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Validation of the Quality of Dying (QOD)-Hospice Scale

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Abstract

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

Objectives—This study tested the properties of the Quality of Death-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 non-profit 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—Seventy caregivers participated in the survey (40 primary caregivers, 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-SF.

Conclusion—Although further testing of the QOD-Hospice measures is needed, preliminary evidence suggests the instruments are reliable and valid for use in hospice.

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Keywords

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

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 U.S. deaths occur while hospice support is involved.¹ Although a primary goal of hospice is to ensure the patient's dying experience is as good as it can possibly be,¹ measuring quality of dying is especially challenging, in part 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 quality of dying 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 quality of dying, patients may be needlessly suffering without the awareness of providers. This study builds on previous research on quality of dying to evaluate the measurement properties of a new scale, the Quality of Dying-Hospice (QOD-Hospice).

Steinhauser and colleagues² interviewed dying patients, their families and providers, and identified five domains related to quality of life at the end of life: completion; relationship with the health care system; preparation; symptom impact; and affective social support. Munn et al.³ built upon this work, identifying six factors related to quality of dying in long-term care. Hales, Zimmerman and Rodin⁴ summarized the literature on quality of dying and death to elicit seven domains: 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 Munn³ and Steinhauser² 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 al.⁶), it is important to highlight measures that have been developed to monitor quality of dying and related outcomes. In a recent review of quality measures appropriate for hospice,^{6,7} only one instrument was identified to evaluate quality of dying – the Quality of Dying and Death (QODD).^{8,9} The QODD is a 31-item instrument designed to assess the quality of the dying 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 to 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: 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 non-cancer populations. It has two versions: one for health care staff, 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. STARTSTART

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 clear conceptual frameworks, poorly described development processes, or limited empirical evaluation.^{8,10,13} To address these concerns, end-of-life researchers and advocates have called for further development and testing of instruments to assess outcomes near death – particularly measures of quality-related factors.^{8,10,13} In response to this call, we developed and tested the QOD-Hospice for use within hospice settings. We crafted the measure to be a conceptually grounded, low burden measure to evaluate a patient's quality of dying from the perspective of a close family member or caregiver. If the instrument withstands empirical scrutiny, the tool will have broad applications for research and quality improvement in hospice. Thus, the purpose of this study was to provide preliminary validation data on the QOD-Hospice including general instrument properties, internal consistency, inter-rater reliability and convergent validity. Additionally, we used a factor analysis to produce a brief version of the measure. An item-by-item correspondence with key conceptual domains is also provided.

Methods

Design

After a brief pilot study, data were collected from a prospective bereavement study in 2008-2009 using two self-administered mailed questionnaires (a pre-death and post-death survey) to examine short-term bereavement outcomes for informal caregivers of hospice cancer patients. With the exception of demographic characteristics, the data presented here come exclusively from the post-death survey wave. Participants were sent the post-death survey three months after the patient's death. Three months after a death is a conventional time point for evaluating short-term bereavement outcomes¹⁴ and the earliest post-death data collection period agreed upon by the approving Institutional Review Boards (Virginia Commonwealth University and Florida State University) and participating hospice.

Development of the QOD-Hospice

The QOD-Hospice scale was adapted from the Quality of Dying in Long-Term Care (QOD-LTC) long form³ and, by extension, the Quality of Life at the End of Life (QUAL-E) scale.^{2,15} Twenty items of the QOD-Hospice scale were selected from 36 items of the QOD-LTC by the authors based on their applicability to the broad range of settings within which hospice operates (e.g., private residences, hospitals, nursing homes), and conceptual comprehensiveness based on the literature.^{3,4,15} Of the twenty items selected for the QOD-Hospice scale, one item regarding place of death was created: “My loved one’s wishes were met regarding the place of death”; and ten items were modified, for example, to reflect a team approach: “There was a [added: hospice staff member] with whom my loved one felt comfortable.”

Sample

Participants were informal caregivers recruited consecutively from a large southeastern hospice in 2008. Potential study participants were identified within 48 hours of admission by hospice social workers using the following criteria: the patient had 1) a primary diagnosis of cancer and 2) at least one informal caregiver. Participation was limited to informal caregivers of cancer patients as this population was the focus of the larger study.^{5,16} Informal caregivers were defined as any person, other than paid staff, that the patient (or proxy) identified as a provider of physical, psychological, emotional, or financial assistance; were 18 years of age or older; and were literate in English. In many cases, multiple caregivers were identified within the same family, in which case all were invited to participate.

A total of 253 eligible informal caregivers of 104 patients were identified during admission to hospice. In 15% (39) of caregiver cases, the patient died prior to consent contact (one week of admission) and, thus, these caregivers were not asked to participate. Recruitment of caregivers of living hospice patients was a requirement of the larger study because of its prospective design. In 28 (11%) of the caregiver cases, the patient or family declined to share their contact information with the research team. Fifty-five caregivers (22%) did not provide consent by mail (i.e., did not return the pre-death survey). In three cases (1%), the contact information was invalid. The remaining 128 (51%) provided informed consent and agreed to participate in the bereavement wave of the study. Post-death surveys were mailed to these 128 informal caregivers of 78 decedents. A total of 80 surveys were returned, for a response rate of 63%. All post-death surveys were received within ten weeks from when the survey was initially mailed (i.e., three months post-death). Ten cases were removed from the sample for having >25% of items missing on key measures; thus the final analytic sample was set at 70 (55% of the sample, related to 40 decedents).

Measures

The Quality of Dying-Hospice—The QOD-Hospice is a 20-item scale designed to measure perceived quality of dying. It is administered retrospectively, asking bereaved family members to reflect on a decedent’s final month of life. We elected the one month time frame based on suggestions that patients need at least one month of hospice before they receive the full benefits of its services.¹⁷ The measure presents statements pertaining to

quality of dying using a five-point response set, 1=not at all to 5=completely. A “don’t know” option also was provided because respondents are asked about information that they may not know or recall. Completed items are summed then divided by the total number of completed items to produce a score (possible range 1-5). Higher scores indicate better quality of dying.

To document preliminary evidence about the QOD-Hospice scale’s construct validity, we tested associations with four conceptually related (but not synonymous) instruments measuring caregivers’: 1) negative emotional states; 2) emotional grief; 3) social support; and 4) satisfaction with hospice care. Based on evidence from the existing literature,^{4,15,18,19} we expected the following measures to converge on the QOD-Hospice scores with moderate, but statistically significant, correlation coefficients (i.e., an examination of convergent validity).

Depression Anxiety Stress Scale-21 (DASS-21)—The DASS-21 is a 21-item questionnaire assessing negative emotional states.²⁰ It comprises three seven-item subscales (depression, anxiety, and stress) and a four-point response set to investigate affective state over the past week. Building from previous evidence,^{4,19} the DASS-21 and its subscales were hypothesized to be negatively associated with quality of dying. The DASS-21 has been evaluated with hospice caregivers, with all subscales demonstrating good reliability and validity.²¹ Furthermore, a large sample of non-clinical respondents produced reliability estimates of 0.88 for depression, 0.82 for anxiety, 0.90 for stress, and 0.93 overall.²²

Texas Revised Inventory of Grief-2 (TRIG-2)—The TRIG-2 is a 13-item assessment of emotional grief using a five-point response scale ranging from “completely true” to “completely false.”²³ The TRIG-2 has shown good reliability (alphas from 0.8 to 0.95) and adequate validity.^{23,24} Based on prior studies,^{4,14,24} quality of dying was expected to negatively correlate with levels of affective grief.

Lubben Social Network Scale- 6 (LSNS-6)—The LSNS-6 measures perceived social support using two three-item subscales: “Family” and “Friendships.”²⁵ Lubben and colleagues^{25,26} found acceptable reliability coefficients for the entire scale ($\alpha = 0.83$) and subscales (0.80-0.89). Based on prior research,^{4,15,18,19} a positive relationship between the LSNS-6 subscales and quality of dying was hypothesized.

Satisfaction With Hospice Care—Satisfaction with care was assessed with the item: “Overall, how satisfied/dissatisfied are you with the care that hospice provided?” Response options ranged from 1=very dissatisfied to 5=very satisfied. Respondents’ satisfaction with hospice care was hypothesized to be positively correlated with the QOD-Hospice scale.^{18,19}

Statistical Analysis

PASW SPSS 18.0 (SPSS Inc., Chicago, IL) was used for statistical analyses. Data were prescreened for outliers and missing values. Missing items were substituted using the expectation maximization method appropriate for validity testing.^{27,28} Construct validity of the QOD-Hospice was evaluated with: 1) a convergent test examining associations with conceptually related measures – the LSNS-6, DASS-21, TRIG-2, and care satisfaction; 2) an

exploratory factor analysis (EFA) exploring the measure's structure. EFA was deemed appropriate despite the limited sample size.²⁹ To determine the number of factors, the study used parallel analysis with direct oblimin rotation.³⁰ For factor selection, we used a conservative loading threshold of 0.50 to ensure parsimony and interpretability.³¹ To examine measurement reliability, the following estimates were calculated: Cronbach's alpha for internal consistency; percentage agreement (i.e., the proportion of scale scores falling within one standard deviation among caregivers of the same decedent) and intraclass correlation (ICC) for inter-rater reliability among caregivers of the same decedent.

Stratification of Caregiver Respondents—Because multiple respondents provided data about the same decedent (75% of the decedent sample), it was important to account for clustering effects. To address potential bias, sample descriptives and measurement properties were stratified into two groups: primary caregivers and secondary caregivers. Primary caregivers were family members who were responsible for the largest portion of the decedent's care. In cases where family members reported providing the same proportion of care, we selected the respondent who had spent the most time with the patient prior to death. Secondary caregivers were respondents from households in which there was already a primary caregiver, but who reported being less involved than the primary caregiver.

Isolating the subsample of primary caregivers ensured that the most knowledgeable observer was providing information about a single patient. This approach eliminated the potential for clustering effects at the family level. Caregiver groups were combined when exploring associations between study variables to ensure adequate sample size for respective tests.

Results

Descriptive Statistics

Table 1 summarizes the sample characteristics of caregiver respondents and patients (i.e., decedents). A total of 70 caregivers were included in the sample, including 40 (57%) primary caregivers. Two-thirds (67%) of the total sample of caregivers was female, the majority white (81%) with a mean age of 58 years (SD = 12.8). Compared with secondary caregivers, primary caregivers were more likely to be the patient's spouse (51% vs. 4%, $P < 0.001$), older (61 vs. 54 years, $P < 0.05$), and co-residing with the patient (65% vs. 7%, $P < 0.001$). Exactly half of decedents were male, and 33% had a cancer diagnosis other than the eight diagnostic categories provided, followed by lung cancer (25%). At admission, patients had a median pain rating of 0 (interquartile range [IQR] = 0 - 4) on a 0-10 scale and were moderately functional (median Palliative Performance Scale score of 40%, IQR = 40 - 50). The median length of stay in hospice was 60 days (IQR = 25 - 91). None of the observed patient characteristics differed between primary and secondary caregiver groups.

Before testing convergent validity, measurement characteristics of the five variables of interest were calculated for the entire sample, and subsamples of primary and secondary caregivers (Table 2). The QOD-Hospice, LSNS-6, DASS-21, and TRIG-2 had high alphas for the combined sample, as well as for primary and secondary caregivers when examined separately. On average, primary caregivers scored a 4.44 (SD=.48) on the QOD-Hospice and secondary caregivers produced a similar score 4.40 (SD=.49).

Missing data on the QOD-Hospice scale were low. Only 1% of items were left blank. Responses of “don’t know” were more prevalent than items left blank, but still relatively low, averaging 4% per item. The item with the most “don’t know” responses was whether the decedent’s treatment preferences were in writing ($n=8$, 11%). Incomplete data (actual missing and “don’t know”) were related to involvement in care ($P=0.002$), with lesser involved caregivers having more incomplete data.

Factor Analysis

Factorability of the 20-item QOD-Hospice scale was examined using three criteria. First, individual items were correlated with remaining items ($r > 0.30$ in all cases) suggesting good factorability. Next, the Kaiser-Meyer-Olkin measure of sampling adequacy had an acceptable score of 0.60, and Bartlett’s test of sphericity was also significant ($P<0.001$). Lastly, only items with communalities above 0.30 were selected. Thus, the assumptions of EFA were supported.³¹

A scree plot was used to determine factors for inclusion in a short-form measure. Seven factors had eigenvalues >1 . Two factors were greater than the mean and 95th percentile of the parallel analysis (Fig. 1) and, therefore, selected.^{30,32} For factor extraction, the EFA produced loadings for all 20 QOD-Hospice items using these two factors.

Table 3 reports results of the EFA with factor loadings by QOD-Hospice item. The two identified factors explained 42% of the variance. The first factor, labeled “Preparation,” consisted of seven items explaining 29% of the overall variance. The item with the highest loading (0.82) was: “My loved one indicated he/she was prepared to die.” Conceptually, this label captures elements pertinent to a patient being prepared for their own dying and death, including advance care planning, “closure,” maintaining a sense of humor, and realistic expectations about the illness.

The second factor, which explained 13% of the variance, comprised six items and was labeled “Security.” The item with the highest factor loading was: “There was someone from hospice whom he/she trusted.” Other items included questions covering relationships with hospice team members, and whether circumstances regarding the death were honored. An examination of factor inter-correlations produced a coefficient of 0.26, suggesting a relationship of moderate strength between the two factors. Given the results of parallel analysis, and to make a parsimonious measure, we selected these two factors and their combined thirteen items (all of which had loadings >0.50) in a new measure. The resulting short-form instrument is heretofore referred to as the QOD-Hospice-SF.

Table 4 presents descriptive statistics for the QOD-Hospice-SF scale and subscales. In general, respondents rated quality of dying highly; all average scores were 4.3 or higher on a 1-5 scale. Reliability coefficients were high: 0.85 for the QOD-Hospice-SF, 0.82 for the Preparation subscale, and 0.85 for the Security subscale. ICC scores indicated moderate agreement among caregivers from the same family, eliciting an overall ICC score of 0.64 on the QOD-Hospice-SF scale. The Preparation subscale showed higher agreement among caregivers (0.80), but the Security subscale had only fair concordance among raters (0.33). Similarly, the percentage of inter-rater agreement among caregivers was acceptable for both

scales, 63% for the QOD-Hospice and 79% for the QOD-Hospice-SF. Agreement was high (89%) for the Preparation subscale and acceptable (63%) for the Security subscale.

Bivariate Analysis

Convergent validity of the QOD-Hospice was examined by comparing predicted associations with selected study measures. Table 5 presents correlations between the two QOD-Hospice scales and other study measures. Using the combined sample, both versions of the QOD-Hospice were associated with the LSNS-6-family, DASS-21-depression, DASS-21-stress, and TRIG-2 ($P < 0.05$ for all tests). All statistically significant relationships were in the expected direction. For example, the greater the level of family support (LSNS-6 family subscale), the better the quality of dying. Conversely, QOD-Hospice scores were negatively correlated with the caregivers' depressive symptoms, stress, and affective grief. A moderate, positive association ($\rho = 0.33$, $P = 0.005$) also was observed between QOD-Hospice scores and satisfaction with hospice care.

Discussion

Our study provides preliminary evidence that the QOD-Hospice and QOD-Hospice-SF scales are reliable and valid for assessing quality of dying in hospice. Although further research is warranted to evaluate instrument properties across different agencies and diverse patient populations, our preliminary findings are promising. Based on this initial work, both of these instruments have good conceptual and structural integrity and are appropriate for research and quality measurement in hospice. We present findings from both the original instrument as well as the short-form version because the full instrument appears to have greater conceptual comprehensiveness, whereas the strength of the short form is its dimensionality and brevity. We also hope to encourage further testing of these new measures with other hospice populations.

A strength of this study was the inclusion of both primary and secondary caregivers, which allowed for an assessment of inter-rater reliability. Because of concerns about the validity of proxy reports, it is critical for observational measures of end-of-life outcomes to maintain consistency across different observers. Results suggest the QOD-Hospice scales have fairly strong agreement among observers and the Preparation subscale, in particular, demonstrated nearly perfect agreement. Alternately, the Security subscale produced only moderate agreement between raters. Lower correspondence may be explained by differing levels of knowledge about the circumstances of care. Primary caregivers may be in a better position to assess these external elements whereas secondary caregivers may be less knowledgeable because they are less involved. Also noteworthy, scores for both versions of the QOD-Hospice were negatively skewed, suggesting a possible ceiling effect and a limited ability to detect the lower range. This skew was expected, however, as hospice users tend to rate outcomes highly. Furthermore, the moderate association between the two subscales suggests the factors are indeed conceptually distinct – and yet related – components of the quality of dying.

The support of friends among caregiver respondents as measured by the LSNS-6 was not significantly associated with either QOD measure or subscale, which suggests a lack of

conceptual relatedness. The Preparation subscale was consistently associated with affective measures (grief, depression, anxiety, stress), and satisfaction with care and social support from the caregiver's family (from the LSNS-6) were the only measures significantly related to the Security subscale. Although the causal direction of the association cannot be determined with these data, perhaps a lack of patient preparation is more emotionally distressing for surviving family members. Future research is needed to explore the link between the emotional state of proxy observers and assessments of quality at the end of life. In terms of convergent validity and the strength of bivariate associations, some statistically significant associations were weaker than hypothesized (e.g., $r < 0.30$). For example, the full QOD-Hospice scale demonstrated weak associations with depressive symptoms and anxiety, which indicates limited relatedness between these variables. Respondent characteristics or environmental circumstances, other than the quality of the decedent's death, may be more influential on the surviving caregiver's symptoms of depression and anxiety.

Interestingly, based on EFA results, no physical items were included in the QOD-Hospice-SF. Because relief from distressing physical symptoms had been identified as a critical component of assessments of the dying experience,^{4,15,18} the short form should be considered preliminary and warrants further testing. Related to this, the time saved by using the short form may not be worth reduction in conceptual comprehensiveness. However, it is possible that, from the perspective of informal caregivers, the personal and social dimensions of dying are more integral to quality of dying than physical aspects.

Findings should be interpreted within the context of study limitations. Participants were recruited from only one non-profit hospice. The participating hospice was large, with 13 branch offices covering about 15,000 square miles of rural, urban and suburban regions. Additional data on the replicability of results in other hospices are needed. Because of the small, relatively homogenous make up of the sample, these data should be treated as preliminary. Of note, our study was limited to decedents with a primary diagnosis of cancer. However, the tremendous growth of the non-cancer patient population requires validity testing across a broader cross-section of patients. Non-response because of families electing to forgo participation, or other selection bias, also may limit the generalizability of results.

Another challenge for evaluating quality of dying in hospice is abbreviated length of stay. Half of hospice patients die within 18 days of enrollment.¹ Thus, the time referent of "the past month" may encompass elements of care prior to hospice admission. In this regard, for patients who die less than one month after admission to hospice, the QOD-Hospice scales may capture aspects of the dying experience that extend beyond the patient's hospice stay and outside of the provider's control. Scale scores, therefore, should be considered with respect to length of stay. Furthermore, because hospice often relies on other caregivers (e.g., family members) to provide hands-on care, elements of care such as "clothes and body clean" may not reflect care by formal care providers. Future research should examine potential modifications to the QOD-Hospice scales to further accommodate patients with short lengths of stay.

The QOD-Hospice measures capture key elements of the quality of the dying experience within a variety of hospice care environments. Although the measures may help guide

clinical decision making, they were not created to assess the quality of care being provided by the hospice team. That said, hospices that encounter low ratings on that QOD-Hospice measures can respond by identifying items that are being consistently rated poorly and then employing clinical interventions to target those underperforming domains. For example, if providers discover that a substantial proportion of their patients' location of death is not in accordance with the patients' wishes (item 12 in Table 3), then hospice team members can address this deficiency by documenting the patient's preferred place of death, communicating that preference to the relevant stakeholders, and proactively planning to ensure that the patient's preferences are honored.

Future research should explore the optimal timing for collecting data from bereaved caregivers. We elected to collect bereavement data at three months after the death to limit burden on grieving families and yet minimize potential for recall bias. However, other intervals (e.g., one month, six months, one year) may prove more sensitive to the family's needs or elicit more accurate data.

Our understanding and measurement of the quality of the dying experience are still evolving in both research and practice. As with other important health care constructs (depression and functionality, for example) it is important to provide researchers and clinicians with a few well-developed, rigorously tested instruments from which to choose. We submit that dissemination of the QOD-Hospice scales will allow potential users to weigh their respective merits and limitations relative to other measures designed to capture the dying experience, such as the QODD and POS.

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References

1. National Hospice and Palliative Care Organization. NHPCO's facts and figures: Hospice care in America 2013. Arlington, VA: NHPCO; 2013. p. 1-18. Available from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf
2. Steinhauser KE, Bosworth HB, Clipp EC, et al. Initial assessment of a new instrument to measure quality of life at the end of life. *J Palliat Med.* 2002; 5:829–841. [PubMed: 12685529]
3. Munn JC, Zimmerman S, Hanson LC, et al. Measuring the quality of dying in long-term care. *J Am Geriatr Soc.* 2007; 55:1371–1379. [PubMed: 17915342]
4. Hales S, Zimmermann C, Rodin G. The quality of dying and death. *Arch Intern Med.* 2008; 168:912–918. [PubMed: 18474754]
5. Cagle, JG. Informal caregivers of advanced cancer patients: the impact of geographic proximity on social support and bereavement adjustment. VCU Digital Dissertation Archive. Available from <http://digarchive.library.vcu.edu/handle/10156/1974>

6. Hanson LC, Scheunemann LP, Zimmerman S, Rokoske FS, Schenck AP. The PEACE project. Review of clinical instruments for hospice and palliative care. *J Palliat Med.* 2010; 13:1253–1260. [PubMed: 20874234]
7. Carolinas Center for Medical Excellence. PEACE Project. [October 3, 2013] Assessment instruments for end of life care. Available from <http://www.thecarolinascenter.org>
8. Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002; 24:17–31. [PubMed: 12183092]
9. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. *J Pain Symptom Manage.* 2001; 22:717–726. [PubMed: 11532585]
10. Mularski RA, Dy SM, Shugarman LR, et al. A systematic review of measures of end of life care and its outcomes. *Health Serv Res.* 2007; 42:1848–1870. [PubMed: 17850523]
11. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the Palliative Care Outcome Scale. *Qual in Health Care.* 1999; 8:219–227.
12. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res.* 2012; 21:671–684. [PubMed: 21814875]
13. Lorenz, K.; Lynn, J.; Morton, SC., et al. End-of-life care and outcomes. Evidence report/technology assessment no 110. Rockville, MD: Agency for Healthcare Research and Quality; 2004. AHRQ Publication No 05-E004-2
14. Stroebe, MS.; Hansson, RO.; Stroebe, W.; Schut, H., editors. Handbook of bereavement research. Washington DC: American Psychological Association; 2001.
15. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA Intern Med.* 2000; 284:2476–2482.
16. Cagle JG, Kovacs PJ. Caregivers of cancer patients: perceptions of preparedness and the need for support during hospice care. *J Gerontol Soc Work.* 2011; 54:92–115. [PubMed: 21170781]
17. Teno JM, Shu JE, Casarett D, et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage.* 2007; 34:120–125. [PubMed: 17583469]
18. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage.* 1999; 17:93–108. [PubMed: 10069149]
19. Carr D. A “good death” for whom? Quality of spouse's death and psychological distress among older widowed persons. *J Health Soc Behav.* 2003; 44:215–232. [PubMed: 12866391]
20. Lovibond PF, Lovibond SH. The structure of negative emotional states: comparison of the depression anxiety stress scales (DASS) with the Beck Depression and Anxiety Inventories. *Behav Res Ther.* 1995; 33:335–343. [PubMed: 7726811]
21. Hackett A, Palmer S, Farrants J. Phase 1 of an investigation into the levels of stress in United Kingdom hospice services. *Int J Palliat Nurs.* 2009; 15:66–72. [PubMed: 19247221]
22. Henry JD, Crawford JR. The short-form version of the Depression Anxiety Stress Scales (DASS-21): construct validity and normative data in a large non-clinical sample. *Brit J Clin Psychol.* 2005; 44:227–239. [PubMed: 16004657]
23. Faschingbauer, TR.; Zisook, S.; DeVaul, R. The Texas Revised Inventory of Grief. In: Zisook, S., editor. Biopsychosocial aspects of bereavement. Washington, DC: American Psychiatric Press; 1987. p. 111-124.
24. Gilbar O, Ben-Zur H. Bereavement of spouse caregivers of cancer patients. *Am J Orthopsychiat.* 2002; 72:422–432. [PubMed: 15792054]
25. Lubben, JE.; Gironde, MW. Centrality of social ties to the health and well-being of older adults. In: Berkman, B.; Harooytan, LK., editors. Social work and health care in an aging world. New York: Springer; 2003. p. 319-350.
26. Lubben J, Blozik E, Gillmann G, et al. Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *Gerontologist.* 2006; 46:503–513. [PubMed: 16921004]
27. Schlomer GL, Bauman S, Card NA. Best practices for missing data management in counseling psychology. *J Couns Psychol.* 2010; 57:1–10. [PubMed: 21133556]

28. Musil CM, Warner CB, Yobas PK, Jones SL. A comparison of imputation techniques for handling missing data. *West J Nurs Res.* 2002; 24:815–829. [PubMed: 12428897]
29. Conway JM, Huffcutt AI. A review and evaluation of exploratory factor analysis practices in organizational research. *Organ Res Methods.* 2003; 6:147–168.
30. Hayton JC, Allen DG, Scarpello V. Factor retention decisions in exploratory factor analysis: a tutorial on parallel analysis. *Organ Res Methods.* 2004; 7:191–205.
31. Tabachnick, GG.; Fidell, LS. *Experimental designs using ANOVA.* Belmont, CA: Duxbury; 2007.
32. Ledesma RD, Valero-Mora P. Determining the number of factors to retain in EFA: an easy-to-use computer program for carrying out parallel analysis. *Practical Assessment: Research & Evaluation.* 2007; 12:1–11. Available from <http://pareonline.net/pdf/v12n2.pdf>.

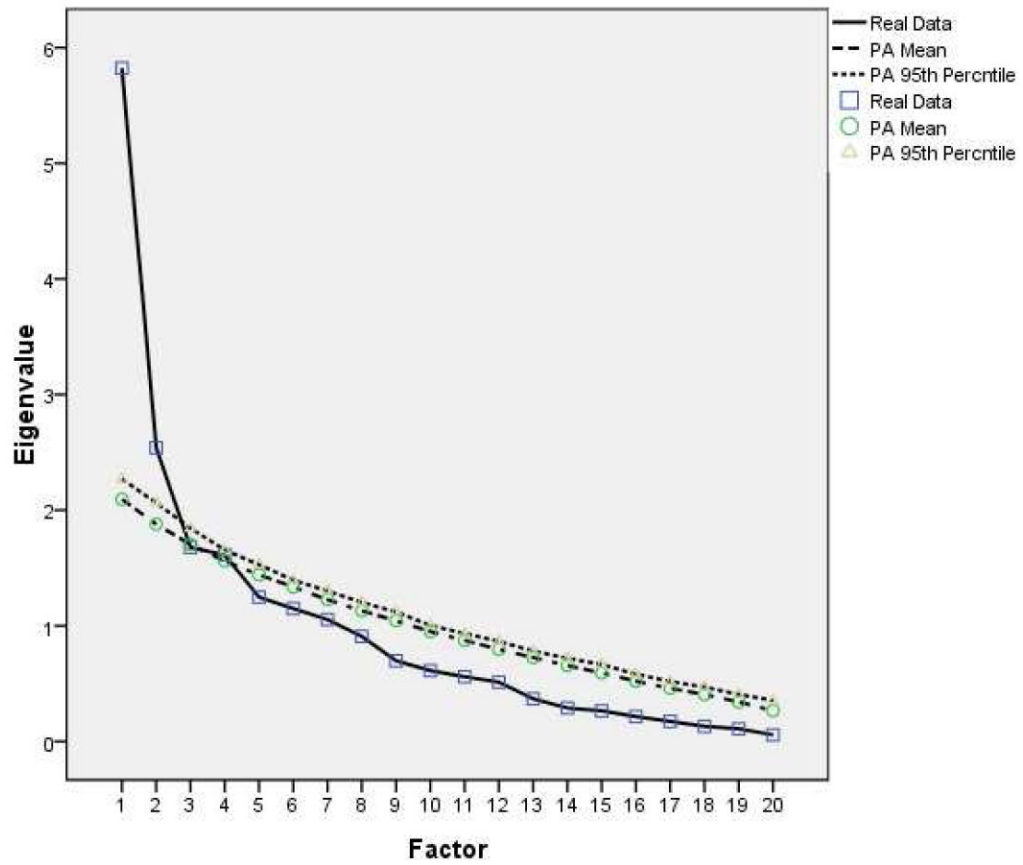


Figure 1. Plot of actual versus randomly generated eigenvalues for the QOD-Hospice Scale

Table 1

Sample Characteristics for Caregivers and Decedents

| | Sample | | | <i>p</i> ^a |
|----------------------------------|-------------|-------------------|---------------------|-----------------------|
| | Total | Primary Caregiver | Secondary Caregiver | |
| <i>Caregiver Characteristics</i> | | | | |
| <i>N</i> | 70 | 40 | 30 | |
| <i>Total, %</i> | 100 | 57.1 | 42.9 | |
| Age, yrs, mean (SD) | 57.7 (12.8) | 60.6 (13.7) | 53.7 (10.4) | 0.024 |
| Gender, % | | | | 0.728 |
| Male | 28.6 | 28.2 | 32.1 | |
| Female | 67.1 | 71.8 | 67.9 | |
| Race, % | | | | 0.430 |
| African American | 8.6 | 12.8 | 3.6 | |
| White | 81.4 | 82.1 | 89.3 | |
| Other | 5.7 | 5.2 | 6.2 | |
| Income, % | | | | 0.359 |
| Less than \$20,000 | 17.1 | 21.6 | 16.0 | |
| \$20,000 - \$25,000 | 8.6 | 8.1 | 12.0 | |
| \$25,000 - \$35,000 | 8.6 | 13.5 | 4.0 | |
| \$35,000 - \$50,000 | 21.4 | 27.0 | 20.0 | |
| \$50,000 - \$75,000 | 14.3 | 13.5 | 20.0 | |
| Over \$75,000 | 18.6 | 16.2 | 28.0 | |
| Education, % | | | | 0.606 |
| Some high school | 7.1 | 7.7 | 7.1 | |
| High school diploma or GED | 30.0 | 38.5 | 21.4 | |
| Some college | 28.6 | 28.2 | 32.1 | |
| College degree | 21.4 | 20.5 | 25.0 | |
| Graduate school | 8.6 | 5.2 | 14.3 | |
| Employment status, % | | | | 0.219 |
| Full time | 30.0 | 20.5 | 46.4 | |
| Part time | 7.1 | 7.7 | 7.1 | |
| Unemployed | 7.1 | 10.3 | 3.6 | |
| Retired | 47.1 | 53.8 | 42.9 | |
| Other | 4.3 | 7.7 | 0.0 | |
| Relationship to patient, % | | | | < 0.001 |
| Spouse/partner | 30.0 | 51.3 | 3.6 | |
| Parent | 5.7 | 2.6 | 10.7 | |
| Child | 38.6 | 33.3 | 50.0 | |
| Sibling | 14.3 | 10.3 | 21.4 | |
| Other | 7.2 | 2.6 | 14.2 | |
| Geographic proximity, % | | | | < 0.001 |
| Living together | 40.0 | 65.0 | 6.7 | |

| | Sample | | | <i>p</i> ^a |
|---|------------|-------------------|---------------------|-----------------------|
| | Total | Primary Caregiver | Secondary Caregiver | |
| Within 10 miles | 34.3 | 27.5 | 43.3 | |
| More than 10 miles | 25.7 | 7.5 | 50.0 | |
| <i>Patient Characteristics</i> | | | | |
| <i>N</i> | 40 | | | |
| Age, yrs, mean (SD) | 76 (14.3) | | | |
| Gender, % | | | | |
| Male | 50.0 | | | |
| Female | 50.0 | | | |
| Cancer diagnosis, % | | | | |
| Lung & Bronchus | 25.0 | | | |
| Prostate | 10.0 | | | |
| Breast | 2.5 | | | |
| Brain | 2.5 | | | |
| Liver & Biliary | 10.0 | | | |
| Pancreas | 10.0 | | | |
| Ovarian | 5.0 | | | |
| Melanoma | 2.5 | | | |
| Other | 32.5 | | | |
| Place of death, % | | | | |
| Home | 72.5 | | | |
| Nursing facility | 10.0 | | | |
| Palliative care unit | 7.5 | | | |
| Pain level (0–10) median (IQF) ^b | 0 (0-4) | | | |
| Palliative Performance Score, median % (IQF) ^c | 40 (40-50) | | | |
| LOS under hospice care, median days (IQF) | 60 (25-91) | | | |

LOS = length of stay.

^aComparisons of primary caregivers vs. secondary caregivers.

^bData on patient pain at admission were obtained from the hospice medical chart: 0 = no pain; 10 = worst possible pain.

^cThe Palliative Performance Scale (PPS) measures functional status on five domains: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level, using deciles (increments of 10%; 100% indicating healthy; 0% indicating death).³¹ PPS scores at admission to hospice were collected from patient medical charts.

Table 2

Description of QOD-Hospice Scale and Other Study Measures

| Instrument | Total ^a | | | | Primary Caregivers | | | | Secondary Caregivers | | | |
|--------------------------------|--------------------|-------------|----------|-------------|--------------------|----------|-------------|-------------|----------------------|--------|-------|----------|
| | M (SD) | Range | α | M (SD) | Range | α | M (SD) | Range | α | M (SD) | Range | α |
| QOD-Hospice | 4.42 (.47) | 3.15 – 5.00 | .86 | 4.44 (.48) | 3.15 – 5.00 | .84 | 4.40 (.49) | 3.25 – 4.95 | .89 | | | |
| LSNS-6 | 18.1 (6.3) | 2 – 30 | .86 | 17.6 (6.5) | 2 – 28 | .85 | 18.8 (6.1) | 4 – 30 | .88 | | | |
| Family | 9.4 (3.5) | 0 – 15 | .84 | 9.2 (3.7) | 0 – 15 | .83 | 9.7 (3.2) | 2 – 15 | .84 | | | |
| Friendships | 8.7 (3.5) | 0 – 15 | .82 | 8.4 (3.8) | 0 – 15 | .86 | 9.1 (3.2) | 2 – 15 | .75 | | | |
| DASS | 11.4 (10.3) | 0 – 39 | .93 | 14.1 (11.3) | 0 – 39 | .93 | 7.7 (7.3) | 0 – 26 | .91 | | | |
| Depression | 3.9 (4.2) | 0 – 18 | .90 | 5.0 (4.5) | 0 – 18 | .89 | 2.6 (3.3) | 0 – 12 | .90 | | | |
| Anxiety | 2.3 (3.1) | 0 – 17 | .79 | 3.0 (3.5) | 0 – 17 | .78 | 1.3 (2.2) | 0 – 8 | .75 | | | |
| Stress | 5.2 (4.2) | 0 – 16 | .87 | 6.2 (4.6) | 0 – 16 | .87 | 3.8 (3.1) | 0 – 12 | .81 | | | |
| TRIG-2 | 41.1 (10.1) | 13 – 61 | .88 | 43.0 (9.6) | 13 – 61 | .86 | 38.7 (10.4) | 13 – 55 | .91 | | | |
| Care Satisfaction ^b | 4.5 (1.1) | 1 – 5 | - | 4.3 (1.3) | 1 – 5 | - | 4.7 (0.5) | 3 – 5 | - | | | |

^a Statistics for the total combined sample may be biased because of cluster effects of including multiple responders from the same family.

^b Satisfaction with hospice care was measured using a single item instrument, therefore Cronbach's alpha is not reported.

Note: Higher scores on the QOD-Hospice represent better quality of dying. Higher scores on the LSNS-6 indicate greater levels of social support. Higher values on the DASS and its subscales represent greater levels of affective distress. Higher TRIG2 scores indicate higher levels of emotional grief. For Care Satisfaction, higher ratings indicate greater satisfaction with hospice care.

Table 3

Descriptives and Factor Loadings for the QOD-Hospice Scale Items (N=70)

| Items | M(SD) | Factor Loadings | | |
|--|----------|-----------------|-------------|---------------|
| | | Factor 1 | Factor 2 | Communalities |
| 1. There was a hospice staff member with whom my loved one felt comfortable. | 4.4(0.9) | 0.48 | 0.53 | 0.51 |
| 2. My loved one received affectionate touch daily. | 4.8(0.6) | | | 0.30 |
| 3. He/she appeared to be at peace. | 4.2(0.9) | 0.68 | | 0.47 |
| 4. Members of the hospice team knew him/her as a whole person including life and personality. | 4.3(0.9) | | 0.76 | 0.61 |
| 5. My loved one had treatment preferences in writing. | 4.3(1.1) | 0.72 | | 0.52 |
| 6. My loved one indicated he/she was prepared to die. | 4.1(1.5) | 0.82 | | 0.68 |
| 7. His/her funeral was planned. | 4.1(1.4) | 0.63 | | 0.39 |
| 8. My loved one had named a decision maker in the event he/she was no longer able to make decisions. | 4.8(0.7) | 0.54 | | 0.37 |
| 9. My loved one maintained his/her sense of humor. | 4.2(1.0) | 0.61 | | 0.39 |
| 10. His/her dignity was maintained. | 4.5(0.9) | 0.47 | | 0.22 |
| 11. His/her clothes and body were clean. | 4.8(0.5) | 0.48 | | 0.23 |
| 12. My loved one's wishes were met regarding the place of death. | 4.8(0.6) | 0.74 | | 0.55 |
| 13. There was someone from hospice whom he/she trusted. | 4.4(1.0) | 0.82 | | 0.76 |
| 14. The hospice staff was comfortable talking about death and dying. | 4.5(0.8) | 0.76 | | 0.64 |
| 15. My loved one was free from pain. | 3.7(1.1) | 0.46 | | 0.32 |
| 16. My loved one was free from shortness of breath. | 3.6(1.1) | | 0.43 | 0.21 |
| 17. His/her wishes were met regarding spiritual support. | 4.7(0.7) | | | 0.13 |
| 18. His/her wished were met regarding who was present at the time of death. | 4.8(0.6) | | 0.60 | 0.36 |
| 19. My loved one knew what to expect about his/her illness. | 4.4(1.1) | 0.65 | | 0.50 |
| 20. There was someone with whom he/she could share his/her deepest thoughts. | 4.7(0.5) | | 0.45 | 0.21 |
| % of variance accounted for | | 29.11 | 12.70 | |
| Factor inter-correlations | | | 0.259 | |

Note: The 13 items selected for the QOD-Hospice-SF are shaded in grey. Factor 1 = Preparation subscale; Factor 2 = Security subscale.

Table 4Descriptive Statistics for the QOD-Hospice-SF and Its Subscales ($N=70$)

| | Caregiver Sample | Items | M(SD) | Skewness | Kurtosis | α | ICC | % Agreement |
|----------------|------------------|-------|------------|----------|----------|----------|------|-------------|
| QOD-Hospice-SF | Total | 13 | 4.40(0.60) | -1.49 | 3.07 | 0.85 | 0.64 | 79% |
| | Primary | | 4.38(0.68) | -1.61 | 2.93 | 0.86 | | |
| | Secondary | | 4.44(0.47) | -0.61 | -0.19 | 0.81 | | |
| Preparation | Total | 7 | 4.30(0.78) | -1.65 | 3.26 | 0.82 | 0.80 | 89% |
| | Primary | | 4.27(0.89) | -1.77 | 3.19 | 0.85 | | |
| | Secondary | | 4.35(0.61) | -0.74 | -0.63 | 0.73 | | |
| Security | Total | 6 | 4.52(0.64) | -1.76 | 2.92 | 0.85 | 0.33 | 63% |
| | Primary | | 4.52(0.73) | -1.77 | 2.49 | 0.85 | | |
| | Secondary | | 4.54(0.50) | -1.39 | 2.03 | 0.85 | | |

Note. The initial QOD-Hospice (20 items) elicited an intraclass correlation (ICC) of 0.49 and the proportion of inter-rater agreement was 63%. ICC values may be artificially low because of skewedness of scale scores.

Table 5

Correlations Between QOD-Hospice Scales and Study Variables (N=70)

| | QOD-Hospice-SF | | |
|-----------------------------------|---------------------|---------------------|-----------------------------|
| | QOD-Hospice | Full Measure | Factor 1 Factor 2 |
| 1) LSNS-6-family | 0.318 ^a | 0.282 ^b | 0.129 0.389 ^a |
| 2) LSNS-6-friend | 0.162 | 0.163 | 0.085 0.210 |
| 3) DASS-depression | -0.248 ^b | -0.321 ^a | -0.401 ^a -0.081 |
| 4) DASS-anxiety | -0.201 | -0.259 ^b | -0.322 ^a -0.068 |
| 5) DASS-stress | -0.248 ^b | -0.295 ^b | -0.355 ^a -0.094 |
| 6) TRIG-2 | -0.339 ^a | -0.385 ^a | -0.413 ^a -0.192 |
| 7) Care Satisfaction ^c | 0.334 ^a | 0.297 ^b | 0.131 0.353 ^a |

^a $P < 0.01$.^b $P < 0.05$.^c Spearman's ρ correlation statistic.*** $p < 0.001$