Conceptual Models and the Outcomes of Caring

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Abstract
Conceptual models and the taxonomies associated with them are inherent tools of goal-directed activity. Conceptual models partition reality, discerning differences within a phenomenologic continuum; a process that is a fundamental requisite for measurement. This paper presents theoretical observations regarding the influence of conceptual models on goal-directed endeavors and explores specific implications for outcome measurement in palliative care. The dominant model of end-of-life care is the problem-based model of adult medicine. In clinical orientation, hospice and palliative care bear strong similarities to a pediatric and family medical model for early childhood care. This essay examines salient features of a conceptual model for palliative care that draws on a life-cycle or developmental model of human experience in critical transitions and explores application of this model to palliative care. J Pain Symptom Manage 1999;17:83–92. © U.S. Cancer Pain Relief Committee, 1999.

Key Words
Theory, measurement, quality, palliative care, hospice, human development

Introduction: The Theory
One afternoon in high school, my physics teacher challenged our class to define “time.” After an initial silence, things quickly became boisterous, and the discussion progressively convoluted and confused. By the end of the hour we were tangled in conceptual knots and thoroughly frustrated. As the bell rang, in preparation for our next class together, he dismissed us with the assertion that, “Time is what is measured by a clock.”

In choosing and applying any measurement tool, inextricably, a conceptual model (or set of models) and corresponding taxonomy are acquired. Using a clock to measure time defines a model for time as proceeding at a consistent pace, in a single direction and brings with it a taxonomy that includes seconds, minutes, hours, days, years, and so forth. Most often the models and taxonomies being employed remain unrecognized and unnamed without adverse effect, because the model’s assumptions are valid and its properties serve the applied function. However, the influence of the conceptual framework that underlies the measurement methodology is exerted whether the model is consciously chosen or is employed in a de facto manner that reflects prevalent assumptions within the general or professional culture.

Conceptual models enable us to partition reality into discernible components and recognize attributes that distinguish some aspects of physical and experiential reality from others. Models serve as intellectualized representa-
tions of reality, allowing us to study, envision and plan for change, and to manipulate our environment (social and physical). Perhaps the most common examples of conceptual models include metaphors and analogies. By making reference to familiar constructs (“Living in this condition is like constantly trying to swim upstream.” or “Emotionally, it’s like being on a seesaw.”) these models assist us in thinking and communicating aspects of the world and our experience. More complex and encompassing conceptual models are sometimes called paradigms. Yet, even the most expansive and inclusive paradigm is never more than an approximation of phenomenologic reality. By their very nature, all of these cognitive tools are reductionistic and contain limitations.

Individual conceptual models are often most apparent in their application to a specific purpose. Certain models are constructed solely for the purpose of advancing a specific goal-directed activity. It follows that, if the goals of an endeavor shift—perhaps the scope of a scientific investigation broadens—the limitations of a prevailing model as an analytic tool may become apparent.

We know, for instance, that some of the key assumptions of Newtonian physics in the strictest sense are not true. Instead, these assumptions are imperfect approximations, nothing more than useful descriptions of reality. Quantum physics has demonstrated convincingly that individual objects are not as finite or discrete as they appear, and that even the distinction between matter and energy is only an approximation of reality. We even have learned that the pace of time is not constant after all, that a moving clock runs slow!

Fortunately, changing from one conceptual model to another does not infer that the data collected within or conclusions drawn from the previous paradigm are erroneous. Thankfully, none of the revelations of quantum mechanics invalidate the facts and formulae of Newtonian physics nor do they impact the vast majority of engineering applications. Both conceptual models are valid for the purposes for which they were constructed, and both are inherently limited. The shift from one conceptual model to another does not necessitate that facts and conclusions be understood within the context; they are valid within the model and to the extent that the assumptions about reality and the goals upon which the model is based apply. The “correct” model is the one that best serves the user’s purpose and is determined by the nature of the scientific inquiry or the goals of the specific endeavor.

Unwittingly using the wrong conceptual model can be dangerous. Confusion, miscommunication, cross-purposes, conflict, and poor outcomes can all result from failing to recognize the limitations of the conceptual model being applied. The effect pertains, whether the endeavor is pure physical science, social science, or clinical practice.

Models need not be entirely discrete, nor mutually exclusive. With any specific goal-directed activity, especially when the activity is as complex as clinical care, several applicable models may be discerned. In focusing on any single issue or specific task, the models that apply may remain distinct from one another, or may overlap or may fit within one another in a telescoping pattern of increasing specificity.

Within the nested schema of this latter pattern, the outermost or “macro” model is defined by a shared set of basic values and assumptions about the world, often meriting the term “world view.” Because they are embedded in and are inherent aspects of the culture of a society, these values and assumptions may seem to be part of the natural order of things and not readily discerned by people who grow up and live within the society. The prevailing world view of Western culture serves as the overarching conceptual model for clinical endeavors. Fortunately, this dominant cultural model is broad enough to contain a variety of component subcultural models, religious and ethnic; each with its own unique eschatologic and metaphysical philosophies, yet all sharing a number of critical assumptions, moral values, and human goals.  

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For instance, while the ten commandments are identified with a Judeo-Christian world view, the moral values and ethic they reflect are quite consistent with those of other major religions. This basic commonality enables communication, cooperation, and collaboration among people of different religious traditions. In most aspects of social life, even the most profound differences in the eschatology and metaphysics of the subcultures do not interfere with goal-directed activities.
The Culture of Health Care

Presently, a discernible clinical paradigm exists across the professions of medicine, nursing, social work, pastoral care, and allied health professions.1 Common values and goals of this paradigm include preservation of life, relief of suffering, avoidance of harm to others, nonabandonment of the ill, support for families, respect for the inherent worth of each individual and for their preferences for care, equality in the distribution of resources, honesty of communications, and integrity of behavior as professionals. Collectively, these values and goals constitute core principles of bioethics. While they may not be applied in absolute or unyielding fashion and may be emphasized differentially within specific professions, they are respected across the disciplines of health care.

These attributes also constitute sentinel features of the culture of health care and, as such, serve as a reference in guiding therapeutic encounters. For instance, there is universal agreement in health care that pain and functional disability are both to be prevented or minimized. Therefore, in virtually all clinical endeavors these values and goals can be appropriately assumed. Utilizing pain severity scales as patient assessment tools and as quality improvement measures is appropriate whether the setting is an emergency department, an operating suite, a rehabilitation center or a pediatric outpatient clinic. Similarly, most applications of measurement in health care take place within the culture of a health care environment with sufficient commonality of outlook, values, principles, and goals that careful inspection of the tool’s conceptual framework and terminology is unnecessary.

In the large majority of clinical situations and settings it is also appropriate to assume that preservation of life is a primary goal. However, this critical assumption is not valid across all of the clinical contexts in which people are cared for in the process of progressive illness and dying. In the hospice and palliative care context, it is commonly necessary to accept that prolongation of life is a secondary, often unattainable goal, and sometimes not a goal at all. In the practice of palliative care, the basic set of health care values and goals must be supplemented by values and goals that are applicable to the final stage of life as well as specific, patient-centered goals that may be unique to the individual.

It is axiomatic that the measurement of the quality of any endeavor carries strong inference regarding the definition of “quality.” As a corollary, tools for measuring the quality of end-of-life care will inevitably influence—and in some applications will determine—standards of care and acceptable approaches to care. Therefore, in the process of development, refinement, and choice of tools for measuring outcomes and quality of palliative care, it is critically important to remain conscious of the relationship between conceptual models for palliative care of terminal illness, standards of practice, and measures of quality.

While no conceptual model or paradigm can perfectly capture the breadth of the dying experience and all of the complexities of physical care and counseling, it is possible to recognize desirable features of a conceptual model for palliative care (Table 1). The ideal conceptual model (or models) would recognize meaningful distinctions and qualities of human experience and would facilitate understanding of patients’ suffering in a manner that was not completely tied to pain or the pathophysiology of their disease. The model(s) would enable consideration of the full range of emotional, psychosocial, and psychospiritual states of persons living with physical discomfort, functional decline, and awareness of impending death. The taxonomy and terminology of the model(s) would convey the potential for positive as well as negative experience. Furthermore, the basic language of the model(s) would be comprehensible to professionals and nonprofessionals alike, and to persons of diverse cultural backgrounds.

Table 1
Features of an Idealized Model for Palliative Care

<table>
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<th>The Model:</th>
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<tr>
<td>• Is applicable to the full breadth of patients’ personal experiences in dying;</td>
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<td>• Facilitates clinical assessment and intervention;</td>
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<td>• Facilitates quantifiable clinical research through creation of meaningful partitions within the continuum of the human experience with dying;</td>
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<tr>
<td>• Lends itself to testing and modification;</td>
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<tr>
<td>• Uses language that is positive, comprehensible to professionals and nonprofessionals alike, and acceptable to people of diverse cultural backgrounds.</td>
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Another pertinent feature of the prevailing conceptual model of clinical practice is worth noting. The contemporary "medical model" is built around the problems of illness and injury and a problem-based approach is utilized by virtually all clinical professions.b

Problem-based medical care emerged in the early 1970s as Weed and associates introduced the problem-based medical record as a means of improving communication and the effectiveness, efficiency, and accountability of medical practice.2 Since that time students of medicine, nursing, and other clinical disciplines have learned to "SOAP" entries in a patient’s chart, organizing information in categories labeled Subjective, Objective, Assessment, and Plan. This has become thoroughly integrated within clinical practice and is second nature to physicians trained in the modern era. The shift to problem-based medicine was a significant advance, bringing focus and efficiency to diagnostic testing and treatment and improving organization and communication within health care. The orientation of surgical specialties and general adult medicine typifies the problem-based model of care.

While this approach serves most aspects of medical practice well, essential aspects of pediatrics and family practice have difficulty finding a place within the problem-based model. While vaccinations, genetic counseling, and screening for specific diseases such as congenital hypothyroidism or phenylketonuria or conditions such as anemia, lead poisoning, or tuberculosis testing can easily be recorded within a "SOAP" format, much of the counseling and anticipatory guidance that are central to the care of families with infants and young children is difficult to capture in a problem-oriented format. To circumvent these limitations, during the introduction of problem-oriented medical records, “health maintenance” was defined as a “problem” on patients’ charts.

There are similar problems in applying a strictly problem-based approach to the care of incurably ill patients. Through the lens of the medical model, the only goals that apply to the terminally ill patient are relief of pain and suffering and restoration (or preservation) of function. During the course of progressive, life-limiting illness such as cancer, human immunodeficiency virus (HIV) disease, or amyotrophic lateral sclerosis (ALS), as function inevitably declines, relief of suffering becomes the sole remaining goal. While this goal can be well served by the problem-based medical record, other key components of palliative care cannot.

A hospice or palliative medical consultant who reviews the hospital chart of a patient referred to a palliative care program typically will find that all of the care delivered to this point has been organized around a set of diagnoses. The “problem list” might read as follows:

1. lung carcinoma, nonsmall cell
2. bone metastases
3. brain metastases
4. hypertension
5. history of alcoholism—remote

This conforms to the way medicine is commonly practiced. From the time the patient presented with symptoms until the moment of the palliative care referral, the clinical interviews and choice of diagnostic testing has been determined by these problems; every serum test, imaging study, biopsy, consultation and every treatment. For each problem on the list, interventions are consistent with the assessment and reflected in the plan.c

b The term “medical model” is being used to refer to the prevailing broad clinical paradigm, recognizing that there are differences between the model of medicine and the model of nursing, and that within the model of medicine differences exist between surgical, internal medicine and psychiatric models of care. Yet in most circumstances, whether the patient is a 3-year-old with pneumonia and dehydration, a multiply-injured adolescent whose single-vehicle accident may have been a suicide attempt, a 55-year-old with an acute myocardial infarction, or an elderly person with a serious, but nonfatal stroke, the care involves shared values, principles, and goals of the “macro” model of medicine that facilitates communication and cooperation across disciplines and efficient, effective action.

c Typically, pertinent symptoms and findings from physical examinations and investigations such as radiographs, magnetic resonance imaging (MRI) or computerized tomographic (CT) scans, and bone scans would be charted under respective problems. Interventions such as chemotherapy, radiotherapy, anticonvulsant, analgesic medications, and antihyper-
Another feature of acute medicine that is derived, at least in part, from this approach stands in contrast with the orientation of palliative medicine. Being focused on acute problems, the health care system presumes that the goals of medical treatment have highest priority for the patient. In most circumstances this assumption is accurate; in dealing with the medical problems, the life of the patient is made better and the patient (and family) naturally assigns highest priority to medical care. Acute care tacitly requests—and often requires—that patients hold their personal priorities in abeyance in service of receiving life-saving or life-prolonging care. This is not inappropriate; by performing an emergency appendectomy or treating sepsis with antibiotics or infusing thrombolytic agents for an acute anterior wall myocardial infarct, the patient is certainly well served. However, for the incurably ill person life-saving measures are, by definition, unavailable; and for many patients at some point in the course of progressive illness, life-prolonging measures are no longer desired, or are otherwise not indicated. While terminally patients may still require acute interventions for the purpose of symptom management and the relief of suffering, dying persons often have a sense that the “clock is ticking,” each day is precious, and life can not easily be put on hold while medical therapy is endured.

As practiced in the setting of hospice programs and within specialized teams or units, palliative care represents an alternative clinical model with an emphasis on values and goals distinct from general medicine. These differences find expression in a distinct hospice or palliative care clinical approach. Salient features of that approach have been well documented and discussed elsewhere.1,3–5

While there is a general tendency for medical interventions to dominate the personal experience of the patient, palliative care strives to minimize intrusions on the personal priorities of the patient and family. Instead, palliative care planning employs medical intervention to enhance the immediate quality of life of the person and family.

Perhaps the most salient feature that distinguishes the hospice or palliative approach to end-of-life care from that of general medicine is palliative care’s departure from the strictly problem-based model. Within palliative care, the experience of dying—that is, the experience of living with progressive, incurable illness and significant disability—can be viewed as a natural and normal part of life. A patient-centered perspective can acknowledge the difficult medical issues involved, and the often arduous and distressing nature of the patient’s experience, while not dismissing the potential value of this time in the life of the person and family.

Consider Mrs. R., a 72-year-old woman whose hospital chart contains the above problem list and who has recently moved to a long-term care facility. She has discussed options for care with her doctor and has declined cardiopulmonary resuscitation (CPR), any further hospitalizations, parenteral antibiotics, and tube feedings. If, at present, Mrs. R. has no uncontrolled symptoms and remains ambulatory, from the perspective of the general medical model, no current evaluation would be indicated and no intervention or new services would likely to be deemed “medically necessary.” If secondary prevention is considered at all, the major items would be prophylaxis for seizures and, perhaps, falls.

Close adherence to a problem-oriented approach leaves little room for therapeutic services to assist patients such as Mrs. R. in identifying or working on issues of life completion and life closure; that is, unless they are causing acute symptoms or signs of acute dysfunction within the person’s family. In contrast, within the context of the hospice or palliative inter disciplinary team care planning, it would be important to know how Mrs. R. is spending her days; with whom is she interacting at the facility? What does she enjoy doing and what does she not? Are members of her family involved in her life, do any of them visit or call regularly? Does she have a religious connection and, whether or not she does, does she have concerns of a spiritual nature? Are there things that Mrs. R. would consider to be “left undone” were she to die suddenly? Given the changed,

tensive medications would also be charted by problems. Within a general medical chart, “history of alcoholism—remote” might not be considered an active problem, or the chart might include a note that there is no evidence of current drinking and to stay alert for overuse of alcohol as a maladaptive coping behavior.
and changing, context of her life situation, what does she consider most important in her life?

The problem-oriented medical record is not abandoned in palliative care. This method of organization is employed to facilitate symptom management and the treatment of reversible complications of illness. Problems are identified and responded to with appropriate application of medical diagnostic and therapeutic interventions. However, conscious attention is also directed toward opportunities for improving the quality of life of the person and family. Thus, within a hospice or palliative plan of care, in addition to the problems on Mrs. R.’s medical chart, one might expect to see one or more categories (perhaps labeled “adaptation to illness” or “anticipatory guidance” or “health advancement”) within which issues can be addressed involving completion of worldly affairs and, to the extent she identifies them as important, efforts to develop a satisfactory sense of closure in interpersonal, intrapersonal, and spiritual dimensions of life.

A Life Cycle or Human Development Model

In important ways, the goals of therapy and general clinical approach of palliative care closely resemble the orientation of infant and early childhood care. Pediatricians and family physicians are taught to recognize the young child with his or her family as the unit of care. The neonatal, infant, and toddler stage of life is a period of rapid change and critical development. At times, the personality of the infant and child seems to change almost daily. Similarly, the daily life and circumstances of the family may change in dramatic ways, repeatedly over the first weeks and months of the infant’s life. The very nature of this early stage of life carries the potential for acute and subacute problems affecting the physical health of the patient and the emotional health and functioning of the family. Clinicians caring for infants and toddlers are taught to be aware of the myriad of physical, social, and developmental problems that can impact both the patient and family.

Within the orientation of pediatric clinicians, the first priority is evaluation and treatment of acute problems that parents identify or that are uncovered during screening examinations. When problems are identified, therapy often embodies a multifaceted response, involving a formal or ad hoc team of specialized providers. Secondly, prevention of problems predictable during this critical time in human life is accorded strong emphasis through thorough physical and psychosocial screening and active anticipatory guidance. Beyond preventing common or predictable problems, this approach focuses significant energy and attention on promoting healthy development for the patient and within the family. In this way the quality of life for the person and family is enhanced.

Within this developmental framework, an infant who experiences suffering (e.g., inconsolable crying and sleeplessness associated with colic) or a family that suffers emotional distress in response to specific health problems (from those as “trivial” as feeding problems and colic to those as potentially serious as meningitis) or other critical stresses on the family system need not be labeled as inherently dysfunctional, psychiatrically ill, or otherwise pathologic. Instead, most cases of distress within the infant–family dyad can be understood as consequences of the difficult, but normal, process of adapting to the profound changes of the stage of life of a family with an infant.

Within the schema of pediatrics (and family practice), when an infant or young child and family members successfully integrate changed circumstances of their living experience and self-identity, they are understood to have accomplished critical developmental landmarks, and may be said to have grown. Naturally, growth for the young person and for the family embodies some characteristics that are universal across human experience, others that are culturally based, and still others that are highly specific to the individual.

Many of these statements also pertain to palliative care: Patients and families who experience suffering associated with dying need not be labeled “ill” or dysfunctional for their distress to be acknowledged and addressed. 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.

The similarity of the palliative care approach to the clinical approach of pediatrics is rein-
forced by key “intervention strategies” delineated in a recent monograph, “A Pathway for Patients and Families Facing Terminal Disease,” by the National Hospice Organization’s Standards and Accreditation Committee. The monograph applies a Treat, Prevent, Promote strategy to organizing and planning therapy for the patient with progressive, incurable illness and the patient’s family.

This approach draws upon many familiar interventions of medicine but does so within a clinical perspective that is not confined by the problem-based medical model. When “health” is tacitly understood as the absence of injury or illness, the dying person is obviously unwell. However, within a developmental model, the experience of suffering can be understood and responded to without conceptualizing the patient or family as pathologic. Living with progressive illness inevitably entails serious challenges arising from having to cope with effects of symptoms and disability, but medical illness per se does not define the person as being unwell.

“In the meantime, I had learned that all the greatest and most important problems of life are fundamentally insoluble. They must be so, for they express the necessary polarity inherent in every self-regulating system. They can never be solved, but only outgrown.”

Carl Jung’s observation offers a valuable therapeutic strategy. A life-cycle or developmental model offers a powerful tool for understanding the continuum of human experience of patients and families confronted with the physical symptoms, functional decline, and emotional challenges associated with progressive, incurable illness. It represents a robust organization schema for evaluating and effectively intervening in suffering that arises in the context of terminal illness, but is not primarily derived from physical symptoms. The developmental model is broad enough to encompass interpersonal issues as well as spiritual or transcendent dimensions of personal identity and experience. A developmental taxonomy can be applied to approach sensitive religious and cultural issues with terminology that is universal, nonjudgmental, and positive. Furthermore, a life-cycle or developmental model provides a framework for proactively assisting patients and families with issues of life completion, life closure, and healthy grieving. In so doing, it does not supplant, but rather complements a problem-based medical model applied to disease modification and the management of symptoms.

**Implications for Palliative Care Outcome Measurement**

The current deficiencies in care for the dying extend deeper than instances of inappropriate use of aggressive, life-prolonging treatment and the needless prevalence of pain and other readily controlled symptoms. Within the clinical culture of contemporary America, “subacute” personal suffering is often undetected and, therefore, ignored until it reaches acutely psychiatric proportions. Most at risk are the advanced elderly as well as those with advanced, chronic illness. Suffering associated with progressive illness, physical and functional dependence, and isolation can occur in all living situations and clinical settings; it is, perhaps, most poignantly observed in nursing homes, especially those that are publicly funded.

An analogous situation can be found within the history of pediatrics and child psychiatry from the early part of the twentieth century. A condition known at the time as “hospitalism” claimed the life of as many as 90% of infants in some public orphanages and, at its best, left every surviving child with profound retardation by the age of five. Rene Spitz, a developmental child psychiatrist, investigated the etiology of this syndrome. He carefully compared critical aspects of care in a foundling home in which severe developmental disability was endemic, with the care in a prison nursery in which incarcerated mothers were allowed to care for their infants until they were 1 year of age. Spitz demonstrated that in most ways, infant care was actually less optimal in the prison, yet the developmental delay there, though measurable, was mild. However, striking differences in care lay in the degree and types of touch and human interaction. In the foundling homes contact with caregivers was almost solely related to feeding, cleansing, and swaddling the infants. In contrast, in the prison nurseries the infants were almost constantly held and played with.

Spitz concluded that the foundling home babies were suffering from a lack of human
attention and touch. By responding to the underlying etiologies through changes in institutional policies and systems of care and through screening for early signs of developmental delay, the pediatric failure-to-thrive syndrome has dramatically diminished in frequency and severity.

Today, however, Spitz’s description of orphaned infants laying still and expressionless in bassinets brings to mind the blank faces of residents within too many of our nation’s nursing homes. Residents may be left to sit or lie for long periods of time, untouched; receiving care only when they are wet or it is time for them to be fed. Despite genuinely caring intentions of staff, a failure-to-thrive syndrome as stark as that described by Spitz is endemic within many accredited long-term care institutions. Nutrition, hygiene, and “medical care” may all be adequate, while the persons who reside there languish. Barriers to better care are fiscal and regulatory, but most fundamentally, they are conceptual. Dominant clinical models and the outcomes tools based exclusively on assessing the presence and response to “symptoms” and complications of disease are incapable of detecting features of this syndrome. Future outcome measures must enable screening for early signs and symptoms of an emerging failure-to-thrive syndrome among people with incurable illness. Institutional and agency policies must apply these tools to trigger effective clinical responses preventing this syndrome from occurring.

The developmental assessment methodologies developed for use in childhood have demonstrated reliability and yielded impressive results in terms of early detection and corrective action. The conceptual orientation and assessment strategies upon which these tools are built could be adapted to the last stage of life and applied for screening, clinical care planning, and investigational use.

A set of outcome measures that included assessment for human development relevant to advanced illness and the knowledge of a terminal prognosis, could be applied as clinical assessment tools to detect patients whose personal needs were going unmet and personal opportunities going unrealized. They could also be applied in the process of programmatic quality improvement. Emotional problems would not have to reach the proportion of clinical depression to be discerned, triggering a clinical (and programmatic) response.

Within a developmental model of progressive illness and dying, without needing to label the person of the patient pathological, clinicians can respond to personal suffering by offering to support and assist the patient in the work of completing those areas and issues of life that the patient identifies as most important. There is no right way to grow up, and there is no right way to die. As is the case in childhood, the last stage of human life is always unique and yet, always embodies features that are common across the human condition. Living with physical discomfort, progressive decline, and knowledge of impending demise is an intensely personal experience, yet there are important commonalities in the challenges terminal illness imposes that universally apply. These commonalities provide a basis for evaluation tools that are useful in clinical care planning and outcome assessment. At both the beginning and the end of life, clinicians can best serve by treating the problems that arise, screening for and preventing foreseeable problems, while preserving and promoting opportunities for growth within the patient and the family.

**Measuring Success**

"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 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."[12]

"I shall long remember the young patient who in dying commented that his final months (which had been characterized by 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..."
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.\textsuperscript{13}

Another critical advantage of adopting a non-problem-based model for the task of outcome measurement is the ability to measure positive experience.

From the perspective of problem-based medicine, the goals of care are a reduction in problems and the only positive outcomes discerned are changes in the direction of the patient’s premorbid baseline physical and functional status. Quality of life, which has been recognized as a cardinal goal for palliative care can, therefore only approach that pre-illness baseline.\textsuperscript{14,15} The consensus among outcomes researchers is that “quality of life” is an entirely subjective construct; it is what the person says it is.\textsuperscript{16} Documented instances of subjectively heightened quality of life of a person who is dying and has neither evidence of dementia nor delirium cannot be explained by the problem-based medicine for these experiences lie outside the boundaries of its conceptual model.\textsuperscript{10,11,17,18}

In contrast, a life-cycle or developmental model can encompasses positive subjective experience. It can, as well, support exploration and understanding of a patient’s transition from suffering to a restored—or enhanced—quality of life. This model therefore has utility for understanding instances of expressed positive personal experience despite persistent physical symptoms.\textsuperscript{2,7,8}

\textbf{Conclusion}

Measures of quality of care and outcomes influence and, at times determine, standards of clinical practice. As we embark on the task of refining individual measurement tools and developing a tool kit of outcome measures for palliative care, we must carefully inspect, choose, and construct conceptual models on which those tools are based. The problem-based model of medicine provides an effective organizational structure for assessing the physiologic needs of patients, including the management of symptoms associated with advanced, incurable illness. Dying persons and their families can be best served by complementing the prevailing problem-oriented approach with a conceptual framework that recognizes opportunities for subjectively meaningful, valuable personal experience throughout the life cycle. A developmental model, similar to that applied in early childhood care, can advance our clinical ability to respond to nonphysical suffering while preserving, and nurturing, human potential through the very end of life. Building on work in child psychology and developmental psychology, this conceptual model also suggests an important strategy and organizational structure for measurement in palliative care.

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