

The Nature of Suffering and the Goals of Nursing

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This article has been chosen for a podcast conversation with the authors, presented by the Oncology Nursing Society. Authors Betty R. Ferrell, RN, PhD, FAAN, and Nessa Coyle, NP, PhD, FAAN, share their experiences with suffering in caring for patients with cancer and discuss how nurses can develop techniques for easing patient suffering and the role of nursing education and mentoring in the process. Nurses who care for patients and families regularly also need to protect themselves from compassion fatigue. Ferrell and Coyle discuss the danger of compassion fatigue and some ways nurses can develop resilience. To access the podcast, visit www.onsforum.org.

Purpose/Objectives: To describe the nature of suffering and the goals of nursing.

Data Sources: Data sources informing this work included descriptions of suffering as derived from the literature; narrative data from patients, family caregivers, and nurses; and personal and professional experiences of the authors.

Data Synthesis: Previous descriptions of suffering from seminal sources are insufficient to elucidate suffering from a nursing perspective. This article is parallel to Cassell's description in 1982 of the nature of suffering and the goals of medicine. Nurses play a fundamental role in caring for those who suffer. Suffering is associated with loss, intense emotions, spiritual distress, and inability to express those experiences.

Conclusions: The 10 basic tenets of suffering describe its nature and the goals of nursing; they include listening, intimate care of the body, and presence.

Implications for Nursing: Oncology nurses witness suffering in their daily work. This article is intended to acknowledge suffering experienced in oncology nursing and to stimulate future research.

In a medical-surgical unit in a small hospital in the mid-western region of the United States, a patient's suffering is reduced by the night shift nurse. The older female patient has lung cancer. She was admitted two days prior with a bowel obstruction, likely the cumulative result of immobility, inadequate food and fluid intake, medication side effects, and progressive disease. Her uncontrollable nausea, vomiting, and pain over the past few days at home now are relieved by a nasogastric (NG) tube, IV fluids, and careful titration of analgesics. Having finally slept a few hours, the woman awakens in the middle of the night. Given the myriad tubes and wires attached to her body, she remains motionless, afraid to move. Still, her wakefulness stirs her exhausted daughter, who is wedged into a cold, hard reclining chair at her bedside.

Mother and daughter exchange mutual queries: "Are you okay?" "Why don't you go home?" the mother suggests.

Key Points . . .

- ▶ Suffering is common across phases of cancer; it is thoroughly individual and intensely personal.
- ▶ Nurses respond to suffering primarily through their presence.
- ▶ As witnesses to suffering, nurses serve as compassionate voices and advocates for patients and families.
- ▶ Nurses help patients regain control in the face of illness and cope with vulnerability and the uncertainty of life.

"This chair is fine," the daughter lies. The patient's husband went home after a few hours at the hospital. After 55 years of marriage, the angst of seeing his wife so miserably ill and the strangeness of the hospital world were enough to propel him home, despite the terrifying and total silence of an empty house. Mother and daughter reaffirm to each other that he is home asleep, but both know he is probably wide awake, sitting in his easy chair in the living room, sipping stale coffee, reading his Bible, and counting on God to come through. After all, God has come through many times before. He has faith. God will come through again.

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The night nurse enters the room, careful not to turn on the bright lights even though she sees that both mother and daughter are awake. She performs the routine checks—NG tube functioning, IV dripping, urinary catheter draining. The same nurse was on duty when the woman was admitted the night before. Comparing her patient's distress then and her current relatively peaceful state, and given the goals of care, she decides to skip the routine vital signs. Instead, she asks the woman how she is doing. The woman politely answers, "Fine." She adds that she did not really know how poorly she had felt until she started to feel better. The nurse resists the urge to hurry out the door to the next patient and to continue her long list of tasks. It is hard to stand still. She sees the woman's cachectic body, she hears the flow of oxygen and the pulsing suction of the NG tube, and she feels the clammy coolness of the woman's arm as she gently touches it. The nurse knows well the signs of approaching death—too well. Death is a frequent visitor in the hospital.

Assured of her patient's comfort, the nurse speaks to the daughter: "You must be relieved your mother is not in pain now." The nurse says how wonderful the daughter's presence has been and acknowledges the daughter's exhaustion. As the daughter's eyes fill with tears, she finds herself grateful that the room is dark. In just two days, she will need to leave to pack her own daughter for college. On the airplane, she will reverse roles, become the mother, and somehow navigate that other—and almost as difficult—rite of passage. After the move to college is completed, her husband will drop her off at the closest airport so she can return to her mother. She has been praying a lot. She asks God whose idea this is—that she may lose her mother and daughter in the same week. Her faith usually is strong, but not this week. She has found her limit.

The nurse senses the quiet tears of the daughter, hidden from her mother's eyes as she lies next to her, staring at the dark ceiling. She asks the daughter if she would like some coffee. It is the mother who answers: "We are tea sippers." She describes how the two of them had "tea parties" all their lives. From the time the daughter was a little girl with a floral porcelain tea set to heartier mugs shared over monumental life decisions, the two have sipped tea. The pale and weak patient perks up and proclaims, "You know, we could have a tea party now!"

The nurse hesitates. The woman cannot have oral fluids because of the bowel obstruction. But given that the primary goal for her patient is comfort, and given the enormous pleasure the ritual would give them, the nurse decides to let her have a few sips of tea. The NG suction will keep the sips from becoming instant, violent nausea. In silence, all three women realize with profound grief that this tea party may well be the last. The nurse excuses herself and goes to her locker to get a "special stash" tea bag. No industrial hospital tea bag will do, not for this occasion.

She returns in a moment with a full cup for the daughter, another smaller cup and a straw for the patient. After a deliberate pause and then an intimate connection as the nurse's hand touches the daughter's hand and lingers, she offers the tea. She leaves only when she is certain that her patient is comfortable, careful to leave the lights off and to close the

door quietly. The mother and daughter sip tea. In the stillness of the room, with only the intermittent sound of the suction machine, they are recipients of the sacred care of a nurse.

The case illustrates the nature of suffering and the goals of nursing. The story is, on one level, a very simple narrative of a common situation. On another level, it is a rich and deep portrayal of the work of nursing delivered at one of the most poignant moments in the lives of a mother and her daughter. The deep and profound experience of suffering is the focus of this paper.

Cassell's Foundational Work on the Nature of Suffering

In 1982, Eric Cassell, MD, published a seminal paper on suffering. The publication in the *New England Journal of Medicine* opened the door to what has become an ongoing professional conversation about suffering in healthcare settings. Cassell's original article later was expanded to a book, and his initial article has been cited internationally by professionals from many disciplines, challenging systems to respond not only to physical injury and disease, but also to human suffering (Cassell, 1991).

The essence of Cassell's description is that suffering is "experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychologic entity" (Cassell, 1982, p. 639). Cassell also asserted that suffering may include pain but is not limited to it and that the relief of suffering is an *obligation* of medicine. His comparisons of pain versus suffering and his exploration of the concept of *meaning* echo the historic themes of medicine and nursing. Although both disciplines have a historic mandate to relieve suffering, the current healthcare system often fails to uphold this basic duty. Nursing and medicine have become highly technical and often quite depersonalized.

Cassell's analysis of the meaning of illness is particularly relevant to nursing. He described *personal meaning* as a fundamental dimension of personhood and explained that the act of recognizing personal meaning is critical to understanding human illness and suffering. He also rebuked modern medicine for ignoring the transcendent dimension—the spirit of human life.

The Need for a Unique Analysis of Nursing and Suffering

Oncology nurses are the professionals most often available to patients and families as they experience cancer across all settings of care. From the acute onset of illness or the moment of diagnosis of cancer, individuals look to nurses for reassurance and understanding, as a human connection in the overwhelming reality of health care. Nurses who bear witness to suffering are a valuable voice to articulate lived experiences of people in their most vulnerable and broken states. The title of "nurse" is a broad category, including a spectrum of human beings as diverse as the patients they serve. A night shift nurse caring for a seriously ill, complex patient with cancer may be a 22-year-old new graduate with limited nursing or life experience. Yet she is the professional on the front line

addressing the needs of a suffering patient. The day nurse who relieves the new graduate may be a 55-year-old man with 30 years of cumulative professional and personal experiences of triumph, loss, relieving pain, and witnessing suffering. He also may bring to the bedside his own intense personal experience of the recent deaths of his parents.

Nursing as a profession often is recognized for addressing whole-person care (Beckstrand & Kirchhoff, 2005). Nurses often are similar to physicians, guilty of using a “fix-it” approach to care (Jackson, 2003). They want to heal the wound, eliminate the pain, relieve the nausea, and increase function. Many oncology nurses, the authors included, were taught that a “good nurse” was one whose patients ate well and consumed sufficient fluids, had functioning bowels and bladders, breathed deeply, and ambulated independently—preferably by the end of the nurse’s shift! Each of those aspects of physical care is important yet incomplete without attention to psychosocial and spiritual concerns. Sister Rosemary Donley (1991), a senior nursing scholar, wrote, “Spiritual dimensions of health care: Nursing’s mission.” Donley wrote, “Nursing response to suffering persons runs parallel to the religious tradition: accompaniment, meaning giving, and action” (p. 179). Yet she articulated concern that the art and mystery of healing have been lost as nurses have become part of a money-making, technologic system, not a sacred system. She described the crisis in health care as a crisis of meaning and values. Donley concluded that “concern with spiritual elements of care brings greater meaning to the work of nursing and a sense of participation in the realm of mystery and grace. When nurses, acting compassionately to alleviate suffering, also search with their patients for a spiritual meaning for the experience, there will be a rebuilding of trust in professional relationships. This restoration will have a positive effect on patients, nurses, and on the healthcare system itself” (p. 183).

Several studies in recent years have documented the lack of palliative care content in nursing curricula and nursing textbooks, and extensive reports from practicing nurses have highlighted the need for attention to end-of-life care (Ferrell, Virani, et al., 2005; Malloy et al., 2006; Paice et al., 2006). For some, nursing education (and thus the journey to “becoming” nurses) has been guided by a nursing process and a nursing care plan that often resembled a checklist of actions to restore the sick to health and the dependent to independence. For some, educational preparation has been void of philosophy, role modeling, or reward for behaviors such as compassion and presence. The focus on communication in nursing practice is sometimes reduced to “patient teaching,” in which an informed nurse directs an uninformed patient regarding cancer treatment.

Yet communication is more than information and includes the art of listening and witnessing suffering. Somewhere on the journey to learning the art of “healing,” many nurses have had the profound gift of witnessing true nursing by a seasoned and compassionate colleague. Watching a nurse who is fully present, who listens carefully and says little but provides the sufferer the opportunity of “voice” as described by Reich (1989), is a true education. Reich described the skilled professional as helping the suffering person who may “scream in pain and suffer in silence” and said that, through listening and patiently waiting, nurses “give voice” to suffering. Such mentors teach that silencing or stifling the voice of suffering serves only to intensify it.

Researchers from Canada (Daneault et al., 2004) explored the nature of suffering and its relief through a qualitative study of 26 terminally ill patients with cancer. Their findings revealed that patients experienced suffering in the dimensions of physical, psychological, and social well-being. The content analysis of the interviews recognized three irreducible, core dimensions of suffering: (a) being subjected to violence, (b) being deprived and overwhelmed, and (c) living in apprehension.

In a similar study, nurse researchers from Finland explored suffering in patients with advanced cancer (Kuuppelomaki & Lauri, 1998). Their research found suffering to exist in the same three dimensions. Physical suffering included fatigue, pain, and side effects of chemotherapy. Psychological suffering, most commonly expressed as depression, was related to the physical changes resulting from the disease and overall debilitation as death became imminent. The physical and psychological effects of worsened disease caused withdrawal and isolation, hence the third dimension of social suffering. The study reinforced the inter-relatedness of the dimensions of suffering and the whole-person phenomenon.

The findings of the Canadian and Finnish researchers were very similar to a study by a nurse researcher in the United States who studied suffering in patients with lung cancer (Benedict, 1989). The similarities in the studies are interesting, as are the common descriptions of distress from patients across diverse countries and cultures. Such studies help nurses to understand patient experiences of suffering and to uncover sources of suffering.

Methods Used for This Work

Three sources of data have informed this descriptive paper on the nature of suffering and the goals of nursing. The first was descriptions of suffering as derived from the literature. The literature reviewed was selected based on searches of medical, nursing, ethics and theology, and other literature, guided primarily by course work and directed readings of the authors. The two authors are doctorally prepared nurses who each, several years postdoctorate, returned to formal study. The first author was completing a master’s degree in theology, ethics, and culture, the second author a nondegree program in medical humanities.

The second source of data that informed this work was narrative data derived from interviews or written comments from patients, family caregivers, and nurses. The data were abstracted from several studies the authors had conducted and analyzed previously. The data were re-evaluated from the perspective of suffering. Narrative data also were collected from nurses attending End-of-Life Nursing Education Consortium courses (www.aacn.nche.edu/ELNEC). The narrative data were interpreted with content analysis methods. The narratives of nurses, patients, and family members were analyzed to identify common themes and concepts related to suffering. This paper, intended for oncology clinicians, includes several case studies as a preferred method of conveying the analysis of suffering.

The third source of information for this work was the personal and professional experiences of the authors. Beverly Harrison (1985) and Carol Gilligan (1982), as well as many other feminist scholars, have acknowledged that personal reflection and experience are valued sources of scholarship.

To embrace the depths of suffering requires scholarly inquiry, synthesis of the literature, and reflection on clinical experiences and the lived observations of those who suffer.

The Unique Relationship of the Patient and Nurse

Many healthcare professionals are involved with patients' suffering from illness, but this analysis addressed only the unique relationship of the patient and nurse. The features of the relationship are illustrated in the following case.

Mrs. K is a 78-year-old Polish woman currently hospitalized after a seizure and diagnosis of a brain tumor. She responded well to the acute care she received in the emergency department and intensive care unit and is now on the neuro-oncology floor of an academic medical center. She is being seen by four medical specialties, as well as speech therapy, physical therapy, and occupational therapy. Now that her condition is stable, she is undergoing further diagnostic work to evaluate her cardiovascular status and to determine her overall health status for treatment planning. She has short-term memory loss, unsteady gait, elevated blood pressure, and some left-sided weakness, as well as some difficulty with speech.

During the night shift, after a day that included encounters with no fewer than 20 different healthcare professionals, attendants, transporters, and visitors, Mrs. K is found sobbing quietly by the night nurse. She denies pain but admits that the reality of the brain tumor "just hit me." She tearfully speaks for a few moments with the nurse, who softly strokes her hand and offers a tissue. As their eyes connect, Mrs. K's quiet sobs become intense. She clutches the nurse's hand, repeating intensely, "I have to get well. ... I have to get well."

After finally calming her, the nurse asks her to try to explain her fears and to specifically express what is of greatest concern. Mrs. Krakaski says that she must return home this week because she is the only caregiver for her husband, who has advanced prostate cancer. She shares that their son has come from another state but can stay only a few days and that he and his father do not get along; thus, she is worried about what may be happening at home. She tells the nurse that she has promised her husband to be there for him as he has always been there for her, including a few years ago when she was treated for breast cancer. She also shares that her 50-year-old daughter died of breast cancer last year.

Mrs. Krakaski asks the nurse to please try to convince the doctors to let her go home. She also asks the nurse whether a priest is ever in the hospital at night; she would like to see him. She explains that she cannot ask for a priest during the daytime when her husband might be visiting because he "no longer believes there can be a God."

The case of Mrs. Krakaski and the night-time encounter with a nurse illustrates the unique relationship of nurse and

patient in a complex healthcare system. Mrs. Krakaski was surrounded by many caregivers yet expressed her suffering only in an intimate, personal encounter with a nurse. In the darkness of her room, the patient shared her greatest fears, explained her life losses, requested help, and exposed her vulnerability as her physical body forced her to become a patient, thus betraying her role as caregiver for her spouse. The nurse became her confidante, the vessel for her anxiety, and the counselor for her spiritual distress.

Witnessing suffering is the everyday work of nurses. In every setting, across diseases, and in people of all ages, suffering is part of being human, often intensified when being human also involves being ill. This paper is intended to be a step toward supporting nurses who care constantly for those who suffer. Nursing scholars Kahn and Steeves (1994) captured the need for attention to suffering by writing, "One characteristic of nursing's development over the past decade is the discovery of its voice—the ability and willingness to express what nurses collectively know and understand about the nature of nursing practice. To continue the development of nursing's voice, it is crucial that we talk freely about what we know, including what we know about suffering" (p. 260).

The Context of Cancer

Analogous to the association of pain with suffering is the association of cancer with death. Despite advances in earlier detection, treatment, and survivorship, the words "you have cancer" are almost always viewed as a death sentence. The prevalence and visibility of cancer are two social factors in the fear of cancer diagnosis. Virtually everyone knows someone with cancer and has witnessed the sometimes devastating effects of the disease. Most people also know of someone who has died from cancer. Unfortunately, society often collectively remembers people who died in pain (Chochinov, 2006; Lin & Bauer-Wu, 2003).

Another major factor in the association of cancer with suffering is the recognition of the caustic effects of cancer treatments. Even with the best prognosis, the effects of surgery, chemotherapy, and radiation therapy are distressing and can be devastating. A legacy exists in which many people diagnosed with cancer are reminded of the public images of those who have died from the disease or of personal experiences of having witnessed cancer's effects and the effects of treatment on loved ones. In the authors' research related to women with ovarian cancer, an unfortunately large number of women shared stories of having witnessed their own mothers or grandmothers die from ovarian cancer and in agonizing pain (Ferrell, Cullinane, et al., 2005). Healthcare professionals must reverse this legacy so that future patients will have legacies of compassionate care and comfort.

Suffering in Cancer Survivorship

All phases of the cancer trajectory—diagnosis, treatment, remission, and recurrence—are associated with suffering. A common perception is that suffering is limited to advanced cancer or to the final months of life as the physical body declines and a living person becomes a dying person. The Institute of Medicine (2005) report *From Cancer Patient to Cancer Survivor: Lost in Transition* recognizes that more than 10 million cancer survivors reside in the United States.

The suffering of those individuals across the trajectory from initial diagnosis, treatment, remission, and even long-term survival is enormous. Cancer caught at even the earliest stage, with the best treatment, leading to the best response, and with the most optimistic prognosis is . . . cancer (Char-maz, 1983). Healthcare providers often believe that if their care is good, then suffering can be avoided. Although suffering can be heard, validated, and diminished, it remains a common response to serious illness and death. The effects on family members of patients with cancer are equally distressing (Lewis & Deal, 1995; Morse & Fife, 1998; Northouse et al., 2002).

Awareness is growing that cancer survivorship may be a time of deep spiritual meaning (McClain-Jacobson et al., 2004). Surviving cancer may result in becoming closer to God or faith to “get through” treatment. Faith can offer protection against the enduring threat that cancer will return. A case illustration follows.

Alan is a 30-year-old Jewish man. He had a slight head injury during a tennis game and is seen in the emergency room. An x-ray reveals a mass in his brain that is believed to be a brain tumor. Alan says that although he has been raised in a very devout Jewish family grounded in multiple generations of religious life, his own faith diminished in early adulthood and his only affiliations at the temple are social in nature, void of any deep meaning. Having had what he described as a “dress rehearsal” for death, Alan becomes deeply involved in his faith and an active leader in the temple. As he returns to an active spiritual life, he encounters many others in his religious community who share a recent life-altering experience that led to their return to formal involvement in their faith. Participating in Rosh Hashanah for the first time after his illness touches him more profoundly than he ever would have imagined.

Alan says that a nursing assistant in the hospital radiology department was his “rabbi.” The nursing assistant, Ben, also is Jewish and met Alan on his initial emergency visit when his mass was discovered. The men share humorous stories of growing up Jewish that Alan finds to be of great benefit as a distraction amidst the terrifying tests. In the weeks that follow, as Alan returns for more diagnostic tests, their conversations become more serious. Alan confides his growing remorse about having abandoned his family heritage. Ben becomes his “rabbi” as Alan practices on Ben what he plans to say to the temple rabbi about his return to the faith community. Ben mostly listens as Alan talks but also offers to pray for Alan.

After three additional weeks, which he describes as “torturous,” Alan is told that the mass is benign and that he will require no further treatment. When Alan receives the biopsy report confirming the unexpected good news, he makes a trip back to the hospital just to thank Ben for his support. Still overwhelmed by the news, Alan says he needs another week to absorb it all, to get his emotions in check before going to his temple. He gives Ben a donation to his temple and asks Ben to pass it on as an offering of thanks.

This case illustrates one of the many opportunities for healthcare professionals to be present to people during life crises as they face their own mortality and revisit their faith traditions. In this case, Ben’s genuine compassion and sharing of mutual faith experiences were vital forces in Alan’s weeks of suffering and now in his reevaluation of life priorities.

Suffering in Advanced Cancer

Advanced cancer has served as a model for studying the concept of suffering. With more than 559,650 cancer deaths each year in the United States (American Cancer Society 2007), suffering in advanced cancer is all too common. Advances in the provision of cancer care, which offer excellent physical care and symptom management combined with psychological, social, and spiritual care, have allowed for the ability to minimize suffering to the extent possible.

Remarkable consistency exists in studies describing the experience of suffering in advanced cancer (Cherny, Coyle, & Foley, 1994; Chochinov et al., 2002). Researchers in diverse settings consistently have concluded that suffering exists across dimensions of physical, psychological and emotional, social and interpersonal, and spiritual and existential well-being (Battenfield, 1984; Benedict, 1989; Kuuppelomaki & Lauri, 1998; O’Connor, Wicker, & Germino, 1990). Coyle (2006) published an article titled “The Hard Work of Living in the Face of Death.” The phenomenologic study captured the essence of simultaneously living with advanced cancer and facing the immediacy of death. The author described the hard work of tasks such as maintaining control, creating a system of support and safety, finding meaning, and creating a legacy.

Nurses play an essential role throughout the disease trajectory in reducing the suffering of cancer. Recognizing losses and speaking of them ranges from circumstances such as a patient’s loss of hair after initial chemotherapy to the loss of a role when a patient becomes too weak to hold a grandchild. Suffering is acknowledged and sometimes reduced by the act of comforting as nurses give voice and a listening presence to the individual’s suffering.

Nurses tend to the physical bodies of patients rendered weak by treatments and advancing disease and, in doing so, help restore a sense of dignity to people with ravaged bodies. Nurses also demonstrate caring to family members who will assume responsibility for the 24-hour-a-day physical care of patients. Family members often observe nurses in their intimate care of patients and model that care. Observing nurses gently turning, massaging, or positioning patients can provide family caregivers with the confidence that they too can touch and care for their fragile loved ones. A participant in the study by Coyle (2006) described the care his family was able to provide after observing the nurse’s care: “They clean my bottom for me and they do it with such grace and beauty, they don’t make me feel like some sort of unhuman person. I am paralyzed, I need their strength, they don’t turn away from me” (p. 270).

The Nature of Suffering and the Goals of Nursing

Works by Cassell and others in the field of medicine inform the perspectives on suffering but are not sufficient

to describe the goals of nursing. In reviewing lay and professional literature, the authors are struck by how often the relief of suffering is attributed to the medical profession alone. This likely represents a broader paradigm in which the relief of suffering is meant to equal the cure of disease—a biomedical perspective that implies that the only true relief of suffering comes from fixing, curing, eliminating, and making a person free from illness.

Nurses play a fundamental role in caring for those who suffer. The relief of suffering is at the core of nurses' work as a profession committed to the human response to illness or injury. Nurses also are dedicated to serving the most poor and vulnerable (Hughes, 2006). The care required may vary considerably, even among individuals with a similar diagnosis. For example, the suffering of a person with AIDS may be dramatically different from one case to another. A middle-class African American man with a dedicated partner and who lives in a comfortable environment with good access to health care is likely to experience a much different trajectory than a Caucasian, homeless drug addict whose physiologic experience of AIDS may be similar but whose life experience is not (Williams, 2004).

Nurses are intimately involved in whole-person care and are, apart from families, the witnesses most often present as people struggle with fundamental ethical concerns and spirituality in illness. Emerging fields of thought, such as feminist ethics and medical humanities, offer a broader paradigm beyond a single focus on cure.

Feminist ethics provides a perspective of women's experiences and women's ways of knowing, being, and doing. *Feminine* refers to women's unique voice and advocacy of an ethic of care, including concepts such as nurturance, compassion, and communication. *Feminist* refers to advancing beyond traditional patriarchal domination and examining the moral experiences and intuition of women. Feminist ethics address patterns of dominance and oppression and power structures that are a part of the tradition of health care and many other aspects of society (Welch, 2000). Medical humanities is an interdisciplinary field including humanities (e.g., literature, ethics, history), social sciences (e.g., anthropology, sociology), and arts (e.g., film, visual arts) to bring a focus on human values and personalized care to medicine (Charon et al., 1995). The perspectives open the possibility that suffering often is not relieved, removed, or resolved but rather is witnessed, supported, accompanied, and borne with companionship and compassion (Potter, 2006).

Suffering often is viewed as an inherent part of illness, especially in serious or life-threatening disease. Illness that cannot be cured is a threat to human integrity because it reminds people that they have no ultimate control—that illness and death will persist. Yet in enduring illness, suffering can be transformative and provide meaning and ways of coping with chronic disease (Morse & Carter, 1996).

Many narratives about nurses are powerful depictions of unique circumstances, but most are profound in their simplicity. Nurses' work actually resembles rather ordinary people enduring very stressful circumstances. Nurses relate to suffering patients with an authentic and gentle approach. Caring nurses offer calm to terrified parents in intensive care units, assurance to families awaiting the outcomes of surgery, hope to patients receiving a first dose of chemotherapy, and consistent presence to patients in long-term care.

What is the nature of suffering by patients and families living through illness? What are the goals of nursing in responding to those needs? Although the questions are not answered easily, an attempt has been made to provide an initial schema of tenets that respond to the questions. The authors offer these tenets for future clinical inquiry and theoretical evaluation.

- Suffering is a loss of control that creates insecurity. Suffering people often feel helpless and trapped, unable to escape their circumstances.
- In most instances, suffering is associated with loss. The loss may be of a relationship, of some aspect of the self, or of some aspect of the physical body. The loss may be evident only in the mind of the sufferer, but it nonetheless leaves a person diminished and with a sense of brokenness.
- Suffering is an intensely personal experience.
- Suffering is accompanied by a range of intense emotions, including sadness, anguish, fear, abandonment, despair, and myriad other emotions.
- Suffering can be linked deeply to recognition of one's own mortality. When threatened by serious illness, people may fear the end of life. Conversely, for others, living with serious illness may result in a yearning for death.
- Suffering often involves asking the question "why?" Illness or loss may be seen as untimely and undeserved. Suffering people frequently seek to find meaning and answers for that which is unknowable.
- Suffering often is associated with separation from the world. Individuals may express intense loneliness and yearn for connection with others while also feeling intense distress about dependency on others.
- Suffering often is accompanied by spiritual distress. Regardless of religious affiliation, individuals experiencing illness may feel a sense of hopelessness. When life is threatened, people may conduct self-evaluation of what has been lived and what remains undone. Becoming weak and vulnerable and facing mortality may cause a person to reevaluate his or her relationship with a higher being.
- Suffering is not synonymous with pain but is closely associated with it. Physical pain is closely related to psychological, social, and spiritual distress. Pain that persists without meaning becomes suffering.
- Suffering occurs when an individual feels voiceless. This may occur when a person is unable to give words to his or her experience or when the person's "screams" are unheard.

Nurses are the confidants for patients who experience the personal threat of injury or serious illness. Nurses provide competent care for pain and other symptoms; in relieving physical problems, they also reduce psychological, social, and spiritual distress. The intimate care of the physical body offers nurses a special opportunity for healing "brokenness" and helping to restore a sense of integrity.

Nurses recognize that witnessing suffering is a part of their daily work, yet they seek to understand each person who is suffering as a unique individual. Nurses respond to suffering primarily through identifying its sources and offering presence. As witnesses to suffering, they serve as compassionate voices and recognize the human response to illness in the confusing and frequently depersonalized healthcare environment.

Nurses listen to patients, helping them to move beyond silent suffering to express their emotional distress. Their distress often includes expressions of sadness, loneliness, fear, helplessness, hopelessness, and a sense of brokenness. Nurses help to relieve distress and restore wholeness through human connection. Nurses respond to the spiritual distress of suffering, regardless of the suffering person's religious affiliation. Through the intimacy of caring, nurses also experience suffering and sometimes respond by seeking a balance of life and work and through deep spiritual reflection.

Nurses help patients to regain control in the face of illness and to cope with vulnerability and the uncertainty of life. As witnesses, nurses support patients in seeking meaning in distressing circumstances. Nurses accompany patients on their journeys; through such ongoing and intimate encounters, they support patients in confronting the weariness of living and dying.

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References

- American Cancer Society. (2007). *Cancer facts and figures*. Atlanta, GA: Author.
- Battenfield, B.L. (1984). Suffering: A conceptual description and content analysis of an operational schema. *Image—The Journal of Nursing Scholarship*, 16(2), 36–41.
- Beckstrand, R.L., & Kirchhoff, K.T. (2005). Providing end-of-life care to patients: Critical care nurses' perceived obstacles and supportive behaviors. *American Journal of Critical Care*, 14(5), 395–403.
- Benedict, S. (1989). The suffering associated with lung cancer. *Cancer Nursing*, 12(1), 34–40.
- Cassell, E.J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306(11), 639–645.
- Cassell, E.J. (1991). *The nature of suffering and the goals of medicine*. Oxford, United Kingdom: Oxford University Press.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168–195.
- Charon, R., Banks, J.T., Connelly, J.E., Hawkins, A.H., Hunter, K.M., Jones, A.H., et al. (1995). Literature and medicine: Contributions to clinical practice. *Annals of Internal Medicine*, 122(8), 599–606.
- Cherny, N.I., Coyle, N., & Foley, K.M. (1994). Suffering in the advanced cancer patient: A definition and taxonomy. *Journal of Palliative Care*, 10(2), 57–70.
- Chochinov, H.M. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *CA: A Cancer Journal for Clinicians*, 56(2), 84–103.
- Chochinov, H.M., Hack, T., Hassard, T., Kristjanson, L.J., McClement, S., & Harlos, M. (2002). Dignity in the terminally ill: A cross-sectional, cohort study. *Lancet*, 360(9350), 2026–2030.
- Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, 32(3), 266–274.
- Daneault, S., Lussier, V., Mongeau, S., Paille, P., Hudon, E., Dion, D., et al. (2004). The nature of suffering and its relief in the terminally ill: A qualitative study. *Journal of Palliative Care*, 20(1), 7–11.
- Donley, R. (1991). Spiritual dimensions of health care: Nursing's mission. *Nursing and Health Care*, 12(4), 178–183.
- Ferrell, B., & Coyle, N. (2008). *The nature of suffering and the goals of nursing*. New York: Oxford University Press.
- Ferrell, B.R., Cullinane, C.A., Ervin, K., Melancon, C., Uman, G.C., & Juarez, G. (2005). Perspectives on the impact of ovarian cancer: Women's views of quality of life. *Oncology Nursing Forum*, 32(6), 1143–1149.
- Ferrell, B.R., Virani, R., Grant, M., Rhome, A., Malloy, P., Bednash, G., et al. (2005). Evaluation of the End-of-Life Nursing Education Consortium undergraduate faculty training program. *Journal of Palliative Medicine*, 8(1), 107–114.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Harrison, B.W. (1985). *Making the connections: Essays in feminist social ethics*. Boston: Beacon Press.
- Hughes, A. (2006). Poor, homeless, and underserved populations. In B.R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 661–670). New York: Oxford University Press.
- Institute of Medicine. (2005). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Jackson, C. (2003). *The gift to listen, the courage to hear*. Minneapolis, MN: Augsburg Fortress.
- Kahn, D.L., & Steeves, R.H. (1994). Witnesses to suffering: Nursing knowledge, voice, and vision. *Nursing Outlook*, 42(6), 260–264.
- Kuuppelomaki, M., & Lauri, S. (1998). Cancer patients' reported experiences of suffering. *Cancer Nursing*, 21(5), 364–369.
- Lewis, F.M., & Deal, L.W. (1995). Balancing our lives: A study of the married couple's experience with breast cancer recurrence. *Oncology Nursing Forum*, 22(6), 943–953.
- Lin, H.R., & Bauer-Wu, S.M. (2003). Psycho-spiritual well-being in patients with advanced cancer: An integrative review of the literature. *Journal of Advanced Nursing*, 44(1), 69–80.
- Malloy, P., Ferrell, B.R., Virani, R., Uman, G., Rhome, A.M., Whitlatch, B., et al. (2006). Evaluation of end-of-life nursing education for continuing education and clinical staff development educators. *Journal for Nurses in Staff Development*, 22(1), 31–36.
- McClain-Jacobson, C., Rosenfeld, B., Kosinski, A., Pessin, H., Cimino, J.E., & Breitbart, W. (2004). Belief in an afterlife, spiritual well-being and end-of-life despair in patients with advanced cancer. *General Hospital Psychiatry*, 26(6), 484–486.
- Morse, J.M., & Carter, B. (1996). The essence of enduring and expressions of suffering: The reformulation of self. *Scholarly Inquiry for Nursing Practice*, 10(1), 43–60.
- Morse, S.R., & Fife, B. (1998). Coping with a partner's cancer: Adjustment at four stages of the illness trajectory. *Oncology Nursing Forum*, 25(4), 751–760.
- Northouse, L.L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., et al. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology*, 20(19), 4050–4064.
- O'Connor, A.P., Wicker, C.A., & Germino, B.B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing*, 13(3), 167–175.
- Paice, J.A., Ferrell, B.R., Virani, R., Grant, M., Malloy, P., & Rhome, A. (2006). Graduate nursing education regarding end-of-life care. *Nursing Outlook*, 54(1), 46–52.
- Potter, M. (2006). Loss, suffering, bereavement, and grief. In M.L. Matzo & D.W. Sherman (Eds.), *Palliative care nursing: Quality care to the end of life* (2nd ed., pp. 273–315). New York: Springer Publishing.
- Reich, W.T. (1989). Speaking of suffering: A moral account of compassion. *Soundings*, 72(1), 83–108.
- Welch, S.D. (2000). *A feminist ethic of risk* (revision). Minneapolis, MN: Fortress Press.
- Williams, B.R. (2004). Dying young, dying poor: A sociological examination of existential suffering among low-socioeconomic status patients. *Journal of Palliative Medicine*, 7(1), 27–37.