Support Care Cancer (2014) 22:3185–3192
DOI 10.1007/s00520-014-2301-5

ORIGINAL ARTICLE

Palliative care-related self-report problems among cancer patients in East Africa: a two-country study

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Received: 5 February 2014 / Accepted: 26 May 2014 / Published online: 24 June 2014

Abstract
Purpose Palliative care-related problems have not been measured in Africa in line with the WHO definition. This study aimed to measure the three-day period intensity of multidimensional problems (physical, psychological, social, and spiritual) among advanced cancer patients in Kenya and Uganda.
Methods Adults with advanced malignant disease gave self-report data to the African Palliative Outcome Scale (POS).
Results Among 210 respondents, more than half had an underlying HIV diagnosis (51.9 %). The worst ranked POS items were pain and information. In three multivariable ordinal logistic regression models with the 3 POS factors as dependent variables, for the first model (factor 1 physical and psychological well-being), as age increased, the well-being also improved ($B=0.022$, $p=0.037$), and as physical function score worsened, factor score also worsened ($B=-0.685$, $p<0.001$). In the second model (factor 2 interpersonal well-being), a trend toward significance was found for gender, with being male predicting a higher (better) factor score ($B=0.502$, $p=0.067$). For the third model (factor 3 existential and spiritual), increasing age was predictive of higher (better) factor score ($B=0.023$, $p=0.032$), and worsening function was predictive of lower (worse) factor score ($B=-0.543$, $p<0.001$).
Conclusions This novel data revealed pain and information to plan for the future to affect patients most severely, underlining the importance of analgesia and social support. HIV infection did not affect the level of need. Our data suggest increasing need as function declines; therefore, home-based models with adequate family support are essential.

Keywords Cancer · Palliative · Outcomes · Self-report · Africa

Introduction

The most recent data suggest that there were an estimated 591,000 cancer deaths in sub-Saharan Africa during 2012 [1]. Data to inform evidence-based clinical practice are urgently needed to improve outcomes for Africans affected by cancer, as by 2030 the developing world is expected to bear 70 % of the global cancer burden [2]. In sub-Saharan Africa, the link between cancer and poverty [3], and limited access to health services, result in cancers progressing to an incurable stage in 80 % of patients by the time of detection and diagnosis [4–6].

Malignancies are a common presentation of HIV [7]. Around 36 % of cancers in Africa are infection related, twice the global average [8]. In Africa, the lifetime risk of a woman dying of cancer is double that of their developed country counterparts [9]. A population-based analysis of cancer survival rates found survival in Africa to be poorer than comparators in Asia and Central America [10], with survival not exceeding 22 % for any cancer site in the Gambia or 13 % (except for breast) in Uganda.

Therefore, public health systems require adequate detection, treatment, and palliative care services. Advances have been achieved in palliative care service provision for cancer

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patients in some countries in Africa [11]. However, a systematic appraisal of the status of palliative care in sub-Saharan African countries found almost no data on the problems and outcomes of patients [12]. A further recent review of cancer palliative care research in Africa found minimal evidence, and identified an urgent need for research to underpin a public health strategy for cancer palliative care on the continent [13].

Among the scant available evidence, a high prevalence and burden of symptoms in advanced cancer has been reported in Eastern and Southern Africa [14], need for better information and communication [15], concerns regarding physical pain and financial problems [16], and an emphasis on spiritual well-being over physical dimensions of quality of life [17]. A five-country African World Health Organization (WHO) qualitative study discovered multidimensional problems of physical, psychological, social, and spiritual origin among dying patients [18], reflecting the WHO definition of palliative care [19]. However, although the WHO public health palliative care strategy requires evidence to achieve adequate integration into public health services for cancer patients [20], to date, no study in Africa has generated data on palliative care needs using a validated patient-reported outcome measure (PROM). The benefits of PROMS are that they promote quality and equity, ensuring that care reflects what matters to patients [20], and are especially important in advanced disease where goals of care and patient concerns are likely to change. Data from Africa show that PROMS, and the Africa Palliative Outcome Scale specifically, is being used to manage patient problems, evaluate treatment plans, audit services, facilitate health care professional/patient/family communication, and allocate resources [21].

This study aimed to measure the 3-day period intensity of self-report multidimensional problems (physical, psychological, social, and spiritual) among cancer patients receiving palliative care in two sub-Saharan African countries.

Patients and methods

This study used a cross-sectional design. This study was undertaken in three palliative care facilities, one in Uganda and two in Kenya, which are two Eastern African countries with similar levels of established cancer palliative care [22]. Ugandan data were collected at a hospice in the capital city, Kampala, which provides home and day care. Kenyan data were collected from two sites. The first Kenyan site is a hospice in the capital city Nairobi, which cares for patients at different points, i.e., at the hospice, home visits, hospital visits, and a mobile clinic in one of the largest informal settlements within the city environs. The second Kenyan site is a rural hospice situated in the Mount Kenya region in Central Province that operates as a satellite of the capital city hospice, providing holistic care within the hospice, day care services, hospital consultations as well as holding a monthly legal aid clinic. All the participating services aim to provide holistic palliative care in line with the WHO definition [19].

Recruitment

Inclusion criteria were consecutive adult patients (at least 18 years old) with a malignancy not responsive to curative treatment and in receipt of palliative care, with sufficient physical and cognitive ability to participate in interviews and provide informed consent. The study was approved by the Ethical Review Boards of the Ugandan National Council for Science and Technology, and the Kenyan clinical facility Research Ethics Committee.

Translation and data collection procedure

The following patient demographic and clinical data were collected: age, gender, household size, number of children responsible for (rather than number of biological children because African adults can often care for children other than their own, e.g., grandchildren, nephews and nieces), primary cancer site, and HIV serostatus. Functional status was measured using the ECOG, a common measure of physical function in oncology [23, 24]. The African Palliative Care Association African Palliative Outcome Scale (APCA African POS) was used to measure the 3-day period burden of multidimensional problems. The tool is based on the family of brief self-report POS measures, validated and implemented in various global settings [25, 26]. POS tools enable the patient and family to score their problems in line with the dimensions of the WHO definition of palliative care [20]. It was developed [27] and fully validated in advanced HIV and cancer patients and families across sub-Saharan Africa [28]. It has the advantages of being developed and validated within Africa, widely reported [29–33] and implemented in routine practice across the region [22].

Factor analysis of the patient-reported items of the APCA African POS revealed a stable three factor structure, each with good internal consistency [34]: (1) physical and psychological problems (three items: pain, other symptoms, and worry); (2) interpersonal (two items: help and advice for family to plan for future, and patient ability to share how they are feeling); and (3) existential and spiritual (two items: feeling life worthwhile and feeling at peace). The tools, information, and consent sheets were translated forward and backward into the main local languages in Uganda (Kiswahili, Dholuo, Runyakitara and Luganda) and Kenya (Kiswahili, Dholuo). Research nurses read out the questionnaire and entered the patient's self-report response on their behalf. Self-completion was not used due to potential limited literacy, and all questionnaires were administered by research nurses in order to reduce any potential bias through using a mixture of self-completion and researcher-completion.

Analysis

The scores were reversed for some APCA African POS scores so that, for all items, 0=worst and 5=best status. Descriptive analysis was undertaken for patient characteristics and APCA African POS item and factor scores, reporting medians and interquartile ranges due to the ordinal scoring. Associations with each factor of the APCA African POS were identified using ordinal logistic regression analyses. Three models were constructed, each model with the dependent variable of an APCA African POS factor. In this way, dimensions of well-being were examined rather than using a total score, which could potentially mask variations between domains. First, univariable analyses were conducted to test the association of sample characteristics with each factor. Due to non-normal distribution of POS factor scores, these were entered as tertiles of three equal groups with first tertile being lowest (worst) score and third tertile the highest (best) score. For factor one (physical and psychological: total of the three items *pain*, *symptoms*, and *worry*) the three level scores were 0–8 (n=77), 9–11 (n=69), and 12–15 (n=64); for factor two (interpersonal: total of the two items *sharing feelings* and *information to plan for the future*) scores 0–4 (n=72) 5–8 (n=72) 9–10 (n=66); for factor three (*existential* and *spiritual*: total of two items *feeling life worthwhile* and *feeling at peace*) 0–6 (n=84) 7–8 (n=58) 9–10 (n=68). As ordinal logistic regression provides a cumulative odds ratio, the independent variables' relationship to the dependent variable were first explored in contingency tables to determine a uni-directional association with ordinal/continuous dependent variables, then entered as follows: age (continuous covariate), gender (factor, two levels of male/female), household size (continuous covariate), whether patient is responsible for any children (factor, two levels of yes/no), HIV status (factor, two levels of positive/negative), functional status (covariate, five ordinal response levels reduced to four levels to make more efficient use of the data, with the two worst categories merged), and country (factor, two levels of Kenya/Uganda). Following each univariate analysis, multivariable models were constructed. Independent variables from the univariable analyses were entered into the multivariable model if significant at the 25 % level [35]. The overall fit of the model was evaluated using the likelihood ratio x^2test, with 5 % significance level considered significant to determine that the model with predictors improved on the intercept-only model. The estimate (log odds regression coefficient) and its 95 % confidence interval, Wald and p (≤0.05 to determine a significant independent variable) for the Wald were reported. For the multivariable models, we present the Nagelkerke pseudo r^2 as a measure of variance explained for a logistic outcome, and the score test of parallel lines to determine that assumption of proportional odds held, with $p>0.05$ set to meet the assumption. Where the assumption was not held (i.e., test of parallel lines $p \leq 0.05$), we conducted post hoc logistic regressions to compare the odds ratios and their respective confidence intervals at the two cutoffs for the dependent POS factor tertiles. The resulting odds ratios and 95 % CI in the multivariable logistic regression were then compared to each other and to the cumulative odds ratio from the multivariable ordinal logistic regression. For all analyses, cases with missing data were excluded.

Role of the funding source

No funder had any role in the design, conduct, analysis, interpretation, or reporting of the study.

Results

Sample characteristics

Uganda and Kenya each recruited 105 patients (N=210). The primary cancer sites using ICD-10 categories were female genitourinary n=50, mesothelial and soft tissue n=40, breast n=39, digestive organs n=33, lip oral cavity and pharynx n=18, head and neck n=12, male genitourinary n=10, hematoncological n=4, and respiratory n=4. The sample and their APCA African POS scores are described in Table 1. The majority were female (60.0 %), over half had an underlying HIV diagnosis (51.9 %), and in terms of physical function a small minority were disabled/limited self care (11.0 %).

Table 1 shows that the worst problems for patients were pain and information. The worst factor scores were for *Interpersonal*, followed by *Physical/psychological*.

Patient well-being and correlates

The univariate analyses with each of the factors as dependent variables are described in Table 2.

All 205 cases were entered into the final models. The three multivariable models are reported in Table 3. For the first model (factor 1 physical and psychological well-being), as age increased, well-being also improved (B=0.022, p=0.037), and as physical function worsened, well-being worsened (B=−0.685, p<0.001). In the second model (factor 2 interpersonal well-being), patients under care in Uganda predicted better well-being (B=1.725, p<0.001), and a trend toward significance was found for gender, with being male predicting better well-being (B=0.502, p=0.067). For the third model (factor 3 existential and spiritual), greater age was predictive of better

Table 1 Patient characteristics and POS scores (n=210)

	Descriptive analysis
Age in years	Mean=50.8, SD=14.0, min=18, max=86
Gender	n=126 female (60.0 %)
Household size	Mean 5.1, SD=3.3, min=0, max=25
Responsible for children	Yes n=179 (85.2 %)
HIV diagnosis	Yes n=109 (51.9 %)
ECOG functional status	
Fully active	n=54 (25.7 %)
Restricted	n=97 (46.2 %)
Ambulatory	n=36 (17.1 %)
Limited self care	n=14 (6.7 %)
Fully disabled	n=9 (4.3 %)
POS patient items (median, IQR)	
Pain	3.0, 3–4
Symptoms	4.0, 4–5
Worry	4.0, 4–5
Sharing feelings	4.0, 4–5
Life worthwhile	4.0, 4–5
At peace	4.0, 4–5
Information to plan	3.0, 3–4
POS factor scores	
Factor 1 physical and psychological (0–15)	10, 7–12
Factor 2 interpersonal (0–10)	6, 4–9
Factor 3 existential (0–10)	7, 5–9

For all POS items and factors in Table 1, lower score=worst status

factor score (B=0.023, p=0.032), and worsening function was predictive of worse well-being (B=−0.543, p<0.001).

All three multivariable models significantly improved on the intercept-only model. The assumption of proportional odds was met for all analyses apart from for factor 2 in relationship to the independent variables gender and country. Post hoc logistic regression analysis revealed that the cumulative odds in the multivariable regression concealed very different odds ratios for the two score cut points. For the cut point comparing lowest/worst score tertile versus middle and highest/best tertiles, the gender odds ratio (OR) in binary logistic regression was 1.188 (95 % CI 0.628, 2.248), whereas at the cut point for lowest (worst) and middle score tertiles versus highest (best) tertile in binary logistic regression, the OR=2.674 (95 % CI 1.353, 5.286). In factor 2, the difference in ORs in binary logistic regression was greater for the independent variable country. At cutoff point lowest (worst) score tertile versus middle and highest (best) tertiles, the OR= 3.801 (95 % CI 2.020, 7.154), while for lowest and middle tertiles versus highest (best) score tertile, the OR=9.464 (95 % CI 4.436, 20.192).

Discussion

These are the first data to describe advanced cancer patient self-report well-being in Africa using a fully validated PROM in line with the WHO definition of palliative care. The relatively young age of this sample of advanced cancer patients (mean age 50.8 years) is noteworthy, and this is also reflected in the large proportion (85.2 %) responsible for children. It is also notable that around half of the sample had an underlying HIV diagnosis. Pain and information to plan for the future were the worst problems, indicating that pain control continues to be a problem even in those who have been able to access palliative care. However, it may be that even though Kenya and Uganda have relatively better integration and coverage of palliative care services compared to other low and middle income countries [22], access is not possible for all with advanced disease; therefore, palliative care services may see those with more complex and refractory pain. The high need for information to plan for the future may reflect the demographics of our sample, i.e., they were relatively young and responsible for children. It also underlines the importance of care beyond physical relief of symptoms.

Poorer physical function was predictive of worse physical/psychological well-being and also predictive of worse existential well-being, but interestingly, no relationship was found with interpersonal well-being. Therefore, although some problems (physical/psychological and existential) worsen as functional status declines, this was not the case for interpersonal problems. This may be because the sharing of their feelings and planning had been adequately managed before their physical decline.

Increasing age was associated with better physical/psychological factor score, and with existential/spiritual factor score, suggesting that younger people require greater clinical attention to manage these problems, findings supported by a prior study in Uganda [36]. It may be that younger people face greater existential difficulties facing advanced disease, and have less ability to endure their pain and symptoms.

The associations with factor 2 (interpersonal) are significant but less clearly interpretable. Those in Uganda had greater odds of being in the top versus middle and bottom score tertiles, i.e., reported less problems with their ability to share feelings and plan for the future. This may be cultural in that Ugandans compared to Kenyans feel more able to discuss their feelings and to engage in planning discussions, it may reflect greater efforts in the care service to address these problems, or it may reflect less perceived needs for these aspects of well-being. Lastly, men were also more likely to be in the top versus the combined middle and bottom score tertiles. This may be because men had lower expectations or perceived need to discuss feelings, or that they felt less responsibility for planning.

Interestingly, an underlying HIV diagnosis was not associated with any of the factors, suggesting that in this sample,

Table 2 Univariable analysis (n=210) with POS factors as dependent variable in each model

Variables	Factor 1			Factor 2			Factor 3		
	Physical and psychological well-being			Interpersonal			Existential well-being		
	Estimate (95 % CI)	Wald	*p*	Estimate (95 % CI)	Wald	*p*	Estimate (95 % CI)	Wald	*p*
Age	0.017 (−0.002, 0.035)	3.228	0.072[a]	0.003 (−0.014, 0.021)	0.133	0.715	0.014 (−0.004, 0.032)	2.450	0.118[a]
Gender (ref: female)	−0.068 (−0.576, 0.440)	0.069	0.793	0.664 (0.149, 1.178)	6.394	0.011[a]	−0.381 (−0.894, 0.132)	2.117	0.146[a]
Household size	−0.061 (−0.140, 0.018)	2.289	0.130[a]	0.082 (0.002, 0.162)	4.036	0.045[a]	−0.037 (−0.116, 0.041)	0.883	0.347
Children (ref: yes)	0.513 (−1.193, 1.218)	2.029	0.154[a]	−0.007 (−0.708, 0.694)	0.001	0.984	0.279 (−0.424, 0.982)	0.605	0.437
HIV status (ref: positive)	−0.396 (−0.826, −0.254)	2.409	0.121[a]	0.086 (−0.411, 0.584)	0.116	0.734	−0.309 (−0.810, 0.192)	1.461	0.227[a]
Physical function	−0.540 (−0.826, −0.254)	13.706	<0.001[a]	0.196 (−0.076, 0.467)	2.002	0.157[a]	−0.459 (−0.743, −0.176)	10.062	0.002[a]
Country (ref: Kenya)	−0.018 (−0.516, 0.479)	0.005	0.942	1.789 (1.236, 2.342)	40.184	<0.001[a]	−0.264 (−0.764, 0.236)	1.071	0.301

[a] Significant at 25 % level and subsequently entered into multivariable model

Table 3 Multivariable models (n=210) with POS factors as dependent variable in each model

Variables	Factor 1			Factor 2			Factor 3		
	Physical and psychological well-being			Interpersonal			Existential well-being		
	Estimate (95 % CI)	Wald	p	Estimate (95 % CI)	Wald	p	Estimate (95 % CI)	Wald	p
Age	0.022 (0.001, 0.043)	4.342	0.037*	–	–	–	0.023 (0.002, 0.043)	4.601	0.032*
Gender (ref: female)	–	–	–	0.502 (−0.034, 1.038)	3.363	0.067	−0.299 (−0.825, 0.227)	1.239	0.266
Household size	−0.050 (−0.132, 0.033)	1.400	0.237	0.039 (−0.045, 0.123)	0.818	0.366	–	–	–
Children (ref: yes)	0.611 (−0.122, 1.344)	2.668	0.102	–	–	–	–	–	–
HIV status (ref: positive)	−0.266 (−0.822, 0.290)	0.878	0.349	–	–	–	−0.088 (−0.644, 0.468)	0.097	0.756
Physical function	−0.685 (−0.993, −0.337)	19.030	<0.001*	0.187 (−0.098, 0.472)	1.650	0.199	−0.543 (−0.845, −0.242)	12.472	<0.001*
Country (ref: Kenya)	–	–	–	1.725 (1.164, 2.285)	36.381	<0.001*	–	–	–
Model summary									
Nagelkerke	14 %			24 %			10 %		
Model fitting	X^2=28.174, df=5, p<0.001			X^2=50.800, df=4, p<0.001			X^2=18.357, df=4, p=0.001		

*Significance is at least at the 5 % level patients with a dual diagnosis experienced a similar intensity of problems. Prior studies of symptom burden in HIV [37] and cancer [14] samples under palliative care in East and Southern Africa found slightly higher burden indices for the HIV group compared to the cancer group for both physical and psychological burden indices (using the Memorial Symptom Assessment Scale short form), although the clinical or statistical significance of this difference is not known.

There are a number of limitations to our study. First, these are patients who have been able to access palliative care, and therefore, they may differ from other oncology patients unable to access this service with limited coverage, and we may present an underestimation of problem intensity compared to patients not receiving palliative care. Second, we recognize the cross-sectional design means we can only determine associations and not causality. Third, we recognize the challenges of self-report outcome measurement among patient populations with potentially limited literacy, and so reduced bias through use of well-validated tools and researcher administration. Fourth, as with all studies of advance disease collecting self-report data, we may have underestimated some problems through exclusion of far-advanced patients unable to participate in data collection.

This novel self-report data from patients with advanced disease under palliative care in sub-Saharan Africa has revealed pain and information to plan for the future to be the problems that affect patients most severely. This supports prior qualitative investigation [15] and underlines the importance of pain relief and social support in advanced cancer for patients in sub-Saharan Africa. However, these data also highlight the importance of multidimensional care for people with progressive illness, and that attention to physical problems alone is not adequate. Cancer palliative care models originated in Western high income countries, and are now increasingly available in response to the enormous need for advanced cancer care in sub-Saharan Africa. The provision of care must be responsive to local settings, and this may mean palliative care that is responsive to the needs of younger patients with an underlying HIV diagnosis, although our data suggest that the presence of underlying HIV infection may not affect the level of need presented. Inpatient palliative care is a far rarer model in Africa than in high income countries, and as our data suggest increasing need as function declines, home-based models with adequate support to families and community teams are required.

Acknowledgments We are grateful to the clinical services at participated and to the patients and families who gave data. No funding was provided for this study.

Conflicts of interest None declared.

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