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The quality of dying and death: a systematic review of measures

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Abstract

To determine whether modern medicine is facilitating 'good' deaths, appropriate measures of the quality of dying and death must be developed and utilized. The purpose of this paper is to identify quality of dying and death measurement tools and to determine their quality. MEDLINE (1950–2008), Healthstar (1966–2008), and CINAHL (1982–2008) were searched using keyword terms 'quality of dying/death' and 'good/bad death'. Papers that described a quality of dying and death measure or that aimed to measure the quality of dying and death were selected for review. The evaluation criteria included a description of the measure development (validated or ad hoc), the provision of a definition of quality of dying and death, an empirical basis for the measure, the incorporation of multiple domains and the subjective nature of the quality of dying and death construct, and responsiveness to change. Eighteen measures met the selection criteria. Six were published with some description of the development process and 12 were developed ad hoc. Less than half were based on an explicit definition of quality of dying and death and even fewer relied on a conceptual model that incorporated multidimensionality and subjective determination. The specified duration of the dying and death phase ranged from the last months to hours of life. Of the six published measures reviewed, the Quality of Dying and Death questionnaire (QODD) is the most widely studied and best validated. Strategies to measure the quality of dying and death are becoming increasingly rigorous. Further research is required to understand the factors influencing the ratings of the quality of dying and death.

Keywords
end of life, measurement, quality of death, quality of dying

Introduction

To what extent has modern medicine helped dying patients achieve a 'good' death? Does this depend upon the degree of symptomatic distress, the cause and location of death, the nature of family and other supports, the quality of end-of-life care, and/or the personal qualities of the patient? These questions are gaining attention now that improvement of the quality of the dying and the death experience is recognized as an important goal,[1,2] and a practical focus of general medicine.[3] The answers to these questions require a clear understanding of the quality of dying and death construct and the availability of valid and reliable measurement instruments.

The quality of dying and death pertains to the period leading up to death, although there is ambiguity about when the transition to the dying phase occurs.[2] There has also been a lack of clarity and consistency in the literature regarding the quality of dying and death construct. Our recent review of research studies in which this construct was conceptualized indicated that seven broad domains are consistently identified by patients, families, and health care providers.[4] These are: (1) physical; (2) psychological; (3) social; (4) spiritual and existential experience; (5) the nature of health care; (6) life closure and death preparation; and (7) the circumstances of death. These multiple domains have also been highlighted in expert opinion papers outlining the good death.[1] Evaluation of the quality of death is by definition subjectively determined, and its judgment is influenced by numerous factors, including culture and type and

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stage of disease. Patients, family members, other caregivers, and health care providers all have unique and valid perspectives on this evaluation.

How is the quality of dying and death, so defined, being measured? Several decades of research have provided information about aspects of the dying and death experience. Large studies in the United Kingdom[5] and the United States[6,7] have demonstrated the high prevalence of pain and other symptoms in the last days of life, the frequent use of life-sustaining interventions at the end of life, and the high proportion of deaths that occur in hospital. While these studies provide a picture of what happens at the end of life, they do not tell us to what extent these would be considered 'good' deaths by those involved.[8] While qualitative research can provide information about the dying experience for small numbers of patients, quality of dying and death measures are needed in order to evaluate this outcome in larger samples. To date, no systematic reviews have examined specifically the measurement of the quality of dying and death. The purpose of this paper is therefore to review and critically appraise measures of the quality of dying and death. This necessarily also includes giving attention to the definition of the quality of dying and death upon which the measures were based.

Methods

The aim of the review is to examine the quality of the currently available quality of dying and death measures. We systematically searched published health care research to identify studies that reported on the primary development, validation, or utilization of measures of the quality of dying and death. Papers were obtained from searches of MEDLINE (1950 to November 2008), Healthstar (1966 to November 2008), and CINAHL (1982 to November 2008), using the keyword search terms 'quality of death', 'quality of dying', 'good death', and 'bad death'. Reference lists of selected papers were also examined for potentially relevant citations. Studies were included if they were reported to measure the quality of dying and/or death in cases of potential or expected death (i.e. advanced disease, life-threatening disease, residence in a long-term care facility, advanced age). The following were excluded: studies using solely qualitative methods, articles not written in the English language, opinion or theory articles, letters, editorials, case reports, historical reports, and reviews. The first author (SH) conducted the search and the second and third authors (CZ and GR) reviewed the selection process. Figure 1 shows a flow diagram of the search strategy.

The criteria for this review were based on those developed by the Scientific Advisory Committee of the Medical Outcomes Trust for the purpose of assessing health status and quality-of-life instruments.[9] These criteria included consideration of the conceptual and measurement model, reliability, validity, responsiveness, interpretability, respondent and administrative burden, alternate forms, and culture and language adaptations. Because the quality of dying and death literature is relatively new, we chose to focus on the conceptual and measurement model, reliability, validity, and responsiveness. We supplemented these considerations with a criterion of multidimensionality and of subjectivity, based on our previous literature review, which revealed seven subjectively determined domains that have been identified consistently as central to the quality of dying and death construct.[4] In evaluating these measures, we specifically examined whether the measure was: (1) developed formally with reported reliability and validity or ad hoc for the purpose of a specific study; (2) based on an operationalized definition of the quality of dying and death that was used as the conceptual foundation; (3) constructed using items generated on an empirical basis (e.g. based on previous research, review of relevant literature, expert opinion); (4) described as capturing the multiple dimensions and the subjective nature of the quality of dying and the death experience; (5) responsive to change.

Results

Our literature search initially identified 1155 papers, of which 103 were identified as suitable for further review. Of these, 31 papers published from 1988–2008, describing 18 different measures, met the inclusion criteria of aiming to measure the quality of dying and death (see Tables 1 and 2). Eleven of the measures were tested on populations in the United States alone,[10–20,23–32] one in Taiwan,[33–35] one in Japan,[36,38], one in Italy,[39] one in the UK,[40] two in Australia,[21], and one in both the US and Canada.[22,41] Measures were used to assess deaths in the following patient populations: patients with cancer,[23–25,33–36,38,39] patients in nursing home or long-term care facilities[10,11,29–31] patients receiving dialysis,[22,26,32,41] patients receiving palliative or hospice care,[13,21,23,28,33–35] non-sudden deaths including those in the community, hospices, or ICUs,[12–20] and deaths of older people.[27] Two measures were used in studies with a quasi-experimental pre-post test designed to evaluate the effect of an intervention on the quality of dying and death[16,20,29] and the remainder only in studies with observational designs.

Six of the 18 measures were published with some reported validity and reliability testing (all since 2002), (see Table 1). Use of the Quality of Dying and Death questionnaire (QODD)[12] or a modified version

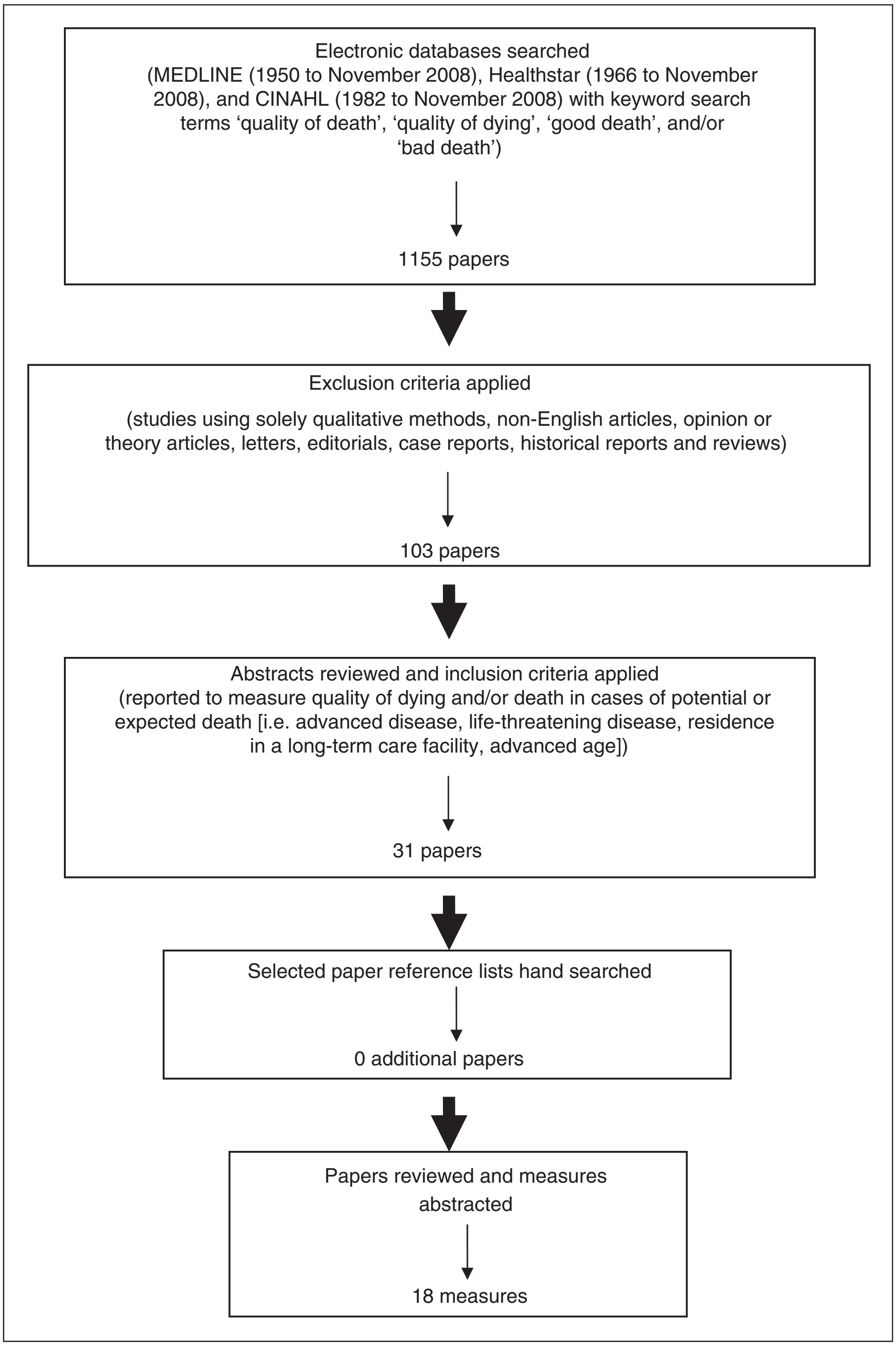

Figure 1. Flow diagram of the search strategy.

was reported in nine studies: the Good-Death Scale[33] was reported in three studies; the Good Death Inventory (GDI)[36] in two studies; the Quality of Dying in Long-term Care (QOD-LTC)[10] in two studies; and one study adapted both the Client Generated Index tool (CGI)[43] and the McGill Quality of Life questionnaire (MQOL)[44] for use by caregiver proxies after patient death. Of these six published measures, the QODD had the most validity and reliability testing. Twelve of the 18 measures reviewed were developed ad hoc with minimal or no report of the development process, reliability, or validity (see Table 2).

Evidence that the measure was derived from a conceptual model was based on a description of the concepts that the measure was intended to assess.[9] An explicit definition of the quality of dying and death

Table 1. Published and validated instruments measuring quality of dying and death

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
GDI									
Miyashita et al. (2008)[36]	Japan: regional cancer center	To develop and test a measure for evaluating death from the perspective of bereaved family members	189 cancer patient deaths	Family members	Not provided	Based on qualitative research and national survey in Japan as well as literature review	18 domains with three or more attribute questions for each domain rated on a 7-point scale from 1 (absolutely disagree) to 7 (absolutely agree); domain score calculated by summing attributes; total scores calculated in three ways: a total of all attributes, a total of 10 core domain attributes (environmental comfort, life completion, dying in a favorite place, maintaining hope and pleasure, independence, physical and psychological comfort, good relationship with medical staff, not being a burden to others, good relationship with family, being respected as an individual) and a total of eight optional domain attributes (religious and spiritual comfort, receiving enough treatment, control over the future, feeling that one's life is worth living, unawareness of death, pride and beauty, natural death, preparation for death); higher scores indicate achievement of good death	Face validity evaluated by two physicians, two nurses and two lay persons; sufficient concurrent validity demonstrated by comparison with the Care Evaluation Scale (Morita et al. 2004)[37] and overall care satisfaction; sufficient internal consistency (Cronbach's alpha 0.74–0.95) and acceptable test–retest reliability (intraclass correlation coefficients 0.38–0.72); factor validity testing identified 18 possible domains	Total GDI scores not reported; mean value of 18 domain scores ranged from 2.7 to 5.5
Miyashita et al. (2008)[38]	Japan: regional cancer center	To explore factors contributing to a good death from the perspective of bereaved family members	165 cancer patient deaths	Family members	Not provided	As above	As above	As above	Total GDI scores not reported; good death associated with death in palliative care unit, patient and family member's age, appropriate opioid medication; barrier to good death included life prolongation and aggressive treatment in last 2 weeks of life

(continued)

Table 1. Continued

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
QOD-LTC									
Munn et al. (2007)[10]	US: nursing homes and residential care/assisted living facilities	To describe the QOD-LTC and Quality of Dying in Long-term Care for the cognitively intact (QOD-LTC-C), measures.	633 nursing home or residential care/ assisted living deaths	Family and health care staff	Not provided	Items partially drawn from the QUAL-E measure, which is based on focus groups and a national survey identifying the attributes of a good death; the items were examined for content validity and chosen to reflect dying overall, circumstances of long-term care setting, and administration to surrogate respondents	11 item QOD-LTC; 23 item QOD-LTC-C; respondents rate statements using a 5-point scale, from 1 (not at all) to 5 (completely), describing aspects of the quality of dying including personhood, closure, preparatory tasks, sense of purpose, closure, social connection; factor scores (means of item scores within each factor) may be averaged for overall quality of dying score (range 1–5 with a higher score indicating a more positive experience) and individual factor scores may be used separately	Cronbach's alpha for QOD-LTC 0.66 and QOD-LTC-C 0.85; factor analysis revealed QOD-LTC consists of three domains (personhood, closure, preparatory tasks); the QOD-LTC-C consists of five domains (sense of purpose, closure, control, social connection, preparatory tasks)	All items positively skewed; item means ranged from 2.92 to 4.84; total and factor scores not reported
Caprio et al. (2008)[11]	US: nursing homes, and residential care/assisted living facilities	To evaluate the relationship between pain, dyspnea, and family perceptions of the QOD-LTC	325 nursing home and residential care/ assisted living deaths	Family caregivers	Not provided	As above	As above	As above	Mean QOD-LTC score for the sample was 4.08 with SD 0.67; QOD-LTC scores were higher for cognitively intact than cognitively impaired residents; QOD-LTC scores did not differ for residents with and without pain; QOD-LTC scores were higher for those with dyspnea than without (we conclude that dyspnea may alert staff to the need for care)
Good-Death Scale									
Tsai et al. (2005)[33]	Taiwan: hospital palliative care unit	To investigate the relationship between the death fear level and good-death scale in two age groups	224 palliative cancer patient deaths	Multi-disciplinary team	A good death is one in which a patient's suffering is reduced as much as possible and death is accompanied by dignity; includes awareness, acceptance, arranging will, and appropriate timing of death	Based on Weisman's definition of good death (see left)	Five factors: awareness of dying, peaceful acceptance, arranging one's will, timeliness/preparation for death, degree of physical comfort; each factor scored 0–3 and was summed for a total score 0–15, with a higher score indicating a better death	Not reported	No significant differences between non-elderly and elderly groups with respect to total good death scores (mean score 13.44 for <65 and 13.05 for >65); a significant negative correlation between degree of death fear and total good death score

(continued)

Table 1. Continued

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
Yao et al. (2007)[34]	Taiwan: hospital palliative care unit	To investigate whether dying at home influences the likelihood of a good death	374 palliative cancer patient deaths	Multi-disciplinary team	As above	As above	As above: evaluations completed after patient admission and prior to death (usually retrospectively)	Reported reliability and validity already established in Taiwanese palliative care units and referenced Tsai et al.[33]; good internal consistency (Cronbach's alpha 0.76)	Total good-death score in the home-death group was higher than that in the hospital-death group at admission (12.80 vs. 10.81, $p < 0.001$) and prior to death (14.13 vs. 13.48, $p < 0.01$); bereavement support, alleviation of anxiety, decision-making participation, fulfillment of last wish, and survival time were independent correlates of the good death score but place of death was not
Cheng et al. (2008)[35]	Taiwan: hospital palliative care unit	To investigate the good death status of elderly patients with terminal cancer, comparing elderly and younger groups and exploring factors related to a good death score	355 palliative cancer patients	Multi-disciplinary team	As above	As above	As above: evaluations completed following patient death	Reported reliability and validity already established in Taiwanese palliative care units and referenced Tsai et al.[33] and Yao et al.[34]; expert panel determined content validity; face validity confirmed by bereaved family members; good internal consistency (Cronbach's alpha 0.71)	Total good death scores increased significantly for both the elderly and younger groups from admission to just prior to death; total good death scores were not significantly different for the elderly (10.94) versus younger (10.84) groups at admission but were significantly lower for the elderly (13.52) versus younger (14.17) prior to death; the elderly group had significantly lower scores in awareness, propriety, and timeliness than the younger group prior to death; respect for autonomy and verbal support were independent correlates of the good death score in the elderly group
QODD									
Curtis et al. (2002)[12]	US: community	To describe the validity of the QODD	205 non-sudden deaths	Original conceptual model incorporated both patient pre-death preferences and after-death reports of the dying experience, but the questionnaire	Quality of dying and death is the degree to which a person's preferences for dying and the moment of death are consistent with other's	Based on a literature review, qualitative interviews on the domains of dying and death, and a review of the existing instruments	31 items and six domains: symptoms and personal care, treatment preferences, time with family, whole person concerns, preparation for death, and moment of death; each item scored from 0 (terrible experience) to 10 (almost perfect experience); the mean score was	Good construct validity, high internal consistency (Cronbach's alpha 0.89)	Mean QODD 67.4, range from 26 to 97; higher QODD scores were associated with death at home, death in a location the patient desired, lower symptom burden, better ratings of symptom treatment, communication about treatment preferences, compliance with treatment

(continued)

Table 1. Continued

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
				was administered retrospectively to family members	observation of how that person actually died		multiplied by 10 to construct a scale from 0 to 100 with higher scores indicating better quality of death		preferences, family satisfaction regarding communication with the health care team, and availability of a health care team member at night or on weekends
Patrick et al. (2003)[13]	US: community and hospice	To describe the quality of death in a community sample (same data as Curtis et al.[12]) and hospice sample	205 non-sudden community deaths and 62 hospice patient deaths	Patient's loved ones	As above	As above	As above	As above	Hospice patient total QODD scores not provided; higher QODD scores of home hospice patients associated with amount of time patients spent with providers, how often providers explained treatments, how often treatment plans followed, better ratings of care, quality of life and moment of death
Hodde et al. (2004)[14]	US: hospital ICU	To determine the feasibility of nurse ratings of quality of dying and death in an ICU and associated factors	178 ICU patient deaths	ICU nurses	Not provided	Items selected from QODD for use in an ICU with nurse respondents; based on a focus group with ICU nurses; item regarding sedation added	14 item QODD for nurses	High internal consistency (Cronbach's alpha 0.96)	Mean QODD score 73.1, SD 21.4; higher scores independently predicted by someone present, no cardiopulmonary resuscitation (CPR) in the last 8 hours, and being cared for by neurosurgery or neurology services
Mularski et al. (2004)[15]	US: hospital ICUs	To measure agreement among family members who rate their loved one's ICU dying experience	38 ICU patient deaths	Family members	Not provided	Items selected from QODD for use in ICU	23 item ICU QODD	Moderate inter-rater reliability among family members	Mean ICU QODD score 60; moderate agreement among family members
Treece et al. (2004)[16]	US: hospital ICU	To evaluate a withdrawal of life support order form	117 ICU patient deaths	ICU nurses	Not provided	Referenced Hodde et al.[14]	14 item QODD for nurses	Responsiveness to change not demonstrated	Mean pre-order QODD 78.3, SD 16.7 and post-order QODD 74.2, SD 21.7; no significant change in QODD scores after intervention
Mularski et al. (2005)[17]	US: hospital ICUs	To explore the quality of the dying experience and associations to higher quality ratings for people who died in an ICU	38 ICU patient deaths	Family members	Not provided	Referenced Mularski et al.[15]	23 item ICU QODD	As above	Mean ICU QODD 60, SD 14; higher ICU QODD scores associated with control of pain, control of events, peace with dying and dignity/self respect

(continued)

Table 1. Continued

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
Levy et al. (2005)[18]	US: hospital ICUs	To compare perceptions of quality of dying and death in ICUs across nurses, resident physicians, attending physicians, and family members	68 ICU patient deaths	Nurses, resident physicians, attending physicians and family members	Not provided	Items selected from QODD for use in ICU	21 item ICU QODD	Low inter-rater reliability among nurses, physicians, residents and family	Mean ICU QODD family 77.7, SD 9.3, physicians 81.5, SD 17.3, residents 67.8, SD 22.5, nurses 66.9, SD 16.3; ICU QODD scores varied considerably between nurses, physicians, resident physicians, and family members; family and physicians gave most favorable ratings compared to nurses and residents
Glavan et al. (2008)[19]	US: hospital ICUs	To identify chart-based markers that could be used as measures for improving end-of-life care	365 ICU patient deaths	Family members	Not provided	Items selected from QODD use in ICUs with family member respondents	22 item ICU QODD (QODD-22); one item overall quality of dying and death rating (QODD-1)	As above	Mean QODD-22 61.8 with SD 23.8; mean QODD-1 score was 6.9 SD 3.1; higher QODD-22 scores were associated with the documentation of a living will, absence of CPR performed in the last hour of life, withdrawal of tube feeding, family presence at time of death, and discussion of the patient's wish to withdraw life support during a family conference; additional correlates with higher QODD-1 score included the use of standardized comfort care orders and occurrence of a family conference
Curtis et al. (2008)[20]	US: hospital ICU	To evaluate the effectiveness of a multi-faceted quality improvement intervention to improve	523 ICU patient deaths	Family members and nurses	Not provided	Referenced Hodde et al.[14] and Mularski et al.[15]	21 item ICU QODD for family members and 14 item ICU QODD for nurses	ICU QODD for nurses demonstrated responsiveness to change	Family ICU QODD showed a trend to improvement (pre, 62.3; post 67.1), but was not statistically significant; nurse ICU QODD showed significant improvement

(continued)

Table 1. Continued

Paper authors	Setting and population	Objective	Population/ type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
		palliative care in the ICU							(pre, 63.1; post, 67.1; $p < 0.01$)
CGI and MQOL									
Bridge et al. (2002)[21]	Australia: home palliative care organization	To assess the quality of dying of palliative care patients and to compare the usefulness and feasibility of the CGI and MQOL tool for assessment of the quality of death in palliative care patients	14 palliative care patient deaths	Family/friend caregivers	Quality of death is quality of life of the client in the last 2 days alive	The CGI and MQOL are existing measures designed to assess patient quality of life	CGI modified to ask for a list of the client's comorbid conditions, list of up to five areas most impacted by illness, grading of areas of living and conditions on scale from 1 to 10, prioritized spending of 12 points on areas of living and comorbid conditions as would have been preference of client if possible to improve impact (higher scores mean worse quality of death); MQOL examined five domains with preselected variables including physical symptoms, physical, psychological and existential wellbeing, and support (higher scores mean better quality of death); both measures administered retrospectively to caregiver proxies regarding the patient's last 2 days of life	Authors referenced previous reports of measurement properties of both measures, although no reported testing of reliability or validity of either measure as a retrospective proxy measure, CGI not tested for reliability or validity with palliative care patients; reported poor face validity of both tools as measures of quality of death by caregiver proxy	Neither tool found to be feasible as a proxy measure of quality of death due to caregiver difficulty perceiving what patient experienced and due to their focus on their own grieving experiences and reflections; authors reported CGI scores were well toward the maximum worse scores while MQOL scores were midway, although actual scores were not provided

Table 2. Ad hoc instruments measuring the quality of dying and death

Paper authors	Setting and population	Objective	Population/type of death evaluated	Source/respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
Dialysis Discontinuation Quality of Dying									
Cohen et al. (1995)[22]	US: dialysis clinics	To examine the quality of dying following dialysis termination	11 dialysis patient deaths after discontinuing treatment	Health care providers	Not provided	Based on expert opinion and literature review	Three domains: pain and suffering, psychosocial factors, shorter duration of dying; each domain given score from 1 to 5 and summed for overall score from 3 to 15 with higher scores indicating better quality of death	High inter-rater reliability	Scores not provided; 7/11 had good terminal courses
Cohen et al. (2000)[41]	US and Canada; dialysis clinics	To examine the quality of dying following dialysis termination	79 dialysis patient deaths after discontinuing treatment	Health care providers	Not provided	As above	As above	As above	Scores ranged from 4 to 15 with a mean of 11.4 (± 0.3); 38% of subjects had very good deaths (>12), 47% good deaths (>8–12) and 15% bad deaths (≤ 8)
The quality of death									
Wallston et al. (1988)[23]	US: hospitals and hospices	To compare the quality of death of patients receiving hospital versus hospice care	Cancer patient deaths (number not provided)	Principal care providers	Quality of death is experienced in the last 3 days of life, feelings and events that terminally ill patients reported they desired	Based on descriptive data from 1000 terminally ill patients regarding what wanted their last 3 days of life to be like	13 items: the presence of significant others, physical ability, freedom from pain, peace/happiness, ability to maintain normal activities, ability to stay at home as long as wanted, to be at peace with god, to die in sleep, to be mentally alert, to complete tasks, to accept death, to know when death is imminent, and to live until a key event has occurred; items coded 1 (present) or 0 (not present) and weighted according to the number of patients who mentioned a given item and multiplied by 100; total score produced by summing item scores with higher scores indicated better quality of death	Not reported	Mean score 79.4 (SD 21.8), range 1.4–136.1 (total possible not provided); better quality of death associated with hospice versus non-hospice patients
Yancey & Greger (1990)[24]	US: community	To determine whether the circumstances of a cancer death influence the grief resolution of the survivor at 1 month after death	43 cancer patient deaths	Family and friends of patients	As above	As above	As above	Reported construct validity demonstrated due to significant differences in the quality of death scores by mode of care; reported Cronbach's alpha 0.63	Mean quality of death score 65.3 for hospital, 63.75 for home, 53.18 for extended care facility; no association with quality of death and grief resolution in the family member 1 month after death

(continued)

Table 2. Continued

Paper authors	Setting and population	Objective	Population/type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
Single-use instruments									
Ray et al. (2006)[25]	US: cancer centers	To examine the way in which patients' baseline awareness of terminal illness and sense of peace influence their mental health, advance care planning, quality of death, and caregiver bereavement outcomes	Advanced cancer patient deaths (280 patients enrolled, number of follow ups not reported)	Hospital/hospice staff or informal caregivers (whoever last attended to the patient before death)	Not reported	Not reported	Single item; quality of death/ last week of life rated on a scale of 0 (worst possible) to 10 (best possible)	Not reported	Mean quality of death scores ranged from 5.06 to 7.09; peacefully aware patients had higher overall quality of death scores
Cohen et al. (2005)[26]	US: dialysis clinics	To describe how dialysis patients die	86 dialysis patient deaths	Family members	Not provided	Based on review of existing instruments	As part of the Post-death Family Questionnaire (PDFQ), the quality of dying was evaluated by asking whether the patient had a peaceful death, scored 0 (no), 1 (unsure), or 2 (yes); and whether the patient died with dignity, rated on a scale of 1 (very much) to 5 (not at all)	Not reported	64% had peaceful deaths; 58% died with much dignity
Ethunandan et al. (2005)[40]	UK: hospital	To evaluate the quality of the dying experience of head and neck cancer patients	32 head and neck cancer patient deaths	Review of administrative data	A good death is one that is pain free, peaceful, dignified, at a place of choosing with relatives present and without futile heroic interventions	Based on a review of literature to determine important indicators of care	Aspects of death described: symptoms, location of death, presence of relatives, CPR and ICU admissions, resuscitation status; emergency admissions; incontinence, infection, bleeding	Not reported	All symptoms managed except for neuropsychological problems, 63% died in hospital, 22% had a relative present, 65% had their resuscitation status documented, none received ICU admission or CPR, 53% were admitted to the ER in the last month of life
Carr (2003)[27]	US: community	To evaluate how the quality of older adult's death affects the surviving spouse's psychological adjustment 6 months after loss	210 elderly married person deaths	Spouses	A good death is characterized by physical comfort, social support, acceptance, and appropriate medical care, and it should minimize psychological distress for dying and their families	Not reported	Aspects of death considered included acceptance, pain, timeliness, spousal interactions, the presence of family, place of death, degree of family burden, full/rewarding life; overall good death score computed by summing the total number of positive death attributes; scores range from 0 to 10	Not reported	Overall good death scores not provided; spousal relationship and pain associated with spousal adjustment 6 months after loss

(continued)

Table 2. Continued

Paper authors	Setting and population	Objective	Population/type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
Ganzini et al. (2003)[28]	US (Oregon): hospice programs	To compare the deaths of hospice patients who hastened death by refusing food and fluids with those who hastened death by legalized physician-assisted suicide (quality of death was a studied outcome)	140 nurse reports of hastened hospice patient deaths	Nurses	Not reported	Not reported	Single item; quality of process of dying rated on a scale from 0 (very bad) to 9 (very good)	Not reported	Quality of death of patients who voluntarily refused food and fluids and who had physician-assisted suicide had a median score of 8; 92% of deaths were rated as good (score of 5–9) and only 8% were rated as bad (score 0–4); bad deaths significantly had higher scores of suffering, pain and younger age
Keay et al. (2003)[29]	US: nursing homes	To determine if an educational intervention designed for nursing home physicians improves the quality of dying for nursing home residents	203 nursing home resident deaths	Chart review	Not reported	Based on the consensus of Maryland medical directors and nationally recognized physicians; quality of care indicators were found to correspond to other measures of quality of care in previous research by the first author	Aspects of death described included the recognition of possible death, the presence of advanced directives, pain control, analgesics used, dyspnea control, control of uncomfortable symptoms, documented hygiene, documented bereavement support, total patient comfort; no summary quantification	Not reported	Nursing facilities that completed the intervention had significant improvements in outcomes
Reynolds et al. (2002)[30]	US: nursing homes	To describe the palliative care needs of dying nursing home residents during the last 3 months of life	80 nursing home patient deaths	Nurses, aides, family members	Not reported	Based on a review of literature, other instruments and a series of focus groups; pilot tested	Single item; yes/no response to question regarding whether or not they believed the resident's dying experience was a 'good death – how he/she would have wanted it'	Not reported	58% of respondents reported a good death
Flacker et al. (2001)[31]	US: long-term care	To examine and compare whether differences in	27 long-term care patient deaths	Primary care team (physicians,	Not reported	Not reported	Single item; quality of death rated on a scale from 1	Good inter-rater reliability given no significant difference across respondents	Mean scores ranged from 3.67 to 3.72; no differences

(continued)

Table 2. Continued

Paper authors	Setting and population	Objective	Population/type of death evaluated	Source/ respondent used	Definition of quality of dying and death	Basis for measure development	Measure description	Reported measure properties	Quality of dying and death evaluations
	facility deaths	perceptions regarding aspects of end-of-life care exist as viewed by different members of the long-term care primary care team		nurses, nurses' aides)			(terrible/uncomfortable) to 4 (peaceful)		among respondents with respect to quality of death
Peruselli et al. (1999)[39]	Italy: home palliative care units	To describe place, circumstances and quality of death of home palliative care patients	401 home palliative care patient deaths	Palliative care team	Not provided	Based on internal audit of steering committee's members	Aspects of death described included the desired place of death, someone present at the time of death, peacefulness, symptom control (pain, dyspnea, emesis), the need for total pharmacological sedation in the last 12 hours of life, state of consciousness, patient's awareness of the situation, performance of life-saving procedures, rituals related to death, family members contacting the team after the patient's death, invasive procedures and instruments implemented at the time of death; no summary quantification	Not reported	90% died in the desired place, 2% died alone, 31% died peacefully, 18% had pain, 28% dyspnea, 12% emesis, 25% were totally pharmacologically sedated, 34% were conscious until death, 84% of families contacted the team after their relative's death, 2% died alone, 56% of patients received invasive instruments, 1% had life-saving procedures, 47% had rituals related to death
Swartz & Perry (1993)[32]	US: dialysis program	To examine the effect of prior advance directives on chronic dialysis patient deaths	182 chronic dialysis patient deaths	Renal team and surviving family members	Not reported	Not reported	Single item; respondents provided subjective assessment of the case outcome with a score of 0 (unsatisfactory), 1 (satisfactory), 2 (good); scores summed to yield a composite score of ≤ 1 (unsatisfactory), 2 (satisfactory), and ≥ 2 (good)	Not reported	50% of deaths rated as good; better death associated with advance directive and with withdrawal as opposed to 'unreconciled' or sudden death

was provided in the description of only seven of the 18 measures reviewed.[12,21,23,27,33,40] Two were based on a definition of the quality of dying and death as the degree to which death occurred in accordance with the patient's wishes.[12,23] Three were based on definitions that referred to a set of predefined criteria, such as dying without symptoms, with support, without heroic interventions,[27,40] or with reduced suffering, dignity, awareness, acceptance, arrangement of a will, and appropriate timing.[33] Two quality-of-life measures were employed in one study that defined the quality of dying and death as synonymous with the quality of life of the patient in the last two days of life.[21] The other 11 measures were described without reference to an explicit definition of the quality of dying and death.[10,11,22,25,26,28–32,36,38,41]

The dying and death phase was defined in the descriptions majority of measures as the last hours,[39] last days,[21,23,24,33–35] or weeks[12–20,25,28] of life. For the QODD[12–20] this phase was defined as the last week of life, or the last month if a patient was unconscious or unresponsive in the last week. One measure, used for deaths following dialysis discontinuation, defined the dying phase as the time from last dialysis until death.[22,41] One measure referenced different time frames, varying from weeks to months, depending on the aspect of dying and death being evaluated.[40] Three measures generally referred to the 'end-of-life period',[36,38] 'final days',[27] or 'near time of death'[32] and four measure descriptions did not specify a time frame.[10,11,26,30,31]

The measure development process was published for 13 of the 18 measures,[12–24,26,29,30,33–36,38–41] but not for the other five.[25,27,28,31,32] Evidence for validity was published for six of the measures. The QODD[12] was based on a literature review, qualitative research, and a review of the existing instruments. The Good-Death Scale[33] was based on expert opinion that a good death is one with reduced suffering, dignity, awareness, acceptance, arrangement of the will, and appropriate timing. The GDI[36] was based on qualitative and quantitative research and a literature review. The QOD-LTC[10] was based on previous research and the Quality of Life at the End of Life (QUAL-E) measure;[42] items were selected to reflect overall dying, the quality of the long-term care setting, and administration of the measure to surrogate respondents. Finally, researchers defining the quality of dying and death as synonymous with the quality of life in the patient's last two days of life, adapting the CGI[43] and the MQOL[44] for a retrospective caregiver proxy report. These two measures were developed based on qualitative research to assess patient quality of life.

Five of the 18 measures employed single items, all developed ad hoc, to evaluate the quality of dying and death, ostensibly allowing the respondents to decide what to consider in providing their evaluations.[25,28,30–32] Two of these five measures relied on categorical responses of yes/no (in response to a question regarding whether patient had a good death)[30] or unsatisfactory/satisfactory/good death.[32] Three of the five measures relied on single-item scales with ranges from the worst possible to the best possible death,[25] very bad to very good death,[28] or terrible/uncomfortable to peaceful death.[31]

Thirteen of the 18 measures assessed multiple aspects of the quality of dying and death, although there was variability in the comprehensiveness of that assessment. The QODD,[12–20] Good-Death Scale,[33–35], GDI,[36,38] and three of the ad hoc measures[22–24,26,41] assessed some aspect of all seven quality of dying and death domains previously identified via the literature review.[4] Three ad hoc measures reported on multiple domains, including symptoms, place of death, presence of relatives, medical interventions applied, symptom control, advance directives, and circumstances of death, but did not assess spiritual/existential experience or death preparation.[29,39,40] The QOD-LTC captured all seven end-of-life domains except symptoms.[10,11] The CGI and MQOL used in one study[21] did not incorporate any aspects of health care, life closure and death preparation, or circumstances of death.

None of the 18 measures reviewed evaluated quality of dying and death with patient respondents. All relied upon retrospective reports by non-patient respondents to generate the quality of dying and death scores, including health care providers alone,[14,16,22,23,28,30,31,33–35,39,41] family/friend caregivers alone,[11–13,15,17,19,21,24,26,27,36,38] both health care providers and family caregivers,[10,18,20,25,30,32] or chart review/administrative data.[29,40] Of the six published and validated measures, the QODD has been used with health care providers, family care providers, and a combination of both; the QOD-LTC has been used with family care providers and a combination of family and health care providers; and the GDI and CGI/MQOL only with family/friend care providers. All measures requested a proxy account of the patient's end-of-life experience and none purported to evaluate the respondent's experience of the patient's dying and death.

Only eight of the 18 measures attempted to account for individual preferences and perspectives regarding the dying and death experience. Three measures incorporated evaluation and item weighting, specifically the QODD,[12–20] the CGI, and the MQOL.[21] The QODD asked respondents how often or whether an event happened and how they would rate this aspect of the patients' dying experience, whereas the CGI and

MQOL included the evaluation of 'client-identified' important variables. Five of the ad hoc measures relied on single-item evaluations, which theoretically would allow respondents to weight more heavily those aspects of dying and death they considered most important.[25,28,30–32] The remaining 10 measures described aspects of the dying and death experience (i.e. place of death, symptoms, advance directives, resuscitation, end-of-life procedures, emergency room (ER) visits or ICU admission, social support and relationships, existential/spiritual experience, death awareness/acceptance/preparation), but did not incorporate the relative importance of these aspects of dying and death to the individual patient.[10,11,22,23,24,26,27,29,33–36,38–41]

Responsiveness refers to a measure's sensitivity to change.[9] Only two of the 18 measures, the QODD and an ad hoc measure, were used in studies with a quasi-experimental pre-post test design to evaluate the effect of an intervention on the quality of dying and death.[16,20,29] The QODD was assessed in two quasi-experimental studies: one showed that the QODD, adapted for ICU and nurse respondents, was sensitive to an intervention to improve palliative care in the ICU[20] and one did not detect any change when a withdrawal of life support form was introduced in an ICU.[16] These studies were powered to detect a 10-point difference and a seven-point difference on the QODD, respectively, but both reported that minimal clinically important differences had not been specified. A study relying on an ad hoc measure of the quality of dying and death in order to evaluate a nursing home physician education intervention reported a positive finding, but did not include any discussion of effect sizes or minimally important differences.[29]

The remaining 12 measures reviewed were employed only in studies with observational designs. One study included a longitudinal assessment and demonstrated improved quality of death scores from the time of palliative care unit admission to just prior to death.[35] Twenty of the 31 studies provided a cross-sectional summary score for the quality of dying and death using a single-item or multi-item measure. Nineteen of these, using 11 different measures, reported the mean quality of dying and death to be in the intermediate to good range[11,12,14–20,25,31,33–35] or found the majority of sample scores to be in the intermediate to good range.[22,28,30,32,41] Only one of the 20 studies reporting a summary of the quality of death scores did not find intermediate to positive ratings. That was the Bridge et al.[21] study which used two quality-of-life measures, the CGI and MQOL, to capture the quality of dying and death.

Discussion

The quality of the dying and death experience has been measured using a variety of approaches with varying levels of rigor. Of the measures identified in this systematic review, more than half were ad hoc with no reported reliability or validity testing, although increasingly rigorous measure development and testing was noted in more recent publications. Less than half of the measures reviewed were based on an explicit definition of the quality of dying and death. There was also great variability in how the dying and death phase was defined, ranging from hours to months. This variability in methodological rigor and conceptual clarity limits the comparability of measures and the conclusions that can be drawn from their use.

Five of the reviewed measures were single-item evaluations of the quality of dying and death. Single-item measures impose little respondent or administrative burden, but they are not recommended unless the construct or domain being evaluated is well defined and unambiguous to the respondent.[45] In view of the complex nature of the quality of dying and death, multi-item measures are likely to yield more meaningful information.

Despite the subjectivity of the quality of dying and death construct,[4] the majority of the measures reviewed did not allow for the evaluation or weighting of items based on patient preferences. There are known individual differences regarding such aspects of death and dying as the desirability of a death at home, a death surrounded by friends and family, or a death with open awareness and preparation.[46–48] While more research is needed to understand the factors that influence end-of-life preferences and experiences (i.e. the nature and stage of the disease, sociodemographic factors, religious and cultural background, individual psychology, and the social and health care context), meaningful quality of dying and death measures must allow for the recognized variability in preferences regarding the end-of-life experience.

A limitation of the currently available quality of dying and death outcome measures is their lack of demonstrated responsiveness to change. Thus far, only the QODD and one ad hoc measure have been used in anything other than cross-sectional and observational research. Of the 20 studies reviewed that provided a summary rating of the quality of dying and death, 19 studies, using 11 different measures, reported ratings in the intermediate to positive range. The one study that reported low summary scores used a quality-of-life measure to evaluate the quality of death, which may account for the discrepant findings.[21] The almost uniform intermediate to positive evaluations of the quality of dying and death are surprising, given that the fear of dying and death is a major source of distress for patients and families. It is unclear whether these reported positive ratings accurately reflect the quality of dying and death, or whether they reflect a measurement error or a retrospective positive bias of the raters. Quality-of-life research has demonstrated that proxies tend to experience and rate quality differently than patients.[49,50]

In several studies, there is the possibility of selection and response bias. In those that reported recruitment data, the proportion of family members approached who consented to these studies ranged from 27%[12] to 57%.[10] Respondents with positive experiences may have been more likely to agree to participate in such research studies. It is also possible that the rating of quality of dying and death is altered retrospectively due to the need of family or health care providers to perceive the end of life in positive terms. Also, many of the study subjects may have received better attention to symptom care or death preparation than is commonly available. Further research is required with well-developed and validated measures replicating the intermediate to positive evaluations that have been reported to date.

This review indicated that the QODD, used in nine of the 31 studies reviewed, is by far the most widely published and validated multi-item measure available. The authors provided an explicit operational definition of the quality of dying and the basis for measure development was broad. The QODD captures the important domains of the quality of dying and death, as well as individual end-of-life preferences. Responsiveness to change has been demonstrated for the QODD in one of two quasi-experimental studies. At present it is the best summary measure to assess the quality of death from any life-threatening illness, thus allowing future comparative research to examine, for instance, the influence of treatment setting and disease type on the dying and death experience.

To increase the interpretability of the QODD and other quality of dying and death measures, further research is required in order to understand the influences on the subjective evaluation of quality of dying and death, specifically, how individuals cognitively evaluate the quality of dying and death and how patient perspectives may differ from those of non-patients respondents. When a subjective evaluation of dying and death is elicited, it remains unclear how respondents make these judgments. The basis for judgment or the comparator used may significantly alter the evaluation provided, and this may pose a threat to the reliability and validity of the measures. For instance, quality ratings based on a comparison to a previously experienced painful or distressed death may be very different from ratings based on comparison to an ideal death experience. In the quality-of-life literature, the phenomenon of response shift has been explained by changing comparators. Calman[51] suggested that quality of life is determined by congruence between expectations and experience, with a smaller gap between the two leading to the perception of a better quality of life. Quality-of-life researchers have used cognitive interviewing to understand better the basis of these evaluations and thus increase the interpretability of quality-of-life measure scores.[52] Similar research with quality of dying and death measures may improve the interpretability of these measures and enhance our understanding of how dying and death is evaluated.

In quality-of-life research, the subjective nature of the construct is cited as a reason for the reliance on patient reports as the gold standard. In principle, this may also be true of the assessment of the quality of dying and death, although it may not be feasible to obtain such information directly from patients. Indeed, all of the studies reviewed relied on retrospective evaluations from non-patient respondents. The reliability and validity of this type of report continues to be questioned.[49,50] Family or health care provider reports may be subject to numerous influences, including their subjective state at the time of the event and at recall, their own individual experiences, the time from event to recall, motivation,[50] and the ability to take another's perspective into account. Respondents also may have difficulty rating aspects of the experience that are not easily observable, such as spiritual and existential experience, psychological experience, and life closure and death preparation. These factors may influence evaluations and explain the low to moderate inter-rater reliability reported with measures such as the QODD.[15,18]

Despite these potential limitations, retrospective reports from non-patient informants are methodologically necessary and clinically valuable. Patient participation in end-of-life research is problematic due to the difficulty of prospectively identifying patients in the dying phase and the challenges inherent in studying a subjective experience in individuals with progressive physical and cognitive impairment.[53,54] In order to provide meaningful data regarding the quality of their dying and death, patient subjects must have some awareness of terminality and a willingness to discuss death-related issues. Perhaps most importantly, it is the event of death that ultimately defines the preceding days and weeks as the dying phase. Many aspects of dying and death, particularly the circumstances of death and the adequacy of life closure and death preparation, may be best captured retrospectively, when there is distance and perspective on a complex and traumatic set of events.

Family members and health care providers are also a legitimate focus of end-of-life care research in their own right. Depending on the medical care setting, health care providers may spend the most time with patients near death and therefore have the most information about the end-of-life experience. Given their knowledge and experience, they may also be uniquely situated to judge whether a dying or death experience was as good as could have been expected. The perspectives of family members are also of clinical importance, given that they are co-recipients of palliative and end-of-life care, are decision makers when patients are incapable, and bear the burden of grief. Whether and how family and health care provider perspectives are distinguishable from those of patients remain unknown and an important avenue for further study.

We focused in this review on the conceptual and empirical basis, development, content and nature, and reliability and validity of measures of the quality of death and dying. Further research is needed to investigate further the intermediate to positive quality of dying and death evaluations that have been reported consistently to date and to consider the relative value of single-item versus multiple-item and general versus disease-specific measures. It should also be determined whether modifications are needed based on language and cultural context, and whether there is any benefit from alternate modes of administration. Research is also required to establish clinically meaningful benchmarks and to identify determinants of the quality of dying and death that will guide clinical care and policy development.

The increasing volume and rigor of published research on the quality of dying and death reflects its growing importance in health care. Of the measures developed to date, the QODD is the most widely studied and appears to be the best suited for use as a general summary measure, capturing the important domains of the quality of dying and death, as well as the individuality of end-of-life preferences. The ability to measure the quality of the dying and death experience with such instruments will allow more rigorous and comprehensive evaluation of end-of-life care that addresses the totality of the dying experience. Just as quality-of-life measures have transformed radically the development of disease treatments and interventions, so may measures of the quality of dying and death bring important empirical evidence to bear that can shape the evaluation of individual cases, clinical programs, and health policy related to end-of-life care.

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