

DANGER SIGNS

Coalition Points to Causes and Consequences Of Inadequate Care of the Dying

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At least 80 percent of the deaths in the United States occur in inpatient settings, primarily acute care hospitals. Only 10 percent to 12 percent of dying persons enroll in hospice programs. Although most healthcare resources and quality improvement efforts are targeted toward curative therapy, the fact remains that human beings die. Unfortunately, much like the greater community, healthcare professionals avoid dealing with death and dying and are unaware that care of the dying may be grossly inadequate.

Healthcare facility leaders should examine their organization for indications that care of the dying may be inadequate (see **Box** on p. 51). For those who find such danger signs, this article outlines the factors that lead to inadequate care and some steps that can help relieve the problem.

BARRIERS TO ADEQUATE CARE

Patients and families repeatedly express their need for supports based on compassion and caring, yet

healthcare efforts focus on often ineffective technological interventions and procedures. Those services which do exist for end-of-life care are based on clinician and physician *assumptions* about what dying persons and families need, rather than their *actual* assessed needs.

Lack of Training Physicians enter their profession with the goals of curing, promoting living, and applying new science to physical healing. Professional healthcare schools provide little or no formal training in pain and palliative symptom management or in the multidimensional approach to care of the dying. Unable to recognize the dying process (see **Box** on p. 52), physicians often transfer patients to intensive care units, where the natural process is seen as a medical complication. They aggressively battle medical complications with ventilators, dialysis, surgeries, and other technological interventions—only prolonging an inevitable death.

Lack of Time The pace of change in healthcare is pushing physicians and other professionals to

Summary Dying patients and their families repeatedly express their need for supports based on compassion and caring, yet healthcare efforts focus on often ineffective technological interventions and procedures. Professional healthcare schools provide little or no formal training in pain and palliative symptom management or in the multidimensional approach to care of the dying. And the pace of change in healthcare leaves little time for communication between the patient, family, and caring team. Physician denial of death and dying has a significant impact on clinical decision making and misleads healthcare administrators about priorities.

Even when clinicians want to practice holistic supportive care, they are often unable to because of competing productivity demands and lack of

reimbursement. Inappropriate therapies may be initiated to justify continued care in acute and skilled nursing environments. Because healthcare professionals may not inform families about what can be done in the way of supportive care, they may choose to "do everything," which often means using inappropriate treatments.

Supportive Care of the Dying: A Coalition for Compassionate Care is a unique collaborative effort to help change the culture of dying in healthcare and to help Catholic and other organizations offer appropriate care based on respect for the sanctity of life, regard for human dignity, and a commitment to stewardship. The coalition intends to develop a comprehensive supportive care model built on Catholic values and tradition.



treat more patients in less time using fewer resources. This leaves little time for high-quality communication between the patient, family, and caring team. Many medical residents report exhaustion and severely diminished empathy during their training as a result of long hours; unreasonable caseloads; and unrealistic expectations of superiors, hospital staff, and patients themselves.

A medical resident recently complained to us that he had become "mean" because of the pressures of his residency program. This young physician openly grieved over his decreased sympathy and empathy with patients. He said he would not survive his residency if he continued to care, to show compassion, and to advocate for patients who needed more time and multidimensional support. And he feared he would not be able to regain his empathy once his residency was complete.

Physician Denial Healthcare professionals regularly witness pain, suffering, and death in an environment that discourages acknowledgment of these events. Physicians, in particular, are groomed in medical schools to remain somewhat distant and aloof from such realities. While nurses may have opportunities to express feelings about a patient's death, physicians are often left out of such debriefings or avoid such interactions with non-physician colleagues. This practice promotes continued denial of death and dying among healthcare professionals. As noted in a recent study,¹ denial has a significant impact on clinical decision making and misleads healthcare administrators about priorities.

Lack of Reimbursement Even when clinicians want to practice holistic supportive (palliative) care, they are often unable to because of competing productivity demands and lack of reimbursement. Healthcare resources are almost exclusively targeted for curative intervention; end-of-life care is a low priority. Revenue-generating services are highly valued in the healthcare system, but we commonly fail to measure end-of-life care against a different template of resource sharing and indirect revenue production.

Even when dying is recognized and the healthcare team has communicated this to the family, inappropriate therapies may be initiated to justify continued care in acute and skilled nursing environments. The natural dying process includes progressive inability to swallow, a reduction in renal function, and subsequent inability for the body to handle fluids. When artificial means of infusing fluids are used in dying patients, the

potential for pulmonary edema is heightened. However, when faced with the choice of (1) allowing intravenous feedings or fluids to justify insurance coverage for continued acute care or skilled nursing facility placement, or (2) allowing the natural dying process to proceed and paying privately for care in intermediate care facilities or at home with hired care givers, a family often opts (with the healthcare team's encouragement) for the former.

DANGER SIGNS

Review the following "danger signs" that care of the dying may be inadequate; note how many are present in your system.

- ☐ Patients are dying in acute care facilities without family and staff communication about the impending death.
- ☐ Healthcare staff uses "sanitized" language for death and dying (e.g., "the patient has expired," "the patient is gone").
- ☐ There is no routine monitoring of outcomes for care of the dying.
- ☐ A general assumption exists that local hospice programs have "got the problem covered."
- ☐ Physicians cite fear of litigation as the rationale for transferring dying patients to intensive care units.
- ☐ Administrators rely on professional education alone to change clinical practice.
- ☐ The words "There's nothing more we can do" are commonly used in reference to a dying person.
- ☐ Clinicians believe that all patients or families must make decisions about cardiopulmonary resuscitation.
- ☐ No support is available for healthcare professionals who work with dying persons and their families.
- ☐ The house staff is exhausted.
- ☐ No formalized bereavement follow-up is offered to survivors of persons who died as inpatients.
- ☐ No diagnosis-related group exists for supportive (palliative) care.
- ☐ No routine spiritual assessment is included in the patient record.
- ☐ Board of directors never asks and is never told about challenges healthcare professionals face in dealing with care of the dying.
- ☐ Average length of stay in hospice program is less than 120 days.
- ☐ Artificial nutrition and hydration are commonly initiated when dying patient loses ability to swallow.
- ☐ Physicians believe that patient deaths mean "physician failure."
- ☐ Everyone believes that completion of advance directives will solve problems listed above.

Did you find more than three or four "danger signs" in your system? If so, the risks of pain and suffering are very great. We urge you to champion change in your system's culture of caring for persons with life-threatening illness.

Likewise, although 85 percent to 95 percent of pain can be adequately managed by the oral or rectal administration of analgesics and adjuvant medications and other "low-tech" interventions, more costly intravenous infusions may be initiated to support skilled care. Clinicians are not promoting these interventions because they want to overtreat patients or inappropriately utilize resources; they may believe they are acting in the best interest of their patients and families. Many clinicians are not aware of the availability of comprehensive supportive care, and, moreover, it is *not* available in many communities.

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emotional, spiritual, and social support to patients and families during illness, and bereavement support to the family after the patient's death, acute care and long-term care facilities rarely provide these services. The crisis of losing a loved one without support and empathetic assistance can lead to complicated grief. Isolation and abandonment during bereavement often lead to increased risk of

morbidity and mortality for surviving family members.

Families' Role in Decision Making Another factor often increasing the use of inappropriate technologies that only prolong the dying process is the patient's and family's involvement in decision making. By asking patients and families to "choose" whether to use a therapy such as ventilation or dialysis, physicians imply there is a choice. Our deceptive presentation of "odds" (e.g., a "5 percent chance of surviving" versus a "95 percent chance of dying" with a certain treatment) influences patient and family decisions. When possible benefits and burdens are clearly and fairly represented, patients may choose to forgo inappropriate treatment. However, many families cannot bear to think they are "allowing" their loved one to die and urge the physician to "do everything." Because healthcare professional may not be aware of or fail to inform families about what can be done in the way of supportive care (keeping people comfortable while they die naturally of disease), "doing everything" often means utilizing inappropriate treatments.

Physicians and other healthcare professionals may erroneously believe they are at risk of litigation if they refuse to follow family directives even when interventions are blatantly futile. In many situations, when patients have communicated their wishes to the physician and have written directives to avoid inappropriate treatment at the end of life, physicians still will treat the patient when families demand it. Not only is this a direct violation of the person's informed choice (with possible legal ramifications), it also places undue burden on the family when this treatment must

PHYSICAL MANIFESTATIONS OF THE DYING PROCESS

When death is the expected outcome, the following signs and symptoms are seen as natural occurrences, rather than medical complications to be obstructed or prolonged:

- Dying person refuses food . . .
- Increasing weakness . . .
- Social withdrawal (refusing visits from neighbors and friends) . . .
- Somnolence (increased sleepiness regardless of whether a person is taking opioids for pain or symptom management) . . .
- Voice initially hoarse, then a whisper . . .
- Refuses fluids . . .
- Emotional withdrawal from loved ones . . .
- Dysphagia (progressive inability to swallow) . . .
- Decreasing blood pressure . . .
- Increasing pulse (initially) . . .
- Cool, moist extremities . . .
- Decreasing pulse . . .
- Mottling (a purplish color variation in skin indicating decreased circulation) . . .
- Cheyne-Stokes respirations (an uneven respiratory pattern with progressively prolonged pauses) . . .
- Cessation of respiration . . .
- Cessation of heartbeat . . .

ultimately be discontinued to allow the patient to die.

A complicated bereavement follows for families who believe they have betrayed their loved ones by forcing unwanted treatment on them or ultimately deciding to stop treatment. Some family members actually feel they have made a decision to "kill" their loved ones by allowing the physician to discontinue a ventilator or some other death-prolonging technology.

SUPPORTIVE CARE OF THE DYING

Supportive Care of the Dying: A Coalition for Compassionate Care is a unique collaborative effort to help change the culture of dying in healthcare and to help Catholic and other organizations offer appropriate care based on respect for the sanctity of life, regard for human dignity, and commitment to stewardship. (See Box.)

Although the coalition's title refers to dying, the six member organizations recognize that the best way to care for the dying is to intervene much earlier. The trajectory of illness begins at the time of diagnosis of a life-threatening illness and ends after comprehensive bereavement care for the family after the patient's death (see Figure, p. 54).

The coalition intends to develop a comprehensive supportive care model that could be implemented in any healthcare organization across the United States. The model will be piloted in selected Catholic healthcare settings, but information will be shared outside of Catholic healthcare as well. Although this model is being built on Catholic values and tradition, the permeable model boundaries will allow a respectful balance between community and individual values, norms, and expectation.

Unlike the current situation in which persons are viewed as "patients" who must come to the healthcare system for care, the supportive care model will promote service to persons in their own supportive environments. This will require that such services move beyond the traditional "walls" and into industry, schools, churches, homes, social service agencies, and rural environments. Services will be tailored to individual and community needs and be supported by health benefits and payer systems.

The supportive care model will be person and family centered rather than disease and physician centered. A dynamic care plan will be developed jointly by the person with life-threatening illness, the family (of origin and/or choice), the interdis-

ciplinary healthcare team, and community supports.

High-priority, high-quality supportive care is not only the "right" thing to do, it also promotes improved patient and family coping and satisfaction, enhances job satisfaction for healthcare professionals, creates an "environment of care" that serves the entire system and community, and generates indirect revenue in the form of individual and industry donations to system foundations and community service agencies.

COALITION WORK IN PROGRESS

While the coalition is building and testing the model, intermediate products will be available. An initial product is a needs assessment. Various focus group sessions to be held across the country between March and June will elicit from five targeted groups the actual information, program, and service needs of individuals dealing with life-threatening illness. The focus group methodology is now being piloted in sessions with:

- Persons with current life-threatening illness
- Personal care givers (family, friends, volunteers)
- Bereaved family members
- Professional care givers of persons with life-

SUPPORTIVE CARE OF THE DYING: A COALITION FOR COMPASSIONATE CARE

The Supportive Care of the Dying coalition was founded in 1995 by the Catholic Health Association and five Catholic healthcare systems: Carondelet Health System, St. Louis; Daughters of Charity National Health System, St. Louis; Franciscan Health System, Aston, PA; PeaceHealth, Bellevue, WA; and Providence Health System, Seattle. The coalition's goals are to:

- Assess the current level of care to identify, develop, and share delivery models pertaining to all dimensions of care for the suffering and dying
- Develop and implement a paradigm of compassionate care that integrates ethical, clinical, and spiritual dimensions
- Develop educational programs for professional care givers, families, and the broader community
- Establish criteria and measurement guidelines to assess processes, outcomes of education, compassionate care services, and methods of assigning accountability for these guidelines and processes
- Foster networking among care givers and identify resources within the broader community that support compassionate care of persons with life-threatening illness

threatening illness

- Community members with little or no experience with death or dying

Information gained from the needs assessment will be used to improve the recommended model of supportive care in order to produce information, programs, and services that more appropriately and directly address needs. These include:

- Education and training modules
- Hands-on mentor program to ensure assimilation of new knowledge and skills into current clinical practice
- Guidelines for both clinical practice and leadership competencies to promote excellence and a high profile for end-of-life care and resource allocation
- A quarterly project newsletter, *Supportive Voice*, to keep members and the broader community abreast of progress and developments (The first edition of the newsletter was mailed in the first quarter of 1996.)

BEYOND ASSUMPTIONS

Until we know more about the actual needs of persons living the experience of life-threatening illness, we risk both underserving persons in need and overutilizing expensive resources for inappro-

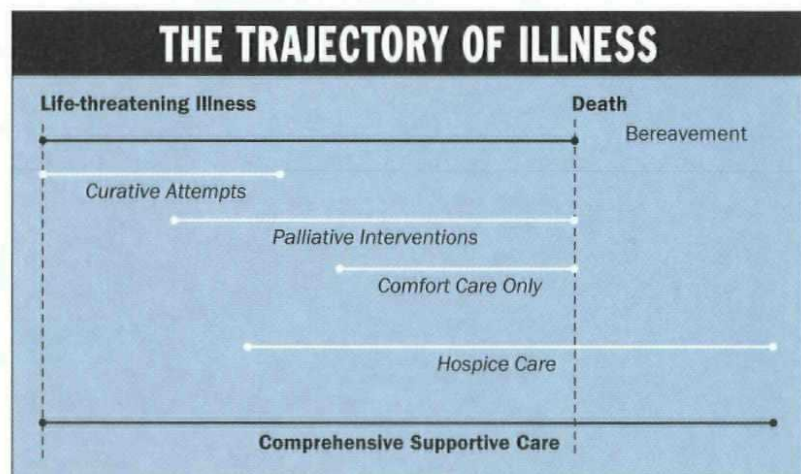
Leaders must change the culture of death and dying in the United States.

appropriate care. Advance directives, software to facilitate clinical decision making, and physician-assisted suicide initiatives are smokescreens to avoid dealing with death and dying and to provide the illusion of control with end-of-life issues. Laws, documents, and blips on computer monitors cannot facilitate the kind of care people really want and need when faced with life-threatening illness.

Just as the care of this population requires time and commitment from compassionate, skillful clinicians and welcoming communities, the training for and implementation of this care will require permanent change and committed resources. Hence leaders in healthcare, government, and local communities must assume their proper advocacy roles to change the culture of death and dying in the United States and bring to life these words from the coalition's vision statement:

In a manner consistent with Catholic teaching, we believe that patients have a right to maximal comfort regardless of the stage of their disease or their life expectancy. We are committed to providing quality care in a way that alleviates pain and minimizes suffering.

We are committed, as well, to establishing and maintaining standards whereby physicians and other members of the healthcare team will be held accountable in working toward this goal. Interdisciplinary clinical teams are an effective antidote to fragmentation of care, while promoting accountability. As values-based organizations we are committed to focusing our energies and to providing resources to further enhance the visibility of this issue within our healthcare systems and beyond. □



☎ For more information on the coalition, or to receive the newsletter, contact Project Coordinator Alicia Super, Providence Health System, 4805 NE Glisan St., 2E09, Portland, OR 97213-2967; 503-215-5053.