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Neonatal End-of-Life Spiritual Support Care

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ABSTRACT

The death of an infant is a profound loss that may complicate, disrupt, or end relationships between parents; and lead to maladaptive grieving, long-term decreased quality of life, and symptoms related to psychological morbidity. Facing neonatal loss is frequently experienced as traumatic assault on parents' spiritual and existential world of meaning. This article highlights the importance of supporting parents through loss by providing comprehensive care that focuses not only on the neonate's physical needs, but also addresses parents' and families' spiritual, religious, and existential needs. Our objective is to increase practitioners' awareness of spiritual and existential distress and to provide strategies to address such needs, particularly at the end of life.

Key words: bereavement, end of life, grief, healthcare teams, interdisciplinary, neonatal, spirituality

Neonatal healthcare professionals' primary focus is typically on the physical life-sustaining care of the child in the neonatal intensive care unit (NICU). Although physical care is vital to the care delivery in the NICU, spiritual care is an essential component in providing support to NICU families.[1] However, many healthcare professionals may be uncomfortable approaching families and discussing issues related to spiritual care. Provision of adequate spiritual care to support families is often hindered by inadequate training of healthcare professionals to assess patients' or families' spiritual needs.[2] The purpose of this article is to raise awareness of religious and spiritual beliefs and provide strategies for clinicians to incorporate spirituality in end-of-life care to support families in the NICU.

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This article explores the spiritual care literature and shares narratives of parents who have experienced the loss of their baby in our NICU. These stories demonstrate that the findings cited throughout the literature apply to clinical practice and serve to further highlight the importance of spiritual care at the end-of-life. The care given to a family before and following the often traumatic neonatal loss can set the stage for a family's entire grieving process. For many parents, the support they receive from the interdisciplinary team after the loss of a baby has crucial effects on the family's grieving process and their ability to incorporate the loss into their life. Therefore, it is essential that every team member provide compassionate care that meets or exceeds parents' expectations. Caregivers in the NICU can benefit from a better understanding of the grief process and the existential, spiritual, and religious needs of parents and families who are experiencing neonatal loss.

BACKGROUND

Most patients want their physicians or professional caregivers to address their spiritual and religious needs.[3] A majority of pediatricians (76%) agree that patient/family spiritual and religious concerns are relevant to their practice, but many pediatricians (51%) never or rarely talk with their patients/families about these concerns and few (10%) do so routinely.[2] In the NICU, caregivers view spiritual and religious concerns of a baby's family as having a place in patient care, yet many feel incompetent to assess a family's spiritual and religious needs because of their lack of sufficient training.[4]

Despite recent technological advances in neonatal care, more children die in the neonatal period or immediately prior to birth than any other period in childhood.[5] The death of a child, whether term or preterm, means losing a potential relationship full of hope and expectations. Parents face the loss of a long awaited and hoped for future. Grief is an expected and normal reaction to such loss.

GRIEF AND ATTACHMENT

Grief is considered a normal, healthy, dynamic, individual, familial, and communal response to loss. It enables the bereaved to integrate the loss into their lives. Grief is a multifaceted and often complex response to loss that includes psychological, behavioral, and physical reactions combined with cognitive, emotional, behavioral, social, spiritual, and somatic elements.[6] Historically, grief has been studied extensively and found to have predictable characteristics, although the intensity and timing of the response varies among individuals. Freud[7] observed that grief is a process. Freud[7] stipulates that the concentration of emotional energy that ties the individual with an object of love is followed by gradual redirection of this energy to other objects of attachment. Since the 1940s when Erich Lindemann[8] first described the symptomatology of acute grief after studying survivors of World War II and the victims of the Cocoanut Grove Fire, the various manifestations of grief have been well described.

Kübler-Ross[9] expanded the field further in the 1960s to 1970s with her recognition of the stages of grieving in dying adults and older children. Although Kübler-Ross identified 5 stages of grief that include anger, denial, bargaining, depression, and acceptance, for caregivers in the NICU, it is important to understand that these stages may not come in any prescribed order. Stages may overlap or be skipped completely. Kübler-Ross' stages of grief are overall controversial. In the context of neonatal loss the concept of acceptance particularly has been criticized. Parents may never adapt to or "get over" the loss of a child. However, if well supported by the healthcare team and their community, parents may have a better chance to incorporate the experience of loss into their own narrative; the biographical story of their previous, current, and future life.

The nature of parental attachment impacts the ability of parents to find meaning and to integrate the reality of living without the physical presence of one's child. Bowlby[10] noted that people strive to keep close the people and objects they care for. There are predictable phases following loss, which include the urge to recover the lost object, disorganization and despair, and reorganization. Kennell and colleagues[11] further elucidated the profound implications of parent-infant bonding in perinatal loss as they observed a higher degree of mourning in mothers who had not touched their babies before their death and/or talked with their husbands about the death. Their landmark article led not only to the recognition of the importance of holding and close contact, but also drew attention to the need for memory making, telling, and honoring the infant's story.

The term "complicated grief" has been used to describe inadequate or inappropriate adjustment to grief. Historically this has inaccurately been labeled as "pathologic grief." Niemeyer[12] points to the challenge of assimilation and adaptation in the context of traumatic loss. Intensive care unit stays are recognized as having the potential to cause posttraumatic stress responses in family caregivers.[13] Parents demonstrate different styles of attachment to their babies. These individual styles each play a role as parents affected by loss undertake "an anguishing attempt to reconstruct a world of meaning that has been shattered. . . ."[12(p44)]

Kaufman[14] suggests that for spiritual and religious people attachment styles in human relationships correspond to attachment to the Divine or Higher Power. Recently, Kelly has posited that expressions of spiritual and religious beliefs, such as prayer, "are intended to see and maintain proximity to God" and are therefore "part of the attachments behavioral system."[14(p60)] In their attempts to make meaning in the midst of crisis, parents may in noticeable or subtle ways avoid, cling to, or relate ambivalently in their spiritual and religious expressions. Supporting the belief in a Divine Power as a secure base may be helpful as parents are in the acute phase of integrating the shock, disbelief, and yearning connected with grief.

SEARCH FOR MEANING AND EXISTENTIAL ANSWERS

For many, spirituality is intensely personal and individual. Spirituality is often defined as encompassing one's relationship to transcendence, finding meaning, or connecting deeply with others.[15] Spirituality can be understood "as a mode of living—a process, an inquiry, a conversation—rather than a separate realm of life."[16(pe68)] Spiritual care is distinct from the medical, nursing, and social work dimensions of care that focus on the identification and resolution of specific problems. In contrast, spiritual care is about accompaniment and presence in the journey of making meaning.[17] Although many healthcare teams draw on the special expertise of a board certified healthcare chaplain, there is growing consensus supporting team collaboration among all caregivers to address spiritual distress.[18] At times of crisis it is not surprising, therefore, that parents find their whole system of being in the world rocked and often shattered. Healthcare teams may struggle with unpredictable parent behaviors that may reflect anger, fright, or other strong emotions. Parents may behave in ways that seem distrustful, irrational, and demanding. In the face of a profound experience of loss they each begin to question their faith and belief systems. Why is this happening to me? What have I done wrong? Why would God allow my baby to suffer? How can I make sense of this? The following 2 cases call attention to the parents' existential questions and search for meaning during times of loss.

Case 1: Christian is 32-week preterm infant with severe arthrogryposis and pulmonary hypoplasia. He was removed from life support after a 12-week struggle. In a letter written shortly after his death his mother reflected on her and her husband's feelings:

> We knew it would be tough-we knew dark days lay ahead. And they did for both of us at different times. We each had periods of feeling very, very alone. I personally questioned where was God-where had he gone? My husband experienced a similar faith crisis. We decided to take a break from all of our church activities and just soak up the worship experience for a while. That really helped—through that came rebirth. I am struck by the imagery of the chrysalis experience through all of this.

Analogous to a caterpillar's transformation to butterfly, to this mother, the chrysalis experience symbolized how Christ could transform her into something beyond her dreams even at times of extreme grief and sorrow. It allowed her to grow beyond herself, opening her life to Jesus' power and love.

Case 2: Julia is a term newborn with an antenatal diagnosis of hypoplastic left heart syndrome and Cornelia De Lange Syndrome. Two months after Julia's death, Julia's mother eloquently documented her experience:

> I again found myself questioning my faith. I was angry. I felt at times like I was being tested on the value of life. Do I do all that I can to fight for her life or do I want the time she has here on earth to be the best? As we spent that week in the hospital and soaked in the unbelievable amount of support from our family and friends, I started to think about what God's purpose was for Julia. Was it to further medical research, increase one's faith, or simply the value of life—no matter how long it may be? It was then I understood how fortunate we were that God chose us to love and care for such a special gift.

Although both cases highlight the despair and disorganization described by Bowlby, they also illustrate the profound impact of faith in God in a parent's ability to accept and to find meaning in an inconceivable and painful reality. Finding meaning is often the first step as parents begin to reorganize their lives.

A HIGHER POWER

Although some individuals may not have a specific religious affiliation or belief in a Higher Power, the majority of Americans do believe in a Higher Power. An overwhelming majority of Americans consider themselves to be religious or spiritual. In fact, 78% of Americans believe in God and an additional 15% believe in a Higher Power or Universal Spirit.[19] Specifically, 84% of Americans think that praying for the sick improves their chances of recovery, 79% believe in miracles, and 72% believe God can cure people given no chance of survival by medical science.[20] If caregivers are to provide comprehensive family-centered care, they need to be sensitive and knowledgeable in assessing a family's religious, spiritual and cultural beliefs, and value systems. This information may be as important as any piece of physiologic data.

RELIGION AS A SOURCE OF COMFORT AND HOPE

It has long been speculated that religion comforts the dying, but until recently, very little research has accompanied this assumption. In a qualitative study of 38 adult hospice patients, Pevey and colleagues[21] found that religion offers comfort by its ability to provide order to life, a personal relationship with a divine other, and the belief in an afterlife. In addition, most religious and spiritual practices offer rituals, organize traditions, and protect transitional, liminal times in life. The concept of an afterlife may be extremely comforting for some parents, particularly after they have watched their child suffer. Although Pevey's study focused on the dying adult patient, one can extrapolate and theorize that these skills may assume an equal or even greater importance to parental coping mechanisms; especially when those involved struggle to understand and take in their situation. Some people who profess stronger spiritual beliefs may resolve their grief more rapidly than people without spiritual beliefs, and are less likely to develop complicated grief (as seen in case 2).[22] However, other studies suggest that religious coping may be associated with receipt of increased life-prolonging care (as seen in case 4).[23] Either way spiritual beliefs may greatly impact parental goals of care.

Case 3 exemplifies the power of an existential framework that guides parents through their grief journey:

Case 3: Mary is a term newborn with a giant omphalocele, severe pulmonary hypertension, and respiratory failure. Mary dies within 24 hours of birth. Her mother wrote of her experience:

> It has been a little over three months since my daughter Mary took her last breath and went into the great unknown. At times it is still very difficult to believe I will never see her again, never hold her hand, laugh or dance with her. Grief is a very consuming animal; it walks with me constantly. Sometimes it literally sits on me like an elephant. Thoughts, feelings and actions now

> seem so unpredictable, life is not at all the same as it was on the day before Mary died. The one and only thing that does continue to remain the same is the God of my understanding. I believe in my darkest moments, when nothing on this earth can comfort me, my God is holding me and will not let me succumb to my grief. My faith in a Power greater than me gives me courage, strength, wisdom and hope. These things I cannot even begin to acquire on my own. My God is the source of all love, peace, strength, and wisdom that I can draw on any moment of any day and know with assurance that I will survive this great loss.

Thus, the belief in a Higher Power can serve to foster and maintain hope.

HOPE AS A NECESSARY INGREDIENT FOR HEALING

Finding and maintaining hope is one of the greatest challenges, and yet one of the greatest gifts that caregivers can offer parents whose children are dying. According to Feudtner,[24] a renowned expert in pediatric palliative care, hope is a fundamental human activity that is a complex phenomenon, which is usually vague and aloof, but at times, contradictory.[25] Yet, hope is an experience as critical to life as the air we breathe. It is a belief in a positive outcome related to events and circumstances in one's life. Typically, life altering/stressful events and suffering or loss precede the activation of hope.[26] At times it appears that hope is not always rational, logical, reasonable, sensible, or even concrete, but hope is an important part of faith, even if not synonymous with it. Hope, in this definition, is based on truth, and does not just represent wishful thinking. This is crucial as caregivers in the NICU often feel frustrated if parents' hopes do not appear to correspond to clinical and medical realities.

Therefore it is frequently emphasized that hope needs to be rooted in reality. It (hope) sees all the problems, all of the obstacles and pitfalls, and the opportunities for failure. Yet, those who draw on true hope are still able to see "a path to a better future."[27(pxiv)] Hope can endure, even when things end poorly. "Hope is not the conviction that something will turn out well, but the certainty that something will make sense, regardless of how it turns out."[28(p181)] Thus, hope is an experience that is related to the process of finding meaning, or making meaning.

Although caregivers should not offer false hope to families, when death is imminent caregivers may help families reconstruct new meanings of hope. For example, honoring the life of a baby through pictures that tell the baby's story may serve to remind parents how much their child was loved and that the child's life had a purpose. Other families will gain hope knowing their child is not suffering anymore, whereas many families find hope in the belief that they will be reunited with their child again in heaven.

STRATEGIES AND CONTINUING EDUCATION FOR PROVIDING SPIRITUAL CARE SUPPORT AND MEANINGFUL COMMUNICATION

Any understanding of our spiritual care giving has to be based on relationship. Similarly, relationships in the context of the NICU need to be based on respect for diverse cultural, spiritual, and religious beliefs, as well as the caregivers' ability and willingness to connect emotionally, listen carefully, and communicate effectively. The following case example will illuminate the importance of both the value of respect and the value of relationship as crucial to compassionate care giving in the NICU.

Case 4: Brian Emanuel is a former 25-week estimated gestational age infant who is now 4 months of age with severe lung disease, status-post-surgical necrotizing enterocolitis, and short bowel syndrome. His parents are active practicing Pentecostals who draw on the resources of their faith for coping and who pray daily at Brian's bedside for a miracle. When asked about the origin of their son's name they revealed that Brian's second name Emanuel means "God is with us." This was extremely useful information to the care team in understanding and managing them in their crisis. Despite their belief that God can and will intervene to restore Brian's health, Brian progresses to end-stage liver failure.

When families believe and at times insist that God will intervene and expect a miracle, the healthcare team often thinks that parents are being unrealistic. Healthcare providers may feel that the baby is suffering needlessly and may experience moral distress and frustration themselves. This interpersonal conflict of wanting to support the family but not wanting to watch the child suffer may result in the healthcare professional's uncertainty of how to continue to communicate and offer support to the family. Some caregivers may cease to engage the family in an ongoing discourse on goals of care fearful that continuation of frank clinical discussion will be inflammatory or disrespectful of a family's religion or belief system. However, it is at this time that ongoing conversations and efforts to sustain relationship with the parents are crucial. Ongoing dialogue is imperative to help families understand both the diagnosis and prognosis of their child's disease. Decision making should never be rushed. Parents need to be given time to process the information they are asked to take in. The difficult choices and decisions they make on their child's behalf may be motivated by conscious or unconscious cultural, spiritual, and religious beliefs. These decisions also have profound implications, impacting both the length, and quality of their baby's life.

Neonatal nurses are in a unique position to foster and support many of these frank discussions with families, yet may not feel equipped to discuss spiritual or religious beliefs. Allowing families opportunities to openly express their values and beliefs in a safe and nonjudgmental environment can be the first step in providing families with compassionate, respectful, and comprehensive end-of-life care. Nurses at the bedside may begin a discussion with families by asking open-ended question such as, "I know this must be so hard for you, how are you managing?" or "given what you have been through, what is it you most hope for?" Posing questions like this will invite parents to share the role spirituality plays in their life, or if faith serves to guide medical decision making. Spiritual assessment tools are available to assist healthcare professionals in developing crucial conversations with families about spirituality within the clinical setting[29,30] have also been developed to help caregivers begin discussions about spirituality.

Providing spiritual care requires that all members of the healthcare team can engage families and invite them into continuing conversations that often demand knowledge of cultural, spiritual, and religious issues. In addition, the role of the board certified healthcare chaplain offers specialized expertise in the dynamics of meaning making as they relate to spirituality and religion. As an integral member of the healthcare team, chaplains may help staff understand the nuances and facets of a particular belief system. The chaplain's role is to support families in spiritual and religious distress, and to help families move toward positive religious and spiritual coping, adaptation, and overall well-being. In collaboration with the healthcare team, it is the task of the chaplain and the clinician trained in spiritual care giving to help families become more aware of and use their beliefs and spiritual resources to navigate the NICU experience. In our experience, chaplains or clinicians trained in spiritual care can be invaluable in understanding the meaning of miracle beliefs as expressed by parents.

INCORPORATING HOPE

As healthcare professionals, we believe that sustaining hope is an important part of providing care, but how does one sustain hope for the dying? Feudtner[24] suggests finding an attitude of maintaining hope towards achieving positive goals. Clinicians need to disclose the "bad news" honestly, clearly, and compassionately.[31] As the grieving process evolves, parents may experience anger and denial. There is tremendous suffering, but hope remains, and part of our job as clinicians is to help illuminate the hope that remains:

> The maintenance of a "miracle" hope can be adaptive, enabling people to cope with adversity and loss, as well as affirmative, conveying the abiding commitment of relationships and love. Judging such a hope as either realistic or false misses the point; rather, we should judge ourselves as clinicians by the degree to which we can help nurture our patients' collection of diverse hopes.[24(p2307)]

Specific strategies to assist clinicians in engaging parents who are hoping for a miraculous healing of their child are reported.[32] It may be helpful to begin a conversation with the family by validating their hope for a miracle. This is a way to acknowledge and respect another's beliefs, values, and faith. To do this genuinely, caregivers need to work through their internal resistance to miracle beliefs. One way of accomplishing this may be for caregivers to emphasize the search for common ground and acknowledge a shared commitment to the well-being of the baby.[32] It is equally important to ensure that the family has an adequate understanding of the clinical situation, including diagnoses and prognosis. The care team needs to be aware that each family member's interpretation of the meaning of the word "miracle" may differ from the care team's definition. Often when probed, the anticipation of a miracle may reflect a family's hope and optimism, rather than cure. In such cases, the interdisciplinary team may be instrumental in helping families reframe their hopes into achievable goals such as maximizing comfort. A primary goal should be to honor and understand the faith traditions of both the family and the healthcare professionals who are actively involved in supporting the family as this impacts communication and decision making.

The team engaged Brian's parents in multiple conversations that involved both active listening and dialogue. The parents realized and were able to express that they believed that it was a miracle to find strength and resilience as Brian fought valiantly to overcome insurmountable odds. Further discussions with the family identified that one of their most important goals was to hold and comfort Brian as he passed from one life to another. Miracles were thus reframed as both Brian's relief from suffering and eternal life with God in heaven. The healthcare team was instrumental in helping this family adapt and maintain hope. When Brian's condition acutely deteriorated, his parents chose to remove him from life support. Brian died peacefully in his father's arms.

SPIRITUAL NEEDS OF PARENTS AT TIME OF INFANT DEATH

Pediatric studies have also focused on parental perspectives and needs of parents whose children are critically ill or dying.[33–36] Exploring the concept of parent priorities during a child's end-of-life, investigators interviewed 56 parents whose children died in the pediatric intensive care unit after withdrawal of life sustaining therapies.[35] Parent priorities included ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith. Four explicitly spiritual/religious themes emerged. When asked what had been most helpful, 73% of parents included themes of spirituality and faith. These themes included prayer, faith, access to and care from clergy, and belief in the transcendent quality of the parent-child relationship.[36] Additional insights into the significance of values such as trust, love, and hope were gained.

In addition to the importance of spirituality and faith in end-of-life care, investigators identified trust in nursing care and physical presence or bearing witness as the most crucial aspects of care.[37] Parents rely on relationships with others as a source of spiritual support.[34] Our task as caregivers is to help parents see the future, in light of the present illness, prognosis and sometimes, even death. Particularly as parents, a big part of the grief and death is the loss of their child's future story. They may question "How can I be a parent if my child dies today?" We can help parents reframe their future story in a way that honors the life of their baby. In Andrew Lester's[38] book *Hope in Pastoral Care and Counseling*, Lester, a narrative theologian, holds that our life is a story and that hope can be understood as our future story, which tells the tale of who we will be beyond the present. This understanding acknowledges that life continues even after the death of a child and that the relationship is transcendent. Furthermore, the role of the parent in relationship with their child continues. Case 5 highlights the transcendental nature of the parent-child relationship.

Case 5 is as follows:

> During the delivery process, I remember an overwhelming feeling of peace. I had complete faith that we were in the absolute best place. My husband, however, was scared to death and didn't feel that peace. He also had the vantage point of seeing them struggle with my son and me at the same time. Our pastor happened to be in the waiting room. They brought our chaplain back. There was no one else who could help us in those moments. During the entire process, we were filled with a constant sense of hope. That never waned—not even at the end. That hope changed to a look forward to meeting again.

The transcendental nature of the parent-child relationship is a theme highlighted in the literature.[34,36] Even in the midst of crisis in the delivery process with the knowledge that her child will not survive, this mother could hold on to the relationship to her child. With support of the local pastor and the chaplain, her belief in an ongoing attachment to her baby that included "meeting again" in a different life, led to an adaptive grief response. The extent, to which a parent is supported in a belief in a relationship to the baby that transcends the loss, can significantly impact the parent's grief journey and foster healing.

CONTINUING EDUCATION: CLINICAL PASTORAL EDUCATION

Routinely providing comprehensive care to infants who are dying and their families can be emotionally and physically draining for healthcare professionals. Yet, many healthcare team members are ill equipped to provide a holistic approach that incorporates cultural, spiritual, emotional, and physical aspects of care. Identifying knowledge and skill gaps and seeking educational opportunities is essential for healthcare professionals to become confident in their ability to provide comprehensive end-of-life care. In collaboration with healthcare chaplains who offer spiritual care, healthcare providers, who are trained and skilled in spiritual care giving, may also address issues of meaning making. Consultation with a team's chaplain may be a pathway to improving spiritual care giving. However, there are opportunities for in depth training for caregivers who may want to take the lead in bringing spiritual supportive care to their institutions.[39] The Kenneth B. Schwartz Center in Boston,[40] Massachusetts supports such a learning opportunity for caregivers. The Kenneth B. Schwartz Fellowship in Clinical Pastoral Education (CPE) for Health Care Professionals, offered through the Chaplaincy Department at Massachusetts General Hospital,[41] is a program that focuses on the development of skill and competence in addressing patients' and families' existential, spiritual, and religious concerns.

The goals of CPE for healthcare providers are to raise clinicians' awareness of religious and spiritual beliefs and values, which may impact patient care and decision making, and to nourish clinicians' ability to empathize with religious traditions or secular beliefs different from their own. Structured after traditional CPE (which addresses the learning needs of clergy and healthcare chaplains), the program is designed to incorporate experience, reflection, insight, clinical practice, and integration. The experience includes didactic presentations in the major faith traditions, with an emphasis on end-of-life care and ethical decision-making in the context of faith traditions. "Experience of faith" papers ask caregivers to explore their personal beliefs and emotions about common clinical themes such as hope, suffering, and vocation. Verbatim seminars lead participants to examine and consider their own experiences as they pertain to clinical situations and spiritual care giving. In the clinical component of the program, the healthcare professional appreciates more deeply that the caregiver's personal views and human emotions may impact on clinical decision making and quality of care provided. The CPE program offers an opportunity to gain a deeper understanding of such dynamics. Such self-awareness is key to any ethically and professionally sound provision of spiritual care. Process groups allow CPE participants to work with other members of the group, learn about group dynamics, and explore one's own life journey. Weekly process notes highlight lessons learned through personal and relational experiences in the program. The CPE group shares and learns from each other as each member struggles with how to incorporate spiritual care giving into daily encounters with patients and their families. Individual hourly meetings with a nationally certified pastoral educator offers an additional opportunity for reflection and integration.[42]

As the primary author of this article, I had the opportunity and support of my division to participate in the 19-week CPE program. I had the amazing privilege to volunteer as a chaplain intern to fulfill the clinical component of the program. In serving in this role there were many important lessons learned that continue to impact clinical practice daily. Most people have deeply held religious beliefs that may provide comfort in times of sorrow, but also guide their decision making. As intensivists, we often find ourselves focusing on the immediate medical concerns, and indeed, families have different expectations of their caregivers based on title and profession. The chaplain has the unique and invaluable role of exploring existential, spiritual, and religious concerns of the patient while offering spiritual support and guidance. In addition through CPE, the author came to understand that as clinicians an awareness of our own religious and cultural beliefs and spiritual perspectives is essential. Our personal attitudes and beliefs not only influence how we, as caregivers, respond to intensely difficult and emotional clinical situations but also affect our ability to effectively engage and support the families that we serve. Most importantly, CPE added a new understanding of the true power of presence. As caregivers we often think we have to do something to be effective or make a difference. However, as one mother related, "their prayers, their hugs, just being there, just knowing they cared, made all the difference. . . ."[34(p424)] I realized that I do not have to do or say anything; the power of presence is profound. As I stepped temporarily into the role of a chaplain, I realized that it is not only possible but also imperative for us as caregivers that we sit with the suffering and share and acknowledge the value of life, no matter how long the life may be. It is our task as any member of the healthcare team to carry the burden of ambiguity of diagnosis and prognosis; especially when there is no cure. We may not be able to "fix things" but we can help the parents reframe the painful realities they are facing. To engage in such a way does not mean to "give up," it means to create new goals. The relationship that develops with a family does not depend on the clinical outcome. When we are present and bear witness, we share our humanity and this helps parents know that they will not be abandoned. In this context, healing begins as this following case underscores.

Case 6: Born at 32 weeks estimated gestational age, CP was diagnosed with hypotonia, arthrogryposis, and pulmonary hypoplasia. He died after a 4-month struggle for survival. The medical team never found a unifying diagnosis. CP's mother went on to say:

> The entire experience was such a process. In the end, we came to realize that miracles do happen. The miracle was our son. The miracle was being in this hospital surrounded by some of the best doctors in the nation. The miracle was getting to experience pregnancy and delivery. The miracle was the earthly angels who surrounded us with love and care daily! We wouldn't have made it through without them. They kept our spirits uplifted. The ultimate miracle has been helping others.

The greatest revelation of CPE was that as a physician, I had always provided spiritual care. As caregivers, part of our task is to connect emotionally and to develop a genuine relationship with those we serve. We can share from our own life story, while keeping the focus on our patients' life experiences. Although the ability and sensitivity of the caregiver to explore a family's emotional, spiritual, or religious sources of strength is a goal of CPE, ANY caregiver provides spiritual care when they are able to balance boundaries with human connection. Caregivers in the NICU do this on a daily basis as they initiate, deepen, and sometimes end relationships. We share our humanity in words, and hugs, and tears. This kind of human care can be transformative not only for the family but also for the caregiver.

Not all NICU's can afford or support an educational intervention like CPE. We can, however, acknowledge that religious and cultural diversity are woven into the fabric of American life today, and valued alongside traditional physical, psychological, and social care. Thus, continued awareness about the role of chaplaincy in patient care and soliciting their advice and participation in multidisciplinary team or family meetings is critical. Inviting the expertise of caregivers who have trained in CPE to facilitate forums, grand rounds, and clinical case conferences can also promote education and sensitivity in this area.

As spiritual care giving also focuses strongly on providing comfort, one might say that the concept of providing spiritual care goes back to the time of Hippocrates. This concept has even greater meaning today as we consider the implications of technology and its potential to impact both positively and negatively on the quality of life. As healthcare professionals, we have the unique ability and responsibility to help families heal, even when there is no cure. Hippocrates' statement still holds true today, "To cure sometimes, relieve often, and comfort always . . . ."

CONCLUSION

The majority of families rely on their faith and spirituality to assist them through their end-of-life journey. Healthcare professionals need to become acquainted with the meanings of spiritual and religious concepts that emerge for patients and families in their clinical area or specialty. Comprehensive care of the whole person, particularly at the end of life or in critical care settings, not only includes physical care but also includes sensitivity to spiritual, religious, and existential concerns. As healthcare professionals become more aware of families' religious and spiritual beliefs, they will likely feel more equipped to incorporate spiritual care at the end of life to support families in the NICU. Although further research is needed in this area, incorporating spiritual support into end-of-life care in the NICU can facilitate a family's grief journey.

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