Original Articles

Ethical Perspectives on Pain and Suffering

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Abstract:

The field of Feminist Ethics can be applied to pain management to understand the perspective of both the patient and nurse. Three concepts derived from Feminist Ethics are applied to the care of people in pain including relationship, compassion, and respect. Through narratives of patients, nurses, and family caregivers this paper explores the experience of pain.
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This meeting of the American Society for Pain Management Nursing is the singular professional organization and annual meeting that brings together a national cadre of nurses committed to the relief of pain and suffering. You, as nurses attending this conference, likely have come to gain new information, to learn of new pharmacologic advances in the treatment of pain, to advance your understanding of the physiologic basis of pain, and to learn from model programs and nurse experts of the innovations in clinical care. However, coming to this national meeting in the company of like-minded spirits also affords the opportunity to pause and consider in a deeper sense what it means to be a patient in pain. Such an opportunity also allows us to pause to consider what it means to be a nurse who cares for a patient in pain.

I have devoted my entire career, which spans 28 years, to the areas of cancer practice, pain management, and palliative care. My career, much like many of yours, has seen amazing advances in the prioritization of pain in the healthcare system and the availability of treatments. Unfortunately, despite these major advances we are here today recognizing the serious undertreatment of pain that continues. As a part of my own continued learning, I began graduate studies in 2004 in the areas of Theology, Ethics, and Culture at Claremont Graduate University in the School of Religion. My hope was to gain insight and continued evolution of my own understanding of these complex phenomenan involving patients in pain or those facing the end of life. It is my hope that through this keynote address, I am able to share with you some beginnings of my evolving understanding of pain and suffering from an ethical perspective. Today I will apply essential ideas that I have gained through exploration of Feminist Ethics and application to the problem of untreated pain. It is my hope that when you leave this conference, you will have not only enhanced knowledge of treatment advances, but also a personal exploration of what it means to be a nurse committed to the relief of pain.

FEMINIST ETHICS

Nurses have been trained within their formal education largely through the paradigm of biomedical ethical principles. We acknowledge basic principles of

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1524-9042/$30.00
© 2005 by the American Society for Pain Management Nursing
doi:10.1016/j.jpmn.2005.06.001

a patient's autonomy and strive to see that patients can dictate their preferences for the treatment of their illness and the pain of their underlying illness. We promote patient autonomy in choice of treatments. Pain management has long supported the principle of beneficence, recognizing our obligation to provide care that benefits the patient and promotes good.

Pain management has become more technologic. We are often faced with treatment choices that have the ability to do good but potentially the ability to do harm such as in the case of invasive procedures or treatments with high toxicity. Thus, the principle of non-maleficence or avoidance of harm has become a part of the ethical practice in pain management. And amid the scarce resources of an intensely burdened healthcare system, we advocate for justice and the means of ensuring that all patients have access to treatment of their pain. Yet for many professionals, myself included, these principles are limited in their ability to guide ethical practice in pain management. Many healthcare professionals have turned toward alternative approaches to their understanding of ethics including the field of feminist ethics.

Feminist ethics provides a perspective of women's experiences and women's ways of knowing, being, and doing (Welch, 2000). The 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 those who argue to advance beyond traditional patriarchal domination and seek a way of examining the moral experiences and intuition of women. Feminist ethics addresses patterns of dominance and oppression and power structures that are a part of the tradition of health care and many other aspects of society (Tong, 1993). Very important, however, feminist ethics applies equally to care of men who are in pain and to male nurses who care for patients in pain. It is a philosophy and of way of thinking and doing, not limited to women.

THE MORAL CRISIS OF UNTREATED PAIN

Pain is described as an unpleasant sensory experience and is generally defined in neurophysiologic terms of nociception, pain transmission, and subjective response to injury (Agency for Health Care Policy and Research [AHCPR], 1994). However, over the past three decades, there has been a growing awareness that pain is more than a physiologic event. Pain is an intensely human experience impacting all dimensions of quality of life (Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991). Pain is often characterized as either acute or chronic based on its duration. Acute pain is associated with surgery, immediate effects of injury, or short-term illness. Chronic pain is associated with ongoing chronic disease such as painful diabetic neuropathy, pain of arthritis, headache, and other medical illnesses. Of special consideration has been the pain associated with terminal disease such as in the case of acquired immune deficiency syndrome or cancer (Cleeland, 1984).

Pain affects people of all ages, although it is more often associated with the elderly and the chronically ill. Although health care is a profession that has generally focused on the physical experience of pain, scholars in psychology, theology, and other disciplines have advanced the understanding of suffering. Suffering has been defined as the "threatening of the intactness of the person" and generally includes dimensions of spiritual distress and existential crisis (Cassell, 1982).

THE EFFECT OF UNRELIEVED PAIN AND SUFFERING

Increased attention to the problem of pain over the past two decades has helped to move thinking beyond pain as the outcome of injury and to explore the effects of pain on the individual. My work since 1984 has focused on the impact of pain on quality of life (Ferrell et al., 1991; Ferrell, Rhiner, Cohen, & Grant, 1991; Ferrell, Taylor, Sattler, Fowler, & Cheyney, 1993). Our conceptual model of pain and quality of life identifies four dimensions impacted by pain including physical well-being, psychologic well-being, social concerns, and spiritual well-being. In the domain of physical well-being, patients have described pain not as a single physical sensation, but rather through the complex effects such as a lack of sleep, fatigue, and other associated symptoms such as nausea or severe gastrointestinal distress from pain or pain medications.

In the psychologic realm, abundant literature has documented that people living with chronic pain experience psychologic effects such as anxiety, depression, and fear of future pain. In the social realm, literature has also demonstrated that people living with chronic pain do not experience the effects of pain in isolation. Rather, pain affects family caregivers and others surrounding the patient by increasing caregiver burden, interfering with sexuality, and greatly impacting roles and relationships. For many, pain becomes a family experience. In the spiritual well-being domain, pain is viewed as a spiritual crisis as patients experience hopelessness or a sense of abandonment, and undertreated pain causes the person to question

the meaning of life and in some situations to consider assisted suicide.

The dimension of spiritual well-being encompasses the religious, such as a sense of abandonment from God or a higher power. Often the expression of pain includes cultural dimensions or traditional perspectives such as the belief by many that pain is necessary or that pain brings one closer to God. Because pain is often associated with serious chronic illness or terminal illness, there is often a spoken or unspoken association of pain with death. For example, if a child is experiencing worsening pain, parents often interpret this as a sign that the child is worse and thus that the child may die sooner. Interestingly, this often results in parents denying that the child is in pain to avoid the reality that their child may be dying soon. Thus, pain has also been described as a metaphor for death (Ferrell, Rhiner, et al., 1991).

THE EVOLVING RECOGNITION OF PAIN AS A SIGNIFICANT HEALTH PROBLEM AND ETHICAL CONCERN

Major advances in health care began in the 1940s, such as the development of diagnostic techniques, surgery, antibiotics, and other treatments for serious illness. Pain was generally a short-term problem because people died rather quickly from serious illness in earlier years. However, advances in health care have meant that individuals now live for decades with chronic illnesses that are associated with pain. For example, women with breast cancer or ovarian cancer now have access to chemotherapy regimens such that they may live for years undergoing continuous treatment. However, the "advances" in health care have meant that individuals live in chronic and, unfortunately, unrelieved pain (Miaskowski & Dibble, 1995). Abundant literature has reached the consensus that people are generally significantly undertreated for pain (Ferrell, Novy, et al., 2001). Approximately 50% of patients with acute or chronic noncancer pain receive inadequate care, and as many as 90% of people with pain associated with cancer or other terminal illnesses are undertreated (AHCPR, 1994; National Institutes of Health State-of-the-Science Statement [NIHSSS], 2002).

PAIN AND SUFFERING

A major voice in recognition of the ethical perspectives on pain and suffering has been Dr. Eric Cassell. His classic article "The Nature of Suffering and the Goals of Medicine" was published in *The New England Journal of Medicine* initially, and later as a text (Cassell, 1982). Cassell contributed to the attention to the problem of pain and suffering. Cassell argued that there are four essential ideas related to patients who are in pain and who are suffering. The first is that "suffering is experienced by persons." He described the historical separation of mind and body and the limiting of personhood if we ignore the subjective context. Cassell suggested that understanding the place of the person in pain requires that we reject the historical dualism of mind and body. His second contention is that "suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration is past or until the integrity of the person can be restored in some other manner" (Cassell, 1982). This philosophy relates closely to the patient in pain who feels the underlying causes of the pain and the destruction of the body and spirit with enduring, unrelieved pain. Cassell has written about suffering beyond the physical. He defines suffering as "a state of severe distress associated with events that threaten the intactness of the person." Finally, Cassell states that suffering can occur in relationship to any aspect of the person.

Although Cassell's writing and perspectives have been directed toward the advancement of medicine, his work can be applied very closely to the profession of nursing. Nurses are intimately involved in the patient's care, often serving as the advocate for the patient in relation to their health care community and caring professionals.

Numerous scholars in feminist ethics have explored concepts that are relevant to the experience of pain. I have selected three central concepts derived from these theorists that I believe are most relevant to the understanding of nursing care of patients in pain. The concepts are respect, relationship, and compassion. Moving away from the bedside to explore these broad concepts allows us to "get higher on the mountain," and it is hoped in doing so nearer to the true experience of nurses caring for patients in pain.

NARRATIVE ETHICS

Feminist ethicists recognize the importance of the individual's story and life experience in understanding the phenomenon in its wholeness. Feminist scholars contend that we learn not only from quantitative, objective data, but rather we learn through an appreciation of the story or narrative of one. Across the past 20 years of my work as a nurse researcher in the areas of pain and palliative care, I have had the opportunity to apply the narrative approach through interviews of individual patients, family caregivers, and nurses, as well as through focus groups and my own clinical practice as a hospice volunteer and by interacting with

patients across my clinical studies. I have reviewed the publications that have been based on these clinical experiences and studied the narratives to try to synthesize a composite narrative for each of these three key perspectives in pain management. The composite narratives based on these stories will be presented in the analysis of these concepts.

RELATIONSHIP

The first concept central to nursing care of a patient in pain is that of relationship. Feminist ethics has articulated the belief that we are most fully human when we are in relationships. A traditional perspective of pain management is one in which the patient is viewed within a broad perspective, for example, within the context of a hospital or clinic. It is through deep reflection of the intimate relationship of nurses with patients and families that we may best grow in our understanding.

One of the most intimate portrayals of a person in pain was written by Elaine Scarry, a Professor of English. Her book, *The Body in Pain* (Scarry, 1985), explores the vulnerability of the human body in pain. Her metaphor of pain and language describes the person in pain as often silent in the ability to express this extreme emotion of pain. She says that pain "resists verbal objectification" (p. 12). Scarry describes the relationship of the sufferer and caregiver as the "model of certainty" in which the person in pain is absolute in her awareness and experience of pain while those external observers live in a "model of doubt," always questioning the person's pain. She says that, "To have pain is to have certainty; to hear about pain is to have doubt" (p. 13). Scarry's work illustrates that the patient is often doubted not only by professionals but also by their own family members.

Nurses hold an intimate place, perhaps a sacred place, in caring for a patient and family in pain. Nurses have the opportunity to "give voice" to pain and, thus, to suffering. Pain has been often described as a moral crisis, particularly given the vast chasm between our ability to relieve pain and actual practice. Nurses in the darkness of night at the bedside, in the isolation of a clinic room, or in the privacy of a patient's home enter into a relationship with a person in pain that offers the opportunity to listen, to hear, and to give voice to pain (Lisson, 1989; McCaffery, Ferrell, & Pasero, 2000; Raines, 2000). Nurses working in the field of pain management often devote more of their energies to family members than to the patient. Support provided to the family caregiver translates to their ability to support the patient in what is often a 24-hour/day commitment.

Of particular interest to me is the way nurses are present in these intimate encounters. A nurse may enter a patient's hospital room when summoned by the call light as the patient requests medication for relief of pain. The nurse may enter in a rush, distracted by the demands of the day, never fully present. Or the expert nurse who understands the place of the person in pain, the essence of the moment, and the complex dynamics intertwined in the request of "I am in pain. Can I have my medication?" may be fully present. Once in that presence, the nurse becomes more therapeutic than the next dose of medication. Nurses bring to the bedside personal histories as humans, as professional caregivers, and often as individuals with years of relationships with countless people who are in pain. How we integrate these cumulative experiences determines our presence in each subsequent relationship.

Feminist ethicists have exposed the power dynamics that exist in many relationships (Held, 1995). For even the most compassionate nurse, there is undoubtedly an overwhelming imbalance of power between the person in pain and the nurse summoned to relieve it (Greipp, 1992). Women, children, those who do not speak English, and any person with substance abuse history are historically identified as at risk for untreated pain. However, the clinical reality is that any person suffering severe pain becomes vulnerable and broken.

Carol Gilligan, a feminist scholar recognized for her pioneering work that challenged traditional understanding of moral development, has written about relationships in a way of great relevance to nursing (Gilligan, 1982). Gilligan's ethic of care emphasizes relationships and responsibilities. She suggests that those in caring relationships struggle to balance professional detachment versus intimate attachment and recognition of the self in that relationship. Caring relationships between nurses and people in pain and their family members require commitment, compassion, and presence. Nursing care of those experiencing or witnessing in pain is not just "doing for." It is "being with."

THE FAMILY CAREGIVER NARRATIVE/ THE WITNESS

"I am the spouse 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, 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 on occasion 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 feel that I am becoming the patient on many levels. 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. I stand in the bathroom, late at night as my wife has just completed another exhausting, tense day. 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."

COMPASSION

Caring for a person in pain requires compassion. This second concept selected from feminist scholarship recognizes that pain is a crisis event and that nurses as moral agents respond from a place of compassion. Compassion is to go with the person in pain, described by Farley as meeting the person in her pain and staying there with her (Farley, 2002). True compassion for the suffering becomes a spiritual act.

Sharon Welch, a Professor of Religious Studies and Women's Studies, wrote of "dangerous memories" as the recounting of stories of defeat and injustice and how recognition of past wrongs and injustices endanger the continued acceptance of injustice and "propel people to courageous acts of resistance" (Welch, 2000, p. 155). Welch writes of movements to correct injustice through communities of resistance. Nurses who speak for those in pain have asserted that pain can and should be relieved. Nurses, we who comprise this national association of pain management nurses, are potentially a community of resistance.

The Pulitzer Prize winning play Wit by Margaret Edson (Edson, 1993) presents a narrative of a nurse, Susie, caring for an English professor, Dr. Vivian Bearing, who has been diagnosed with ovarian cancer. The dynamics of the relationships in the play are complex. The story depicts dilemmas such as decisions about aggressive treatment and research-focused care contrasted with the intensely personal needs of a frightened, seriously ill woman whose life is assaulted by a devastating disease and treatment.

In one poignant scene, Susie (the nurse) enters Vivian's room late at night to discuss the issue of resuscitation out of her concern that Vivian may be subjected to the indignity of a futile resuscitation attempt as her life ends. Vivian's life as a reserved, detached professor is unraveling as she becomes a vulnerable, broken person subjected to indignity and an acute awareness of her likely death. In recognition of this reality, Vivian says:

> Now is not the time for verbal sword play, for unlikely flights of imagination and wildly shifting perspectives, for metaphysical conceit, **for wit**.
>
> And nothing would be worse than a detailed scholarly analysis. Erudition. Interpretation. Complication.
>
> Now is the time for simplicity. Now is the time for, dare I say it, **kindness**.
>
> I thought being extremely smart would take care of it. But I see I have been found out (p. 69).

In the next scene, Vivian awakens in severe pain. She explains to the audience:

> I want to tell you how it feels. I want to explain it, to use *my* words. It's as if . . . I can't . . . There aren't . . . I'm like a student and this is the final exam and I don't know what to put down because I don't understand the question and I'm *running out of time.*
>
> The time for extreme measures has come. I am in terrible pain. Susie says that I need to begin aggressive pain management if I am going to stand it.
>
> "It": such a little word. In this case, I think "it" signifies "being alive."
>
> I apologize in advance for what this palliative treatment modality does to the dramatic coherence of my play's last scene. It can't be helped. They have to do something. I'm in terrible pain.
>
> Say it, Vivian. *It hurts like hell. It really does.*

To be compassionate is to be fully human. To be compassionate for the other in pain is to recognize the emotions of the person in pain, the family witness, and the nurse. This is not to avoid thinking or reason; rather compassion has cognitive value. Held (1995) described compassion as a means of thinking about moral action.

THE NURSE

"I am the nurse who cares for the patient in pain. I became a nurse to make people better, to restore people to wellness. Wanting to be a nurse, I learned

that the goal of my profession was to restore and renew, to solve problems, relieve symptoms, and to repair the broken. And yet early in my career, I realized that it is seldom that we do those things. Despite the advances of technology and science, people increasingly live with chronic and life-threatening illness. To care for people is to care for those for whom illness and pain become a part of the fabric of their being. We care for diseases, tumors, medication's side effects, and yet at the heart of it all, we care for people, persons, humans. People who live with chronic or life-threatening disease, often live in a state of pain. I am reminded of how seldom pain is only physical and how important is the combination of treatments for body and soul. I am the advocate for my patients in pain. I speak their pain and push the patient to expect a degree of pain relief. I am taught to accept pain as what the person says it is, existing when he or she says that it does. It is this focused intention that allows me to advocate loudest for the underserved, the poor, the homeless, and those whose life-histories include substance abuse. I have taken an oath to serve my patients and to avoid harm. And yet, with each dose of medication I pour, with each assessment within the privacy of a patient's home, I am challenged to provide the best of care with the least of harm. There is much I have to learn. How do I respond to the pain? Did I recognize the spiritual crisis? What can I do to help the patient receive control of pain? Within the course of the day, I am reminded of how much of my time is spent on the problem of pain. I am at the bedside assessing pain and encouraging the depleted, frightened woman to aggressively seek help for her pain. I am at the bedside of my patients who, despite agonizing pain, wish to avoid medication for fear of clouding their final days. I have spoken to patients, even those at the end of their lives, who are so consumed by the fear of addiction that they opt to live in pain. Yet I have seen so many times what happens when pain is relieved. Patients want to live again. Silences are broken. Patients and their families resume living. There are days when I feel I have performed a miracle. Imagine that—relieving pain. At the core of my being, I know that to relieve pain is what it means to be a nurse."

A powerful contribution to feminist scholarship is the book by Melissa Raphael, a lecturer in Theology and Religious Studies at the University of Gloucestershire, titled *The Female Face of God in Auschwitz* (Raphael, 2003). This feminist theology of the Holocaust challenges the notion of the hiddenness or absence of God in the Holocaust by examining women's experiences in Auschwitz. Raphael graphically describes women as the face of God as they cared for the bodies of the ill, the dying, and those most devastated by the unimaginable conditions of imprisonment. Raphael describes the touch of these women and their attempts to cleanse and comfort the dying and suffering as kindnesses of an ethic of care but also symbolic of women's restoration of the human and, therefore, the divine. Perhaps nurses are the face of God in pain.

RESPECT

The third concept derived from the work of feminist ethicists is that of respect. With confidence, I can assert that every nurse in this room and every nurse committed to pain is familiar with the definition of pain introduced in 1968 by the "godmother" of nursing care of patients in pain, Margo McCaffery. Her definition, "Pain is what the person says it is and exists whenever he or she says it does" (McCaffery, 1968), has revolutionized the field of pain management. Prior definitions of pain provided only physiologic perspectives and defined pain from the tissue level, not the human level. McCaffery's contribution is often recognized as providing a clinically relevant, simple definition. Far more important, McCaffery's definition challenged the field of pain management in a way similar to the feminist scholar Gilligan's questioning of moral development (Gilligan, 1982). McCaffery's admonition that "pain is what the person says it is . . ." was also a different voice. This nursing voice spoke of pain as personal, as individual, and of the patient as expert. McCaffery was laying a foundation for *respect* of people in pain.

Feminist scholar and theologian Katie Cannon wrote the text *Womanism and the Soul of the Black Community* (Cannon, 1995). Cannon has explored a deeper level of feminist scholarship in her writings of black feminism, described by author Alice Walker as "Womanist is to feminist as purple to lavender." Walker is known for her portrayal of African American women in her book *The Color Purple*. Walker helps portray the issues of not only women, but women who are further disadvantaged due to the ethnicity or economics.

Cannon's discourse on the plight of black women includes vivid descriptions of pain and suffering endured in the era of slavery. Cannon writes of physical abuse of women as slaves in questioning, "What are the emotional resources for dealing with forgotten memories that lie dormant in our bodies and therefore our souls" (Cannon, 1995, p. 75). She concludes that having no language to carry the memory of suffering is the final devastation.

In recent years, nurses have advocated for the need for improved pain relief for the most vulnerable in society—the poor, the elderly, women, children, and diverse communities. Pain is a problem society wants to avoid. Nurses have the ability to speak of pain and its consequences. As Cannon wrote, "The womanist voice is one of deliverance from the deafening discursive silence that the society at large has used to deny the basis of shared humanity" (Cannon, 1995, p. 127).

Recognition of pain as a deeply human experience, more than a neurologic phenomenon, is a critical step toward a social recognition of its urgency. Feminist scholars have challenged traditional perspectives and recognized the value of women's experiences, women's ways of knowing, and women's ways of being and doing (Tong, 1993; Welch, 2000). These feminist ways of knowing provided a much better lens than traditional thought in understanding the experience of pain.

Jaggar, a feminist ethicist and philosopher, has written extensively of the role of emotion in understanding (Jaggar, 1989). Recognition of the intense emotions of pain (fear, anxiety, powerlessness, anger, and depression) is essential if we are to recognize the full impact of the pain experience. Jaggar contends that emotions bring us closer to the truth because emotions are not only a way of feeling but also of knowing. Jaggar writes of "outlaw emotions," those which are unacceptable by society. This is applicable to the plight of women in pain, particularly women experiencing pain from chronic noncancer causes, who are often further alienated from their caregivers when they express emotions.

Of special significance in application of the work of feminist ethics to the problem of unrelieved pain has been work by Margaret Farley, a professor of Christian ethics and a Catholic lay woman (Farley, 2002). Farley contends that medical ethics has emphasized the autonomy of patients while neglecting social contexts and responsibilities. Farley challenges us to combine compassion with our duty to be merciful, to be just, and to act. Her work also challenges us to avoid a paternalistic notion ("I will relieve your pain") and instead through our compassionate respect we mobilize the patient and family. She writes:

> The point is that suffering in some form, great or small, overwhelming or overcome, has the power to grasp us when we see it in others. It has the power to hold us so that we cannot avoid the reality of the sufferers or the reality of ourselves. Insofar as we genuinely behold it, it awakens in us a moral response—to alleviate it, ameliorate it, prevent it in others, or if none of this is possible, to companion and literally "bear with" the sufferer, in love and respect (p. 41).

Farley wrote of the disparity of a healthcare system that has neglected persons with acquired immune deficiency syndrome and other life-threatening diseases. She proposed the notion of "Compassionate Respect," aligning these two concepts while also contrasting their unique meanings. She states that "compassion requires at its core not only love but truth—not only the passion of compassion but the truth that compels respect" (p. 20). She explains that these concepts are "mutually illuminating" and that compassionate respect means compassionate justice and provides a framework for medical ethics by "requiring care to be respectful of embodied autonomy as well as every level of need in the person to whom care is owed" (p. 43).

THE PATIENT NARRATIVE

"I am the voice of the patient in pain. I am a 40-year-old woman who has been transformed from a soccer mom, room mother, and teacher to the terrified woman with ovarian cancer. A month ago amidst the chaos of my daily life, I experienced symptoms. Pressure, burning, bloating, tenderness, all sensations of pain, and yet no one listened. The more that my complaints fell on deaf ears, the more I questioned their reality. They say that ovarian cancer is a 'silent killer.' My symptoms were not silent. It is simply that no one would listen. It is devastating enough to be facing a life-threatening disease, but it is a greater insult to live in pain. What I have learned so far is that pain is not a symptom; it is a way of being. To be in pain means to become dependent, to be exhausted, to never sleep. Pain is an emotion combining anxiety, depression, fear, and distress into one overwhelming state of being. Yet the more emotional I become, the more likely it is that my pain will not be listened to. There are moments I doubt myself and question what is real. Pain is taking over my family, not just my life. I see my pain in my family's eyes and feel that I am letting them down. There is an unspoken message between us that if my pain is worse, I must be worse. Even imagining that death will come sooner gives me every reason to now join the conspiracy that silences my pain. I am walking a delicate tightrope in which part of me thinks I must aggressively treat the pain with medications, specialists, and all means because surely there is a way to relieve this terrible state of pain. I balance those moments of symptom control with a cascade of fears. I fear I'll become addicted to the pain medication. I fear that if I take the medications now, nothing will help me later. I fear giving into the pain. Yet with every day of unrelieved pain I feel more depleted and unable to advocate for myself".

"I go to the clinic and anxiously await the results of the latest scan or laboratory work. In the stillness of the examination room, the physician will reveal my destiny. I am in intimate connection with the nurse. The nurse asks about my pain, first by asking me to "give a number." How does one begin to describe a pain of 15 on a scale of 0 to 10? Which pain is it that you want to know about? Is it the pain in my belly; the pain in my soul; the pain in my family's face? But in your asking, I feel humbled, valued, acknowledged. And I believe that despite your hectic day, you have paused to recognize me as a person living not only with a dreaded disease but living in pain. You are my voice."

CONCLUSION

The experience of pain is an overwhelming, whole-person experience with devastating effects on the experiencing person, the family witness, and the nurse. Reflection on the meaning of pain and the meaning of nursing's responsibility to respond to pain is a challenging endeavor. We are guided by essential concepts of respect, relationship, and compassion through an ethical perspective of feminist scholars. It is through a deeper view of pain as Alice Walker might say, "moving from lavender to purple," that we may become the fullest of professionals and moral agents providing relief of pain and suffering.

Acknowledgment

The author acknowledges the advice and support of Dr. Ellen Marshall, Claremont Graduate University. Also this paper was presented as the keynote address at the ASPMN annual meeting in April, 2005.

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