

## Original Article

**Cite this article:** Goombs M *et al.* (2024) The quality of death and dying of patients with advanced cancer in hospice care in Uganda and Kenya. *Palliative and Supportive Care* 22(5), 1169–1178. <https://doi.org/10.1017/S1478951523001463>

Received: 30 August 2023

Accepted: 15 September 2023

**Keywords:**

Advanced cancer; Hospice care; Kenya; Quality of dying and death; Uganda

**Corresponding author:** Gary Rodin;

Email: [gary.rodin@uhn.ca](mailto:gary.rodin@uhn.ca)

# The quality of death and dying of patients with advanced cancer in hospice care in Uganda and Kenya

Mary Goombs, <sup>1</sup>H.B.Sc., <sup>1</sup> ID, Kenneth Mah, <sup>1</sup> Ph.D., <sup>1</sup> ID, Eve Namisango, <sup>2,3</sup> Ph.D., Emmanuel Luyirika, <sup>4</sup> M.D., <sup>2</sup> Faith Mwangi-Powell, <sup>5</sup> M.Sc. Econ., <sup>4</sup> Ph.D., Nancy Gikaara, <sup>4</sup> B.A., <sup>4</sup> Lesley Chalklin, <sup>1,5</sup> M.Sc., <sup>1,5</sup> Anne Rydall, <sup>1</sup> M.Sc., <sup>1</sup> Camilla Zimmermann, <sup>1,5,6,7</sup> M.D., <sup>1,5,6,7</sup> Ph.D., Sarah Hales, <sup>1,6</sup> M.D., <sup>1,6</sup> Ph.D., Kayla Wolofsky, <sup>1,5,7,8,9</sup> M.D., <sup>1,5,7,8,9</sup> Alyssa Tilly, <sup>10</sup> M.D., <sup>10</sup> Richard A. Powell, <sup>11</sup> M.A., <sup>11</sup> M.Sc., <sup>4,11</sup> and Gary Rodin, <sup>1,5,6</sup> M.D., <sup>1,5,6</sup> ID

<sup>1</sup>Department of Supportive Care, University Health Network, Toronto, ON, Canada; <sup>2</sup>African Palliative Care Association, Kampala, Uganda; <sup>3</sup>Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, London, UK; <sup>4</sup>MWAPCO Health Development Group, Nairobi, Kenya; <sup>5</sup>Global Institute of Psychosocial, Palliative and End-of-Life Care, Toronto, ON, Canada; <sup>6</sup>Department of Psychiatry, University of Toronto, Toronto, ON, Canada; <sup>7</sup>Division of Palliative Medicine, Department of Medicine, University of Toronto, Toronto, ON, Canada; <sup>8</sup>Division of General Internal Medicine, Department of Medicine, University of Toronto, Toronto, ON, Canada; <sup>9</sup>Department of Medicine, University Health Network, Toronto, ON, Canada; <sup>10</sup>Palliative Care Program, Division of General Medicine and Clinical Epidemiology, University of North Carolina School of Medicine, Chapel Hill, NC, USA and <sup>11</sup>Ethnicity and Health Unit, Department of Primary Care and Public Health, Imperial College London, London, UK

**Abstract**

**Objectives.** Minimal information is available about the quality of dying and death in Uganda and Kenya, which are African leaders in palliative care. We investigated the quality of dying and death in patients with advanced cancer who had received hospice care in Uganda or Kenya.

**Methods.** Observational study with bereaved caregivers of decedents (Uganda:  $n = 202$ ; Kenya:  $n = 127$ ) with advanced cancer who had received care from participating hospices in Uganda or Kenya. Participants completed the Quality of Dying and Death questionnaire and a measure of family satisfaction with cancer care (FAMCARE).

**Results.** Quality of Dying and Death Preparation and Connectedness subscales were most frequently rated as good to almost perfect for patients in both countries (45.5% to 81.9%), while Symptom Control and Transcendence subscales were most frequently rated as intermediate (42.6% to 60.4%). However, 35.4% to 67.7% of caregivers rated overall quality of dying and overall quality of death as terrible to poor. Ugandan caregivers reported lower Preparation, Connectedness, and Transcendence ( $p < .001$ ). Controlling for covariates, overall quality of dying was associated with better Symptom Control in both countries ( $p < .001$ ) and Transcendence in Uganda ( $p = .010$ ); overall quality of death, with greater Transcendence in Uganda ( $p = .004$ ); and family satisfaction with care, with better Preparation in Uganda ( $p = .004$ ).

**Significance of results.** Findings indicate strengths in spiritual and social domains of the quality of dying and death in patients who received hospice care in Uganda and Kenya, but better symptom control is needed to improve this outcome in these countries.

**Introduction**

Despite medical advances in recent years, global cancer prevalence and mortality rates and the need for palliative care continue to rise, particularly in lower-resource settings (Connor 2020). Although there has been substantial development of palliative care in Africa, there is still limited access to palliative care for individuals in need in many African countries (Rhee *et al.* 2017). Further, there has been a paucity of research on the quality of dying and death of Africans with advanced or terminal disease (Hannon *et al.* 2016).

Uganda and Kenya have been regarded as African leaders in developing palliative care infrastructure and services (Fraser *et al.* 2018): Uganda has been rated as having preliminary palliative care integration into mainstream service provision; and Kenya, as having generalized palliative care provision without mainstream integration (Connor 2020). These ratings are based on objective criteria, such as affordability of palliative care, integration of palliative care education into health care, and access to pain medication (Connor 2020;

Fraser *et al.* 2018). However, data on the end-of-life experiences of African patients with advanced disease have been lacking. Such data are essential to determine the effectiveness of palliative care services and to inform needed improvements (Dudgeon 2018).

The Quality of Dying and Death (QODD) questionnaire (Curtis *et al.* 2002; Patrick *et al.* 2001), the best-validated measure of the quality of dying and death currently available (Hales *et al.* 2010), has been utilized in research in North America (Hales *et al.* 2014), Europe (Gerritsen *et al.* 2013), Israel (Braun *et al.* 2014), and South America (Pérez-Cruz *et al.* 2017). The interview-based questionnaire is administered to proxy raters, most often bereaved caregivers of deceased patients, who are asked to rate retrospectively the patients' quality of dying and death (Curtis *et al.* 2002). The tool includes 31 content items and 2 single-item ratings of overall quality of dying and moment of death. It assesses 6 conceptual domains: Symptoms and Personal Care, Preparation for Death, Moment of Death, Family, Treatment Preferences, and Whole Person Concerns (Patrick *et al.* 2001). In factor-analytic research, a truncated version of the measure was generated with 4 empirical domains: Symptom Control, Preparation, Connectedness, and Transcendence (Downey *et al.* 2010).

We previously compared the quality of dying and death of patients with advanced cancer who had received care in Kenyan hospices to that of patients in Ontario, Canada, by comparing the 2 groups on the QODD's individual items (Mah *et al.* 2019b). Similarly, we investigated the quality of dying and death of patients with advanced cancer who had received care in Ugandan hospices by examining the QODD item ratings (Mah *et al.* 2023). To identify region-specific challenges and opportunities to improve end-of-life care, it may be of greater value to compare general domains of quality of dying and death between countries that are geographically and socioeconomically similar (Fraser *et al.* 2018). The present observational study aimed to compare domains of quality of dying and death in Uganda and Kenya in patients with advanced cancer who had received hospice care in either country. Based upon their rated palliative care development levels, we hypothesized that Ugandan caregivers would report better overall and domain-specific quality of dying and death than Kenyan caregivers.

## Methods

### Participants

Participants were primary caregivers of deceased patients with advanced cancer who had received hospice-based palliative care at either Hospice Africa Uganda or Kitovu Mobile Hospice in Uganda or at Eldoret, Nairobi, or Nyeri Hospices in Kenya. Inclusion criteria for the study were caregivers who were 18 years or older and whose loved one had died within the preceding 2 to 12 months.

### Materials

All measures administered in Uganda were translated into Luganda, Runyankore-Rukiga, and Swahili, and those administered in Kenya were translated into Kiswahili, using a rigorous forward- and back-translation process (Wild *et al.* 2005). Caregivers provided caregiver and patient demographic and medical data. Patient data were also obtained from chart reviews.

The QODD questionnaire (Curtis *et al.* 2002; Patrick *et al.* 2001) was used to measure the quality of dying and death. We utilized the 4 truncated domains identified by Downey *et al.* (2010) in

our analyses, rather than the original 6 QODD domains (Patrick *et al.* 2001), to reduce the substantial missing item responses and cultural nonrelevance of some QODD items (Curtis *et al.* 2013). These 4 domains, comprising 13 items, include: Symptom Control, reflecting symptom management and autonomy; Preparation, reflecting tangible preparations for dying, such as funeral planning and visits with a religious/spiritual advisor; Connectedness, reflecting closeness with family and friends; and Transcendence, reflecting death acceptance and readiness for death (Downey *et al.* 2010). Two additional items assess the overall quality of life in the last 7 days of life and the overall quality of the moment of death. All items are rated on the quality of the patient's experience from 0 (terrible experience) to 10 (almost perfect experience). To address potential literacy limitations, participants could use a face-rating scale that has been shown to be valid for use in African patient samples (Blum *et al.* 2014). Summed subscale scores were calculated and then standardized to a 0 to 100 scale, with higher scores indicating better quality of dying and death.

Caregivers also completed the FAMCARE scale, a validated, 20-item measure of family satisfaction with care for patients with advanced cancer (Kristjanson 1993; Ringdal *et al.* 2003). Satisfaction with aspects of care is rated from 0 (very dissatisfied) to 5 (very satisfied), and a summed total score is calculated; higher scores indicate greater family satisfaction with care.

### Procedure

In Kenya, the Institutional Research and Ethics Committee of the Moi Teaching and Referral Hospital (#FAN: IREC 1700) provided ethics approval for the study to be conducted at the Eldoret and Nyeri Hospices. The Nairobi Hospice Ethics and Standards Committee (no approval number) provided ethics approval for this study to be conducted at the Nairobi Hospice. The study in Uganda received approval from the Hospice Africa Uganda Research and Ethics Committee (#HAUREC-034/17) and the Uganda National Council for Science and Technology (#SS 4434). Both studies also received ethics approval from the Research Ethics Board of the University Health Network, Toronto, Ontario, Canada (Kenya study: #15-5080-BE; Uganda study: #18-5055). The Kenyan study was conducted from November 2016 to May 2017; the Ugandan study was conducted from November 2018 to September 2019.

Eligible bereaved caregivers available within the data-collection timeframes were identified by hospice staff or volunteers 2 to 12 months after patient death. They were contacted in person, by telephone, or via text to inform them that research staff would be approaching them about the study. Interested caregivers were then contacted by research staff and given the details of the study. Written informed consent was obtained from those willing to participate; if literacy was insufficient, approval by thumbprint or documented verbal consent was obtained. Questionnaires were administered either by telephone or in an in-person interview that took approximately 45 to 90 minutes to complete. Participants were compensated either US\$5 or US\$15 for travel costs.

### Statistical analyses

All analyses were conducted using SPSS version 25 software. The alpha level was set at .05. Missing data were treated with listwise deletion. Demographic characteristics of patients and their caregivers and the medical characteristics of patients were summarized using descriptive statistics. Patients and caregivers were compared

between the 2 countries on the characteristics using independent-samples *t*-tests or Pearson's chi-square tests. Characteristics that differed significantly between countries were included as covariates in multivariable analyses. We examined ranges of overall quality of dying and quality of moment of death ratings for both countries by plotting percentage frequencies for categorized quality ranges of item ratings: ratings from 0.0 to 2.9 reflected terrible to poor quality of dying or death; ratings from 3.0 to 6.9, intermediate quality; and ratings from 7.0 to 10.0, good to almost perfect quality (Curtis et al. 2002).

Comparisons between Uganda and Kenya of the QODD subscale scores and the overall quality of dying and quality of moment of death ratings were conducted using univariate ANOVAs. Comparisons between Uganda and Kenya of the categorized quality ranges of scores for the subscales and for the quality of dying and quality of moment of death ratings were conducted using Pearson's chi-squared tests.

Using multiple linear regressions, the QODD subscale scores were then examined as predictors of quality of dying, quality of moment of death, and family satisfaction with cancer care for each country. These analyses were conducted with and without empirically identified sociodemographic and medical covariates.

## Results

### Sample characteristics

The sample included 202 of 205 (98.5%) approached Ugandan caregivers (2 declined participation; 1 became distressed during interview) and 127 of 129 (98.4%) consenting Kenyan caregivers (Table 1). The majority of Ugandan caregivers were recruited from Kitovu Mobile Hospice (53.0%), and the majority of Kenyan caregivers were recruited from Nyeri Hospice (55.1%). The Ugandan caregivers were significantly younger than the Kenyan caregivers at time of interview ( $p = .049$ ), at patient diagnosis ( $p = .002$ ), and at patient death ( $p = .001$ ). Half of the Ugandan caregivers (49.0%) identified as Catholic, whereas almost all Kenyan caregivers (96.1%) identified as Christian ( $p < .001$ ). Fewer Ugandan than Kenyan caregivers were employed (Uganda = 67.8%, Kenya = 85.8%,  $p < .001$ ). The majority of caregivers were parents (Uganda = 31.2%, Kenya = 45.7%) or spouses/partners (Uganda = 20.8%, Kenya = 37.0%,  $p < .001$ ) of patients.

No significant age differences were observed in patients between countries ( $p = .060$ – $.172$ ). Fewer Ugandan than Kenyan patients had been married or in a common-law relationship (Uganda = 47.5%, Kenya = 60.6%), while more Ugandan patients than Kenyan patients had been separated or divorced (Uganda = 17.3%, Kenya = 3.9%,  $p = .003$ ). In Uganda, the most commonly reported cancer was "other cancer" (37.6%), whereas in Kenya, the most common cancer was gastrointestinal cancer (47.2%). Ugandan patients were more likely to die at home (Uganda = 65.8%, Kenya = 42.5%) and less likely to die in a hospital (Uganda = 31.2%, Kenya = 52.8%,  $p < .001$ ).

### Comparison of QODD overall quality of dying and death and subscale score categorical frequencies

In Figure 1, there were significant differences between the countries in the frequency distributions across quality response categories for both overall quality of dying and overall quality of moment of death ( $p < .001$ ). Ugandan caregivers rated the overall quality of dying of

their deceased loved one less frequently as terrible to poor than did Kenyan caregivers (Uganda = 47.0%, Kenya = 67.7%) and more frequently as intermediate (Uganda = 33.7%, Kenya = 11.0%). Equally small proportions of caregivers from both countries indicated good to almost perfect quality of dying (Uganda = 17.8%, Kenya = 17.3%). Compared to Kenyan caregivers, Ugandan caregivers more frequently rated overall quality of moment of death as terrible to poor (Uganda = 47.0%, Kenya = 35.4%), intermediate (Uganda = 25.2%, Kenya = 13.4%), and good to almost perfect (Uganda = 23.3%, Kenya = 18.1%). Kenyan caregivers showed substantial missing ratings for quality of moment of death (33.1%).

In Figure 2, there were significant differences between Ugandan and Kenyan caregivers in the frequency distributions across quality response categories for all QODD subscales (Symptom Control,  $p = .007$ ; Preparation,  $p = .003$ ; Connectedness,  $p < .001$ ; Transcendence,  $p = .004$ ). Smaller proportions of Ugandans than Kenyans rated their loved ones' Symptom Control (Uganda = 26.2%, Kenya = 38.6%) as terrible to poor. Larger proportions of Ugandans than Kenyans rated their loved ones' Symptom Control (Uganda = 60.4%, Kenya = 43.3%), Preparation (Uganda = 52.0%, Kenya = 32.3%), and Connectedness (Uganda = 36.6%, Kenya = 15.0%) as intermediate. Smaller proportions of Ugandan than Kenyan caregivers reported good to almost perfect Symptom Control (Uganda = 12.4%, Kenya = 18.1%), Preparation (Uganda = 45.5%, Kenya = 63.0%), Connectedness (Uganda = 56.4%, Kenya = 81.9%), and Transcendence (Uganda = 15.3%, Kenya = 26.0%).

### Comparison of Uganda and Kenya on QODD domains scores

In Table 2, Ugandan caregivers reported significantly lower ratings on Preparation (Mean  $\pm$  SD: Uganda =  $67.82 \pm 16.75$ , Kenya =  $77.78 \pm 18.98$ ,  $p < .001$ ), Connectedness (Uganda =  $68.71 \pm 23.59$ , Kenya =  $83.07 \pm 21.58$ ,  $p < .001$ ), and Transcendence (Uganda =  $39.08 \pm 27.83$ , Kenya =  $52.14 \pm 31.17$ ,  $p < .001$ ). No significant difference was found between countries on Symptom Control ( $p = .308$ ).

### QODD domains as correlates of overall quality of dying and death and family satisfaction with care

In Table 3, without controlling for covariates, better overall quality of dying in Ugandan patients was associated with better Symptom Control ( $\beta = .31$ ,  $p < .001$ ) and Transcendence ( $\beta = .23$ ,  $p = .002$ ). In Kenyan patients, better overall quality of dying was associated only with better Symptom Control ( $\beta = .47$ ,  $p < .001$ ). These relationships remained when accounting for covariates.

Better overall quality of moment of death in Ugandan patients was also associated with better Symptom Control ( $\beta = .20$ ,  $p = .009$ ) and Transcendence ( $\beta = .29$ ,  $p < .001$ ), whereas it was not significantly associated with any QODD domain in Kenyan patients. When controlling for covariates, only the association involving Transcendence remained significant in Ugandan patients ( $\beta = .26$ ,  $p = .004$ ).

Better family satisfaction with care given to Ugandan patients was significantly associated with better Preparation, both without ( $\beta = .27$ ,  $p < .001$ ) and with ( $\beta = .25$ ,  $p = .004$ ) covariates.

## Discussion

This study of the quality of dying and death of patients who had received hospice care in Uganda and Kenya demonstrated

**Table 1.** Caregiver and patient demographic and medical characteristics

Characteristics	Caregiver			Patient		
	Uganda ( <i>n</i> = 202)	Kenya ( <i>n</i> = 127)	<i>p</i>	Uganda ( <i>n</i> = 202)	Kenya ( <i>n</i> = 127)	<i>p</i>
Age at interview, mean years (SD) <sup>a</sup>	43.65 (11.99)	46.56 (12.97)	.049	–	–	–
Age at diagnosis, mean years (SD) <sup>a</sup>	41.78 (11.51)	46.64 (13.77)	.002	56.82 (17.89)	59.78 (15.24)	.172
Age at patient death, mean years (SD) <sup>a</sup>	42.91 (11.93)	47.61 (13.58)	.001	57.57 (18.31)	61.33 (14.93)	.060
Gender, <i>n</i> (%)			.609			.539
Female	141 (69.8)	85 (66.9)		116 (57.4)	68 (53.5)	
Male	60 (29.7)	41 (32.3)		86 (42.6)	58 (45.7)	
Missing	1 (0.5)	1 (0.8)		0 (0.0)	1 (0.8)	
Marital status, <i>n</i> (%)			.125			.003
Married/common-law	105 (52.0)	59 (46.5)		96 (47.5)	77 (60.6)	
Single	35 (17.3)	14 (11.0)		35 (17.3)	21 (16.5)	
Separated/divorced	11 (5.4)	8 (6.3)		35 (17.3)	5 (3.9)	
Widowed	50 (24.8)	45 (35.4)		34 (16.8)	22 (17.3)	
Missing	1 (0.5)	1 (0.8)		2 (1.0)	2 (1.6)	
Country of birth, <i>n</i> (%)			<.001			–
Uganda	196 (97.0)	1 (0.8)		–	–	
Kenya	1 (0.5)	126 (99.2)		–	–	
Tanzania	3 (1.5)	0 (0.0)		–	–	
Rwanda	1 (0.5)	0 (0.0)		–	–	
South Sudan	1 (0.5)	0 (0.0)		–	–	
Primary language, <i>n</i> (%) <sup>b</sup>			–			–
Luganda	161 (79.7)	0 (0.0)		162 (80.2)	0 (0.0)	
Kalenjin	0 (0.0)	10 (7.9)		0 (0.0)	11 (8.7)	
Kikuyu	0 (0.0)	85 (66.9)		0 (0.0)	83 (65.4)	
Luhya	0 (0.0)	11 (8.7)		0 (0.0)	10 (7.9)	
Missing	0 (0.0)	0 (0.0)		0 (0.0)	3 (2.4)	
Religion, <i>n</i> (%)			<.001			–
Catholic	99 (49.0)	0 (0.0)		–	–	
Muslim	32 (15.8)	1 (0.8)		–	–	
Christian	51 (25.2)	122 (96.1)		–	–	
Anglican	16 (7.9)	0 (0.0)		–	–	
Missing	4 (2.0)	4 (3.1)		–	–	
Level of education, <i>n</i> (%)			.129			–
No education/primary (incomplete)	24 (11.9)	22 (17.3)		–	–	
Primary (complete)	52 (25.7)	26 (20.5)		–	–	
Secondary (incomplete)	18 (8.9)	18 (14.2)		–	–	
Secondary (complete)	49 (24.3)	34 (26.8)		–	–	
Post-secondary/undergraduate/college	22 (10.9)	14 (11.0)		–	–	
Professional	34 (16.8)	11 (8.7)		–	–	
Missing	3 (1.5)	2 (1.6)		–	–	
Employment status, <i>n</i> (%)			<.001			–
Employed	137 (67.8)	109 (85.8)		–	–	
Unemployed	57 (28.2)	2 (1.6)		–	–	

(Continued)

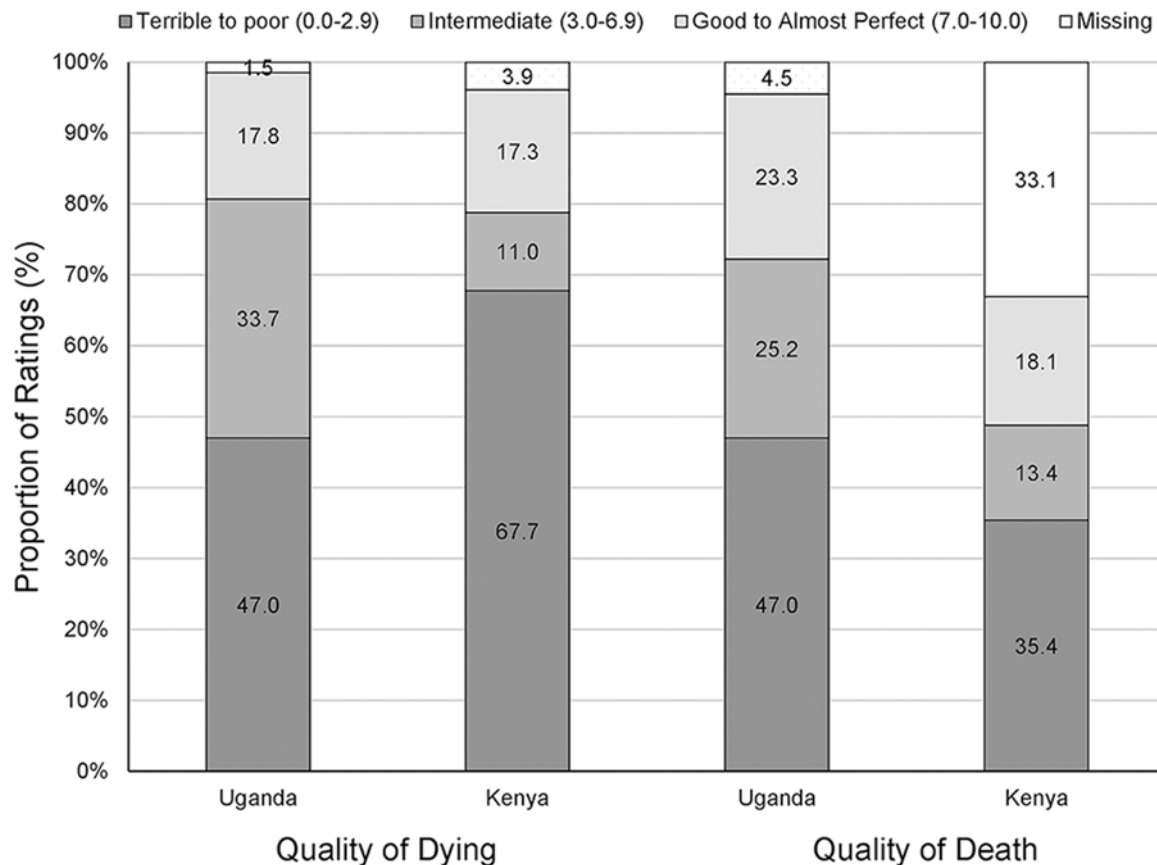
Table 1. (Continued.)

Characteristics	Caregiver			Patient		
	Uganda (n = 202)	Kenya (n = 127)	p	Uganda (n = 202)	Kenya (n = 127)	p
Retired	4 (2.0)	2 (1.6)		–	–	
Disability	1 (0.5)	0 (0.0)		–	–	
Other	2 (1.0)	0 (0.0)		–	–	
Missing	1 (0.5)	14 (11.0)		–	–	
Relationship to patient, n (%)			<.001			–
Spouse/partner	42 (20.8)	47 (37.0)		–	–	
Parent	63 (31.2)	58 (45.7)		–	–	
Son/daughter	39 (19.3)	1 (0.8)		–	–	
Sibling	30 (14.9)	13 (10.2)		–	–	
Other family	23 (11.4)	4 (3.1)		–	–	
Friend/other	5 (2.5)	1 (0.8)		–	–	
Missing	0 (0.0)	3 (2.4)		–	–	
Hospice, n (%)			–			–
Uganda						
Kitovu Mobile	–	–		107 (53.0)	–	
Hospice Africa Uganda	–	–		94 (46.5)	–	
Missing	–	–		1 (0.5)	–	
Kenya						
Nairobi	–	–		–	42 (33.1)	
Nyeri	–	–		–	70 (55.1)	
Eldoret	–	–		–	15 (11.8)	
Primary cancer diagnosis, n (%)			–			<.001
Breast	–	–		12 (5.9)	13 (10.2)	
Gastrointestinal	–	–		24 (11.9)	60 (47.2)	
Genitourinary	–	–		17 (8.4)	14 (11.0)	
Gynecologic	–	–		26 (12.9)	18 (14.2)	
Hematologic	–	–		4 (2.0)	3 (2.4)	
Lung	–	–		7 (3.5)	2 (1.6)	
Melanoma/skin	–	–		3 (1.5)	4 (3.1)	
Oral	–	–		11 (5.4)	4 (3.1)	
Sarcoma	–	–		1 (0.5)	2 (1.6)	
Other cancer	–	–		76 (37.6)	0 (0.0)	
Other diagnosis	–	–		19 (9.4)	4 (3.1)	
Missing	–	–		2 (1.0)	3 (2.4)	
Place of death, n (%)			–			<.001
Home	–	–		133 (65.8)	54 (42.5)	
Hospital	–	–		63 (31.2)	67 (52.8)	
Hospice	–	–		1 (0.5)	1 (0.8)	
Missing	–	–		5 (2.5)	5 (3.9)	

SD = standard deviation.

<sup>a</sup>Caregiver age at interview, diagnosis, and patient death: both countries had missing age-related data, which accounts for the older mean caregiver age at patient death than at interview in Kenyan caregivers.<sup>b</sup>Primary language: only language categories with frequencies >5% are reported; a statistical comparison of the countries was not conducted with this characteristic due to the numerous languages reported.





**Figure 1.** Comparison of percentage frequencies of overall dying and death ratings between Ugandan and Kenyan Caregivers.

Significant differences were noted between the countries in frequency of ratings within each response category for Quality of Dying and Quality of Moment of Death,  $p < .001$ . Adapted with permission from Wolters Kluwer Health, Inc. Mah et al. (2019b); and Mah et al. (2023).

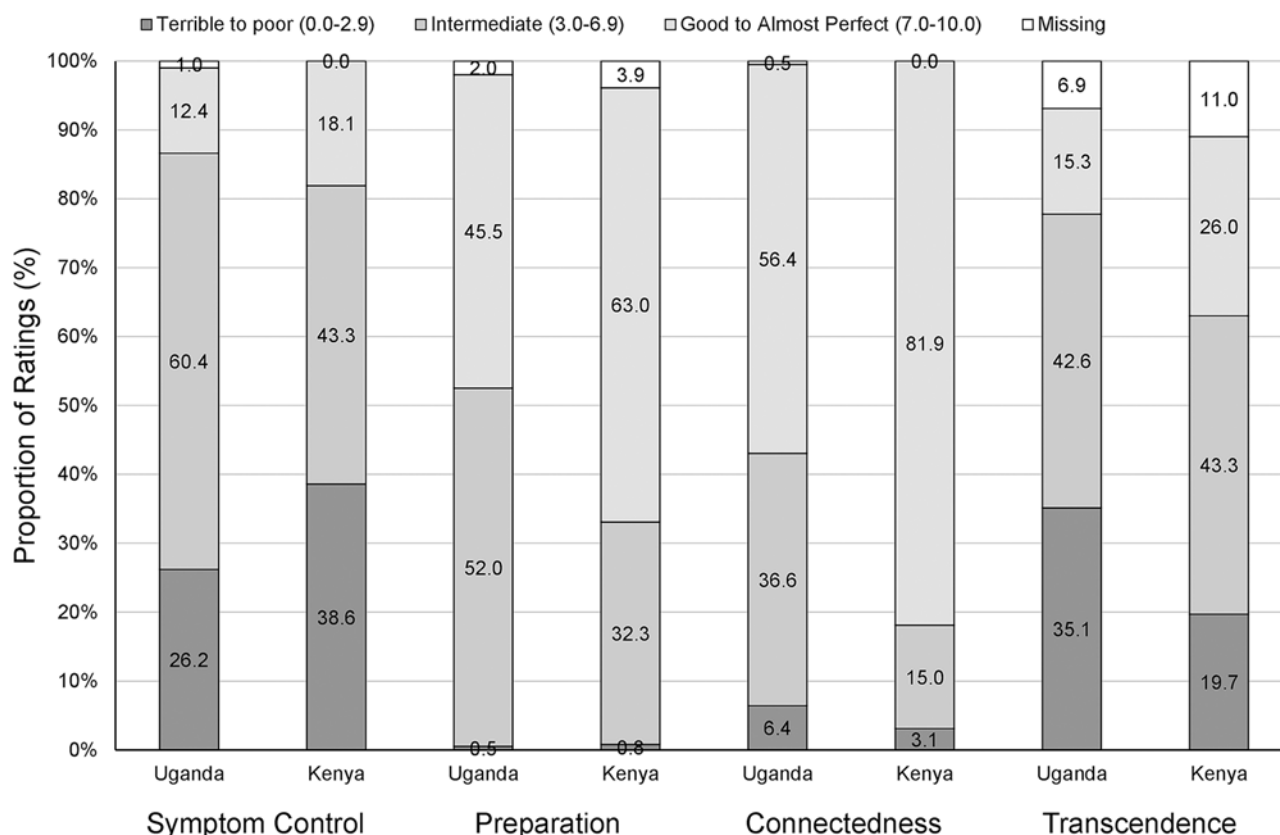
that preparation and connectedness were frequently rated good to almost perfect in both countries, while symptom control and transcendence were frequently rated as intermediate. However, almost half of the patients in hospice care in Uganda and over two-thirds in Kenya reportedly experienced overall terrible quality of dying and death. The preparation, connectedness, and transcendence domains were unexpectedly poorer in Ugandan than Kenyan patients, contrary to the countries' relative palliative care development rankings based on objective quantification metrics. It is unclear to what extent these differences were due to differences between the 2 countries in the nature of care, cancer types, or caregivers' demographic characteristics.

The relatively low ratings on symptom control in both countries are consistent with reports of inadequate pain and symptom management in African palliative care settings (Fraser et al. 2018; Harding et al. 2011; Kikule 2003; Namukwaya et al. 2021; Powell et al. 2017). We found that poor symptom control was significantly related to poor quality of dying, corresponding to the findings of our earlier Ontario study (Mah et al. 2019a). This finding highlights the urgent need in both countries to improve access to effective pain and symptom management in palliative care. Efforts in both countries to increase opioid availability, such as adopting less restrictive prescribing policies and legalizing prescription privileges for clinical officers and nurses, have met with barriers. These include lack of storage capacity for medications, trained personnel to administer them, supply problems, and sociocultural fears

of addiction (Finkelstein et al. 2022; Fraser et al. 2018; Kamonyo 2018).

The psychosocial domains of preparation for death and interpersonal connectedness notably were rated relatively highly in both countries. These ratings may reflect the importance of religion, spirituality, and communality in African cultures and the close involvement of significant others with individuals who are near the end of life (Agbiji and Swart 2015; Etta et al. 2016; Grant et al. 2011a; Selman et al. 2018). Although preparation for death, connectedness to others, and spirituality have also been regarded as important by seriously ill patients and bereaved family members in Western settings (Steinhauser et al. 2000), their relative contributions to a good death and the potential for them to be supported may be shaped by the cultural context. In that regard, we previously reported that Kenyan caregivers rated their loved ones as faring better on interpersonal and spiritual concerns near the end of life than did Canadian caregivers (Mah et al. 2019b). Spirituality and family support may be important resources in the African context that facilitate coping, even when there is poor pain management (Selman et al. 2010, 2011).

Based on caregiver reports in the present study, the Kenyan patients showed better preparation for death, connectedness with loved ones, and transcendence than Ugandan patients, contrary to our hypothesis. This could be due to differences in the samples, treatment settings, or resources. It may also be that objective ratings of palliative care development (Connor 2020) do not correspond to



**Figure 2.** Comparison of percentage frequencies of subscale scores between Ugandan and Kenyan Caregivers.

Significant differences were noted between the countries in frequency of scores within each response category for Symptom Control ( $p = .007$ ), Preparation ( $p = .003$ ), Connectedness ( $p < .001$ ), and Transcendence ( $p = .004$ ).

**Table 2.** Comparison of QODD subscale scores between Uganda and Kenya

QODD subscale	Mean (SD) [n]		p
	Uganda	Kenya	
Symptom Control	41.23 (22.27) [200]	38.18 (31.85) [127]	.308
Preparation	67.82 (16.75) [198]	77.78 (18.98) [122]	<.001
Connectedness	68.71 (23.59) [201]	83.07 (21.58) [127]	<.001
Transcendence	39.08 (27.83) [188]	52.14 (31.17) [113]	<.001

SD = standard deviation.

the subjective experience of dying and death. Challenges in palliative care delivery in Africa include the lack of trained palliative care providers, medication shortages, and limited palliative care funding (Kamonyo 2018; Namukwaya et al. 2021). Community-level comparative studies with patients and their caregivers from both countries are needed to elucidate other sociocultural factors that may underlie these differences.

In the Ugandan subsample, transcendence (i.e., death acceptance) was the most consistent correlate of better quality of dying and death, and preparation for death was a correlate of greater family satisfaction with care. These relationships were not observed with Kenyan patients, possibly due to the smaller size of the Kenyan subsample and correspondingly reduced power in multivariate analyses. We previously reported a similar relationship between acceptance of dying and the overall quality of dying and death in Ontario patients with advanced cancer (Mah et al. 2019a).

However, the relatively low transcendence scores for both Ugandan and Kenyan patients may arise from a lack of prognostic information provided to seriously ill patients in Africa and consequent expectations about being cured (Grant et al. 2011a, 2011b; Love et al. 2020) or the cultural prohibition of conversations about death (Ekore and Lanre-Abass 2016; Love et al. 2020). Nonetheless, African palliative care practitioners have reported that patients with advanced cancer responded well when end-of-life conversations were initiated prior to palliative care referral (Low et al. 2018). The relationship between better family satisfaction with care and greater preparation for death in Uganda may reflect the hospice services provided. As preparation for death includes spiritual care and practical matters such as funeral and financial planning, it is possible that the hospices provided holistic support to the patient that both was satisfactory to the family and addressed these preparatory issues. However, the specific care practices at each hospice were not available for analysis.

### Limitations

This is the first study to compare the quality of dying and death in Uganda and Kenya using a proxy-reported outcome measure of the patient's experience. These findings complement the global palliative care rankings based on objective indicators (Connor 2020). Limitations of this study should be noted. The proxy ratings of the quality of dying and death were based on the experience of patients who had received hospice care and therefore may not generalize to the experience of individuals who died without such care. The

**Table 3.** QODD subscale scores as correlates of overall quality of dying and death and family satisfaction with Cancer Care in Uganda and Kenya

Outcomes	Nonadjusted						Adjusted for covariates					
	Uganda			Kenya			Uganda			Kenya		
	B (SE)	B 95% CI	$\beta$	p	B (SE)	B 95% CI	$\beta$	p	B (SE)	B 95% CI	$\beta$	p
Quality of Dying												
Symptom Control	.04 (.01)	.02–.06	.31	<.001	.05 (.01)	.03–.08	.47	<.001	.04 (.01)	.02–.07	.33	<.001
Preparation	.01 (.01)	–.02–.03	.03	.615	–.02 (.02)	–.05–.02	–.08	.387	.01 (.01)	–.02–.03	.03	.666
Connectedness	–.01 (.01)	–.02–.01	–.04	.564	–.01 (.02)	–.05–.02	–.08	.416	–.01 (.01)	–.03–.01	–.07	.343
Transcendence	.03 (.01)	.01–.04	.23	.002	.01 (.01)	–.01–.03	.09	.356	.02 (.01)	.01–.04	.20	.010
Quality of Moment of Death												
Symptom Control	.03 (.01)	.01–.06	.20	.009	.00 (.02)	–.03–.04	.03	.789	.03 (.01)	–.00–.05	.15	.075
Preparation	.01 (.02)	–.02–.04	.07	.337	.03 (.03)	–.03–.09	.15	.276	.00 (.02)	–.03–.04	.02	.781
Connectedness	–.01 (.01)	–.03–.01	–.06	.381	.04 (.02)	–.01–.09	.23	.083	–.01 (.01)	–.03–.01	–.06	.466
Transcendence	.04 (.01)	.02–.06	.29	<.001	–.01 (.02)	–.04–.03	–.03	.798	.03 (.01)	.01–.06	.26	.004
FAMCARE												
Symptom Control	.01 (.02)	–.03–.04	.03	.707	.03 (.02)	–.01–.08	.18	.101	.03 (.02)	–.01–.07	.14	.148
Preparation	.08 (.02)	.04–.12	.27	<.001	.04 (.03)	–.03–.11	.12	.238	.07 (.03)	.02–.12	.25	.004
Connectedness	.02 (.02)	–.01–.05	.11	.150	–.05 (.03)	–.11–.01	–.18	.101	.02 (.02)	–.01–.06	.11	.175
Transcendence	–.01 (.01)	–.03–.02	–.03	.718	.03 (.02)	–.02–.07	.14	.211	–.02 (.02)	–.05–.02	–.10	.300

B = unstandardized coefficient, SE = standard error,  $\beta$  = beta (standardized coefficient), CI = confidence interval.  
Covariates for overall quality of dying include caregiver relationship to patient ( $p = .044$ ) and patient place of death ( $p = .027$ ). Covariates for overall quality of moment of death include caregiver age at patient death ( $p = .049$ ) and patient primary diagnosis ( $p = .001$ ). Covariates for FAMCARE include caregiver age at patient death ( $p = .023$ ), caregiver marital status ( $p = .039$ ), caregiver religion ( $p < .001$ ), caregiver level of education ( $p = .011$ ), patient primary diagnosis ( $p = .004$ ), and patient place of death ( $p = .001$ ).



QODD and the FAMCARE were rigorously forward- and back-translated, but these measures have not yet been formally validated for use in African settings, and certain QODD items may not be culturally applicable (Mah et al. 2019b). Although proxy ratings by bereaved caregivers are the most practical method to assess dying individuals' experiences, there can be memory and recall bias. The caregivers' emotional state during data collection may also bias their ratings, although previous research suggested that QODD ratings by bereaved caregivers are not affected by degree of bereavement grief (Hales et al. 2014).

Our analyses were based on the 4 truncated QODD domains (Downey et al. 2010) to minimize substantial missing item responses due to their individual or cultural nonrelevance (Curtis et al. 2013). A more culturally relevant and generalizable measure of the quality of dying and death is urgently needed for research and clinical application in Africa and in other global regions.

## Conclusions

This study of the quality of dying and death of patients with advanced cancer in hospice care in Uganda and Kenya revealed both strengths and limitations in this outcome in both countries. A high degree of spiritual preparation and social connectedness was reported for the majority of patients in hospice care in Uganda and Kenya. However, there was poor symptom control and poor overall quality of dying and death in both countries. These findings highlight the urgent need for funding, training, and resources to improve the quality of palliative and end-of-life care in this region. Future research may benefit from a modified QODD to enhance its cultural relevance and validity for use in diverse end-of-life care settings; such research is now underway (An et al. 2022).

**Acknowledgments.** The authors would like to thank the bereaved caregivers in both Uganda and Kenya for their participation in the study. The authors would like to thank Lesley Chalklin, Coordinator, Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC), for coordinating the Uganda quality of dying and death study, Jacqueline Namulondo and Rose Nabatanzi for coordinating caregiver recruitment, and Timothy Muwanguzi and Mackuline Atieno for their work on data collection. They thank the hospice managers and staff for facilitating data collection in Kenya and Zipporah Ali, MD, MPH, and her staff at the Kenyan Hospice and Palliative Care Association for their support. This article presents independent research. The views expressed in this publication by Richard A. Powell are his own and not necessarily those of the NIHR or the Department of Health and Social Care, London, UK.

**Funding.** This work was supported by internal funding (no grant number) from the Global Institute of Psychosocial, Palliative and End-of-life Care (GIPPEC: Princess Margaret Cancer Centre, University Health Network; and University of Toronto), Toronto, Ontario, Canada, and, for Richard A. Powell, by support from the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Northwest London.

**Competing interests.** The authors declare none. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

## References

Agbiji OM and Swart I (2015) Religion and social transformation in Africa: A critical and appreciative perspective. *Scriptura: Journal for Contextual Hermeneutics in Southern Africa* 114(1), 1–20. doi:10.10520/EJC179142

- An E, Tilly A, Mah K, et al. (2022) Protocol for the development and multisite validation of the Quality of Dying and Death-Revised Global Version scale. *BMJ Open* 12(7), e064508. doi:10.1136/bmjopen-2022-064508
- Blum D, Selman LE, Agupio G, et al. (2014) Self-report measurement of pain & symptoms in palliative care patients: A comparison of verbal, visual and hand scoring methods in Sub-Saharan Africa. *Health and Quality of Life Outcomes* 12, 118. doi:10.1186/s12955-014-0118-z
- Braun M, Hasson-Ohayon I, Hales S, et al. (2014) Quality of dying and death with cancer in Israel. *Supportive Care in Cancer* 22(7), 1973–1980. doi:10.1007/s00520-014-2163-x
- Connor SR (2020) *Global Atlas of Palliative Care*, 2nd edn. London: Worldwide Hospice Palliative Care Alliance.
- Curtis JR, Downey L and Engelberg RA (2013) The quality of dying and death: Is it ready for use as an outcome measure? *Chest* 143(2), 289–291. doi:10.1378/chest.12-1941
- Curtis JR, Patrick DL, Engelberg RA, et al. (2002) A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *Journal of Pain and Symptom Management* 24(1), 17–31. doi:10.1016/s0885-3924(02)00419-0
- Downey L, Curtis JR, Lafferty WE, et al. (2010) The Quality of Dying and Death Questionnaire (QODD): Empirical domains and theoretical perspectives. *Journal of Pain and Symptom Management* 39(1), 9–22. doi:10.1016/j.jpainsymman.2009.05.012
- Dudgeon D (2018) The impact of measuring patient-reported outcome measures on quality of and access to palliative care. *Journal of Palliative Medicine* 21(S1), S76–S80. doi:10.1089/jpm.2017.0447
- Ekoré RI and Lanre-Abass B (2016) African cultural concept of death and the idea of advance care directives. *Indian Journal of Palliative Care* 22(4), 369–372. doi:10.4103/0973-1075.191741
- Etta EE, Esowe DD and Asukwo OO (2016) African communalism and globalization. *African Research Review* 10(3), 302–316. doi:10.4314/afrrrev.v10i3.20
- Finkelstein EA, Bhadelia A, Goh C, et al. (2022) Cross country comparison of expert assessments of the quality of death and dying 2021. *Journal of Pain and Symptom Management* 63(4), e419–e429. doi:10.1016/j.jpainsymman.2021.12.015
- Fraser BA, Powell RA, Mwangi-Powell FN, et al. (2018) Palliative care development in Africa: Lessons from Uganda and Kenya. *Journal of Global Oncology* 4, 1–10. doi:10.1200/JGO.2017.010090
- Gerritsen RT, Hofhuis JGM, Koopmans M, et al. (2013) Perception by family members and ICU staff of the quality of dying and death in the ICU: A prospective multicenter study in the Netherlands. *Chest* 143(2), 357–363. doi:10.1378/chest.12-0569
- Grant L, Brown J, Leng M, et al. (2011a) Palliative care making a difference in rural Uganda, Kenya and Malawi: Three rapid evaluation field studies. *BMC Palliative Care* 10, 8. doi:10.1186/1472-684X-10-8
- Grant L, Downing J, Namukwaya E, et al. (2011b) Palliative care in Africa since 2005: Good progress, but much further to go. *BMJ Supportive & Palliative Care* 1(2), 118–122. doi:10.1136/bmjspcare-2011-000057
- Hales S, Chiu A, Husain A, et al. (2014) The quality of dying and death in cancer and its relationship to palliative care and place of death. *Journal of Pain and Symptom Management* 48(5), 839–851. doi:10.1016/j.jpainsymman.2013.12.240
- Hales S, Zimmermann C and Rodin G (2010) Review: The quality of dying and death: A systematic review of measures. *Palliative Medicine* 24(2), 127–144. doi:10.1177/0269216309351783
- Hannon B, Zimmermann C, Knaul FM, et al. (2016) Provision of palliative care in low- and middle-income countries: Overcoming obstacles for effective treatment delivery. *Journal of Clinical Oncology* 34(1), 62–68. doi:10.1200/JCO.2015.62.1615
- Harding R, Selman L, Agupio G, et al. (2011) The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. *European Journal of Cancer* 47(1), 51–56. doi:10.1016/j.ejca.2010.08.003
- Kamonyo ES (2018) The palliative care journey in Kenya and Uganda. *Journal of Pain and Symptom Management* 55(2S), S46–S54. doi:10.1016/j.jpainsymman.2017.03.026

- Kikule E** (2003) A good death in Uganda: Survey of needs for palliative care for terminally ill people in urban areas. *BMJ* **327**(7408), 192–194. doi:10.1136/bmj.327.7408.192
- Kristjanson LJ** (1993) Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. *Social Science & Medicine* **36**(5), 693–701. doi:10.1016/0277-9536(93)90066-d
- Love KR, Karin E, Morogo D, et al.** (2020) “To speak of death is to invite it”: Provider perceptions of palliative care for cardiovascular patients in western Kenya. *Journal of Pain and Symptom Management* **60**(4), 717–724. doi:10.1016/j.jpainsymman.2020.05.003
- Low D, Merkel EC, Menon M, et al.** (2018) End-of-life palliative care practices and referrals in Uganda. *Journal of Palliative Medicine* **21**(3), 328–334. doi:10.1089/jpm.2017.0257
- Mah K, Hales S, Weerakkody I, et al.** (2019a) Measuring the quality of dying and death in advanced cancer: Item characteristics and factor structure of the Quality of Dying and Death Questionnaire. *Palliative Medicine* **33**(3), 369–380. doi:10.1177/0269216318819607
- Mah K, Namisango E, Luyirika E, et al.** (2023) Quality of dying and death of patients with cancer in hospice care in Uganda. *JCO Global Oncology* **9**, e2200386. doi:10.1200/GO.22.00386
- Mah K, Powell RA, Malfitano C, et al.** (2019b) Evaluation of the quality of dying and death questionnaire in Kenya. *Journal of Global Oncology* **5**, 1–16. doi:10.1200/JGO.18.00257
- Namukwaya E, Mwaka AD, Namisango E, et al.** (2021) Current state of palliative care in Uganda. In Silberman M ((ed)), *Palliative Care for Chronic Cancer Patients in the Community: global Approaches and Future Applications*. Cham, Switzerland: Springer International Publishing, 267–278.
- Patrick DL, Engelberg RA and Curtis JR** (2001) Evaluating the quality of dying and death. *Journal of Pain and Symptom Management* **22**(3), 717–726. doi:10.1016/s0885-3924(01)00333-5
- Pérez-Cruz PE, Padilla Pérez O, Bonati P, et al.** (2017) Validation of the Spanish version of the Quality of Dying and Death Questionnaire (QODD-ESP) in a home-based cancer palliative care program and development of the QODD-ESP-12. *Journal of Pain and Symptom Management* **53**(6), 1042–1049.e3. doi:10.1016/j.jpainsymman.2017.02.005
- Powell RA, Ali Z, Luyirika E, et al.** (2017) Out of the shadows: Non-communicable diseases and palliative care in Africa. *BMJ Supportive & Palliative Care* **7**(2), 128–132. doi:10.1136/bmjspcare-2014-000751
- Rhee JY, Garralda E, Torrado C, et al.** (2017) Palliative care in Africa: A scoping review from 2005–16. *The Lancet Oncology* **18**(9), e522–e531. doi:10.1016/S1470-2045(17)30420-5
- Ringdal GI, Jordhøy MS and Kaasa S** (2003) Measuring quality of palliative care: Psychometric properties of the FAMCARE Scale. *Quality of Life Research* **12**(2), 167–176. doi:10.1023/a:1022236430131
- Selman L, Harding R, Agupio G, et al. and The Spiritual Care in sub-Saharan Africa Advisory Group** (2010) *Spiritual Care Recommendations for People Receiving Palliative Care in sub-Saharan Africa: with Special Reference to South Africa and Uganda*. London: Cicely Saunders International.
- Selman LE, Brighton LJ, Sinclair S, et al. and InSpirit Collaborative** (2018) Patients’ and caregivers’ needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine* **32**(1), 216–230. doi:10.1177/0269216317734954
- Selman LE, Higginson IJ, Agupio G, et al.** (2011) Quality of life among patients receiving palliative care in South Africa and Uganda: A multi-centred study. *Health and Quality of Life Outcomes* **9**, 21. doi:10.1186/1477-7525-9-21
- Steinhauser KE, Christakis NA, Clipp EC, et al.** (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* **284**(19), 2476–2482. doi:10.1001/jama.284.19.2476
- Wild D, Grove A, Martin M, et al.** (2005) Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value in Health* **8**(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x