

Understanding the Moral Distress of Nurses Witnessing Medically Futile Care

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This article has been chosen as being particularly suitable for reading and discussion in a Journal Club format. The following questions are posed to stimulate thoughtful critique and exchange of opinions, possibly leading to changes on your unit. Formulate your answers as you read the article. Photocopying of this article for group discussion purposes is permitted.

1. How often does this unit face a patient care situation we could label as morally distressing?
2. Focus on one case example (either a real-life example or a composite case study devised by the group leader).
 - a. What were the issues?
 - b. What strategies worked, and what made the situation worse?
 - c. What were the outcomes?
 - d. Are different points of view being expressed? Can the differences be resolved?
3. What strategies do we use as a unit to discuss troubling situations at work?
4. How might we improve on those strategies?
5. Identify workplace resources for assisting staff and patients when morally distressing situations arise.

At the end of the session, take time to recap the discussion and make plans to follow through with suggested strategies.

Purpose/Objectives: To explore the topic of moral distress in nurses related to witnessing futile care.

Data Sources: Literature related to moral distress and futility; analysis of narratives written by 108 nurses attending one of two national continuing education courses on end-of-life care regarding their experiences in the area.

Data Synthesis: Nurses were invited to share a clinical situation in which they experienced moral distress related to a patient receiving care that they considered futile. Nurses described clinical situations across care settings, with the most common conflict being that aggressive care denies palliative care. Conflicts regarding code status, life support, and nutrition also were common. Patients with cancer were involved quite often, second only to geriatric patients and patients with dementia. The instances created strong emotional responses from nurses, including feeling the need for patient advocacy and that futile care was violent and cruel. Important spiritual and religious factors were cited as influencing the clinical experiences.

Conclusions: Instances of futile care evoke strong emotional responses from nurses, and nurses require support in dealing with their distress.

Implications for Nursing: The ethical dilemma of futile care is complex. Additional research and support are needed for patients, families, and nurses.

Key Points . . .

- ▶ Issues of medical futility have arisen as healthcare technology has made life-prolonging treatments possible.
- ▶ Nurses experience moral distress when they witness care that they consider futile.
- ▶ Nurses require emotional and spiritual support in instances of moral distress arising from futile care.

with growing concern regarding healthcare resources have brought attention to the social, legal, and ethical issues surrounding medical futility. Much less attention has been focused on the human impact on nurses caring for patients for whom they believe treatment is futile. Discourse in the field of ethics has begun to recognize that participation in medically futile efforts undermines the core of nursing practice and creates moral distress that is destructive to individual nurses and to the profession (Daly, 1994). The purpose of this article is to explore more fully the impact on nurses

Medical futility, defined as life-sustaining care that is highly unlikely to result in meaningful survival, has become a topic of increased attention (Brody, Campbell, Faber-Langendoen, & Ogle, 1997; Callahan, 2003). Prominent cases depicted in the media combined

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of witnessing treatment deemed to be futile. The nursing perspective of medical futility is explored through literature review and use of narratives provided by 108 nurses.

Understanding the Moral Distress of Nurses Witnessing Medically Futile Care: Case Example

A 36-year-old female physician was transferred to an intensive care unit (ICU) from a medical oncology unit in an urban hospital. The brilliant, young female physician had just begun her career when she was diagnosed with leukemia. After an initial, difficult course of intensive chemotherapy, the patient experienced a remission. The healthcare professionals and her family had great anticipation that she was cured of her disease. The wonders of medical science and the best that cancer care could offer had resulted in success. Unfortunately, just when life seemed to be back in order, the patient experienced recurrent disease. Hospitalized, the patient began an intense downward spiral. The leukemia clearly was ravaging her body, she had no response to treatment, and she began to have multiple organ failure.

The patient was admitted to the ICU and experienced extensive cardiac, pulmonary, liver, and renal complications during the following two weeks. Although the patient's physical condition declined and she developed complications that even the best of medical science could not reverse, her family members, all devout Catholics, maintained incredible hope that a miracle would occur. Her attending physician, likely influenced by the emotions of the very hopeful family and the dynamics involved in caring for a physician colleague, also seemed to be denying the reality of the patient's declining status. The physician, a Mormon, was known by the staff as a deeply religious man and someone often uncomfortable with dying patients.

The nurses were keenly aware that the treatment they were providing was futile. The prognosis was not questionable; an objective assessment of the patient's status by any professional would have concluded that the patient was experiencing multiple organ failure, that medicine had no chance of reversing the course of the devastating disease, and that the continued ventilator support and other medical treatments were only prolonging her inevitable death. The ICU nurses described the treatment with terms such as "torture," "violence," and "cruelty." Nurses often discussed their own religious views on the treatment. Each day, the physician would make rounds and encounter the hopeful family, always holding on to the possibility that a miracle would occur today or that the physician would have yet another treatment to try. The course of aggressive treatment was continued, and, as the physician left each day after making rounds, the nurses realized that once again they would devote the day to providing futile treatment. The nurses' outward emotions of anger and frustration were symptomatic of deeper moral distress.

The Historical Context in Which the Problem of Medical Futility Arises

Since 1970, unprecedented advances in medical technology have occurred. Science and medicine have developed

unimaginable treatments, such as the use of ventilator support of respirations, advances in antibiotics and other pharmacologic agents, the ability to perform diagnostic and therapeutic procedures, as well as advances in chemotherapy, blood transfusion, and organ transplantation (Ahronheim, Morrison, Baskin, Morris, & Meier, 1996; Callahan, 2003). It has been a time of "Star Wars" medicine, in which many conditions and illnesses that previously were considered fatal now are deemed manageable and, in many instances, curable.

The cumulative effect of the technologic advances has been that consumers, as well as healthcare professionals, believe that death can be avoided (Angus et al., 2004). The technologic advances have meant that life can be sustained and death avoided in many instances. However, one resulting dilemma is that the physical lives of individuals often are sustained far beyond the point of meaningful quality of life. Callahan (2003) wrote "Living and Dying With Medical Technology" and challenged healthcare providers to establish a "meaningful tension" to balance the aim of preserving life and making peaceful death possible.

Social Expectations

As a result of the advances in science and medicine, the American public has come to believe in "the miracles of medicine." The era of intense media influence means that each day the public sees images of Lance Armstrong, actors, politicians, and other public figures who have overcome extreme odds to survive and thrive beyond serious illness. Ethicists have articulated the very subjective nature of the concept of medical futility. Daly (1994) wrote of the complex nature of decisions regarding life-sustaining treatment, requiring considerable thought by healthcare providers before approaching families to make decisions.

Issues of futility have varying meanings in a personal context for patients and families and raise significant emotional responses and frustration by staff (Alspach, 1997). Nurses and other healthcare professionals should recognize that their perspectives on the best treatment decisions are based on years of experience and education, whereas most patients and families are facing life and death decisions with little or no previous information or experience.

Legal Implications

Often cited in discussions of medical futility is a fear of lawsuits among healthcare professionals. "Defensive medicine" is described as a tendency to do all that is possible for fear of being thought of as neglectful or of providing inadequate care (Camunas, 1997). Thus, physicians encountering patients in an emergency room and oncologists caring for patients with cancer are very likely to err on the side of doing more than necessary rather than possibly being accused of providing less care than was available. Once aggressive therapy is introduced, such as placing a patient on a ventilator, the discontinuation of that therapy becomes a highly complex act also fraught with legal implications (Ahrens, Yancey, & Kollef, 2003). The defensive approach generally is attributed to medical care, but nurses also may be inclined to do all that is possible or support aggressive care out of legal concern.

Professional Distress

Two physician leaders in the field of critical care, Curtis and Burt (2003), wrote a thoughtful commentary titled “Why Are Critical Care Clinicians So Powerfully Distressed by Family Demands for Futile Care?” The authors challenged the usual rationale for moral distress in staff, including protection of patients, avoidance of care that clinicians would not choose for themselves, and conservation of financial resources. They suggested instead that staff distress is related to distrust by families who decline staff recommendations to withdraw care and a feeling that administering care believed to be unlikely to succeed is seen as infliction of physical abuse on dying people. The authors advocated for further exploration of staff distress to advance understanding of medical futility.

Nurses consistently have identified issues related to futile treatment as among the most stressful aspects of critical care. A survey by Beckstrand and Kirchoff (2005) included responses from a national, random sample involving 864 critical care nurses. When asked to identify the most common obstacles to good end-of-life care, among the highest rated obstacles were disagreement about direction of dying patients’ care, actions that prolong patients’ suffering, and physicians who were evasive and avoided conversations with family members. Nurses also perceived family factors, such as lack of understanding about care, nonacceptance of poor prognoses, and overriding patients’ advance directives, as significant obstacles.

Effective communication between healthcare providers and families often is cited as key to resolving conflicts regarding goals of care. Ahrens et al. (2003) reported results of a study of 43 patients who received care by a “communication team” of a physician and RN focused on facilitating family communication as compared to 108 patients receiving usual care. Patients in the communication intervention group had shorter ICU stays, shorter hospital stays, and lower costs.

A similar survey published by Puntillo et al. (2001) involved 906 critical care nurses. Thirty-four percent indicated that they sometimes had acted against their consciences; 6% had done so to a great extent. Meltzer and Huckabay (2004) evaluated the relationship between nurses’ perceptions of futile treatment and their effect on burnout. The study, involving 60 critical care nurses, concluded that the frequency of morally distressing situations regarding care perceived as futile or nonbeneficial had a significant relationship with nurses’ emotional exhaustion.

One of the few surveys on the topic conducted in oncology nursing (Ferrell, Virani, Grant, Coyne, & Uman, 2000) reported data from 2,333 nurses regarding end-of-life care. Nurses reported discontinuing life-sustaining therapies and withholding or withdrawing nutrition or hydration as common end-of-life care dilemmas. Avoidance of death by family members or healthcare professionals was cited as a barrier to effective care.

Another survey included three children’s hospitals and four general hospitals with pediatric ICUs (PICUs) in eastern, southwestern, and southern parts of the United States. The population-based sample was composed of attending physicians, house officers, and nurses who cared for children (aged one month to 18 years) with life-threatening conditions in PICUs or in medical, surgical, or hematology/oncology units. A total of 781 clinicians were sampled: 209 attending

physicians, 116 house officers, and 456 nurses. Fifty-four percent of house officers and substantial proportions of attending physicians and nurses reported, “At times, I have acted against my conscience in providing treatment to children in my care.” Thirty-eight percent of critical care attending physicians and 25% of hematology/oncology attending physicians expressed those concerns, whereas 48% of critical care nurses and 38% of hematology/oncology nurses did so (Solomon et al., 2005).

Scarcity of Resources: Issues of Justice

An interesting dichotomy exists in that at the same time the healthcare system has developed expensive, highly technologic, life-sustaining treatments, a major healthcare financial crisis is occurring. While costly therapies are used with greater frequency, the same healthcare systems are challenged by millions of citizens who are denied access to basic health care. For example, on the same day that the patient described in the case earlier was receiving treatment with likely costs in the range of \$10,000–\$15,000 per day, the same medical center was undoubtedly in a position to decline admission to poor women newly diagnosed with breast cancer who had no resources to pay for their care. Such delay in treatment translates to women having much poorer prognoses. Nurses cite issues of social justice as a part of their distress, particularly in communities serving the poor (Brinker & McCauley, 2002; Campbell, 2002; Corley, 1995).

Theologic Issues Related to Moral Distress and Futile Treatment

Increasingly, people are recognizing that serious illnesses, particularly illnesses such as cancer that likely might result in death, include a strong spiritual dimension (Borneman & Brown-Saltzman, 2006). Patients and families who face decisions regarding the end of life are influenced by many factors related to their own religious and spiritual experiences (Baggs & Schmitt, 1995; Eschun, Jacobsohn, Roberts, & Sneiderman, 1999). In the case described earlier, theologic issues arose, such as belief by the patient and family that God would prevail and a miracle would occur. The Mormon religion of the attending physician and the faith of the patient and family, who came from a very strong Catholic tradition, undoubtedly played a vital role in the dynamics that occurred. Other theologic issues related to questions of futility include the essential meaning of life and death, the meaning of hope, and the sanctity of life (Kumasaka & Miles, 1996; Nelson-Marten, Braaten, & English, 2001).

Conflicts involving religious beliefs may result in distress for nurses. An example of conflict frequently cited in the literature related to futility is the instance of patients or families seeking continued aggressive treatment based on belief in miraculous healing when their healthcare providers have determined such treatment to be contrary to personal and professional ethical behavior (Badger, 2005; Schneiderman, Jecker, & Jonsen, 1996).

Soelle (1975), a theologian, wrote a text on suffering in which she described mute suffering as “reducing one to a silence in which no discourse is possible any longer, in which a person ceases to be a human agent” (p. 68). Her work is applicable to patients who suffer as they become powerless and vulnerable

and to the moral distress of nurses who feel powerless and vulnerable as they witness treatment they believe to be futile.

Ethical Issues

Ethical issues of medical futility have been addressed primarily through a biomedical ethics paradigm emphasizing concepts such as autonomy, beneficence, nonmaleficence, and justice. The paradigm may be useful in analyzing clinical cases but is insufficient to explore the related moral distress of nurses (Ferrell, 2005).

Feminist scholars have provided an alternative paradigm in advocating for an ethic of care and applying concepts such as nurturance, compassion, and communication (Tong, 1993; Welch, 2000). Feminist ethicists have acknowledged issues of power and domination (Tong) that can be applied to the domination of medical technology in disempowered, vulnerable patients. Feminist ethics also offer a greater appreciation for the individual experience rather than an established template for ethical decision making.

Use of narrative and qualitative analysis is consistent with feminist scholarship (Gilligan, 1982). Telling of stories by nurses, as depicted in the narratives to follow, illustrates the value of understanding caring relationships, compassion, and presence. Farley (2002) wrote of moral agents, such as nurses, responding in a place of compassion and being fully present for people experiencing severe illness. Welch (2000), a scholar in women's studies and religion, wrote of those who act on instances of injustice by creating communities of resistance.

Several feminist scholars and ethicists have used the metaphor of language to describe moral distress in the disempowered. Cannon (1995) spoke of black feminism and the importance of moral agents in giving voice to those silenced. Farley (1990) wrote of the silencing of those whose voices are dominated by others. She referred to radical suffering, which she said has "the power to dehumanize and degrade human beings" (p. 12). Farley (1990) contended that compassion can be empowering: "Compassion labors to make whole human beings out of broken ones" (p. 87).

Nursing Narratives Regarding Moral Distress and Futility: Ethical Perspectives

To explore nursing perspectives of this ethical concern, the author applied qualitative research methods through analysis of written surveys of nurses participating in two end-of-life nursing education courses in October 2005. The first course was in Pasadena, CA, and the second was in Washington, DC. Both courses were part of the End-of-Life Nursing Education Consortium, a three-day, intensive training program for nurses in end-of-life care. One hundred twenty-three nurses attended the first course, and 149 nurses attended the second. During the opening session of the two training programs, nurses were invited to participate in a journaling activity related to ethical issues in end-of-life care. A written survey was distributed, and the nurses were asked to complete it that evening and return it the next morning. Nurses were informed that the activity was voluntary, although they were encouraged to participate as an example of using journaling to express their experiences.

The survey was a single page, including a space to indicate whether they granted permission for their examples to be used in research and publications or as examples for future training programs. At the first course, 75 of the 123 nurses completed the survey; of them, 51 indicated their permission to share their narratives. At the second course, 75 of the 149 participants completed the survey; of them, 57 provided consent for their narratives to be used. Thus, a total of 108 nurse narratives were included in the analysis. The narratives varied in length but averaged approximately one page when typed single spaced.

The survey was titled "Moral Distress and Futility" and initially consisted of two parts: Please describe a distressing clinical experience you have had as a nurse when you witnessed care that you would describe as futile. How do you believe this experience affected you as a nurse?

Initial review of the survey responses revealed that, although the narratives were excellent, depictions of instances of moral distress and theologic elements were not cited frequently, and the nurses reflected on the experiences only from an individual perspective, rather than considering the impact on the profession of nursing. Therefore, prior to the second course, the survey was changed slightly. The first part remained the same, but the second was altered and a third added. The questions were: Please describe a distressing clinical experience you have had as a nurse when you witnessed care that you would describe as futile. How do you think this experience affected you as a nurse? How do these experiences affect the profession of nursing? Were there spiritual/religious factors influencing this clinical situation or your response to it?

Demographic data were not collected separately for the survey but were extracted from participant applications for the course. Data indicated that approximately 31% of nurses had baccalaureate degrees, 32% had master's degrees, and 36% had associate degrees. Approximately half of the attendees worked in acute care hospital settings, one-third in hospice, 15% in universities or schools of nursing, and 10% in other clinical settings.

Methods Used for the Analysis of the Narratives

The first step of the content analysis process was to enter the narratives into a word processing program for use in extracting examples and analyzing the data. Each narrative was typed with an identification number attached to ensure that the responses across questions remained intact for each nurse. The narratives were coded to identify the setting in which the conflict occurred (e.g., ICU, hospital inpatient setting, home), the type of conflict (e.g., withdrawal of life support, nutrition, hydration), those involved in the conflict (e.g., nurse, physician, patient, family member), cultural factors identified as influencing the clinical experience (e.g., patient ethnicity), spiritual or religious factors identified, the patient's diagnosis, and the nursing response or emotion.

The author coded each narrative to identify quantitatively the elements of the experience of moral distress as well as to obtain qualitative examples. A summary table was created using the quantitative coding to describe the experience of moral distress. The author's coding was reviewed by a nursing colleague with expertise in palliative care and ethics and by her faculty advisor, whose expertise included feminist ethics

and theology. The data are described in the following section and depicted in Table 1. The second aspect of the process was to select the most meaningful excerpts (see Figure 1).

Description of Instances of Moral Distress

The primary setting of care was the inpatient hospital unit, followed by the intensive care setting. Other settings included the emergency room, hospice, extended or long-term care, outpatient setting, and operating room. The distribution of settings is not surprising because they represent areas with a high degree of technology and focus on prolongation of life.

However, the instances did not occur only in an intensive care environment but across settings of care.

Table 1 also describes the conflicts as identified from the nurse narratives. The most common was “aggressive care.” Nurses described the consequence of patients receiving aggressive care deemed futile to be that patients were denied palliative care. The nurses described how patients in an ICU, on a ventilator, or separated from family did not have the opportunity to die peacefully at home surrounded by loved ones, free of pain, receiving palliative care focused on their physical and spiritual needs. The conflict of “aggressive care denying palliative care” was by far the most predominant.

Table 1. Characteristics of Cases Identified

Characteristic	n	Characteristic	n
Setting		Disease or Patient Group	
Inpatient	49	Geriatric patients or those with dementia	40
Intensive care	35	Cancer	37
Outpatient	7	Dialysis or renal disease	9
Emergency room	6	Cardiac	8
Hospice	4	Pediatric	6
Extended care or long-term care	4	Pulmonary	5
Operating room	2	AIDS	4
		Stroke	3
Conflict		Trauma	3
Aggressive care denying palliative care	41	Diabetes	2
Code status or resuscitation	20	Amyotrophic lateral sclerosis	1
Ventilator or life support	17	Neonatal intensive care unit	1
Nutrition, hydration, or feeding tube	17	Multiple sclerosis	1
Chemotherapy	9	Mental illness	1
Pain management	8		
Dialysis	5	Nursing Response and Emotions Identified	
Violation of patient decision	5	Advocacy	32
Blood transfusion	4	Torture, assault, violence, or cruelty	16
Physician dishonesty	3	Frustration	13
Diagnostic procedure	2	Distressed	11
Research participation	1	Anger	11
Neglecting to treat	1	Career change to palliative care	9
Surgery	1	Demoralized, powerless, helpless, or hopeless	9
		Cost concern	6
Those Involved in Conflict		Felt supported or growth	6
Physician, patient, family, and RN	39	Supporting patient or family choice	6
Physician, family, and RN	14	Guilt, failure, or failed the patient	5
Physician and RN	13	Refer to ethics committee	4
RN, RN, and family	6	Sorrow	4
Physician and family	5	Fearful or awareness of own mortality	2
Family and RN	4	Difficulty defining futility	1
Family members	4	Aware of own mortality	1
Patient and RN	2	Felt betrayed	1
Physician and patient	2	Uncertainty	1
Family and patient	1	Felt spiritual support	1
Physician and physician	1	Positive experience of aggressive treatment	1
Physician, family, RN, and RN	1	Care was demeaning	1
Family, patient, and hospice	1		
		Nursing Profession's Response to Futile Care	
Culture		Divides physicians and RNs	4
Ethnicity	8	Diminishes nursing	1
Poverty or homelessness	2	RNs lose sight of the goal	1
Spiritual Issues			
Patient, family, religion, or spirituality	31		
Nurse's religion or spirituality	12		

N = 108

A number of other conflicts also were described, including use of a ventilator or life support, code status and resuscitation, nutrition and hydration, and blood transfusions. Examples were given of patients being denied pain management,

futile use of chemotherapy or dialysis, and use of surgery or diagnostic procedures, all of which were deemed to be futile. Table 1 depicts the various combinations of the individuals involved in the conflicts identified through the narratives.

“My first experience with death, as a new nurse, was a frail man who came into the intensive care unit (ICU) after he coded at home. The patient coded again shortly after his arrival in the ICU. As I mentioned before, this patient was very frail, emaciated, and his body was a bright yellow-orange. The doctor in the unit was a young intern. He led the code. It was evident to all the nurses on the unit the code should have been called. But the intern insisted on continuing. By the time he called the code, there were many ribs broken. The memory of that patient has been etched in my mind since 1972. That was when this incident occurred.”

“Seventy-two-year-old female with new diagnosis of lung cancer. Offered surgical excision of cancerous lung lobe. Pulmonary function tests prior to surgery indicated that respiratory function after surgery would probably be inadequate, requiring ventilation. Patient’s husband insisted on surgery anyway, and patient remained ventilated in ICU for three weeks after surgery. The patient was awake and sitting up in chair for one hour when she went into acute respiratory distress. At the bedside (I was a student nurse at the time), the patient grabbed my hand and pleaded, ‘Please just let me go. . . . Please just let me go.’ The medical residents arrived, reintubated the patient, inserted the nasogastric tube, which went into the patient’s lungs and resulted in frothy bloody discharge from the mouth and nose. The patient remained sedated and ventilated in ICU another two weeks before dying.”

“Mrs. Z is a 66-year-old woman with a diagnosis of pancreatic cancer. She was diagnosed approximately one year ago and underwent multiple chemo regimens. The most recent was 10 weeks ago, and she developed severe dehydration requiring hospitalization. The cost of this treatment is very expensive—\$5,000 per month—the machine is \$22,000. Patient calls me ‘the torturer’ and ‘Nurse Rachel.’”

“I worked as an oncology RN in the ICU at a renowned cancer research hospital in 1982. I took care of a 28-year-old man who was being treated for non-Hodgkin lymphoma. He was engaged to be married. Within one week after I met David, he experienced a medical crisis and was placed on a ventilator. He remained in the ICU on a ventilator for four weeks as I watched him continue to deteriorate. The doctors approached his fiancée and parents to permit further chemotherapy or a new research protocol to hopefully delay the disease’s progress or to provide David with more comfort and/or his parents with more hope for a recovery. He did receive treatment via the new research protocol but received little relief for his pain, discomfort, anxiety, spiritual distress, etc. Finally, by the grace of God, David died, after spending five weeks in the ICU. David died on my watch as my patient, and I was so relieved to have him finally die.”

“I’ve been a nurse for 30 years, 25 of which have been focused on quality end-of-life care. I see more ‘suffering’ today than I did 25 years ago. Our technology has surpassed our humanity, and our current focus on ‘technological brinksmanship’ has increased costs while decreasing quality of life. As a nurse who has seen numerous ‘deaths’ that occurred peacefully and gently, I am always saddened when I see one that isn’t. I think it’s extremely hard on nurses when all of our life experiences and lessons learned from these dying can’t make an impact.”

“A 43-year-old mother of an eight-year-old with a malignant brain tumor had extensive treatment radiation and CyberKnife® [Accuray Incorporated, Sunnyvale, CA] over three years. She was admitted to hospice with uncontrolled seizures. She made a beautiful living will while in the hospital. She continued to deteriorate over the next few weeks. Her oncologist kept giving her parents and husband encouragement that more radiation would help, etc., and talked them into a feeding tube, which was much against her living will. In the final days, we were

suctioning secretions and tube feeding. It was a violation of her wishes, near assault in my opinion. A horrible, smelly way to pass, most undignified.”

“The patient had metastatic kidney cancer, sepsis, thrombocytopenia purpura, and was end-stage. But he was 58 years of age, a healthy man six months prior, and his wife was unable to let go, regardless of the knowledge presented to her with regard to the outcome. For four weeks, we kept this patient on dialysis, platelets, and red blood cells, transfused every other day. The patient was bleeding from the mouth; liver failure set in. He was looking like a corpse and his family suffering every day. Yes, it was futile, expensive, and did not change the outcome. At the end his wife said, ‘Stop. It is not right transfusing all these blood products into my husband’s dead body.’”

“I was working on a medical/surgical floor with a patient with end-stage liver cancer. The oncologist decided to do a bone marrow biopsy. There was no benefit to the patient; he just wanted to see what was happening with her. He was not going to change any treatment. My sense was he just wanted to satisfy his curiosity. I was a relatively new nurse and I questioned him some but then let it go.”

“A few months ago, one of my patients with leukemia had a bone marrow relapse one year after diagnosis. This was her third relapse. Her prognosis from the very early stage of her leukemia was never quite good. She had every possible complication, both from her disease and from chemotherapy, right from the beginning. She could not even get her induction treatment started because of a coagulopathy problem she presented with. She had steroid-induced diabetes, meningeal toxicities from her intrathecal chemotherapy causing neurological changes and septic episodes, just to name a few. When she relapsed for the third time, she was in renal failure. Her attending physician clearly stated to her parents that there was no hope for a cure and that there were no more drugs that the patient had not been treated with in the past that could possibly bring her back to remission. However, the doctor did mention that there is a phase I drug that could be given to the patient if we are able to get her kidneys to work. That little bit of hope is a big thing to the parents. I understand the importance of clinical trials, but there is a point when one has to think of the ethical issues, the dilemmas, and focus on how to help the patient die comfortably.”

“Mr. M was a 70-year-old man admitted for resection of a liver tumor. Post-op, he was admitted to our ICU. Mr. M had been in our ICU for several weeks. He had never awakened post-op and was ventilator dependent. At the insistence of the nursing staff, we convened a multidisciplinary conference with the family. During the discussion, the physicians never used the words death or dying in spite of the fact that it was clear to them and the team that Mr. M would not survive hospitalization. It was clear that the family never completely understood the severity of the illness, so when they were asked to make decisions, they did not have the information to make an informed decision. I realized that, as the nurse, I needed to function as not only the advocate but also the interpreter.”

“A 72-year-old male patient had been admitted for scheduled colectomy for colon cancer. His post-op course involved multiple complications—bowel leak, peritonitis, infection, respiratory failure, renal failure, and skin breakdown, sepsis. The patient’s family was adamant we continue all aggressive treatment per their religious beliefs. They could not withdraw support.”

“The case involved a 43-year-old cervical cancer patient. There was a family/patient/physician/hospice/RN meeting. The family asked, ‘How will she die?’ The physician responded, ‘She’ll starve to death.’ The logical inference from what the physician said is if the patient is going to die by starving to death, if we keep her well nourished, we will beat death.”

Figure 1. Examples of Narratives of Moral Distress

Those in conflict included physicians, patients, family members, nurses, family members in conflict with each other, and nurses in conflict with other nurses. Nurses did not see themselves as passive observers but rather powerfully involved in the ethical conflicts.

Recognizing how infrequently issues of culture were identified in the narratives is of great interest. Only eight of the narratives described any issues of patient culture focused on ethnicity. For example, in one case, a nurse believed that an African American's ethnicity contributed to avoidance of death and continuing futile therapy. Two other instances identified the culture of poverty, including a narrative of a mother who refused to discontinue care for a child because she believed that poor patients would be denied care so that organs could be harvested for rich patients.

The issue of spirituality also was of interest to discern theologic tenets related to the ethical concern of futile care. In the first group of nurses, who were not explicitly asked about spiritual factors, only 7 of the 51 narratives made any mention of religion or spirituality. Those narratives regarding moral distress of nurses and end-of-life care did not describe issues of theology. However, in the second group of nurses, with only a simple prompt of "Were there spiritual/religious factors influencing the clinical situation or your response to it?" 36 of the 57 participating nurses described theologic elements of their experiences. Of the total respondents, 31 described families' or patients' spirituality, generally examples of religious traditions that prohibited them from discontinuing life support. Other examples included patients or families who believed in miracles from God or that "care was in God's hands," which prohibited them from making decisions to discontinue futile treatment. In 12 instances, the narratives revealed issues of the nurses' own faith or spirituality influencing the nurses' responses to the clinical situations.

Table 1 also includes an analysis of the diagnoses or diseases most often cited from which the narratives of futility were derived. The most common patient group was geriatric patients ($n = 40$), followed closely by patients with cancer ($n = 37$). They are examples in which patients likely were extremely ill or had limited capacity to make their own informed choices. The instances of futility were described as occurring because of conflicts between proxy decision makers and healthcare providers in making decisions for patients. Other diseases referenced included cardiac disease, pediatric diseases, and other chronic illnesses.

The survey asked the nurses to identify how the experiences affected them. Nurses provided powerful examples of their own responses and emotions. The most common response was that the experiences had made them become strong advocates for patients' best interests. Other common responses described the nurses' emotions of feeling demoralized, powerless, helpless, hopeless, frustrated, angry, distressed, or guilty that they had failed patients. Nurses identified a number of issues, including feeling obligated to support patient and family choices. In a few instances, nurses described positive experiences amidst the conflicts, such as feeling supported in the process or experiencing professional growth. A very interesting finding was that nine nurses said that a particular patient experience had caused them to change their career, moving out of the acute care setting and becoming hospice or palliative care nurses.

Despite altering the survey for the second group of nurses, the additional clause "How do these experiences impact the profession of nursing?" yielded few responses. Only six responses were provided about impact of moral distress on the nursing profession. Four of the nurses identified the impact as creating a division between nurses and physicians, one other acknowledged that instances of futility "diminished nursing," and another participant documented that the experiences caused nurses to "lose sight of the goal."

Examples of Narratives

Each of the narratives was reviewed and analyzed to identify concepts within nurses' experiences of moral distress and futility. Figure 1 includes examples derived from the analysis. Each of the examples was selected from cases involving patients with cancer. The examples illustrate the powerful experiences of nurses witnessing futile care in oncology. Figure 2 depicts excerpts from the narratives in which nurses identified religious or spiritual influences in the instances of moral distress and futility. Examples illustrate spiritual issues from patients or families and from nursing. The narratives are insightful examples of the experiences and illustrate the theologic tenets underlying the ethical conflicts.

Discussion

Issues of moral distress in nurses related to futile treatment frequently have been focused on ICU settings (Corley, 1995; Kirchoff et al., 2000) and, generally, physicians' decision making (Fins et al., 1999). Increased attention to the topic is needed in oncology nursing as evidenced by the literature review and analysis of narratives as described. The most common distress for nurses was described as the recognition that continuing aggressive care deemed futile denies patients the benefits of palliative care. The distress may become more prominent as the field of palliative care expands and nurses recognize that comfort-focused care is possible.

Nurses identified themselves as being centrally involved in the conflicts involving physicians, patients, and family members. Future research should identify what sources of support exist for nurses in such situations. The findings of this study highlight the importance of support for nurses as professionals intimately involved with patients and families. Nurses recalled patient stories from many years ago often in vivid detail, and the experiences resulted in great distress. Future research should explore in more detail nurses' demographic variables, such as culture and religion, and their influence on moral distress.

The theologic elements of the experiences also were very insightful and suggest the need for chaplaincy or other spiritual support for nurses. The narratives suggest the need for collaboration with chaplains to assess and meet spiritual needs of patients and families as well as respond to nurses' spiritual distress. Nurse managers and staff development educators also should be aware of the distress of nurses as an area of priority.

Summary

The problem of moral distress related to nurses' experiences of medical futility is an important concern. The dilemma has

"I pray—please God, tell us when 'enough is enough.' I thank God for colleagues and family who listen, support, and care. And it's by the grace of God that I am able to be strengthened each day, renewed each day, to do the Lord's work. Thank you for the opportunity to speak my heart's message."

"We as humans do not have all the answers. As long as there is a will, there is life. How can anyone say this is hope? There can always be some benefit from our actions. Even if we can't see them."

"The mother verbalized that she couldn't 'give up and let her daughter die.' We had offered chaplain support, but the family declined—I do believe that if she had allowed chaplain visits that she might have been more accepting of this death."

"I know in my heart Gary would be in a better place because he would be going to his maker—to his God—to his heaven. I also could feel Gary leave his body at the time he 'expired,' and it was an awesome and spiritual experience for me."

"The patient was of the Catholic faith and had been active in her church family prior to a second stroke. The priest in the parish was older and felt that stopping dialysis was a form of suicide."

"She was a faithful Southern Baptist, and her personal pastor told her she would 'not go to heaven' if she stopped hemodialysis."

"The patient's religious beliefs were central to the treatment this patient received. For my own response, this patient's beliefs did not parallel my own, and I did struggle at times with the contrast and needing to set my beliefs aside and support this family with their own beliefs and needs. I believe also that, had the intensive care unit (ICU) staff been aware of the patient's beliefs sooner, their reactions may have been different. It may also have helped them provide appropriate care in a respectful and caring manner."

"There is a time to end the 'cure' phase and move on to the 'care' phase. The outcome is not in our hands. When our work is finished, it's finished."

"I'm everything I do. My strong spiritual beliefs affect how I respond."

"This patient had made a decision she wanted to die, and we should respect that. By trying to force a tube feeding on her, we were attacking her spirit. She had made her decision and her peace. It was disturbing to me that we were affecting her spirituality. I do not know what the next world will hold, the grave versus heaven versus limbo, waiting to come back. However, I believe that a peaceful death with family and friends and pets around would

be more desired than the sounds of a ventilator, restrictions of restraints, the glare of overhead light."

"The staff required spiritual connection in this situation. They questioned—'Why, God, can I decide if this woman was to live or die?' They believed that they were administering lethal doses, and the responsibility of that hastening her death was fear. We focused daily on spiritual support for one another, the patient, and family. We had a prayer circle around the patient with staff, clergy, and the family."

"The patient and her family were very religious, and I think that played a huge part in their decisions. They really believed God would help. I am not a very religious person, but I can understand that faith and God are important to others. I believe that years ago, when we did not have so much technology and medicine, we were more accepting of death and could be comforted about religion and God. Her leukemia had returned. To make a long story short, her family continued to want everything done. She went to the ICU several times with infection and bleeding. We always had to keep a restraint on her because she had no sense of her limitations and fell if she were not restrained. She ended up in terrible emotional distress and pain at times. Her family avoided do-not-resuscitate discussions and hospice. This woman's last few months of life seemed to be full of suffering, and she coded and died in ICU without her family with her."

"I was angry with the medical staff for not taking responsibility for relieving this man of his suffering. I was confused and wanted the family to understand that sometimes God's miracle is heaven. I was fearful that this could easily have been me or one of my friends or family."

"I kept asking God to take her. It was time. God tried, but the hospital staff wouldn't let go because of 'policy.'"

"I don't know, I guess my own spiritual beliefs that there is a God who loves me and that there is life after death and the hope that gives me cause me not to fear death and influence my belief that length of life at all costs isn't the goal."

"My own personal spiritual beliefs of death with dignity were violated."

"At this time, I did not invest much time in spirituality. Over the years, I have realized that the spiritual and religious factors play a huge role at the end of life."

"My core value as a person and nurse is respect. I feel ashamed of the ways in which we violate patients."

"I realized 'hell was on earth' with what patients are put through. This made my being a patient advocate even stronger."

Figure 2. Examples of Religious or Spiritual Influences on Distress

a critical historical context amidst current healthcare technology. Although the theologic issues were not as explicit, the review of nursing narratives revealed a rich source of information about the relationship of ethics, theology, and the culture of care. Taylor (1995), a nurse ethicist, wrote "Medical Futility and Nursing," suggesting the important role of nursing in negotiating compromise between patients and clinicians regarding futility. Taylor argued for greater nursing voice in the area, particularly given the vulnerability of patients in such situations.

On a daily basis, oncology nurses confront patients and families facing the life-threatening disease of cancer. Medical futility and the moral distress experienced by nurses are likely to remain important concerns amidst the technologic advances

in care and the many cultural and emotional issues surrounding decision making. Feminist scholars have addressed the silence of the vulnerable in society who face ethical issues such as futility. Oncology nurses, individually and collectively, should give voice to the topic through greater support of nurses, scholarship, and advocacy for patients.

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