

# Evaluation of the Quality of Dying and Death Questionnaire in Kenya

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**PURPOSE** A culturally appropriate, patient-centered measure of the quality of dying and death is needed to advance palliative care in Africa. We therefore evaluated the Quality of Dying and Death Questionnaire (QODD) in a Kenyan hospice sample and compared item ratings with those from a Canadian advanced-cancer sample.

**METHODS** Caregivers of deceased patients from three Kenyan hospices completed the QODD. Their QODD item ratings were compared with those from 602 caregivers of deceased patients with advanced cancer in Ontario, Canada, and were correlated with overall quality of dying and death ratings.

**RESULTS** Compared with the Ontario sample, outcomes in the Kenyan sample (N = 127; mean age, 48.21 years; standard deviation, 13.57 years) were worse on 14 QODD concerns and on overall quality of dying and death (*P* values ≤ .001) but better on five concerns, including interpersonal and religious/spiritual concerns (*P* values ≤ .005). Overall quality of dying was associated with better patient experiences with Symptoms and Personal Care, interpersonal, and religious/spiritual concerns (*P* values < .01). Preparation for Death, Treatment Preferences, and Moment of Death items showed the most omitted ratings.

**CONCLUSION** The quality of dying and death in Kenya is worse than in a setting with greater PC access, except in interpersonal and religious/spiritual domains. Cultural differences in perceptions of a good death and the acceptability of death-related discussions may affect ratings on the QODD. This measure requires revision and validation for use in African settings, but evidence from such patient-centered assessment tools can advance palliative care in this region.

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## INTRODUCTION

With increasing cancer morbidity and mortality worldwide, disparities in access to quality palliative care (PC) between high-income and low- and middle-income countries is a growing global concern.<sup>1-3</sup> Although PC access in Africa has increased in recent years,<sup>1,4,5</sup> these services still reach less than 5% of those in need.<sup>6-9</sup> This may account for the substantial symptom burden still observed in patients with cancer in Africa,<sup>6,10,11</sup> where cancer remains the second-leading cause of death.<sup>12</sup>

Collaborative grassroots advocacy in Africa, particularly in sub-Saharan African countries such as Kenya, has motivated PC research in this region.<sup>1,4,13,14</sup> However, the lack of culturally appropriate, patient-centered outcome measures validated for use in Africa has limited research rigor and limited ability of advocacy to improve PC services.<sup>4,15-20</sup> The Quality of Dying and Death Questionnaire (QODD)<sup>21,22</sup> is the most widely used, best-validated comprehensive measure

of the quality of patients' dying and death experiences.<sup>23</sup> It has been applied in end-of-life studies in North and South America and Europe,<sup>21,24-35</sup> but its utility in Africa has not been investigated. In our research using the QODD with patients with advanced cancer in Ontario, Canada, who had universal access to high-quality PC, most patients reported good quality of dying and death, although a substantial minority still experienced poor symptom control and concerns near the end of life.<sup>36,37</sup>

In the present pilot study, we administered the QODD to caregivers of deceased patients who had received PC services at hospices in Kenya. Our aim was to examine its utility with item-level evaluations, to gain initial insight into how its items work with Kenyan respondents. We investigated patterns of omitted QODD item ratings of patients' experiences; the relationship between occurrence of each item's concern and its rated experience; the differences between item ratings from Kenyan caregivers and those from caregivers of deceased patients with cancer in Ontario, Canada,<sup>38</sup>

## ASSOCIATED CONTENT

### Appendix

### Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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## CONTEXT

### Key Objective

How well can items of the Quality of Dying and Death Questionnaire (QODD) assess the quality of dying and death experiences of patients receiving palliative care in Kenya? Our pilot evaluation provides a first step toward addressing the current lack of culturally applicable outcome-assessment tools for use in African palliative care settings.

### Knowledge Generated

The QODD items may measure patients' experiences with symptom, interpersonal, and religious concerns relatively well. However, other QODD concerns relating to death-related preparations, treatment preferences, and moment-of-death experiences require revisions or replacement to enhance cultural relevance to African palliative care.

### Relevance

Validating a comprehensive patient-centered outcome-assessment tool like the QODD can generate valuable patient-centered data to help advocacy efforts target quality improvement of palliative care services in Kenya and throughout Africa to patients' specific needs.

hypothesizing that Kenyan caregivers would report poorer experiences than Ontario caregivers; and the relationships between item ratings and overall quality of dying and death.

## METHODS

### Participants

Caregivers of deceased patients who had received PC services at Kenya's Eldoret, Nairobi, or Nyeri hospices were recruited. Eldoret Hospice is based in Eldoret, Kenya's fifth-largest city, located in western Kenya. Nairobi Hospice opened in 1990 and was the first hospice established in eastern Africa. Nyeri Hospice, Kenya's first rural hospice, is located in central Kenya. All three offer outpatient and home-based PC services, including pain and symptom management, information, psychosocial or family support, and counseling. Inclusion criteria were caregivers, age 18 years or older, whose loved ones had received PC services at a participating Kenyan hospice and died within the preceding 2 to 12 months.

### Measures

Measures were translated into Kiswahili using standard forward- and back-translation process<sup>39</sup> as described in the Appendix. Because of possible limitations in literacy,<sup>40</sup> participants could complete measures using a faces-rating scale instead of a numeric-rating scale; the faces-rating scale has demonstrated validity with African respondents.<sup>41</sup> Caregivers provided personal demographic data and patient demographic and medical data. Patient data were also obtained from hospice chart reviews.

For this study, we focused on the QODD (Data Supplement). The 31-item, interviewer-administered QODD<sup>21,22</sup> assesses perceptions of the quality of patients' dying and death experiences with concerns across six domains: Symptoms and Personal Care, Preparation for Death, Moment of Death, Family, Treatment Preferences, and Whole Person Concerns.<sup>22</sup> We applied these domains only for descriptive purposes in this article, as they require

construct validation for African populations. Two additional items assess overall quality of dying and overall quality of the moment of death. The measure is administered to bereaved caregivers as proxy respondents who retrospectively rate patients' experiences in the last week of life (or last month of life if the patient was unresponsive during the last week) from 0 (terrible experience) to 10 (almost perfect experience). Higher scores indicate better quality of patient experiences. All QODD items include "don't know" and "no response" response options (Data Supplement).

Each item includes a question about the concern's occurrence (ie, whether the concern was experienced by the patient; Data Supplement). For items 1 to 16, respondents rate how frequently the concern occurred, from 0 (none of the time) to 5 (all of the time). For items 12, 13, and 16, frequency of occurrence is rated only if respondents indicate that the patient had a spouse/partner, children, or pet, respectively; if not, respondents skip to the next item. Items 17 to 28 and 30 ask whether the concern occurred or not (yes/no). Item 29 asks respondents to specify the location of patient death. Item 31 asks whether the patient was awake, asleep, or unconscious/in a coma just before death. For items 17 to 31, respondents skip to the next item if they indicate "don't know" or "no response" to the occurrence question.

### Procedure

The study received ethics approval from Moi Teaching and Referral Hospital's Institutional Research and Ethics Committee (#FAN: IREC 1700), Eldoret, Kenya, to launch at Eldoret and Nyeri Hospices; Nairobi Hospice Ethics and Standards Committee (no approval number assigned), Nairobi, Kenya, to launch at Nairobi Hospice; and University Health Network Research Ethics Board (#15-5080-BE), Toronto, Ontario, Canada. Eligible caregivers were approached by the local study coordinator and given information about the study. Those who agreed to participate provided informed consent either in writing or, if literacy

was insufficient, with their thumbprint on the consent form. Caregivers received \$5 or \$15 (US\$) compensation for travel costs, depending on distance traveled. A research assistant verbally administered the measures in English, Kiswahili, or both, as participants preferred. Measures required 45 to 90 minutes to complete.

### Statistical Analyses

Caregiver and patient characteristics were summarized using descriptive statistics. For item-level evaluations, we examined omitted ratings across QODD items and their reasons (don't know/not applicable/no response/skipped), using descriptive analyses. To establish the meaning of item ratings on the basis of the occurrence of concerns, we examined the relationships between an item's rating and frequency of the concern's occurrence, using Spearman rho correlations (items 1 to 16); the concern's occurrence/nonoccurrence, using independent-samples *t* test (items 17 to 28, 30); or the different categories of the concern, using one-way analysis of variance and post hoc pairwise comparisons with the Tukey test (items 29, 31). Independent-sample *t* tests were used to compare cross-culturally the QODD item ratings from the Kenyan caregivers to those from 602 caregivers of deceased patients with advanced cancer, recruited mostly from hospitals in Toronto, Ontario, Canada, in a study of the quality of dying and death.<sup>38</sup> Finally, we examined the relationships between QODD item ratings and overall quality of dying and death ratings using Spearman rho correlations ( $r_s$ ). Alpha level across analyses was set to .01 to control for chance significance.

## RESULTS

### Sample Characteristics

Of 129 consenting caregivers, 127 provided data, and Tables 1 and 2 list the characteristics of the 127 caregivers and deceased patients. The majority were recruited through Nyeri Hospice (55%). More caregivers and patients were women (54% to 67%) than men. Many

caregivers were children of the patients (41%); on average, caregivers were 48 years of age, and patients were 61 years. The majority were of Kikuyu ethnicity (67% to 68%). Almost all patients had a cancer diagnosis (97%), and mean time between diagnosis and death was 1.5 years. Mean duration of hospice care was approximately 7 months.

### Patterns of QODD Omitted Ratings

Table 3 shows that 14 QODD items had substantial numbers of omitted ratings, defined as more than 10% omitted ratings. Because only five participants provided ratings for all items, internal consistency could not be evaluated.

Of these 14 items, 12.6% to 42.5% of caregivers responded with "don't know" to the following 10 concerns, as well as to overall quality of death (item 33):

- Preparation for Death items 6 to 7, 19, 21, 23, and 26 to 27 (peace with dying, unafraid of dying, attend events, say good-bye, spiritual service, clear up bad feelings with others, funeral arrangements)
- Treatment Preferences items 24 and 28 (medical prolongation of life, discuss end-of-life care with doctor)
- Moment of Death item 30 (anyone present).

Furthermore, 13.4% to 33.9% skipped the following three items because of "don't know" responses to concern-occurrence questions:

- Treatment Preferences item 28 (discuss end-of-life care with doctor)
- Moment of Death item 31 (state of consciousness)
- Preparation for Death item 26 (clear up bad feelings).

Two Family items were skipped because patients did not have a spouse/partner (item 12: 33.9%) or a pet (item 16: 70.9%). The latter had the most omitted ratings; Treatment Preferences item 28 (discuss end-of-life care with doctor) had the second-most omitted ratings.

Nine items showed fewer than two omitted ratings:

**TABLE 1.** Kenyan Caregiver and Patient Mean Demographic and Medical Characteristics (N = 127)

Characteristic	Caregiver		Patient	
	Mean (SD)	Range	Mean (SD)	Range
Age, years	48.21 (13.57)	23-102	61.21 (15.52)	17-105
Age at diagnosis, years	—	—	59.34 (15.82)	15-102
Monthly household income, KSH	22,982.11 (49,975.79)	0-400,000	—	—
Time between diagnosis and death, years	—	—	1.50 (1.76)	0-14
Duration of receipt of hospice services, days	—	—	213.18 (394.36)	1-3,656
No. of hospice visits	—	—	4.16 (3.42)	1-17
No. of medications	—	—	4.92 (2.65)	1-17

NOTE. Because of substantial numbers of incomplete dates, patients' ages, ages at diagnosis, and times between diagnosis and death were calculated using years of dates only.

Abbreviations: KSH, Kenyan shilling; SD, standard deviation.

**TABLE 2.** Frequencies of Kenyan Caregiver and Patient Demographic and Medical Characteristics (N = 127)

Characteristic	Caregiver	Patient
Hospice recruitment site		
Eldoret	15 (11.8)	—
Nairobi	42 (33.1)	—
Nyeri	70 (55.1)	—
Hospice referral		
Health care professional	68 (53.5)	—
Self-referral	37 (29.1)	—
Relative	3 (2.4)	—
Friend	9 (7.1)	—
Other	4 (3.2)	—
Missing	6 (4.7)	—
Sex		
Female	85 (66.9)	68 (53.5)
Male	41 (32.3)	58 (45.7)
Missing	1 (0.8)	1 (0.8)
Marital status		
Married/common law	59 (46.5)	77 (60.6)
Single	14 (11.0)	21 (16.5)
Widowed	45 (35.4)	22 (17.3)
Separated/divorced	8 (6.3)	5 (3.9)
Missing	1 (0.8)	2 (1.6)
Ethnicity		
Kalenjin	9 (7.1)	11 (8.7)
Kamba	3 (2.4)	4 (3.1)
Kikuyu	86 (67.7)	85 (66.9)
Kisii	3 (2.4)	3 (2.4)
Luhya	11 (8.7)	10 (7.9)
Luo	8 (6.3)	7 (5.5)
Meru	3 (2.4)	4 (3.1)
Other	4 (3.1)	2 (1.6)
Missing	0 (0.0)	1 (0.8)
Language		
Dholuo	7 (5.5)	7 (5.5)
English	2 (1.6)	2 (1.6)
Kalenjin	10 (7.9)	11 (8.7)
Kamba	3 (2.4)	2 (1.6)
Kikuyu	85 (66.9)	83 (65.4)
Kisii	2 (1.6)	3 (2.4)
Kiswahili	3 (2.4)	1 (0.8)
Luhya	11 (8.7)	10 (7.9)
Meru	3 (2.4)	4 (3.1)
Other	1 (0.8)	1 (0.8)
Missing	0 (0.0)	3 (2.4)

(Continued on following page)

- Three Symptoms and Personal Care items 1 to 4 and 9 (pain controlled, control, feed self, control over bladder/bowels, have energy)
- Four items reflecting interpersonal and religious/spiritual concerns:
  - Family items 14 and 15 (spend time with family/friends, spend time alone)
  - Whole Person Concerns item 18 (hugged by loved ones)
  - Preparation for Death item 22 (visits from religious/spiritual advisor).

### Relationships Between Occurrence of QODD Concerns and QODD Ratings

Table 4 shows that concerns that occurred, or occurred more frequently, were mostly correlated with better quality of patient experiences with concerns ( $P$  values  $\leq .002$ ):  $r_s$  values were positive and significant (items 1 to 16), or mean scores in the Yes column were significantly larger than those in the No column (items 17 to 31). Exceptions included Preparation for Death item 10 (worry about strain on loved ones:  $r_s = -0.54$ ) and Family item 15 (spend time alone:  $r_s = -0.60$ ): negative  $r_s$  values indicated that more frequent occurrence of these interpersonal concerns was linked with worse experiences. Lower Yes than No ratings, indicating worse quality of experiences with concern occurrence, were also observed for:

- Medical prolongation of life (Treatment Preference item 24)
- Having died at home or other location, compared with in hospital or hospice (Moment of Death item 29)
- Being unconscious before death, compared with being awake or asleep (Moment of Death item 31).

All 109 respondents to Treatment Preferences item 25 (means to end life) indicated that the concern did not occur.

### Cross-Cultural Comparison of Kenyan and Ontario Caregivers' QODD Ratings

Table 5 indicates that Kenyan caregivers reported significantly worse ratings than Ontario caregivers on the following 14 items, as well as on overall quality of dying and death (items 32 and 33;  $P$  values  $\leq .001$ ):

- Family item 16 (spend time with pets)
- Moment of Death items 29 to 31 (location, anyone present, state of consciousness)
- Preparation for Death items 10 and 19 to 21 (strain on loved ones, attend events, health costs taken care of, say good-bye)
- Symptoms and Personal Care items 1 to 3 (pain controlled, control, feed self)
- Treatment Preferences items 24 and 28 (medical prolongation of life, discuss end-of-life care with doctor)
- Whole Person Concerns item 8 (laugh/smile).

As evident in Figure 1, Kenyan caregivers rated overall quality of dying and death (items 32 and 33) as terrible to

**TABLE 2.** Frequencies of Kenyan Caregiver and Patient Demographic and Medical Characteristics (N = 127) (Continued)

Characteristic	Caregiver	Patient
<b>Education</b>		
No schooling	3 (2.4)	0 (0.0)
Primary (not completed)	19 (15.0)	37 (29.1)
Primary (completed)	26 (20.5)	23 (18.1)
Secondary (not completed)	19 (15.0)	8 (6.3)
Secondary (completed)	34 (26.8)	18 (14.2)
Postsecondary/undergraduate	23 (18.1)	10 (7.9)
Professional school/postgraduate	1 (0.8)	0 (0.0)
Missing	2 (1.6)	31 (24.4)
<b>Religion</b>		
Christian	123 (96.9)	124 (97.6)
Muslim	1 (0.8)	1 (0.8)
Missing	3 (2.4)	2 (1.6)
<b>Caregiver relationship to patient</b>		
Spouse/common-law partner	47 (37.0)	—
Sibling	13 (10.2)	—
Child	52 (40.9)	—
Parent	2 (1.6)	—
Other family	6 (4.7)	—
Friend	1 (0.8)	—
Missing	6 (4.7)	—
<b>Diagnosis</b>		
Breast cancer	—	13 (10.2)
GI cancer	—	62 (48.8)
Genitourinary cancer	—	14 (11.0)
Gynecologic cancer	—	16 (12.6)
Hematologic cancer	—	4 (3.1)
Lung cancer	—	2 (1.6)
Oral cancer	—	5 (3.9)
Sarcoma cancer	—	2 (1.6)
Skin cancer/melanoma	—	3 (2.4)
Other cancer	—	2 (1.6)
Other disease	—	4 (3.1)
<b>Pain medication received (WHO classification levels)</b>		
No pain medication	—	17 (13.4)
Nonopioids	—	6 (4.7)
Weak opioids	—	32 (25.2)
Strong opioids	—	48 (37.8)
Both opioids	—	24 (18.9)
<b>Place of death</b>		
Home	—	55 (43.3)
Hospital	—	66 (52.0)
Hospice	—	2 (1.6)
On way to hospital	—	4 (3.1)

NOTE. Data presented as No. (%).

poor 2.16 to 3.61 times more frequently than Ontario caregivers. Ontario caregivers rated them as good to almost perfect 2.36 to 3.75 times more frequently than Kenyan caregivers.

Kenyan caregivers demonstrated better ratings of patient experiences on the following five items that included interpersonal and religious/spiritual concerns ( $P$  values  $\leq .005$ ):

- Family item 14 (spend time with family/friends)
- Preparation for Death items 22 and 26 (visits from religious/spiritual advisor, clear up bad feelings with others)
- Treatment Preferences item 25 (means to end life)
- Whole Person Concerns item 11 (dignity/self-respect).

The caregiver groups did not differ on quality ratings of the following 12 concerns ( $P$  values  $\geq .01$ ):

- Family items 12, 13, and 15 (spend time with spouse/partner, spend time with children, spend time alone)
- Preparation for Death items 6, 7, 23, and 27 (peace with dying, unafraid of dying, spiritual service, funeral arrangements)
- Symptoms and Personal Care items 4, 5, and 9 (control over bladder/bowels, breathe comfortably, have energy)
- Whole Person Concerns items 17 and 18 (find meaning/purpose, hugged by loved ones).

The patterns of findings remained the same when controlling for caregiver age (mean ages [SD]: Kenyan caregivers = 48.21 [13.57] years; Ontario caregivers = 57.75 [13.04] years;  $P < .001$ ).

### Relationships Between QODD Ratings and Overall Quality of Dying and Death

Table 6 indicates that quality of dying was significantly and positively correlated with better patient experiences on the following 11 items ( $r_s = 0.30$  to  $0.57$ ;  $P$  values  $< .01$ ):

- All six Symptoms and Personal Care concerns items 1 to 5 and 9 (pain controlled, control, feed self, control over bladder/bowels, breathe comfortably, have energy)
- Five items that include interpersonal and religious/spiritual concerns:
  - Preparation for Death items 10, 19, and 22 (strain on loved ones, attend important events, visits from religious/spiritual advisor)
  - Whole Person Concerns items 8 (laugh/smile)
  - Treatment Preferences item 25 (means to end life).

However, significant negative correlations suggest that Preparation for Death item 22 (visits from religious/spiritual advisor:  $r_s = -0.41$ ;  $P < .001$ ) and Treatment Preferences item 25 (means to end life:  $r_s = -0.30$ ;  $P = .002$ ) were related to worse quality of dying. Better quality of moment of death was significantly correlated with better patient experiences with Treatment Preferences item 24 (medical prolongation of life:  $r_s = 0.38$ ;  $P = .001$ ) and Moment of Death items 29 and 31 (location:  $r_s = 0.34$ ;  $P = 0.002$ ; state of consciousness:  $r_s = 0.50$ ;  $P < .001$ ).

**TABLE 3.** Omitted Ratings Across QODD Items

QODD Item No.	QODD Item	QODD Domain	Do Not Know	Not Relevant	No Response	Reasons for Omitted Ratings, No. (%)		Total
						Skipped Rating Question*	Reason for Skip	
16	Spend time with pets	F	2 (1.6)	—	—	90 (70.9)	90: no pets	92 (72.4)
28	Discuss end-of-life care with doctor	TP	54 (42.5)	—	2 (1.6)	24 (18.9)	24: do not know	80 (63.0)
31	State of consciousness in moment before death	MD	10 (7.9)	1 (0.8)	—	42 (33.1)	42: do not know	53 (41.7)
12	Spend time with spouse/partner	F	—	4 (3.1)	—	43 (33.9)	43: no spouse/ partner	47 (37.0)
26	Clear up bad feelings with others	PD	23 (18.1)	1 (0.8)	1 (0.8)	16 (12.6)	15: do not know 1: no response	41 (32.3)
27	Have funeral arrangements in order	PD	35 (27.6)	1 (0.8)	2 (1.6)	—	—	38 (29.9)
30	Anyone present at moment of death	MD	17 (13.4)	2 (1.6)	1 (0.8)	10 (7.9)	10: do not know	30 (23.6)
6	Feel at peace with dying	PD	26 (20.5)	—	1 (0.8)	—	—	27 (21.3)
24	Mechanical ventilator or kidney dialysis to prolong life	TP	22 (17.3)	—	1 (0.8)	—	—	23 (18.1)
21	Say good-bye to loved ones	PD	19 (15.0)	—	1 (0.8)	2 (1.6)	2: do not know	22 (17.3)
23	Have a spiritual service or ceremony	PD	22 (17.3)	—	—	—	—	22 (17.3)
7	Unafraid of dying	PD	17 (13.4)	1 (0.8)	2 (1.6)	—	—	20 (15.7)
19	Attend important events	PD	16 (12.6)	—	4 (3.1)	—	—	20 (15.7)
25	Have means to end life	TP	8 (6.3)	1 (0.8)	—	9 (7.1)	8: do not know 1: no response	18 (14.2)
17	Find meaning and purpose in life	WPC	—	—	—	11 (8.7)	10: do not know 1: not relevant	11 (8.7)
10	Worried about strain on loved ones	PD	7 (5.5)	1 (0.8)	—	—	—	8 (6.3)
11	Keep dignity and self-respect	WPC	2 (1.6)	2 (1.6)	1 (0.8)	—	—	5 (3.9)
13	Spend time with children	F	—	—	—	5 (3.9)	5: no children	5 (3.9)
20	Health care costs taken care of	PD	4 (3.1)	1 (0.8)	—	—	—	5 (3.9)
29	Location of death	MD	1 (0.8)	2 (1.6)	1 (0.8)	—	—	4 (3.1)
5	Breathe comfortably	SPC	—	1 (0.8)	2 (1.6)	—	—	3 (2.4)
8	Laugh and smile	WPC	1 (0.8)	—	1 (0.8)	—	—	2 (1.6)
1	Have pain under control	SPC	—	—	1 (0.8)	—	—	1 (0.8)
2	Have control over what was going on	SPC	1 (0.8)	—	—	—	—	1 (0.8)
3	Able to feed self	SPC	—	—	1 (0.8)	—	—	1 (0.8)
4	Have control over bladder/bowels	SPC	—	—	1 (0.8)	—	—	1 (0.8)
14	Spend time with other family and friends	F	—	1 (0.8)	—	—	—	1 (0.8)
15	Spend time alone	F	—	1 (0.8)	—	—	—	1 (0.8)

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**TABLE 3.** Omitted Ratings Across QODD Items (Continued)

QODD Item No.	QODD Item	QODD Domain	Do Not Know	Not Relevant	No Response	Reasons for Omitted Ratings, No. (%)	
						Skipped Rating Question*	Reason for Skip
18	Hugged by loved ones	WPC	1 (0.8)	—	—	—	1 (0.8)
22	Have visits from religious or spiritual advisor	PD	1 (0.8)	—	—	—	1 (0.8)
9	Have energy to do most things	SPC	—	—	—	—	0 (0.0)
32	Overall quality of dying	—	4 (3.1)	1 (0.8)	—	—	5 (3.9)
33	Overall quality of moment of death	—	39 (30.7)	1 (0.8)	2 (1.6)	—	42 (33.1)

NOTE. Items are ordered by total number of omitted ratings, followed by QODD item number.

Abbreviations: F, Family; MD, Moment of Death; PD, Preparation for Death; QODD, Quality of Dying and Death Questionnaire; SPC, Symptoms and Personal Care; TP, Treatment Preferences; WPC, Whole Person Concerns.

\*Indicates the number of caregivers who skipped the rating question for items 12 and 13 and 16 to 31 because of a negative or nonresponse to the preceding occurrence question, as indicated in the Reason for Skip column.

**TABLE 4.** Associations Between Occurrence of QODD Item Concerns and QODD Item Ratings

QODD Item No.	QODD Item	QODD Domain	$r_s$ [n]	Concern Occurred? Mean (SD) [n]		<i>P</i>
				Yes	No	
1	Have pain under control	SPC	.58 [126]	—	—	< .001
2	Have control over what was going on	SPC	.77 [126]	—	—	< .001
3	Able to feed self	SPC	.84 [126]	—	—	< .001
4	Have control over bladder/bowels	SPC	.88 [126]	—	—	< .001
5	Breathe comfortably	SPC	.79 [124]	—	—	< .001
6	Feel at peace with dying	PD	.53 [100]	—	—	< .001
7	Unafraid of dying	PD	.30 [107]	—	—	.002
8	Laugh and smile	WPC	.82 [125]	—	—	< .001
9	Have energy to do most things	SPC	.68 [127]	—	—	< .001
10	Worried about strain on loved ones	PD	-.54 [119]	—	—	< .001
11	Keep dignity and self-respect	WPC	.67 [122]	—	—	< .001
12	Spend time with spouse/partner	F	.65 [80]	—	—	< .001
13	Spend time with children	F	.46 [122]	—	—	< .001
14	Spend time with other family and friends	F	.63 [126]	—	—	< .001
15	Spend time alone	F	-.60 [126]	—	—	< .001
16	Spend time with pets	F	.66 [35]	—	—	< .001
17	Find meaning and purpose in life	WPC	—	9.06 (1.63) [78]	0.87 (2.15) [38]	< .001
18	Hugged by loved ones	WPC	—	8.99 (1.81) [117]	1.56 (3.32) [9]	< .001
19	Attend important events	PD	—	9.80 (0.45) [5]	0.76 (1.98) [101]	< .001
20	Health care costs taken care of	PD	—	8.98 (1.98) [93]	2.10 (3.10) [29]	< .001
21	Say good-bye to loved ones	PD	—	7.41 (3.94) [41]	3.55 (4.00) [64]	< .001
22	Have visits from religious or spiritual advisor	PD	—	9.52 (1.22) [116]	2.90 (3.48) [10]	< .001
23	Have a spiritual service or ceremony	PD	—	9.66 (0.76) [64]	2.12 (2.94) [41]	< .001
24	Mechanical ventilator or kidney dialysis to prolong life	TP	—	2.34 (3.39) [35]	7.81 (3.40) [69]	< .001
25	Have means to end life	TP	—	— [0]	9.30 (1.71) [109]	—
26	Clear up bad feelings with others	PD	—	9.65 (0.90) [66]	4.60 (4.01) [20]	< .001
27	Have funeral arrangements in order	PD	—	9.18 (1.47) [17]	6.13 (3.70) [72]	< .001
28	Discuss end-of-life care with doctor	TP	—	2.50 (3.54) [2]	5.20 (3.94) [45]	.346
29*	Location of death	MD	—	Patient's home: 3.43 (4.06) [49] <sup>a</sup> (hospital: <i>P</i> < .001; hospice: <i>P</i> = .047)		< .001
				Surrogate home: 4.00 (5.66) [2] <sup>ab</sup>		
				Other home: 0.00 (—) [1]		
				Hospital: 8.74 (2.30) [62] <sup>b</sup>		
				Inpatient hospice: 10.00 (0.00) [2] <sup>b</sup>		
				Other: 2.50 (4.18) [6] <sup>a</sup> (hospital: <i>P</i> < .001; hospice: <i>P</i> = .044)		
30	Anyone present at moment of death	MD	—	5.82 (4.27) [68]	6.21 (3.87) [29]	.678
31†	State of consciousness in moment before death	MD	—	Awake: 5.40 (4.61) [25] <sup>a</sup> ( <i>P</i> = .034)		.001
				Asleep: 7.00 (3.35) [36] <sup>a</sup> ( <i>P</i> = .001)		
				Unconscious: 2.00 (3.85) [13] <sup>b</sup>		

NOTE. Correlations (items 1 to 16) or group differences in mean item ratings (items 17 to 31) are considered significant where *P* < .01.

Abbreviations: F, Family; MD, Moment of Death; PD, Preparation for Death; QODD, Quality of Dying and Death Questionnaire;  $r_s$ , Spearman rho; SPC, Symptoms and Personal Care; TP, Treatment Preferences; WPC, Whole Person Concerns.

\*Item 29: analyses excluded the single participant indicating "other home." Different superscript letters indicate significantly different scores between subgroups; for "patient's home" and "other," the locations with which each significantly differed are superscripted and in parentheses, along with corresponding *P* values.

†Item 31, Different superscript letters indicate significantly different scores between subgroups, with *P* values superscripted and in parentheses.



**TABLE 5.** Comparison of QODD Item Ratings Between Kenyan (N = 127) and Ontario (N = 602) Caregivers

QODD Item No.	QODD Item	QODD Domain	Mean (SD) [n]		95% CI of Mean	Group Difference	Group Difference	P
			Ontario (N = 602)	Kenya (N = 127)				
16	Spend time with pets	F	5.65 (3.23) [218]	2.49 (3.11) [35]	2.01 to 4.32	O > K	< .001	
29	Location of death	MD	8.22 (2.71) [595]	6.15 (4.23) [123]	1.29 to 2.86	O > K	< .001	
30	Anyone present at moment of death	MD	8.39 (2.68) [579]	5.94 (4.14) [97]	1.59 to 3.31	O > K	< .001	
31	State of consciousness in moment before death	MD	7.38 (3.00) [541]	5.58 (4.25) [74]	0.79 to 2.82	O > K	.001	
10	Worried about strain on loved ones	PD	4.55 (3.10) [582]	3.23 (4.03) [119]	0.55 to 2.10	O > K	.001	
19	Attend important events	PD	5.06 (2.86) [597]	1.19 (2.73) [106]	3.29 to 4.46	O > K	< .001	
20	Health care costs taken care of	PD	8.55 (2.23) [598]	7.34 (3.72) [122]	0.52 to 1.90	O > K	.001	
21	Say good-bye to loved ones	PD	6.58 (3.33) [570]	5.06 (4.39) [105]	0.63 to 2.41	O > K	.001	
1	Have pain under control	SPC	6.15 (3.15) [598]	3.11 (3.99) [126]	2.30 to 3.79	O > K	< .001	
2	Have control over what was going on	SPC	5.26 (3.19) [595]	2.87 (4.01) [126]	1.64 to 3.14	O > K	< .001	
3	Able to feed self	SPC	4.79 (3.27) [594]	2.66 (4.00) [126]	1.38 to 2.88	O > K	< .001	
24	Mechanical ventilator or kidney dialysis to prolong life	TP	8.09 (2.51) [587]	5.97 (4.26) [104]	1.26 to 2.97	O > K	< .001	
28	Discuss end-of-life care with doctor	TP	7.81 (2.61) [572]	5.09 (3.92) [47]	1.56 to 3.90	O > K	< .001	
8	Laugh and smile	WPC	5.77 (3.13) [599]	3.92 (4.07) [125]	1.09 to 2.61	O > K	< .001	
12	Spend time with spouse/partner	F	8.42 (2.15) [429]	7.62 (3.71) [81]	-0.05 to 1.64	O = K	.063	
13	Spend time with children	F	7.99 (2.30) [493]	8.27 (2.87) [122]	-0.83 to 0.28	O = K	.326	
15	Spend time alone	F	7.03 (2.67) [594]	7.25 (3.52) [126]	-0.88 to 0.43	O = K	.503	
6	Feel at peace with dying	PD	5.96 (3.27) [546]	6.04 (4.16) [100]	-0.95 to 0.79	O = K	.849	
7	Unafraid of dying	PD	6.51 (3.16) [549]	6.64 (3.87) [107]	-0.91 to 0.66	O = K	.748	
23	Have a spiritual service or ceremony	PD	7.09 (2.58) [588]	6.71 (4.16) [105]	-0.46 to 1.20	O = K	.379	
27	Have funeral arrangements in order	PD	7.60 (2.59) [595]	6.71 (3.59) [89]	0.10 to 1.67	O = K	.027	
4	Have control over bladder/bowels	SPC	4.21 (3.44) [596]	3.32 (4.20) [126]	0.11 to 1.69	O = K	.026	
5	Breathe comfortably	SPC	5.98 (3.19) [602]	5.56 (4.27) [124]	-0.38 to 1.22	O = K	.302	
9	Have energy to do most things	SPC	2.44 (2.56) [600]	1.69 (3.22) [127]	0.14 to 1.35	O = K	.016	
17	Find meaning and purpose in life	WPC	6.89 (3.10)[538]	6.37 (4.25) [117]	-0.29 to 1.35	O = K	.206	
18	Hugged by loved ones	WPC	8.86 (1.68) [599]	8.46 (2.73) [126]	-0.10 to 0.89	O = K	.120	
14	Spend time with other family and friends	F	7.50 (2.24) [601]	8.13 (2.73) [126]	-1.08 to -0.19	O < K	.005	
22	Have visits from religious or spiritual advisor	PD	7.32 (2.52) [589]	8.99 (2.34) [126]	-2.13 to -1.21	O < K	< .001	
26	Clear up bad feelings with others	PD	6.91 (2.83) [569]	8.48 (2.97) [86]	-2.25 to -0.89	O < K	< .001	
25	Have means to end life	TP	6.49 (2.81) [557]	9.30 (1.71) [109]	-3.21 to -2.41	O < K	< .001	

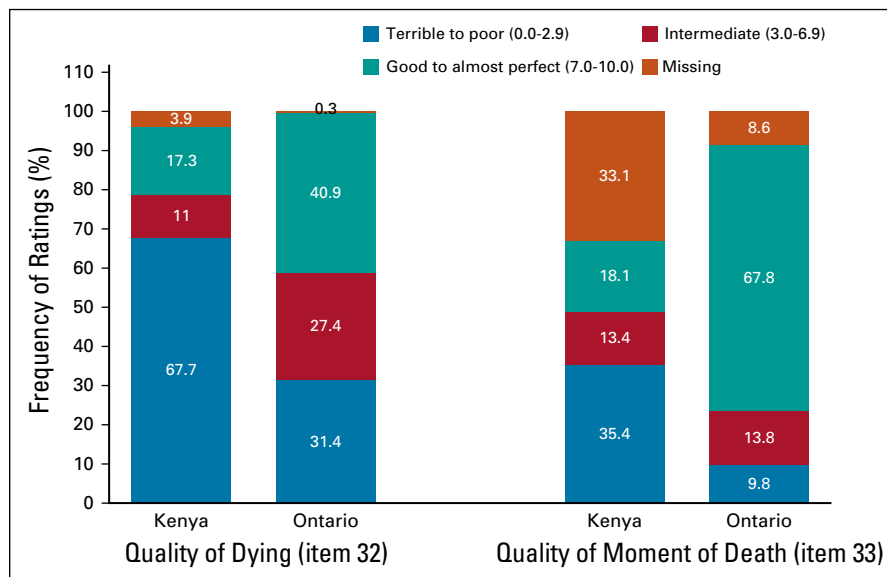
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**TABLE 5.** Comparison of QODD Item Ratings Between Kenyan (N = 127) and Ontario (N = 602) Caregivers (Continued)

QODD Item No.	QODD Item	Mean (SD) [n]		95% CI of Mean Group Difference	Group Difference	P
		Ontario (N = 602)	Kenya (N = 127)			
11	Keep dignity and self-respect	7.31 (2.96) [598]	8.20 (2.97) [122]	-1.47 to -0.31	O < K	.003
32	Overall quality of dying	4.83 (3.37) [600]	2.30 (3.46) [122]	1.88 to 3.20	O > K	< .001
33	Overall quality of moment of death	7.40 (2.95) [550]	3.60 (3.99) [85]	2.90 to 4.69	O > K	< .001

NOTE. Items are ordered by direction of group difference, followed by QODD domain, and then by QODD item number. Group differences are considered significant where  $P < .01$ . Abbreviations: F, Family; K, Kenya; MD, Moment of Death; K, Kenya; O, Ontario; PD, Preparation for Death; QODD, Quality of Dying and Death Questionnaire; SD, standard deviation; SPC, Symptoms and Personal Care; TP, Treatment Preferences; WPC, Whole Person Concerns.

**FIG 1.** Comparison of percentage frequencies of overall quality of dying and death ratings between Kenyan and Ontario caregivers.



## DISCUSSION

This study provides valuable preliminary data on the use of the QODD to measure quality of dying and death in Kenyan hospices. Compared with their Canadian counterparts, Kenyan caregivers reported worse quality of patient experiences with symptoms and personal care, death-related preparations, treatment preferences, and moment of death and with overall quality of dying and death but better experiences on some interpersonal, religious, and whole-person concerns. However, some QODD items require revision to increase their relevance and applicability in Kenya.

Symptoms and Personal Care items performed most coherently and had the fewest omitted responses, perhaps because these features are universal in advanced disease and more easily observed by caregivers. These items seem to be relevant in Kenya and merit additional validation. Kenyan caregivers rated patients' pain control worse than Ontario caregivers, consistent with the lesser availability of PC in Kenya and with evidence that poorly controlled end-of-life pain is common in Africa.<sup>1,6-9</sup> Better patient experiences across Symptoms and Personal Care concerns were associated with better dying experiences. All of these findings highlight the centrality of pain and symptom management to PC<sup>42</sup> in supporting quality of life near the end of life.<sup>43,44</sup>

Concerns involving significant others or religious/spiritual support exhibited some consistent attributes. Better patient experiences with most were associated with their greater occurrence, but better patient experiences with worrying about strain on loved ones and spending time alone were linked with their lower occurrence. Compared with Ontario caregivers, Kenyan caregivers reported the same or better patient experiences on interpersonal (eg, spending time

with others) and religious/spiritual concerns (eg, visits from spiritual/religious advisor). These concerns were also related to the dying experience. However, the negative relationship observed between positive experiences concerning visits from a religious/spiritual advisor and poorer quality of dying is unexpected, given the importance of religious support near the end of life in Africa.<sup>45-48</sup> This paradoxical finding may have occurred because patients with worse dying experiences were more likely to see a religious advisor for comfort. Collectively, however, these findings correspond with the value placed in African culture on social interconnectedness, community, and familial support to seriously ill individuals,<sup>6,11,45,49,50</sup> as well as on religious support.<sup>45-48</sup>

Many patients did not have spouses/partners or pets, with ratings to the latter being the most often omitted. Our Canadian study<sup>38</sup> and a Chilean QODD study<sup>34</sup> excluded both Family items and "spend time with children" because of nonrelevance to many patients. Reducing the specificity of these and other items—for example, replacing the spouse/partner and children items with a single "family" item—may make them more universally applicable.

Preparation for Death, Treatment Preferences, and Moment of Death items demonstrated the most omitted ratings, suggesting that their utility is limited within the Kenyan PC setting. The extent to which the Kenyan caregivers understood these concepts or considered them relevant or appropriate to discuss is uncertain. End-of-life care discussions with doctors (which had the second most omitted ratings), funeral arrangements, and medical prolongation of life exhibited many "don't know" responses. This may be because death-related discussions are uncommon in Africa<sup>6,45,51-53</sup> because of fears that they will hasten death,<sup>1,45,52,53</sup> because patients or families prefer not to discuss care at the end of life,<sup>50</sup> or because such

**TABLE 6.** Spearman Rho Correlations Between QODD Item Ratings and Overall Quality of Dying and Death

QODD Item No.	QODD Item	QODD Domain	Quality of Dying in Last Week of Life	Quality of Moment of Death
1	Have pain under control	SPC	<b>.57*</b>	.14
2	Have control over what was going on	SPC	<b>.49*</b>	-.13
3	Able to feed self	SPC	<b>.39*</b>	-.01
4	Have control over bladder/bowels	SPC	<b>.40*</b>	.02
5	Breathe comfortably	SPC	<b>.31†</b>	.12
6	Feel at peace with dying	PD	.08	.04
7	Unafraid of dying	PD	.25‡	.11
8	Laugh and smile	WPC	<b>.45*</b>	.03
9	Have energy to do most things	SPC	<b>.37*</b>	.03
10	Worried about strain on loved ones	PD	<b>.38*</b>	.09
11	Keep dignity and self-respect	WPC	-.04	.23‡
12	Spend time with spouse/partner	F	-.11	.30‡
13	Spend time with children	F	-.17	.11
14	Spend time with other family and friends	F	-.19‡	.18
15	Spend time alone	F	.01	.14
16	Spend time with pets	F	.37‡	.23
17	Find meaning and purpose in life	WPC	.01	.11
18	Hugged by loved ones	WPC	-.04	.21
19	Attend important events	PD	<b>.31†</b>	.05
20	Health care costs taken care of	PD	.06	.03
21	Say good-bye to loved ones	PD	.04	.13
22	Have visits from religious or spiritual advisor	PD	<b>-.41*</b>	.10
23	Have a spiritual service or ceremony	PD	-.12	-.05
24	Mechanical ventilator or kidney dialysis to prolong life	TP	.18	<b>.38†</b>
25	Have means to end life	TP	<b>-.30†</b>	.09
26	Clear up bad feelings	PD	-.20	.17
27	Have funeral arrangements in order	PD	-.17	.13
28	Discuss end-of-life care with doctor	TP	.04	.09
29	Location of death	MD	-.02	<b>.34†</b>
30	Anyone present at moment of death	MD	.16	.24‡
31	State of consciousness in moment before death	MD	.06	<b>.50*</b>

NOTE. Spearman rho correlations are considered significant where  $P < .01$  (in bold).

Abbreviations: F, Family; MD, Moment of Death; PD, Preparation for Death; QODD, Quality of Dying and Death Questionnaire; SPC, Symptoms and Personal Care; TP, Treatment Preferences; WPC, Whole Person Concerns.

\* $P < .001$ .

†.01 >  $P \geq .001$ .

‡.05 >  $P \geq .01$ .

discussions are uncommon in medical practice in Kenya.<sup>45,51,53</sup> QODD items relating to treatment and preparations near the end of life may require revision or may need to be replaced by items with greater relevance and cultural utility in Africa.

The study has limitations. Because we recruited caregivers from Kenyan hospices, the generalizability of our findings to other PC settings in Kenya, to other African countries, or to patients not receiving PC is unknown. Virtually all

participants were Christian, and the majority identified as Kikuyu, the largest ethnic group in Kenya, limiting generalizability to other groups. Caregivers' retrospective reports offer the most feasible approach to assess the quality of dying and death, but memory, emotions, and other person-related factors may bias their reports.<sup>54</sup> Study strengths include the large Kenyan sample and the comparison with a large Canadian sample. To our knowledge, our pilot is the first to evaluate the QODD in an African setting and raises

questions about cross-cultural validation that require additional investigation.

Cultural disparities in what is regarded as a good death<sup>3,55</sup> can affect responses and limit cross-cultural comparisons.<sup>56</sup> Numerous omitted ratings from the Kenyan caregivers suggest that increasing the cultural generalizability of the QODD requires attention.<sup>57</sup> Although the QODD may usefully assess symptom, interpersonal, and religious concerns in African settings, revision or replacement of other concerns is needed. Cognitive interviews by well-trained local interviewers can help to elucidate item comprehension, the

perceived importance of assessed concerns, and reasons for nonresponses.<sup>56,58</sup> Interviews can also identify African-specific concerns, such as those related to finances<sup>58</sup> and family decision making,<sup>6,45,50</sup> to incorporate into the QODD to enhance relevance to the African setting. A modified scale can then be validated by establishing relationships between QODD scores and PC quality indicators. A culturally applicable version of the QODD can generate patient-centered data on quality of dying and death domains to inform advocacy and target ongoing quality improvement of PC in Africa.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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## APPENDIX

### Description of the Forward- and Back-Translation Process and Prestudy Practice Interviews

A native Kenyan team member, fluent in English and Kiswahili and knowledgeable about Kenyan culture, first translated the measures to Kiswahili. Another native Kenyan team member, also fluent in both languages, then independently back-translated them to English. The Kenyan research team examined the concordance of the back-translated and original English versions and identified discrepancies, which seemed limited to minor wording issues. Team members, which included native Kiswahili speakers, then discussed the discrepancies and reconciled the linguistic versions by modifying the Kiswahili

version where they considered appropriate. Their discussions and reconciliations were reviewed with the Toronto research team.

The study interviewer, a research assistant, conducted informal practice interviews with two available Kenyan caregivers before the current study. During these interviews, the caregivers mentioned issues concerning relevance of some of the QODD concepts. However, we chose not to alter the QODD, to obtain quantitative data on how each item worked with Kenyan respondents in the present pilot study.