taboo" in a professional situation, not properly addressing them is even more problematic. Parents who say they are hopeful for a miracle disclose their emotive position; they are distressed and know there are limited options available. Immediately present is an opportunity to engage and

be present in the parent's suffering. Parents are expressing their distress, a perception of outcome and pathology, and their coping strategy. If any part of that seems to be at odds with the team's understanding of prognosis, not engaging in this discussion only fosters misunderstanding, mistrust, and confusion (York, 1987). Moreover, responses that do not speak to the distress being presented can interject an awkwardness into the relationship, by appearing to ignore the parents' position of suffering or dismiss the depth of their suffering.

Sometimes, team members may recognize the need to respond to parents' distress but still not engage their miracle language: *I try to hear this language for what it's indicating when parents use it and find out, for spiritual support, what their religion is providing them and what they may need.* Here, the parent's discussion of miracles and their religious perspectives on care is viewed as though it were a new presenting symptom that needed to be handled by and referred to an appropriate specialist. If a baby born with one anomaly exhibits pathology indicative of potentially additional anomalies, the team will call for appropriate specialists for diagnosis. Similarly, when a family starts to make religious references or spiritual petitions, some team members respond by merely calling in the chaplains or suggesting the family contact their religious leaders—signaling an unwillingness or limited ability to engage in the discussion themselves. Spirituality and religion are seen as a specialty beyond their area of expertise, no different from needing neurology, urology, gastrointestinal, cardiology, infectious disease, or pulmonology when a specialized symptom presents itself. There is a specialist for that, and the interaction should be left exclusively to the specialist. However, the parents have chosen very specifically to raise these religious discussions with the person immediately

present. They are not indicating a new “symptom” in their experience of enduring their child suffering, but an indication of how they are coping or trying to cope. The team’s responsibility to the relationship with the family is to hear and acknowledge this, and to be immediately present to the family’s position. Chaplains and religious leaders may well have a role to play too, but the team’s role is primary.

For some health care team members, leaving the parents’ invocation of miracles unanswered or not well-answered may leave them with considerable distress. Physicians, in particular, may resort to more data-driven responses, hoping that reviewing the data, risks, and benefit will make the situation clearer, or provide some semblance of comfort: *I am known for being pretty direct and honest with parents when we talk. If something does not look good and we know the outcomes won’t be what we hope for . . . there was a family where the baby just was not going to make it, and I told them so. They believed that there would be a miracle and brought an outside pastor, and had lots of community engaged in praying and hoping for this baby . . . We just could not get through to them. And the baby died. They left, and I have always wondered what happened to them once they left here.* Data-heavy responses seem comfortable to some physicians; perhaps if the suffering could be framed in terms of statistical probabilities as beyond anyone’s construct and control, it would not be as difficult to come to terms with. Or perhaps understanding the data better will help to explain the experience. Yet understanding the data and the science does not get to the existential problem of *Why?* Why is an innocent child suffering? The disconnect between the data driven response and the parent’s spiritual belief can create distress for the team members: *I have always wondered what happened to them once they left here. Most of the time families leave here and we never*

hear back from them. We get autopsy reports and call them to let them know that the reports are ready and they can come back in and we can explain the report to them. Most of the time they never come back. I had one mom come back years later wanting to go over the autopsy. She was worried that they had given up too quickly, that they should have done more. I just could not imagine, living with that for years. What do we do?

Physicians who focus on conveying information may worry about the quality of their interactions with parents and about how their interactions influence parents' experiences. It is clear to me that data responses are not satisfying to either the family or the team when religious discussions are presented. Not being able to engage a family in these sorts of discussions creates confusion and distress for both physicians and parents. A lifetime of distress can result because practitioner and parent are on different pages (K. Lee & Dupree 2008; Lipson, 2005; Rockwell, 2007).

K. Lee and Dupree (2008) differentiate between two different forms of distress experienced by health care team members: conscious and moral distress. Moral distress "occurs when one knows the morally right action to take, but is unable to do the right thing due to outside constraints. There are two important elements in this definition: (1) outside constraints affecting action and (2) the right action not being taken" (p. 989). With moral distress there exist what is believed to be a right and a wrong option, and some compulsory mechanism that restricts the physician's ability to do the morally right option. Conscious distress is a different: "[I]nstead of the right action not being taken, participants showed a compassionate understanding for the needs of the other stakeholders in the situation, and ultimately felt that the team had done "right" by the child and family . . . Despite understanding and support of others decisions, participants

were still left with feelings of disquiet” (K. Lee & Dupree, 2008, p. 989). I believe that both types of distress may result from not properly engaging the religious and spiritual dimensions of a family’s perspective on medical interventions.

The religious and spiritual dimensions of a parent’s perspective will contextualize many medical decisions (York, 1987), and if not properly considered during the shared-decision making process and properly weighed in clinical judgment, a final decision could isolate stakeholders, which could leave the family worse off. I believe that the team missing these opportunities contributes to families returning years later asking to review autopsy reports because they feel that not enough was done. Perhaps distress may not be the immediate results of a medical decision, but a team member’s look back can later reveal a crucial missed opportunity, and distress may result from recognizing the failure to have engaged the proper discussions to make better decisions for all parties concerned.

The inability to engage parents from their perspective can affect how parents perceive prognosis and care: *Doctors will tell these parents that things don’t look good, and the child survives one crisis, and the parents view that as the child showing them that they’re getting better, or able to survive. The children are crisis survivors, it does not mean their overall prognosis has changed, they just survived a crisis, and the parents hold on to that. It becomes like a “miracle cycle” where the child appears to be getting better for a little bit, then gets worse, then gets better, then worse. The children go through rounds of what the parents think is “proving the doctors wrong.” Outcomes, have not really changed, but the parents think that when these children survive these crisis, they’re “proving the doctors wrong.” The process can erode the trust we have with a parent.* Presenting the family with truthful information about prognosis is

important, but so is being willing to walk through the process of living that experience, and being receptive to the family's point of view in the experience is important as well. Parents who do not agree with the medical opinion about the prognosis for their child may not be denying the truth, but processing the experience through their own perspectives and values.

Clearly there can be significant tension and even conflicts when the physician's clinical judgment and the parents' experience and opinions do not seem to match. A physician's ability to meld clinical judgment, ethical assessment and practical wisdom to assess and understand the parents' value systems is crucial to effective shared decisions making for any medical decision in the NICU. In a paper presentation (Krug, 2015), Dr. Ernest Krug stated,

The desire to understand the parents' preferences and commitments in addition to as complete an understanding of the medical facts as possible promotes our humanity by being respectful of involved parties and by sharing the burden of making difficult decisions . . . [T]he ethical imperative to make and to keep human life human requires respectful inclusion of responsible parties and recognition of the moral authority of the parents to determine what maximizes the existential humanity of the infant and the family as a relational whole.

Appreciating others' perspectives is essential: *We also have to be careful about what we tell parents about outcomes. Sometimes doctors believe the child will have a poor quality of life and believe this equates to suffering. But we have had cases where, yes things were tough, but they were happy children, capable of relationships.* The relationship of parent to child is based on a web of value systems and personal beliefs. In order to engage in

shared decision making, an attuned physician is receptive to different beliefs and values, even if they seem to come from the complicated realm of religion or spirituality.

Being present in the family's most distressing moments, without a medical agenda (such as "we need to think about next steps for care") will help build trust and understanding between the medical team and the parents. It allows for a better understanding of values, coping mechanisms, and the parents' hope, which might be different from the physician's clinical judgment. Often times the team can underestimate the parents. *There are times where the parents determine the miracles. We have a parent whose kid was not supposed to make it home, but that mom got her out of here. Parents can be involved and advocate for resources that really make the difference in these children's outcomes.* The hope is to be always marrying clinical judgment, practical wisdom, and the family's values to foster the decision making process. In a paper presentation (Krug, 2015), Dr. Krug ended with the following example:

The parents of an infant born with trisomy 18 were told that their infant had a low statistical chance of survival [True] and should not receive any medical interventions beyond palliative care. The infant was discharged from the nursery requiring oxygen. The parents persisted in looking for ways to reduce the burden of breathing experienced by their child and found an otorhinolaryngologist willing to operate in order to advance her small and posteriorly placed jaw. The oxygen requirement was eliminated. The child is now 6 and ambulates with a walker. There appeared to have been a lack of openness to trying to solve this infant's respiratory difficulty because of a focus on statistics about prognosis for her condition. The parents wanted their child treated and surrounded her with a

warm, loving family willing to try reasonable options to enable her to thrive. If the humanity in this situation had governed decision making, rather than statistics about prognosis, intervention might have occurred sooner and with less struggle on the part of her parents.

There are several issues to link at this juncture. First, data driven responses may not facilitate the best outcome for the family. The quality of life for this trisomy 18 girl is most dependent on the love, advocacy, and humanity her parents are willing and able to provide. This may not be the case for every family confronting trisomy 18; however, data responses do not neatly incorporate the human feature of medical decisions that may include religious or existential values for the family. Had the family been petitioning for a miracle, the team would have needed to sit in those moments and understand better what that miracle would look like to them. The converse of the family's wishes for their child when outcomes seem limited is detailed in this thesis in Chapter 2, in Forman's (2009) account of her request for a DNR for her micro-preemies, and her experience subsequent to the team's convincing her and her family otherwise. It is clear that not appropriately engaging the various values of a parent means that goals and expectations are likely to differ between practitioner and parent. Parents may see symptoms and events in a different context than the prognosis of the physicians. For example, parents may see time, any time, as being quality time with their child, regardless of the circumstances. Parents may see intensive interventions of any sort as excessively painful, burdensome and unnecessary, especially when outcomes for the child are not clear. Other parents may put time and days into the context of positive care progress; each day that the child is stable maybe a tally on the "good days" side and one step closer to getting better. The

parents' perspective on a child's illness provides the context; parents' perception of what their child is enduring, both medically and existentially, may lead them to value, oppose, or feel conflicted about particular medical interventions. It is important that perspectives from the treatment team and the parents, including parental perspectives based religious or spiritual values, be heard and understood in order to reach a mutual understanding and achieve the best possible outcomes for the patient and family (K. Lee & Dupree, 2008).

The breakdown in shared decision making is also relevant here. The practitioners' versus the family's perspectives on outcomes and meaningful time and relationship may not match, but the patient can benefit when the medical team engages the family's understanding better. The first step in that process is being present in these discussions as they arise, without an agenda of one's own. Further, being present when a family makes spiritual or religious petitions about their child's care requires a physician not to "guide" the conversation toward a decision or goal, but to be present and humanly receptive to what the family is struggling with in that moment. Babies and children with limited outcomes may be able to have fully integrated familial relationships and a quality of life that the team may not have been able to foresee. On the other hand, families with inaccurate understandings of medical outcomes endure tremendous financial and emotional toll. Families who say: *It is out of our hands* or *we know there will be a miracle* may encounter significant financial stress and guilt over how much time is devoted to the care of their medically disabled child and away from the other siblings. I believe that accurately attuned and engaged discussions that include a family's relevant religious and spiritual perspectives may help to facilitate the best outcome for the patient,

family and health care team. This starts with a physician who is able to lay aside goals and agendas when a family is presenting important parts of their value systems and hope.

The position of *mirari* or wonderment is not necessarily a religious one. It can be the experience of a child surviving a crisis that the medical team had indicated would not be possible. It could also be the advocacy efforts of a parent, or time that parents invest in their child, the inexplicable strength they are able to conjure to handle their child's illness. For other families, death could be the ultimate miracle. *If we really stop and think about it, we have millions of miracles that happen to us every day. There is a very fine line between life and death at all times. On my drive here, someone could have run into my car, or a tree could have dropped a branch on my head. Millions of things in one day happen that are miracles.* The beauty of appreciating wonderment is that it is an experience any person of any background and understanding can have. It is crucial to understand that *mirari* is not something that skews the reality of a situation, it helps to clarify the understanding and values of the perceivers of the event.

Nonetheless, differences in religious perspectives can cause tensions between a physician and a parent. Tensions may arise if the perceived religious perspective of the physician is dissimilar to the religious convictions of the parents. *I get asked "Are you a Christian?" or "Are you a good Christian?" which is uncomfortable, because I am Jewish. Normally, parents are asking me this right before we are about to treat their child, which makes me really uncomfortable. I don't want to respond in a way that makes them feel uneasy.* If the religious convictions of both practitioner and family match, parents may feel comforted knowing that a practitioner shares their religious values when making healthcare choices. It may also provide some spiritual comfort to the parents that

they have a “Godly” physician. Physicians are aware that parents may seek comfort in knowing their religious convictions are analogous, and when they are not, it can cause discomfort for the physicians as well: *I want them to have confidence in my ability, I am taking their children into my hands. No doubt if I am a “good” Christian this would add some confidence, and I am a “good” Jew. I think this happens a lot when people get scared or uneasy, looking for an added source of comfort. So I try to get to risks in the consent process so they feel confident in the process. The risks of medical interventions are no different from the risks taken by people who get into their cars to drive over to the hospital. In fact they are more likely to die on the drive over than in a hospital. I try to put things, risks, into perspective.* In these cases, physicians must do their best to hear the underlying anxiety about unknown or risky outcomes and respond in a way that could provide some ease. Yet, as I have tried to show, focusing on the data does not get to the heart of the existential worry and distress immediately at hand.

Can alternate religious and spiritual perspectives communicate in some sort of common space? Or should a Jewish practitioner hand over a case to a Christian practitioner in the example given above? In a conference plenary (Mohrmann et al., 2015a), Dr. Margaret Mohrmann, MD, Rabbi Saul Berman, JD, and Dr. Ahsan Arozullah, MD addressed whether physicians should only treat patients whose views match their own spiritual or religious convictions. The consensus in the plenary was that effective physician communication and presence during the existential suffering of a patient or family is dependent on two factors- relationship and competence. Physicians must cultivate a responsive relationship with their patients and families in order to respond to these sorts of emotional and spiritual disasters. Physicians must know enough,

religiously and spiritually speaking, to respond to the unique perspective of individual patients. Yet this does not require physicians to know every nuance and every religious or spiritual perspective. In addition, Dr. Mohrmann cautioned against ambitious cultural competence in favor of cultural humility, which requires a physician to be much more present and open. She also cautioned that there may be a risk in familiarity; “a too-quick move to understanding can distort or even foreclose helpful exploration as much as outright dismissal can.” Her conclusions were that both assuming one knows it all already and assuming one does not know enough to engage are problematic; Dr. Mohrmann concluded with “You won’t know until you ask” (Mohrmann et al., 2015a).

Rabbi Berman argued that it is the responsibility to that “image of God” in all of us, and to our common descent (regardless if we believe in Adam and Eve or evolution), to address the existential suffering in all humans as they are presented to us. The responses physicians give should not be to gratify their own convictions, but to fulfill the *duty* to rescue a fellow human being who is in crisis. There should be no perceived restriction on rescuing or coming alongside a family in distress over perceived differences of faith or spirituality. We should not abandon those who are experiencing existential suffering by avoiding the opportunity to be present and abide with another human in distress.

Physicians can often feel restricted by professional expectations from engaging in discussion that involves offering their own viewpoints or experiences—even good communicators who are able to talk *with* parents. When religious or spiritual invocations present themselves, physicians who do not feel comfortable (or appropriate) engaging parental religious or spiritual perspectives on care restrict their ability to understand and

appreciate these parents because they are unable or unwilling to respond in a meaningful way (e.g., with verbal tracking). However, many do their best to handle these spiritual conflicts in other ways.

One case recounted to me involved a traumatic birth and resuscitation. The child had a very poor prognosis, and would probably not be able to interact with the family; the team believed the child not would survive for long. *I had a good relationship with the mother, and we all told her that this child could not survive. But this mother told us that God would heal her, that there would be a miracle.* The physician was concerned about not just the child's medical prognosis, but the status of the family as well. *There is more to it than just keeping machines on and medicines and stuff, you know studies have shown that for these sort of medically dependent children there is also a high incidence of the father's leaving. And we talked about all the stresses and other issues too together, the mother and I. Sure enough dad left. But this mom kept coming back to us 1, 2 and 3 years later, and we would talk, because we did have a good relationship, despite what I would tell her and kept telling her, and she kept saying that God would heal her child.*

Another case involved a child of Islamic parents who also had a terrible prognosis. In this case the medical team had not initially discussed the goals of care. After reaching a juncture in care requiring more interventions, the various specialists involved with the child's care met, discussed, and agreed that it was not advisable to continue with scheduled surgeries and interventions. The medical consensus was that treatment needed to move toward palliative care. *So we brought the family in to talk to them. The Dad left, saying he couldn't make this decision. We were all in shock, what just happened? Did he just leave? The mother is sitting there crying. So after a little bit when*

she was calmer, we talked to her. She talked about God and if we should do everything for a miracle, and we told her that we could do everything, but that won't change what God has given this child—that we now had to make a choice. The mother did agree to withdraw. These two mothers, who clearly came from strong religious backgrounds, made different decisions based on presented clinical judgments: *I do not know what the difference is between those two cases. Both mothers were clearly of some faith and miracle understanding, but one heard what we were saying differently from the other.*

The distress for physicians recounting stories like this can be palpable. In the moments of miracle discussion when the team and parents meet, it would be an appropriate time to ask about the parents' values and understand their perspective better, not just for the benefit of shared decision making, but also to address the distress the team perceives.

Sometimes when parents tell me they're hoping for a miracle, or they believe there will be one, I tell them I am too, I am hoping I am wrong. Sometimes we can be wrong...I have spent many years battling with my religious upbringing, I am sure the church kicked me out a long time ago. But I believe in a consciousness that exists outside of the body. No matter what, no one can take that away from these parents. I never know how or when to talk to them about how I think of these things. It's not appropriate. It is clear that not engaging in this conversation does not allow physicians the opportunity to relay details to the parents about their positions on care beyond clinical judgments—insights that could be healing or helpful to both the physician and the parent. Being present to the parents' suffering in this way, and showing authentic concern by revealing their own meditations on suffering and loss could build trust and deepen the relationship between the physician and parent. Engaging in these religious and spiritual dimensions of care can make clearer

the decision making process for the family and might allay the physician's experience of distress.

Some physicians can identify with a conception of an all-loving God who should intervene on behalf of the innocent, and the distress of not knowing why this has not happened or may not happen. The complications for communication and the physician/parent relationship come when the medical prognosis conflicts with the belief in an omnibenevolent God. Indeed, confronting the large, vexing issue of the "problem of evil" can be daunting, and the "fix" may not be to have the right reasons, but more importantly the right human responses. *Most of the time if we can talk with a family and explain things well enough to them one-on-one, listening, talking with them, holding their hands, we can come to an understanding with them. We cannot underplay the importance of human touch and the importance of just sitting in silence. Just being present. If we do a good job in how we communicate then we can have real meaningful relationships with these parents. There will always be those we cannot help. But that doesn't mean we shouldn't try. I believe that bad things happen at random, I could not make sense of things in my own life if I believed God planned suffering out.*

Some physicians with their own developed religious and spiritual understandings feel unable to communicate these appropriately with parents. They may attribute this restraint to a perceived adherence to medical professionalism and being culturally sensitive. However, I believe this restraint in effect bans potential meaningful discussion between practitioners and parents. It is evident in the expressions and sincerity of these practitioners that their personal beliefs come from meaningful processing of personal tragedy and the day to day perceived issues of theodicy in the NICU setting. This level of

authenticity and openness to the suffering of a family and child is a crucial component to facilitating trust and relationship with a family in a foreign environment. *Families are experiencing intense fear in the NICU. Their children, their babies are in peril and they have no control. We're speaking a language they do not understand, we are in a world they do not feel comfortable in.*

I believe that, if shared, the authenticity in a physician's expression of her personal beliefs would find concordance with parents seeking spiritual ease and understanding of their experiences. *We have to be there with parents for these moments, and really listen, respond to them in the language that they are using. They are not dumb. They know when we are lying or not genuine. They may not understand all the technical terms, but they can understand if we break things down for them, and we can have a relationship if we are present and genuine. They are in the NICU, where everything is out of their control, out of their comfort zone. We have to crawl into the foxhole with them and show them we are on their side and bring them to our side too. When we're needed by parents we need to just be there, just listen, and tell them we are in it with them.*

Physicians must find an authentic way to translate their own compassion for a parent's religious or spiritual perspective and position of distress into taking the time to *abide* with the parent, devoid of an agenda. Being wholly present in these moments will deepen the trust and relationship between the physician and parent, and allow both parties meaningful insight that could benefit future communication. It will also lessen the lingering distress experienced by practitioners by allowing them to engage their humanity, which is at the root of their disquiet. If physicians feel that their clinical judgments and their existential beliefs are in harmony and effectively being

communicated, *and* there is mutual respect between physician and parent, then whatever decision is made following these discussions will cause less distress for both parties.

The experience for parents of watching their baby suffer, born fighting for its life, is essentially unjust; they seek ways to understand the experience. Most NICU parents do not have substantial medical training, so medical and scientific explanations can be difficult to comprehend, especially combined with the psychology of being in an overwhelming environment that is so different from the common experience of having a baby. It is not unreasonable, then, that parents' turn to positions they feel are more accessible to them to explain the *why* of their situation—positions that are easier to understand than the medical and scientific explanations. However, there are moments when even the turn to faith can fail them, when what they believe to be true about Providence and God's will does not turn out to be so. The experience of witnessing this crisis of faith is incredibly difficult for both parents and for the medical team (Black, 2011; K. Lee & Dupree, 2008; Lipson, 2005; Rockwell, 2007).

I believe effective engagement can be forged through *acknowledgment* and *practical wisdom*, and much depends on the manner and approach of the physical presence of the medical team. However, this must be coupled with a genuine and educated understanding of religious perspectives. Appropriately engaged physicians will not only address any medical misconceptions that a parent may have, but also help to resolve any issues concerning theodicy and the failure of God. I believe that there is a level of respect that can be granted to alternate religious perspectives that can help facilitate the alliance between physicians and parents, possibly improving parents' and

physicians' coping abilities with the spiritual conflicts they experience and encounter in the ICU.

There do exist physicians who are able to engage fully with religious parents, who feel strongly (or demonstrate strongly) their own religious or spiritual convictions. Practitioners who are most able to comfort and respond to the religious perspective of parents are able to (a) agree with the parents and acknowledge the parent's perspective as relevant and powerful, and also (b) engage parents by explaining their own perspective in a religious or spiritual discussion using the parent's terminology and position (verbal tracking). These physicians are also comfortable communicating this perspective with colleagues and trainees. Notably, these physicians are often *widely* referenced by their colleagues, across specialties, as being "excellent communicators" and "really good at being able to challenge parents like this." To be sure, in my experience, the firmness in conviction of theological or religious convictions was no different between the physicians who identified the "excellent communicators" and the excellent communicators themselves; the distinction was that these physicians felt more confident and compelled (most often by their convictions themselves) to engage parents in these discussions. These physicians did not partition their world view from their professional calling: *I am a Christian, and I hold that to be important in what I do. The first thing I do is help to set the right expectations; we always want to be part of a save, but I try to explain clearly what I can and cannot do, and that I do not always know the outcome.* For such physicians, part of their value system requires that they be present and engage this sort of existential suffering. In doing so, these physicians do not just use their religious views, but incorporate other values and qualities that are similar to the family's.

Such a physician is not trying to justify clinical judgment in a new way, but deepen the relationship and trust with the family. The physician has already identified that there is something greater at stake in the conversation than religion—feelings of guilt and inadequacy—and is authentically engaging these fears. These responses originate from a place of authentic empathy, not just an attempt to justify a medical decision: *When parents who come to me in this way, I tell them that I am on their side too. That I am Christian, but because I am Christian I also know what Heaven is, and that I can accept things that happen on Earth because I know it gets better. I know that a child is going to a much better place. I also try to tell them that children have a way of telling us what they need, when they need it, beyond what the disease tells us. It is not really our decision in the end. But I invite them to do some reality testing. I do believe in miracles, but I know that we can't count on them, and we can't plan on them. We still have to act with what we are given.*

Such a physician has moved to the side of the parent by making the conversation more about the family, the child, their values and hopes, and less about anything medically related. The physician has even gone so far as to say that ultimately the child will show the team and their parents what should be done. Such physicians meaningfully engage their own personal understandings of suffering and respond authentically to the distress immediately at hand.

These physicians are praised by their colleagues on how peacefully mutual understanding is arrived at in family care consultations, even when religious language is used by parents—how comfortable everyone involved feels after conferences with them. There is a sense of relief when these practitioners are present in difficult case discussions

with families, not because they will break apart a family's conceptions of care and theology, but because they will be able to fully engage both the clinical judgment presented by the physicians and the value system of the parents to achieve the best results for the patient and family. Interestingly, these "good communicator" physicians are fundamentally in agreement with the conceptions of miracles from the Jewish, Christian and Islamic traditions I described in Chapter 1. They cannot affirm a miracle will happen. They recognize God's ability to intervene but also His sovereignty.

Compassionate physicians who know what they are morally required to do and how to handle difficult situations have come to terms with their own religious and spiritual convictions. They have wrestled with the role of suffering and are able to engage these conversations meaningfully. I think, after careful discussion, a harmony in understanding could be achieved, regardless of differences in religious perspectives.

Physicians who *acknowledge* that there is value in a parent's religious convictions are a key part of the success of these conversations. The end result is a sense of catharsis, the experience of mutual understanding and ability to achieve a working relationship founded on true trust and understanding. These physicians are able to discuss the difficult medical truth, but are also able to handle questions of theodicy and injustice with families, and thus are able to bring parents to an appreciation of bad news as well to posit some hope, comfort and understanding. The role of authenticity and comfort with engaging spiritual beliefs cannot be downplayed: *When parents talk to me about believing in miracles, I tell them "Me too! I am hoping for a miracle too! But I know God is sovereign, and He will do whatever He wants to." We cannot instruct Him on what to do. And He doesn't do what we want Him to do. He does what is best for us. So we might*

get a miracle, but it might not be in the package we had wanted. We also have to listen to His instructions. I am with them; I am not going to abandon them. I try to climb into the foxhole with them. I tell them and I really mean that I do hope that I am wrong. I hope they're right, that God will heal their child. I believe, too, that if He wanted to He could give their child complete health, but I also know He is sovereign, and will do what He knows is best for us.

These responses are different from “reframing” responses because these physicians engage the parents in *discussion* on miracles. Physicians who are good communicators do not devalue the parents’ conception of God, nor demean the parents’ understandings. They also do not dismiss the hope of a miracle, but engage the discussion on the family’s concept of miracles. They bring up relevant and related functions of God in concordance with what the parents are expressing, to relate their own positions on care. They may also express a belief in (or conception of) miracles either religiously, spiritually, or from a position of *mirari*, independent of any religious context. When they address miracles in the context of care they do not rule out miracles (or something outside of the routine and expected) as a possibility. But they theologically address the limitations in performing or expecting them, and address next steps for the medical team and parents in the context of the spiritual and religious constructs of the family. These physicians provide a way for parents to hope for a miracle while helping parents and the care team to make appropriate decisions based on the present situation within the parents’ religious values.

Dr. Elizabeth Kübler-Ross’s extensive work with the dying shows that most patients and their families want to move past grief to achieve some sort of peace and

understanding when confronted with suffering or a terminal prognosis (Trenoweth, 1995, pp. 37–59). A physical experience such as illness intersects with the ethics, culture and theology of a family in a compelling way that necessitates meaningful discussions of all their relevant value systems, including the religious and spiritual (Trenoweth, 1995, p. 43). These conversations should not be separated from technical and medical conversations on care, especially when religion is invoked by parents or patients. The spiritual and religious values of a family are a crucial context that must be engaged and understood to forge a meaningful rapport and an effective therapeutic alliance.

Restricting oneself from engaging in religious conversations does not help the therapeutic relationship between the practitioners and the family (Trenoweth, 1995, pp. 37–59). Engagement happens readily if practitioners exhibit a strong religious conviction of some sort of their own, yet it is not necessary that a practitioner have strong personal theological perspectives. When physicians do not have their own firm convictions, they may feel at a considerable loss as to how to communicate in these terms with parents. I do believe that practitioners must have some sort of training with various religious perspectives to know how to ask the right questions and to better understand their families' religious values. However, this is not a call for practitioners to find God in order to relate to their patients. Paramount is the importance of taking the moments that parents are exhibiting existential suffering to be present, abide with, and authentically engage in their position. Practitioners must be able to genuinely “get into the family’s foxhole” empathetically. The process does not mean that they should suspend their own interpretations; rather they should bring these interpretations into the process of discussion using the parent’s own terminology to *engage* understanding in a meaningful

and powerful way. Conversely they also will have to know when it is appropriate to integrate their religious or spiritual perspectives, and when they must “leave themselves at the door” to better understand and accommodate an alternative perspective. This sincere level of engagement shows the humanity of the physician.

Finally, practitioners who have a solid personal understanding of issues of theodicy, and a religious perspective or other spiritual means of addressing them, are able to talk with residents and medical students on how to approach these issues as well. These practitioners are of a certain personal religious or spiritual conviction *and* able to respond to the needs of patients, attracting trainees who seek their guidance for their own struggles on the topic. This allows for thoughtful mentorship of trainees in their personal struggles with issues of theodicy and how to approach these issues with patients and families. Providing meaningful training for engaging in these sorts of discussion stands to benefit all parties involved: patient, parent and practitioner (Aein & Delaram, 2014; Makoul, 1998).

I asked physicians I talked with about how they had become “good communicators” (as recognized by their colleagues). Physicians who were identified by their colleagues as being better at engaging these spiritual and religious discussions said they had been mentored and affected directly by other physicians who were good communicators. This perspective is validated by research into the topic of imparting bad news (Makoul, 1998; Schenck & Churchill, 2012). Mentors are described as sage-like physicians who were able to talk with patients and families, and able to be present. They use physical touch, sit in silence, allow for time, and facilitate discussion to engage families and respond better to their needs. Watching this ability in action and being

mentored by a strong communicator are important in developing these abilities. This sort of training and mentorship is paramount. *You know, when I was in medical school we had training on how to interact, talk with patients and good communication. But that drops off as you go through your training. It should be continued, for residents, fellows, and attendings. How we think about these things and communicate with parents determines everything.*

I noticed that physicians able to engage families spiritually and religiously also meaningfully engaged with the residents and students in this process. They invited them to be present in family meetings and discussed approaches on rounds. When a family's religious or spiritual need was expressed, residents and medical students sought the interventions and guidance of these "strong communicators." However, trainees do need to resolve their own personal struggles with God, theodicy, and injustice. Fellows, residents and medical students sometimes struggled to understand why babies from "good families" suffered or died. Being able first to understand these issues of theodicy for themselves will help them to better address them in practice. Further, it will help them become more genuine and engaged communicators.

One physician graciously provided the following email he sent to a trainee as an example of meaningful mentorship:

I wanted to follow up with you about a comment you made at the debriefing for "patient X." You mentioned the conflicted feeling of having friends pray in earnest faith for her healing while you knew in your own heart that she would die. Our work as [physicians] allows us to see behind the curtain, but not always to change the way the next scene will play out. Being a Christian and being a

[physician] in situations like that feels like hypocrisy, ambivalence, or both. Moments like that make it hard to stay true to both callings. That feeling never really goes away. It comes to me as an attending when I tell families what will be the worst news of their life—“Your child is dying”—and I receive in reply the question, “Do you believe in miracles?” This is not the most common response when I tell families of their child’s death, but it does come to me often enough. I always stumble a little when I answer. The most honest answer is the answer that I never give, “Yes, but not for your child.” Even just to write the words out seems cruel. I usually try to speak to their faith, their love for their child, and the irrefutable truth that their child will die soon. I leave divine rescue out of the conversation. “Lord, help my unbelief.” The truth is that God does help me in times like that, and He will help you at these times in your future. The real privilege is that as [physicians], we are uniquely positioned to enter into situations in the lives of these families with both credibility and care in a way that priests and pastors cannot. Not in that way. Not in our way. Families have an ear for the things that we tell them that is tuned differently. This is part of the Christian calling to [medicine], not merely that when families are facing dying times, we have the *possibility* of coming alongside them with the love of Jesus, but that when families are facing these times, we *belong* alongside them with this love. Chaplains and priests may not make it to the bedside in time, and sometimes when they do, their involvement is awkward. Stay true to both callings. God helps us as we are helping His patients. (Dr. John Petty, MD, personal communication, August, 26, 2014)

This response is powerful for many reasons. First, the physician recognizes that it can be difficult to be in-between a religious understanding and a medical understanding. Second, the physician identifies that this can have personal effects, and explains how he has addressed the issue. Third, the physician posits the duty of *engaging* these discussions. This physician states clearly that religious conviction requires being in the same “foxhole.” This perspective is yearned for in Broyard’s (1992) and Forman’s (2009) books recounting their own medical interactions.

Timely and genuine engagement is a duty the physician must undertake. Physicians must be able to speak to spirituality and religious needs in the context of care as needs arise. For families who do not separate what happens to their children in the NICU from their religious or spiritual conceptions of the world, this ability is crucial. These discussions present a vulnerability that must be engaged with an authentic presence in the immediacy of the moment when these religious and spiritual petitions present themselves. The discussion is originating in a crucial moment for parents, and directed at the person they are seeking a response from; not responding is often times dismissive. Priests and chaplains may enter into care at points that are awkward because they come too late; they have to play catch up and learn the family and patient’s history, what has led to this juncture. Since the priest or chaplain may not have built the same step-by-step relationship through the pathology of a patient’s course over time, there may not be the same sense of comfort and familiarity with the chaplains and priests as there has been with the medical team. This progression through the course of treatment and time in the hospital helps to strengthen the trust, therapeutic alliance and shared decision making

process between practitioners and families. This trust can be deepened by a physician's receptiveness to a family's religious or spiritual suffering.

Practitioners often express clear and deep-seated values in their personal understandings of religion or spirituality. However, there are instances where they feel unable to translate or barred from expressing themselves to parents in for a number of reasons—most often, perceived professionalism or general discomfort. All of the physicians I talked with took the time to listen, integrate the family in discussions, and respond to the questions families had. However, when parents referred to miracles, the physicians who did not feel comfortable engaging these discussions talked *to* the parents about the medical implications and data, and avoided the religious discussion. Their engagement centered more on the medical implications and taking time to explain and re-explain pathology and prognosis. Not being able to cross over from their own convictions to these sorts of religious and spiritual discussions made it difficult for them to talk *with* these parents in a way that integrated religion into medical treatment. It made adverse outcomes feel especially weighty to these physicians, that they could not address this need with parents or discuss pathology in the context of religious perspective. Thus, the practitioners I talked with who did not feel they had the proper tools to engage miracle language or religious discussion displayed significantly more distress. It seems from observations and discussions I had that practitioners who were comfortable abiding with parents in their moments of existential distress seemed more satisfied with the interactions they were able to have. Practitioners are not immune to the suffering and struggles of the innocent (Vohra, 2014). This creates distress over notions of justice, God, good and evil. As is evident in the discussions cited earlier in this chapter, physicians and

staff can be significantly moved by the anguish of their patients and families who are dealing with the illness of their children.

Physicians who were inspired by their religious convictions were much more comfortable talking *with* parents about religious perspectives. They were able to authentically engage in these discussions, and speak with the same sort of assuredness they had in discussing medical pathology. These physicians incorporate *verbal tracking* and are able to engage families where they are in religious or spiritual language they use and understand. They displayed much more peace and confidence when recounting difficult past cases.

The cultural experience of infant/child death and illness is no longer as prevalent as it was 50-60 years ago in first world countries (O’Leary & Warland, 2013; Philip, 2005). Thus there is a lack of cultural models for the experience. In addition, the advent of new medical technologies has given rise to cultural and theological expectations that suffering should no longer happen to children and babies. The old stories of these innocents suffering now seem archaic because we have the means to avoid suffering or intercede when it happens. Coupled with the deeply rooted history of physicians as conduits of hope and healing (Katz, 1984; Kee, 1986; K. Lee & Dupree, 2008), the end result is a common inability by practitioners and families to embrace and understand suffering as part of the human experience in first world countries (Vohra, 2014). But because new diseases, natural disasters and random acts of violence and “evil” will continue to manifest, it is necessary to continue to make progress in alleviating such sufferings; we are all vulnerable to the random human experience (Kushner, 1981; Vohra, 2014).

In the NICU/PICU, real suffering is happening to small children and babies daily. Being able to find a meaningful way of understanding this should not be unique to a handful of practitioners. There exists a spiritual and even scholarly yearning to make peace with this anguish, as demonstrated both in the discussions I have been part of and in the research into distress at the end of life and during life sustaining treatment (Forman, 2009; Kushner, 1981; K. Lee & Dupree, 2008; Lipson, 2005; Rockwell, 2007). There is evidence in much of the literature on NICU/PICU care that clear and honest communication between caregivers and families helps to facilitate the best outcomes for all (Cleave et al., 2014; K. Lee & Dupree, 2008; Lipson, 2005; Harrison, 2008). Specifically, I believe that discussion of the religious and spiritual comprehension of the experience should not be omitted or limited; but fully and empathetically engaged for mutual support and understanding. The inability to express distress creates practitioner burnout, moral or conscious distress, and psychological illness, distress, complex grief, and PTSD for families as well as medical staff (K. Lee & Dupree, 2008; O'Leary & Warland, 2013).

In conclusion, I believe that my observations and discussions with practitioners show that remaining removed from religious discussions increases distress in practitioners, and is less effective in facilitating a shared decision making process and therapeutic alliance. All engaged, empathetic and invested team members can be the same "good communicators," if they take the time to develop their personal understandings in order to communicate better with parents. There are meaningful and sensitive ways to engage these conversations either by starting from a personal theological perspective or by coming to understand, appreciate and put into context a

parent's. This is what I think is meant by being able to "get into the family's foxhole" or by identifying the role of a physician as "belonging alongside a family" in order to come to a mutual understanding. I believe that religious discussions can serve as a tool to help foster shared decision making even when practitioners and parents initially seem to be at odds. It provides the opportunity to sit with a family and acknowledge their position of distress, without an agenda, and abide with a fellow human being who is suffering.

The process involves two steps: (a) validate and acknowledge the parent's perspective as relevant and powerful, and (b) empathize with the parents by bringing the physician's own perspective in a theological discussion using the parent's terminology and position (verbal tracking) and/or incorporating the parent's religious perspective into the discussion of the patient's medical care. This process is enhanced when practitioners talk *with* parents by engaging the religious and spiritual perspectives, and not *to* parents by reviewing the data and medical perspective. Practitioners need to recognize that petitions for miracles and instances of miracles often happen in moments of sheer desperation, hopelessness, or suffering. Rote responses such as "I am praying for your peace" do not immediately engage the level of desperation and suffering that parents express when they say they are hoping for a miracle. The essential point is not that they are asking for a miracle, but what that reveals about how they are coping and what they are experiencing. Physicians must respond appropriately and in a way that helps parents maintain hope and faith, even when the prognosis is grim. On a spiritual level, there is a meaningful way to communicate various theological understandings that can facilitate a trusting relationship and help practitioners and families come to terms with the suffering (and potential loss) of their infant or child.

CHAPTER 4. THE CALL TO PRESENCE

J.B.: It's too dark to see.

Sarah: Then blow on the coal of the heart, my darling...
Blow on the coal of the heart.
The candles in the churches are out.
The lights have gone out in the sky.
Blow on the coal of the heart
And we'll see by and by...
 We'll see where we are.
The wit won't burn and the wet soul smolders.
Blow on the coal of the heart and we'll know...
We'll know...

—Scene Eleven, Sarah, from *J.B.* by, A. MacLeish

Being human means enduring suffering that sometimes seem unjust. The NICU forces patients, families and practitioners into intensely vulnerable positions as small innocent lives are born into suffering. Parents struggle to find their identity in this foreign world that is complete with its own language and culture (Arockiasamy, Holsti, & Albersheim, 2008; Forman, 2009; Schenk & Kelley, 2010). Physicians and nurses do their best to offer hope and healing, yet there is a culture of silence in the history of medicine that has to be overcome. Here is the time where faith is tested. Those caught up in the experience cannot put it on the back-burner and come back to their religious understandings on Fridays, Saturdays, and Sundays. Everything that has been taught and read is now being put to the test. Where is God in the NICU? Where is justice? Why is there such a place if God is a loving God?

The purpose of Chapter 1 was to give an account of miracles from religious texts and experts. It was also to posit the idea that miracles as positions of wonderment—*mirari*—is not unique to a religious person. The most important thing about the expressed hope for a miracle is the position it reveals of a parent. Chapter 2 was a review of the

history of the patient-physician relationship to trace past reluctance about truth-telling and breaking bad news to patients. Truth-telling is necessary as it allows families to grasp the reality of the situation. Its absence and delay impedes the grief process. Practical wisdom requires the ethical physician to speak the truth, but more importantly, to know how to speak it and what to do once bad news been given. This ability to empathically discuss bad news and be present to its effects is part of being a compassionate healer. In Chapter 3 we saw physicians struggle with *mirari*, medicine, hope, and truth. The call up to this point has been to *hear and acknowledge* what petitions reveal about the position of the family; *be truthful*, be able to handle the results of bad news, and allow parents the time necessary to go through the process of grief and reach acceptance and adaptation; and *find meaning* in the physician's own understanding of suffering and be able to convey their responses to the expressed needs of the family.

There exists an extensive literature on how physicians should be *present* and *human*, while, at the same time, studies have shown how various technologies and lingering paternalistic values *dehumanize* and *distance* physicians and patients. Pellegrino (1987) argues that attempts to connect the physician and patient in a deeper way have been long standing (p. 10). As far back as the first century A.D. the physician/patient relationship was challenged by Scribonius Largus to move from the more superficial *philia* (friend love) as a means to an end (physician achieving obedience from patient for adherence to medical care) to *humanitas* (love of mankind) and *miser cordia* (mercy) as the motivation to heal. Yet book after book emerges about the rarity of healers who are able to meet the total, *holistic* needs of their patients, from Forman (2009) to Broyard (1992) to Schenck and Churchill (2012). I pondered the title *Healers, Extraordinary*

Clinicians at Work by Schenck and Churchill (2012, emphasis added) and my own observations in the NICU. Why are they “extra-ordinary” and not “normal”? Why are there only a few physicians to whom colleagues can point as being *extraordinary* communicators? I do not believe that this is completely due to inadequate training and poor screening; I think it is rooted deeper in our human psychology, and more importantly, in our *existential* understandings of the world around us. As human beings, we are essentially uncomfortable with failure. As spiritual (or as Paul Davies puts it, mystical) beings, we are uncomfortable with senseless suffering.

The Ought

Compassion has a moral quality; it is not just a fine bedside manner or a capacity to have a physiological or psychological empathy with the patient . . . But compassion is something more. It means . . . “feeling with,” “suffering with,” the patient.

—Pellegrino, 1987, p. 15

It may seem a high price to require physicians to *suffer with* patients, but my observations and much research concludes (E. Lee et al., 2015; Vohra, 2014) that physicians already do suffer. Yet instead of *suffering together*, the relationship has maintained distance: the physician suffers separately from the patient, and that distance *further complicates* the suffering. The physician suffers from failing to thwart the suffering of the patient and thus the perceived failure of his/her profession, and also as a sympathetic human being observing the spiritual suffering of a patient and family, unable to know how to help. The patient and family suffer as they endure the burden of the illness (Pellegrino, 2012) while trying to make sense of the experience in a foreign world (Schenck & Churchill, 2012).

The separation of the two parties in the same space does more to add to the suffering than alleviate it. If physicians value healing then the separation is not beneficial to that process. It denies the opportunity for a physician to be present with someone who is suffering, an action Menahem Mendal terms as “God’s language” (Kushner, 1981, p. 154; Trenoweth, 1995, p. 151) in humanity.

Whether one uses Beauchamp and Childress’s (2008) concepts of beneficence and non-maleficence, or if we love and protect others as we do ourselves (Leviticus 19:18), the common universal moral or ethical requirement is that humans should be and act as *compassionate* beings. In this sense, the constructed distance between a physician, patient, and family is not ethical. An ethical physician is one who is compassionately present with the patient, *suffers with* the patient instead of at a distance, or compartmentalizes the experience. This also means that when a family petitions a physician in religious terms, the physician must be able to find a meaningful way to engage this aspect of healing, through genuine *acknowledgment*. This religious angst is part of the family’s suffering. “Compassion becomes a moral requirement because a truly healing action requires some comprehension of what this illness means to **this person**” (Pellegrino, 1987, p. 15). If illness to *this family* has religious components, the compassionate, the ethical physician must have modes of addressing this.

Differences in beliefs. Chapter 1 set forth the understanding that miracles may not necessarily be interventions in the “natural order” of the universe by a deity. *Mirari* is the experience of an individual who witnesses something that exceeds the *individual’s* understanding of how the world around him or her operates. Miracles are not necessarily disruptions in the “natural order” but reveal more about our limited understanding of the

world. Another crucial theological aspect of miracles is when they are petitioned for and why. Miracles are petitioned for and may appear at moments of great distress or suffering. Therefore it is *not* a requirement that a compassionate physician be religious. Nor is it true that a physician from one religious background is unable to address the religious utterances from families with a variant belief. An atheist is as capable of experiencing a moment of wonder as an Orthodox Jew and both are susceptible to existential suffering. Anyone can be baffled by the perceived injustice and blindness of suffering (Kushner, 1981, p. 66). *Why me?* is not necessarily a Jewish, Christian, or Muslim question. Pellegrino (1987) states,

[I]n a morally pluralistic society, universal agreement between physicians and patients on fundamental moral issues is no longer possible. It is more than ever imperative, then, that patients and physicians recognize where their value systems coincide and where they diverge. In the vulnerable state of illness, patients must be protected against submersion of their value systems without, on the other hand, expecting the physician to sacrifice his own. (p. 14)

A physician should be able to understand and bear witness to what the family is experiencing. In Chapter 1, I mentioned a physician who said doctors have to learn how to *sit* with a problem that is not medical in nature, but medically related. There is a yearning of all humans to be *acknowledged*. In Chapter 3, a “good” communicator said that physicians have to learn how to get into a family’s fox hole. This does not come from immediately calling the chaplains when a family starts in on religious conversation. When parents introduce a religious or spiritual perspective to the care of their child or infant, the parents have provided crucial insight to their adaptation process and to their

value system that helps pilot their coping and medical decisions. When “We believe there will be a miracle” or “we are praying for a miracle” is entered into the equation, parents are giving new clues for communication. They’re expressing both their hope and their position of deep distress. Responding means going beyond the differences and bearing witness to our common human vulnerability to illness and suffering.

Religion is one of the two conversations that polite society is advised not to engage in (the other being politics). It is considered private, messy, and in conversation, at risk for heated argument. There are so many various traditions within each major religion, it can seem an impossible task to find any commonalities. However, after my own investigation, I do not believe that in the face of suffering and illness the divisions are necessarily so problematic. I also believe that the commonalities provide a moral impetus to engage with one another spiritually and religiously when we are suffering, physically and existentially. To repeat Rabbi Berman’s charge in Chapter 3, we have a human duty to rescue.

With One Voice (Temple, 2009) is a Netflix original documentary that traces mysticism across most of the major religions East to West. The conclusions of this movie and Trenoweth’s (1995) book *The Future of God*, are nearly the same; that which divides us is not necessarily important. From physicist Paul Davies, Archbishop Desmond Tutu (in Trenoweth’s book), and the various mystics in *With One Voice*, the same understanding of *oneness* regardless of differences, the common sense of *belonging to each other*, emerges. Fundamentally, most faith traditions believe that “healthy spirituality is about coming together” (Ina May Gaskin, as cited in Trenoweth, 1995, p. 91). There is even less division in how religions require us to treat one another. As a

monk in *With One Voice* says, spirituality calls us to stop “worshiping the tea pot and drink the tea.” In other words, we must apply the teachings in our lives and delve more deeply into the human experience. Medicine provides this opportunity, caring for a patient and family who are both physically and existentially vulnerable. We are called universally to act *compassionately*. When a fellow human being is suffering existentially, physicians must roll up their sleeves and delve into these “messy” religious and spiritual positions and conversations in order to *rescue*.

Nowhere is the fragility of life as clear as it is in the NICU, with tiny bodies attached to machines and wires, struggling against death and illness. Physicians can *suffer with* their families by simply *acknowledging* the great distress of having a baby in an intensive care unit. Movement toward being an *extraordinary* physician is to let go of perceived professional limitations on engaging religious and spiritual dimensions of care and to become vulnerable with a patient and family. In Schenck and Churchill’s (2012) book, the term *surrender* plays a key role in a physician’s ability to do this effectively. As Ina May Gaskin puts it, “you have to be in a state of grace to receive grace and I think that’s true. If there are negative emotions, you can’t tell that something subtle and spiritual and sacred is happening” (as cited in Trenoweth, 1995, p. 86). I believe this is a crucial part of “getting in the foxhole” with a patient: Surrendering the distance between physician and family and the desire to “fix,” sitting down as one human being to another, *acknowledging* and bearing witness to their suffering. A physician at the Fourth Annual Conference on Religion and Medicine said we need to *abide* with patients.

The physicians in Chapter 3 who feel uncomfortable or restrained by the belief that religious conversations are inappropriate between physicians and patients are

restrained by unfounded beliefs. First, it is not *the physicians* seeking to discuss these matters, but the patient and family experiencing illness and medical treatment who seek these responses from their physicians. The faux pas of religion as a topic of conversation is when it is approached randomly, for the sake of argument. When a family brings forth the conversation as a result of a mutual experience with illness, normal social mores no longer apply. “We are praying for a miracle” is a petition for those who hear it to understand their position of distress. There is a common experience all parties share, and a suffering they are all part of that they can discuss. The parent may not be seeking to argue or make a point, and neither should the physician. The family’s experience with questions of the problem of evil adds to their suffering. Their petition requires that the physician put aside any differences or even fears, and meet them on some sort of common spiritual ground. Therefore, when it is presented to physicians, there should be questions, active listening and appropriate engagement. The physician must *surrender* or “set myself aside” (Schenck & Churchill, 2012, p. 124) “[become] the hollow bone” the “empty vessel” (p. 79) to “open up” to the viewpoints and understandings of their patients and families (Schenck & Churchill, 2012).

I believe that “the virtue of practical wisdom, as the capacity for deliberation, judgment and discernment in difficult moral situations” (Pallegrino, 2002, p. 8), is an important characteristic of a physician for two reasons. First, physicians who use practical wisdom recognize and choose the right action despite its being difficult or unpleasant. Second, and most importantly, they know how to compassionately handle the difficulties that come with doing the right thing. It is not just that they know how to make the right decision in difficult circumstances, it is that they also know how to make these

decisions well. The physician in the NICU who has practical wisdom knows that breaking bad news is morally required and must be done in a timely way. Most importantly, that physician knows that bad news will begin a grief process and is prepared to *acknowledge* and *be present* with the grief process. With religious discussions, physician who use practical wisdom have to come to a meaningful place regarding their own conception of suffering in the NICU. *Why do innocent babies suffer?* The vulnerability of any innocent person to suffering is not just a theological problem, it is a human problem. Whether religious, spiritual, or not, experiencing babies and children suffering is an existential crisis. In a webinar (Kogan, 2015), Dr. Kogan stated that physicians must be grounded in their own spiritual or religious understandings, otherwise they are responding to their patients and families on a superficial level, missing a crucial opportunity and introducing awkwardness into the relationship. Schenck and Churchill (2012) address this as well, recounting how a physician awkwardly ends up praying with a patient. It does not end well:

“Anything else we can do for you, Mr. Jones?” And he says, “I want you to pray with me.” So she’s suddenly on the spot, because she’s got ten ducklings she’s responsible for, and she herself is not a particularly religious person. But she says, “OK. That’s fine,” . . . He grabbed her hand and another person’s, and suddenly they become this little prayer circle . . . He looks up at her and says, “Go ahead and start.” And now she’s getting really uncomfortable, but she goes, “Mr. Jones why don’t you go ahead and pray?” And so he starts. . . . and he’s getting into it, getting more and more animated, getting louder and louder. And, working himself up into a Pentecostal-type frenzy, he calls out, “Take the spirit! Take the spirit,

someone! Take the spirit!” And he is clearly wanting somebody else to pick up the prayer . . . At this point, my colleague realizes she can’t go on with this, and so she breaks in and says, “We all have respect for you and for your religion, Mr. Jones, but we can’t go any farther at this point.” And then she tries to stop it. At which point, he starts calling out “Oh, Lord! They have science, but they do not have faith!” (pp. 113–114)

Schenck and Churchill point out that the moral of the story is the clinician’s realizing her limits and lack of training for this sort of event. I offer an additional concern: The problem was not that the physician answered the petition for prayer with the patient, nor that she had not been trained or lacked cultural sensitivity. The problem was that she had not resolved these sorts of religious needs and issues enough in herself and in her prior practice. Therefore she did not know *how to* genuinely engage to these sorts of requests. The results of such an encounter could be catastrophic for a family and a physician. The patient in this vignette clearly values the role of God and Spirit in his care and health. He has now confirmed that his team does not share this conviction. There is a significant amount of room here for him not to trust or feel confident in his care. As I have discussed, for the religious person as it was for ancients, medical knowledge is something that has been bestowed by God. If the team does not appear to be in communion with God, then there can be doubt in their ability to heal. The physician also is now clearly uncomfortable, there is now an awkwardness introduced into their relationship. How does one recover from such an event? Had the physician engaged practical wisdom as part of her clinical judgment to come to an appreciation for religious ritual and her own

conceptions of prayer, she could have meaningfully engaged the request *or* asked enough appropriate questions prior to the prayer to help guide the situation more constructively.

It is not beyond the scope of foreseeable possibilities that religious discussions and petitions to pray with families will arise. Compassionate physicians will have sat and struggled with these concepts themselves in order to acknowledge them appropriately and genuinely, if only to preserve a trusting relationship. Perhaps she could have said, “Mr. Jones, prayer is often an incredibly private and personal ritual, I am humbled you would invite me into this. I completely understand how vulnerable your illness has made you and the strength and hope you are seeking in prayer. Can you tell me more about what you are asking for in me praying? What does this look like for you?”

There are other benefits to taking the time to understand and engage a religious viewpoint. The compassionate physician can avoid the common problem with shared decision making discussed in chapter two by helping a family reach a “good decision [that] will fit this particular person, at this age, and this situation in life, with this person’s aspirations, expectations, and values” (Pellegrino, 1987, p. 12). This does not come from separating a family’s religious concerns, their belief in miracles, from the medical needs of their child, but engaging them. Physicians have to ask the right questions, sit with the information and set aside their own biases (Schenck & Churchill, 2012, pp. 77–78) to reach trust and a meaningful resolution. The results of not being comfortable or able to discuss illness in this way are illustrated in the angst of physicians who experience distress as described in Chapter 3.

Physicians must come to a meaningful understanding of suffering and spirituality in care for themselves to engage these sorts of discussions with their families. For

physicians, the experience of leaving such a conversation unaddressed can carry distress about the experience across a lifetime. The dehumanizing experience of watching others suffer and die can cause burnout and moral distress. Kübler-Ross stated that “we all must do more to increase our own individual capacity for love” (as cited in Trenoweth, 1995, p. 39), which she believed meant facing fear and suffering head-on:

. . . all that fear is bound to make you ill. Or you can say, this is an opportunity to practice unconditional love, and then you go out and stick your neck out and you help those people. You don't judge where they come from or how they got it because that's not your business. What is your business is that this is a suffering fellow human being whom you can help. If you stick your neck out, you'll move forward. If, like an ostrich, you put your head in the sand, you're bound to get stuck. It's your choice. Choose love and you'll be blessed beyond what you can imagine. Choose fear and it could quite literally kill you. (pp. 45–46)

Kübler-Ross addresses what Mohrmann discussed in the plenary (Mohrmann et al., 2015a), that physicians cannot know what patients or families may need, or what they are speaking to, spiritually or religiously, unless they are willing to ask. Kübler-Ross also emphasizes that physicians must be engaged in this process, not just for the benefit of the physician-patient relationship, but also because of its importance in self-care.

Conclusion

Kushner's (1981) book, *When Bad Things Happen to Good People*, provides a good way to capture the main points of this thesis:

1. When bad things happen to good people, when innocent babies are born ill and suffer, the ultimate question is *not* why this has happened. It should be

well established that suffering is random; illness and accidents do not know if you are a child, a good person or a bad person. The important question is “Now that this has happened, what shall I do about it?” (p. 151). We have to appreciate that the world does not always make sense (p. 102) and that “we are [not] the cause of what happens” (pp. 102–103). “Laws of nature treat everyone alike” (p. 66). “Pain is the price we pay for being alive” (p. 72).

2. Suffering calls others to be present, to *acknowledge* the suffering in others. “Job . . . needs to be told that what is happening to him is dreadfully unfair.” Kushner says that in the story of Job, while his friends gave bad advice, the first thing they did right was show up (p. 100) they “mustered the courage to face him and confront his sorrow” (p. 101). For Schenck and Churchill, Broyard, and Forman, the call is for physicians to *sit with patients and families in their suffering*, not to apologize for the world or God (pp. 156–157) but to *acknowledge* the experience of distress and vulnerability. *Affirm* the individual’s position of self-worth by genuinely presenting “You are a good person, and you deserve better. Let me sit with you so that you will come to know that you are not alone” (p. 157). Kushner references *J.B.*, a play by MacLeish, to make his final point: Sarah, Job’s wife in the play says, “You wanted justice, didn’t you? There isn’t any . . . there is only love” (p. 159). The concept of loving a patient and family is also echoed in the work of Schenck and Churchill, Pellegrino, and Katz on the physician/patient relationship.

Ethical physicians must come to their own spirituality and spiritual understanding of suffering and theodicy. They must become humble, and take all complicating factors and set them aside to confront and be present to suffering. Individuals who are suffering are morally owed the *acknowledgment* that they are suffering and that it is terrible. When these moments are not engaged in an authentic and meaningful way, the long term outcomes for both the physician and family can be poor. The root of compassion is *suffering with*. The miracle of religious language and petitions for miracles is the intensely human moments they supply for the physician, patient and family relationship. In the quote from *J.B.* by MacLeish, Sarah says that there are situations and circumstances that happen in life that do not have satisfactory answers in, or hope from, religion or spirituality (*the candles in the churches are out*). Even reviewing the data as to why one is experiencing suffering does not alleviate the experience of suffering. In the experience of the problem of evil or theodicy, one can have one's hope extinguished (*the lights have gone out in the sky*). However, individuals survive or endure these ordeals through the presence of other human beings in their lives. The results are not immediate (*and we'll see by and by*), but the humanity, the compassion of those around us, can restore us in the moments of suffering. *Blow on the coal of the heart and we'll know . . .*

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- Ethics of Health Care Communication (BIE 709) Dr. Michael Hyde, PhD
- Independent Research Study: Neonatal Intensive Care Unit Communications (BIE 721) Dr. Ana Iltis PhD and Dr. Christine Bishop, MD. Brenners Children's Hospital, Winston-Salem, NC.

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- Spiritual Care Workshop: An Interprofessional Model of Spiritual Assessment and Treatment. Christina Puchalski, MD, MS. George Washington University.

Health Care Experience:

Founder: Avery's Angels Gastroschisis Foundation,

International September 2009-Present

Major Accomplishments:

- Created a variety of programs to promote and provide education, awareness, and support for families, patients, and communities affected by the birth defect gastroschisis.
- Collaborate with large community hospitals with a diverse multi-cultural patient population including Brenner's Children's Hospital, UNC Chapel Hill Children's Hospital, Cincinnati Children's Hospital, Boston Children's Hospital, Texas Children's Hospital (Houston), University of Texas Medical School (Department of Pediatrics), the University of Utah (Department of Pediatrics).
- Consultation with research organizations including the National Birth Defects Prevention Network, the Center for Disease Control, the National Organization of Rare Diseases, and the March of Dimes.
- Established collaboration with Beads of Courage, Icing Smiles and Now I Lay Me Down to Sleep.
- Created an international campaign and established presence in collaboration Australia, South Africa, the United Kingdom, Canada.
- Developed legal framework, budget, global growth, and fundraising strategies.
- Created volunteer training and implemented HIPAA compliance for all volunteers
- Responsible for communication with the official Board.
- Entrepreneurial Summer Fellows Internship Program sponsored by the WFU Center for Innovation, Creativity and Entrepreneurship (CICE) for Day Symposium at UT Houston Medical Center, Summer 2015, in conjunction with DHHS Texas and Texas Children's Hospital, under the direction of Dr. Stacey Moore-Olufemi, MD.

Education Experience:

Teacher Assistant/Behavioral Specialist Johnston County School System

Cooper Elementary- Clayton, NC

September 2008 - May 2013

- Teacher assistant and behavioral specialist for special needs students.
- Assisted teachers and staff with educational needs of 10-15 students K-5 at a Title 1 (80% socioeconomically challenged) elementary school and developed and implemented lesson plans.
- Worked both independently and in small groups of students with a variety of health and developmental disabilities.
- Helped provide inclusion with mainstream classrooms, advocated for programs and inclusion.
- Coordinated schedules for students and teacher and Helped with parent/teacher, administration, psychological and special therapies communications.
- As a behavior specialist, helped implement the schools In School Suspension (ISS) program and positive behavior support (PBS).
- As an ISS teacher, coordinated individual lesson plans, communication and reported development/concerns for parents, teachers, guidance counselors and administration.

Sales Experience

Store Manager bebe Inc.

Raleigh, NC

January 2005-2008

- Helped to establish and open store in Raleigh, NC Crabtree Valley Mall.
- Grew business to \$1.4 million in first year as Store Manager.
- Completed store scheduling, employee assignments and work results.
- In charge of coaching, developing, counseling and disciplined store employees as well as recruited, selected, oriented, trained and evaluated employee results.
- In charge of achieving financial objectives, loss prevention and inventory as well as contributing to team effort by accomplishing related results as needed.
- Identified current and future customers by establishing rapport, communication and individualized customer service.
- Oversaw merchandising and visual displays for the store as well as determined marketing strategy by reviewing and departmental sales records.
- Partnered with local magazine and event coordinators and produced fashion shows, displays and styled ads, promotional and photography shoots.

Presentations

Fourth Annual Conference on Religion and Medicine

Cambridge, MA.

March 2015

Miracle Language in the NICU

American Society for Bioethics and Humanities

San Diego, CA.

October 2014.

Pediatric Surgical Innovations

Complicating Features of Organ Donation in Pediatrics and Neonatology

Affiliations

American Society for Bioethics and Humanities (2013-Present)

National Birth Defects Prevention Network (2010-Present)

Family Advisory Board NCCC UNC Hospitals (2012-2013)