

Evaluating the Quality of Dying and Death

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Abstract

We propose a model for evaluating the quality of dying and death based on concepts elicited from literature review, qualitative interviews with persons with and without chronic and terminal conditions, and consideration of desirable measurement properties. We define quality of dying and death as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Expected level of agreement is modified by circumstances surrounding death that may prevent following patient's prior preferences. Qualitative data analysis yielded six conceptual domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. These domains encompass 31 aspects that can be rated by patients and others as to their importance prior to death and assessed by significant others or clinicians after death to assess the quality of the dying experience. The proposed model uses personal preferences about the dying experience to inform evaluation of this experience by others after death. This operational definition will guide validation of after-death reports of the quality of dying experience and evaluation of interventions to improve quality of end-of-life care. J Pain Symptom Manage 2001;22:717-726 © U.S. Cancer Pain Relief Committee, 2001.

Key Words

Dying, death, palliative care, quality of life, outcomes, terminal diseases

Introduction

Unser Leben kann sicherlich durch die Ärzte um keinen Tag verlängert werden wir leben so lange es Gott bestimmt hat, aber es ist ein grosser ob wir jämmerlich, wie arme Hunde, oder wohl und frisch, und darauf vermag ein kluger Arzt viel.

Johann Wolfgang von Goethe, in a conversation with F. von Müller, August 12, 1827.¹

Our lives can be prolonged by physicians not one day; we live as long as God has decided. But there is a great difference whether we live miserably, like poor dogs, or well and healthy; a clever doctor can do a lot in that respect.

Improving the quality of end-of-life care has become a major agenda for patients, families, and the loved ones of persons near death as well as health care professionals, researchers, and policy makers who organize and provide care. What happens at the end of life is receiving the attention of policy makers and the public at large, influenced by debates on physician-assisted suicide, by scientific and technological advances that can prolong life, and by the chal-

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lenges of facing death and providing comfort in dying.

Professional groups have considered what constitutes good quality end-of-life care.²⁻⁴ Prior qualitative research has also described patients' views of the quality of care at the end of life.^{5,6} Not surprisingly, many patients desire survival as long as life extension has acceptable quality.⁷ In light of these preferences, the goals of high quality end-of-life care include adequate pain and symptom management, achieving a sense of control for persons who are dying, and respecting wishes of patients and their loved ones. These *processes* of care are sometimes linked to desirable *outcomes* such as improved quality of life at the end of life, a notion that has currency for both lay persons and professionals.⁶

The focus on outcomes requires methods to identify the determinants of high quality dying and to evaluate interventions purporting to increase quality of the dying experience.⁸ Efforts to improve the quality of dying have included randomized controlled trials of interventions such as the promotion of advance directives,^{9,10} educational programs with patients or physicians,¹¹ and the provision of prognostic information to patients and physicians.¹¹ Yet these interventions have not been shown to be highly effective in improving end-of-life experiences. This ineffectiveness may be attributed, in part, to the lack of accurate and responsive means for identifying the most important issues and for developing outcome measures to assess these issues.¹²

A taxonomy of quality of life for dying persons defined quality of life for patients and for loved ones at the end of life.¹³ This framework also included a separate domain labeled the *quality of dying*, defined as a personal evaluation of the dying experience as a whole, including a subjective evaluation of concepts according to expectations and values. This approach is consistent with the notion of the quality of death defined by the Committee on End-of-Life Care of the Institute of Medicine as "a death that is free from avoidable distress and suffering for patients, families, and their caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."³ Each dying person, family member or loved one in this conceptualization may have a different sense of what a good death might be. Views could

therefore be sought from the patient throughout the dying process and from loved ones and caregivers after death. In this way, *quality of life* at the end of life is different from the *quality of dying and death* by virtue of focus and emphasis. Quality of life emphasizes activities and experiences while living with a life-threatening or terminal illness, and the quality of dying emphasizes experience of preparing for, facing, and experiencing death itself.

Viewing the quality of dying and death as a measurable concept by assigning a number to reflect quality can be seen as an ultimate form of reductionism. As one Scottish novelist recently noted when contemplating death: "Is . . . death only a negative number in our combat readiness or population totals? Or is it a major intellectual and emotional loss? How will our species prosper if we treat ourselves according to Numerical Facts, as no more than arithmetic? Humanity, its potential and inherent strengths as expressed in the human brain, are being systematically erased."¹⁴ As applied scientists using positivist principles, it is not our intention to define all that dying means or might possibly mean as this can be known only to each person himself or herself or to demean any of the richness of life or the dying experience. The overall objective is to apply humanistic thinking and measurement principles to end-of-life experiences to obtain a summary measure that can be applied to populations.

In this article, we present a conceptual model and operational definition for measuring the quality of dying and death distinct from quality of life at the end of life. This definition guides future measurement of patient preferences prior to death and assessment of the degree to which these preferences can be and are followed.

Methods

The conceptual model and operational definition were developed in five steps.

1. Previous Studies of the Dying Experience: After-Death Reports

Innumerable authors have considered the dying experience using the methods of the humanities and social sciences, and our review was necessarily selective. We focused on major research reports describing the actual end-of-life experiences of dying individuals that in-

clude after-death reports or comparisons of pre- and post-death reports. In the United Kingdom, extensive surveys were conducted in 1969 and 1987 amid rapid demographic and social change and the institutionalization of the hospice movement.^{15,16} Symptoms dominated after death reports, including pain, sleeplessness, lack of bladder and bowel control, mental confusion, trouble with breathing, and many other sensations.¹⁶ Despite the frequent desire for people to spend their last days at home and as independent as possible, intensive and expert nursing needs were evident that placed considerable burden on caregivers, primarily relatives.

Many other studies followed these early landmark surveys from the United Kingdom and have been well-reviewed in previous reports.^{3,13} Of particular importance is a major study of seriously ill hospitalized patients and the dying experience that included interviews with the patient's surrogate decision maker between 4 and 10 weeks after a patient's death.¹⁷ In this study, where the majority of patients were conscious and many had significant pain, dyspnea, and fatigue, family members after death believed patients preferred comfort over life extension. Nevertheless, life-sustaining treatments were often used.

Common to all these studies is an emphasis on life events, including dying, as matters of personal choice or autonomy. Dying persons have become participants in decision-making as joint adventurers with professionals in the social construction of the end-of-life experience.¹⁸ This role as active participants requires meaningful communication among dying patients, their loved ones, and clinicians. The importance of autonomy and communication was demonstrated in a recent study of seriously ill patients, unrelated family members after death, physicians, and other care providers. In a mail survey, respondents reported good consensus and strong endorsement for the importance of symptom management, ability to prepare for the end of life, and strong relationships with health care providers.¹⁹

Only a few studies, however, have directly compared the account given by dying persons with their loved ones or caregivers. In a follow-up study to the early surveys in the United Kingdom, reports of pain were found incongruent between caregivers and actual patients.²⁰ In

contrast, other studies found congruence between relatives and hospice patients' acceptance of death²¹ and between professional caregivers and patients ratings of outcomes of palliative care.^{22,23} A ground-breaking study comparing relatives' retrospective reports of terminal illness with patients and relative reports prior to death indicated only moderate reproducibility on symptoms of vomiting, dyspnea, and immobility and poor congruence on pain, anorexia, and depression.²⁴ The author of this study concluded that "this study and other available evidence indicate that relatives' retrospective reports of terminal illness, measured against current ratings, are moderately reliable for some items but can vary or be potentially misleading over other aspects, including pain."²⁴

This literature review provided support for a conceptual model that incorporated both patient pre-death preferences and after-death reports of the dying experience in understanding and improving the quality of dying and death.

2. Qualitative Interviews Defining Domains of Dying and Death

In previous studies, patients with advanced AIDS and their primary care clinicians were recruited into a prospective cohort study.^{25,26} We conducted qualitative one-on-one interviews with 52 patients (5 patients died during the six-month period) and held focus groups with 47 patients based on sex, ethnicity, and injection drug use.²⁷ Three focus groups, including 16 patients with end-stage COPD, were conducted to compare explicitly with AIDS patients. During these interviews and focus groups, an experienced interviewer asked patients to describe what they considered a good and bad death. Scripted probes were used to encourage patients to continue talking about the features of a "good and bad" death.

One-on-one interviews and focus group sessions were audiotaped and transcribed verbatim. The transcripts were reviewed independently by the investigators to identify themes of a good death and a bad death. All themes were underlined independently by each investigator. A preliminary coding scheme was developed from reviewing the transcripts and this scheme was used and augmented by each investigator. To address the trustworthiness of the data, we compared coding across investiga-

tors and examined passages together for themes that were not identified by both investigators. All themes identified from the transcript review were identified in at least two different focus groups or individual interviews, suggesting that additional interviews were unlikely to have identified more themes.²⁸

3. Findings from Authors' Prior Qualitative Research

We reviewed a previously published qualitative study of issues pertaining to the health and social circumstances that patients considered states worse than death.²⁹ In this study, 56 patients were interviewed from six groups: mild to moderate cognitive impairment, terminal illness (including cancer), chronic illness, AIDS, nursing home residents, and well adults. Participants were asked to discuss circumstances or situations that might make death preferable to living and why this situation led them to consider these situations as worse than death. Transcripts produced phrases that could be used for defining domains of dying and death, including the percentage of respondents who mentioned different considerations. Subsequent studies of preferences for health states considered worse than death³⁰ and their relationship to preferences for life-sustaining treatment³¹ further defined domains and specific items for the measure of the quality of dying and death.

In another study, patients with a wide variety of conditions who survived intensive care, patients residing in nursing homes, and families of these patients were interviewed to identify circumstances in which they did or did not want life-sustaining treatments.^{32,33} These studies helped to identify issues of concern at the end of life associated with refusal or withdrawal of treatments. Finally, we reviewed results of a qualitative study of patients with one of three terminal diseases: metastatic cancer, end-stage COPD, and advanced AIDS. The study used focus groups of patients as well as focus groups of family members who had lost a loved one to one of these diseases, to elicit the domains and components of physician skill at end-of-life care.⁵ This study provided information about the components of care that is important to patients and families and helped to distinguish quality of end-of-life care from quality of dying and death.

4. Review of Existing Instruments

A large number of *quality of life* measures have been employed with people with terminal illness covering domains that may bridge quality of life at the end of life and the quality of dying and death.³⁴ We searched the literature and selected studies of dying patients that addressed the conceptual domains or used measures to assess quality of life or quality of dying.^{5,20,35-49} Concepts and domains from these measures were identified and listed for possible inclusion into the conceptual model and operational definition.

5. Desirable Measurement Properties

The overall goal of creating a conceptual model and operational definition of quality of dying and death was to develop an outcome measure for use in evaluating the process of end-of-life care. Thus we considered that our conceptualization should include measurement purpose and ideal properties for an operational definition.⁵⁰ We considered that the conceptualization should include: 1) a clearly identified measurement model and domain structure for instrument development; 2) concepts and language used by patients and families themselves; and 3) the expression of individualized concerns or those issues and concerns most important to individual patients at the end of life as well as a standardized measure that could be used across persons. The conceptual model also had to take into account different dying trajectories³ as well as the views of different stakeholders, most notably the patients themselves prior to death and family members, caregivers, and loved ones both prior to and after death.

For improving the quality of end-of-life care, we consider the *ideal* instrument to be a previously validated one that could be administered retrospectively (after death) to proxy respondents such as family members or health care workers. A valid, retrospective measure will be more feasible than paired pre- and post-death assessments, because of the inherent difficulties in identifying dying persons⁸ and the relative intrusiveness of pre-death interviews.⁵¹ Empirical evidence is needed, however, to determine the extent to which after-death reports are valid without pre-death assessment of patients' preferences.

Results

A Conceptual Definition

We define the *quality* of dying and death as the degree to which a person’s preferences for dying and the moment of death agree with observations of how the person actually died as reported by others. Like other prospective studies of advance directives,³² level of agreement must be modified by unavoidable circumstances surrounding death that may have prevented the realization of patient prior preferences. For example, patients may state that they wish to die with their children present, but the child’s death precedes the parent. Thus, agreement would not be expected. Unavoidable circumstances are those that might change patients’ preferences or reasonably prevent agreement between preferences prior to death and observations after death.

The conceptual model for this definition and its determinants are shown in Figure 1 as an expansion of a previously published framework.³⁴ The oval represents the overall concept of the quality of the dying experience and indicates that preferences are moderated by the unavoidable circumstances surrounding death.

Although the timing for measurement is not contained in the model shown in Figure 1, preferences of persons who are dying by definition must be assessed prior to death and the reports and ratings of the quality of dying and death obtained from others after death. In eliciting patient preferences for dying and death, we propose a focus whenever possible on the *last week* of life. This time period is arbitrary and the actual time period of “dying” depends on the trajectory of dying. Picking one time period, however, allows standardization across in-

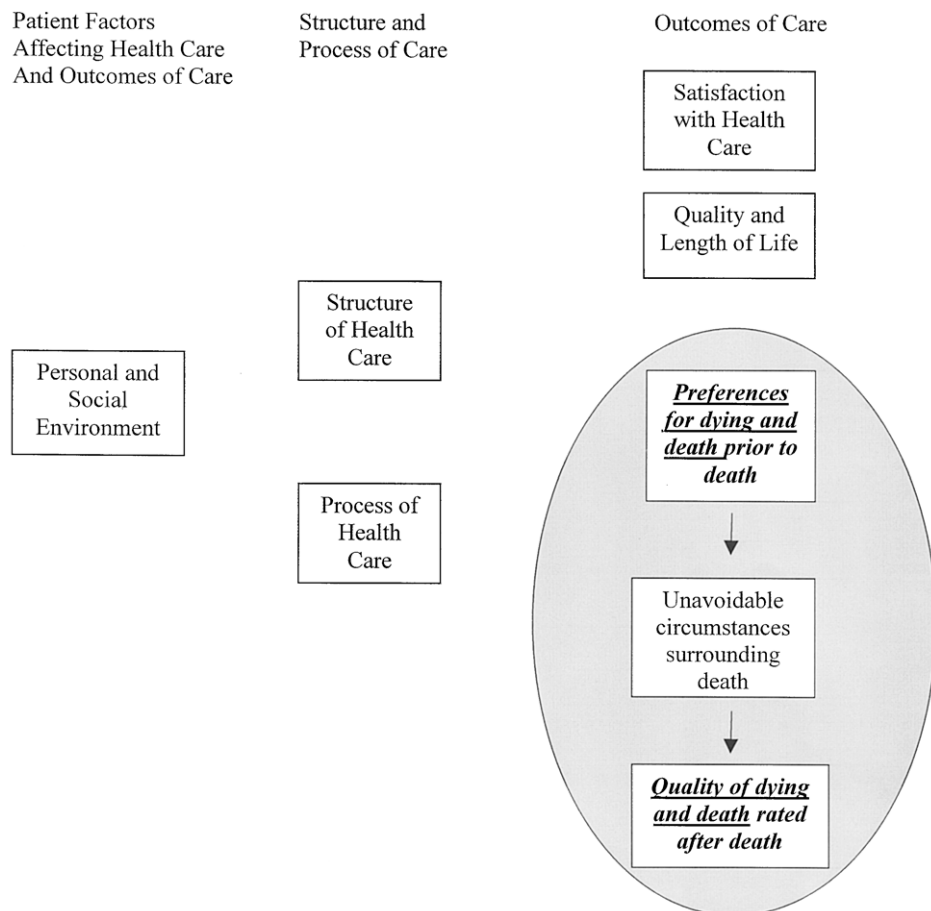


Fig. 1. Conceptual model for measuring quality of dying and death (contained in the shaded oval) and its place in the overall conceptual model of factors affecting quality and length of life of dying patients and their families.

dividuals. In assessing the quality of dying and death after death, we propose that the raters (family members or health care workers) be asked about the last week of life to facilitate a standardized reporting period. If the patient was unable to communicate in the last week of life, ratings of the quality of dying may be unobtainable and a one-month or longer recall period would be necessary. Although arbitrary and subject to empirical verification, these consistent time periods will allow summarizing reports and ratings across patients and raters.

Domains of Dying and Death

Table 1 lists 6 domains and 31 specific issues derived from the literature review, patient interviews and focus groups, prior research, existing instruments, and desirable measurement properties. Empirical validation using traditional psychometric techniques and modern test theory will be required to address the conceptual groupings.

1. Symptoms and Personal Care (6 items). These items are drawn primarily from the literature, but also previous instruments and qualitative interviews. This domain includes the control of symptoms (e.g., pain and breathing) as well as many of the activities of daily living that are important to dying patients (e.g., feeding, bladder and bowel control, energy, overall control). These items reflect the need for control, self-efficacy, and autonomy that was identified in the literature reviews, interviews, and focus group analyses.

2. Preparation for Death (10 items). Based on the previously identified notions of autonomy, this domain includes items involving planning, controlling and completing events prior to death, particularly as they enable the patient to structure the dying experience as they would like. These include: attending important events, taking care of health care costs, taking care of funeral arrangements, saying goodbye to loved ones, clearing up bad feelings and avoiding strain or worry on loved ones. This domain also captures important religious and spiritual customs and beliefs, such as having visits from a religious leader and having a spiritual service before death. Finally, it includes items involving acceptance of death such as feeling at peace and feeling unafraid.

Table 1
Conceptual Domains and Items for Measuring the Quality of Dying and Death (QODD)

Symptoms and Personal Care
1. Having pain under control
2. Having control over what is going on around you
3. Being able to feed oneself
4. Having control of bladder, bowels
5. Being able to breathe comfortably
6. Having energy to do things one wants to do
Preparation for Death
1. Feeling at peace with dying
2. Feeling unafraid of dying
3. Avoiding strain on loved ones
4. Having health care costs covered
5. Having visits from a religious leader
6. Having a spiritual service or ceremony before death
7. Having funeral arrangements in order
8. Saying goodbye to loved ones
9. Attending important events
10. Clearing up bad feelings
Moment of Death
1. Dying in the place of one's choice
2. Dying in the state of one's choice (i.e., asleep, awake, unconscious)
3. Having desired people present at the time of one's death
Family
1. Spending time with spouse/partner
2. Spending time with children
3. Spending time with family, friends
4. Spending time alone
5. Spending time with pets
Treatment Preferences
1. Have discussed end-of-life wishes with your doctor
2. Avoid using a ventilator or dialysis
3. Have the means to end life, if desired
Whole Person Concerns
1. Being able to laugh and smile
2. Being touched and hugged
3. Finding meaning and purpose
4. Keeping one's dignity and self-respect

3. Moment of Death (3 items). This domain involves the place (home, hospital) and state (awake or asleep) of one's choice and the people one wishes to be present at the actual death.

4. Family (5 items). This domain involves spending time with spouse or partner, children, family or friends, pets, or time alone. It includes issues specific to some individuals (e.g., only those with children) as well as issues that apply to all persons (e.g., time with family or friends, time alone). The wide range of family structures and variability in potentially important interactions, such as those with pets, require the inclusion of issues that are not universally applicable. The quality of dying, like the quality of life, may be individual, creating a demand for measures specific to individuals or at

least dynamic measures with different but comparable items.⁵²⁻⁵⁵

4. Treatment Preferences (3 items). Treatment preferences include items about having discussed treatment preferences with the patient's physician, wishes to avoid the use of ventilator or dialysis, and having the means to end one's life if desired. These items reflect physician-patient communication, as well as issues of control and autonomy.

5. Whole Person Concerns (4 items). These items draw on both interview and research data^{5,19} suggesting that dying patients feel the need to be understood as a whole person. They include: being able to laugh and smile, being touched and hugged, finding meaning and purpose, and keeping one's dignity and self-respect.

The concepts and domains listed in Table 1 apply both to preferences prior to death and ratings of quality of dying and death obtained from others after death. Unavoidable circumstances surrounding death might include *unavoidable medical events*, such as small bowel obstruction or a sudden worsening of respiratory status; *family or support events*, such as the declining health status of a spouse or unavoidable absence of a family caregiver; *structure and processes of care*, such as reimbursement practices; and *personal and social environmental changes*, such as changes in values or changes in residence and caregivers. These circumstances will not always be easy to identify or classify given differences of perspectives among everyone involved in a person's dying and death, including the person himself or herself.

Discussion

This conceptual model provides concrete guidance to the spectrum of domains for measuring the quality of dying and death and suggests a method by which one could develop and provide evidence of validity to proxy reports obtained after death. No doubt individual disagreement exists on exactly the concepts and measures on which to place the most importance, as the end-of-life field involves potentially divergent stakeholders. The domains elicited, however, suggest that the quality of the dying experience can be distinguished from the quality of life, even at the end of life.

Our conceptualization permits a focus on the features of a good or bad death that are distinct from the important features of quality of life at the end of life, such as functional status or satisfaction with one's functional status. The domains of dying and death are focused on the wide diversity of individuals' experiences with dying including social and spiritual components and are, for the most part, distinct from the medical care received at the end of life. We believe that differentiating these concepts—quality of life at the end of life, quality of medical care at the end of life, quality of dying and death—and measuring each independently are the major steps in identifying the determinants of a good dying experience and identifying and evaluating interventions that will improve the dying process.

The prospective design suggested by the model allows information obtained directly from patients to be compared to that reported by proxy respondents. We hypothesize that the most valid assessment of the quality of dying and death will use patients' preferences about dying and death (assessed as ratings of the importance of specific items) to inform the after-death assessment of the quality of this aspect of the dying experience. Empirical research will be necessary to determine how important these pre-death preferences are to the validity of the measure of the quality of dying and death.

Assessing patient preferences about dying and death is an important part of the conceptual model for evaluating the quality of dying and death, but the practical aspects and limitations of this endeavor require careful attention. Patient preferences, if possible to obtain, may also change prior to death and thus the stability of these preferences is important to ascertain. Dying patients are hard to identify in advance, and the accuracy of prognoses is limited, making reliance on patient preferences difficult.³ Furthermore, it is estimated that approximately one in three persons are unable to be interviewed in the last week of life.¹¹ Preferences for dying and death are implicit in advance care planning informing treatment decisions at the end of life and these outcomes may need to be elicited as part of advance care planning.⁵⁶ Patients who can be identified prior to death, including patients with terminal diseases and those in hospice care, provide a means for validating proxy reports used more universally.

Ideally, preference elicitation for patients should take place near death. Prior research suggests that treatment preferences are relatively stable over time³⁰ but further research will need to be done to determine whether preferences about dying and death are also stable over time.

Studies on proxy reports have addressed who is the best proxy respondent and how proxy reports change with bereavement.^{21,51,57} These studies suggest that proxy reports of observable behaviors and characteristics are more consistent with patient reports than reports of unobservable feelings or preferences. This finding is similar to other fields in which proxy reports of functioning and activities have been compared to patient reports, observations, or performance measures.^{58,59} Comparison of the person's prior preferences about dying and death and the proxy's assessment of these preferences is one way to examine validity and identify optimal proxy respondents. Proxy reports after death are being obtained at varying time intervals post death. This is an important topic of research and should include examination of circumstances surrounding death, the context of care-giving, and the priorities of caregivers and providers themselves that have been examined in prior studies and are the subject of continuing inquiries.^{22,42,60,61} The reliability of reports obtained many months after death have not been examined, and evaluation of the time interval is an important part of the research agenda for measuring and improving the dying experience.⁸

Finally, a cautionary note is in order that patient preferences about dying and death may conflict subtly or strongly with family members, loved ones, and professional caregivers.⁶² Autonomy may be advocated but then denied, particularly in circumstances where patients are dependent or a professional judgement labels the patient "incompetent." Vulnerable populations require special attention. Effective communication is necessary and little is known as yet about how well these preferences are communicated, if ever, and throughout the dying trajectory. Each stakeholder may hold a determined position, but the social context may force consensus at the surface where conflict is not easy to observe or mediate. Further research will be necessary to determine the effect of these factors.

Measuring the quality of dying and death could be an important advance for clinicians

caring for dying patients, researchers interested in defining and improving the quality of dying, and policymakers interested in improving care for the dying. Features of the quality of dying are likely to differ across different populations and care settings. Furthermore, the dying experience is likely to differ across health care systems and types of health care providers as well as across cultures and social groups. Identifying variability and identifying systems, providers, and processes that provide the highest quality dying experience for different persons could improve the dying experience. Measures of dying and death could also be used to evaluate interventions in randomized controlled trials or demonstration projects on continuous quality improvement. Researchers and providers interested in testing such interventions will need reliable and valid measures of the quality of the dying experience that are sensitive to small but important changes in order to accurately assess the value of such interventions. These uses await repeated experience in research and clinical practice of various models for defining and measuring the quality of dying and death.

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