

MINISTERING TO PERSONS WHO FACE DEATH

Practical Guidance for Care Givers Of Persons Making End-of-Life Treatment Decisions

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Unsure of how to translate faith convictions into practical guidelines for ethical decision making, many care givers ignore spiritual and other nonmedical needs of persons struggling with end-of-life decisions. Seeking refuge in technical proficiency, such care givers minister well to the body, but absent themselves from any discussion about the need to rethink treatment priorities as the prospect of cure dwindles. Conversely, some care givers rigidly and at times erroneously apply religious directives in a manner that violates the autonomy of patients and other healthcare professionals. It is time care givers learn how to minister effectively and sensitively to those making end-of-life treatment decisions.

HOW WE VIEW DEATH AND DYING

To minister effectively to persons struggling with end-of-life treatment decisions, care givers need to be aware of the various meanings death and

dying hold. Culture, religion, past experiences with death and dying, and current situations can all influence the way persons perceive death and dying. The **Box** discusses the predisposing variables to undertreatment and overtreatment. The following vignettes illustrate the importance of beliefs and values in decisions about end-of-life treatment.

Culture Recently two young women were dying of breast cancer in our medical intensive care unit at Georgetown University Medical Center. One, an Ethiopian woman, and her family understood that death was inevitable. They were prepared to accept compassionate palliative care once a decision was reached that further aggressive treatment promised no medical benefit. The second, an American woman, could not believe that God would let her die, leaving behind a three-year-old daughter. She and her family were in denial and kept insisting that modern medicine would cure her, that it was only a matter of finding the right treatment.

Summary It is time care givers learn how to minister effectively and sensitively to those making end-of-life treatment decisions. To do so, care givers need to be aware of the various meanings death and dying hold. Culture, religion, past experiences with death and dying, and current situations can all influence the way persons perceive death and dying.

Sensitivity to who the patient and family are, to how they perceive the disease or illness, and to how this perception influences their ability to achieve their life goals is a critical care-giving skill. Sensitivity, however, need not result in value neutrality or tolerance. Care givers should not be mindless executors of patient or family demands.

Care givers must learn to talk honestly with patients and families about how a particular dis-

ease is most likely to progress and about the types of decisions they are likely to need to make. And then care givers need to present options, remaining sensitive to the patients' beliefs, values, and interests.

Persons who care for the dying will face three types of patients, who will require different types of responses. The three types are patients who welcome death, patients who accept death, and patients who fight death.

For all types of patients, care givers must keep the care patient centered and responsive to patients' priorities; facilitate informed decision making; promote communication among the patient, family, and healthcare team; support autonomous decision making; mediate conflicts; and offer spiritual counseling.

Religion Nowhere does religion seem more problematic than in pediatrics. While some parents refuse lifesaving medical care for children with irreversible problems for religious reasons, others demand futile care because they believe God will work a miracle for their child. Nurses on a gynecologic-oncology floor were frustrated recently when a pregnant Buddhist woman insisted on ignoring a large pelvic mass because she did not want to do anything that could harm the baby she was carrying.

Past Experiences with Death and Dying Two men, who had both recovered from serious illnesses, could not accept that their father would not recover from multiple-organ failure. They demanded that everything be done for their father, who, as a result of their intervention, spent the last six months of his life receiving aggressive therapy in an intensive care unit.

In a different vein, a woman newly diagnosed with breast cancer refused treatment because her father had died six weeks after being diagnosed with fulminating nasopharyngeal cancer. Her expectation was that death would come quickly, so why fight?

Current Life Situation Two elderly widows with similar medical histories became septic. One was tired of living, regretted that she had outlived most of her friends, and welcomed death. The

other was expecting the birth of her first grandchild and believed she had everything to live for.

PERTINENT CATHOLIC TEACHINGS

Sensitivity to who the patient and family are, to how they perceive the disease or illness, and to how this perception influences their ability to achieve their life goals is a critical care-giving skill. Sensitivity, however, need not result in value neutrality or tolerance. Care givers should not be mindless executors of patient or family demands.

Catholic medical ethics rejects both active euthanasia *and* the pursuit of earthly immortality through efforts to extend life indefinitely. Both attempt to substitute human control for God's dominion over life. Catholic teaching commits us to a presumption in favor of life, where hard decisions are made about the effectiveness of therapy and of its benefits and burdens. The challenge for care givers is to devise creative and compassionate strategies to meet the physiological, psychological, and spiritual needs of patients and to struggle with patients and families as they make complex decisions about the use of life-sustaining therapies.

Edmund D. Pellegrino summarizes Catholic teachings in an essay on human finitude:

Our lives are gifts of God over which we are stewards, but not absolute masters.

UNDERTREATMENT AND OVERTREATMENT: PREDISPOSING VARIABLES

The following are predisposing variables to undertreatment and overtreatment.

UNDERTREATMENT

Patient

- Welcomes death
- Finds life disproportionately burdensome
- Has no will to live

Family

- Experiences care taker burnout
- Is unable or unwilling to assume responsibility for care
- Is unprepared emotionally to wait out an uncertain future
- Wants to get on with living

Care Giver

- Is concerned with healthcare economics (may give greater weight to good of society than to good of one

patient, or may place personal or institutional good over patient good)

- Holds bias (may think that patient—because of age, finances, social position or worth, life-style, history of compliance, and other characteristics—does not deserve expensive, high-technology care)
- Believes dying process has been overmedicalized

OVERTREATMENT

Patient

- Fears or rejects death
- Is not ready to die, or has unfinished business
- Denies seriousness of prognosis
- Has misplaced confidence in medicine's ability to cure
- Does not trust healthcare professionals to provide appropriate care

Family

- Is unready to accept loss of loved one
- Denies seriousness of prognosis
- Has unrealistic expectations—faulty reasoning
- Depends on patient—emotionally, physically, socially, financially
- Experiences unresolved emotional issues such as guilt and anger

Care Giver

- Holds religious convictions that favor aggressive treatment
- Believes medicine should do everything possible to preserve life
- Accepts life in a vegetative state as an appropriate end of medicine
- Lacks knowledge of ethical norms governing the appropriate use or nonuse of life-sustaining therapies
- Views death as an enemy
- Fears legal liability

PATIENT RESPONSES TO DEATH AND CARE GIVERS' RESPONSIBILITIES

PATIENT WELCOMES DEATH

Patient Response Patient desires to hasten death, to choose the time and manner of dying:

- Suicide
- Assisted suicide
- Direct voluntary euthanasia

Care Givers' Responsibility

- Attempt to understand patient's motivation and work with the patient to determine if this desire is consistent with his or her beliefs, values, and interests (authentic autonomy).
- Correct patient misperceptions and unrealistic expectations.
- Address patient's fears (e.g., fear of losing control, dying alone, increasing dependence, intractable pain, meaningless days).
- Resolve underlying emotional issues.
- Treat depression.
- Resolve question of rational suicide; compatibility of assisting suicide or killing with ends of medicine and other healthcare professions; and individual conscience issues.
- Clarify related institutional, professional, and societal issues.
- Withdraw from case and prepare patient for transfer if indicated.

PATIENT ACCEPTS DEATH

Patient Response Patient accepts inevitability of death; welcomes death "when it comes."

Care Givers' Responsibility

- Keep interdisciplinary team focused on chief goal of medicine—restoration and cure; stabilization of functioning; compassionate, palliative care.
- Continue to evaluate the plan of care; a time-limited trial of life-sustaining treatment may be indicated; recognize when the best efforts to promote life are merely prolonging dying.
- Help patient or surrogate to weigh the benefits and burdens of new and continuing therapeutic options. Respect the patient's right to refuse minimally effective or disproportionately burdensome life-sustaining treatments.

PATIENT FIGHTS DEATH

Patient Response Patient "fights" or rejects imminent death (wants "everything" done, including medically futile care).

Care Givers' Responsibility

- Attempt to elicit source of patient's inability to accept impending death (e.g., fear, anger, denial).
- If patient has "unfinished business," provide necessary assistance to secure its completion (be sensitive to needs for forgiveness and reconciliation).
- Identify care giver variables that may be alienating the patient or family and impairing conflict resolution.
- As a last resort, refer to institutional futility policy.

Acceptance of finitude entails accepting death when it comes. It rejects the pursuit of earthly immortality by artificial prolongation of the dying process. To take advantage of effective and beneficial medical treatment on the one hand, and to reject what is ineffective and superfluous on the other, are charitable acts. To cut off life abruptly at our choice of time or by our own hands, or to ask for it at the hands of others, is to deny the reality of the Passion and Atonement in our lives. It is to belie Jesus' own admonition that we must take up our cross and follow him. ("A Philosophy of Finitude," in G. R. Winslow and J. W. Walters, eds., *Facing Limits: Ethics and Health Care for the Elderly*, Westview Press, Boulder, CO, 1993, pp. 31-53)

Although these teachings are clearly articulated in many Church documents and stem from a long tradition of Catholic medical ethics, many care givers and patients need assistance when applying them to actual decisions.

CARE GIVER RESPONSIBILITIES

Ministering to those making end-of-life treatment decisions is not the responsibility of any one group of healthcare professionals. But this task poses a special challenge to those who hold a particular set of faith convictions. We must learn to talk honestly with patients and families about how a particular disease is most likely to progress and about the types of decisions they are likely to need to make. And then we need to present options, remaining sensitive to the patients' beliefs, values, and interests.

Respecting patients' autonomy entails more than noninterference as decisions are made. It obligates care givers to promote autonomy by helping patients make decisions that reflect their identity, decisional history (how and why they made past decisions), and moral norms. *Choosing the right and good healing action* for any patient entails evaluating an intervention's probable effectiveness (ability to reverse or retard the underlying disease) and the proportionality of benefits and burdens. The former is an objective medical determination; the latter, a subjective determination only the patient or those who know the patient well can make.

Persons who care for the dying will face three types of patients, who require different types of responses (see Box, left). The following general guidelines will be helpful in caring for all dying patients:

- Keep care patient centered and responsive to patients' priorities.

- Facilitate informed decision making by ensuring that patients correctly understand the medical conditions, natural history of the disease, and prognosis and by "walking patients through" diagnostic and treatment options (including no treatment) and exploring likely consequences (effectiveness and benefit-burden ratios).

- Promote patient-family and patient-health-care team communication.

- Support authentic autonomous decision making (i.e., decisions consistent with patients' beliefs, values, and interests). Whether the patient or family professes a belief in transcendent life meaning may be important.

- Challenge decisions that conflict with the internal morality of medicine or violate care givers' conscience. Mediate the conflict and withdraw from cases when necessary. Patient autonomy does not compromise care giver autonomy.

- Document patient decision-making capacity

and preferences, and help prepare and implement advance directives.

- Ensure treatment goals are clearly articulated and communicated to the entire healthcare team, especially in intrainstitutional and interinstitutional transfers.

- Offer spiritual counseling.

- Mediate conflicts when patients' families or care givers contest patients' preferences. Clarify pertinent ethical norms governing the appropriate use or nonuse of life-sustaining treatments.

Care givers need to carefully explore the underlying fears that may give rise to requests for suicide assistance or euthanasia. Quiet tolerance legitimizes these options, so it is important to challenge these requests—but in a compassionate manner that offers other options to a suffering person.

Care givers should be familiar with the arguments for and against the involvement of health-care professionals in euthanasia and be able to articulate religious, as well as nonreligious, arguments against such involvement. If a patient per-

CASE STUDIES

A PATIENT WHO DESIRES DEATH

Mrs. Bittner, a 64-year-old widow, has suffered from emphysema and degenerative joint disease for the past 10 years. During her latest hospitalization, she explains to you that she simply cannot go on living this way. She is no longer able to do anything she wants to do either because it is too painful to move or because she does not have the breath to do it.

Mrs. Bittner lives with her daughter, who works all day and has three children. Mrs. Bittner says she will not impose on her daughter's kindness any longer. "Can't you give me something that will just put me to sleep forever? I've thought about this for a long time, and I'm convinced that this would be the best thing for my family and me. Surely God couldn't have intended for us to be so miserable."

You have cared for Mrs. Bittner during several past hospitalizations and know that this is not a new request. You also believe that she is not depressed; rather, she has evaluated her situation fairly accurately and concluded that this

would be the best course of action for both her and her family.

A FAMILY THAT DISAGREES

John and Jacob Meisner approach you as a Catholic healthcare professional whom they respect and trust. They are concerned about treatment decisions that will soon need to be made for their father, who is in a nursing home on an Alzheimer's disease unit.

Recently, the home asked Mr. Meisner's daughter (who has durable power of attorney for her father), John, and Jacob, to consider whether they want their father to receive nutrition through a tube, since he is no longer able to take in sufficient calories orally. The sons believe that their father would never have wanted to live this way and would view this inability to swallow as part of the disease and accept (and welcome) his impending death. John and Jacob are concerned that their sister will insist on a feeding tube, since she is committed to doing everything medically possible to keep their father alive. She has informed her brothers

that this is what Catholic doctrine demands.

A FAMILY FIGHTING DEATH

You are caring for a five-year-old boy with leukemia for whom all conventional therapies, including bone marrow transplant, have failed. His attending physician believes that he is in the last stage of his illness. The boy's parents believe that he will beat the odds and be cured. They know of another boy (the same age as their child) who recovered. "We believe God will cure our son if we can only be patient," say the parents.

When the boy's kidneys fail, the consulting nephrologist notes that dialysis is a possibility, but he does not recommend its use, since at best it would extend this child's dying and give him another month of painful life. The attending physician is unsure of whether dialysis should be presented as an option. Her belief is that the parents will choose to dialyze the child despite the recommendation against it because they are not ready to accept their son's death.

sists in demanding suicide assistance or euthanasia, care givers in Catholic institutions are morally obligated to withdraw from the case and to arrange for the patient's transfer. Catholic health-care organizations can provide moral leadership in these issues by sponsoring educational sessions that invite healthcare professionals to examine the

notion of rational suicide and explore the compatibility of assisting suicide and killing with the ends of medicine, nursing, and the other health-care professions.

When caring for patients or families who reject imminent death and demand aggressive care that care givers believe is physiologically, statistically, or disproportionately futile, care givers need to understand and mediate the source of the conflict. As the popularity of "futility policies" increases, it is important not to appeal too rapidly to a policy that gives care givers the authority to refuse the patient's or family's demands. This should only be used as a last resort after all efforts to understand how unrealistic expectations, illogical thinking, or unresolved emotional or spiritual issues—on the part of care givers, patients, and families—are influencing decision making. Without careful mediation, these types of conflicts typically result in a family's alienation from care givers. This can color all the family's future interactions with healthcare professionals.

The three cases discussed in the **Box** on p. 61 can be used to assess your competence and confidence in responding to patient and family requests for assistance in making end-of-life treatment decisions.

CARE GIVERS' RESPONSIBILITIES

Care givers and sponsoring religious institutions are charged to provide moral leadership in meeting the needs of persons struggling with end-of-life treatment decisions. As care givers, our responsibilities are to:

- Provide patient-centered care
- Clearly articulate the goal of therapy and ensure that the entire team is committed to this goal
- Develop a care system in which it is clearly communicated that comfort and palliation are valued as highly as restoration and cure
- Value and reward creative care strategies for addressing the fears that underlie requests for voluntary euthanasia or assisted suicide
- Challenge the belief that death is always the enemy and a symbol of failure
- Continue to educate ourselves about ethical norms governing the use or nonuse of life-sustaining therapies
- Respect a patient's right to refuse minimally effective or disproportionately burdensome treatments
- Identify the care-giver competencies essential to providing high-quality compassionate care, and hold care givers accountable for these competencies

TREATMENT DECISION RESOURCES

CATHOLIC MEDICAL ETHICS

B. M. Ashley and K. D. O'Rourke, *Healthcare Ethics: A Theological Analysis*, 3d ed., Catholic Health Association, St. Louis, 1989

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