Original Article

How to Analyze Palliative Care Outcome Data for Patients in Sub-Saharan Africa: An International, Multicenter, Factor Analytic Examination of the APCA African POS

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Abstract

Context. The incidence of life-limiting progressive disease in sub-Saharan Africa presents a significant clinical and public health challenge. The ability to easily measure patient outcomes is essential to improving care.

Objectives. The present study aims to determine the specific factors (if any) that underpin the African Palliative Care Association African Palliative Outcome Scale to assist the analysis of data in routine clinical care and audit.

Methods. Using self-reported data collected from patients with HIV infection in eastern and southern Africa, an exploratory factor analysis was undertaken with

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1337 patients; subsequently, a confirmatory analysis was done on two samples from separate data sets ($n = 445$).

Results. Using exploratory factor analysis initially, both two- and three-factor solutions were examined and found to meet the criteria for simple structure and be readily interpretable. Then using confirmatory factor analysis on two separate samples, the three-factor solution demonstrated better fit, with Goodness-of-Fit Index values greater than 0.95 and Normative Fit Index values close to 0.90. The resulting three factors were 1) physical and psychological well-being, 2) interpersonal well-being, and 3) existential well-being.

Conclusion. This analysis presents an important new opportunity in the analysis of outcome data for patients with progressive disease. It has advantages over both the total scoring of multidimensional scaling (which masks differences between domains) and of item scoring (which requires repeated analyses). The three factors map well onto the underlying concept and clinical goals of palliative care, and will enable audit of facility care. J Pain Symptom Manage 2013;45:746–752.

Key Words
Palliative, progressive, HIV, cancer, factor analysis, Africa, outcome measure

Introduction

For patients with life-limiting progressive disease, palliative care is necessary throughout the disease trajectory because of the multidimensional (physical, psychological, social, and spiritual) problems that are experienced.[1–6] Therefore, palliative care is advocated by the World Health Organization for the 22.4 million people in sub-Saharan Africa who live with HIV infection, the 1.4 million of those who die annually,[7] and the 542,000 patients who die of cancer annually in sub-Saharan Africa and their family members.[8]

Despite the epidemiology of progressive disease in Africa, and the need to measure and improve outcomes for infected persons and their families, there has been a dearth of evidence[9] of outcomes and effectiveness. The ability to measure and improve care is essential in responding to the need for effective palliative care, and African patients also deserve measurable care that can be demonstrated to improve the outcomes that matter to them and their families. To enable clinicians and researchers to measure outcomes in patients with progressive conditions in Africa, the African Palliative Care Association African Palliative Outcome Scale (APCA African POS) was developed in eight sub-Saharan African countries[10] and validated at five sites.[11] The APCA African POS uses the approach of the original POS, which is a widely used tool that has been validated and applied in a number of regions around the world.[12]

The APCA African POS comprises 10 items, seven of which are oriented to the patient (and are the subject of the factor analysis presented here) and three to the family, and has good psychometric properties. Each item is scored from 0 to 5, with reversed scoring for some items to indicate worst possible outcome. Each of the items can be scored and considered separately, and they also can be summed to yield a total score. It is currently the only multidimensional tool that has been fully validated in the African palliative care populations. In addition to the English version, the APCA African POS has been translated into local languages in east and southern Africa.

For those who use tools to measure patient outcomes, factor analysis can reduce the number of variables to a number that reflects the underlying areas of interest being measured. Therefore, in addition to analyzing a tool using a summative score (or total score), or analyzing by all individual items, it is possible to measure a small number of variables (or factors) that describe the outcomes in a number of fields that can be appraised and responded to clinically. A recent factor analytic

study of the 10-item POS with patients in the U.K. reported two underlying factors: one reflecting psychological status and the other quality of care.[13] The present study aims to determine which specific factors (if any) underpin the APCA African POS to assist the analysis of data in routine clinical care and audit.

Methods

Design

This study was a secondary analysis of cross-sectional APCA African POS data from a sample of patients with incurable progressive illness at 17 HIV or palliative care facilities in three sub-Saharan countries (Kenya, Uganda, and South Africa). Data were collected as part of two larger studies: the HIV care and support Public Health Evaluation study[14] and the ENCOMPASS (Ensuring Core Outcomes and Measuring Palliation in Sub-Saharan Africa) validation study of the APCA African POS.[11] These are described separately below.

Settings

The Public Health Evaluation study was conducted in public health HIV facilities in Kenya and Uganda in 2009 to 2010. One hundred adult outpatients with a confirmed HIV diagnosis were consecutively recruited at each of the 12 largest PEPFAR (U.S. President's Emergency Plan for AIDS Relief)-funded sites (total $n = 1337$ patients) from a stratified random sample of facilities. Stratification was by the size of the patient population, and all 12 sites provided outpatient HIV care and support. The exclusion criteria were facilities that treated only the pediatric population or were inaccessible (e.g., insecure and no road access). Data included in the analysis were from the baseline data of this longitudinal study.

The ENCOMPASS study was conducted in three nonprofit palliative care services and one state service in South Africa, and one voluntary sector hospice service in Uganda during 2008–2009. Criteria for selecting the five participating sites were: established palliative care services that are able to support research, fulfill recruitment criteria for the study, and represent a range of service types (home-based care and inpatient units) and locations (rural, urban township and urban), to enhance the generalizability of findings.[15] All services aimed to offer holistic palliative care in line with the World Health Organization definition,[16] provided by multi-professional teams. Two cross-sectional surveys using the POS were conducted on two separate samples (Sample 1, $n = 215$; Sample 2, $n = 230$) and both data sets were analyzed in this study.

Data Collection and Management

Public Health Evaluation Study. Following informed consent, research staff took demographic details (age, gender, number of dependents, and Eastern Cooperative Oncology Group [ECOG] functional status[17]) and read aloud the APCA African POS, and respondents gave verbal responses, which the researcher recorded. All data were double entered into EpiData software (EpiData Association, Odense, Denmark), cleaned and checked. Any discrepancies during data checks were reconciled with reference to the original paper questionnaire. All participants were paid $5 for participation to cover the cost of transport, sustenance, and opportunity cost of attendance.

ENCOMPASS Study. After obtaining informed consent, the research staff took demographic details (age, gender, number of dependents, and ECOG functional status) and read aloud the APCA African POS, and respondents gave verbal responses, which the researcher recorded. Data were entered into Excel spreadsheets and checked for errors; discrepancies during data checks were reconciled with reference to the original paper questionnaire.

Ethics

Ethical approval for the Public Health Evaluation study was granted by King's College London (CREC/06/07-140), the Ugandan National Council for Science and Technology (SS 1964), and the Kenyan Medical Research Institute (KEMRI/RES/7/3/1). Ethical approval for the ENCOMPASS study was granted by the Universities of Cape Town (128/2006), KwaZulu Natal (E025/06) and Witwatersrand (M060366); the Ugandan National Council for Science and Technology (HS143), Hospice Africa Uganda; and the Hospice Palliative Care Association of South Africa (001/06).

Statistical Analysis

The data were imported into PASW® Statistics 18 (SPSS Inc., Chicago, IL) for exploratory factor analyses and AMOS™ 18 (SPSS Inc., Chicago, IL) for confirmatory analyses.

Analysis 1. In analysis 1, we used principal component analysis (PCA) and varimax rotation to explore the factor structure of the APCA African POS, as these typically result in relatively clear, interpretable solutions.[18,19] The exploratory factor analysis (EFA) examined two- and three-factor rotated solutions using the sample of 1337 participants from the Public Health Evaluation study.

Analysis 2. To compare the robustness of the two- and three-factor solutions, we examined both solutions using confirmatory factor analysis (CFA). The advantage of CFA over EFA is that it does not rely solely on a judgment based on visual inspection of the rotated factor loadings as in EFA, but produces a goodness-of-fit test that quantifies how well the data actually fit the hypothesized model. We obtained four indices of goodness of fit. These indices and cut-off values are recommended by Ullman, who also advises against relying on any one single index.[20] The first was the Chi-square in which we sought a low, nonsignificant value, which would indicate a close fit between the data and the model. However, as this index can be misleading with large samples, Ullman has proposed that, as a rule of thumb, a Chi-square to degrees of freedom ratio of less than 2.00 may be deemed to reflect a good fit to the model.[20] This ratio, therefore, was used as our second index. For our third index, we used the Goodness-of-Fit Index (GFI) in which we sought a high value, approaching 1.00 and preferably greater than 0.95, to indicate a good fit to the model. The fourth fit index we used was the Normative Fit Index (NFI) where values greater than 0.90 indicate a good fitting model.[20] Finally, for our fifth index, we used the root mean square of approximation (RMSEA), which may be thought of as a measure of badness of fit; therefore, we sought a very low value, approaching 0.00 and preferably less than 0.06 to indicate a good fit.

The CFA was performed on two separate data sets from the ENCOMPASS study ($n = 215$ and $n = 230$). A very small number of missing data points ($n = 5$) in the second ENCOMPASS data set were replaced with a "2" (i.e., the midpoint on the response scale). Using the midpoint of the scale has a neutral effect on any correlations employed in the subsequent factor analyses. It thus allowed us to retain and use the full data set, while not affecting any results.

Results

Sample Characteristics

Public Health Evaluation Study Sample. Of the 1337 participants, 696 were from Kenya and 641 from Uganda. For the entire sample, the mean age was 34.8 years (SD = 9.0); 68.3% were female; and they had a median of four dependents. Their functional status ECOG scores[17] were fully active, $n = 803$ (60.1%); restricted, $n = 408$ (30.5%); ambulatory, $n = 102$ (7.6%); limited self-care, $n = 21$ (1.6%); and completely disabled, $n = 2$ (0.2%) (missing, $n = 1$).

ENCOMPASS Study Sample 1. Of the 215 patients, 40 were from Uganda and 175 from South Africa. The mean age across the sample was 37.3 years (SD = 10.4); 66.0% were female; the mean number of dependents was 2.9 (SD = 2.0, range 1−12); and 11.2% of patients also had a cancer diagnosis. ECOG scores were fully active, $n = 23$ (10.7%); restricted, $n = 47$ (21.9%); ambulatory, $n = 51$ (23.7%); limited self-care, $n = 72$ (33.5%); and completely disabled, $n = 22$ (10.2%).

ENCOMPASS Study Sample 2. Of the 230 patients, 46 were from Uganda and 184 from South Africa. The mean age across the sample was 36.7 years (SD = 9.5); 70.9% were female; the mean number of dependents was 2.4 (SD = 1.9, range 0−12); and 15.2% also had a cancer diagnosis. ECOG scores were fully active, $n = 17$ (7.4%); restricted, $n = 55$ (23.98%); ambulatory, $n = 68$ (29.6%); limited self-care, $n = 72$ (31.3%); and completely disabled, $n = 18$ (7.8%).

Analysis 1

The results of the PCA for the Public Health Evaluation study sample ($n = 1337$) are presented in Table 1. Two components were identified with an eigenvalue greater than one, and

Table 1
Principal Component Analysis of the African Palliative Care Association African Palliative Outcome Scale ($n = 1337$)

Item	Component 1	Component 2
Q3 Worried about illness	0.71	
Q1 Pain	0.71	
Q6 Felt at peace	0.69	
Q2 Other symptoms	0.64	
Q7 Help and advice/family		0.74
Q4 Share feelings/family		0.67
Q5 Felt life worthwhile		0.41

All loadings rounded to two decimal places and loadings < 0.35 hidden for clarity.

together these two components accounted for 49% of the total variance. The scree plot also indicated a two-factor solution. Inspection of Table 1 reveals two components of which one is primarily concerned with internal physical symptoms and psychological well-being, and the other with the patient's external interactions and relationship with family. Although these results seemed to indicate a reasonably good two-factor solution, we examined both two- and three-factor rotated solutions to reduce the potential for "under-factoring."

The results of the two- and three-factor rotated solutions are presented in Table 2. The two-factor rotated solution is virtually identical to the solution from the PCA, and hence strongly suggests two orthogonal or uncorrelated factors. The first factor comprising items 1, 2, 3, and 6 is primarily concerned with the individual burden of disease in terms of physical well-being (pain and symptoms) and existential well-being (worry and peace) and the second factor with an interpersonal dimension. The three-factor solution, which accounted for 63% of the total variance, also seemed to provide a readily interpretable solution suggesting three factors—with Factor 1 reflecting symptoms, including physical and psychological symptoms; Factor 2 interpersonal; and Factor 3 an existential dimension. As both the two- and three-factor solutions met the criteria for simple structure and seemed interpretable, we compared both models on two independent data sets using CFA.

Table 2
Two- and Three-Factor Varimax Rotated Solutions for the African Palliative Care Association African Palliative Outcome Scale ($n = 1337$)

Item	Factor 1	Factor 2	
Q1 Pain	0.71		
Q3 Worried about illness	0.71		
Q6 Felt at peace	0.68		
Q2 Other symptoms	0.64		
Q7 Help and advice/family		0.74	
Q4 Share feelings/family	−0.35	0.66	
Q5 Felt life worthwhile		0.42	
Item	**Factor1**	**Factor 2**	**Factor 3**
Q1 Pain	0.75		
Q2 Other symptoms	0.73		
Q3 Worried about illness	0.67		
Q7 Help & advice/family		0.82	
Q4 Share feelings/family		0.74	
Q5 Felt life worthwhile			0.90
Q6 Felt at peace	0.51		0.59

All loadings rounded to two decimal places and loadings < 0.35 hidden for clarity.

Analysis 2

We tested a two-factor model in which items 1, 2, 3, and 6 comprise one factor and items 7 and 4 a second factor, and the two factors were correlated; and a three-factor model where items 1, 2 and 3 comprise one factor, items 4 and 7 a second, and items 5 and 6 a third factor. Both models were tested on both samples. The results for the two- and three-factor models tested in Sample 1 and Sample 2 are displayed in Table 3. Inspection of Table 3 demonstrates that the three-factor model showed much better fit across both of the samples. Indeed, the two-factor model shows quite a poor fit, as reflected in the NFI values well below 0.90, and RMSEA values both greater than 0.10. In contrast, the three-factor model has quite a good fit, as reflected in both GFI values greater than 0.95, and both NFI values close to 0.90.

Discussion

In the present study, we examined the stability of two- and three-factor solutions across 1337 patients with HIV infection. We observed a reasonably clear three-factor solution that comprised the following factors: Factor 1, physical and psychological well-being; Factor 2, interpersonal well-being; and Factor 3, existential well-being. These three factors were confirmed in two independent samples of 215 and 230 patients receiving palliative care. These results provide evidence of the major

Table 3
Results of the Two- and Three-Factor Confirmatory Factor Analyses for Two Samples

Index of Fit to the Model	Two Factors	Three Factors	Two Factors	Three Factors
Sample	ENCOMPASS Sample 1, ($n = 230$)	ENCOMPASS Sample 1, ($n = 230$)	ENCOMPASS Sample 2, ($n = 215$)	ENCOMPASS Sample 2, ($n = 215$)
Chi-square	94.82	35.47	55.60	24.50
df	13	11	13	11
P	0.00	0.00	0.00	0.01
Chi-square/df	7.29	3.22	4.28	2.22
GFI	0.89	0.96	0.93	0.97
NFI	0.62	0.86	0.68	0.86
RMSEA	0.17	0.10	0.12	0.08

ENCOMPASS = Ensuring Core Outcomes and Measuring Palliation in Sub-Saharan Africa; df = degrees of freedom; Chi-square/df = Chi-square to degrees of freedom ratio; GFI = Goodness-of-Fit Index; NFI = Normative Fit Index; RMSEA = root mean square of approximation.

dimensions that underpin the APCA African POS items, and hence support the construct validity of the measure. The APCA African POS is currently being used as an outcome tool for research to evaluate palliative care in eastern and southern Africa, as a primary outcome tool in clinical trials and as a routine clinical assessment tool.

There are a number of study limitations, and the results need to be considered in this context. Although the three-factor solution demonstrated a reasonably good fit and makes intuitive clinical sense, it was not a perfect fit. Only one GFI indicated excellent fit, with three (Chi-square to degrees of freedom ratio, NFI, and RMSEA) only falling close to the cutoff for very good fit. Thus, the three-factor model was clearly superior to the two-factor model but showed adequate rather than excellent fit. This might be because we completed the EFA on a large sample from Kenya and Uganda and ran the confirmatory analyses on two smaller samples from South Africa and Uganda—and there were differences in the clinical characteristics of the respective samples. For example, the samples from the ENCOMPASS study were more functionally restricted than in the Public Health Evaluation study. Hence, clinical differences in the EFA and CFA samples might explain the less than perfect fit achieved. Certainly it would be desirable to replicate these results with an independent sample.

Interestingly, the three-factor structure reported here (psychological well-being, interpersonal well-being, and existential well-being) is somewhat different from the two factors (psychological well-being and quality of care). This might reflect cultural differences, with family and spirituality being highly important for most African participants,[2] or it could reflect differences in the clinical composition of the African and U.K. samples. It is important to note here that the U.K. version of the POS has 10 items compared with the seven-item APCA African POS, and this also might account for some of the differences in factor structures reported.

On an individual patient basis, when using the tool to assess and inform care planning, we recommend that clinicians consider the total score for all seven items and check all seven items individually for elevated scores. However, we propose that the three-factor solution provides an appropriate conceptual summary of the important areas of clinical concern here, namely physical and psychological, interpersonal, and existential well-being. The advantage of the provision of dimensions (i.e., factors) over total scoring of a multidimensional tool is that a total score may mask the change that is not routinely of the same direction and magnitude across items. The ability to score factors offers a useful analytic approach that allows a reduced number of variables although still enabling clinicians and researchers to report patient outcomes according to the underlying domains that constitute multidimensional palliative care. Therefore, the use of these factors offers a reduced scoring system to three clear and stable factors, and we recommend that clinicians use these at audit level to enable a simple approach to measuring and improving care at the facility level. For researchers, the provision of these domains enables the analysis of three subscales that map clearly onto the goals of palliative care, and offers the opportunity to conduct

fewer analyses than using individual items while offering a more detailed analysis than using a total score. This analysis, therefore, provides a new opportunity to measure and improve care for patients with progressive, life-limiting illness in sub-Saharan Africa.

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