

# THE ETHICS OF LOVING CARE

**A**s the 21st century begins, dissatisfaction with medical care is high and the U.S. health care system is in need of repair. Costs continue to climb, while quality is uncertain. Medical errors are rampant.<sup>1</sup> Both acute and chronic pain are undertreated, and a public health crisis involves care of patients with advanced, incurable illness and support (or the lack of it) for those patients' families. Medical services are commonly viewed as impersonal and lacking in human values. Too often, relationships among patients, their professional caregivers, and the health care system verge on adversarial.<sup>2</sup>

The situation is particularly grave in the realm of end-of-life care. Contemporary studies of medical care for dying persons and support for their families reveal many deficiencies.<sup>3</sup> Pain among patients with advanced disease is often inadequately evaluated and treated.<sup>4</sup> Communication between doctors and patients often falls victim to a conspiracy of denial involving patients, their families, and physicians.<sup>5</sup> Increasingly, time-pressured clinical encounters make it easy to avoid talking about the real implications of disease progression and about dying. Absent discussions of the full range of caring options, the "system default" is to persist with aggressive life-prolonging treatment as long as possible and at all costs. The human costs incurred can extend to entail needless physical discomfort and loss of all sense of dignity for the person dying.<sup>6</sup>



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BY IRA BYOCK, MD

## HOW DID THIS PREDICAMENT DEVELOP?

Much has been written on the evolution of medical treatment during the 20th century and the trends which have shaped our current approach to seriously ill patients.<sup>7</sup> However, several key assumptions and cultural features of clinical practice deserve attention for their synergistic effect of constricting our care and limiting our ability to perceive a full range of possible human responses to suffering people and their families.

**"Subtractive" Themes in Practice and Biomedical Ethics** The principles of autonomy, nonmaleficence, and distributive justice have dominated clinical ethics in the 20th century. A corresponding reduction of emphasis on beneficence has contributed to "subtractive" themes in practice and ethical discourse. This trend is reflected in the literature, discussion, and debate related to withholding or withdrawing potentially life-sustaining treatments. Early formative developments of clinical ethics focused on the sanctity of a person's body and protection of the body from unwanted intrusion. Landmarks in this trend include *Union Pacific Railroad v. Botsford* (1891) and *Schloendorff v. New York Hospital* (1914); the Quinlan, Barber, and Cruzan cases; and the report of a presidential commission and a number of key white papers.<sup>8</sup> Each of these court decisions and published statements emphasized principles concerning patient autonomy and non-maleficence. Collectively, they established parameters and guidelines for avoiding or removing treatments that were prolonging or might prolong life.

Throughout this period, the assumed community standard of medical care has been maximal life-saving medical interventions. "Doing everything" for a patient has meant doing anything possible to keep the patient alive. Ethical advocacy in this context often emphasized protection from unwanted medical interventions, including the right to refuse surgery, cardiopulmonary

resuscitation, mechanical ventilation, and artificial nutrition and hydration. Similarly, many advances in clinical ethics have taken the form of carefully crafted guidelines and procedures for withholding, withdrawing, or refusing medical therapies. Extensions of these principles have led to broad agreement regarding the role, responsibilities, and rights of families (or formally named legal surrogates) to refuse medical interventions on behalf of seriously ill, injured, or otherwise incapacitated persons.<sup>9</sup> Advance directives, developed as tools for extending an individual's personal autonomy into a possible future period of incapacity, have been used almost exclusively to refuse unwanted treatments. In this context, beneficence has been generally understood as saving life whenever possible; withdrawing treatments when unwanted; and alleviating suffering, especially when cure is not possible.

As ethical thought evolved, the clinical professions and society as a whole asserted their rights as stakeholders to participate in decisions regarding the propriety of medical interventions and the use of limited resources. This has been reflected in cases and literature related to withholding or withdrawing life-prolonging medical treatments under the principles of futility or distributive justice and the responsible allocation of limited social resources. More recent ethical debate has included questions related to defining categorical circumstances within which society and the clinical professions may offer less-than-maximal life-prolonging care.<sup>10</sup> Each of these topics concerns services being reduced, withdrawn, or avoided.

The active debate regarding legalization and social sanctioning of physician-assisted suicide and euthanasia—the intentional removal of life in service of the sufferer—may be seen as a logical extension of these subtractive themes in clinical ethics and care.

To its advocates, physician-assisted suicide represents a new medical service that responds to the demands of suffering patients, their families, and a public fearful of suffering. Proponents of legalizing physician-assisted suicide<sup>11</sup> and euthanasia<sup>12</sup> assert that in certain circumstances of suffering, pre-empting death is beneficent as well as an extension of personal autonomy. A countervailing view holds that while beneficence encompasses any caring intervention, including sedation for otherwise intractable symptoms, it does not encompass *eliminating the sufferer*. Intentionally causing another person's death falls outside the realm of acceptable human interactions, even in response to suffering. Therefore, actions to pre-empt death fall outside the realms of proper clinical practice and biomedical analysis.<sup>13</sup> In this view, whether or not death is considered to be in an

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individual's best interests or desired by the person him- or herself, the nature of care—reflected in the definition “to look after, to provide for”<sup>14</sup>—extends to an open-ended future in which death is inevitable but not predetermined.

Opponents of euthanasia and physician-assisted suicide thus enthusiastically welcome the development of new ways to alleviate suffering.

**The “Problem-Oriented Model” of Medicine** The “problem-oriented model” of medicine had its inception in the development of the problem-oriented medical record. Introduced in the 1970s, this innovative reporting format revolutionized the manner in which medical care is organized.<sup>15</sup> Having heard a patient's chief complaint and made an initial evaluation, a physician creates what is known as a “problem list” for the patient. The problem list then serves as a table of contents for his or her medical record. The physician will approach each identified problem through the collection of *subjective* and *objective* information; for each problem an *assessment* is made and a *plan* of care is developed. This S-O-A-P format of charting shapes the contemporary clinical encounter. It has emerged as the de facto conceptual framework for medical care and has inadvertently contributed to a narrowed understanding of beneficence. Its unintended consequences have rarely been examined.<sup>16</sup>

Within the prevailing medical model, people come to doctors with problems. If a person should appear to have no identifiable problem, the physician may assume that no substantive evaluation or interventions are required. Faced with an asymptomatic patient, clinicians may well assume that there is nothing to do, or at least that nothing *needs* to be done. (In adult medicine, vaccinations and limited, disease-based screening comprise the extent of nonproblem-oriented care.) In an era of increasing financial pressures, this approach may at times provide a convenient rationale for constraining the scope of care. Within this operational framework, the tacit definition of “health” is the absence of identified problems associated with illness or injury.

Today an individual patient's plan of care is the aggregate of plans for specified problems. Active efforts to improve a person's quality of life find no place in this approach. In mainstream medicine, unless a patient manifests depression or disruptive behavior, or his or her psychological distress crosses the threshold of a psychiatric diagnosis described in the *Diagnostic and Statistical Manual of Mental Disorders*<sup>17</sup>, nothing triggers the health system to act. In general, patients today must earn their doctors' attention by suffering.

This constraining influence is reflected in the

domains and individual items that comprise commonly used "quality of life" (QOL) scales.<sup>18</sup> The items that constitute most QOL surveys, scales, and indices have to do almost exclusively with symptoms, social and physical function, and independence. Such assessment tools may deliberately exclude domains of personal experience, even those of central importance to patients. As a key researcher of QOL assessment has noted, apparently without irony, "Undoubtedly, such issues as happiness and life satisfaction factor heavily into an individual's judgment of his or her quality of life. Yet, these issues are so distal to the goals and objectives of health care that it would seem inappropriate to apply them as criteria against which to judge the efficacy of medical interventions."<sup>19</sup>

This kind of thinking tends to be reinforced by the problem-oriented clinical model and corresponding QOL assessment tools in common use. Embedded in many such tools is the assumption that a person's QOL can be improved only in direct proportion to the extent that pre-illness performance can be restored. This assumption may be valid for most people during most phases of illness, but there are important exceptions.

Although the assumed linear relationship between QOL and a person's physical and functional status may be valid during earlier stages of illness, it commonly proves to be false in the context of far-advanced illness. Empirical evidence from clinical narratives reveals that, in the face of death, people can experience contentment and an *ongoing sense of importance, meaning, and value* in life despite considerable discomfort and profound functional limitations.<sup>20</sup>

As two observers have noted:

From time to time, a terrible event happens to someone, and yet the survivor finds herself or himself better off. Through injury, a person is rendered paraplegic, or even quadriplegic; cancer strikes, requiring debilitating chemotherapy and raising the specter of a shortened life. The person suffering the calamity transcends the suffering and the loss and finds new meaning in life. Living becomes a richer, more satisfying experience and, in extreme instances, people feel that they never really appreciated life until their tragedy."<sup>21</sup>

One such individual has been described in an early paper concerning the limitations in QOL assessment.

I shall long remember the young patient who in dying commented that his final months (which had been characterized by

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relentless physical deterioration and considerable suffering) had been "the best year of my life." The day he made that comment this young athlete, scholar, and executive who had measured 10/10 on the [Spitzer] QL [scale] throughout his life, measured 2/10. Clearly he was referring to something not embraced by the scales measuring activities of daily living and not reflected in the Spitzer QL."<sup>22</sup>

#### PALLIATIVE CARE AND PEDIATRICS: SAFE HARBORS FROM PROBLEM-BOUND MEDICINE

Two disciplines in contemporary health care have resisted the confining influence of problem-oriented medicine: palliative care and pediatrics. They would, at first glance, seem unlikely partners in this resistance. However, the conceptual frameworks through which the two approach the clinical encounter are remarkably similar. Beginning as the hospice movement, palliative care in America was a response to the perception that care for dying patients had become often ill-considered and inhumane. Hospice in the United States originated outside the mainstream of health care. In its early years, hospice represented a counterculture among the clinical disciplines in its approach to care. Hospice advocates alleged that a technological imperative within medicine resulted in patients becoming depersonalized objects of medical intervention.

Earlier in the 20th century, a pivotal development in pediatrics had occurred in response to an epidemic of "hospitalism" (later known as the "pediatric failure to thrive" syndrome), a devastating condition that resulted in many thousands of childhood deaths and near-universal, profound retardation among infants raised in orphanages. The discovery that this syndrome was caused, not by some toxin or infectious agent but rather by deficiencies in simple human interaction, gave rise to a mandate for physicians who care for infants to focus on the whole person of their patients, including patients' families (see **Box**, p. 15).

A poignant analogy to the hospitalism occurring in many foundling homes of the early 20th century can be found in too many 21st century nursing homes for America's most frail and elderly patients. Sensory and emotional deprivation, engendered by the sparse physical and psychosocial environments of institutionalized elders, results in a syndrome of geriatric failure to thrive as stark as that described by the researchers who discovered hospitalism among foundlings.<sup>23</sup> While many factors contribute to the paucity of human interactions that nursing home residents experience, a pervasive and insidious influence is exerted by revenue streams for long-term care and a regulatory

environment that turn on documented medical problems—problems that are increasingly tightly defined: No active problems, no active service.

A nursing home resident's problem list and corresponding routine and as-needed medications comprise the plan of care. Diagnoses such as high blood pressure, mild dementia, osteoarthritis, osteoporosis, and benign prostatic hypertrophy provide the lens for clinical assessment and response.

From this perspective, a nursing home resident's care may appear adequate even though the person languishes. Since staffing and supportive therapy resources are in short supply in today's long-term care facilities, physical and occupational therapies are instituted only when there is a documented medical necessity and demonstrated potential for rehabilitation. In many long-term care settings, routine psychosocial screening is minimal. A resident's sense of personal well-being is not a matter for professional concern unless the person's distress is overtly expressed as "pain" or through disruptive behavior. Absent medical indications for specific therapies, residents may remain untouched and unstimulated for long periods of time and receive attention only when they are wet or it is time for them to be fed. It is no wonder that people can feel infantilized by the manner in which they are cared for.<sup>24</sup>

The meager nature of much nursing home care is widely recognized.<sup>25</sup> Many people experience placement in a nursing home as abandonment by their families. Correspondingly, adult children, while recognizing they had little choice, may feel guilty about putting a loved one in such a home. It is common to hear someone describe how a grandparent or parent "seemed to give up" after being admitted to a nursing home.

While this distressing state of affairs is widespread, it is rarely caused by either malfeasance or lack of caring. Indeed, even family members who emotionally describe the withering of a relative often explicitly emphasize that the nurses and aides were doing all they could.

Insufficient staffing is one root cause of this woe-filled predicament. No amount of caring intention can suffice when there is no one to answer a call bell and help the person to the bathroom; or to sit with a person who is agitated, lonely, or afraid. Here again, the insidious forces that constrain individuals' plans of care collectively pare staffing to a bare minimum, or beyond. Each line item in the budget of an agency, department, or clinical program must be justified by delineated needs.

#### TOWARD A BALANCED APPROACH

Within an ethic of caring, principles of autonomy and protection from unwanted intrusion can be

balanced by giving proportionate weight to the principle of mutual responsibility. Attention to nonmaleficent avoidance of harm and beneficent protection from unwanted life-prolonging care must be balanced with reliable provision for basic needs for shelter, hygiene, assistance with eating, drinking, and elimination.

It is insufficient to call attention to the pernicious constraints imposed by prevailing assumptions and trends without also exploring alternatives to them. Fortunately, such an exploration is supported by empirical data in both biographical literature and the clinical literature of palliative care. Individual narratives provide compelling evidence that the human experience with illness and

### The Discovery of "Hospitalism"

It had long been recognized that neonates institutionalized in orphanages universally suffered from profound deficiencies in cognitive and behavioral development, often had stunted physical growth, and were at greatly increased risk of dying during infectious epidemics.

Researchers documented that the key difference among care settings lay in the amount and quality of interactions with the child.\* Infants in the foundling home were well-fed, cleansed, and swaddled. They subsequently lay undisturbed in bassinets until they were next scheduled to be fed or have their diapers changed. The researchers concluded that the syndrome was caused by profound sensory and emotional deprivation during a critical early stage in childhood development.† Subsequent prevention of this syndrome by prescribed "normal" interaction and stimulation of newborns confirmed the etiology. Independently, other researchers provoked a nearly identical syndrome by raising infant macaque monkeys in circumstances of emotional deprivation.‡

In hindsight, the cause of pediatric failure to thrive seems obvious. It is important to note, however, that it was not at all obvious at the time. Despite their best intentions, staffs of foundling homes focused their attention on the physical necessities. As they saw it, an infant had no problem unless something was physically wrong, such as difficulty feeding or diarrhea or a fever. The recognition of pediatric failure to thrive as a profound, often fatal, and entirely preventable syndrome spurred expansion of responsibility within pediatric medicines. Pediatric providers were henceforth required to monitor and protect the emotional and intellectual growth of the child. By extension, this mandate entails attention to the health of the family system, at least as it affects the level of infant stimulation, the child's living environment, and the quality of parenting.

\*R. Spitz, "Hospitalism: An Inquiry into the Genesis of Psychiatric Conditions of Early Childhood," in R. Eissler, ed., *The Psychoanalytic Study of the Child*, vol. 1, 1945.

†R. Spitz, "Hospitalism: A Follow-Up Report on the Investigation Described in Volume 1," in R. Eissler, ed., *The Psychoanalytic Study of the Child*, vol. 5, 1946.

‡H. F. Harlow and R. R. Zimmerman, "Affectional Responses in the Infant Monkey," *Science*, vol. 130, 1959, pp. 421-432; and H. F. Harlow and C. Mears, *The Human Model: Primate Perspectives*, V. H. Winston & Sons, Washington, DC, 1979.

dying encompasses more than suffering or its alleviation. The narratives suggest that at times life with illness, even when acknowledged to be terminal, can be highly valuable for the affected person as well as for those who love them. Stories about positive aspects of people's experience with dying challenge us *conceptually* to expand our understanding of beneficence. They challenge us *clinically* to extend the range of caring services and human interactions so that those services and interactions can potentially benefit seriously ill individuals and their families.

The principle of beneficence finds completion and internal balance when it complements alleviation of suffering with *preservation of opportunity*. Correspondingly, in clinical practice interventions to alleviate suffering can be complemented with caring efforts to improve quality of life, including deliberate efforts to evoke pleasure and joy.

Palliative care clinicians relate stories about withdrawn and profoundly demented patients who have been determined to be dying, but then thrive, becoming more alert and interactive, once they have been admitted to a hospice program. Ironically, under current reimbursement rules and regulatory scrutiny, sustained improvement renders a patient ineligible for continued hospice care—and thereby forces his or her withdrawal from the very services that might well improve the quality of his or her life. The success of pro-

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grams to improve stimulation of people with dementia, and of the Eden Alternative movement in nursing homes, offer persuasive evidence of the positive impact that increased stimulation can have on institutionalized elders, particularly patients with moderate and advanced dementia.<sup>26</sup> (For an example of such a case, see "The Story of Ester O'Hara," below.)

#### A DEVELOPMENTAL FRAMEWORK FOR END-OF-LIFE CARE

The conceptual framework of lifelong human development underlies a therapeutic approach to palliative care that resembles mainstream pediatrics. Palliative care recognizes dying as a normal stage in the life of the individual and his or her family and applies a "treat, prevent, promote" intervention strategy to alleviate suffering, improve quality of life, and preserve meaningful opportunities for patients and their families.<sup>27</sup> Dying, at whatever chronological age the process occurs, constitutes a profound developmental challenge for every person. Suffering in the context of a terminal condition commonly includes physical discomfort and functional disability, but it also often extends into other dimensions of a person's life. Suffering often derives from a felt loss of meaning and purpose in life and the impending disintegration of one's self.<sup>28</sup> The dying person is forced to confront discomfort, disability, dependence, and ever-closer death.

### The Story of Ester O'Hara

Ester O'Hara, a woman in her late 80s, resided in a nursing home. She had dementia and slowly progressive weight loss and was withdrawn, noncommunicative, and entirely dependent on others for her activities of daily living. When she developed a breast mass, her family asked that she receive hospice care.

Hospice intervention began with a review of Mrs. O'Hara's chart, multiple medical problems, and prescribed medications, wound care, and other physical treatments. The hospice physician performed a physical examination, explaining each step to Mrs. O'Hara before proceeding. She kept her eyes closed and remained mute and entirely passive during the examination. When the doctor finished, he said, "Mrs. O'Hara, I am done now. Thank you for your patience. It is a pleasure to meet

you and to help care for you." At that moment she abruptly opened her eyes, looked the doctor squarely in the face, and replied, "Of course it is!" These were the first words anyone had heard her utter in many months.

Mrs. O'Hara's response reminded the physician, the hospice team, and the nursing home staff that they were caring for a whole person. Together they developed a new plan of care that complemented the skilled nursing care she was receiving. They made certain that Mrs. O'Hara had family members or volunteers who would visit and talk or read to her. At meal times, her visitors would encourage and help her to eat. For two months she began to gain weight and became more responsive.

During this time, Mrs. O'Hara evinced a child-like quality that was in contrast to her advanced years. While respecting

the dignity of her age and place as matriarch of a large family, the clinical team instituted a program of nurturing Mrs. O'Hara, a program similar to the care that would be provided to a young child. A favorite Teddy bear became her constant companion, and she clutched it tightly during uncomfortable dressing changes and treatments. She still spoke only intermittently and usually with just a word or two, but at times her words seemed surprisingly well-considered. One day when the hospice chaplain commented to Mrs. O'Hara that it was good to see her with her bear, she said, "He and I have been through a lot together."

When Mrs. O'Hara died several months later, she was surrounded by nursing home staff and family, some softly humming, each lovingly touching a part of her body.

From the perspective of developmental psychology, the challenge involved in integrating these unwelcome facts into one's ongoing personal experience resembles other life-stage crises. An ill person's assumptions about the world and sources of confidence and stability may be threatened. The expectations of others toward the dying person tend to shift and the person may discover that habitual ways of being no longer fit, having become irrelevant to his or her new life situation. All the activities, roles, relationships, plans, and possessions that have hitherto given meaning, purpose, and pleasure to life and on which a person's very sense of self is built may be threatened by a terminal illness. It might seem impossible (despite its similarities with earlier developmental crises) for a person to adapt to, perhaps even grow through, such a crisis, since death portends personal annihilation. In the world of experience, however, we observe that such adaptation and growth can occur.

Although suffering associated with dying is all too common, it is neither ubiquitous nor immutable. Instances of people emerging from the depths of hopelessness to a sense of wellness in the face of death may be uncommon, but the fact that such transformations occur, even if only rarely, provides a window into the core of the therapeutic encounter.<sup>29</sup> Indeed, ignoring this aspect of the phenomenology of human experiences would erode the scientific integrity of palliative care.

One important advantage of having a developmental framework for clinical care is that patients who experience suffering associated with dying need not be labeled "ill" or "dysfunctional" for their distress to be acknowledged and addressed. Instead, most cases of emotional turmoil and personal suffering can be understood as part of the difficult—but normal—process of living with the profound challenges of progressive illness, functional disability, and the awareness of impending demise.

When "health" is tacitly understood as the absence of injury or illness, the dying person is obviously unwell. However, the fact that a person has a medical illness need not in itself define him or her as unwell. A developmental model can encompass an understanding of suffering as arising from the symptoms and physical disability of illness and the attendant loss of social roles and accustomed sources of meaning and felt purpose in life. Yet a developmental framework is not confined to symptoms and suffering. It can encompass positive experience associated with the last phase of life and can assist in understanding the transitions that sometimes occur between these poles of human experience evoked by confrontation with death.<sup>30</sup>

Preservation of opportunity for human devel-

opment at the end of life has been recognized as an essential component of palliative care.<sup>31</sup> A developmental model better enables clinicians to assess and understand the psychological and emotional dynamics that underlie personal adaptation. Each person approaches the end of life with a unique sense of what is most important and what would be left undone if he or she were to die suddenly. A developmental conceptual framework provides a clinical framework for actively assisting patients and families with issues of life completion, life closure, and healthy grieving. In doing this, it does not supplant, but rather complements, a problem-oriented medical model which is appropriately employed in countering disease pathophysiology and symptom management.

The development framework is sufficiently broad and flexible to encompass issues of interpersonal relationships, as well as spiritual or transcendent dimensions of personal experience. Developmental terminology that is affirming and nonjudgmental can be used in exploring religious and cultural concerns. The concept of lifelong human development provides a basis for assessing patients' personal experience and a means of bringing specificity to psychosocial and spiritual interventions.

#### A CONSISTENT ETHIC OF CARING

It may seem that, for the patient, the absence of an anticipated future constitutes a fundamental difference between palliative and pediatric care, and that the proximity of death renders issues of human development irrelevant for hospice and palliative care. This existential objection assumes that the value of life is rooted in its duration. An alternative premise appears at least equally valid: that the value of life is rooted entirely in the present moment—that the days of life remaining to a person, no matter how few, are more precious *because* they are limited.

In truth, the concept of value is wholly subjective, and the value of a life would seem solely dependent on the perspective of the individual whose life it is. In addition to duration, the intensity, depth, importance, and meaning of life and one's satisfaction in living all contribute to life's subjective value. Adept clinicians recognize and make use of people's capacity to shift perspective, thereby assisting seriously ill, functionally compromised patients to reframe their life situation in ways that contribute to improving their experienced quality of life. Additionally, because ill or injured patients and their families are intertwined and together constitute an inextricable unit for palliative care, they have a living future to be considered. For these reasons, those who provide palliative care should pay attention to issues of

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A developmental approach to therapeutic planning and intervention fosters additive themes in clinical care and ethical analysis. The fullest extension of beneficent approaches that complement alleviation of suffering with efforts to preserve personal opportunity and enhance quality of life is expressed by the phrase "tender, loving care." The philosophical and ethical ramifications of this approach merit consideration.

"Love" in this context is not an abstract notion or philosophical stance. Neither is it merely a quality that emanates from the environment, beatifically radiated by caregivers toward their patients. In the circumstance of a clinical response to a suffering patient, *active* modes of care are required. Loving care may occur through routine nursing tasks—such as bathing, toileting, and grooming—each of which is performed in a manner that intentionally evokes feelings of comfort, pleasure, and nurturance. An onlooker, watching a skillful nurse or aide bathe a patient, might think the purpose of the bath was to soothe and bring pleasure to the patient. The fact that the patient becomes clean often seems almost incidental to the process.

Actively loving care opens a realm of therapeutic possibilities that is foreclosed by a strictly problem-oriented medical model. Clinicians ministering to a patient in relentless suffering, despite proper application of all the pharmacologic potions and clinical protocols, are provided by loving care with tangible things to do. In this way loving care provides an antidote to the therapeutic paralysis that results when clinicians feel helpless, impotent, and unable to imagine what else might be done to aid a dying patient.

Gently massaging a patient's hands or feet, or oiling a patient's skin can be soothing interventions. They are frequently used in many hospice and palliative programs, but are infrequently recognized as the potentially powerful therapeutic modalities they are. Soft song, even lullabies, can soothe dying patients in distress. Listening is a profound skill for any clinician. Simply keeping company with a patient in distress can at times be a powerful intervention.

Although interventions of these sorts are often relegated to nursing, no ethical constraint precludes physicians from engaging in these direct aspects of care. Physicians can practice loving care most simply by "showing up." A brief home visit to a bed-bound patient or even a short phone call can represent therapeutically powerful interventions. Often by simply stating what is most obvious—"You have been on my mind and I wanted to see and hear how you are doing"—a physician can communicate genuine caring and

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strengthen his or her therapeutic connection with the dying person. There may be little else that needs to be said. Besides attending to a patient's discomfort, a doctor can, with moments of active listening that bear witness to and perhaps acknowledge fears and struggles, provide tangible evidence to such patients that they still matter to their physician.

Whether or not such services prove effective in quelling a given patient's distress, they reflect beneficent intent and fulfill the ethical mandate to *do no harm*. Caregivers are sometimes concerned that touching patients with the intention of causing comfort and even eliciting pleasure will be seen as manipulation or even sexual exploitation. They need not worry. As legitimate caring interventions, these practices are subjects of care planning and remain open to inspection. Indeed, they require and deserve oversight, scrutiny, and study.

As a society we can strive for a vision in which people are born into the welcoming arms of a loving community and die from the reluctant arms of a loving community.

#### AN ALTERNATIVE TO EUTHANASIA AND SUICIDE

Problem-oriented medicine and an incomplete concept of beneficence have contributed in mutually reinforcing ways to narrow the scope of clinical practice and the care of people who are dying. Physician-assisted suicide and euthanasia are, in a sense, the logical result of this narrowing tendency in medical care and biomedical ethics. To some people, these preemptive, deliberate deaths seem almost merciful, given the constricted prevailing clinical and ethical framework. When suffering is severe and persisting, appearing to capture every thread of a person's existence, there may seem to be nothing else to do.

Drawing on lessons from pediatrics, palliative care can complement the problem-oriented approach to disease treatment and symptom management with a fuller concept of beneficence and within a conceptual framework of lifelong human development. Caregivers can, by examining empirical evidence drawn from the range of human experience with illness and dying, strengthen the scientific basis of palliative care and expand the range of therapeutic options. Tender, loving components of human caring offer potentially powerful interventions for alleviating suffering and improving the quality of patients' lives. By integrating approaches that complement problem-oriented medical modalities, we can fortify the ethical foundation of therapeutics and enhance our capacity to serve suffering and dying persons. □

## NOTES

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## LISTENING TO STORIES OF PAIN AND JOY

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**I**t is unwise to be afraid to talk openly about spirituality.

plan. In all of these conversations, it is important to be respectful of the patient and noncoercive. And it is critical to realize that spiritual care is interdisciplinary care. All members of the health care team should address patients' spiritual needs and form caring relationships with them. The physician, in considering the action needed, should remember that other members of the team, particularly chaplains or the patients' own clergy, are partners in the spiritual care.

Some of my colleagues address spiritual concerns by asking the patient what gives him or her meaning. From my own clinical experience, I have found that this question is, in the clinical setting, sometimes seen as esoteric and confusing: What does meaning have to do with illness? Instead, I usually wait to ask that question until *after* I've asked the open-ended question about spiritual beliefs. The patient's response to the spiritual belief question then often leads in naturally to the question about meaning and purpose in the patient's life.

Just as with the "D" word—dying—it is, I think, unwise to be afraid to talk openly about spirituality and religion. Spirituality is integral to who we all are as human beings. It is very relevant to the health care setting, because it is the way people understand who they are and is a lens through which people understand the world. It is a way people may cope with suffering, and also a way people come to understand what their illness and their dying mean.

### COMPANIONS ON THE JOURNEY

Alice and Mary will be returning to my office next week. I have held them in

my heart for the past two weeks and have thought of them often. We ended the last visit with a plan to think about what had been said, and a recommendation that Alice think about a "dream list" of things she may want to do in whatever time she has left. Mary wants to pray more about the situation; Alice wants to think and come to terms with her choices.

Next week, I will listen to their stories, what they are thinking about, what they are afraid of, and what they wish and hope for. Together we will walk a journey that is uncharted and uncertain. Along the way, I will learn more about their lives and what gives meaning and hope to them. I will work with the hospice team—nurse, chaplain, and social worker—to help meet the needs of this family.

There will be tears and laughter. There will be sadness and happiness. Maybe Alice will find a deeper, new sense of meaning in her life. Maybe she will say, as many of my patients do, that life is richer and fuller than ever before. Maybe she will have deep despair that does not result in resolution. Maybe her desire to be present to her daughter will give her the will to live as long as she can, for her daughter.

These are the unknowns, but the journey is Alice's and I am simply her companion. I will support her and her daughter through the process and offer her any resources that might help her. I hope for peace and meaning in Alice's and Mary's lives. And when Alice dies, I will grieve her loss. She will become part of my life forever, as have all the patients I have been so privileged to care for, to partner with, and to love. □

## THE ETHICS OF LOVING CARE

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