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# Palliative Care: A Bioethical Definition, Principles, and Clinical Guidelines

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*At Montefiore Medical Center, the Bioethics Committee and the Bioethics Consultation Service are repeatedly confronted with both theoretical and clinical issues related to end-of-life care. Inevitably, discussion would founder on the questions, "But what exactly is palliative care?" "When do you shift from aggressive treatment to palliation?" In response, a Palliative Care Subcommittee was appointed to draft a definition of palliative care, general profiles of patient groups for whom this type of care would be appropriate, and a set of principles and guidelines. Although still a work in progress, the guidelines presented here represent one articulation of the profound issues encountered by patients, families, and caregivers as they struggle to face the end of life in ways that are principled and compassionate.*

In setting the stage for a discussion of palliative care, it is important to note that providing comfort is neither a departure from nor an abdication of the traditional responsibilities of medicine and nursing. Indeed, it is worth remembering that, until the middle of this century, the cure of disease and the prevention of death were not the primary therapeutic goals because they were largely beyond the capability of those who ministered to the sick; rather, they were the hoped-for by-products of efforts aimed at easing the discomfort of the afflicted (Jecker and Self 1991; Starr 1982). It was only with the relatively recent advent of biotechnology that "caregivers" came to be seen as "curegivers," and comfort came to be seen as what was left when there was "nothing more to do." In the process, death was perceived as a failure of skill and dying was unseemly for professionals to attend (Brody et al. 1997; Nuland, 1993).

Within the past few years, a number of factors have contributed to a heightened awareness of the importance of palliative care. Both the public and professionals are troubled by the reality of overtreated disease and undertreated pain at the end of life (Lynn et al. 1997; SUPPORT 1995). A combination of insufficient pharmacological knowledge about pain relief, inadequate support

services, ethical and legal concerns about withholding and withdrawing care, a "do everything" philosophy of medical education, managed care and cost containment policies, and underuse of or lack of respect for advance health care decision making have raised fears that the quality of life is being sacrificed to the imperatives of treatment (Sulmasy and Lynn 1997; Post et al. 1996; Dubler 1993). The depth of this concern can be measured by the fact that the vehicle for discussion has become the questionable right of terminally ill patients to receive physician assistance in ending rather than easing their lives (Foley 1997; Foley 1995; Quill 1995). Individuals and organizations dedicated to health care have responded with focused attempts to study end-of-life care and identify appropriate policies and procedures for providing palliative care (The American Board of Internal Medicine End-of-Life Care Project Committee 1996; Council on Scientific Affairs 1996). Finally, the Health Care Financing Administration (HCFA) has approved a new palliative care diagnosis code, the use of which will indicate in medical charts that palliative care was provided to hospitalized dying patients. Analysis of these records may result in the creation of a diagnosis-related group (DRG) authorizing payment for end-of-life care in the

hospital setting (Cassel and Vladeck 1996).

At Montefiore Medical Center, the Bioethics Committee and the Bioethics Consultation Service are repeatedly confronted with both theoretical and clinical issues related to end-of-life care. Inevitably, discussion would founder on the questions, "But what exactly *is* palliative care?" "When do you shift from aggressive treatment to palliation?" In response, a Palliative Care Subcommittee drafted a definition of palliative care, general profiles of patient groups for whom this type of care would be appropriate, and a set of principles and guidelines, some general and some specific to frequently encountered clinical situations. The Subcommittee used the term "palliative care" rather than "comfort care" because the former seems to have received greater acceptance within the wider medical center community. Because the definitions, principles, and guidelines are still being revised and refined, it is hoped their dissemination at this early stage will stimulate discussion and feedback.

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### **Palliative Care Definition**

Palliative care is *active intervention*, which has as its goal the achievement of *maximum comfort and function* of the *total patient*. While palliation can and should always be an integral part of the entire spectrum of patient care, it stands alone as the care for the patient who has been diagnosed with an *irreversibly deteriorating* or *terminal* condition and for whom *curative treatment* is no longer the goal of care.

Palliative care shares with cure-oriented care the qualities of plan-driven activity, purposeful organization and evaluation, range of treatment options, and caregiver-patient engagement and

collaborative decision making. The only distinguishing characteristic is the goal of care: palliation has *compassionate caring* rather than cure as its goal. Because palliation remains on the care continuum after cure is no longer the goal, it may encompass particular comfort measures posing risks to life that might not have been acceptable when cure was still the goal of care.

### **Terminology**

*Active* - sustained hands-on engagement of the care provider with the care recipient

*Intervention* - care or treatment that has measurable results and can include aggressive measures, such as surgery and radiation

*Maximum comfort and function* - promotion of the best possible levels of pain control, consistent with physical conditioning, alertness and cognitive activity, mobility, emotional well-being, and independence in activities of daily living, with the patient's comfort taking priority over function

*Total patient* - encompasses all aspects of the person, including the physical, cognitive, emotional, and spiritual

*Irreversibly deteriorating* - slowly and inexorably worsening incurable condition

*Terminal* - in the last stages of a fatal condition

*Curative treatment* - intervention that has as its goal eliminating, reversing, or halting the disease

### **Substantive Criteria**

The following substantive criteria are suggested for determining appropriate clinical situations in which the palliative care definition would be applied:

- Patients who determine that the small probability of cure or reversal, or the brief period of remission offered by indicated curative interventions are outweighed by the burdens of pain and suffering caused by the interventions;
- Patients for whom the benefits of prolonged

life, as defined by the patient or the surrogate, are outweighed by the burdens of unrelievable pain and suffering caused by the disease process;

- Patients for whom the benefits of prolonged life, as defined previously by the patient in an advance directive or contemporaneously by the surrogate, are unexperienced because the patient is cognitively unaware of or unresponsive to his or her surroundings;
- Patients for whom all indicated medical, surgical, radiological, and chemotherapeutic options have been attempted and found ineffective in curing or reversing the disease process;
- Patients for whom diagnostic evaluation reveals that no medical, surgical, radiological, or chemotherapeutic options offer any likelihood of curing or reversing the disease process; and
- Patients for whom no cure is possible, but for whom there is the certainty or substantial likelihood that therapeutic intervention will produce short-term benefit in improved comfort and/or function.

## **Palliative Care Principles and Guidelines**

### *Philosophy*

- Promoting the patient's physical and emotional comfort is always a therapeutic goal. There is a time when this becomes *the* therapeutic goal—a time when care, not cure, becomes paramount.
- Palliation is not a response that begins when the patient is in pain. Palliation is a philosophy and a set of active behaviors that continue throughout the care giving process.
- Caregivers have a responsibility to communicate to patients and families their commitment to promoting patient comfort, and to provide reassurance that the patient will not be abandoned.
- Caregivers have a responsibility to recognize when the goal of care shifts from cure to comfort and to engage patients, families, and

other caregivers in discussing and planning for the change in orientation.

- Palliation is a multidisciplinary undertaking, involving the patient and family, and calling on the efforts and skills of medicine, nursing, pain management, bioethics, social services, clergy, and recreational therapy.
- Because notions of health, illness, pain, and relief are perceived and interpreted according to the backgrounds and traditions of patients and caregivers, knowledge of and respect for culture and religion are integral to the responsibilities of caregivers.

### *Assessment*

- The accurate determination and assessment of the patient's diagnosis and prognosis by the physician(s) form the basis of a care plan that adequately reflects the patient's care needs. Because the situation is not static, this assessment is ongoing and the care plan is modified frequently to reflect the patient's changing condition. Although the care plan is determined and directed by the physician, this assessment can be triggered by and benefits from the observations and insights of the entire interdisciplinary care team.
- Caregivers have a responsibility to employ the skills and attention necessary to continually evaluate the patient's physical and emotional comfort, including but not limited to symptoms of pain, fatigue, weakness, depression, gastrointestinal and respiratory discomfort, irritability, confusion, loneliness, and fear.
- Caregivers have a responsibility to evaluate and address verbal and behavioral indications of discomfort in a manner that is careful, thorough, sensitive, objective, unbiased, and nonjudgmental.
- The patient's preferences, values, and goals are integral to the palliative assessment and the design of an appropriate plan of care. Caregivers have a responsibility to engage patients and families in discussion of patient

wishes and expectations, and to determine whether these have been articulated in advance directives.

- In the event of disagreement between or among patient, family, and/or the care team, palliative care issues should be resolved through a process of mediation such as that used for other health care or treatment decisions.

### *Communication*

- In addition to physical discomfort, illness is usually accompanied by a sense of apprehension, uncertainty, disorientation, anger, and profound vulnerability. The more serious and protracted the illness, the more acute and disruptive the emotions experienced by both patient and family, and this phenomenon is especially pronounced in terminal illness.
- Caregivers have a responsibility to facilitate communication with the patient and family as a way of providing information, indicating their ongoing commitment to the patient's well-being, and promoting the therapeutic relationship. Recognizing that communication is a dynamic and ongoing process rather than isolated information sessions, caregivers have a responsibility to sustain interaction throughout the therapeutic relationship.
- Anxiety is a barrier to effective communication, making it difficult for patients and families to verbalize, hear, and recall what has been said. Caregivers have a responsibility to attend carefully to the patient's verbal and nonverbal communications, and to make their communications responsive to the patient's needs.
- Caregivers have a responsibility to communicate clearly, truthfully, and sensitively, especially when disclosing bad news or discouraging developments. This responsibility includes helping patients communicate difficult or sensitive information to family, and providing opportunities for all parties to deal with changing health care situations, especially the recognition of a terminal diagnosis

or impending death.

- Caregivers have a responsibility to explain clearly to the patient and others selected by the patient the diagnosis, prognosis, and care options, and to ensure that their communications are received and understood. This includes reviewing discussions, clarifying misunderstandings, providing opportunities for further questions, and even suggesting written or recorded documentation of the discussions for future reference.
- Absent indications that disclosure of medical information would be harmful, a capacitated adult patient has the right to be informed about his or her diagnosis, prognosis, treatment options, and their consequences. Even a capacitated minor should be engaged in such discussions whenever possible. Only when the disclosure of health information has been determined to be medically or culturally contraindicated should it be withheld from the patient and discussed only with the family.
- Notwithstanding the right to full disclosure, not all patients wish to know their medical conditions or make treatment decisions. This reluctance may stem from the individual's personality, customary problem solving behaviors, and/or cultural and spiritual background. Caregivers have a responsibility to determine whether patients would prefer to have these communications and the attendant decision making responsibilities delegated to family or close friends.
- Even though family members and friends indicate a desire to know the patient's condition and participate in health care decisions, the determination about who has access to medical information rests with the patient. Caregivers have a responsibility to determine and respect the capacitated patient's decisions regarding disclosure of medical and treatment information, and to protect the privacy rights of the incapacitated patient.
- The very personal nature of health care data

supports the notion that control of the information is an expression of patient autonomy and privacy. Caregivers have a responsibility to treat all patient communications as confidential. This responsibility includes explaining to the patient that, while numerous professional staff will have access to the medical record for the purpose of providing health care, every effort will be made to prevent unauthorized access and disclosure of information.

### *Skills and Knowledge*

- Care givers have a responsibility to become skilled in identifying the physical and emotional symptoms exhibited by patients at the end of life, and the various available treatment options, including drugs, radiation, surgery, psychotherapy, counseling, rehabilitation, nutrition, and other palliative treatment modalities.
- Caregivers have a responsibility to become familiar with the ethical issues and principles, as well as the hospital policies and procedures, related to end-of-life care, including informed consent; patient right to refuse treatment; withholding or withdrawing life-sustaining treatment, including nutrition and hydration; do-not-resuscitate, do-not-intubate, and do-not-hospitalize orders; advance directives, including living wills and health care proxies; determination of decisional capacity and surrogate decision making; and the doctrine of futility.
- Caregivers have a responsibility to understand and communicate to patients and families that, while there may be an *emotional* resistance to discontinuing therapy that is already in place, there is *no legal or ethical distinction* between withholding and withdrawing life-sustaining treatment. It is also imperative to understand and demonstrate that discontinuing *medical treatment* does not mean discontinuing *care*.

### *Education*

- The culture of medicine and medical

education has increasingly promoted the notion of cure as the paramount goal, making aggressive cure-oriented treatment the approved focus. The physical and emotional well-being of patients, and the professionalism and effectiveness of caregivers depend upon broadening the therapeutic goal to include the provision of high quality palliative care.

- The approval by the Health Care Financing Administration of a new diagnosis code for palliative or terminal care reflects the growing recognition of the importance of quality end-of-life care. This code will inform chart reviewers that patients received palliative care in the hospital, providing data for the possible establishment of payment for hospital-based end-of-life care. Because of the medical, fiscal, and social implications of this potential support, caregivers have a responsibility to accurately document in the medical record the provision of palliative care to their patients.
- Health caregivers and researchers have a responsibility to study the effectiveness of palliative care protocols and interventions.
- Health care educators have a responsibility to inculcate in their medical and nursing students, house staff, and other caregivers the notion that helping patients at the end of life achieve a peaceful, comfortable, and dignified death is a legitimate care goal.

## **Palliative Care Principles and Guidelines**

### *Pain Management*

- Caregivers have a responsibility to be knowledgeable about the various treatment options and resources available for pain management, including but not limited to:
  - pharmacologic agents — their effects, side effects, interactions, especially the properties of narcotic agents;
  - alternate routes of analgesia administration, including oral, sublingual, topical, subcutaneous, percutaneous, intramus-

cular, and intravenous, as well as patient-controlled analgesia (PCA);

- palliative surgery;
  - acupuncture; and
  - hypnosis and biofeedback.
- Caregivers have a responsibility to communicate clearly and truthfully, informing patients about the full range of treatment options, their benefits and risks, and the appropriateness of each for the patient's situation. This includes a thorough understanding of the distinctions among addiction, dependence, and tolerance.
  - Caregivers have a responsibility to become skilled in pain assessment, including the accurate recognition and evaluation of pain and related symptoms, such as fatigue, sleepiness or inability to sleep, weakness, loss of appetite, anxiety, shortness of breath, and depression.
  - Caregivers have a responsibility to demonstrate respect for the patient by giving credence to the reports of pain and other symptoms, and communicating that belief to the patient.
  - Because the patient's physical and emotional condition, diagnosis, prognosis, and lifestyle are all elements in the management of pain, it is essential to compile a complete record of information for analysis. Caregivers have a responsibility to obtain a complete history and physical, and a thorough and accurate pain history, including use of a valid pain scale and information regarding onset, duration, type, intensity, and relief of pain.
  - Successful pain management depends, in large part, on the patient feeling *in control of*, rather than *controlled by*, the pain. Caregivers have a responsibility to make patients partners in the management of their pain by involving them in the formulation and implementation of the plan of care.
  - Caregivers have a responsibility to provide reassurance that the pain will be attended to and managed, and also to help the patient

accept the limitations of what can be accomplished in providing relief of pain.

### Withdrawal of Ventilatory Support

- Caregivers have a responsibility to be knowledgeable about intubation and its implementation and discontinuation, including the physiological and psychological effects of withdrawal of ventilation, as well as the medication and other measures that assist in withdrawal of ventilation.
- Caregivers have a responsibility to honor the request of a capacitated patient who authorizes, either contemporaneously or through an advance directive or a health care proxy agent, the withholding or withdrawal of ventilatory support. This includes engaging the patient in a thorough discussion of the benefits, burdens, and risks of intubation and extubation, with the understanding that, even if ventilatory support is initiated, it may subsequently be discontinued if requested. This discussion should also involve a bioethics consultation and analysis, as well as a risk management assessment if appropriate. In the event that a caregiver is uncomfortable withholding or withdrawing intubation, s/he has a responsibility to transfer the patient's care to another caregiver.
- Caregivers have a responsibility to help patients understand what to expect in terms of discomfort and air hunger if they elect not to be intubated or to have ventilatory support withdrawn. Patients should be reassured that, although they will experience discomfort, they will be given whatever doses of appropriate medication are necessary to make them as comfortable as possible. This reassurance should be given to patients' families as well.
- Caregivers have a responsibility to promote the goal of comfort when capacitated patients consent to a do-not-intubate (DNI) order or to withdrawal of ventilatory support already in place. Patients who go into acute respiratory distress should be given oxygen by mask

and repeated and escalating doses of morphine by slow IV push until they are sedated and as comfortable as possible. When the goal is comfort and not the hastening of death, morphine administration is both completely legal and an ethical imperative.

- Caregivers have a responsibility to attempt to wean from ventilatory support patients who capably authorize withdrawal. If weaning is not possible, the patients' families should meet with caregivers to determine if it is appropriate for relatives to be present for withdrawal of ventilatory support. Caregivers have a responsibility to help families understand what to expect during withdrawal, and reassure them that the patient will receive whatever medication is necessary to promote comfort.
- Following withdrawal of ventilatory support, caregivers have a responsibility to provide the patient and family continued support and maximal comfort until respiratory stabilization or death has occurred. This includes maintaining a presence at the bedside whenever possible and providing measures to promote the patient's physical, emotional, and spiritual comfort.
- Caregivers have a responsibility to provide families an appropriate amount of private time with their deceased loved ones, including the opportunity to conduct any appropriate religious ceremonies. During this important time, caregivers have a responsibility to offer families psychosocial support and the opportunity to discuss postmortem plans, including autopsy, organ donations, and funeral arrangements.

### *Dialysis*

- Caregivers have a responsibility to be knowledgeable about dialysis, including the effects, side effects, long- and short-term indications for its use, and the consequences of withholding or withdrawing treatment.
- Caregivers have a responsibility to confer

with patients for whom dialysis may be indicated and help them to weigh the benefits, burdens and risks of the intervention, as well as the effects of withholding or withdrawing treatment. Exceptions to a full and frank discussion should be rare. Such exceptions might include cases in which the patient is so unstable that death is imminent, not within months or weeks, but within hours or days, or cases in which patients and families have made explicit their choice to forgo dialysis.

- Because dialysis can be either a long-term chronic treatment or a short-term palliative treatment, a clear understanding of the patient's values and treatment goals is essential in formulating a care plan. While it may be appropriate to begin dialysis, knowing that it may be discontinued at a later time, it is imperative to engage the patient and family in discussion about the indications for initiating or continuing treatments.

### *Artificial Nutrition and Hydration*

- There is a general conception that nutrition and hydration are basic human needs, rather than medical care. Current knowledge regarding the dying process, however, questions the appropriateness of providing artificial nutrition or hydration for all dying patients whenever they become unable to take food and drink by mouth. Caregivers have a responsibility to be knowledgeable about the appropriateness of artificial nutrition and hydration for each dying patient and become skillful in assessing each dying patient's nutrition and hydration needs.
- The goal of palliative care is to relieve suffering and in some cases initiating artificial nutrition or hydration involves painful procedures and surgery. Caregivers have a responsibility to distinguish between those times when artificial nutrition and hydration are appropriate, will relieve temporary suffering, and will prolong life, and those times when it will increase the patient's suffering and prolong dying, and to help patients and fam-

ilies weigh the benefits and burdens of this therapy.

- Caregivers have a responsibility to understand and alleviate fears and distress regarding nutrition and hydration at the end of life. To this end, caregivers should educate family and friends regarding the potential burdens imposed by inappropriately providing artificial nutrition and hydration, such as increased edema; increased urinary output requiring catheterization, bedpans, diapering, or trips to the bathroom; increased vomiting; and increased difficulty breathing.
- Caregivers have a responsibility to understand the physical consequences of not providing nutrition or hydration and provide relief for any symptoms of discomfort, such as dry mouth and lips, cracked mucosa, elevated temperature, and constipation.
- Insistence on artificial nutrition and hydration by family and friends may be a manifestation of guilt, a reflection of grief at the prospect of losing a loved one, or a response to religious imperatives. Caregivers have a responsibility to recognize these reactions and provide as much emotional and spiritual support as possible.

## Conclusion

Although this most recent draft of the Palliative Care Principles and Clinical Guidelines reflects the comments and suggestions of the full Montefiore Bioethics Committee, it is still a work in progress and is intended to spur wider and deeper discussion. Nevertheless, it represents one articulation of the profound issues encountered by patients, families, and caregivers as they struggle to face the end of life in ways that are principled and compassionate.

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