

# Optimal Healing Environments in End-of-Life Care and Beyond

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## ABSTRACT

This paper is based on the premise that end-of-life care (EOLC) is the incarnation of an optimal healing environment (OHE). EOLC is characterized by factors that distinguish it from other forms of care or patient populations. These include: (1) formal EOLC did not evolve within the health care “industry,” but was a reaction to that industry, created as an OHE; (2) patients nearing the end of life may be cared for in a formal “end-of-life” environment or may be located in other settings or systems; and (3) EOLC has a preordained outcome. Patients die in a variety of settings for medical, cultural, and accessibility reasons, and EOLC principles and practices are only beginning to be integrated into the full range of care settings. This paper proposes and defends the use of a single-question intervention to study the effect of EOLC care on its recipients, and considers the difficulty of establishing meaningful outcome variables. This paper also suggests that the principles of EOLC are well-suited to all phases of health services delivery and recommends the practical application of its elements throughout the medical services arena.

**T**he formal designation end-of-life care (EOLC) first came into the United States as a concept when hospice care was imported from Great Britain to address comprehensively the needs of those whose death was anticipated within 6 months. A decade or so later, palliative care emerged with a similar approach for those whose life expectancy was limited, but unquantifiable. Both qualify as EOLC, and in this paper are differentiated unless the difference is relevant.

This discussion is based on the premise that EOLC is the incarnation of an optimal healing environment. When the principles are translated into actual care delivery, the environment is optimized. EOLC is characterized by factors that distinguish it from other forms of care or patient populations. The following numbered comments underlie the discussion and research in the field.

### **1. Formal EOLC did not evolve within the health care “industry,” but was a reaction to that industry, created as an optimal healing environment.**

EOLC, specifically hospice, began as a social movement rather than as a deliberate construct of the medical services industry. The social history of EOLC is pertinent to a dis-

ussion of its relevance to optimal healing environments (OHE). Typically, dying patients spent their final days in the hospital, subjected to futile treatments aimed at cure rather than care, sometimes isolated and often in pain. Tens of thousands of individual Americans, distraught at the treatment of a loved one who had died in a hospital, cried out for an alternative. The creation in 1974 of a hospice in Connecticut modeled on St. Christopher’s in England, coupled with the publication in a United States newspaper of an account by Victor and Rosemary Zorza of their daughter’s death in a British hospice, made hospice the focal point of medical-consumers-turned-activists. Indeed, hospice was a protest against conventional medical care, and its proponents conceived of a service outside of the hospital and out of the medical mainstream.<sup>1</sup>

Initially, almost all hospices offered care for the whole person, emphasized home care, utilized volunteer providers, and offered service regardless of ability to pay. But in due course, the second generation of hospice workers redirected their programs back to establishment health care. Today, hospice and palliative care are regulated, reimbursed and generally institutionalized, in marked contrast to the constructs of the earlier pioneers. Thus, although its genesis establishes hospice as a *bona fide* program founded on patient-centered

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principles, and what can be considered a deliberate, if unspoken, attempt to create an OHE, its journey from outside to inside the “system” has tempered its idealism with the realities of practicing medicine in the twenty-first century.

There are similarities in the individual elements of formal EOLC and optimal healing and some have been delineated.\* EOLC is described in recurring phrases such as: “a concept of care rather than a place,” “care rather than cure,” “patient-centered care,” and “comfort and dignity in a patient’s last days.”<sup>2–5</sup> Working principles were operationalized by hundreds of individual hospice and palliative care programs, and eventually codified by the National Hospice and Palliative Care Organization (NHPCO), just one of numerous professional organizations in the end-of-life field. The protocol for formal EOLC now is similar wherever it is practiced.

Specifically, the EOLC program may receive a referral of a patient whose illness has reached the final stages, when cure is no longer possible. The patient may be hospitalized or at home, and the referral may come from a physician, other medical professional, from the patient or family. At intake, a full report and assessment is made of ongoing treatment, current physical symptoms, emotional status of the patient and the family, pastoral needs, and the patient’s and family’s needs, goals, and preferences. The intake process is conducted by a nurse but, within days, the patient and family may be seen by a full team of end-of-life providers including a physician, social worker, clergy, therapist, and trained volunteer. Throughout the course of care, the members of the care-giving team remain consistent and visit the patient and family regularly. In each case, the provider conveys his or her intent to help the patient achieve the greatest possible comfort, mindful that pain and distress result from a combination of physical, emotional, and spiritual factors.

The palliative medicine practiced today combined with pharmacology, while not aimed at cure, is highly sophisticated. It may be augmented by utilization of complementary techniques such as acupuncture, meditation, or massage in the management of pain and other physical symptoms. Speech or physical therapists may address difficulties with eating, mobility, or communication, while social workers and clergy help the patient cope with the emotional pain of dying. Relieved of the physical discomfort of the disease, and with emotional and spiritual support, the patient has the opportunity to resolve his or her life issues and achieve a greater degree of wellness in spite of the prognosis.

Home care is the goal of most hospice programs, while palliative care programs may be more prevalent in the hospital where the patient may be undergoing life-extending treatments. At home, providers visit the patient and family routinely throughout the week. They are also available

throughout the day and night to address needs as they arise, a fact that provides confidence and support to family caregivers. Volunteers may perform routine household tasks for family caregivers so that the family member may remain at the bedside, or the volunteer may stay with the patient to give the family member an opportunity to attend to other tasks.

An inpatient setting is available to provide a respite for weary caregivers either briefly or long term. In cases where care in a facility is indicated, the setting is designed to be as home-like as possible, with special attention to light, nature, and sound in the environment. Families are encouraged to prepare favorite foods, visiting hours are extended, and bans on children and pets are lifted.

The care plan changes as often as the patient’s needs change, but the provider team remains constant throughout the patient’s illness so that important therapeutic relationships are formed. The relationship extends to the family, at least a year beyond the patient’s death, to offer support through the bereavement period.

Taken together, the considerable descriptive literature can be condensed into five principles:

1. There is never a comment that there is “no more that can be done.” Rather, comfort replaces cure as the goal, and hope is redirected from recovery to personal fulfillment.
2. Patients benefit from being treated as integrated human beings, and personal efficacy is enhanced by reducing fear, depression, pain, and other discomfort while maximizing physical, emotional, and spiritual wholeness.
3. Families are both care recipients and caregivers. Their need of support to fulfill their roles and to withstand fatigue and grief is recognized.
4. Patients should have access to the information they need to maintain a sense of personal control and choice regarding treatment, setting, companionship, and daily activities. Wellness during illness is not a contradiction in terms.
5. Synergy is achieved with the use of a multidisciplinary care team, with the patient and family at the center and each member focused on the whole rather than on a single specialty.

EOLC, both philosophically and pragmatically, and the components of OHE appear to coincide. This allows the suggestion that the former is on the end of the spectrum of healing on a continuum from harmful to healing environments. A matrix comparing EOLC principles and practice with the principles of OHE demonstrates their congruence (Table 1).

## **2. Patients nearing the end of life may be cared for in a formal “end-of-life” environment, or may be located in other settings or systems.**

A consideration of EOLC cannot disregard the fact that most people do not die in formal end-of-life programs or

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\*Samueli Institute. Evaluating the impact of optimal healing environments. Executive Summary. See Jonas and Chez paper in this issue, pp. S-1–S-6.

TABLE 1. COMPARISON OF EOLC AND OHE PRINCIPLES

<i>EOLC principles</i>	<i>OHE principles</i>	<i>EOLC practice</i>
There is never “no more that can be done,” but rather hope is redirected from recovery to personal fulfillment	Intention awareness Enhancing belief	Assistance understanding diagnosis, prognosis; clarifying priorities, goals, promoting informed choices; patient participation in care planning; assistance with life review and closure
Patients benefit from being treated as integrated human beings and efficacy is enhanced by reducing fear, depression, pain, and other discomfort while maximizing physical, emotional and spiritual wholeness	Wholeness and energy Enhancing integration	Physical, emotional, social, spiritual relief of suffering; sensitivity to personal, cultural values, beliefs, practices through which patients find meaning; use of complementary meditative energy modalities
Comfort replaces cure; Families want and need a role in care giving and need support to fulfill their role and to withstand fatigue and grief	Healing relationships Enhancing care	Focus on caring; continuity of caregivers; family part of unit of care
The patient should maintain a sense of personal efficacy and choice regarding treatment, setting, companionship, and daily activities; wellness during illness is not a contradiction in terms	Health promotion Practicing healthy lifestyles	Home or home-like setting; attention to physical environment; personal choice regarding food, pets, visits, etc.; bereavement follow-up care
Synergy is achieved with the use of a multi-disciplinary care team, with the patient and family at the center and each member focused on the whole rather than on a single specialty	Collaborative treatments Enhancing treatment choices	Multidisciplinary care team; conventional and complementary techniques utilized

EOLC, end-of-life care; OHE, optimal health environment.

settings. The NHPCO reported that of the 2.4 million Americans who died in 2002, 885,000 patients were served in American hospices (not all who were served actually died in 2002).<sup>5</sup> Overall, approximately 50% of deaths take place in hospitals, 20%–25% in nursing homes, and 25% at home.<sup>5</sup> The place of death does not determine whether or not a patient died in formal EOLC because hospice, and particularly palliative care, deaths occur in all three. It has been established, however, that some 70% of Americans express the desire to die at home.<sup>5</sup>

The reasons for dying outside of a formal EOLC program are varied. Sudden deaths account for a substantial number of non-EOLC fatalities, while lack of knowledge about EOLC explains others. Acute care providers, who are in the most logical position to refer patients to EOLC, may themselves, be uninformed. In other cases, they may be reluctant to refer patients to EOLC because of an ingrained perception that resorting to palliation is the equivalent of personal failure.

Lack of access to EOLC is by now less a problem of location than of outreach. Hospices are geographically well distributed according to the NHPCO. Of 3200 nationwide in 2000, 13% served urban areas, 49% served rural areas, and 38% served both. Ethnically, the distribution of care is less representative as 82% of hospice patients were white, 8.2% were black, and 1.6% were Latino.<sup>5</sup>

A considerable but uncounted population of patients, oth-

erwise eligible for and accessible to formal EOLC, declines to participate. Instead, in most cases, they receive care until the end of their lives in systems designed for acute or long-term care. Dying patients voluntarily opt out of formal EOLC for several reasons. These include that they do not accept the terminal prognosis, that they want to seek a cure aggressively until they die, and that their families or significant others cannot or do not wish to participate in EOLC giving, particularly at home.

Beyond individual preferences, the complexities of social-cultural morés may impact the decision to utilize EOLC. The notion of a “death house” is antithetical to some people. And to those who have been traditionally underserved by the health care system, EOLC may be perceived as an effort to withhold the “best” life-saving medicine from disenfranchised members of society. Finally, for patients whose dying is more gradual, lasting years or more through a combination of chronic ailments, EOLC has been rarely adapted to the settings in which those patients are found.

Nonparticipants do receive *de facto* EOLC nonetheless. It is simply delivered in other health care settings without the requisite organized actions and principles that characterize formal EOLC. Chronic care and acute care have both received attention in this regard. The area of chronic care is well covered by Lynn and Adamson who point out that 9 of 10 elderly (Medicare eligibles) die with cancer, organ system failures, dementia, or stroke, and that 40% of the years

past age 65 include some disability.<sup>6</sup> Coupled with frailty, in which all body systems have little reserve, the prognosis for older people generally is ambiguous in that they may be sick enough to die, but may go on living for a number of years. Consequently, these authors recommend that service needs, rather than the diagnosis or care setting, dictate the nature of EOLC for this population.<sup>6</sup>

One model is the Program of All-Inclusive Care of the Elderly (PACE), a series of more than 30 sites nationwide that coordinate medical and nursing care, day care, meals, social services, specialists including dentists and podiatrists, prescriptions, hospital, and as a last resort, nursing home care. Capitated under Medicare and Medicaid, PACE serves people in the community who are otherwise eligible for nursing home care. The emphasis in PACE is on providing comprehensive services, and implicitly responding to the general preference to remain in one's own home rather than in an institution. The driving values and principles so prominent in discussion of formal EOLC are not articulated by PACE, but personal control, choice, and dignity can be inferred from the program's motivation to keep elders at home.<sup>7</sup>

Additional efforts have been made to enhance EOLC in nursing homes. The Institute for Family-Centered Care identifies and shares resources among care settings dedicated to enhancing the quality of patients' experiences. They cite Providence-Mount St. Vincent, a nursing home in Seattle, WA, as an example of a facility in which a change in philosophy and culture, along with physical renovations, have created a new practice paradigm.<sup>8,9</sup> Residents are arranged in small clusters or "neighborhoods." According to its own description, the goal of each care team within the neighborhood is to "respond to each resident's needs and personal choices. Each staff member is there to honor the dignity and diversity of residents, and to make every effort to encourage and help restore wellness."<sup>9</sup> In assisted living apartments, the cornerstones of the program are self-empowerment, negotiation, and collaboration.

Neither PACE nor individual nursing homes are designed exclusively for the dying. Average length of stay in both is measured in years rather than weeks or months. However, most patients admitted to either program die while in its care, and so the dying process is experienced under its supervision.

Similarly, acute care for patients with potentially terminal outcomes is the subject of recent attempts to incorporate end-of-life principles and services. The literature includes a very large number of descriptions of pilot projects, initiatives, and models. An excellent compilation of such efforts is offered by The Robert Wood Johnson Foundation through its priority program area, Promoting Excellence in EOLC.<sup>11</sup>

A single example conveys the spirit of the numerous efforts. Lehigh Valley Hospital and Health Network, with foundation funding, has implemented EOLC measures in three intensive care units: medical, surgical, and acute care.

Citing a "cultural change that fuses palliative care practices with intensive care unit (ICU) practices,"<sup>12</sup> Lehigh has begun interdisciplinary rounding to include pastoral care and family participants, palliative/curative care planning from the point of admission, and formalized patient/family shared decision making. A palliative care nurse specialist was added to the ICU staff, and a computerized palliative care training program was made available to other nurses. These initiatives serve a small number of the acute and chronically ill populations, while the rest receive care of varying intensity, quality and outcome.

The most comprehensive effort to integrate EOLC principles into conventional settings is an initiative sponsored jointly by the Center for Palliative Care Studies and the Institute for Healthcare Improvement called the National Quality Improvement Collaborative to Improve EOLC. The goals of the Collaborative are to train representatives of health care institutions in the specifics of EOLC ranging from pain and dyspnea management to securing advance directives, gathering information for a database on dying, and mobilizing providers to push for systemic changes in EOLC delivery. Participants may pay to join in-person or online ([www.medicaring.org](http://www.medicaring.org)), and telephone sessions take place over a period of 10 months. A substantial text is available online for anyone interested in reading the training material (see above for Web site). These early efforts indicate that end-of-life as a stage and as an approach to care is extending backward along the life cycle continuum.

### 3. EOLC has a preordained outcome.

The endpoint for patients in EOLC is not variable. EOLC patients will, after all, die. Unlike surgery, or treatment for an acute or chronic disease, or even prenatal care and childbirth, all of which may result in degrees of success or failure depending upon the treatment, EOLC proceeds to its inevitable conclusion irrespective of the nature of the care preceding it. One might therefore conclude that all EOLC is as successful as it possibly could be. However, to move forward, one must accept the notion that, for the purpose of discussion, the objective outcome death is supplanted by inputs that constitute a process called dying. Among those inputs are the prescribed actions, tasks, and standards attached to caring for patients at the end of life, and the highly subjective principles, concepts and values that organized EOLC promotes (Table 2).

Over the short history of formal EOLC, the literature through the mid-1990s was largely descriptive, and attempts at measurement were dominated by studies of cost. This might be explained by the hospice movement's pursuit of a benefit under Medicare (achieved in the 1980s), and its immediate need to prove its cost effectiveness. The trend began to change in the later 1990s, and Robinson made the point explicitly in 1996:

TABLE 2. INPUTS FOR END-OF-LIFE CARE

<i>Actions, tasks, standards</i>	<i>Principles, concepts, values</i>
Control of pain and physical symptoms	Comfort
Emotional and spiritual care	Fulfillment
Interdisciplinary care team	Integration
Care for family	Hope
Home-like setting	Efficacy
Bereavement care	Dignity
	Wholeness
	Caring
	Continuity
	Choice
	Control

The question of hospice cost-effectiveness would seem to be a question of the past. Other questions offer even more substantial challenges to continuing hospice care as it is now offered and into the future. There are no data to allow a critique of current structure of hospice services, or to support the link between individual components of service and outcomes.<sup>12</sup>

The popular press and individual anecdotes suggest that EOLC “works” for patients and their families. The challenge has been and continues to be identifying what works and why. A MEDLINE® search of terms reveals that little outcomes research on individual components has been completed. For example, keywords “hospice AND dignity” yielded 94 citations, but “hospice AND dignity AND measurement” produced only 4, none of them relevant. Similarly, “end-of-life AND healing relationship AND outcome” produced no citations while “end of life AND healing relationship” provided 11. These results reinforce the assertion that EOLC care was created with optimal healing components in mind, and although these are well represented in the descriptive literature, the effort to quantify the impact of those values is limited.

Distinct components, particularly the value components of EOLC, are being identified and efforts are being made to define them and establish instruments for rating individual patient’s experiences of them. For example, Warner and Williams<sup>13</sup> assert that meaning in life is a value that should be measured in EOLC to expand the usual outcome assessments applied to the curably ill. They define meaning in life as the patient’s sense of purpose, beliefs and faith, and have constructed and validated a 15-item rating scale.

Similarly, dignity is well described and defined.<sup>14–18</sup> The terms autonomy, self-determination, self-respect, personhood, self-worth, embodiment, shame, relationship, desire, and integrity are all associated with dignity in the literature. Chochinov and colleagues,<sup>14</sup> using semistructured interviews and content analysis, identified categories, themes and subthemes for inventorying dignity among the dying.

A 49-item instrument measuring comfort in the four contexts of physical, psychospiritual, environmental, and social was developed for use with end-of-life patients by Novak and others.<sup>19</sup> Their survey was based on another instrument and revalidated for use with patients at the end of life. One of the most intensely studied aspects of EOLC is spirituality. A MEDLINE® search produced 411 citations, including several proposing measurement tools.<sup>20,21</sup> Perhaps the aspect of EOLC least surveyed is the mandated “home-like environment.” Only two articles could be located, one of them in Swedish.<sup>22,23</sup>

A second approach to measuring EOLC consists of determining proxy outcomes in place of the inevitable death, and identifying or constructing instruments to obtain data. Twenty-three (23) articles were reviewed representing four proxy outcomes: quality of life,<sup>24–34</sup> quality of death or good death,<sup>35–38</sup> satisfaction with or quality of care,<sup>39–44</sup> and needs met.<sup>45–46</sup> While most of the articles validate instruments but stop short of utilizing them to report on outcomes, those that do evaluate present a mixed image of the effect of EOLC. The National Hospice Study (an early comparative study) was equivocal in its findings. With the exception of pain and symptom control, which were superior in hospice, the study found little difference in quality of life between hospice and conventional care patients.<sup>32</sup> In direct contradiction, McMillan<sup>33</sup> found that pain relief was inadequate in hospice patients, and separately reported from the same study that overall quality of life remained stable over time.<sup>34</sup> Cohen,<sup>31</sup> on the other hand, reported improved physical well being in hospice along with enhanced psychological and existential measures. To confuse the picture further, Tierney<sup>42</sup> found a relationship between satisfaction with care and quality of life, but not between symptoms and satisfaction and quality. Despite variations in level of symptoms and quality of life scores, most patients were satisfied with their care.<sup>42</sup>

Taken collectively, the literature reviewed is illustrative of the status of research in EOLC. It is in the preliminary stages of measuring the impact of individual elements of EOLC, and inconclusive in determining outcomes. While we may know impressionistically that EOLC “works,” it presents unique obstacles to meaningful analysis. These include:

#### *Nonresponse bias*

Among the population being studied, most if not all patients will reach a state in which they can no longer be surveyed because they are too ill, too confused, or unconscious. The quality of the EOLC experience will thus not be measured when its patients are sickest. Potentially, a portion of the care of every patient could remain unevaluated.

#### *Family members as surrogate responders*

When patients cannot respond, the closest family caregivers may be asked to speak for the patient. McPherson<sup>40</sup>

found that family members' ratings are most reliable with respect to observable symptoms and quality of service. In subjective realms such as pain, anxiety and depression, family responders are less accurate. Further, Bretscher et al.<sup>25</sup> found that family members tend to rate patients' quality of life lower than patients rate it themselves. Finally, Teno,<sup>39</sup> who agrees that family ratings are not wholly reliable, argues strenuously that family members' ratings should be preserved as an outcome of their own. She notes that a patient's death is the final memory of a loved one, and because EOLC is mandated to care for the family along with the patient, the family's perception of the patient's experience is a valid measurement of EOLC.

### *Change over time*

One assessment of a patient's experience in EOLC is not adequate to describe the totality. Because the patient's condition may change rapidly, and with it his feelings and needs, assessment might be repeated as often as biweekly or even weekly. Furthermore, in any given survey, the patient should be asked to consider his experience over a recent, brief and defined time period rather than the course of care to date. A series of such ratings will yield a more accurate composite than a single recollection of care received.

### *Reports versus ratings*

Teno<sup>39</sup> is instructive on the value of collecting ratings both through forced-response surveys and reports in patients' own words. She cites examples in which a yes or no answer to an objective question might produce a positive response (e.g., "were you told your options for treatment?"), but when the patient is asked to report on the event, the manner of the telling (of the options) might be highly negative.<sup>39</sup> And the same patient might rate his satisfaction with the program as high, despite the obvious lapses. She suggests that patients may need to be educated to raise their expectations for care.<sup>39</sup>

### *Right way to die*

The construction of standards to describe the optimal dying environment is value-laden and subject to defect. Indeed, we are reminded by Hart et al.<sup>47</sup> that the dominance of a "good death" ideology can label patients "good" or "bad," and lead to new attempts to coerce patients into socially accepted behaviors and choices. EOLC dogma includes the tenet, "meet the patients where they are (emotionally, behaviorally)," and so the notion of conformity is, or should be, anathema to the fundamental principles of EOLC.

One article explicitly states that the patient's preferences for dying and the moment of death define quality dying and uses those preferences as the benchmarks against which the actual dying process is measured.<sup>48</sup> In other words, the as-

essment is not of "how much dignity," or "how much pain control" the patient experienced, externally contrived standards. Rather, the evaluative question becomes, "How much of what the patient preferred (whatever that may have been) was achieved?" The qualitative difference between the two captures the essence of the difficulty in measuring EOLC.

To summarize, EOLC is more advanced than other health care settings in approaching an OHE because of the intent of its earliest consumer proponents.

## **4. There is an Alternative Approach to Capturing the Impact of EOLC.**

Measurement of EOLC has thus far consisted largely of defining and establishing tools to investigate the meaning and presence of subjective values in the dying experience. But it falls short of documenting the impact those values have on the dying. Proxy outcomes, such as quality of life, measure impact, but are subject to the shortcomings described. The elements of good EOLC and OHE are potentially so variable among patients that an attempt to investigate the power of each, while lacking an objective outcome variable, may not be productive. Furthermore, experience teaches there is synergy among the components, and that EOLC care at its best is a total package of practices, values and milieu that should not be dissected, but rather left whole. Instead, I propose that a single, carefully constructed question can capture and convey the elements of EOLC and OHEs and might be the foundation for investigating their impact. No other single-question protocol has been located in the end-of-life literature. Specifically, upon admission to EOLC and every day thereafter, the patient and family would be asked the question, "How can we make things better today?" The answer would constitute the care plan for the day. The question is at once therapeutic and evaluative. It is designed to avoid the numerous potential pitfalls noted, and is the result of many considerations, such as:

1. Asking about "better" is entirely open to interpretation. Rather than asking about "more comfortable" or "more in control," the question conveys a healing intent without limitation to any particular domain (physical, emotional, spiritual) that may or may not be of concern to the patient.
2. The question can be answered in concrete terms without prior agreement on the definition of concepts or values.
3. The answer leads to results. If the answer is "relieve my pain," or "bring my dog," or "stay with me," the action on the part of the caregiver is clear. If the answer is not actionable—"make me well" or "make me die today"—it does, at the very least, create a starting point for more in-depth conversation with appropriate caregivers. And if the patient is so disempowered as to be unable to assert an expectation, the caregiver can offer cues such as, "Are you hurting?" "Is there a member of the family you

would like to see?” “Would you like to spend more time alone?”

4. Asking about “today” eliminates the need to think far into the unknown future. Asking daily captures changing needs and feelings.
5. Over time, daily responses create a record of the patient’s preferences. The pattern that emerges can be used to infer needs and desires at times when the patient is too ill, confused or comatose to answer. Surrogate responders would be unnecessary.
6. Retrospectively, actual expectations can be compared to actual actions in order to evaluate the impact and appropriateness of the care. Proxy outcome measures need not be devised.
7. Responses that are repeated day after day might indicate that caregivers have not been successful in meeting needs and should change their approach. “Success” would be achieved when expectations were met at a consistently high rate.
8. Soliciting responses from family members to the same question places them within the unit of care.
9. The very asking of the question establishes a healing relationship and imparts dignity, choice, and control. The process is the product.

After asking the question, patient responses or expectations would be written in the chart daily along with actions taken to satisfy each expectation expressed in the response. If the question were asked daily in an EOLC setting, a study, primarily methodological, might be constructed around it. Such a study might test the following questions:

- Can regular review of the chart yield a rating of expectation satisfaction (e.g., completely, somewhat, not at all, or a numeric rating)?
- Who should review and rate the chart (e.g., the patient’s caregivers, caregivers not treating the patient, family members)?
- Based on the responses, can caregivers formulate care plans to take effect when the patient is nonresponsive?
- Can expectation satisfaction be correlated with results of a standard quality-of-life survey?

A second phase of the study might introduce a sham question (e.g., “how are you?”) to part of the patient population. The sham question is not one that elicits expectations or actions, but is used to distinguish the effect of being asked any concerned question versus being asked a question that should convey patient control and result in action. Finally, the study might seek an association between expectation satisfaction and the few hard outcome measures available (e.g., quantity and frequency of pain medication needed, or morbidity or mortality among survivors within one year of the patient’s death).

### **5. Advance from the analysis of EOLC to practical application of its elements and principles throughout the medical services system.**

If, based on experience, intuition, and research, we accept that EOLC has intrinsic value on a patient-by-patient basis, can we ethically delay or withhold that approach from patients in other medical settings and circumstances? What would be the effect of enhancing the quality of the healing environment of every person-as-patient? Traditionally, on assuming the role of patient, a person has willingly surrendered his sense of comfort and personal control in exchange for a cure. But we have long suspected that surrender may be self-defeating. Medical outcomes may be diminished when the patient lacks control, information, and support. Conversely, if these inputs are maximized, the patient may recover more quickly and completely, and have a higher quality of life, whatever the ultimate outcome.

The opportunity and advantage of applying the EOLC approach to the full spectrum of medical encounters is evident. Acute and chronic care, whether ambulatory or inpatient, have a multitude of measurable outcomes. These include cure of the disease, daily function, length of stay and necessity of medication for pain or symptoms. Each may be impacted by the quality of the environment in which care is delivered. The question, “How can we make things better today?” is as applicable here as in end-of-life settings. And given the plethora of quantifiable outcome variables, we can ask what were the optimal-environment inputs that affected the eventual condition of the patient? We can investigate the impact of the total environment, intercorrelate the variables so that the impact of individual elements is teased out, and even examine the effect on the delivery system. All of these effects can be evaluated as rigorously as the effects of medication and surgery:

- How much did the patient participate in decision making?
- How much support and companionship did the patient have during treatment?
- What techniques were used to mobilize the powers of the mind to enhance wellness?
- Have hospital days been avoided or reduced?
- Did length of stay vary by the degree to which the patient exercised choice of treatment options?
- How has the existence of the program affected referrals to and patient selection of the provider?

The most pervasive trend in health care delivery today is cost containment. The science of outcomes measurement and the development of clinical practice guidelines are driven by the utilitarian question, “How can we get the most for the least?” Primary physicians as gatekeepers, preapproval or denial of surgery by insurance companies, and premature discharges from hospitals are a few of the less attractive out-

growths of the trend. On the more positive side, however, considerable resources are being expended to eliminate costly trial and error care from care giving by determining just which treatments are most often effective against disease. The logical next step is a rethinking of the elements of "treatment," and the role of OHEs is an obvious component in an expanded view.

Given popular sentiment and professional forays into enhanced healing environments, and the market-driven quest for cost efficiency, a comprehensive demonstration model is urgently needed. The program would include the identification and implementation of system-wide enhanced healing environments in association with an assessment of their effect, organized in a community setting judged best to impact the medical mainstream. Abolishing the erection of artificial boundaries between EOLC and the continuum that precedes it, we embrace the idea that what is right about the EOLC concept is right for all patients, dying or not. As end-of-life components are extended to patients generally, the spirit of EOLC will permeate the notions of patient control and comfort-enhancing treatment options as patients' lives are enriched and medical outcomes maximized.

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