CHAPTER 2

Ethical and Theological Perspectives on the Nature of Suffering and the Goals of Nursing

Chapter 1 presented an overview of thoughts related to suffering derived from the medical and nursing literature and experience. In this chapter, we apply scholarly work from the fields of theology and ethics to provide a different perspective on suffering. The chapter begins with a foundational exploration of the limits to current approaches to suffering and then explores ethical perspectives followed by theological perspectives. Within the theological perspective, we explore the concept of forgiveness to show that the depth of understanding of suffering available in this field can be applied to the nursing perspective. We also follow with a discussion of meeting diverse religious beliefs with particular concern for nursing amidst our increasingly diverse society.

LIMITS OF CURRENT APPROACHES TO SUFFERING

The profession of nursing shares many characteristics with the medical profession. This is not surprising because, until relatively recently, the nursing curriculum has paralleled that of medicine. Although nurses have always been educated separately, the early focus of nursing education was

on nurses following medical orders. Both disciplines focus on goals of cure, rehabilitation, restoration, and optimizing function. Both fields are often characterized by a "fix-it" approach, where a professional makes a diagnosis and then "fixes" the broken body part, organ, or function.

From the earliest clinical experiences as nursing students, we are rewarded for our skill at identifying problems and solving them. We move the patient from dependence to independence, from brokenness to wholeness. Nurses are "doers;" our work is in doing procedures, medicating, teaching, ambulating, documenting, and communicating. We also have been taught to be listeners and mediators as we bridge communication among patients, families, and multiple clinical personnel. Given this historical and educational foundation of "doing" and "fixing" and "mediating," it is not surprising that so few nurses feel comfortable and competent to "be with" a person who is suffering. The ability to "be with" suffering and bear with the sufferer is an art, generally mastered after extensive life experience, self-reflection, and concentrated professional development (Dahlin and Giansiracusa, 2006).

The deficiencies in our collective nursing ability to respond to suffering can be seen in our approach to the assessment of spirituality. In our increasingly diverse culture, we are called to recognize that spirituality is a broad term. For our purposes, we use the definition of spirituality as the "transcendent dimension of life which extends beyond organized religion" (Kemp, 2006). The basic spiritual needs include seeking meaning or purpose, hope, relatedness, forgiveness or acceptance, and transcendence (Kemp, 2006).

Even in major health-care settings, assessment of spirituality is often limited to a brief question on a hospital admission form of religion, generally followed by a short list of choices such as Protestant, Catholic, Jewish, or "Other." Our systems of care, with a few exceptions, even for those facing life-threatening disease, rarely explores any aspect of spirituality, meaning, and relationship to God or a higher power or the importance of faith (Borneman and Brown-Saltzman, 2006).

ETHICAL PERSPECTIVES ON SUFFERING IN NURSING

The phenomenon of *presence*, which is so central to nursing, was described poignantly by theologian and ethicist William Reich (1987, 1989). Reich described the experience of suffering through the metaphor of language. He described the person's struggle to discover a voice in the search for the meaning of suffering, divided into three phases. These include mute suffering, expressive suffering, and new identity.

In mute suffering, patients are so affected by their circumstances that they cannot verbally express their needs. This is not "suffering in silence," because Reich asserted that these individuals may be "screaming in pain." In expressive suffering, the sufferer seeks a language. The language may be one of lament (complaint), storytelling (in telling their story they gain voice, transform the suffering, or gain distance), or interpretation (often through metaphor). The third phase is new identity, or having a voice of one's own. This occurs through experiencing solidarity with compassionate others and by taking on a language of suffering through reframing one's story, which then identifies the new self. Reich's work can be aptly applied to the compassionate work of nurses who respond to the "screams of pain" by patients who only appear to "suffer in silence" (Reich, 1987, 1989).

Similar to the concentration placed on cure or "fixing," medical and nursing orientation to ethics is also often narrowly focused. We have given predominant attention in our training, coursework, and clinical ethics consultation to a biomedical model. The principles of autonomy, beneficence, nonmalfeasance, and justice serve as the primary approach to virtually all ethical dilemmas (Stanley and Zoloth-Dorfman, 2006). However, there are nursing educational programs and ethics committees that have recognized other frameworks and approaches to clinical dilemmas. The contribution of feminist scholarship offers a valuable alternate lens for nursing with an emphasis on concepts such as care, respect, and compassion (Farley, 1990; Procter-Smith, 1995; Townes, 1995) in addition to autonomy and beneficence.

The following is a case example of the complex needs inherent in a clinical dilemma.

An 86-year-old man is admitted to the hospital after a fall in a nursing home, which fractured his hip. Following his hip pinning, the man continues to experience complications of anesthesia and unrelieved pain, resulting in sleep deprivation with subsequent confusion, urinary incontinence, and a wound infection. His son arrives from out of town and is distraught at seeing his father, whom he has not seen in months. He expresses his remorse at "putting my dad in a damn nursing home." When the patient continues to decline and develops pneumonia and an arrythmia, the son elects to "do it all," requesting a feeding tube, mechanical ventilation, tracheostomy, and transfer to another hospital "if you idiots who are killing my father can't turn this around." This request comes despite a completed advanced directive on record in which the father has clearly indicated he wants no life-prolonging treatments. The son insists his father wouldn't need his life prolonged

were it not for the "idiots" in the nursing home who let him fall and the hospital "idiots" who made him worse.

Resolution of this complex, but not uncommon, scenario requires more than a matter of ethical principles, laws, forms, procedures, or blame. It requires allowing a process to unfold embracing the concepts of care, compassion, and respect. This includes listening to the son's story as he gives voice to his suffering and frustration at the same time as respecting the dignity and advance directives of his father.

Ethical approaches based on the concept of care provide a framework for transcending a place of obligation (what we ought to do based on laws or professional standards) so we can determine our moral obligation as compassionate witnesses. Dr. Daniel Sulmasy, a physician and Franciscan Friar, has been a thoughtful contributor to the evolving understanding of the professional as healer in relationship with the sufferer (Sulmasy, 2006). Sulmasy wrote *The Rebirth of the Clinic: An Introduction to Spirituality in Health Care*, in which he challenges the medical profession to evaluate itself and to restore a sense of the sacred to health care. He cites Jewish philosopher and theologian Abraham Heschel (1955), who said "To heal a person, one must first be a person." Awareness of one's own spirituality may be one prerequisite to ethical behavior and to meeting the challenge posed by Sulmasy to treat all patients as people first.

Sulmasy's challenge to reform the "clinic" is directed toward physicians, as "spiritual–scientific practitioners," but his work has profound implications for nurses. As we advance the education and research of our profession, we are challenged to also advance our understanding and clinical competence in aspects of spirituality. Sulmasy wrote:

> Under this new medical covenant, a spiritual-scientific practitioner would affirm that the transcendent is made manifest at the edge of the surgeon's knife, at the tips of the palpating fingers of the pediatrician, in the firm handshake of the internist, in the birth of the child whose unwed mother has AIDS, in the tears of the woman who feels a hard lump in her one remaining breast, and in the vacant stare of the elderly man with dementia. A spiritual-scientific practitioner would affirm that the transcendent is there when disease and suffering are recognized together, when the hand that performs the spinal tap distills compassion into the needle's point, the objectivity of science with the subjectivity of God's healing will; the particularity of the case at hand with the universality of a profession under oath; the finitude of the moment and the infinity of a life lived in the service of love. Thus might the clinic be reborn. (Sulmasy, 2006, 85)

What will it take to instill the sacred to nursing? Most would agree that the state of health care is chaotic at best. In some settings, it is disastrous. Instilling a sense of the sacred is a big step for a nurse who is focused on survival: both her patients' and her own. Patient acuity is at an all-time high. The nursing shortage grows. With all these issues, how can we even consider suffering? Perhaps more importantly, how can we not?

Caring for the dying is only one of nursing's many challenges for alleviating suffering. Nurses care for countless patients who suffer from chronic illness and are not considered "terminal." However, tending to those who are dying allows nurses to reflect on the sacred nature of their work as they witness both despair and transcendence in others. As Sulmasy wrote:

> The dying person brings his or her entire life to the moment of death. Christian theology teaches that if a life has the love of the Incarnate God as the foundation of its value, the source of its hope, and its model of right relationship, this trinity of value, hope, and right relationship is exactly what will be irrevocably, absolutely, and eternally determined in the dying of that person. Caring for a patient who is dying in such a manner is a remarkable privilege. When I enter the room of such a patient (which happens far more often than those who do not care for dying persons might think), I sometimes wonder if I should remove my shoes because I know that the ground on which I am about to tread is holy. I find that I am the one transformed, the one to whom enormous grace has been revealed. Such an experience is more than enough to sustain a doctor or nurse in hospice or palliative care. It is grace enough for the dying. (Sulmasy, 2006, 212)

This grace is perhaps why nurses are drawn to the bedside of a patient who is "dying well." Such a person expresses wonder and awe in what they see unfolding before them. The nurse might be mystified about how this person seems so accepting and peaceful, when so many others die in such anguish. Why is this death different? Nurses not infrequently stand at the foot of a bed watching as a patient takes his last breath. Where has the life force gone? Where has the person gone? The man or woman who was here before us just a moment ago is gone and what is left is a body vacant of life. What has the nurse witnessed?

THEOLOGICAL PERSPECTIVES

Nurses, as the intimate caregivers of those who suffer, are often confronted by questions such as, "Why does my father have to suffer?" "What did I do

to deserve this?" "How can God cause my mother such pain?" The questioning of God and the search for meaning in overwhelming situations of illness is equaled and often surpassed by family and friends who witness the patient suffering. The suffering of a spouse is described here.

I am the husband of a patient in pain. My wife has been diagnosed with a disease but it is the devastation of that disease that we live each day. I am my wife's support, her cheerleader, her shoulder, her hope. I put on a deceiving face of hope and smile. And yet, my spirit could not feel more depleted. In my life at work, I control 100 people, and yet at the end of the day I return to my home, which is controlled by pain. How much can you watch; how long can you endure the face of pain? I am walking a tightrope. One in which my daily wish is for the nightmare to end and for my wife's disease to be better. Between those hopes, I occasionally allow myself to face an unspoken wish that if she cannot be cured of this disease, must she be made to live with this unrelenting pain? Bearing witness to illness is one thing. Bearing witness to pain is quite another . . . I, too, cannot sleep. I am anxious and depressed and fearful. I am attempting to be provider, spouse, father, and mother. I turn to my fragile and damaged life partner seeking intimacy and find an even more frail and delicate person than I have recognized. Amidst my myriad of roles, I am now asked to be the primary care provider for my wife in the home . . . As I measure medication, I shudder at the reality that I am pouring a dose of morphine for my wife. Am I delivering mercy? Relief? Should I be fearful of these medications? Am I doing harm? There is something surreal about this way of being that now fills my daily life. I am not the patient in pain. I am the witness. (Ferrell, 2005)

Watching the suffering of the loved ones of patients can create an additional burden for nurses to carry, especially if they are unschooled and unprepared in how to "work with" this suffering.

In a pediatric oncology unit, a mother comforts a young child undergoing a bone marrow biopsy for relapsed leukemia. After hours of holding and comforting a bald, cachectic, bruised, and exhausted child, the father arrives to offer respite, and the mother retreats to the nurses' station. She asks for a cup of coffee. As the nurse hands the mother the coffee, there is a connection: first of hands, then eyes and hearts. Without a spoken word, the mother cries, releasing the burden of the last few hours. The nurse offers a tissue and a chair. More importantly, she offers an acknowledgement of the suffering with her presence, the presence of a person unafraid to listen. Questions such as, "How can this be?" "How much more can he take?" "Isn't there an easier way?" are common. So is anger. The overwhelmed mother asks, "Why can't I be the one who is sick, not him?" She tells the nurse, "When I get to heaven, there's going to be some serious conversation between me and God."

Some scholars have described suffering as "spiritual pain" (Chochinov, 2006). Suffering is described as an existential crisis and loss of meaning. Suffering at the end of life commonly includes hopelessness, a feeling of being a burden to others, loss of dignity, and the will to live (Chochinov, 2006).

In a recent text titled *Health and Human Flourishing—Religion, Medicine, and Moral Anthropology*, the authors (Taylor and Dell'Oro, 2006) cited Scheler's statement that, "In the ten thousand years of history, we are the first age in which man has become utterly and unconditionally problematic to himself in which he no longer knows who he is, but at the same time knows he does not know" (Scheler, 1962). Taylor and Dell'Oro conclude by saying that in the twenty-first century, we know much about man as a biological being but not as much about who, what, or why he is and that, "without a clearer idea of what man is, we will enter and remain in a dark moral forest without a compass" (Taylor and Dell'Oro, 2006, 267). A deeper understanding of suffering may provide that moral compass, giving us both values as well as direction and the opportunity for daily practice.

The writings of French philosopher and mystic Simone Weil (Springstead, 1998) and German theologian Dorothee Soelle (1975) are relevant sources to support the compass that can guide nurses' understanding of suffering. Weil wrote of suffering in her treatise on "The Love of God and Affliction." She converted from agnosticism to Christianity and wrote from her personal experiences with tuberculosis and anorexia. These diseases ended her life in early adulthood. Weil distinguished physical pain from suffering. She said that pain is of "little account" and that "an hour or two of violent pain caused by a bad tooth is nothing once it is over" (Springstead, 1998, 42). Weil described "affliction" as "suffering." Worse than affliction, she said, is extreme affliction. "Extreme affliction means physical pain, distress of soul and social degradation, all together, is the nail. The point of

the nail is applied to the very center of the soul, and its head is the whole of necessity throughout all space and time" (Springstead, 1998, 54).

William Reich, a theologian cited previously for his comments on mute suffering, also wrote on the subject of compassion. He said that examination of compassion must begin with an understanding of suffering because the need for compassion is created by suffering, not just by pain. He further defined suffering as "an anguish we experience on one level as a threat to our composure, our integrity, and the fulfillment of our intentions but at a deeper level as a frustration to the concrete meaning that we have found in our personal existence" (Reich, 1989, 85).

Similar to the phases of suffering previously described, Reich also identified three phases of compassion (Reich, 1989). The first phase is silent empathy/silent compassion. In this phase, the caregiver is silent in witnessing the suffering of another. The second phase is expressive compassion in which caregivers help to "give voice to the voiceless" by listening to their stories and helping convert the sufferers' experiences into comprehensible words. The final phase is a compassionate voice of one's own. In this phase, the compassionate caregiver is also transformed by witnessing the suffering of another and by making systematic changes to relieve the suffering.

Reich's phases of compassion can be applied to nursing. A neonatal nurse has worked for several years in an inner city NICU, listening with compassion to the tears and voices of young parents whose preterm infants have died despite the high-tech heroic efforts of neonatal care. The nurse is distraught in knowing that these parents leave the hospital with no follow-up, no money for funeral costs, and no access to counseling or bereavement services. The nurse appeals to hospital administration, sharing years of her observations of these dying babies and their parents, giving voice to the inadequate system that ignores their suffering during the NICU stay and after death.

The nurse's own suffering, and that of her colleagues, is diminished as they are successful in changing the system of care. Despite the desperate lack of resources, the hospital arranges for a psychology intern placement and part-time chaplain for the unit. A referral arrangement is made for bereavement support in the local mental health clinic. The nurses establish a routine of sending bereavement cards to parents and an annual memorial service is established. The infants, their parents, and the nurses now experience a transformed system responsive to suffering.

Similarly to the writings of Reich, McGrath (2002) described spiritual pain as a sense of diffuse emotional and existential pain related to meaninglessness and pain resulting from a break with usual relationships that connect one to life. Spiritual pain and suffering are often described in terms of despair, depression, request for hastened death, and hopelessness

(McClain-Jacobson, et al. 2004; Ersek, 2006). People facing chronic disabling illness or those at life's end often become overwhelmed with the burdens of daily life and the recognition of the burden of their life on others.

There is growing consensus regarding the key factors influencing psychological and spiritual well-being in terminal illness. Lin and Bauer-Wu (2003) conducted an extensive literature review and concluded that key factors in psychospiritual coping included self-awareness, coping and adjusting to stress, relationships/connections to others, faith, a sense of empowerment and confidence, and living with meaning and hope.

Another model of care responsive to suffering has been work by Chochinov (2006), who has developed a psychotherapy program titled "Dignity Therapy," which integrates spiritual issues and resources for people with cancer. The four concerns of the program content are: control, identity, relationships, and meaning (Chochinov, 2006). Breitbart (2002) has conducted similar work in testing a "meaning-making intervention," which builds on classic work by Victor Frankl (1963). Frankl described the devastation of suffering that splits the whole person into fragments. He suggested that people are destroyed not by suffering itself but by suffering that is void of meaning. The intent of both these therapies is to increase the sense of meaning, dignity, and hopefulness in the face of serious illness or other devastating circumstances.

A CASE ILLUSTRATION OF FORGIVENESS

The concept of forgiveness serves as an excellent example of the relevance of theology to the clinical care of patients at the end of life. Individuals facing death often reflect on their lives and relationships and confront unresolved conflicts from the past. The following case illustrates this topic.

Mr. Farber is a 60-year-old Jewish man who, with his young family, moved from Israel to America 30 years ago. He was first a bookkeeper and, after many years of evening classes, became an accountant. He has worked hard to provide for his wife and five children. His wife is diabetic and has had many physical complications over the years. Mr. Farber is a loving husband and has nurtured his children, their spouses, and his grandchildren throughout their lives. Four months ago Mr. Farber was diagnosed with pancreatic cancer and more recently developed extensive brain metastasis. Two weeks ago he developed

seizures, which was the final breaking point for his wife, who has tried desperately to care for him at home.

Now a patient in an inpatient hospice setting, Mr. Farber is visited by his entire family. The evening nurse is moved by this kind man. She finds herself touched by his gentle manner and his overt expressions of love for his family. His hospice room is covered with family portraits, albums filled with family vacation photos, cards made by grandchildren, and several books on Judaism. Before the family leaves for the evening, they join hands and surround the bed, praying together that God will be with him through the night and offering thanks for their blessing of family.

After the family goes home, the nurse returns to Mr. Farber's room. She feels intuitively that there is something he is concerned about that may be preventing him from being at peace. She begins to talk with him and comment on his wonderful family. When Mr. Farber becomes quiet, the nurse sits quietly by the bedside. After a few moments, tears come to Mr. Farber's eyes. The nurse asks, "Mr. Farber, is there something bothering you, something I can help with?" His tears continue and he says simply, "I am not a good man."

The nurse is surprised by the contrast between his words and her image of this gentle, loving father, spouse, and grandfather. He repeats the words, "I am not a good man," and then tells the nurse about how he had an argument with a brother over 30 years ago, and now, despite his brother's pleas, he has refused to reconcile with him. Mr. Farber openly sobs, telling the nurse how sorry he is that he has never forgiven his brother and how he hopes that his brother can forgive him after his death.

The above case illustrates a scenario of a patient seeking forgiveness through dialogue with a nurse. This is not unusual; however, hospice and palliative care literature has often addressed such a request for forgiveness as a simple process: the patient expresses regret, and the professional listens to the request, offers consultation, and then facilitates the patient in seeking forgiveness through saying, "I'm sorry." The person who has been offended accepts the apology. All is forgiven. The life-long burden is relieved in a few hours, or perhaps a few minutes. We fix things.

Review of theological literature suggests that the process of forgiveness is seldom this simple. An illustrative citation is the work by Ashby (2003), "Being Forgiven: Toward a Thicker Description of Forgiveness." Ashby (2003) builds on other theological works (Enright and Coyle, 1998; Alken, 1997; Muller-Fahrenholz, 1997; McCullough, Pargament, and Thoreson, 2000) that have explored forgiveness at a much deeper level.

These theologians emphasize a forgiveness that goes beyond a simple act of pardoning, excusing, forgetting, or denying (Ashby, 2003). Ashby wrote of a parallel process in which one person seeks forgiveness and one grants forgiveness. Ashby wrote of the "being forgiven" process as an intricate work that includes the injured party being open to offering that forgiveness. The injured person accepts and bears the pain of the insult and thus develops compassion for the offender. The injured person finds deep meaning in the suffering associated with the injury. Ashby (2003) and Enright and Coyle (1998) have suggested that the act of seeking forgiveness may go even deeper when the offender also seeks self-forgiveness.

Keeping these levels of forgiveness in mind, we can see that Mr. Farber's confession will not be reconciled by simple assurance by the nurse that he is a "good man." The depth of his suffering will also not likely be resolved in the next few moments or even by a simple "fix" such as an offer by the nurse to contact the brother or to assist the patient in writing a note to his estranged brother. Forgiveness that offers relief for long-held suffering might best be facilitated through a more intricate process, even in the face of impending death. The nurse may also be most effective when acting as a partner in an interdisciplinary team that includes a chaplain (in this case, a rabbi) and social worker, whose collective efforts can best facilitate the process of forgiveness. In the end, it is an intensely personal act for Mr. Farber to forgive himself or to seek forgiveness. The nurse may offer presence and serve as a confessional source for the patient. The nurse's very presence offers acceptance of the injury, and with that acceptance may come relief of suffering or self-forgiveness. Few words on the nurse's part need be spoken.

RECOGNITION OF DIVERSE RELIGIOUS AND SPIRITUAL BELIEFS

Another critical concern for nursing is learning to respond to the diversity in cultures and faith traditions among patients. Health professionals often have little competence in spiritual assessment or intervention, and their skill is often limited to responding to those whose religion is the same as their own. The following case illustrates the need for competence in addressing diverse spiritual needs.

Ernest Littlejohn is a 78-year-old Native American recently diagnosed with lung cancer. Mr. Littlejohn has lived his life on an Arizona reservation and reluctantly moved to Los Angeles 2 months ago to live with his son Edward. Mr. Littlejohn's wife died 3 years ago from

diabetic complications. Neither of Edward's parents have used health-care services beyond the Native American healer. Despite his declining condition, Mr. Littlejohn has refused to seek health care; however, over the past week, he has experienced increased dyspnea and has now come to the emergency room (ER). An X-ray in the ER identified a large mass in his right lung, presumed to be a tumor. He reluctantly agrees to be admitted if his breathing can be relieved but says he wants no medical treatment for "whatever you find on those tests."

Over the following 3 days, the doctors confirm a diagnosis of advanced lung cancer. Mr. Littlejohn's symptoms are improved with oxygen, morphine, and antibiotics, and he is now calm and comfortable. He is adamant about going home by morning. The nurses have observed that although Mr. Littlejohn has improved over the last 3 days, his son Edward and his daughter Gloria (who arrived from New Mexico) have become extremely anxious.

Overhearing a conversation at the nurses' station, a hospital orderly tells the nurses that he may know why the son is anxious. The orderly shares that yesterday he was talking with Edward in Radiology after transporting Mr. Littlejohn for an X-ray. The orderly and Edward began to discuss their shared experiences of caring for ill parents. Edward is worried that his father will kill himself once he is discharged. Two of his uncles have killed themselves after becoming ill. Edward told the orderly, "My father will not want to be a burden. He will want to honor his heritage and dignity."

The nurses responsible for Mr. Littlejohn want to offer compassionate, respectful, competent, and culturally sensitive care. Although the aforementioned case does not mention an organized religion, it is rich in factors related to the meaning of health and illness, beliefs about life and death, and issues regarding relationships between a son and father as well as among professionals, families, and patients. It also offers the opportunity for self-evaluation of health beliefs by the providers of care.

While knowledge of diverse religious traditions and beliefs is important, it is also helpful for nurses to recognize diverse perspectives on suffering (Puchalski, Dorff, and Hendi, 2004; Kemp, 2006). Nurses can do much to support spiritual care of patients and families. Exploring the patient's spiritual history, cultural beliefs, family traditions, and prayers can create a foundation for respecting and supporting spiritual needs (Fox, 2001).

People who hold Christian beliefs may see suffering through the life and death of Jesus Christ. People who are Catholic or Protestant may see suffering as an experience of being "with Christ"—as Christ suffered, so I

suffer. Suffering may mean that the soul is tested, sins are forgiven, and redemption is gained. As a case example, a mother of a young adolescent boy dying from sarcoma refused pain medications for her son, despite his agonizing bone pain. This illustrative case follows.

The mother was not evil or "crazy" but she explains that her son had been in a gang and had never been "saved." She hopes his suffering would bring him close to God, and she also explains that pain medicine makes him sleepy and that it was important to keep him awake so that she could pray with him. When a well-intentioned home-care nurse asks the mother how she can stand to see her son spend his last days in pain, the mother becomes very angry. "You nurses think you care more about my son than I do. You are worried about a few days. I am worried about his eternal life." Fortunately, through expert and sensitive efforts by the nurse, chaplain, and a social worker, the mother was able to agree to a medication schedule that would allow her son to sleep pain-free for hours, with scheduled "alert time" so that he could confess and "be saved."

Many people find great comfort in the association of Christ's suffering with their own. Parents whose children are dying may find solace in thinking of God's suffering in the death of His son. Suffering in a Christian tradition that envisions the process of redemption and forgiveness may also impact human relationships. The following case illustrates this issue.

Lucy Guaterez is a 40-year-old homeless patient newly diagnosed with liver cancer. She reports that she has no living relatives. Her symptoms are controlled, but she is aware she likely will die in a matter of weeks. As the hospital social worker struggles to find a place for Lucy to live, given her multiple symptoms and complex medications, she finally confesses that her elderly mother lives nearby. They have not spoken in over 10 years; their relationship was destroyed because of Lucy's drug addictions. Lucy admitted to having stolen money from her mother and physically abusing her during the worst times of her life.

Lucy says she cannot call her mother but agrees to have the social worker make the call. Her mother, without hesitation, agrees to take in Lucy for the final weeks of her life. The hospice program assists in the

transfer home and offers extra support, given the dynamics of the patient and her mother. Lucy does remarkably well once discharged to her mother's home, with the exception that her pain is not well-controlled. Her nausea and depression are much improved, and she enjoys her mother's cooking and sleeping in a soft bed. Until the last few days of life she tries to be independent, wanting to be as little burden as possible. The hospice has been able to meet Lucy's request for a daily home health aide visit for bathing. Lucy and her mother do not discuss the past and actually speak little. They spend considerable time sitting quietly together.

Frustrated by their inability to manage her pain, the hospice physician and nurses make numerous changes to her pain medications. In the weekly team meeting, the professional staff discuss the various drug options remaining. The home health aide interrupts to share her observation that although Lucy takes all of her own medications, she does rely on her mother to give pain medications. The aide further observes that Lucy only takes pain medicine if offered by her mother and then relies on her mother to decide if she should have one pill or two. One intense dynamic of this "prodigal daughter" seems clear: Lucy is asking for forgiveness from her mother in the form of pain medication.

Religious beliefs about suffering generally are based on scripture and family tradition and may be enacted in sacred ritual. For example, the Muslim tradition identifies suffering through the tradition of the Qur'an, recognizing God's divine power and the presence of illness or suffering as an aspect of life. The Qur'an and other sacred texts cite the story of Job and his appeal to God for relief from suffering. The Muslim faith values patience and devotion in times of suffering.

Faith traditions may teach about healing, miracles, and suffering. Death may be seen as a transition to a future existence. Islamic belief emphasizes the ultimate Will of God, whether it be in the form of surgery that extends life through a delicate procedure and highly advanced technology or in the form of supportive care if surgery is either unsuccessful or unwarranted.

One ICU nurse observed a Muslim family who waited patiently at the bedside of a teenage boy with acute renal failure from antibiotics given for a severe, untreated urinary tract infection. The family was just as diligent to regularly leave the ICU to pray in the adjacent waiting room. After a few days, the nurse felt comfortable enough with the family to comment about their devotion. She admitted she knew little about Islam, yet was quite moved by the family's persistent prayer for their son. The nurse was stunned to hear the father respond, "When we leave this room to pray, we are praying for you. We ask Muhammad to guide your hands on the dialysis machine so that you will save our son." The nurse first joked with her colleagues, "Imagine a Muslim praying for me, a Methodist!" Upon deeper reflection, the nurse shared how deeply touched she was by this Muslim prayer and how it caused her to reflect on her work not as a dialysis nurse "technician" but her role as a sacred healer and an instrument of God.

Another case illustrating the importance of culture follows.

An oncology nurse recalled a Chinese family who came to the patient's room every day with different herbal remedies, soups, and special foods to cure the patient's illness. The patient was a 35-year-old woman with recurring ovarian cancer. Upon discovery of the return of her cancer, her husband left her, knowing that she would not be able to provide him with the son he wanted. She had been admitted to the hospital previously for treatment; the chemotherapy, the surgery, and the days and nights spent in the hospital with uncontrolled symptoms were all familiar. Speaking very limited English, this patient always had a niece or nephew there to translate for her. Her family was very faithful. They went to the temple every weekend to pray for their beloved daughter, sister, aunt. They trusted that a higher power would help save her. They prayed at her bedside for her recovery. They believed that the bitterness of her life would be rewarded with health from this disease that they could not understand. It just simply could not be that "the one with white hair would send off the one with dark hair," that the daughter would die before the mother. Although the nurse did not know what the family's rituals meant or what kinds of foods they were feeding her, she understood that this ritual was necessary. It was their way of doing something. It was the only way they could accept what was happening before their eyes.

In the early 1900s, Max Scheler, a sociologist, wrote on the philosophy of religion and the concept of suffering. He described three major ways of dealing with suffering: *(1)* dulling it to the point of apathy, *(2)* struggling

heroically against it, and *(3)* suppressing it to the point of believing it is an illusion. He contrasts Christian perspectives of suffering as redemptive and Christ-like with the Buddhist views of suffering as an opportunity for understanding and insight (Bershady, 1992). Scheler's work is a reminder of the importance of cultural consideration and assessing individual responses to common medical diagnosis.

There are extensive resources to guide nurses in understanding various religious perspectives on illness and death and on specific issues such as organ transplantation, autopsy, care of the body after death, and grieving (Berry and Griffe, 2006; Puchalski et al., 2004; Kagawa-Singer, 1994). Beyond the specific details of each religion or tradition lies the important common need for nurses to respect diverse cultures and to support patients and families in their faith traditions.

Each of the stories in this chapter illustrates the importance of relationship. Nurses offer relief of suffering through presence. They offer compassion and trust. There are few real "quick fixes" in nursing. Nonetheless, nurses are performing sacred work as they remain steadfast in the face of impossible suffering. They help to find meaning in that suffering, seek and grant forgiveness, and transcend even the worst of life circumstances. As Weatherhead said:

> The man who inquires into the problem of suffering may be compared with one who from some sunny street, steps into the comparative gloom of a vast cathedral. After the blaze outside, all seems dark. As his eyes grow accustomed to the darkness he notices unsuspected windows which throw light upon the way he treads . . . and in the end there is no darkness to make him afraid. (Weatherhead, 1936, 25)

SACRED ACTS IN THE ABSENCE OF RELIGION

Marvin Wilson is a 62-year-old African-American man who went through a bitter divorce 3 years ago. Marvin and his ex-wife Gail have not been on speaking terms since their separation. Both fought bitterly in dividing their property, and their two adult daughters became enemies as they each took sides with one of the parents. These past years have included hostile interactions, court appearances, restraining orders, and police visits. Both Marvin and Gail have since remarried. Marvin just weeks ago sustained a critical spine injury after diving into a shallow pool. He is now quadriplegic and has a brain-stem injury. He is comatose and ventilator-dependent. After extensive deliberation and consultation, a decision is made to discontinue his life support and allow him to die.

In the first week of his hospitalization, the daughters argued angrily, and hospital security was called on at least three occasions. Since then, as the reality of their father's prognosis has sunken in and exhaustion has replaced hostility, the family members have remained separated but become more peaceful. The families decline any chaplaincy involvement. Marvin had no prior religious affiliation and, when interviewed, Marvin's new wife said she "used to believe in God" but that "there is no God if a man as good as Marvin is allowed to die."

All of the extended family members and the daughters and their respective spouses ask to be present as Marvin's life support is discontinued. A joint decision is made about a funeral home, but the nurse is aware that the families are planning separate funeral services.

Recognizing the impact and power of stopping the ventilator and Marvin's subsequent death, the nurse is also aware of the absence of any ritual, prayer, or other sacred acts. On this, the entire family seems to agree. After he dies, the nurse notices that the daughters linger behind. She asks if they would like to stay and help her bathe and dress Marvin before the mortuary comes. In absolute silence but constant tears, each daughter takes a side of his body, guided gently by the instruction of the nurse as their father's body is cleaned and prepared.

Even in the absence of religion, faith community, or a recognized ritual, nurses have the ability to bring a sense of humanity even in the most difficult of circumstances. Nurses are guided by ethical perspectives that extend beyond professional codes and call upon basic human kindness and compassion as they are called to embrace spirituality in its most global sense. Nurses hear confessions, perform "baptisms," affirm faith, and support the process of forgiveness, all within the context of their daily work.

The expert nurse knows that much redemption happens when a hostile family member assists in a bath. Nurses know that asking the frightened husband to spoon-feed his spouse a few sips of soup or coaching a grandson to massage the back of his grandfather are more than physical acts. They are sacred acts and they are actions that become the life-long memories of those who live beyond the illness or death of a loved one.

SUMMARY

The understanding of suffering from a nursing perspective has been enriched by the work of scholars in the fields of ethics and theology. An early

nursing contribution to the exploration of suffering included research conducted by Battenfield (1984), who used qualitative methods to develop an operational schema of suffering through interviews of nine patients facing serious illness. She concluded her paper by saying:

> Nurses, long accepted as comforters in time of human need, have developed and refined multiple skills, arts, and knowledge to enable them to alleviate suffering at times of physical pain and emotional upheaval. Perhaps the suffering schema, as a small addendum to their bag of tools and rules, could lend an enriched awareness to the concept of suffering and expand the nurse's ability to aid fellow human beings to climb from a depth of turmoil to the height of a mind at peace. (Battenfield, 1984, 40)

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