

Brief Methodological Report

Validation of the Quality of Dying-Hospice Scale

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Abstract

Context. Measuring the quality of dying (QOD) experience is important for hospice providers. However, few instruments exist that assess one's QOD; and those that do have not been well validated in hospice.

Objectives. This study tested the properties of the QOD-Hospice Scale (QOD-Hospice) to provide preliminary validation data on internal consistency, inter-rater reliability, convergent validity, and factorability in a hospice setting. Additionally, results of the factor analysis were used to create a brief version of the measure.

Methods. Bereaved informal caregivers who had provided care for a hospice patient were recruited from a large nonprofit hospice. Participants completed post-death surveys, which included the QOD-Hospice and other study measures. Convergent validity was tested by exploring hypothesized associations with related instruments measuring negative emotional states (Depression Anxiety Stress Scale-21), emotional grief (Texas Revised Inventory of Grief-2), social support (Lubben Social Network Scale-6), and a single-item measure of satisfaction with hospice care.

Results. A total of 70 caregivers participated in the survey (40 primary and 30 secondary caregivers), most of whom were female (67%) and white (81%). The QOD-Hospice produced an alpha of 0.86, an intraclass correlation of 0.49 between caregivers of the same decedent, and was correlated with all measures testing convergent validity ($P < 0.05$; in the hypothesized direction) and most, but not all, subscales. An exploratory factor analysis elicited two factors, Preparation (seven items) and Security (six items), which were combined to create a 13-item version of the scale, the QOD-Hospice-Short Form.

Conclusion. Although further testing of the QOD-Hospice measures is needed, preliminary evidence suggests that the instruments are reliable and valid for use in hospice. *J Pain Symptom Manage* 2015;49:265–276. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Hospice, quality, good death, end of life, palliative care, psychometrics

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Introduction

Hospice is an interdisciplinary, patient/family-oriented model of end-of-life care that emphasizes the comfort, dignity, and quality of life. Approximately 45% of the U.S. deaths occur while hospice support is involved.¹ Although the primary goal of hospice is to ensure that the patient's dying experience is as good as it can possibly be,¹ measuring quality of dying (QOD) is especially challenging, partly because of the need to rely on proxy informants when patients cannot respond for themselves. Additionally, few instruments exist that provide a global assessment of one's dying, and those that do, either have not been well validated in hospice, are potentially burdensome (e.g., complicated or lengthy), or have not been tested within the U.S. The lack of well-validated measures to assess QOD has direct implications for quality improvement in hospice. Without valid measures, hospices may be unable to determine their successes or failures on this crucial outcome and thus, unable to adjust their practice behaviors accordingly. Furthermore, if hospices cannot monitor QOD, patients may be needlessly suffering without the awareness of providers. This study builds on previous research on QOD to evaluate the measurement properties of a new scale, the QOD-Hospice (QOD-Hospice).

Steinhauser et al² interviewed dying patients, their families, and providers, and identified five domains related to quality of life at the end of life namely, completion, relationship with the health care system, preparation, symptom impact, and affective social support. Munn et al³ built on this work, identifying six factors related to QOD in long-term care. Hales et al⁴ summarized the literature on QOD and death to elicit seven domains, namely physical; psychological, social, spiritual and existential experience, the nature of health care, life closure and death preparation, and the circumstances of death. These studies provided the empirically derived conceptual domains targeted by the QOD-Hospice scale (see Cagle,⁵ Munn et al,³ and Steinhauser et al² for more information on the conceptual underpinnings of the scale).

Although a full review of existing measures is beyond the scope of this article (see Hanson

et al⁶), it is important to highlight measures that have been developed to monitor QOD and related outcomes. In a recent review of quality measures appropriate for hospice,^{6,7} only one instrument was identified to evaluate QOD—the Quality of Dying and Death (QODD).^{8,9} The QODD is a 31-item instrument designed to assess the QOD experience from the perspective of bereaved family members. The scale demonstrated good reliability ($\alpha = 0.89$) and acceptable factorial and construct validity. The measure has been recommended for use with end-of-life populations.¹⁰

The QODD was developed using interviews with surviving family members between one and three years after the death. Because of the substantial time since death, respondents were susceptible to recall bias. Additionally, the original version of the QODD implied that hospice is a location by asking respondents' to report the decedent's place of death using three mutually exclusive options, namely home, hospice, or hospital.⁹ Furthermore, in the hospice validation study, developers of the QODD excluded families when a patient's illness was too severe (i.e., estimated survival of less than two weeks or could not complete a pre-death interview).¹⁰

The Palliative Care Outcomes Scale (POS)¹¹ also has been endorsed for use in end-of-life care settings.¹⁰ Originally designed for oncology patients, it has since been used with noncancer populations. It has two versions, namely one for health care staff and one for patients. In the development study, the POS showed marginal internal consistency ($\alpha = 0.65$ patients; $\alpha = 0.70$ staff) and test-retest reliability for patients during consecutive clinic visits with raw agreement (mostly >80%) and greatly exceeding kappas (0–0.6). More recently, the POS was modified for use with bereaved family members and found to have high ratings of relevance, moderate correlations with other end-of-life measures, and modest reliability ($\alpha = 0.64$).¹² The POS, however, has not been well validated in hospice settings.

Despite the availability of some promising measures that capture key end-of-life processes and outcomes, there is limited evidence about the applicability of these measures in hospice settings. Furthermore, currently available measures have been generally criticized for lacking

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