The Concept of Quality of Life of Dying Persons in the Context of Health Care

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Abstract

Considerable research has addressed quality of life and quality of care; however, it has not addressed adequately the experiences of patients and their families at the end of life. Health care may have a greater effect on quality of life during the dying process than it normally does. Building on research and expert review, a conceptual framework is presented that specifies and integrates quality of life and quality of health care indicators. Five main concepts include patient/family context, structure of care, process of care, satisfaction with care, and quality and length of life. Patient and family perspectives are considered. The framework emphasizes quality of life, thus detailed definitions of each quality of life domain are provided. The goal is to facilitate development of a comprehensive set of measures to describe the quality of life of dying persons and evaluate the care they receive, to be used to improve end-of-life care. J Pain Symptom Manage 1999;17:93–108. © U.S. Cancer Pain Relief Committee, 1999.

Key Words

Health status indicators, quality of life, palliative care, quality of care, quality assurance, health care, outcome assessment, death, patient satisfaction, terminal care

Introduction

Increasing attention is being given to the way people die. Because the majority of older and seriously ill persons die in acute care hospitals or nursing homes, the quality of care provided during the last few months of life can strongly affect the quality of life of both patients and their loved ones, as well as the length of life of the patient. Nevertheless, patients are at risk for poor quality of care, particularly with increasing economic incentives on health care organizations to control costs at the end of life. This makes it increasingly important to document the quality of care and quality of life experiences of dying patients and their families. Such information could help investigators compare outcomes across settings (e.g., home versus hospital), compare alternative approaches to end-of-life care (e.g., hospice versus traditional care), and compare care given by different types of providers (e.g., primary care versus palliative care specialists). It could also evaluate efforts to improve quality of care, which would in turn improve quality of life.
Prior to selecting or developing instruments to assess quality of life and quality of care, it is useful to have a comprehensive conceptual framework that specifies and defines all relevant domains that are appropriate for describing and evaluating end-of-life care and how it affects patients and families. To serve as a marker of the experiences of those going through this time, the quality of life domains need simply to be salient to those who are dying as well as their families and loved ones. However, for quality of life domains to serve as quality of care indicators, the domains must be able to be improved with optimal care. To be useful to providers, administrators, and evaluators, an important goal is to distinguish quality of care indicators (e.g., structure and process of care variables) from indicators of quality of life.

In this paper, we present a general conceptual framework that specifies and integrates indicators that are relevant for evaluating the quality and outcomes of care of seriously ill dying patients and their families, specifically those in the last months of life. We then focus on the quality of life portion of the model, defining these concepts in detail as they apply to dying persons and their families. The goal of this work is to facilitate development of needed measures to adequately assess the components of the model, particularly the quality of life domains.

**Overall Framework of Quality of Life of Dying Patients and Their Families in the Context of Health Care**

An overview of our conceptual model of the quality and outcomes of care of terminally ill patients is presented in Figure 1. This framework incorporates and builds on domains proposed by the American Geriatrics Society (AGS), and incorporates ideas from an extensive literature cited throughout this paper. The framework includes three overarching categories: (1) patient and family factors affecting health care and its outcomes, (2) the structure and process of care (from which to glean quality of care information), and (3) patient and family outcomes of care including satisfaction with care and quality and length of life.

Both the structure and process of health care can affect satisfaction with care and quality of life. The structure of care can affect process of care in myriad ways, including referral constraints, services actually provided, and type of health care setting (e.g., hospice care at home, hospital, or nursing home). In turn, process can affect outcomes through the nature and quality of those processes.

Structure and process variables are not in and of themselves quality indicators. Structural variables may either facilitate or hinder good quality of care, however, an observer of the structural characteristics must make that judgement. The nature of the process can similarly be described either in terms of what happened (reports) or in terms of judgments made by providers or external quality assurance reviewers (e.g., Joint Commission on Accreditation of Healthcare or the Health Care Financing Administration) about whether the process meets standard criteria for quality. Efforts to define quality of care standards at the end of life have been undertaken by the National Hospice Organization and the Canadian Palliative Care Association. Although some processes are valued by most people (e.g., sensitive and compassionate interpersonal style of provider), others may not be. For example, because not all patients or families desire extensive information about their condition, some processes need to be evaluated in light of patient/family preferences.

Quality of life can also be an indicator of quality of care. However, it has many other determinants, thus it needs to be demonstrated that the quality of life outcomes are attributable to antecedent health care. Although some suggest that the magnitude of the effect of medical care on quality of life in general tends to be quite small, end-of-life care may have a much greater effect. To the extent that the structure and process of care are strong determinants of quality of life, they become points of intervention by which to improve quality of life.

Based on the premise that palliative care is patient-focused and family-centered, our framework considers the patient, family, and loved ones as important. Indeed, dying redefines the family as a direct participant rather than an intermediary for the patient, thus, the family’s present and future well-being is strongly
affected by the care given to the patient.\textsuperscript{11,18,19}

We specifically include loved ones to clarify that the primary caregiver or caregivers may be a mixture of family, friends, volunteers, and health professionals. We are referring to the person or persons who are intimately involved with the patient, are concerned and aware of the patient on a regular basis, and who love the patient. These persons could be defined by the patient as those he or she would turn to for decision-making advice and/or emotional and tangible support. For simplicity, we will usually refer to the family and loved ones as the “family.”

In Figure 2, we elaborate on the content of each element identified in Fig. 1, thus presenting a more detailed version of the conceptual model.

**Patient Factors Affecting Health Care and Outcomes of Care**

**Personal and Social Environment.** The personal and social environment provide the context within which the patient and family seek end-of-life care. They include the patient’s and family’s situation such as their financial resources and concurrent life issues.\textsuperscript{13} Clinical status includes diagnosis, severity, history, and trajectory of illness, to allow case-mix adjustments when comparing settings or providers. Social support available to the patient and the family comprise essential contextual factors. To the extent that support is desired but not available as part of the patient’s environment, it could be considered an unmet need that should be provided by the health care system. Many people do not have the intact support network needed to qualify for hospice care, thus the personal environment of the patient can be another barrier to desired end-of-life care. All of these contextual factors can affect the structure, process, and outcomes of care.

**Structure and Process of Care**

**Structure of Care.** Aspects of the structure of care that a person is eligible to receive include access to care within the system, organization of care, formal support services available, and the physical environment of care. We have included an access category to allow for the fact that individuals have varying levels of access to care, given system variations (private, public). Even with private systems, many administrative and regulatory barriers often make palliative care difficult to obtain.\textsuperscript{19} For example, payment can be obtained for aggressive, expensive technical care at the end of life but not for palliative care, thus current incentives support the provision of the former.\textsuperscript{20}

The organization of care within this framework focuses on management and leadership values and on the availability of providers trained in delivering end-of-life care. The organizational mission and values regarding end-of-life care can influence processes and outcomes considerably.\textsuperscript{21} Organization also includes the nature of the racial/ethnic mix of providers that could enable patients to be cared for by an
**Fig. 2.** Detailed conceptual model of factors affecting quality and length of life of dying patients and their families.

<table>
<thead>
<tr>
<th>PERSONAL AND SOCIAL ENVIRONMENT</th>
<th>STRUCTURE OF CARE</th>
<th>PROCESS OF CARE WITH PHYSICIANS, NURSES, SOCIAL WORKERS</th>
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<td>WITHIN SYSTEM</td>
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<td>Preferences honored</td>
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<td>Culture, religion</td>
<td>Availability of hospice and palliative services</td>
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<td>regarding way of dying</td>
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<tr>
<td>Financial resources</td>
<td>Financial access to hospice and palliative services</td>
<td>Appropriate, timely referral for support services, counseling, specialty care</td>
<td>Satisfaction with:</td>
<td>Social functioning and</td>
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<tr>
<td>Socioeconomic status</td>
<td>(e.g., services covered by health insurance)</td>
<td>Knowledge and attentiveness in managing dying patient</td>
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<td>Caps on care</td>
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**LENGTH OF LIFE**

Perceptions by patient, family, loved ones of quality of dying of patient
ethnically matched provider should they so desire. The formal support services available (and accessible) within the health care setting could help meet the needs of patients and their families. The site of death or the physical location of the patient during the dying process, and the site characteristics (e.g., aesthetics, noise, opportunities for social interaction) can strongly affect quality of life.22–24 A current problem is that patients are often transferred to another location which is extremely disruptive to both patients and their families due to loss of staff contacts, lack of continuity of information, and the subsequent unfamiliarity of the patient and family with the new staff. Upon admission to hospice care, many policies require physicians to turn care over to hospice physicians, which also disrupts the continuity.

**Process of Care.** The process of care is perhaps the heart of indicators of quality of care for persons in the last phase of life; we include care given by physicians, nurses, case managers, and social workers. Within process, we distinguish technical process; decision-making process with both the patient and the family; information and counseling provided to patients and their families; and the interpersonal and communication style of care providers. We have specifically delineated these four aspects of the process of care, since each may uniquely affect outcomes. Technical process also includes the continuity and coordination of care provided, which can be affected by the structure of care. Coordination and continuity take on new meaning at the end of life, as there are many types of providers providing a variety of services.

Kristjanson25 found that the most important processes of care that family members of dying patients perceived as helpful to the patient and themselves pertained to prompt and thorough medical care. The top five processes rated in three different settings were: pain was relieved quickly, the patient’s needs were responded to quickly, the patient had trust and confidence in the physician, the doctor referred the patient to a specialist promptly, and the patient knew it was okay to call for help at any time. Better communication was desired by 44% of family members in another study.26 In this study, nearly one-fourth of family members could not recall a discussion of decisions regarding treatment.

Because symptom management is regularly deficient in the care of dying patients,3,11,27,28 health care providers must assiduously attend to the treatment of pain and minimize side effects from such treatment. This suggests a need to attend to the process of communication and negotiation. Patients should be involved in choices made in order to obtain a valued balance.29 For example, patients may face the tradeoff of total pain relief and terminal sedation. An issue that warrants discussion is that persons view some states of health as worse than death.30–32 In the SUPPORT study, numerous people said they would rather die than live on a ventilator, in a coma, or in a nursing home.33

**Outcomes of Care**

**Satisfaction with Health Care.** Satisfaction with health care (not to be confused with satisfaction with outcomes) is defined separately for patients and their families. The AGS suggests that for end-of-life care, patient and family satisfaction with health care is an integral part of clinical practice.11 Although satisfaction with various processes of care is relevant for both patients and families, there are some differences. For example, different types of information, and counseling may be provided to patients and families.

**Quality and Length of Life.** The remaining outcome categories are described in more detail in the next section, as these are the focus of the paper.

**Framework of Quality and Length of Life**

**Quality of Life of Patient**

The quality of a person’s life is determined both by the nature of his or her experiences, and by the values and meaning that the person attaches to those experiences. People adapt to adverse circumstances and may continuously reevaluate the meaning inherent in those circumstances. Thus, it is essential to define quality of life in terms of subjective evaluations by individuals, rather than in terms of the meaning others attribute to the experiences of the individual.

In considering how to define quality of life, many have noted that although dying is often thought of as a time of suffering and severe
problems, it also can be a very important time for patients and their loved ones.\textsuperscript{1,11,34,35} While at one time in their life, perceived quality of life might have been determined largely by functional ability and psychological well-being, different domains may be more influential for dying persons. As stated by Morris,\textsuperscript{36} “for those who are dying, life takes on a new shape: it narrows, sometimes to a single room; work and running a household are no longer part of it. Friends and family are seen in a new way. Values change. What was once important may seem insignificant, while things once ignored have greater weight” (p. 48).

Persons confronting death, and their loved ones, may thus define quality of life differently from those not facing imminent death.\textsuperscript{9} Quality of life at the end of life may focus to a greater extent on peace of mind, comfort, and spiritual understanding than when more interaction with the social and physical environment was possible. For many dying persons, attending to spirituality and transcendence is very important. Seeking resolution and making peace could substantially contribute to living well while dying. The spiritual dimension may be important at first recognition of the imminence of dying and again at the very end, when the physical or biological process of dying is in denouement. Dying patients, during different phases of their experience, may concentrate more heavily on one aspect such as cognitive ability to recognize family and friends, than on others such as walking or even bodily functions. They may give more emphasis to personal dignity and the meaningfulness of life than to physical symptoms or functioning.\textsuperscript{9}

In considering how to conceptualize quality of life during the dying process, many of the domains listed in Figure 2 are the same as in more general conceptualizations of quality of life and health-related quality of life (e.g., pain, psychological well-being). However, a major difference lies in how these domains are defined and operationalized. Table 1 presents a proposed definition of each domain for purposes of describing dying persons, and includes an indication of how this definition differs from more traditional definitions of that domain. The information in Table 1 is intended to provide a basis for selecting or developing appropriate measures. Note that our framework does not prioritize the domains.

**Physical Comfort.** One of the most important wishes of dying persons is that their last days be as comfortable as possible.\textsuperscript{36} Physical comfort (or discomfort) can be described by a variety of symptoms that range from specific symptoms such as pain or dyspnea, to somewhat more generalized states of fatigue or malaise (see Table 1). The failure to attend to patients’ physical comfort is often an important indicator of inadequate quality of care that patients receive in their last days of life.

**Pain and Other Specific Symptoms.** Numerous studies have found that dying patients experience considerable amounts of pain and other physical symptoms.\textsuperscript{9} Cancer-specific studies have described the most common symptoms experienced by terminally ill cancer patients.\textsuperscript{1,2,37–41} Because pain is experienced by 75 to 80% of noncancer patients in the last year of life\textsuperscript{2,15} and because there are wide variations in pain between nursing homes using a case-mix adjusted model (personal communication, Vincent Mor), pain may be the most important element of physical comfort and should be assessed as a separate and distinct symptom.

There is a paucity of research on the degree to which symptoms other than pain can be ameliorated. Two other common symptoms in patients near the end of life are fatigue and dyspnea.\textsuperscript{2} For example, nearly 70% of cancer patients experienced dyspnea in the last 6 weeks,\textsuperscript{42} and fatigue affected nearly 80% of dying patients in a survey of their surrogate decision-maker.\textsuperscript{2}

Because it may not be practical to assess a long list of potential symptoms, and because shorter lists may miss symptoms that are causing a great deal of distress, it may be more useful to ascertain how patients view their own symptoms. The main element of information could be the extent to which the symptom is distressing, bothersome, or interfering with overall quality of life\textsuperscript{39,45} or the extent to which patients find the symptoms difficult to tolerate.\textsuperscript{2} It has been long recognized that the degree of perceived burden from a given symptom and the physiological disturbance from a given disease do not perfectly correlate. For example, different patients with the same physiologic indicators of the severity of chronic obstructive pulmonary disease may have different perceptions of breathlessness. For dying patients, this observation is very important. This
<table>
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<th>Domain</th>
<th>Definition</th>
<th>Differences from Traditional QOL Assessments</th>
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<tr>
<td><strong>Physical Comfort</strong></td>
<td>Pain and Other Specific Symptoms: Specific symptoms common in persons in the last period of life, especially those that cause physical discomfort and/or distress. Includes pain, shortness of breath, weakness, fatigue, nausea/vomiting, appetite, dry mouth, coughing, sleep problems, constipation, diarrhea, incontinence, skin problems (bed sores, itching), and difficulty seeing and hearing. Can assess frequency, severity, duration, distress, bothersomeness, difficulty tolerating symptoms, or number of days without symptoms. Ability to control/manage symptoms promptly without undesired side effects.</td>
<td>Pain and Other Specific Symptoms: Focuses on symptoms more commonly experienced by terminally ill (symptom lists of terminally ill are available).</td>
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<tr>
<td><strong>Psychological Well-Being</strong></td>
<td>General Malaise: Feeling not well, bad, ill, or sick. May include inability to tolerate physical symptoms</td>
<td>General Malaise: Malaise is seldom included as a specific concept.</td>
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<td></td>
<td>Emotional Well-Being: Status on a full range of positive and negative emotions, especially anxiety, depression, sadness, loneliness, fear, and feelings of being calm and peaceful, happy, at peace. Also, extent of worry about family being economically harmed by patient’s health care expenses.</td>
<td>Emotional Well-Being: Traditional approaches focus on depression and anxiety. Some include positive emotions. Existing approaches need to be examined to determine if they are appropriate for dying patients.</td>
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<td>Dignity/Esteem: Sense of being valued as a person, sense of not being a burden to others, body image, sense of being attractive (clean, groomed, dressed for visitors).</td>
<td>Dignity/Esteem: Traditional self-esteem concepts focus on feelings of worth as a person, feeling useful; in this context, need to focus on more immediate self-esteem. No traditional measures assess dignity.</td>
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<td>Sense of Control, Autonomy: Has desired privacy, perceives control of daily life, has choices, feels in control of the overall dying process, able to “die on one’s own terms,” self-determined life closure.</td>
<td>Sense of Control, Autonomy: Traditional measures focus on sense of mastery in life, ability to control one’s life.</td>
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<td></td>
<td>Resilience: Ability to withstand stress and maintain emotional equilibrium, extent of physiologic reserve</td>
<td>Resilience: Seldom measured as part of quality of life instruments, but concept is similar to traditional approaches. Traditional approaches for assessing social functioning focus on limitations in role and social activities due to health problems that are not the primary concern in this context. Very few (if any) measures focus on these specific aspects of social well-being</td>
</tr>
<tr>
<td><strong>Social Functioning and Well-Being</strong></td>
<td>Communication: Ability to communicate, quality of communication, ability to communicate important thoughts and feelings, quality of interactions with significant others</td>
<td>These domains seldom included in traditional QOL profile approaches, although specific definitions and measures of spirituality are available.</td>
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<td></td>
<td>Social Connection and Sense of Closure: Not isolated and alone, presence of significant others, presence of individuals patients want to be there, able to spend time with significant others in quiet atmosphere. Sense of having said all important things, leave-taking, closure, making contact with all significant others</td>
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<td><strong>Spiritual Well-Being, Meaningfulness of Life</strong></td>
<td>Spiritual Well-Being, Meaningfulness of Life: Ability to find meaning in current life and in daily experience, acceptance of death, feeling at peace with life or God. Satisfaction with life lived in its totality (e.g., lived the life one wanted to live), meaningfulness of that life.</td>
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<td>Transcendence: Ability to prepare for the loss of one’s physical self, surrender to the transcendent, find meaning beyond the lifespan.</td>
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<td>Suffering: Anguish, terror, hopelessness (severe states of emotional, social, or psychological distress) that dying patients may experience.</td>
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(continued)
approach is also important because of the remarkable ability of patients to accommodate to their symptoms. Another approach that could be particularly useful with respect to dying patients is the amount of time (e.g., number of days) without symptoms or toxicity, the Q-TWiST approach.44,45

**General Malaise.** General feelings of malaise, i.e., not feeling well, are seldom defined as part of physical comfort in traditional approaches. However, there are a number of ways that malaise could be defined based on available measures. These include assessing when patients do not feel well, as well as the extent to which they feel bad or somewhat ill.46–48 Such an approach could provide a shorter alternative to asking about specific symptoms, but may be less sensitive to interventions.

**Psychological Well-Being.** Measures of psychological well-being must allow for the possibility of positive as well as negative psychological and emotional states.4,49 Lawton and colleagues50 in a study of the last year of life found that 82% of those who died experienced a “majority of positive quality months in their last year.” The quality of dying scale of Wallston and colleagues31 includes states of calm and happiness. In assessing the dying patient, a sense of dignity or self-esteem, and a sense of control are all important. Further, the resilience of the dying person, i.e., the ability to withstand stress, can be considered part of psychological well-being.52

Thus, we conceptualize four major components of psychological well-being: emotional well-being, dignity/esteem, sense of control, and resilience.

### Table 1 (continued)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Definition</th>
<th>Differences from Traditional QOL Assessments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>Independence, mobility, ability to care for self, walk,</td>
<td>Traditional approaches tap full range of physical activities including walking, climbing stairs, and doing housework that may not be as relevant for most terminally ill persons.</td>
</tr>
<tr>
<td></td>
<td>not be confined to bed; physically able to do what they want to do at this time.</td>
<td></td>
</tr>
<tr>
<td>Cognitive Functioning</td>
<td>Ability to think, mental alertness, comprehension, attention, and avoiding confusion</td>
<td>Traditional approaches tap a broad range of components that may not be relevant in this context. May want to focus on components of special importance during dying process.</td>
</tr>
<tr>
<td>Overall Perceived Quality of Life</td>
<td>Overall rating of current quality of life</td>
<td>Traditional approaches tend to ask about overall satisfaction with current life, which may be appropriate. Overall quality of life questions exist in some palliative care instruments. Approaches that ask about satisfaction with various domains of life are probably not appropriate.</td>
</tr>
<tr>
<td>Quality of Dying of Patient</td>
<td>Perceptions of overall quality of dying or of death, from perspective of patients, families, and loved ones. Includes being free of avoidable distress and suffering for patients and families, in accord with patients' and families' wishes, and reasonably consistent with clinical, cultural, and ethical standards.</td>
<td>Nontraditional</td>
</tr>
</tbody>
</table>

Table 1 (continued)
their health care, they may be concerned over being unable to leave an inheritance to their children or families. Thus, a specific element of emotional well-being for dying persons is their worry about financial issues.

**Dignity/Esteem.** In terminal care, profound respect for the patients’ dignity should be a matter of course. The right to dignity and personal integrity is one of five rights of the dying person developed by the Council of Europe. However, the concept of dignity during the dying process is difficult to define. The Institute of Medicine (IOM) Committee on Care at the End of Life suggested that a dignified death is one in which the care given honors and protects those who are dying, conveys that dignity resides in people (not their physical attributes), and helps people preserve their integrity while coping with unavoidable physical insults and losses. From a less global perspective, the dignity of a hospitalized patient could refer to issues of self-presentation, i.e., having to wear a hospital gown, not being able to wash one’s hair as often as usual, smelling bad, and for women, not being able to apply one’s usual makeup to feel attractive for visitors. Although these may be assumed to be “secondary” concerns of those who are dying, they may in fact be an essential part of feeling that one can relate to one’s family and friends from a position of self-respect. Much can be done to maintain the personal dignity and self-esteem of the dying person such as generally treating persons with respect.

**Sense of Control, Autonomy.** Dying is a critical time when both patients and families may feel they have few opportunities for choice and control. Thus, the degree to which patients and families feel they were presented with and understood various options, and felt in control of the choices is important. Such things as scheduling a visit on the patient’s schedule of the choices is important. Such things as scheduling a visit on the patient’s schedule rather than that of the health care providers can provide some sense of control.

Control can also be defined more globally in terms of control over the entire process of dying, perceiving that one is able to “die on one’s own terms.” Were patients’ preferences honored regarding the approach to care and the degree of use of medical treatments? This is referred to as “self-determined life closure” by the National Hospice Association. One of the major tenets of hospice care is to provide people with the opportunity to “die as they choose,” thus hospice care aims to support self-determination by the patient and family. Wallston and colleagues note that the opportunity to regain a sense of control by obtaining the type of death preferred is an important element of quality of life at this time.

**Resilience.** Resilience has been defined as the capacity for health, the ability to withstand stress, maintaining emotional equilibrium, and the extent of physiologic reserve. Physiologic reserve refers to the unused capacity of the organism that can be called upon in times of stress or crisis. Although some portion of physiologic reserve is genetic, part can be affected by health care.

**Social Functioning and Well-Being.** Social functioning and well-being traditionally focus on limitations in role and social activities because of health problems, which are not the primary concern in this context. For those who are dying, we define two components of social well-being: communication, and social connection and closure.

**Communication.** Terminal illnesses and their treatments may cause sedation and loss of mental alertness, as well as losses of hearing and sight. The inability to communicate may be a serious problem for many patients and their families. Indeed, nearly half of seriously ill dying patients in one study were unconscious during the last 3 days of life. For those who can communicate, because of the urgency of communicating important thoughts and feelings to loved ones and care providers, the quality of communication is important. Supportive environments that provide quiet and privacy may thus greatly improve quality of life.

**Social Connection and Closure.** For many dying persons, the presence of significant others (family and friends) and the chance to bring closure to important relationships are key elements of quality. These are not possible without appropriate control of symptoms and an atmosphere that is conducive to close communication. To be able to communicate with individuals to the point of feeling that they have finished all necessary business and said everything they wanted to say provides patients with a sense of completion or closure of their relationships, and can allow patients to feel a sense of calm.
ten a high priority at the end of life, in fact, some persons remain alive until a loved one arrives to say goodbye. Rituals of farewell are also common religious and cultural practices, in part for the dying person and in part for others.

**Spiritual Well-Being, Meaningfulness of Life.** Spiritual well-being could well be one of the most important aspects of quality of life at the end of life. It has been defined as the ability to find meaning in life and in daily experience, and the ability to transcend physical discomfort, accept death, surrender to the transcendent, and feel at peace. The ability to find meaning in life can pertain to one’s current situation as well as to one’s satisfaction with the whole life lived. Others have defined spiritual well-being in terms of transcendence, self-determined wisdom (possessing knowledge that integrates and stabilizes the person in the context of his or her physical and sociocultural environment), and acceptance of the totality of life (taking comfort in all experiences of one’s unique life and having no despair). As a person’s physical condition declines, spiritual issues may gain in importance. Further, individuals can have improved spiritual well-being in conjunction with declining physical well-being. Palliative care such as hospice care is dedicated to improving spiritual well-being.

**Transcendence.** Although transcendence is an element of spiritual well-being, its importance at the time of dying is paramount, thus it merits distinction. Transcendence has been defined as the crossing of a boundary beyond the self to a sense of the spirit of the universe, and as a level of awareness that exceeds ordinary physical boundaries and limitations. Transcendence can also pertain to the sense that one’s life extends beyond one’s physical self—into the future as into the lives of others. It can also refer to preparing for the loss of that physical self, preparing to bring one’s life to a close, and to making peace with life or with God. The quality of transcendence may be affected by one’s belief in an afterlife. Those who believe they are “going to their maker” may have a sense of calm.

**Suffering.** The only way to learn the extent to which physical or emotional pain is causing suffering is to ask the individual. For dying patients, suffering is not just based on physiologic abnormalities, but on the social or psychological distress from the knowledge of the destruction of oneself. Even when no symptoms are present, a dying person may suffer greatly if life has lost its meaning. Cassell notes that although suffering is a subjective concept, able to be known only by the sufferer, it nevertheless cannot be ignored. The IOM Committee on Care at the End of Life also notes that suffering is prominent in many religious and philosophies, thus, some people may value suffering over the alleviation of physical symptoms. Quality medical care must attend to the concept of “total pain,” i.e., suffering may be based on physiologic abnormalities, social isolation, spiritual angst from knowledge of the impending loss of self, and other psychological processes. Thus, patients’ views of their own suffering are of prime importance in examining quality of life.

**Physical Functioning.** Traditional approaches to assessing physical functioning include limitations in walking, climbing stairs, reaching, bending, and so forth—physical movements that are essential to more complex functions and activities such as working and recreational activities. These functions may be less relevant to the majority of seriously ill dying patients. Measures of physical functioning for severely ill older adults focus more on their ability to perform self-care activities such as bathing, dressing, and using the toilet (typically defined in terms of the need for help, representing a loss of independence). Being confined to bed is common in those who are dying and represents a severe loss of functioning and independence. On the other hand, in a study by Wallston and colleagues, one of the most valued aspects of quality of life for dying persons was to be physically able to do what they wanted to do. For example, dying persons may desire the physical ability to travel to an important place, to get outside the home, or to be in the garden. However, only 1 in 20 terminally ill cancer patients were able to achieve this in Wallston’s study.

**Cognitive Functioning.** Many dying individuals experience difficulties in thinking, being mentally alert, comprehending, and paying attention because of medications or illness. These in turn can impede communication and independence. Traditional approaches to cognitive
functioning tap a broader range of components such as memory, orientation, and concentration. To describe the quality of life of those who are dying, it is preferable to focus on those cognitive symptoms that are most prevalent and most problematic to communicating with family and friends. One aspect of cognitive functioning that occurs frequently in dying individuals is delirium. It is prevalent and may be related to medications and thus could potentially be controlled.

Overall Perceived Quality of Life. Researchers often need to conceptualize (and measure) an “overall summary” of quality of life. One approach is to have the person summarize all important aspects of their lives into a single rating. The advantage of such a global quality of life indicator is that it allows people to “define” quality in their own way, whereas relying on a combination of specific predefined indicators means that quality is defined by the investigators. Because perceived global quality of life depends on the personal meaning assigned to one’s current state, for those who are able to transcend their physical distress, quality of life can remain stable or even improve as physical suffering and disability increase. Thus, when those who are in the last phase of life (i.e., limited by the illness that will eventually be fatal) report having a high overall quality of life, they may mean something quite different than when those who are not in this phase report a high quality of life. As part of the development of the McGill Quality of Life Questionnaire designed for people with advanced disease, a single-item overall quality of life scale was used. Cohen and her colleagues found that this overall item was most highly correlated with a meaningful existence measure (r = 0.62); the second highest correlation was with an outlook on life measure (r = 0.40). The item was least correlated with physical and psychological symptoms (r = 0.16 and 0.21, respectively). These findings support the definition of global quality of life as a subjective integration by patients of the aspects of their life that they deem relevant.

Quality of Life of Family and Loved Ones

Family members and loved ones can be strongly affected by the quality of care of the dying person. Because palliative care is patient-focused and family-centered, clinicians are actually caring for the patient in the context of the patient’s caregiving network. One of the main features of hospice and palliative care is that it emphasizes providing support to the family as well as the patient. Indeed, family members and loved ones may need as much or more support as the patient since they are facing an imminent loss, experiencing anticipatory grief, attempting to provide emotional and tangible support to the patient, feeling guilt, worrying about being left behind, and, in addition, are likely to be overburdened as caregivers attempting to provide necessary care in the context of their own lives. Although the quality of life domains for the family members are often the same as for the patient, e.g., psychological and physical well-being, additional elements are relevant as well.

Several investigators have identified needs of family members caring for dying persons, many of which focus on the extent to which care meets the patients’ needs as well as their own. For example, in a qualitative study to identify aspects of patient and family quality of life, families indicated that the patient’s needs were more important than theirs (e.g., “take good care of him and you take good care of me”). Thus, one key aspect of families’ quality of life is that the patient is comfortable. Another potential approach would be to assess family quality of life more generally, using global indicators such as their overall rating of their quality of life at this time.

Dawson outlines several family-specific domains in her Need Satisfaction Scale including having the time to say goodbye, being present when the patient died, and being able to talk with staff after the patient’s death about events surrounding the terminal illness. Hind, notes that families expressed a need for a place where they could turn to discuss their fears. Although families may not express a lot of personal needs, to the extent that care is provided that can relieve their stress, they will be better caregivers and have a more positive experience of the dying of their family member.

Bereavement is a key issue for family and loved ones. There is a dramatic impact of grief on the surviving spouse. In one study, recently bereaved (less than 6 months) men and younger spouses experienced an increased likelihood...
of excess mortality. For all survivors, grief resulted in lost productivity. Yet, there is little study of the degree to which interventions could improve grief resolution.

**Quality of Dying of Patient**

The quality of dying is a personal evaluation of the dying experience as a whole, a subjective integration of some of the above distinct concepts according to one’s expectations and values. Thus, each dying person, family member, and loved one may have his or her own sense of what a “good death” would be. In one qualitative study, a “good death” was described by patients as dying in one’s sleep, dying quietly and with dignity, being pain-free, and dying suddenly. Hospice staff in this same study defined a good death in terms of adequate symptom control, family involvement, peacefulness, and lack of distress. The IOM Committee on Care at the End of Life suggests that a good death is one that is free from avoidable distress and suffering for patients and their families, in accord with the patients’ and families’ wishes, and reasonably consistent with clinical, cultural, and ethical standards. Wallston and colleagues defined the quality of death as “experiencing in the last three days of life feelings and events that terminally ill patients reported they desired.” Thus, their focus was on the extent to which patients’ preferences were met. Similarly, Cohen and colleagues assessed the quality of death in terms of the duration of dying, discomfort, and psychosocial circumstances. This definition was based on a consensus among health care providers of end-stage renal disease patients whose dialysis had been discontinued.

There are two possible sources of information on the quality of dying. First, one can query the patient as often as possible throughout the dying process. Second, once a person has died, family members, caregivers, or friends can rate the overall quality of dying from their perspective.

**Length of Life**

Length of life or survival is not a simple outcome measure to interpret. Although length of life is important, decisions that affect it need to be made in ways that reflect preferences, against a background practice style that serves most patients and families. That is, patients may make a personal tradeoff between length and quality of life. This becomes complex in an era of discontinuing dialysis and ventilators, accepting nondiagnosis and nonintervention (especially for older adults), and physician-assisted suicide. One care system could look dramatically better than another in terms of quality of life, cost, satisfaction of family, etc., if it coherently counseled for, and delivered on, early death. It would help to know the effects of overall practice style on survival time.

**Discussion**

Our framework provides an important initial effort to outline a conceptual map of the patient/family context, structure and process of care, satisfaction with care, and quality of life during the dying process. Our focus has been on quality of life, as the definitions of the domains vary substantially from traditional definitions when considering the dying process. Our goal is to stimulate development of a comprehensive approach to describing and improving the quality of care of patients who are dying, as well as their families and loved ones, with the goal of improving their quality of life. We discuss here some issues that need to be addressed to advance the framework.

Several steps are needed to validate the domains in the framework and assure their relevance. Studies comparing outcomes between care provided in hospitals and in hospice settings often find no differences in quality of life, despite differences in satisfaction with care. However, little is known regarding whether the outcomes being utilized are important (on average) to patients and their families. In addition, many of the concepts defined tend to overlap with others (e.g., dignity, sense of control). Thus, the definitions may need to be refined, or some domains combined, to assure that these concepts could be adequately measured. To achieve these refinements, qualitative studies (e.g., focus groups, in-depth interviews) of family members, or perhaps patients in the early phases of dying, can explore the relevance of various domains, the way in which individuals discuss some of the concepts, and how these individuals perceive the dying process. Because responses may differ by race/ethnicity and socioeconomic status, diverse groups should be represented in these studies.
Concepts also need to be prioritized for measurement development. Such criteria could include, for example, identifying aspects of quality of life most likely to be improved with better care, aspects most important to patients, aspects that health care can actually do something about, and the ability to obtain data at a relatively low cost.

The interrelationships among the elements in the model need to be studied, to understand the nature of any causal and confounding relationships among them. Although no causal pathways were suggested in this paper, the depiction of context, structure, process, satisfaction, and outcomes implies a chronology. The importance of understanding these relationships lies in the fact that the domains are dynamic and interactive, i.e., a change in any one domain at any point in time may change variables noted in preceding domains in the model or even in domains among one of the overall categories (e.g., process of care). There are three basic ways in which this model could be tested: (1) examine relationships among variables that are under the control of the health care provider and system; (2) examine the links among the structure of care, process of care, and quality of life/dying outcomes; and (3) examine the relationships among various outcomes, and between family and patient quality of life outcomes. Such tests could lead to improvements in the framework so that it more precisely fits existing data.

It is important to develop or assemble good measures of these concepts that could be administered as a comprehensive instrument. Only a few efforts have developed comprehensive measures of quality of life and quality of care appropriate for those who are dying. Although measures of some of the separate domains are currently available, they need to be reviewed for content validity against the validated framework and for their measurement properties. For many of the domains, new measures will need to be developed, based on existing literature, given the differences in definitions from traditional measures as noted in Table 1.

Another issue in studies of dying persons is the “denominator” problem, that is, knowing who the persons are that can be counted as among the “dying.” Different diseases have different dying trajectories. For example, cancer patients quite typically lose function in the last months of life. This is in marked contrast to patients with congestive heart failure (CHF) who may be slowly dying for years. Since many CHF patients die of arrhythmias, death may be quite unexpected and the person’s level of function may not show a precipitous decline. Because uncertainty is present to some extent in each disease’s dying trajectory, we may need to rely on assessing the quality of care and quality of life among two groups of persons—those diagnosed with a terminal illness and those who are actively dying. Further, some people may “decide” that they are in the last few months of life, for instance, if they are weary of receiving numerous treatments or if they experience an acute severe episode of their chronic condition. Thus, the end-of-life period may be determined by patients who lose their will to continue. Deciding that a person is dying is also important because certain provider expectations are linked to this classification. Current care for dying patients tends to focus on those who are easily recognized as dying. Hence, attention may be needed on how to care for persons with life-threatening illnesses who may currently be receiving mixed management, including both aggressive treatment and some discussion of end-of-life issues. We will need to look to professional organizations to outline standards by which persons ought to be classified as “living with terminal illness” or “actively dying,” such as the American Medical Association or other professional societies.

Even when we think we have identified a “dying person” who might qualify for studies of quality of care, the issue remains as to precisely when investigators should approach that person and their family with a request to provide information. This falls under the purview of ethical considerations in collecting data on seriously ill and traumatized individuals. When is it acceptable for families to be interviewed without intruding on their well-being, yet is an appropriate time point for obtaining useful and valid information about the quality of care during the dying process? Even more troublesome is determining the point at which a patient could be interviewed.

There are several potential applications of the measures that have been or will be developed from the concepts outlined above. Measures of the quality of life or quality of dying
could be used to systematically describe the experiences of patients and their families during the last months of life. Measures could also be used to compare settings (e.g., hospice at home, hospital), facilitate quality improvement within a setting, and develop regulatory standards, or to evaluate various treatments or services (e.g., as outcomes of clinical trials).

In summary, our proposed conceptual framework of the context, structure, process, satisfaction, and quality of life of seriously ill dying patients and their families is intended to distinguish structure and process domains from quality of life domains, and to provide a foundation for developing measures. It was also intended to distinguish concepts of structure and process of care from concepts of “quality of care,” which must be determined by external judgment of the structure and process variables. Although good measures of many of these domains exist, development of a complete profile of measures (incorporating existing measurement approaches) will enable more research to be conducted on assessing and improving quality of care at the end of life for both dying persons and their families. To the extent that such improvements can be made, we can begin to attain the high standards for quality of care that are being advocated.

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References


51. Wallston KA, Burger C, Smith RA, Baughier RJ.


75. The Center to Improve Care of the Dying. (George Washington University). Toolkit of Instruments to Measure End of Life Care. 1996.