

Making Sense of Suffering and Death: How Health Care Providers' Construct Meanings in a Neonatal Intensive Care Unit*

WENDY CADGE and ELIZABETH A. CATLIN

ABSTRACT: Biomedical technology has progressed at a pace that has created a new set of patient care dilemmas. Health care providers in intensive care units where life-sustaining therapies are both initiated and withdrawn encounter clinical scenarios that raise new existential, theological, and moral questions. We hypothesized that there might be broad patterns in how such staff understand these questions and make sense and meaning from their work. Such meaning making might be the key to working with the critically ill and dying while helping to create and sustain a meaningful context for personal living. This article presents themes evident in an in depth analysis of open-text responses to a spiritual and religious questionnaire survey completed by staff in one neonatal intensive care unit. The data reveal the central roles of perceived infant suffering and death in these providers' work experience and details how they understand the ultimate meaning of the suffering and death. We investigate patterns in how different providers articulate their individual attributes and motivations for working in intensive care. We found a surprising range of religious, spiritual, existential, and other meaning-making systems that underpin how staffs understand their work and how, certain of them, even define their purpose in life as caring for critically ill infants and their families.

KEY WORDS: neonatology; health care providers; religion and spirituality; suffering; death.

Wendy Cadge received her Ph.D. in sociology from Princeton University. She is currently an Assistant Professor of Sociology at Bowdoin College and a Robert Wood Johnson Foundation Scholar in Health Policy Research at Harvard University. Her research examines a range of topics related to religion in contemporary American life including religious pluralism, religion & immigration, religion & sexuality, and religion & the arts. Her first book is titled, *Heartwood: the First Generation of Theravada Buddhism in America* (Chicago: University of Chicago Press, 2005). Dr. Cadge's current research focuses on the history, presence, and significance of religion and spirituality in American hospitals.

Elizabeth A. Catlin is a senior faculty neonatologist at the Massachusetts General Hospital (MGH) in Boston and an Associate Professor of Pediatrics, Harvard Medical School. Dr. Catlin completed general pediatric training at Tufts University School of Medicine, Boston, followed by subspecialty training in neonatal-perinatal medicine at Brown University School of Medicine, Providence, Rhode Island. Dr. Catlin served as Chief of Neonatology at MGH from 1992 to 2004. She completed a Kenneth B. Schwartz Foundation fellowship in Clinical Pastoral Education in 1999. Dr. Catlin has a long-standing interest in spiritual distress, tragic decision-making, suffering, bereavement, and religious components of patient care in neonatal intensive care. Correspondence to Elizabeth A. Catlin, ecatlin@partners.org.

Introduction

A significant body of social scientific research focuses on the personal challenges and stresses of working as a physician, nurse, or other direct health care provider (for recent examples see (Arnetz, 2001; Chopra, Sotile, & Sotile, 2004; Hoff, Whitcomb, & Nelson, 2002)). Social scientists have explored how providers learn to cope with these stresses, and various policies and programs have been implemented to reduce burnout and increase retention among direct care providers in hospitals and other health care settings (Lake, 1998; Robinson et al., 1991; Thomas, 2004). Individuals who work in acute care settings such as intensive care units or who are regularly engaged in end-of-life care often face particular challenges making sense of and coping with the serious illness and death present in their daily work environments (Foxall, Zimmerman, Standley, & Bene, 1990; Guntupalli & Fromm, 1996; McNamara, Waddell, & Colvin, 1995).

Neonatal intensive care unit (NICU) staff care for critically ill newborn babies and face daily stresses and workplace challenges that may be particularly distressing (Downey, Bengiamin, Heuer, & Juhl, 1995; Neuer, Bengiamin, Downey, & Imler, 1996; Oehle & Davidson, 1992; Reddick, Catlin, & Jellinek, 2001). The nurses, physicians, respiratory therapists, administrators, and others who work in these units care for the sickest infants in the hospital in highly technological, medically demanding and emotionally charged contexts. While biomedical research and improved technology have steadily reduced the number of infants who die in neonatal intensive care units, NICU health care providers now often face the clinical dilemma of over treatment. Throughout their work, these providers confront existential and spiritual questions about suffering, disability, quality of life, meaning, and moral responsibility.

This article presents an analysis of results from a pilot study of how NICU health care providers understand and construct meaning systems in the context of their work. Following the classic example of Peter Berger and Thomas Luckman in *The Social Construction of Reality*, we begin to describe how a range of people in one neonatal intensive care unit construct realities in light of the suffering and death of infants' they observe and respond to as a central part their work (Berger & Luckmann, 1966). We find that while one portion of NICU providers describe being unable to make any sense out of infants' suffering and deaths, others construct explanations for and meanings of this suffering with implicit and explicit reference to religious and spiritual traditions. Providers further describe a number of factors, ranging from the intellectual and technical challenges of their work to their compassionate and otherworldly motivations, which enable them to continue working in this unit in light of the existential challenges implicit in caring for sick and dying infants. A range of religious, spiritual, scientific, and other socially con-

structured knowledge and meaning-making systems underlie how the health care providers' described here understand and sustain themselves as they care for critically ill newborns and their parents.

Research on neonatal intensive care: a brief overview

Neonatal intensive care units are the central physical location for patient care and treatment in neonatology, a medical subspecialty of pediatrics focused on newborn babies. While the word neonatology dates only to 1960 and the American Board of Pediatrics subspecialty exam in neonatal-perinatal medicine to 1975, systematic efforts to save fragile or premature babies began in the mid-nineteenth century and are credited to French obstetricians, particularly Stephane Tarnier and Pierre Budin (Cone, 1985; Desmond, 1998; Raju, 2002; www.neonatology.org: References on the History of Neonatology). In the United States, the first NICU was established at Yale-New Haven Hospital in Connecticut in 1960 and the number of such units has expanded dramatically since that time. In 2005, the American Hospital Association reported that 928 hospitals across the country have neonatal intensive care units.

The NICU has been the focus of much historical, medical, and social scientific study. Historical and medical researchers have focused on particular contributors, technical achievements, clinical trials relevant to therapeutic innovations, and the development and practice of neonatal nursing (Baker, 1996; Cone, 1985; Desmond, 1998; Farah, 1996; Guillemin, 1984; Guillemin and Holmstrom, 1986; Lussky, 1999; Raju, 2002; Strauss, 1968). Social scientists and ethicists have also devoted considerable attention to these units, particularly because of the ethical issues brought into focus by life and death decisions made by health care teams and parents. While ethicists tend to consider how life and death decisions *should* be made in the NICU, research by sociologists and others describes how these decisions are *actually* made in their legal, familial, cultural, and medical contexts (Anspach 1993; Frohock, 1986; Heimer & Stevens, 1997; Heimer, 1999; Heimer & Staffen, 1995; Lantos, 2001; Lyon, 1985; Orfali, 2004; Pinch, 2002; Sosnowitz, 1984).

A portion of research about neonatal intensive care units specifically analyzes the experiences of health care providers, primarily neonatologists and neonatal nurses. Studies describe the amount of time physicians, nurses, and other health care providers spend with the infants and analyzes how the information available to these providers shapes their experiences of and decisions about infants' care (Anspach, 1987; Sosnowitz, 1984; Zupancic & Richardson, 2002).

Earlier surveys of neonatologists suggested that most were satisfied with their jobs (Clarke et al., 1984) but recent data is mixed. Leigh, Kravitz, Schembri, Samuels, and Mobley (2002) found neonatologists to be significantly

more likely to be very satisfied with their careers compared to physicians in family medicine. However, Shugerman et al. (2001) found that pediatric subspecialists report levels of work stress and burnout that exceed that of pediatric generalists and both adult subspecialists and generalists. Studies of neonatal nurses point to high levels of burnout, fatigue, and physical and emotional distress, largely because of the amount of direct contact time they spend with patients (Downey et al., 1995; Neuer et al. 1996; Oehler & Davidson, 1992; Rashotte, Fothergill-Bourbonnais, & Chamberlain, 1997). Some of these studies further illustrate how neonatal nurses act as surrogate parents, engaging in “foster bonding” with infants in which they assign infants a range of sometimes well developed personalities and roles in ongoing social interactions (Landzelius, 2003; Palmer & Noble, 1985).

Largely missing from these studies are detailed considerations of how neonatal care providers make sense of their work, in their own words, and respond to the existential “why” questions implicit in the infants’ illness, suffering, and sometimes death, that they observe and respond to daily. While it is possible that some portion of neonatal care providers do not consciously consider these questions, relatively high rates of turnover as well as experiences of stress and burnout in some units suggests that such questions are present for many providers, even if not explicitly addressed.

As one step in understanding the meaning systems of neonatal intensive care providers, this case study contributes to social scientific and ethics based research about other aspects of neonatal intensive units an example of how health care providers find and construct meanings in their workplaces. It also furthers a body of research by medical sociologists and medical researchers about what sociologist Renee Fox describes as the “human condition of health professionals,” in an article of the same name, with particular attention to their religious and spiritual beliefs (Fox, 1988). Finally, it complements a growing body of research about the presence and roles of religion and spirituality in hospitals and medical institutions (Armbruster, Chibnall, & Legett, 2003; Grant, O’Neil, & Stephens, 2004; Messikomer & De Craemer, 2002; Puchalski & Larson, 1998).

Previous quantitative analyses of the data presented here show that more than 80% of the healthcare providers surveyed draw from religious and spirituality teachings as they privately pray for the infants in their care. While fewer report praying with their patients’ families in the NICU, the presence of prayer alone points to strong undercurrents of religion and spirituality in the study unit (Catlin et al., 2001). This article analyzes qualitative data collected alongside this quantitative data to offer more detailed descriptions and analyses of the meaning and knowledge systems, both religious and secular, underlying the ways healthcare providers make sense of their patients’ conditions and their own work in one neonatal intensive care unit.

Research methods

The data presented here were collected by Elizabeth A. Catlin, MD, in the neonatal intensive care unit at the Massachusetts General Hospital for Children (a children's hospital within a general hospital). This NICU was started in 1972 and at the time of the study had 18 beds. Data was gathered through an anonymous survey, designed to assess spiritual and religious components of patient care and providers' experiences. Study participation was voluntary and the questionnaire was completed by NICU staff on a computer in a private area of the NICU between September 1999 and February 2000. All staff, including nurses, neonatal nurse practitioners, respiratory therapists, social workers, pediatric residents, fellows, pediatric surgeons, and neonatologists were invited to complete this survey, which included 45 questions, about two-thirds of which were close-ended, and took approximately 30 min to complete. Scant previous research examines the presence of religion and spirituality among health care providers in neonatology making this study exploratory by design.

Forty-seven people completed the survey, 66% of the staff who spend the majority of their work time in the NICU. Sixty-three percent of neonatal nurses completed the survey, 67% of neonatal nurse practitioners, and 100% of the neonatologists. Respondents ranged in age from 25 to 59 (mean 40.3) and were largely female (87%). More than 90% were Caucasian, self-identified as Irish, Swedish-American, Italian, Greek, etc. While some had worked in the NICU for less than 1 year and others for 30, the median was 12 years with multiple modes. Respondents were largely Christian: Catholics (51%), Protestants (32%), including Episcopalian, Lutheran, United Church of Christ, Methodist, Presbyterian, and evangelicals; 11% were Jewish, 2% Hindu, 2% Unitarian-Universalist, and no religious affiliation was reported by 2%.

Statistical analyses of these data based primarily on the close ended questions was published elsewhere and pointed to a strong under-current of religion and spirituality in the NICU (Catlin et al., 2001). Open-ended responses to separate questions about the best and more difficult parts of healthcare providers' jobs, the ways they make sense of the suffering they observe in the NICU, and the characteristics that enable them to work in neonatal intensive care (and their motivations for so doing) are analyzed here, providing rich information, in providers' own words, about how they understand and find meaning in their work. We followed a grounded theory approach to data analysis coding these open-ended responses by theme in ways that allow providers' own voices to be heard (Strauss & Corbin, 1990). These data are unique in the glimpses they provide into the social worlds of health care providers' in the NICU. They are limited to the extent that non-respondents may have important different, modifying, or secular viewpoints which are not represented here and need to be explored in future study.

Findings and discussion

Setting the context: infants' suffering and death as orienting concerns

All but one of the surveyed health care providers believe infants' suffer during their time in the NICU, and such suffering is a central theme in their descriptions of their work. Eighty percent of providers believe they can help to alleviate this suffering, though they find the suffering of the infants' and their families personally draining, particularly when the baby is likely to be disabled or to die in the unit. This suffering was a central theme in the closed and open-ended questions on the survey, particularly evident in providers' responses to an open-ended question about the most difficult aspects of their jobs. The largest fraction of respondents, more than half, wrote about the suffering or death of infants' in their responses to this question.

A special care nursery nurse who has worked in the NICU for more than 20 years, for example, described the hardest part of her job as, "Watching and not being able to relieve the suffering of patients." Others voiced similar challenges through comments like, "seeing children suffer," and, "the inability to heal all children." A fraction of providers' pointed specifically to the challenge of being with families as they suffer in response to their infants' illnesses. "Watching parents try to deal with what is going on with their baby when the outcome is not going to be a good one," is the hardest part of the job according to a NICU nurse with 3 years of experience. Others described the challenges of being with the families as well as the infants, describing the worst part of their jobs as, "watching parents watch their child die," "dealing with the sadness of a family losing their child," and, "seeing the pain and anguish families suffer having a sick child." A few providers, mostly nurses, feel they sometimes prolong families' suffering through over treatment as physicians may not want to give up too soon or at all writing "we sometimes put [cause] families to suffer too much by prolonging the inevitable."

The death of an infant in the NICU and the period leading up to his or her death was emphasized or highlighted by many healthcare providers as the *most difficult* part of their work. Nurses, respiratory therapists and physicians all pointed to the death of a patient as the hardest part of their job writing comments in responses to this question such as, "the loss of a child," "the death of a baby," and "seeing babies die." Physicians and nurses not only feel agonized by the emotions surrounding a baby's death but they frequently experience a component of professional failure as well in not being able to send a healthy baby home with their family. The role of technology in unnecessarily prolonging the lives of infants who respondents felt were going to die anyway comes through in their comments about infants' death. As one nurse wrote, the hardest part of the job is, "When I feel that a baby has gone through extreme measures to keep him/her alive and it was obvious that they were not going to make it." The finality of removing a baby from the ventilator, pro-

nouncing death, and delivering the baby's body to the morgue was described by many of the NICU nurses. They pointed to their experiences taking infants to the morgue, previously located on Allen Street, by describing the worst parts of their job as "going to Allen Street." Trips to Allen Street remained in nurses' memories, as evident in comments like, "I have done it [gone to Allen Street] way too much. During April 1987, in a 20 day period I personally brought 17 of my patients to Allen Street." This example is noteworthy not just because so many infants died (this was prior to the introduction of surfactant, a therapeutic innovation in the early 1990s that enabled many more premature infants to survive) but because it happened 13 years prior to the survey and the memory continues to inform her thinking about her work.

Health care providers' strong emotions underlie many of their comments about the suffering and death of infants in the NICU. Differing relationships with their emotions were evident in their comments, with some trying to contain them and others struggling to express and find support for them. An attending physician, for example, pointed to struggles with his own emotions and those of infants' families when he described the hardest part of his job as, "remaining objective to provide input to emotional situations" while simultaneously pointing to his challenges dealing with parents writing, "I often do not know what to say. I try to be reassuring to them, but I do not want to get their hopes up that there will be a happy outcome." A nurse wrote, "I can't always separate my own personal feelings and go on...it can be so sad in here." Other respondents describe the "bonds" they have forged with families and the emotions this wells up in them; "I feel this way [sad because of an inevitable bad outcome for an infant] because I often find myself relating to the parents. How would I feel if this was my infant? I think of my own children," wrote one nurse. And several point to a lack of support they feel for their emotional responses to their work. A nurse described the "lack of staff support and general follow-up for these difficult issues" surrounding the death of an infant as the most difficult part of her job and an attending physician wrote simply that "no support for attendings' feelings" was the most challenging aspect of his job.

Making sense of suffering: three central themes

Healthcare providers' consistent descriptions of the suffering and death of infants' and their general understanding of the neonatal intensive care unit as an intense emotional environment point to broader existential questions about how they make sense of the suffering that is a regular part of their work. When asked what ultimate sense they make of the suffering of infants and family members in the unit, respondents tended to have one of three responses emphasizing that there was no sense to be made, that this was a part of a larger cosmic plan they did not understand, or that this was part of a larger cosmic plan that included God or a higher power who had varying degrees of agency over infants' suffering.

Before describing these three themes, which represent the responses of about half of the healthcare providers surveyed, it is important to recognize that a number of respondents did not answer these open-ended questions substantively perhaps because they had not thought about them consciously or were not prepared to respond on a short survey form. A few respondents suggested as much, for example a resident wrote, "I haven't really thought about that...I guess my religion tells me that it [suffering] is because of something their souls did in a previous birth, but I don't really apply that to my patients." A nurse responded to this question writing simply, "This is not a short answer inquiry."

Among those who did respond to these questions substantively, one group of providers, the smallest group of the three, was not able to make any sense of the suffering that happens in the NICU. A pediatric surgeon, for example, wrote, "I honestly don't know; it almost seems beyond my comprehension." And another respondent wrote, "I have no idea what the ultimate meaning is..." and another, "I don't know what to make of it." People in this group often expressed the need for a framework or other way to make sense of suffering, evident in comments such as, "I wish I had an explanation."

A second group of providers, the largest portion, pointed to larger cosmic or otherworldly plans they believe exist as they struggled to make sense of the infants' and families' suffering in the NICU. These respondents' were often clear that they did not know about or understand these plans, as evident in the following comment, "I believe all events happen for a reason, we just may not be enlightened enough to understand the reasons" and, "There is a meaning but one that I think we are not privy to know." Another respondent wrote, "I would like to think [suffering] does serve some purpose," though did not elaborate on what that purpose is or might be. A few people described the meaning of infants' suffering with reference to a general kind of learning. One nurse, for example, wrote, "NICU babies learn earlier than other babies that life is difficult and painful..." and another explained, "we are all here to learn, all experiences good and bad," implying both the infants and their healthcare providers can learn from their suffering.

The third group of providers' explicitly or implicitly referred to the presence of God or a higher power in their explanations for the infants' suffering. Some of these respondents described an active God who is involved in and directs actions in the world while others described a more passive God or higher power. Providers' who envision an active higher power who is engaged with and has some agency over the actions of humans described making sense of infants' suffering through comments like, "God gives you what you can handle and, hopefully, it will make you a better person," and "God is divinely sovereign, His grace and mercy is given at His will to either relieve the suffering or strengthen through it." Belief in an active or involved God or otherworldly power was further evident in some respondents' comments about how families suffer in the NICU. The language of "testing" was evident as several providers'

described having children in the NICU as a test God gives to some families; “I feel that all families endure tests of their faith and we never do it alone,” and, “I believe suffering is a part of life. A test for some...maybe to become stronger people.” Both of these respondents were clear that they believe God is with families as they struggle, as the first explained, “Our higher power, above or what lives within us, strengthens us and brings us closer to the ones we love and depend on.”

The majority of survey respondents who pointed towards an active and involved God imagined a God that had direct control over events in the world. All but one had no comment on how the relationship between God and the patients and families in the NICU actually worked. The nurse who was this exception placed herself in relationship to the infant and God seeing herself as having some influence on God’s behaviors. She described how she thinks she can relieve babies’ suffering through prayer, writing, “I do not know why we have suffering babies in the NICU but I do know that when they are dying and sometimes they recover I think it is because I prayed to God, that helps me, makes me think it does make a difference.” While she is not implying that it is her prayer alone that makes the child recover, her comments point out what she, and perhaps others in the unit, believe about both their responsibilities in the patient–God relationship and about the power and healing possibilities of prayer.

While certain NICU healthcare providers were clear about the plans of God or an otherworldly power and emphasized the need to trust in them, others were more ambivalent, expressing uncertainty in their written responses about why God selects some infants but not others to suffer. In comparison to the less ambivalent providers who wrote things like, “Everything happens for a reason. I am sure God is suffering with them [the infants] and he has some reason for what is happening,” and, “I believe God never hands us more than we can handle” others wrote, “Babies are special and you have to wonder why God chooses some to suffer.” A respiratory therapist also expressed ambivalence writing “there is a purpose in all things, we do not know God’s plan for us” while another respondent revealed an even greater ambivalence, “I believe most things are God’s plan, but I can’t imagine this is...” While none of the providers surveyed offer complete explanations for why some infants are ill and others are not, those who believe in a God who has agency and is directly involved in the world express differing personal theodicies or explanations, as evident in these comments, for why an all powerful God allows infants to suffer.

Among the healthcare providers who refer to God or a higher power as they explain how they make sense of suffering in the NICU, some reveal understandings of that higher power or God who is present but less engaged with humans’ daily lives. A Jewish physician, for example, pointed not to the responsibility of God or a higher power but to the responsibilities of humans to alleviate suffering writing, “G-d is not involved in the moment-to-moment

happenings of this world. It is the responsibility of people to respond, act, and deal.” A nurse further described a less active God who is involved in some, but not all parts of the world, writing “God doesn’t create suffering but does help us through the suffering.” While these people were fewer than those who imagined an engaged all-powerful God, their presence and theological understandings require study in future research on this topic.

The explanations NICU providers’ began to develop in their responses to questions about the ultimate meaning of infants’ suffering, quoted above, are revealing on several levels. First, they point to the range of scientific, philosophical, religious and other meaning make systems that underlie individual healthcare provider’s work in the NICU. While the lack of traditional “scientific” voices quoted above may be because of selectivity in who completed the survey, it might also suggest that just as there are “no atheists in a foxhole” few people who work in neonatal intensive care units have strictly scientific responses to the existential dilemmas of their work. Second, the majority of providers referred to otherworldly plans including, or not including, a God or specific higher power, pointing to the presence and significance of general spiritualities as described by sociologist Robert Wuthnow and religious beliefs in the meaning making that takes place in the unit (Wuthnow, 1998). While these themes are largely invisible in the seemingly secular day-to-day work on the unit, their presence begs for further investigation and explanation.

Sustaining work in the NICU: initial patterns

In addition to considering how healthcare providers make ultimate sense of the suffering and death that takes place in the NICU, it is also important to analyze how they describe being able to work in an environment that is so stressful and emotionally draining. While many wrote eloquently in response to questions about the ultimate meaning of the suffering in the NICU, most were much more comfortable responding to a question about what it is about them that makes their work in the neonatal intensive care unit possible. Their responses to this question provide insight into how the suffering of the infants and families so many describe as central to their work is negotiated and understood on a daily basis.

The majority of respondents felt they understood and could articulate qualities about themselves that contribute to their effectiveness and sustainability in the neonatal intensive care unit. One staff nurse with 10 years of NICU experience, for example, responded to this question by writing: “My love of babies, my compassion, knowing that I have something to offer these babies and families that will get them through probably the most difficult time in their lives; perseverance.” Taken together, the respondents fell along a broad continuum of intellectual, compassionate, and otherworld motivations for working in the NICU. While a few respondents were unable to describe the strengths and motivations that enabled them to care for infants in the NICU, others fell into one or more groups we describe as analytic points along this continuum.

Only a few healthcare providers were unable to describe their personal characteristics that enable work in the NICU representing the lowest level of engagement of NICU staff either in the profession or with the survey. One respondent was a resident doing a first rotation in a NICU with no prior NICU experience to draw on in order to construct an answer. Another staff member answered only 2 of 16 open-ended questions and her response, "This is not a short answer inquiry. To do so without explanation would make me question the validity of the survey" suggested discomfort with the survey and perhaps hostility or disengagement from the NICU. It is possible that since this was the last question on the survey and was open-ended rather than multiple choice or yes/no format, some respondents may have run out of time and felt the need to return to clinical duties, bypassing the question in the process.

Among the majority of providers who fell along the continuum described, a small group was emotionally detached and emphasized their intellectual interest in NICU work focusing primarily on its technical components. They tended to emphasize their medical competence in the face of challenging medical conditions describing their NICU strengths in a somewhat detached, self important, technical manner with statements such as: "I enjoy curing critically ill children" or, "[My] clinical understanding and ability to handle situations that arise in the NICU." Another staff member replied, "Despite all the other distractions, I still love the medicine." These responses differed from the majority in that they are characterized by scant mention of humanity and largely focus on the clinical expertise and interests of the respondent.

A second small group of healthcare providers combined intellectual and compassionate motivations for working in the NICU in their descriptions of themselves as introspective functionalists who believe that self-knowledge and limit setting are the keys to navigating and surviving the NICU. These staff responded to the question about what makes their work possible by describing qualities that contribute to their functionality in the NICU. "I feel I am sympathetic to families when they are going through hard times..." Another replied, "I understand how to sustain myself when I begin to feel stressed or burned out in this setting." This category of respondents exhibits a moderate level of psychological, emotional and spiritual engagement in the NICU, more attached and involved than those staff in the previous groups.

A third larger group expressed compassion for the infants and NICU parents in their response to the question of motivation. One respiratory therapist replied, "I have a very caring and sensitive heart as well as a genuine concern for the well being of all my patients and their extended families" while a nurse wrote, "I feel I have a lot of patience and compassion for others." Altruistic motivation was evidenced in this group with statements such as, "I love babies. I like to help families and to feel that my work is meaningful." Along similar lines another member of the staff responded, "I am a nurturing person. I have refined a skill I believe makes a difference in lives. I have a strong faith and wish to use God-given ability for the benefit of others."

The final large group of respondents emphasized a divine or larger-than self kind of “calling” to their work in the NICU and described the practice of neonatology as a vocation in which their “love” of babies is central. Many of these respondents mentioned God or faith in response to this question. For example, “I really care about the kids. This is the job God gave me to do. I try to do the best I can...” Members of this group (specifically, 13 respondents) described “love” for the NICU babies and passion for their work. For example, “I’ve loved babies since I was a toddler, I believe the work that we do has a significant impact on quality of life, and the individual stories touch me deeply, as parents experience the miracle of taking their baby home.” In this category, the responses come full circle to focus on the newborn, the center of the NICU microenvironment, and a spiritual “calling” to the work. One attending physician replied, “God has blessed me with a very big, warm heart, many abilities, as well as a strong faith.” This category represents the deepest level of NICU engagement for staff: emotional, professional, spiritual, and personal involvement.

Among those respondents who described the qualities that made it possible for each to do NICU work, it is important to recognize that few mentioned their personal qualities alone. In addition to itemizing personal qualities, most providers also identified resources that fueled them. Schematically, the resources providers described that underpin their personal strengths include faith, family, God, the babies themselves, nature, NICU colleagues, and NICU families. The fellowship of the NICU team was particularly important for survey respondents. That the team itself fills a vital role for individual staff is shown by answers such as, “I...somehow feel “called” to the NICU, I’m a people person, enjoy teaching, enjoy the team approach to care, and am invested in the colleagues that I’ve worked with for the past 10 years.” Another replied, “Knowing that together with all my colleagues that we will help this family become a family.” Individuals’ understood their personal strengths such as self-knowledge, compassion, technical competence, love of the infants, patience, and altruism as being fueled by different combinations of these resources, and listed them as key to enduring and thriving in the NICU.

In contrast to the suffering and death emphasized in providers’ descriptions of the worst parts of their work, *the medical successes* they described when asked about the best parts of their jobs are also a dominant sustaining force for all NICU staff. Both because of the acute nature of their patients’ medical conditions and the high degree of uncertainty about medical outcomes, remembering patients who emerged from the unit as healthy infants is a final key part of what sustains providers’ in their work. One respondent commented, “...I get great satisfaction seeing sick children make remarkable recoveries” while another wrote, “[I have] a love for caring and the wonderful feeling which accompanies a successful outcome.” Also, “There’s nothing better in the world than when they get well.” The NICU environment is intense and highly stressful; staff view healthy children as the light at the end of the tunnel and as providing a key ‘feel-good’ part of neonatal practice.

The continuum of motivations described by NICU staff and the social contexts of the NICU team and families as well as personal families and friends provide insights into how healthcare providers make sense of their work and sustain themselves in the NICU on a regular basis. Selected NICU staff emphasized their technical abilities, while many more drew on their compassion for patients and their families or talk about a kind of vocation or religious calling they feel towards NICU work. While more detailed information about how these providers' came to work in neonatology is needed to understand their divine or secularly inspired callings, the voices of healthcare providers quoted here suggest strongly religious or spiritual motivations, particularly among nurses, in this unit.

Conclusions

Taken together, the views of the healthcare providers characterized and quoted here point to a strong, though largely silent, undercurrent of religion or spirituality in one neonatal intensive care unit. Though Massachusetts General Hospital has a large chaplaincy department, at the time of this research there was not a chaplain specifically assigned to the neonatal intensive care unit and little overt religious or spiritual presence in the unit on the part of the hospital. At least a fraction of the nurses, physicians, respiratory therapists and others working in the unit, however, drew on their religious and spiritual backgrounds in understanding and making meaning of the suffering and death they observed in their day to day work. While very few spoke about these issues with their colleagues or in the context of patient care, they are central to understanding how some, certainly not all, healthcare providers make meaning in their work in unit.

Among respondents who explicitly described a God or otherworldly power in their responses to open-ended survey questions, a number of themes are evident which might guide future research. First, as in American culture more broadly, all of the healthcare providers here were, by virtue of their work, aware of suffering and what religious studies scholars refer to as theodicy or the problem of evil. Many wanted to imagine an all powerful God who would not chose to have infants suffer but, as witnesses to that suffering, were uncertain or ambivalent about how to make sense of its presence in light of their understandings of God. The personal understandings they began to piece together, which could be further investigated in more detailed interviews, have the potential to advance work in sociology and religious studies about "lived religion" or the ways individuals understand and practice their religious traditions outside of religious institutions (Hall, 1997). Of particular interest here is the role of prayer in the NICU, not just its presence but how and what healthcare providers pray for and in the pathways along which they believe their prayers influence their patients' developments' in the unit. Some research

suggests that Christian patients pray for God to guide their physicians, who can then help them recover from illness, while others believe God can directly intervene. Investigating these pathways in the prayers of healthcare providers would further these lines of research (Mansfield, Mitchell, & King, 2002).

Second, this pilot study clearly suggests that religious or spiritual motivations inform some healthcare providers' work but it does not provide enough information to identify clear patterns among the people studied. Patterns by religious tradition, occupation, gender, and other demographic factors known to influence religious belief and practice might be evident within individual neonatal intensive care units, but this is unknown. The role of institutional factors in the shape of the religious affiliation of the hospital or the religious interest or sympathy of hospital and unit leaders are important contextual influences to investigate in studies comparing more than one unit. Related, as is becoming evident in recent studies about the role of religion and spirituality among nurses in hospitals, is investigating how and in what context spirituality and religion come up and are addressed by physicians, nurses, and chaplains in neonatal intensive care units and other medical settings (Armbruster, Chibnall, & Legett, 2003; Grant et al., 2004).

Finally, this article points to the need for future research about the roles of religion and spirituality in medical settings analyzed at multiple levels. Several studies have assessed the presence of chaplaincies and departments of pastoral care in hospitals, but little recent research considers how religion and spirituality are present in institutions among physicians, nurses, patients, social workers, administrators, and other employees. While a growing number of papers examine religion and spirituality among one group of healthcare providers, normally nurses, this pilot study points to the importance of not abstracting these individuals from their institutional contexts and of considering in more depth how multiple people in one unit, hospital or other institutional context understand and draw on religious and spiritual meaning making systems, among others, as they consider the existential questions present in so many areas of medical practice in the contemporary United States.

Acknowledgment

This project was made possible by the Kenneth B. Schwartz Foundation and the support of the Robert Wood Johnson Foundation Scholars in Health Policy Research Program.

References

- Anspach, R.R. (1987). Prognostic conflict in life-and-death decisions: The organization as an ecology of knowledge. *Journal of Health and Social Behavior*, 28(3), 215–231.

- Anspach, R.R. (1993). *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press.
- Armbruster, C.A., Chibnall, J.T., and Legett, S. (2003). Pediatrician beliefs about spirituality and religion in medicine: Associations with clinical practice. *Pediatrics*, 111, e227–e235.
- Arnetz, B. (2001). Psychosocial challenges facing physicians today. *Social Science and Medicine*, 52(2), 203–213.
- Baker, J. (1996). *The Machine in the Nursery: Incubator Technology and the Origins of Newborn Intensive Care*. Baltimore: The Johns Hopkins University Press.
- Berger, P., and Luckmann, T. (1966). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Garden City NY: Doubleday.
- Catlin, E.A., Guillemin, J.H., Thiel, M.M., Hammond, S., Wang, M., and O'Donnell, J. (2001). Spiritual and religious components of patient care in the neonatal intensive care unit: Sacred themes in a secular setting. *Journal of Perinatology*, 21, 426–430.
- Chopra, S.S., Sotile, W.M., and Sotile, M.O. (2004). Physician burnout. *Student Journal of the American Medical Association*, 291(5), 633 .
- Clarke, T.A. (1984). Job satisfaction and stress among neonatologists. *Pediatrics*, 74, 52–57.
- Cone, T.E. Jr. (1985). *History of the Care and Feeding of the Premature Infant*. Boston: Little Brown and Company.
- Desmond, M.M. (1998). *Newborn Medicine and Society: European Background and American Practice (1750/1975)*. Austin: Eakin Press.
- Downey, V., Bengiamin, M., Heuer, L., and Juhl, N. (1995). Dying babies and associated stress in NICU nurses. *Neonatal Network*, 14(1), 41–46.
- Farah, A. (1996). The history of the neonatal nurse practitioner in the United States. *Neonatal Network*, 15(5), 11–21.
- Fox, R. (1988). The human condition of health professionals. In *Essays in Medical Sociology: Journeys into the Field* (pp. 572–587). New Brunswick: Transaction Books.
- Foxall, M.J., Zimmerman, L., Standley, R., and Bene, B. (1990). A comparison of frequency and sources of nursing job stress perceived by intensive care, hospice and medical-surgical nurses. *Journal of Advanced Nursing*, 15(5), 577–584.
- Frohock, F.M. (1986). *Special Care: Medical Decisions at the Beginning of Life*. Chicago: University of Chicago Press.
- Grant, D., O'Neil, K., and Stephens, L. (2004). Spirituality in the workplace: New empirical directions in the study of the sacred. *Sociology of Religion*, 65(3), 265–283.
- Guillemin, J. (1984). Priceless lives and medical costs: The case of newborn intensive care. *Research in the Sociology of Health Care*, 3, 115–134.
- Guillemin, J.H., and Holmstrom, L.L. (1986). *Mixed Blessings: Intensive Care for Newborns*. New York: Oxford University Press.
- Guntupalli, K.K., and Fromm, R.E. Jr. (1996). Burnout in the Internist-Intensivist. *Intensive Care Medicine*, 22(7), 625–630.
- Hall, D.D., (ed.), (1997). *Lived Religion in America: Toward a History of Practice*. Princeton: Princeton University Press.
- Heimer, C. (1999). Competing institutions: Law, medicine, and family in neonatal intensive care. *Law & Society Review*, 33(1), 17–66.
- Heimer, C.A., and Staffen, L.R. (1995). Interdependence and reintegrative social control: Labeling and reforming 'inappropriate' parents in neonatal intensive care units. *American Sociological Review*, 60(5), 635–654.
- Heimer, C.A., and Stevens, M.L. (1997). Caring for the organization: Social workers as frontline risk managers in neonatal intensive care units. *Work and Occupations*, 24(2), 133–163.
- Hoff, T., Whitcomb, W.F., and Nelson, J.R. (2002). Thriving and surviving in a new medical career: The case of hospitalist physicians. *Journal of Health and Social Behavior*, 43(1), 72–91.
- Lake, E.T. (1998). Advances in understanding and predicting nurse turnover. *Research in the Sociology of Health Care*, 15, 147–171.
- Landzelius, K.M. (2003). Humanizing the imposter: Object relations and illness equations in the neonatal intensive care unit. *Culture, Medicine, and Psychiatry*, 27, 1–28.
- Lantos, J.D. (2001). *The Lazarus Case: Life and Death Issues in Neonatal Intensive Care*. Baltimore: The Johns Hopkins University Press.
- Leigh, J.P., Kravitz, R.L., Schembri, M., Samuels, S.J., and Mobley, S. (2002). Physician career satisfaction across specialties. *Archives of Internal Medicine*, 162, 1577–1584.

- Lusky, R.C. (1999). A century of neonatal medicine. *Minnesota Medicine*, 82, 1–8.
- Lyon, J. (1985). *Playing God in the Nursery*. New York: W. W. Norton & Company.
- Mansfield, C.J., Mitchell, J., and King, D.E. (2002). The doctor As God's mechanic? Beliefs in the Southeastern United States. *Social Science and Medicine*, 54, 399–409.
- McNamara, B., Waddell, C., and Colvin, M. (1995). Threats to the good death: The cultural context of stress and coping among hospice nurses. *Sociology of Health and Illness*, 17(2), 222–244.
- Messikomer, C.M., and Craemer, W.De. (2002). The spirituality of academic physicians: An ethnography of a scripture-based group in an academic medical center. *Academic Medicine*, 77(6), 562–573.
- Neuer, L., Bengiamin, M., Downey, V.W., and Imler, N.J. (1996). Neonatal Intensive Care Nurse Stressors: An American study. *British Journal of Nursing*, 5(18), 1126–1130.
- Oehler, J.M., and Davidson, M.G. (1992). Job stress and burnout in acute and nonacute pediatric nurses. *American Journal Critical Care*, 1(2), 81–90.
- Orfali, K. (2004). Parental role in medical decision-making: Fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Sciences and Medicine*, 58(10), 2009–2022.
- Palmer, C.E., and Noble, D.N. (1985). Nurse–neonate relationships: The creation of symbolic interaction within a neonatal intensive care unit. *Sociological Spectrum*, 5, 331–345.
- Pinch, W.J.E. (2002). *When the Bough Breaks: Parental Perceptions of Ethical Decision-Making in NICU*. New York: University Press of America.
- Puchalski, C.M., and Larson, D.B. (1998). Developing curricula in spirituality and medicine. *Academic Medicine*, 73, 970–974.
- Raju, T.N. (2002). A.A. Fanaroff and R.J. Martin. (eds.), *From Infant Hatcheries to Intensive Care: Some Highlights of the Century of Neonatal Medicine*. *Neonatal-Perinatal Medicine*, Mosby.
- Rashotte, J., Fothergill-Bourbonnais, F., and Chamberlain, M. (1997). Pediatric intensive care nurses and their grief experiences: A phenomenological study. *Heart Lung*, 26(5), 372–386.
- Reddick, B.H., Catlin, E.A., and Jellinek, M.S. (2001). Crisis within crisis: Recommendations for defining, preventing, and coping with stressors in the neonatal intensive care unit. *Journal of Clinical Ethics*, 12(3), 254–265.
- Robinson, S.E., Roth, S.L., Keim, J., Levenson, M., Flentje, J.R, and Bashor, K. (1991). Nurse burnout: Work related and demographic factors as culprits. *Research in Nursing and Health*, 14(3), 223–228.
- Shugerman, R., Linzer, M., Nelson, K., Douglas, J., Williams, R., and Konrad, R., for the Career Satisfaction Group. (2001). Pediatric generalists and subspecialists: Determinants of career satisfaction. *Pediatrics* 108, 1–6.
- Sosnowitz, B.G. (1984). Managing parents on neonatal intensive care units. *Social Problems*, 31(4), 390–402.
- Strauss, A.L. (1968). The intensive care unit: Its characteristics and social relationships. *Nursing Clinics of North America*, 3, 7–15.
- Strauss, A.L., and Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage.
- Thomas, N.K. (2004). Resident burnout. *Journal of the American Medical Association*, 292(23), 2880–2889.
- Weir, R. (1984). *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine*. New York: Oxford University Press.
- Wuthnow, R. (1998). *After Heaven: Spirituality in America Since the (1950)s*. Berkeley: University of California Press.
- Zupancic, J.A., and Richardson, D.K. (2002). Characterization of neonatal personnel time inputs and prediction from clinical variables – a time a motion study. *Journal of Perinatology*, 22(8), 658–663.