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Initial validation using after-death interviews
with family members.

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A Measure of the Quality of Dying and Death: Initial Validation Using After-Death Interviews with Family Members

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Abstract

A reliable and valid measure of the quality of the dying experience would help clinicians and researchers improve care for dying patients. To describe the validity of an instrument assessing the quality of dying and death using the perspective of family members after death and to identify clinical correlates of a high quality death, a retrospective cohort study evaluated the 31-item Quality of Dying and Death (QODD) questionnaire. The questionnaire was administered to family members of patients who died in Missoula county Montana in 1996 and 1997. The interview included questions assessing symptoms, patient preferences, and satisfaction with care. Measurement validity was examined for item and total scores and reliability analyses for the QODD total score were assessed. Construct validity was assessed using measures of concepts

hypothesized to be associated with the quality of dying and death. There were 935 deaths, of which 252 (27.0%) family interviews were represented. Non-enrolled decedents were not significantly different from enrolled decedents on age, sex, cause of death, or location of death. We excluded sudden deaths ($n = 45$) and decedents under age 18 ($n = 2$), leaving 205 after-death interviews. A total QODD score, on a scale from 0 to 100 with higher scores indicating better quality, ranged from 26.0 to 99.6, with a mean of 67.4 and Cronbach's alpha of 0.89. The total QODD score was not associated with patient age, sex, education, marital status, or income. As hypothesized, higher QODD scores were significantly associated with death at home ($P < 0.01$), death in the location the patient desired ($P < 0.01$), lower symptom burden ($P < 0.001$), and better ratings of symptom treatment ($P < 0.01$). Although the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences ($P < 0.01$), compliance with treatment preferences ($P < 0.001$), and family satisfaction regarding communication with the health care team ($P < 0.01$). Availability of a health care team member at night or on weekends was also associated with a higher QODD score ($P < 0.001$). The QODD total score demonstrated good cross-sectional validity. Clinicians caring for dying patients should focus on improving communication with the patient and family and improving symptom assessment and treatment. Health care teams should focus on continuity of care, including having a team member familiar with the patient available for calls at nights and on weekends. Future work will assess the potential role of the QODD in improving the quality of the dying experience.



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Keywords

Dying; death; palliative care; quality of life; outcome

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