

# An Ethical Approach To Providing Palliative Care To Patients With Cancer Who Lack Decision-Making Capacity

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## Abstract

**Objective:** To assess the ability of ethical approach to providing palliative care to patients with cancer who lack decision-making capacity. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision.

**Methods:** Consecutive patients referred for surgical clinic and oncology department, Shohada Medical Center, underwent evaluation. The study includes 650 patients with cancer disease. 250 patients have severe disease and lack decision-making capacity.

**Results:** 148 males and 152 females and age averages in females (26-72) and males (32-75) and guided by family, physician, surgeon, nurses and other caregivers.

We performed 21 gastrostomies and 10 jejunostomies for feeding and 81 cases for nerve block. All patients consulted with a psychologist.

**Conclusion:** Palliative care is designed to relieve a patient's suffering in order to maximize dignity and quality of life.

## INTRODUCTION

Making palliative care decisions for a patient with cancer who lacks decision-making capacity presents several challenges. Other people, such as family and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision. This paper presents a study of patients with cancer disease and describes a consensus-based decision-making strategy that keeps what is known about the patient's wishes and values in the foreground but also expects guidance from the physician and elicits input from family members and other people who care for and have knowledge about the patient. The steps of this process, including key clinical prompts and potential transition statements are outlined and described. The overall goal of the commentary is to demonstrate that physicians can guide a highly emotional and personal process in a structured manner that has meaning for the patient, family, physician, and other caregivers.

## MATERIAL AND METHODS

The Shohada Medical Center, at the Shahid Beheshti University Medical sciences is a referral center for severe cancer disease (including GI, Breast, Head and Neck and extremity). Approximately 350 patients with cancer are admitted annually and over 20% are advanced stages. Approximately all of patients operate and adjuvant therapy was begun by oncology and radiotherapy departments

The study includes 650 patients with cancer disease. 250 patients have severe disease and lack Decision-Making Capacity. 148 male and 152 female with age averages in female of (26-72) and in male of (32-75) were guided by family, physician, surgeon, nurses and other caregivers.

How can a busy internist address these problems in a manner that achieves consensus among decision makers? This study illustrates an approach to developing palliative care plans for patients with severe cancer disease

I use two principles to help think through the decisions we face. First, consider your understanding of what patients

would want if they could tell us. Second, we should balance the burdens and benefits of each option in terms of its ability to relieve their suffering and maximize their dignity and the quality of her remaining life.

## **RESULTS**

In this study the first step was to identify potential decision makers. If the patient didn't have an advance directive, we could turn to close family members and others who know the patient well with the assurance that the family's standing to serve as surrogate decision makers is established by both case and statutory law. We performed 21 gastrostomies and 10 jejunostomies for feeding and 81 cases for nerve blocks. All of patients consulted with a psychologist.

## **DISCUSSION**

Theory and practice of an informed consent is an essential aspect of the nurse's role. There are many challenges to this process in the oncology setting because of the severity of the diseases and the complexity of the research, and nurses must be prepared to assure that informed decision-making takes place. (8\*21\*6)

Palliative care is designed to relieve a patient's suffering in order to maximize dignity and quality of life (5). Respect for a patient's autonomous choices is a foundation of Western bioethics, but a patient with severe cancer disease can no longer decide whether to receive predominantly palliative care or to continue potentially life-prolonging therapy. Other people, such as family members and caregivers, must choose for the patient. The goals and values of these decision makers may conflict with those of each other and with those of the patient, who now lacks the capacity to participate in the decision.

The patients could not tell us whether they were suffering or describe their quality of life. The meaning of their signs and symptoms had to be interpreted. Furthermore, as a wife, mother, parent, and resident of a nursing home, they lived in a diverse community that had different views about what ought to be done for their. Despite this lack of evidence, those who care for and care about these patients must make decisions.

When new treatments, such as experimental drugs, are used in patient care, the issues of informed consent to treatment and the balancing of risks and benefits may be especially difficult to resolve. By understanding the functions and elements of informed consent, nurses can assist their patients

to ask for and to comprehend the information they need to be truly and fully informed about treatment choices. Likewise, assessing the risks and benefits of an experimental treatment option, such as an experimental drug for the treatment of primary hypertension, may be important to the long-term health of patients. Nurses assist patient decision making and the assessment of relevant risks and benefits by being fully informed about the planned research and by applying knowledge of ethical principles to patient care. When nurses incorporate this type of ethical flexions and moral skill into nursing practice, they meet minimal moral obligations to patients.

These cases illustrate a palliative care strategy grounded in the theory that decisions for patients such as the result of dialogue and consensus building. The physician's initial investment of time may minimize the time and effort needed for future decisions. The physician's duty is to teach all participants that end of life, irreversible, and ultimately fatal disease but also to learn from these participants about patient's values and quality of life. This frames decisions about hospitalization, chemotherapy, radiotherapy, and enteral nutritional support as medical choices that ultimately shape the way they will live the last phase of their life.

As a result of this dialogue, a family may decide that continued efforts to prolong life are critical regardless of the severity of the patient's disease. In general, physicians should guide the process because of their familiarity with medical processes and prognoses, but the surrogate decision makers must try to represent the patient's voice. Differences should be explored through dialogue that focuses on the patient's best interests and seeks common ground. Except when decisions seem to clearly violate the patient's best interests or prior wishes, the family has the final say in representing the patient in decision-making. Families have to live with themselves and their role in these decisions long after the patient has died.

Conversely, some medical practitioners or long-term care institutions see their primary job as prolonging life under all clinical circumstances because of religious principles or personal training. These practitioners or institutions should make their philosophy known from the outset, especially if they feel obligated to override the values and wishes of patients and families, because they will be unable to pursue this consensus-based approach.

The meaning of suffering is personal and subjective.

Evaluating the suffering of patients with cancer who cannot speak for themselves is inherently challenging. Even when suffering is recognized, its relief may be relegated in the pursuit of another goal, such as the preservation of life at all costs or hope for a miraculous cure. Yet through the process of repeatedly listening to the perspectives of each participant and involving the participants in a consensus-based interaction, decisions that respect the patient's dignity and quality of life can generally be achieved.

Finally, the physician guided the family on ethical standards for decision making: 1) Consider what is known of the patient's wishes and preferences given her current condition (for example, a living will or potentially relevant statements made when the patient was competent) and 2) balance the burdens and benefits of each option in terms of its ability to maximize patients with cancer dignity and quality of life.

After some discussion the physician must to say to the family's patients: "Their cancer disease has progressed to the point where they dying. I believe we ought to come up with a plan that minimizes their immediate suffering and maximizes their dignity and their quality of life."

If patients with cancer had completed an advance directive that included a durable power of attorney for health care, that person would be her main representative in decision making. However, most patients in nursing homes do not have advance directives<sup>(13)</sup>, and even when they do, the contribution of others, such as family and formal caregivers, can greatly assist the designated surrogate in decision making<sup>(14, 2)</sup>. Even if the patient doesn't have an advance directive, the physician can turn to close family members and others who know the patient well with the assurance that the family's standing to serve as surrogate decision makers is established by both case and statutory law<sup>(16)</sup>. Except in cases in which the patient has no family or has a family that does not represent the patient's best interests, the physician is under no moral or legal authority to seek a guardian (a forthcoming paper from the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel will focus on legal issues)<sup>(16, 4)</sup>

The purpose of this dialogue is to achieve a consensus among decision makers about the patient's current disease state, prognosis, quality of life, and previously stated values<sup>(14)</sup>. This sharing of narratives may expose important differences in beliefs and understandings in any of these domains that must be reconciled before consensus-based

decision making can proceed. The more the physician understands these various perceptions, the more likely he or she is to develop a plan that will respect Mrs. B. as a person. Even when the physician has a long-term relationship with the family and patient, this step in consensus building should not be skipped. Research showing that physicians often inadequately understand their patients' preferences for health care supports this point<sup>(5,1)</sup>

Although this physician believes strongly in a palliative approach that includes pain and symptom management and avoidance of invasive treatments for patients with severe Alzheimer disease, he must respect that others may value an approach in which available medical technology must always be used to prolong life. Before a consensus about what might be included in a palliative approach for a particular patient is possible, the physician must learn what "treated with dignity and respect" means in this family.

Achieving consensus about her current quality of life, although a subjective and personal process, incorporates the families, physicians, and health care team's perceptions of her circumstances into what is known about her past preferences and values.

Missing from these recommendations to the family is an exclusive appeal to futility as grounds for decision making. Futility refers to the claim that no desirable benefit can be achieved by potentially life-prolonging treatment<sup>(20)</sup>. Physicians frequently cite futility as their reason for terminating further treatment<sup>(17)</sup>. Although the concept of "medical futility" exists to communicate extremely poor prognosis, it can also inadvertently convey an unequivocal, unilateral, and negative judgment about a patient's quality of life without leading to an explicit discussion of these issues from the differing perspectives of physicians and families. Furthermore, too frequently, the term connotes that "nothing more can be done" for a patient, that further intervention would be meaningless, or that her life is of no current value. Therefore, a physician who relies exclusively on futility as a reason to pursue palliative care can obscure an honest discussion of how people understand and value the patient's continued existence and of the range of possibilities for palliative and life-prolonging interventions.

This decision-making process exposed two common features of caring for patients with severe cancer disease. First, clear information about the patient's wishes is typically unavailable. Second, decision makers often have differing

assessments of the patient's preferences and quality of life (22).

Dialogue is essential for achieving consensus on a course of action that is responsive to both past and present patient realities, as well as to the concerns and priorities of the family (14, 2, 12). The goal of dialogue is not to provoke conflict but to clarify common ground and differences and lead to better appreciation of the meaning of the decision for the patient and their family (14, 19). This approach to decision making is grounded in narrative theory that unifies the clinical and moral dimensions of medicine (3, 11). Clinical medicine is grounded in a series of stories told and interpreted from a variety of perspectives.

This theory has some limitations. Consensus occurs in the context of choices. However, in the care of patients with severe cancer who live in nursing homes, local customs, beliefs, and systems of care can limit reasonable choices. For example, long-term care regulations are often wrongly believed to require that all residents with neurogenic disorders sever dysphagia receive artificial nutrition and hydration. Surrogate decision-making laws are often misinterpreted to require a legally designated guardian for noncompetent patients who lack an advance directive (15). Although in U.S.A. a few state laws (in Missouri and New York) require a high degree of proof of a surrogate decision maker's knowledge of a patient's wishes to allow the surrogate to withhold or withdraw artificial hydration or nutrition from noncompetent patients, in Iran as the most states support the legal right of surrogate decision makers to refuse any and all unwanted medical treatments when this decision is based on a consensus of the patient's wishes and best interests (15). In addition to legal inconsistencies and misperceptions, both health care systems and local community practices powerfully influence choices and decisions. For example, in the same community, two otherwise high-quality nursing homes may have dramatically different rates of parenteral feeding for patients with severe cancer. Research shows that large national variations in the rates of dying at home correlate with regional inpatient bed availability, not with patient or family preferences (18)

In addition to exploring the benefits and burdens of these technical interventions, the physician's duty is to teach the family about palliative care options for patients with complications caused by severe cancer for example in fistula due to esophageal carcinoma who develop aspiration pneumonia. The decision to use or not to use a feeding

jejunostomy is not a *prima facie* determinant of the quality of palliative care for a patient with severe cancer. In addition, enteral feeding may not prevent weight loss or the progression of pressure ulcers (10) and is associated with substantial 1-year mortality rates (9).

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