Brief Methodological Report

A Psychometric Evaluation of the Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale With Palliative Care Samples in Three African Countries

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Abstract

Context. Although sub-Saharan Africa suffers the greatest burden of progressive illness, there are few outcome measures with adequate properties to measure needs and outcomes.

Objectives. To examine the psychometric properties of the Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) among people receiving palliative care in three African countries.

Methods. Adult patients in South Africa, Kenya, and Uganda gave self-reported data to the core FACIT-G plus Pal subscale. Data were subjected to factor analysis, corrected item-total correlations, and Cronbach's α for full scale and subscales.

Results. The resulting four factors bear a strong similarity to the original Functional Assessment of Cancer Therapy-General in our sample of 461: physical symptoms, functional well-being, friends and family, and emotional well-being. Cronbach's α for the full 27-item scale was 0.90 and for the physical well-being, social/family well-being, emotional well-being, and functional well-being subscales, it was 0.83, 0.78, 0.80, and 0.87, respectively. Varimax rotation of the 19-item FACIT-Pal scale showed three clear interpretable factors. Factor 1, a sense of purpose and meaning in life; Factor 2, physical symptoms; and Factor 3, social integration. For the 19-item FACIT-Pal, Cronbach's α was 0.81, and individual corrected item-total correlations ranged from 0.24 to 0.61. Cronbach's α for the eight items comprising

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Factor 1 (meaning in life) was 0.83. For the other two factors, it was 0.70 (physical symptoms, six items) and 0.68 (social integration, three items).

Conclusion. The FACIT-Pal is a reliable multidimensional scale for people with life-limiting incurable diseases in sub-Saharan Africa, and the observed factors are interpretable and clinically meaningful. J Pain Symptom Manage 2014;48:983–991.

Key Words

Palliative, Africa, self-report, quality of life, cancer, HIV

Introduction

The accurate measurement of quality of life among people with chronic and incurable illness is essential for evaluating service delivery and testing the effectiveness of interventions. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System provides a psychometrically robust instrument for the measurement of health-related quality of life (HRQoL) in a range of chronic and/or incurable conditions.[1] The FACIT was originally developed as a 27-item measure of HRQoL for people with cancer known as the Functional Assessment of Cancer Therapy-General (FACT-G).[2] Since then, the FACT-G has been modified for a broad range of cancers as well as multiple sclerosis and HIV/AIDS by adding an additional set of specific items tailored to each condition.[2]

Use of the FACIT system to measure HRQoL has now been extended to palliative care with the addition of 19 specific palliative care items to the existing 27 FACT-G items: the newer 46-item FACIT-Pal. However, to date, there has been only a single study reporting on the psychometric properties of the FACIT-Pal. In the study, Lyons et al.[3] reported on the internal consistency, factor structure, and construct validity of the FACIT-Pal for a sample of 256 people taking part in a randomized controlled trial of a palliative care intervention for advanced cancer in the U.S.

A pilot investigation has shown that the FACT-G can be translated into African languages,[4] and although the study established adequate internal consistency of the existing factor structure in one African country, the factor structure was presumed to fit for this population and to date no study has determined whether the proposed FACIT-Pal factor structure is reproducible among African populations. Within sub-Saharan Africa, there is an imperative to generate local robust evidence. Despite around 1.2 million HIV-related deaths during 2012,[5] and more than 500,000 cancer deaths,[6] there is a dearth of evidence of needs and outcomes.[7–9] Although some data have been generated on the needs and symptoms of African HIV and cancer populations,[10–13] advanced disease populations have been rarely investigated using locally well-validated outcome measures. Moreover, because of the challenges of opioid supply and accessibility in Africa, the palliative care research agenda has been dominated by the study of pain and access to medication.[14–19] This risks the potential for patient management and palliative care to be reduced to pain relief, to the detriment of a broader understanding of the trajectory symptomatology of incurable progressive disease and the patient holistic experience of advanced illness. Therefore, the selection of patient-reported outcome measures that are fit for purpose and reflect patient concerns is essential in promoting quality and equity.[20]

The aim of the present study was to examine the psychometric properties of the FACIT-Pal with a large sample of people receiving palliative care in three African countries. In particular, we sought to test the internal consistency of the FACIT-Pal and its subscales and to explore its dimensionality or factor structure.

Methods

Design

This regional study used a cross-sectional self-reported design among adult patients in South Africa, Kenya, and Uganda.

Table 1
Demographic and Clinical Characteristics of Participants From Uganda, Kenya, and South Africa

Country	Uganda ($n = 154$)	Kenya ($n = 153$)	South Africa ($n = 154$)
Mean age (SD, range)	46.25 (14.39, 19–86)	48.94 (13.02, 18–85)	45.44 (15.67, 19–94)
Gender: M (%), F (%)	68 (44), 86 (56)	52 (34), 101 (66)	26 (17), 127 (83)
Primary HIV diagnosis: yes (%)	114 (74)	91 (59)	99 (65)
Primary cancer diagnosis: yes (%)	40 (26)	62 (41)	55 (36)
Household size, mean (SD)	5.96 (4.4)	4.27 (2.25)	4.30 (2.49)
Children responsible for, mean (SD)	4.34 (4.03)	2.78 (2.26)	1.51 (1.54)
Functional status, *n* (%)			
Fully active	40 (26)	73 (48)	17 (11)
Restricted	73 (47)	46 (30)	36 (23)
Ambulatory	23 (15)	25 (16)	34 (22)
Limited self-care	11 (7)	7 (5)	60 (39)
Completely disabled	7 (4.5)	2 (1)	5 (3)
Missing	—	—	1
Place of care, *n* (%)			
Home	11 (7)	1 (1)	137 (89)
Inpatient	7 (4.5)	—	1
Day care	45 (29)	43 (28)	—
Outpatient	61 (40)	109 (71)	—
Other	30 (19.5)	—	14 (9)
Missing	—	—	2

Setting

South African data were collected at two palliative care facilities of similar size and serving communities in metropolitan areas with a range of socioeconomic status, including informal settlements. The first hospice has 10 inpatient beds and serves community patients in the Western Cape Province. The second South African site is a hospice with an eight-bed inpatient unit and a community team serving patients in a metropolitan community in the Eastern Cape Province. 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, that is, at the hospice, home visits, hospital visits, and they have a mobile clinic in one of the largest informal settlements within the city environments. 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, and holding a monthly legal aid clinic. All the participating services aim to provide holistic palliative care in line with the World Health Organization definition.[21]

Recruitment

Inclusion criteria were adult patients (at least 18 years old) with a confirmed HIV and/or cancer diagnosis known to the patient, under palliative care, with sufficient physical and cognitive ability to participate in interviews. Patients were recruited consecutively. All information and consent forms and tools were translated from English (forward and back) into the principal languages of isiXhosa, Afrikaans, Kiswahili, Kikuyu, Runyakitara, Luganda, Kiswahili, and Kikuyu. Existing FACIT-Pal translations were used, where available from the tool provider.[4] Informed consent was obtained from all participants. Translation was carried out by the collaborating African research organizations and crosschecked by staff fluent in both English and the relevant local language. The study was reviewed and approved by the Ethical Review Board of the Hospice Palliative Care Association of South Africa, the Uganda National Council for Science and Technology, and the Kenyan Medical Research Institute.

Data Collection

The following patient demographic and clinical data were collected: age, gender, primary diagnosis (HIV or cancer), household size, number of children responsible for, and primary place of palliative care (home, inpatient/outpatient unit, day care facility). We

Table 2
Distribution of 27 FACT-G Items

FACT-G Item	*N*	Missing	Not at All, *n* (%)	A Little Bit, *n* (%)	Somewhat, *n* (%)	Quite a Bit, *n* (%)	Very Much, *n* (%)
1. I have a lack of energy	460	1	113 (24.6)	69 (15.0)	77 (16.7)	60 (13)	141 (30.7)
2. I have nausea	460	1	28 (6.1)	36 (7.8)	41 (8.9)	51 (11.1)	304 (66.1)
3. Because of my physical condition, I have trouble	460	1	171 (37.2)	71 (15.4)	41 (8.9)	53 (11.5)	124 (27.0)
4. I have pain	458	3	99 (21.6)	81 (17.7)	73 (15.9)	81 (17.7)	124 (27.1)
5. I am bothered by side effects of treatment	460	1	56 (12.1)	42 (9.1)	41 (8.9)	56 (12.2)	265 (57.6
6. I feel ill	457	4	63 (13.8)	82 (17.9)	68 (14.9)	74 (16.2)	170 (37.2)
7. I am forced to spend time in bed	459	2	67 (14.6)	39 (8.5)	41 (8.9)	63 (13.7)	249 (54.2)
8. I feel close to my friends	459	2	58 (12.6)	39 (8.5)	52 (11.3)	72 (15.7)	238 (51.9)
9. I get emotional support from my family	459	2	45 (9.8)	26 (5.7)	41 (8.9)	65 (14.2)	282 (61.4)
10. I get support from my friends	460	1	72 (15.7)	33 (7.2)	54 (11.7)	84 (18.3)	217 (47.2)
11. My family has accepted my illness	459	2	21 (4.6)	10 (2.2)	36 (7.8)	53 (11.5)	339 (73.9)
12. I am satisfied with family communication about illness	459	2	31 (6.8)	10 (2.2)	30 (6.5)	63 (13.7)	325 (70.8)
13. I feel close to my partner (or my main supporter)	448	13	65 (14.5)	13 (2.9)	20 (4.5)	52 (11.6)	298 (66.5)
14. I am satisfied with my sex life	421	40	159 (37.8)	17 (4.0)	21 (5.0)	23 (5.5)	201 (47.7)
15. I feel sad	459	2	72 (15.7)	47 (10.2)	64 (13.9)	60 (13.1)	216 (47.1)
16. I am satisfied with how I am coping with my illness	459	2	24 (5.2)	28 (6.1)	40 (8.7)	75 (16.3)	292 (63.6)
17. I am losing hope in the fight against my illness	459	2	45 (9.8)	27 (5.9)	28 (6.1)	38 (8.3)	321 (69.9)
18. I feel nervous	457	4	45 (9.8)	44 (9.6)	45 (9.8)	59 (12.9)	264 (57.8)
19. I worry about dying	459	2	52 (11.3)	27 (5.9)	27 (5.9)	37 (8.1)	316 (68.8)
20. I worry that my condition will get worse	459	2	77 (16.8)	34 (7.4)	40 (8.7)	52 (11.3)	256 (55.8)
21. I am able to work (include work at home)	455	6	118 (25.9)	82 (18.0)	69 (15.2)	76 (16.7)	110 (24.2)
22. My work (include work at home) is fulfilling	440	21	110 (25.0)	79 (18.0)	66 (15.0)	61 (13.9)	124 (28.2)
23. I am able to enjoy life	459	2	85 (18.5)	61 (13.3)	60 (13.1)	72 (15.7)	181 (39.4)
24. I have accepted my illness	458	3	5 (1.1)	17 (3.7)	36 (7.9)	48 (10.5)	352 (76.9)
25. I am sleeping well	458	3	51 (11.1)	33 (7.2)	75 (16.4)	73 (15.9)	226 (49.3)
26. I am enjoying the things I usually do for fun	459	2	101 (22.0)	59 (12.9)	58 (12.6)	79 (17.2)	162 (35.3)
27. I am content with the quality of my life right now	459	2	53 (11.5)	41 (8.9)	72 (15.7)	62 (13.5)	231 (50.3)

FACT-G = Functional Assessment of Cancer Therapy-General.

elected to collect data on the number of children who respondents were responsible for, rather than the number of biological children. This was because in Africa adults may often care for children other than their own, for example, grandchildren, nephews, and nieces, a situation that has been exacerbated by AIDS-related deaths.

The following tools were administered. Functional status was measured using the Eastern Cooperative Oncology Group scale, a very commonly used measure of physical function.[22,23] The FACT-G is a 27-item tool that measures the seven-day period prevalence and intensity of problems across four primary quality of life domains: physical well-being, social/family well-being, emotional well-being, and functional well-being.[2] It has been used and validated in other chronic conditions such as HIV. The additional 19 items of the FACIT-Pal module measure palliative care-related outcomes and are not specific to cancer.

Research nurses (i.e., clinically experienced palliative care nurses trained in research methods) read out the questionnaire items and entered the patient's self-reported response on their behalf. Self-completion was not used because of limited literacy, and all questionnaires were completed using research nurses to enter responses to reduce any potential bias through using a mixture of self-completion and researcher completion. Research nurses then entered data into purpose-designed EXCEL databases, and they were subsequently imported into IBM SPSS Statistics 19 for analysis (IBM, Armonk, NY).

Analysis

For the psychometric analyses, the three African samples were merged to create a single

Table 3
Distribution of the 19 "Pal" Items

Item	*N*	Missing	Not at All, *n* (%)	A Little Bit, *n* (%)	Somewhat, *n* (%)	Quite a Bit, *n* (%)	Very Much, *n* (%)
I maintain contact with my friends	458	3	50 (10.9)	45 (9.8)	53 (11.6)	63 (13.8)	247 (53.9)
I have family members who will take on my responsibilities	459	2	65 (14.2)	20 (4.4)	44 (9.6)	62 (13.5)	268 (58.4)
I feel that my family appreciates me	459	2	26 (5.7)	17 (3.7)	28 (6.1)	63 (13.7)	325 (70.8)
I feel like a burden to my family	458	3	79 (17.2)	35 (7.6)	43 (9.4)	33 (7.2)	268 (58.5)
I have been short of breath	459	2	25 (5.4)	26 (5.7)	38 (8.3)	47 (10.2)	323 (70.4)
I am constipated	459	2	37 (8.1)	33 (7.2)	56 (12.2)	54 (11.8)	279 (60.8)
I am losing weight	458	3	75 (16.4)	59 (12.9)	44 (9.6)	84 (18.3)	196 (42.8)
I have been vomiting	458	3	22 (4.8)	22 (4.8)	15 (3.3)	34 (7.4)	365 (79.7)
I have swelling in parts of my body	459	2	30 (6.5)	48 (10.5)	42 (9.2)	45 (9.8)	294 (64.1)
My mouth and throat are dry	459	2	60 (13.1)	36 (7.8)	58 (12.6)	71 (15.5)	234 (51.0)
I feel independent	458	3	84 (18.3)	59 (12.9)	47 (10.3)	76 (16.6)	192 (41.9)
I feel useful	459	2	36 (7.8)	36 (7.8)	38 (8.3)	59 (12.9)	290 (63.2)
I make each day count	459	2	9 (2.0)	29 (6.3)	37 (8.1)	63 (13.7)	321 (69.9)
I have a peace of mind	458	3	34 (7.4)	30 (6.6)	41 (9.0)	69 (15.1)	284 (62.0)
I feel hopeful	458	3	17 (3.7)	18 (3.9)	30 (6.6)	49 (10.7)	344 (75.1)
I am able to make decisions	459	2	3 (0.7)	11 (2.4)	22 (4.8)	42 (9.2)	381 (83.0)
My thinking is clear	457	4	7 (1.5)	10 (2.2)	19 (4.2)	46 (10.1)	375 (82.1)
I have been able to reconcile (make peace) with other people	459	2	17 (3.7)	16 (3.5)	32 (7.0)	66 (14.4)	328 (71.5)
Able to openly discuss my concerns with people closest to me	459	2	15 (3.3)	12 (2.6)	21 (4.6)	39 (8.5)	372 (81.0)

Pal = palliative care.

sample. As there were almost no missing data, for those few participants with missing data on one or two items, the sample mean for that item was imputed.

The 27 FACIT-G and the 19 Pal items were analyzed separately. For both questionnaires, we completed the following analyses: 1) factor analysis, 2) corrected item-total correlations, and 3) Cronbach's α for the full scale and its subscales/factors. The Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity were used to ensure that both correlation matrices were suitable for factor analysis.[24]

For the factor analysis of the 27-item FACT-G, we extracted four factors because it has four subscales, and it is based on inspection of the Scree test. As subscales have not been reported for the 19 Pal items, we extracted three factors based on the Scree test and the two additional criteria of simple structure and interpretability. Both factor analyses used principal components analysis with varimax rotation as these typically result in clear and interpretable solutions.[25]

Results

Samples of 154, 154, and 153 participants were recruited in South Africa, Uganda, and Kenya, respectively, giving a total sample of 461. Their sample characteristics are described in Table 1. In all the three countries, most of the sample was female and had HIV disease. Household sizes were similar, although Ugandan respondents were responsible for a greater number of children compared with the Kenyan and South African samples. The Kenyan sample had the best physical function and South Africa the least, and more patients in South Africa were under homecare compared with the other sites. These data reflect the contextual and palliative care model differences between African countries.[26]

Tables 2 and 3 present the score distribution and numbers of missing responses for each item.

Table 4 presents the results of the four-factor analysis of the 27 items of the FACT-G. Inspection of Table 2 shows evidence of four clear factors that bear a strong similarity to the four original subscales of the FACT-G. These four factors accounted for 55% of the total variance in responding. The first factor comprises items concerned with physical symptoms or well-being (e.g., *I feel ill*), the second comprises items concerned with functional well-being (e.g., *I am able to work*), the third is mostly items concerned with friends and family (e.g., *I get emotional support from my family*),

Table 4

Results of Four-Factor Analysis With Varimax Rotation of the 27-Item FACT-G[a]

	Factor[a]			
Item	1	2	3	4
I have a lack of energy	0.646			
I have nausea	0.519			
Because of my physical condition, I have trouble	0.639			
I have pain	0.756			
I am bothered by side effects of treatment	0.597			
I feel ill	0.771			
I am forced to spend time in bed	0.654			
I feel close to my friends			0.709	
I get emotional support from my family			0.785	
I get support from my friends			0.691	
My family has accepted my illness			0.753	
I am satisfied with family communication about illness			0.790	
I feel close to my partner (or my main supporter)			0.588	
I am satisfied with my sex life		0.451		
I feel sad				0.517
I am satisfied with how I am coping with my illness		0.570		
I am losing hope in the fight against my illness				0.729
I feel nervous				0.573
I worry about dying				0.823
I worry that my condition will get worse				0.818
I am able to work (include work at home)	0.561	0.593		
My work (include work at home) is fulfilling	0.563	0.596		
I am able to enjoy life		0.698		
I have accepted my illness		0.662		
I am sleeping well		0.517		
I am enjoying the things I usually do for fun	0.464	0.669		
I am content with the quality of my life right now		0.617		

FACT-G = Functional Assessment of Cancer Therapy-General.

[a] All item-factor loadings < 0.45 concealed for clarity.

and the fourth factor comprises items about emotional well-being (e.g., *I worry that my condition will get worse*).

Corrected item-total correlations ranged from 0.24 to 0.71 with only three correlations below 0.30 (I get emotional support from my family, my family has accepted my illness, I am satisfied with family communication about my illness). Cronbach's α for the full 27-item scale was 0.90, and for the physical well-being, social/family well-being, emotional well-being, and functional well-being subscales, it was 0.83, 0.78, 0.80, and 0.87, respectively.

Table 5 presents the results of the three-factor analysis with varimax rotation of the 19-item FACIT-Pal scale. Inspection of Table 3 shows three clear and interpretable factors that account for 45% of the total variance in responding. Factor 1 represents a sense of purpose and meaning in life (e.g., I make each day count, I feel hopeful), Factor 2 is concerned with physical symptoms (e.g., *I am losing weight, I am constipated*), and Factor 3 with social integration (*I feel that my family appreciates me, I have family members who will take on my responsibilities*). For the full 19-item FACIT-Pal, Cronbach's α was 0.81, and individual corrected item-total correlations ranged from 0.24 to 0.61. Cronbach's α for the eight items comprising Factor 1 (meaning in life) was 0.83. For the other two factors, it was 0.70 (physical symptoms, six items) and 0.68 (social integration, three items).

Discussion

In the present study, we aimed to examine the psychometric properties of the FACIT-Pal, in particular, its reliability and factor structure, using a large sample combining participants from palliative care settings in three different African countries. To our knowledge, this is the first time that the FACIT-Pal has been evaluated psychometrically with African participants. We were able to demonstrate that the FACIT-Pal has a robust factor

Table 5
Results of Three-Factor Analysis With Varimax Rotation of the 19-Item Pal[a]

	Factor		
Item	1	2	3
I maintain contact with my friends			0.450
I have family members who will take on my responsibilities			0.802
I feel that my family appreciates me			0.853
I feel like a burden to my family			
I have been short of breath		0.519	
I am constipated		0.632	
I am losing weight		0.693	
I have been vomiting		0.599	
I have swelling in parts of my body		0.561	
My mouth and throat are dry		0.618	
I feel independent	0.456		
I feel useful	0.725		
I make each day count	0.786		
I have a peace of mind	0.636		
I feel hopeful	0.759		
I am able to make decisions	0.701		
My thinking is clear	0.644		
I have been able to reconcile (make peace) with other people	0.488		
Able to openly discuss my concerns with people closest to me			0.519

Pal = palliative care.
[a] All item-factor loadings < 0.45 concealed for clarity.

structure and that the factors observed are both interpretable and clinically meaningful. The FACIT core 27 items demonstrated four factors that reflected physical, emotional, social, and functional well-being, which is quite consistent with the original FACIT subscales, scoring protocol, and theoretical underpinnings. The 19 FACIT-Pal items were analyzed separately and showed three clear factors representing meaning in life, physical symptoms, and social integration. Importantly, we also observed high internal consistency for both the two scales and also the items comprising the different factors observed for each scale. This is especially important if these measures are to be used in clinical trials because high internal consistency equates to low measurement error, which means increased statistical power, smaller confidence intervals, and larger effect sizes.[27]

Our results were similar but not identical to the only previous factor analysis of the FACIT-Pal by Lyons et al. with a U.S. sample. Notwithstanding the cultural differences in the two studies, this is most likely because of the fact that Lyons et al.[3] combined all the 27 FACIT and all the 19 Pal items into one factor analysis of the total 46 items. In contrast, we chose to factor analyze the two instruments separately, and indeed the FACIT resources propose that when using the FACIT-Pal, the FACT-G core items should be summed into the original subscales and the Pal items reported separately. Both analytic strategies are valid, with the former focusing on what the measures have in common and our approach focusing on their unique aspects.

In our limitations, we note that to sample a palliative care population, we had to apply inclusion criteria that may have introduced a sampling bias, which means our data did not reflect the problems of those with the poorest capacity. By collecting only self-reported data, we avoided any potential bias of using both self-reported and caregiver/professional reported responses. We were unable to analyze the data within country by language as 10 subjects are usually required per tool item for exploratory analysis, and this would require a much larger future study to confirm the structure for each language.

Our findings offer potential for greater use of outcome measures in palliative care populations in sub-Saharan Africa, adding to prior studies showing good psychometric properties of the African Palliative Care Association African Palliative Outcome Scale,[28–30] which is currently the most commonly used tool in Africa,[31] the Missoula-Vitas,[32,33] and the Spirit 8.[34]

In conclusion, we note how clearly the dimension of "meaning in life" is measured by the Pal, demonstrating the utility of the Pal items in this population. This is particularly important for palliative care as this existential dimension is likely to become increasingly important to people as their physical functioning declines, and spiritual/existential concerns have previously been found to be of greatest concern when measuring quality of life among palliative care populations in Africa.[35] Our data provide evidence that the FACIT-Pal is a multidimensional scale with a robust factor structure and reliable subscales for use among people with life-limiting incurable disease in sub-Saharan Africa.

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