

*Original Article*

# Understanding Bereaved Caregiver Evaluations of the Quality of Dying and Death: An Application of Cognitive Interviewing Methodology to the Quality of Dying and Death Questionnaire

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## *Abstract*

**Context.** To increase the interpretability of quality of dying and death measures, research is needed to understand potential sources of response variation.

**Objectives.** The aim of this study was to understand how bereaved caregivers assess the quality of dying and death experience with the Quality of Dying and Death questionnaire (QODD) by exploring the cognitive processes that underlie their evaluations.

**Methods.** Bereaved caregivers of former metastatic cancer patients were asked to take part in a cognitive interview protocol after formulating the 31 quality ratings that contribute to the total QODD score. Qualitative content analysis was applied to transcribed interviews, with a specific focus on the information retrieved, the judgment strategies used, and any difficulties participants reported.

**Results.** Twenty-two bereaved caregivers were interviewed with the protocol. Information that formed the basis of quality ratings referred to the perspective of the patient, the caregiver, other family/friends, or a combination of perspectives. Quality rating judgment strategies were generally comparative, and the most common standards of comparison were to “a hoped for or ideal dying experience,” “a state before the dying phase,” “a state of distress/no distress,” or “normalcy/humanness.” All respondents relied on multiple perspectives and standards of comparison when answering the QODD.

**Conclusion.** These results suggest that the quality of dying and death is a complex construct based on multiple perspectives and standards of comparison. These findings have implications for clinical care, which, if it aspires to improve how dying and death are evaluated, must ensure that the family is the unit of care and aid in preparation for the dying and death experience. J Pain Symptom

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### **Key Words**

*Quality of death, good death, bad death, cognitive interviewing*

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### **Introduction**

If the “good death” is a goal of modern health care, research methods that go beyond enumeration of patient symptoms in the last week of life, and meaningfully capture subjective evaluation of the multiple dimensions of the quality of the dying and death experience, are required. Measures that evaluate the dying and death experience across large samples could explore determinants of better deaths and provide meaningful outcomes for interventions that aim to improve end-of-life care. However, the development, testing, and validation of measures to assess the quality of dying and death have proved challenging.<sup>1</sup> Even after careful design and application in numerous studies, the interpretability of such measures has been questioned.<sup>2–4</sup>

Most instruments attempting to quantify the subjective evaluation of the multidimensional experience of the final days of life, such as the Quality of Dying and Death questionnaire (QODD)<sup>5</sup>—the most reliable and valid measure of the quality of dying and death currently available<sup>1</sup>—are administered to bereaved caregivers or health care providers after the patient’s death. Although after-death assessments of this kind are the most feasible means to study the dying and death phase, as proxies for patient experience, concerns have been raised regarding the potential influence of the emotional state and frame of reference of the caregiver, motivation to recall, and the impact of the time elapsed since the death of the patient on recall of events.<sup>6</sup> It also is recognized that numerous differences (e.g., diagnosis of the deceased, individual psychology, cultural group, and social roles of the patient and the caregiver) may influence how the quality of dying and death is constructed and, therefore, contribute to variability in dying and death evaluations.<sup>7</sup>

With respect to the QODD in particular, previous research has raised questions about the reliability and validity of respondent evaluations.

Mularski et al.<sup>8</sup> found only moderate concordance among family member QODD scores, and Levy et al.<sup>9</sup> found that family members and physicians tended to give more favorable ratings of intensive care unit (ICU) deaths than nurses and residents. These study authors suggested that sources of variation in the ratings of the same death could include both “noise” or measurement error and “real differences” as a result of different experiences or interpretations of these events. To enhance the interpretability of the QODD and similar quality of dying and death evaluations, research is needed to better identify potential sources of variation. More specifically, greater understanding of the information and strategies that respondents use to judge the dying and death experience would shed greater light on the meaning and significance of test scores.

Cognitive interviewing is a qualitative methodology that closely examines the question and answer process. It is increasingly used to improve survey and questionnaire construction, explore potential threats to validity and reliability, and inform how measures are implemented and the way in which resulting quantitative data are interpreted.<sup>10,11</sup> Cognitive interviewing is based on theories of survey response, such as the four-stage model by Tourangeau et al., which includes comprehension, retrieval, judgment, and response.<sup>12</sup> There are a number of variations on the four-stage model, such as the model of quality-of-life appraisal by Rapkin and Schwartz.<sup>13</sup> Because of the similarity in required cognitive processes, such models of quality-of-life appraisal could be adapted to quality of dying and death appraisal. The four meta-categories of their model are (1) frame of reference (i.e., experiences individuals deem relevant to their response), (2) sampling strategy (i.e., the specific experiences that are sampled), (3) standards of comparison (i.e., subjective standards by which the experience is judged), and (4) the combinatorial algorithm (i.e., the

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