

# Measuring and Improving the Quality of Dying and Death

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Improving end-of-life experience is a major challenge to successful aging. Deaths that are reasonably free of discomfort, in accordance with patients' wishes, and within acceptable professional and ethical standards are high-quality deaths. The authors developed a 31-item measure of the quality of dying and death and applied it in a community sample and a sample of hospice enrollees. Scores on the Quality of Dying and Death Instrument and measures of perceived quality of care were collected from patients' loved ones after death. Higher overall after-death ratings of the quality of care received from all providers and from physicians were associated with higher-quality dying and death. How well patients' symptoms were controlled in the community study and how well wishes were followed and treatments were explained in

the hospice study were associated with higher-quality dying.

Major challenges to end-of-life research include recruiting representative population samples, given widespread reluctance of patients and loved ones to participate in research at the end of life; important variation in evaluations among different reporters after death; reluctance of loved ones to assign negative evaluations to dying experiences after death; and the highly individual and dynamic nature of dying experiences. Overcoming these challenges is of great importance in the search for the social, organizational, and individual determinants of high-quality dying in the U.S. cultural and health care context.

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Older adults face what is perhaps the ultimate challenge for successful aging: dying and death. Our deepest hopes and fears are triggered by personal experiences with dying people; the allure of technological advances; media depictions of deaths good and bad; public debates on assisted suicide; and an almost universal wish to extend life, avoid death, and avoid even thinking about dying and death. The challenge is to come to terms with dying and death so that death occurs without undue discomfort, according to one's goals and wishes, and within the context of one's beliefs and cultural traditions (1).

Although often conflated at the end of life, quality of care, quality of life, and quality of dying and death may be usefully distinguished (Table 1). Most deaths in the United States occur in the hospital, and thus dying and death are influenced by access to and experience of institutions (2). The Institute of Medicine report "Crossing the Quality Chasm" defined high-quality health care as that based on continuous healing relationships, customization according to patient needs and values, the patient as the source of control, shared knowledge and the free flow of information, evidence-based decision making, the need for transparency, anticipation of needs, and cooperation among clinicians (3). These criteria apply equally to end-of-life care, with one necessary addition: coordination among caregivers, patients, and families (4). Other professional groups concerned with quality end-of-life care (5) and qualitative patient research (6) reinforce the content validity of these criteria.

To focus on the period of life closest to death, a separate domain, *quality of dying and death*, has been defined as a personal evaluation of the dying experience as a whole, including a subjective evaluation of patients' expectations and values (7). The Institute of Medicine Committee on End-of-Life Care defined the notion of high-quality dying as a death "free from avoidable distress and suffering for patients, families, and their caregivers; in general accord with the patients' and families' wishes; and reasonably con-

sistent with clinical, cultural, and ethical standards" (1). Quality of dying emphasizes activities and feelings experienced if and when preparing for, facing, and experiencing the final months or days of life and the moment of death. We have proposed an operational definition of *quality of dying*: the degree to which a person's preferences for dying and the moment of death are consistent with others' observations of how the person actually died (8). We recognize that a person's wishes may be modified by circumstances surrounding death that may prevent the realization of previous preferences or may change preferences. These concepts assume that dying is recognized and that preparation is possible and valuable, a situation that describes many but not all deaths.

*Quality of life at the end of life* can be distinguished from the quality of dying and death by virtue of a focus on functional status or the fulfillment of needs essential to living even when a person is near death, an emphasis that may or may not be recognized by patients, loved ones, or caregivers (8). Quality of life at the end of life emphasizes the experience of living a satisfactory life in the face of terminal illness (9, 10). *Quality of care at the end of life* is differentiated by virtue of its focus on care and on satisfaction with the care received (11). Quality of care may influence quality of dying and death and quality of life at the end of life, but the concepts and measurement differ.

Use of valid and acceptable measures of experiences that truly matter to patients, loved ones, and providers is one way to evaluate and disseminate evidence-based end-of-life care (12). Using literature reviews, reviews of existing instruments, and a series of qualitative studies, we developed a self-reported measure of the quality of dying and death, the Quality of Dying and Death Instrument (available at <http://depts.washington.edu/~eolcare>) (8, 13). Full measurement, according to our definition, requires elicitation of patient preferences about dying and death before death. Patients' predeath preferences can then be compared with reports from loved ones or caregivers after death. In

this paper, we suggest ways in which assessments of the quality of dying and death obtained from loved ones after death can be used to improve quality of care at the end of life. We also summarize how evaluations of the quality of care can be related to after-death ratings of the quality of dying and death. In this summary, we use results from a published community study conducted in Missoula, Montana (13), and a hospice study reported here for the first time. In addition, we suggest future research strategies to improve use and application of these measures.

### THE QUALITY OF DYING AND DEATH INSTRUMENT

The Quality of Dying and Death Instrument contains 31 items asking the respondent to report on and rate the quality of the dying experience in the decedent's last 7 days or, if the patient was unconscious or unresponsive throughout the last 7 days, over the last month before death. Items are rated on a scale of 0 (terrible experience) to 10 (almost perfect experience). A total score is calculated by adding the scores on all items and dividing this score by the number of items answered. This mean score is multiplied by 10 to construct a scale ranging from 0 to 100, with higher scores indicating a better quality of dying and death.

Quality-of-care indicators were adapted from questionnaires from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (14) and from the Toolkit of Instruments to Measure End-of-Life Care (15). Quality-of-care domains covered satisfaction with care, communication, treatment appropriateness, and overall ratings of quality of care from all providers and from physicians in particular. We expected higher Quality of Dying and Death scores to be significantly and positively associated with better symptom treatment, better communication with the health care team, death at home, death according to patient preferences, and higher satisfaction with care. Ratings measured continuously were analyzed with the Pearson product moment correlation or were aggregated and evaluated by using the *t*-test. Reports of events measured categorically were analyzed with analyses of variance, and group differences were identified by using Scheffe post hoc procedures when all categorical response values had been endorsed. For variables in which all response values were not used or were infrequently endorsed ( $n \leq 2$ ), we grouped response categories conceptually and used pairwise *t*-tests. A *P* value less than 0.05 indicated statistical significance.

### THE COMMUNITY STUDY

Community study results, with *P* values less than 0.01, indicated that death at home, better symptom treatment, better communication, and higher satisfaction with care were all associated with higher-quality dying (13). Clinician-patient communication and clinician-family communication about end-of-life care were associated with a better rating of the dying experience by family members. Listen-

**Table 1. Quality of End-of-Life Care, Quality of Life at the End of Life, and Quality of Dying and Death: Concepts and Domains**

Quality of end-of-life care
Continuous healing relationships through death and after death for loved ones
Focus on the dying patient's needs and respect for treatment and dying preferences
The dying patient as source of control whenever possible; loved ones involved at all times
Shared knowledge and information about prognosis and all aspects of care up to death
Shared decision making based on evidence
Transparency in care and decision processes
Anticipation of individual needs both inside and outside care settings
Cooperation and communication among providers
Coordination among caregivers, patients, and families
Quality of life at the end of life
Physical
Self care
Activities of daily living
Walking
Mobility
Eating
Sleeping
Psychosocial
Interaction with loved ones
Receiving and giving help
Contribution to community
Recreation
Sexual life
Income
Respect
Variety in life
Cognitive and communication
Thinking and remembering, speaking
Overall happiness
Quality of dying and death
Symptoms and personal care
Preparation for end of life
Moment of death
Family
Treatment preferences
Whole-person concerns, meaning and purpose

ing, explaining the patient's condition, and communicating in language that patients and families could understand were associated with higher-quality dying and therefore are important areas for improving quality of care. The community study also found an association between provider accessibility and the quality of the dying experience. Having someone available at night or on weekends who was familiar with the patient, having one physician who was primarily responsible for the patient's care, and having a member of the health care team who was responsible for making sure good care was delivered were significantly associated with better Quality of Dying and Death scores ( $P < 0.05$ ).

### THE HOSPICE STUDY

The hospice study involved enrollees in two community hospice programs in the Seattle, Washington, area. We recruited a sample of 96 patients and their family members or loved ones. Most screened enrollees who did

not participate were ineligible because of illness severity (28% [ $n = 1621$ ]); estimated survival of less than 2 weeks (16.3% [ $n = 941$ ]); or delirium, dementia, or fatigue that would interfere with their ability to complete an interview (26.5% [ $n = 1531$ ]). Among 309 eligible individuals, 189 patients or family members declined to participate. Reasons for nonparticipation included patients' reporting poor health (13.2% [ $n = 25$ ]) or lack of interest in or time for participating (13.8% [ $n = 26$ ]) and family members' reporting poor health or lack of time on behalf of the patient (11.1% [ $n = 21$ ]). Of the 96 patients enrolled, 79 have died, and 62 family members or loved ones have completed after-death surveys. Six loved ones have declined the after-death interview.

Home hospice patients were primarily women with a diagnosis of terminal cancer, and caregivers were predominantly white, similar to the Seattle population. After-death reports were obtained primarily from spouses or children of patients or from persons who had known the decedents for more than 40 years. These reports were completed an average of 3 months after a patient's death. Higher Quality of Dying and Death scores were associated with reports of satisfaction with the amount of time providers spent with patients ("way too little" differed significantly from "too little/just right"), how often providers explained treatments ("sometimes" differed significantly from "usually/always"), and how often treatment plans were followed ("sometimes" differed significantly from "usually/always"). Higher Quality of Dying and Death scores were also associated with better ratings of care, quality of life during last days, and moment of death. The Pearson correlation between the total Quality of Dying and Death score and the quality-of-care ratings ranged from 0.34 for the overall rating of the quality of care received from the patient's physician to 0.51 for the rating of the quality of the moment of death. We found that *t*-tests on the four rating items, using dichotomized scores (0 to 7 vs. 8 to 10), were significant; for all rating items, scores of 0 to 7 were significantly less common than scores of 8 to 10 (*P* values ranged from 0.01 to 0.04) (Table 2). Loved ones or surrogates did not report problems with pain control.

## DISCUSSION

Major avenues for improving the quality of end-of-life care involve significant and difficult-to-make changes in delivering such care. Although recognized as components of good dying, dying at home, adequate pain and symptom control, and effective communication are hard to achieve. Previous research supports the results from the community study showing that better pain and symptom management was associated with a better dying experience (16). That this finding was not replicated in the home hospice setting can be explained by the emphasis that hospices place on pain control. After-death reports of how often providers explained treatments were associated with higher-quality

dying in the hospice study. This kind of end-of-life communication requires a substantial investment of time and improved communication skills on the part of providers (17, 18). Increasing continuity of care was also important in the community study, particularly the availability of a provider 24 hours a day. Continuity is a major challenge for deaths occurring outside hospice. Higher ratings of overall quality of care from all providers, and from physicians in particular, were associated with higher-quality dying, establishing a strong link between care practices and the quality of dying and death.

Important methodologic and practical challenges to end-of-life research must be addressed to assist the translation of research findings into improved practice and end-of-life care. Because it is not possible to get patients' reports of the dying process very near or at the moment of death, evaluation of the dying experience depends on reports from loved ones or other surrogates. Previous research indicates wide variation in reports from different after-death reporters; this is not surprising, since people often vary in how they view significant events (10). Of particular concern is the potential for cognitive dissonance, accommodation, and response shift by reporters after death. Few people want to remember the deaths of loved ones as terrible experiences, and after-death reevaluation of the events just before death may influence reports obtained months or even weeks later. Such accommodation is a natural and welcomed part of the bereavement process for many persons but may confound research results.

Family members must also deal with their own burdens and stressors as a loved one is dying (19). Their assessments are shaped by their own experiences, by grief, or by other complicating factors, such as guilt (20). We found no systematic differences in Quality of Dying and Death scores across respondent characteristics in the community study, including the type of relationship with the deceased or the time from death to assessment. This finding, however, does not rule out important biases related to varied times from death to interview or differences in respondents. Health care providers are another source of information but may spend only limited time with patients during the actual dying process and may have their own biases. Research is needed on agreement among after-death reporters, the meaning of disagreements that exist, methods of identifying or assimilating "accurate" reports, and the most appropriate timing for after-death interviews.

Sample selection of both patients and after-death reporters is a major threat to the generalizability of end-of-life research findings (12). Patients and families who participate in end-of-life studies are prepared to talk about death and thus represent a small and highly select segment of the population. It is difficult to obtain reasons for nonparticipation in studies where recruitment depends on providers, many of whom are reluctant to ask patients and family members to participate in research. Many patients simply decline to be contacted at all, for reasons related to

Table 2. Association between Total Quality of Dying and Death Scores and Quality of Care Reports and Ratings

Quality of Care Indicators	Median Quality of Dying and Death Score (Difference between 75th and 25th Percentiles)*	P Value
<b>Reports: categorical responses†</b>		
Satisfaction with care		
Was patient treated with respect?		0.06
Never	0	
Sometimes	46.7 [1]	
Usually	73.4 (3)	
Always	76.8 (15.2) [52]	
Were providers sufficiently helpful?		0.06
Never	0	
Sometimes	46.7 [1]	
Usually	74.4 (13.3) [13]	
Always	77.2 (15.3) [42]	
Did providers spend sufficient time?		0.05
Way too little	46.7 [1]	
Too little	76.9 [3]	
Just right	77.2 (15.0) [48]	
Communication		
Was patient listened to carefully?		0.06
Never	0	
Sometimes	0	
Usually	71.6 (18.2) [10]	
Always	78.0 (14.3) [44]	
Was patient listened to respectfully?		0.06
Never	46.7 [1]	
Sometimes	0	
Usually	74.4 (13.5) [9]	
Always	77.2 (14.0) [44]	
How often did providers explain treatments?		0.02
Never	0	
Sometimes	46.7 [1]	
Usually	72.7 (14.5) [13]	
Always	78.3 (15.7) [37]	
Treatment		
Were there problems with pain control?		>0.2
Definitely no	74.4 (15.3) [49]	
Probably no	81.4 [2]	
Probably yes	64.4 [2]	
Definitely yes	73.2 [2]	
Were treatment plans followed?		0.002
Never	0	
Sometimes	0	
Usually	55.9 (23.2) [4]	
Always	77.7 (14.9) [49]	
Was treatment appropriate over last days?		>0.2
Way too little	0	
Too little	71.0 [2]	
Just right	76.8 (14.6) [52]	
<b>Ratings: continuous responses‡</b>		
Summary ratings of quality of care		
Quality of care from all providers		
Scores 0–7	62.1 (23.7) [5]	
Scores 8–10	77.7 (15.0) [51]	
Pearson correlation	0.41	0.002
<i>t</i> -test for scores 0–7 vs. scores 8–10		0.04
Quality of care from physician		
Scores 0–7	62.1 (28.1) [7]	
Scores 8–10	78.0 (15.0) [48]	
Pearson correlation	0.34	0.01
<i>t</i> -test for scores 0–7 vs. scores 8–10		0.01
Summary ratings of quality of dying		
Quality of life during last days		
Scores 0–7	71.5 (15.9) [33]	
Scores 8–10	82.0 (13.5) [24]	
Pearson correlation	0.39	0.003
<i>t</i> -test for scores 0–7 vs. scores 8–10		0.01
Quality of moment of death		
Scores 0–7	66.3 (29.7) [7]	
Scores 8–10	77.7 (14.8) [43]	
Pearson correlation	0.51	<0.001
<i>t</i> -test for scores 0–7 vs. scores 8–10		0.01

\* Higher scores indicate better quality of dying and death. Values in square brackets are numbers of respondents.

† Items with categorical responses using analysis of variance.

‡ Items with continuous responses using correlational analyses.

the stress of dying or talking about dying. One attractive way to address this problem would be conducting studies that investigate willingness to participate in end-of-life research and strategies to improve participation.

Examining patient views and preferences before death is important. A recent report summarizing research supported by the Agency for Healthcare Research and Quality concluded that high-quality care involves discussions among the patient, the family, and the physician about treatment options, including the length and invasiveness of treatment, chance of success, overall prognosis, and the patient's quality of life during and after the treatment (21). The Institute of Medicine report on improving care at the end of life (1) and the definition of quality of dying and death guiding our research (8) both incorporate patient preferences elicited before death. Interviewing patients in the weeks and days just before death has been shown to be difficult, most often because of inability to complete interviews (10). Difficulties in determining when patients are dying, complex trajectories of dying, and timing of assessments suggest that a major commitment to research is necessary within the context of palliative care. In community studies, it is difficult to identify dying persons without enrolling a large number of providers and care settings willing to recruit patients for end-of-life research. Research is also needed to determine whether patients' preferences about the dying experience can or should be used to modify the assessment of the quality of that experience provided by loved ones or other surrogates after death.

Dying and death are individual experiences, and situations and desires surrounding death may be different for one person than for others (for example, opinions on the importance of having pets present at the end of life or relationships with family and friends) (22). Static measures result in items and domains of assessment that are not relevant to all patients and after-death reporters. Individualized assessments, item banking, and dynamic interviewing strategies might be developed to match the personal, specific nature of the quality of dying and death.

Linking individual and environmental determinants to processes and outcomes of end-of-life care requires large samples from different settings. A majority of persons report that they wish to die at home, but, for many reasons, at-home deaths are in the minority. Studies of at-home deaths are as necessary as those conducted in institutional or organized care settings if we are to identify and disseminate preferred pathways to dying and death. Collaborative relationships among investigator teams and care settings are required for demonstrations that will yield knowledge about high-quality dying.

Finally, it is impossible to completely separate quality of care, as included in evaluations of treatments, from quality of life at the end of life or quality of dying and death. If a loved one reports after death that he or she was happy with the care a dying patient received before death, is the death reported of higher quality? Confounding between

treatment and outcome makes such causal explanations for observed results difficult but does not necessarily complicate the ultimate goal of improving quality of care to improve the quality of dying and death.

Identifying correlates of a good death is important to older adults and to all of us. Just as many persons seek to find the conditions of life associated with high-quality living, older persons and their loved ones and providers urgently need to find and follow a successful pathway to dying and death. End-of-life research, if successful, will aid this ancient yet contemporary odyssey.

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