A vast literature exists on the ethical aspects of decisions to limit life-sustaining treatments, and much of it deals with the way decisions ought to be made. Little is known, however, about how decisions are made in actual clinical practice. Empirical studies have not investigated the decision-making process directly and, with one exception, have only focused on physician practices. Through the use of a case, this paper examines the nature of hospital cancer nurses' involvement in the decision-making process. Three practice domains are identified: assisting patients to reach a truly autonomous choice, helping families to understand and to cope with the realities of the situation, and communicating with and encouraging open communication among all those involved. In addition, the potential value of the in-between position of the nurse is noted, and nurse responsibilities are summarized.

INTRODUCTION

Advances in science and technology, over the past two decades, have provided an ever-increasing capability to monitor, treat, and consequently prolong the lives of patients with cancer. Ordinarily, both patients and health professionals want to use this life-prolonging capability. In fact, many patients undergo long stretches of aggressive therapy in an effort to obtain a cure or remission of their disease. When, however, patients have advanced, irreversible disease, serious concerns arise as to whether the burdens of the treatments themselves and of life after treatment seriously outweigh the benefits to the particular patient. Paralleling these concerns is the recognition that patients have differing needs and wishes during the final stages of their disease. Consequently, it is often necessary, in these situations, to consider whether to forego a fully aggressive approach to care and to limit life-sustaining treatments.

A vast literature exists on the ethical aspects of decisions to limit life-sustaining treatments, and much of it deals with the way decisions ought to be made [1–5]. Little is known, however, about how decisions are made in actual clinical practice. Empirical studies about clinical practices in the hospital setting have not investigated the decision-making process directly; instead, they have examined decisions indirectly by using questionnaires and/or reviewing clinical data, demographic characteristics, and the medical records [6–9]. In addition, with one exception [10], these studies have focused only on physician practices. Therefore, the nature and extent of the involvement of other members of the health care team are relatively unknown.

In this paper, I present a case to illuminate the nature of nurse participation in decisions to limit life-sustaining treatment. Specifically, it focuses on the practices of
hospital staff nurses who care for adult patients with cancer. Before proceeding, however, three points of clarification seem in order.

First, as suggested earlier, there is only a modicum of research data regarding nurse practices. Therefore, the material presented in this discussion is drawn from my own observations of these practices. Such an experiential approach is not necessarily systematic. Experience neither exposes one to all practice situations, nor does it always include every aspect of a particular situation. The potential still exists for some nurses to remain uninvolved with these decisions.

Second, there is no intent to suggest that the degree of nurse participation in the decision-making process is the same for all nurses. Such factors as the practice environment, the nurse's years of clinical experience and knowledge of ethics, and the nurse's knowledge of the particular patient are likely to influence the degree of nurse involvement [11].

Third, decision making as to whether or not to limit life-sustaining treatment is not, in this discussion, equated with selecting a course of action. Rather, it is viewed as a process which involves at least three stages: information collection and problem identification, consideration of alternative strategies, and selection of a course of action for implementation. Thus, nurse involvement in decisions means involvement anywhere in the process.

NURSE PARTICIPATION

The involvement of hospital cancer nurses in decisions regarding limitation of treatment can be viewed as existing in three domains: assisting patients to reach a truly autonomous choice, helping families to understand and to cope with the realities of the situation, and communicating with and encouraging open communication among all those involved. These domains are evident in the following case.

Case Example

Mr. M., a 73-year-old widowed man with advanced prostate cancer, was admitted for evaluation of a recent onset of severe pain. Tests revealed extensive disease in his pelvic bones, and a course of radiation was initiated. In addition, he was started on an around-the-clock narcotic regimen.

On day 3 of hospitalization, the primary nurse, D.V. (the nurse who was responsible for his nursing care from admission until discharge), was approached by the family, which consisted of two sons and a daughter. They were much upset that their father was confused and lethargic and, subsequently, expressed the feeling that their father was receiving "poor" care.

They explained that their father, until admission, had been driving a car and taking care of himself. One son, with whom he lived, reported that he always prepared lunch for his dad to eat and that his sister always stopped by during the day. He continued on to explain that his sister "just can't stand seeing him like this"; she had not recovered from the death of their mother four months ago.

They did not, he reported, tell their mother that she had cancer, and they believe that this omission was why she lived so long: "She would have given up, if she had known." Thus, he explained, they were extremely upset that, two months ago, when their father went to the emergency room for difficulty with breathing, a resident mentioned the fact that he had cancer. He felt that his father is different now that he knows.
This son then expressed great concern about how he will care for his father when he is discharged from the hospital. He stated that they know that their father has "bad" disease, but they wanted everything done for their father, including resuscitation and placement on a "respirator" if necessary. Moreover, they indicated that they did not want their father to be lethargic and confused, even if this alertness meant that he would experience some pain.

After listening carefully to the family, D.V. indicated that she would work closely with them and would start by communicating their concerns to the attending physician. In addition, she encouraged them to telephone the attending physician themselves.

D.V. then called the attending physician to: (1) clarify the patient’s current health status, potential for further cancer treatment, and prognosis; (2) communicate the family’s concerns and share the historical and contextual information which might be influencing their responses; (3) plan Mr. M.’s care. Both D.V. and the attending physician agreed that, in light of the irreversible nature of the patient’s disease and his deteriorating condition, the appropriateness of aggressive therapies (such as resuscitation and placement on a ventilator) needed to be explored further with the family.

D.V. expressed her concern that confusion and impaired communication were preventing the patient from participating in these decisions about treatment and care. It was agreed that the confusion was most likely related to the opiates and that the difficulty in understanding the patient’s words, during his rare lucid periods, was caused by mucosal dryness and debris from oral thrush which was adhering to his dentures. D.V. recommended a revised pain management plan and requested medication for the oral thrush to include in her mouth care regimen. The physician agreed with the recommendations for oral medication and pain management.

D.V. then mentioned the potential hazards of immobility such as pneumonia and hypercalcemia, which could lead to impaired mental function, and asked for clarification regarding the patient’s mobility; that is, could he be ambulated safely without causing a pathological fracture? Since this possibility was not a risk, they agreed on a plan of progressive ambulation, which would take into account safety issues and degree of patient comfort. Last, the physician and the nurse agreed that they should be in daily communication; the discussion closed with the physician asking D.V. to tell the family that he would call them in the morning.

In the subsequent days, the patient’s mental capacities were restored, and he was able to communicate with D.V. and his family; however, he did not wish to talk explicitly about his situation. During the many hours that D.V. spent giving him physical care and assisting him to ambulate, he would simply allude to the fact that he did not have long to live. He did, however, express satisfaction with management of his pain.

D.V. spent much time with each individual family member. She helped them to understand their father’s prognosis, the various levels of care from intensive care to comfort care, and the fact that he was near the end of life. They all expressed the fear that their father would experience prolonged suffering. In addition, they shared the fact that their father did not like “all the things that they do to you in the hospital.” They did not wish, however, to consider explicitly limiting aggressive therapies or to discuss that subject with their father. Furthermore, they rejected the idea of a family
meeting with the attending physician, stating that they preferred to talk with him individually over the telephone.

In an effort to resolve the issue, D.V., after discussion with the physician, raised the idea of hospice care. After a week of numerous discussions about what hospice care meant and a visit to an inpatient hospice, they agreed that this choice would be a good plan, which would help all of them. They were hesitant to discuss it with their father, however, because “Dad knows all about hospices and why people go there.” Finally, with D.V.’s support and presence, they presented the proposal of a hospice to their father. Mr. M. not only agreed, but actually seemed relieved at this suggestion and wanted to know how soon he could go.

In essence, the patient, with his family, knowingly chose to forego aggressive treatment but did so indirectly. D.V. respected their values and interaction style, but also helped to resolve the issue by refocusing the discussion away from direct decision making about limiting treatment to decision making about where the patient would like to live his remaining days.

**Assisting Patients to Reach a Truly Autonomous Choice**

Cancer nurses know that the principles of informed consent apply to decisions about whether or not to forego life-sustaining treatments. They also know that, as members of the health care team, they have a moral responsibility for the quality of the consent (or refusal). This obligation may not always be a formal “knowing,” but is evident in their care practices. They are concerned about whether patients have the ability to make decisions, have adequate information, understand that information, and whether or not they are being unduly coerced.

Consider the following practices. Nurses often help patients to clarify the medical information that they have already received. During that process, nurses assess the patient’s understanding and capacity to make decisions. Patients, on the other hand, may identify the need to obtain further information from their physicians. Nurses not only encourage them to seek this information, but often help them to formulate the questions they wish to ask. In addition, because a nurse knows that a patient often becomes overwhelmed when such sensitive information is discussed, the nurse may suggest that a family member be present or may offer to stay with the patient herself.

Simultaneous with this clarification of medical information, nurses help patients to clarify their values and goals. In addition, they often do what Gadow [12] proposes: that is, assist patients to integrate personal wishes with the medical data, so that the alternatives can be fully understood. This interaction is a complex process of helping patients to think through how they would like to live and die.

And, finally, nurses mitigate one possible source of coercion: fear of pain and suffering. They do this in two ways: (1) by informing patients about the availability of supportive care, and (2) by providing intensive “caring” to patients. This “caring” not only entails comfort measures (perhaps in the midst of highly invasive therapies), but also compassion, respect, and concern.

In the situation of Mr. M., some of the nurse practices described above were not instituted. Instead, Nurse D.V. chose (and I think correctly) to respect Mr. M.’s wish not to examine options explicitly in relation to his values and goals. Through attention to the physiological dimensions of his care, however, D.V. helped to restore and to maintain Mr. M.’s lucidity and ability to communicate. Thus, ultimately, he was able to participate in the decision as to how and where he wished to live and die.
Helping Families to Understand and Cope with the Realities of the Situation

The case of Mr. M. illustrates a number of nurse practices in relation to families: assessment of the effect and the meaning of the limitation-of-treatment issue on the family, clarification of medical information and the various levels of care (intensive to comfort care), facilitation of the family's decision-making process, and support of the family as they deal with the impending death of a loved one.

In those situations where patients do not have the capacity to make such decisions, nurses also help families to integrate the medical information with what they know about the patient's wishes. If the patient's wishes are unknown to the family, then nurses help families to think about treatment(s) in relation to pain and suffering, the medical information about the potential for restoring function, and the medical information about both the potential condition of the patient after implementation of life-sustaining treatment and the expected life span.

Communicating with and Encouraging Open Communication Among All Those Involved

Achieving clear and open communication in the context of a fast-paced hierarchical setting is challenging and may not be successful. Nevertheless, to promote patient autonomy, cancer nurses continue to value and pursue such communication.

The situation of Mr. M. informs us about nurse practices in this domain. There was extensive dialogue between Nurse D.V. and the family, and between Nurse D.V. and the physician. In addition, Nurse D.V. encouraged communication between the family and the physician.

CONCLUSION

Decisions about whether to limit life-sustaining treatment are usually difficult and often complex. Nurses are not only involved but also have an in-between position between the patient and the physician. Therefore, they may be best positioned to facilitate and participate in cooperative decision making [13].

Those who value the traditional hierarchical approach may reject a cooperative approach to decision making. Since interaction and communication seem to influence the outcomes of intensive care positively [14], however, it may be that open communication and mutual decision making lead to the best clinical-ethical decisions. Thus, there is an urgent need for empirical studies on the decision-making process and the outcomes of that process.

Meanwhile, the particular vulnerability of hospitalized patients with advanced, irreversible cancer requires that nurses, along with other health professionals, actively assist patients and their families as they examine and face the realities of the situation. Specifically, a knowledgeable nurse, who has developed a relationship with the particular patient and family, can and should sensitively help them to clarify the alternatives, examine the alternatives in relation to the patient's values and goals, and cope with the realities of the situation. Concurrent with these activities, nurses must also communicate with all those involved. And, finally, nurses have a responsibility to provide knowledgeable and compassionate nursing care.

REFERENCES

1. Brody BA: Life and Death Decision Making. New York, Oxford University Press, 1988
2. Hastings Center: Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. New York, The Hastings Center, 1987
3. Povar G: Withdrawing and withholding therapy: Putting ethics into practice. Journal of Clinical Ethics 1(1):50–56, 1990
4. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to Forego Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions. Washington, DC, U.S. Government Printing Office, 1983
5. Veatch R: Death, Dying, and the Biological Revolution: Our Last Quest for Responsibility. New Haven, CT, Yale University Press, 1989
6. Bedell S, Delbanco TL: Choices about cardiopulmonary resuscitation in the hospital. N Engl J Med 310:1089–1093, 1984
7. Lo B, Glenn S, Strull W, Thomas E, Showstack J: ‘Do not resuscitate’ decisions. Arch Int Med 145:1115–1117, 1985
8. Wachter RM, Luce JM, Hearst N, Lo B: Decisions about resuscitation: Inequities among patients with different diseases but similar prognoses. Ann Int Med 111:525–532, 1989
9. Younger S, Lewandowski W, McClish DK, Juknialis B, Coulton C, Bartlett ET: ‘Do not resuscitate’ orders: Incidence and implications in a medical intensive care unit. JAMA 253:54–57, 1985
10. Bedell S, Pelle D, Maher PL, Cleary PD: Do-not-resuscitate orders for critically ill patients in the hospital. JAMA 256:233–237, 1986
11. Donovan CT: Toward a nursing ethics program in an acute care setting. Topics in Clinical Nursing 5(3):55–62, 1983
12. Gadow S: An ethical case for patient self-determination. Semin Oncol Nurs 5:99–101, 1989
13. Bishop AH, Scudder JR: Nursing ethics in an age of controversy. Adv Nurs Sci 9(3):34–43, 1987
14. Knaus WA, Draper EA, Wagner DP, Zimmerman JE: An evaluation of outcomes from intensive care in major medical centers. Ann Int Med 104:410–418, 1986