

Cross Cultural Adaptation and Cognitive Testing of a Psycho-Social-Spiritual Healing Measure, the NIH Healing Experiences in All Life Stressors-NIH-HEALS

Global Advances in Health and Medicine

Volume 11: 1–11

© The Author(s) 2022

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/21649561211067189

journals.sagepub.com/home/gam



Eve Namisango, PhD^{1,2} , Emmanuel B. K. Luyirika, FAMMED¹, and Ann Berger, MD³

Abstract

Background: Cancer is associated with trauma and stress which impacts the physical, psychological, and spiritual/existential well-being of patients. Psychological/behavioral healing may help alleviate this distress and the associated health-related suffering. Psycho-Social-Spiritual healing outcome measures are thus needed to stimulate service development. The NIH Healing Experiences in All Life Stressors (NIH-HEALS), is a novel 35-item measure of psycho-social-spiritual healing, developed in USA and is yet to be validated and adapted for use in African countries.

Objectives: This study aimed to assess the face and content validity of the NIH-HEALS in the population of cancer patients in Uganda and to culturally adapt this measure.

Methods: Cross-sectional study using cognitive interviewing alongside standard piloting. We recruited adult (18 years and above) patients with advanced cancer from Hospice Africa Uganda. Interviews were conducted in two phases, using the think aloud technique and concurrent probing and were audio recorded. Phase 1 was used to identify initial concerns around clarity of the statements, and phase 2 further explored whether the issues of clarity had been addressed, alongside the standard cognitive interview parameters. The transcripts were imported into NVivo-12 analyzed using the content analysis technique and categorized using Tourengau's information processing model.

Results: We recruited thirty-five (35) patients: phase one (n = 5) two (n = 30). The median completion time was 20 minutes. Problems identified included comprehension of some statements, words, and phrases, suggestions to include local examples, highlighting of potentially sensitive statements that lean towards difficult conversations, and some cultural differences in the construction of the "Trust and Acceptance" construct, our sample showed less emphasis on family/friend relations. This feedback was used to adapt the NIH-HEALS for the local context.

Conclusion: The NIH-HEALS has sufficient face and content validity properties to be used among palliative cancer patients in Uganda. We propose some changes to inform the adaptation of this measure for the local context.

Keywords

NIH healing experiences in all life stressors, psycho-social-spiritual healing, cross-cultural-use-Africa

Received August 3, 2021. Accepted for publication November 29, 2021

¹African Palliative Care Association, Kampala Uganda

²African Field Epidemiology Network, Kampala, Uganda

³National Institutes of Health Clinical Center, Bethesda, MD, USA

The award was granted to Ann Berger

Corresponding Author:

Eve Namisango, PhD, African Palliative Care Association, Plot 95, Dr Gibbons Road, Kampala, Uganda.

Email: eve.namisango@africanpalliativecare.org



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (<https://creativecommons.org/licenses/by-nc/4.0/>) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and

Open Access pages (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

Background

Cancer remains a leading cause of death in resource limited settings, and according to the GLOBOCAN, globally there were over 1,109,209 new cases and 71,1429 deaths in 2020.¹ Africa is projected to have the highest proportional increase in the cancer cases and deaths globally.² The cancer care in sub-Saharan African is characterized by late-stage presentation, which limits the utility of curative options.³ In Uganda, there are over 34,000 new cases of cancer per year and 22,992 deaths.⁴ The deaths are seen more rapidly among older persons but also among the youth and middle-aged population, partly because of the high prevalence of HIV, which pre-disposes the affected to cancer.⁵ Cancer is associated with multi-dimensional symptoms and concerns, which are poorly managed in most African countries because of the late presentation, lack of services and other health system challenges.⁶ In addition, a cancer diagnosis and its treatment are associated with trauma and stress and pre-dispose patients to mental, spiritual, psycho-social distress, and health-related suffering.⁷ Psycho-social and spiritual concerns have been notable in symptomatology literature for cancer patients.⁸ Some patients may encounter psychological, social and spiritual positive changes regardless of the disease outcome.⁹ This has been described as Psycho-Social-Spiritual healing, which happens at the psychological/behavioral level and positive life transformation events of the outcome of the illness.^{10,11} Psycho-Social-Spiritual healing may relieve patients from suffering⁷ and may offer then an opportunity for growth and meaning despite.⁹ It is thus important that care providers are trained to re-direct patients' attention towards such potentially useful resources in their illness journey. Screening and identifying patients for spiritual/psycho-social healing is also pivotal to the impeccable assessment of symptoms in palliative care, to identify patients who are vulnerable to mental and health distress and setting up mitigation plans to avert these undesirable outcomes. To increase the uptake for the best practice, of screening and measurement there is a need for measures with sufficient psychometric properties to inform such measurements. The NIH Healing Experiences in All Life Stressors (NIH-HEALS), a 35-item measure of Psycho-Social-Spiritual healing, is composed of three factors: Connection, Reflection and Introspection, and Trust and Acceptance.¹² The NIH-HEALS was developed in USA,¹² before use in other settings, it is important to assess its face and content validity and suitability for use in other cultural settings. This is in line with the COSMIN guidelines for improving the selection of outcome measurements instruments in research and clinical practice.¹³ This study therefore aimed to assess the face and content validity of the NIH-HEALS measure in adult cancer patients receiving palliative care and to undertake a cultural adaptation for its use in Uganda.

Ethics

The study received ethical approval from the Hospice Africa Uganda Research and Ethics Committee and the protocol was registered with Uganda National Council for Science and Technology (HS957ES). The study also received approval from the National Institutes of Health. All patients gave written informed consent. Patients were free to choose to be audio recorded or not. Light refreshments were served during the interviews, and patients were re-imbursed for their transport costs.

Methods

This was a cross-sectional qualitative study that used the cognitive interviewing methodology, and our reporting is aligned to the Consolidated criteria for reporting qualitative research.¹⁴ The cognitive interviewing technique involves the use of the thinking aloud and use of verbal probing techniques to obtain information on the acceptability of a measure, the interpretation of items, how the responses are formulated,¹⁵ the comprehension and whether any key concepts have been missed. It is a powerful technique for identifying the cause and nature of response problems in measures, which improves the quality of data collected.¹⁶ This may not be achieved with the use of traditional interview methods.

The study was conducted at Hospice Africa Uganda, a tertiary/specialist palliative care site in Uganda. The data were collected from September 2020 to May 2021. We recruited adult patients with advanced cancer, who had sufficient cognitive ability to engage in the study and to give informed consent.

Data Collection Tools

The NIH Healing Experiences in All Life Stressors. The NIH-HEALS is a 35-item measure of psycho-social-spiritual healing. It is underpinned by a three-factor structure.

1. Connection—belief in and connection to a higher power, religion, religious community, and family.
2. Reflection and Introspection—finding meaning, purpose, gratitude and joy in nature, activities including those that connect mind and body, interconnectedness, present moment orientation, and an increased sense of awareness about the fragility of life; and
3. Trust and Acceptance—accepting what is, feeling resolved, feeling at peace, and trusting that caregivers, friends, and family will respond to needs as they arise.

The measure can be self-completed or read out aloud with the respondent selecting the most suitable response option, which relates to their psychosocial/spiritual well-being. The NIH-HEALS has been validated in the USA and high scores for internal consistency were reported (Cronbach's = .89) suggesting good reliability.¹⁷ The measure also demonstrated

good convergent and divergent validity properties with statistically significant correlations between the NIH-HEALS and its three factors with similar measures, (i)the Healed factor of the Self-Integration Scale (SIS), and (ii)Meaning, Peace, and Faith factors of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being-12 Scale (FACIT-SP12).¹⁷ We included an open-ended question “what does the term Psycho-Social-Spiritual healing mean to you” to generate one data about the conceptualization of the construct from the local population.

Other Tools

Socio-demographic data were collected using a tailored questionnaire. Data on clinical variables such as disease stage and type of diagnosis were extracted from patients’ medical records. To assess for cognitive performance, we used the rapid dementia/cognitive ability scale assessment¹⁸ adapted for cancer. This includes memory assessment and motor movement assessment tasks. Using the cut off of less than or equal to 10, the sensitivity and specificity for dementia with the measure were 80% and 55%, respectively, in the Uganda cohort. These cut offs were adopted for this study and patients suspected to have any signs of dementia, based on this measure were referred for further evaluation by the facility-health workers.

We assessed function performance using the ECOG (0-normal activity; 1-symptoms but nearly full ambulatory; 2-some bed time but needs to be in bed less than 50% of the time of normal day time; 3-needs to be in bed more than 50% of the time of normal day time; 4-unable to get out of bed).¹⁹ All measures were translated from the source language (English) to the two target languages (Luganda and Runyakore-Rukiga) using the forward and backward method,¹³ followed by a reconciliation of the two versions. Any inconsistencies were resolved through discussion and consultation with the measure developers where appropriate.

Recruitment and Data Collection

The data were collected by two interviewers 1 male, 1 female (EN and LM). LM is a theologian, philosopher, and psychologist and EN is a palliative care specialist with training in clinical psychology and spirituality. At the time of the study, LM was a volunteer at the clinical site and EN was a researcher, the latter was not known to patients a prior. The interviewers were introduced to potential study participants by the facility’s clinical teams, in a face-to-face interaction. The interviewers subsequently briefed them about the goals and procedures of study and sought their informed consent to participate in the study and then consecutively recruited them in the study. Patients were consecutively recruited from the outpatient clinic, homebased care, or community outreaches if they met the inclusion criteria. The interviews were conducted in two phases; phase one was the pilot, preliminary

analysis from phase one was used to develop relevant narrative to explain the meaning intent for each of the statements, in the subsequent interviews.

The interviews were conducted using a structured topic guide and the think aloud technique alongside the standard piloting and probing methods.²⁰ Interviews were conducted in quiet locales, (in the patient counseling rooms, under tree sheds, or sitting rooms) and were audio recorded. All patients were seeing the measure for the first time. The interviewer read aloud each question and patients were asked to provide a response that most represented their status. They were then asked to think aloud about their answers and what the statement meant to them. The interviewers used concurrent and spontaneous probing throughout the interview, to establish if any of the statement were unclear and if any of the words or phrases were confusing. For situations where lack of clarity was mentioned, the interview read aloud the meaning intent and the patients were requested to rephrase the statement in their own words to aid the re-phrasing to improve clarity. The interviewers documented non-verbal behavior such as hesitation, confusion, or long pauses. Upon completion of the 35 statements, patients were also asked if they felt any important content had been omitted, and the responses were recorded. The patients were also asked to explain in their own words what the term spiritual/psycho-social healing meant to them. The responses were also recorded verbatim.

Data Management and Analysis

All interviews were transcribed verbatim, those that were conducted in local languages were translated into English and thereafter the transcripts were reviewed against the audio recording by an expert in African languages, who was also fluent in the respective language. Disagreements were resolved through discussion. The transcripts were imported into Nvivo-12 for content analysis. The data analysis was conducted by two members of the research team (EN and AB) and it focused on identifying content and contextual problems in the questionnaire, the response options and to identify emerging themes in the definition of the construct of spiritual, psycho-social healing. We tabulated all cognitive interview data by item into a excel spread sheet. These were categorized according to Tourangeau’s²¹ information processing model, which includes interpretation comprehension and retrieval. We convened a study team meeting to review the comments for each of the NIH-HEALS items. Dialogue was used to reach a consensus regarding what changes should be implemented. The revised version of the NIH-HEALS was shared with the research team and a sub-sample of twenty study participants for further comments and was thereafter finalized. To validate the factor structure of the NIH-HEALS, the excerpts from the patients’ responses to the question, “what does the term Psycho-Social-Spiritual healing mean to you?” were analyzed using content analysis,²² followed by mapping these themes reflected by the responses on to the

Table I. Socio-Demographic Characteristics of the Study Participants.

Variable	N(%) / Median and Range
Age in years	Median 56 Range (21–86)
Number of dependents (includes adults and children)	Median 05 Range (0–30)
Interview setting	
Home	05 (14.3%)
Health facility	25(71.4%)
Community outreach	05 (14.3%)
Sex	
Male	18 (51.4%)
Female	17(48.6%)
Marital status	
Married	12(34.3%)
Widowed	11(31.4%)
Separated/divorced	7(20%)
Single	5(14.3%)
Type of residence	
Rural	23(65.7%)
Urban	12(34.3%)
Religious affiliation	
Catholic	14(40.0%)
Anglican	12(34.3%)
Born-again	04(11.4%)
Muslim	04(11.4%)
Seventh day	01(2.9%)
Highest level of education	
Primary	18 (51.4%)
Secondary	13(37.1%)
Degree	04(11.4%)
Type of cancer	
Cervix	10(28.6%)
Prostate	10(28.6%)
Breast	06(17.1%)
Kaposi sarcoma	03(8.6%)
Myeloma	02(5.7%)
Leukemia	02(5.7%)
Head and neck	01(2.8%)
Presence of other co-morbidities	
Yes	15(42.8%)
Type of co-morbidities	
HIV	8(53.3%)
Hypertension	4(26.7%)
Diabetes	1(6.7%)
Epilepsy	1(6.7%)
Persistent deep vein thrombosis	1(6.7%)
Has a primary caregiver	
Yes	27(77.1%)
ECOG functional performance score	
0	0
1	9(25.7%)
2	10(28.6%)
3	11(31.4%)

(continued)

Table 1. (continued)

Variable	N(%) / Median and Range
4	05 (14.3%)
Disease stage	
1	0
2	12(34.2%)
3	08(22.8%)
4	04(11.4%)
Unknown	11(31.4%)

Table 2. Problems with the NIH-HEALS as identified in Phase I of the Interviews (n = 5).

		Comments
which helath proffesionalns find difficult to initiate and engage in	Appearance and format	0/5
6Item /statement number	Comprehension difficulties with specific statements	
1	I am content with my life	Do you want to say I am happy about my current situation? [1/5] Is it to say that I am happy with this adversity? [1/5]
3	The connection with a higher power is important to me	What do you mean by higher power? [3/5]
12	I survive difficult circumstances because of a higher power	The meaning of higher power is not clear [3/5]
26	I seek more of a connection in my relationships	I do not understand the statement, give me some examples [1/5] What do we mean here? [2/5]
05	Suggestion for including contextual examples I enjoy activities that involve the body and mind such as meditation, prayer, yoga, tai chi, chanting	I think you should remove examples that do not apply here, what is tai chi? [1/5] I do not understand some of the examples, why not add praise and worship? [1/5]
14	My religious beliefs help me feel calm when faced with difficult circumstances in life	Why not add practices as well [1/5]
33	Creative arts bring peace to my life	We need examples here, for example, music, art, and drama [3/5]

Figures in brackets refer to the number of interviews in which problem was identified out of total interviewed in first phase.

NIH-HEALS three factors.¹² This mapping was done by one member of the research team (EN) and a clinical psychologist, inconsistencies were resolved through discussion.

Results

Socio-Demographic Characteristics

A total of forty-five (45) patients were approached, two declined and eight were excluded because they were too weak to endure the study procedures, we thus completed 35 cognitive interviews, five in phase 1 and 30 in phase 2. Most of the patients (71%) were interviewed at the

hospice premises. The median age was 56 years, about half were male 18 (51%). The majority resided in rural settings (67%), 77% reported having a primary caregiver, and about half (51%) attained primary education. Ten (28.6%) of the thirty-five participants had cancer of the prostate and (28.6%) had cancer of the cervix. Other details are presented in [Table 1](#).

Findings from Phase One of the Interviews

The major themes related to comprehension of a few of the statements, and a need to include some local examples, we used probes to gather data to burden of completion and

Table 3. Findings from the Second Phase of the Cognitive Interviews.

#	Statement	Comments
	Appearance and format of the questionnaire Consider including some more phrases to statements more inclusive	0/30
17	I get support from my religious community	Should include, religious, or spiritual communities <i>maybe we should be more inclusive, I get support from my religious community and believers of other religions and spiritual groups.</i> UG-18-202
18	My religious beliefs give me hope	Argument that this should not be just about religious beliefs but also spiritual and cultural to accommodate diversity. (6/30) <i>It means to me that one has to rely on religious beliefs alone for hope, which is not true. May be change to spiritual beliefs.</i> UG-24-2021
23	I am not getting the support I need	Lack of clarity on what support is needed and whether all patients should get support and from who? (12/30) <i>What support or support from who? You could expect support that you cannot get because even those you expect to give you support don't have it.</i> UG-23-2021 <i>I see people give me what they can because I cannot force anybody to give me what I want even my own children.</i> Ug-07-21
	Difficult conversations	
9	Working through thoughts about the possibility of dying brought meaning to my life	Talking about the possibility of dying is a sensitive issue (3/30) <i>It is difficult working through thoughts about the possibility of dying because God hide the secret of death from us, but it is a reality—</i> UG-16-021
29	Working through my own grief has brought meaning to my life	Grief is a difficult thing, but we must face it with courage (3/30) <i>When you get problems, your life is taken back, you don't progress. Having pity on yourself is not good. When you have a lot of pity for yourself, God does not like it. You should take everything as normal whether you have your needs or not, grief, accept and move. When you cannot move forward in what you are doing, it affects your life. It is not good. Support is needed for patients struggling with it. It is a good question.</i> UG-30-2020

Figures in brackets refer to the number of interviews in which problem was identified out of total interviewed in second phase.

experiences of the completion process, see [Table 2](#) for details.

Modifications Made

Based on the findings from the first five interviews, for statements that were difficult to comprehend, we provided some explanatory notes as part of the interviewer's guide. The term content was explained as "*satisfied and happy with what one is,*" the term higher power was explained as the power larger the self and may be God or gods or that other thing larger than the self, which one believes in. Connection in relationships was also accompanied with some explanatory notes. We also considered the giving of local examples like praise and worship for activities that involve the body and mind and then music and plays for examples of creative arts.

Findings From the Second Phase of the Cognitive Interviews

In the second phase of the interviews, patients appreciated the minor modifications which helped them appreciate the meaning intent and no further queries were raised. There were also some concerns around the comprehension of some phrases in the

statements, for example, "the moment" to be qualified further as follows "to be in the present moment." In addition, more concerns emerged with a need to include more phrases to make the statements more inclusive, for example, religious beliefs to be expanded to include spiritual and cultural beliefs, which may matter to non-religious patients ([Table 3](#)).

Modifications Made Following Phase 2 Interviews

Following the feedback from the interviews, it was agreed that the term "support I need" should be qualified more to give details on possible sources of support, for example, community, family, or care providers. Religious beliefs were expanded to include practices as advised by patients who argued that hope comes from belief and practices. Three patients noted that the statements about grief and possibility of dying were difficult conversations, but part of the reality of living with cancer. As such the NIH-HEALS users should be adhere to sensitivity when asking about these issues.

In addition, local examples were included for acts that involve the body and mind for statement 5 for clarity. Statement 33 was also revised to include this clause "examples include 'music, play, art, drama and theatre'". The revised NIH-HEAS is presented in [Table 4](#).

Table 4. The Modifications to the NIH-HEALS Following Feedback for the Cognitive Interviews.

	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
1. I am content with my life. [similar terms include satisfied and happy]	1	2	3	4	5
2. I have a sense of purpose in my life	1	2	3	4	5
3. The connection with a higher power is important to me. [A higher power could be God or gods or the larger than the self that you believe in]	1	2	3	4	5
4. I gain awareness from self-reflection	1	2	3	4	5
5. I enjoy activities that involve both mind/body such as meditation, [praise and worship], prayer, yoga, tai chi, chanting	1	2	3	4	5
6. I feel isolated	1	2	3	4	5
7. I feel calm even though I am not in control of my situation	1	2	3	4	5
8. I accept things that I cannot change	1	2	3	4	5
9. Working through thoughts about the possibility of dying brought meaning to my life	1	2	3	4	5
10. Difficult circumstances in my life have increased my compassion towards others	1	2	3	4	5
11. I want to make the most of my life	1	2	3	4	5
12. I survive difficult circumstances because of a higher power. [A higher power could be God or gods or the larger than the self that you believe in]	1	2	3	4	5
13. My situation strengthened my connection to a higher power. [A higher power could be God or gods or the larger than the self that you believe in]	1	2	3	4	5
	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
14. My religious/[spiritual] beliefs help me feel calm when faced with difficult circumstances in life	1	2	3	4	5
15. My personal religious/[spiritual] practice is important to me	1	2	3	4	5
16. My participation in a religious/[spiritual]community is an important aspect of my life	1	2	3	4	5
17. I get support from my religious/[spiritual]community	1	2	3	4	5
18. My religious/[spiritual] beliefs [and practices] give me hope	1	2	3	4	5
19. Doing something I am passionate about gives me purpose during difficult times (e.g., work, hobbies, volunteering, my religious institution, reading groups)	1	2	3	4	5
20. I find meaning in helping others	1	2	3	4	5
21. Connection with my family has become my highest priority	1	2	3	4	5
22. Support from my family lifts my spirits, which gives me hope during difficult times in life	1	2	3	4	5
23. I am not getting the support I need [from my community/family/ friends]	1	2	3	4	5
24. I am confident that my medical caregivers will respond to my needs	1	2	3	4	5
	Strongly Disagree	Disagree	Neither Disagree or Agree	Agree	Strongly Agree
25. My friends provide the support I need during difficult times	1	2	3	4	5
26. I seek more of a connection in my relationships	1	2	3	4	5
27. I take more time to be in the [present] moment	1	2	3	4	5
28. My experience with multiple losses has made it hard to be hopeful during difficult times (such as death, divorce, competency, and physical disability)	1	2	3	4	5
29. Working through my own grief has brought meaning to my life	1	2	3	4	5
30. I have a sense of peace in my life	1	2	3	4	5
31. I have an increased sense of gratitude	1	2	3	4	5
32. Being surrounded by nature is meaningful	1	2	3	4	5

(continued)

Table 4. (continued)

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
33. Creative arts bring peace to my life. [such as music, drama, art, or theatre]	1	2	3	4	5
34. Life challenges interfere with activities that are important to me	1	2	3	4	5
35. Life challenges raised my desire to be more positive	1	2	3	4	5

The modifications/adaptations are in square brackets.

Experiences on using the NIH-HEALS

We noted that the statements on “Connection, Reflection” took patients more time to think about and process the answers. One respondent noted that one needed to search their inner world, think, reflect, and then respond. Otherwise, patients appreciated the experience and none of them was distressed by the content or procedures.

R: You’re coming, and this interview has encouraged me. UG-16-2021

The respondents noted that the statements in the NIH-HEALS were closely related to their situations, for example, the connection to a higher power is important to me, the three patients spontaneously noted that the higher power was a great source of strength, since they received the bad news.

“Oh, he (God) is the most important thing, everything else is slipping away” UG-01-2020

Also, on reading statement seven—*I enjoy activities that involve both mind and body such as meditation, prayer, yoga, tai chi, and chanting.* The respondent noted that the statement strengthens her, “*even though I have a disability God considers me among the normal people or even more.*” UG-22-2021

We also noted some motivations behind their responses, for example, in responding to the statement “I am content with my life” two patients were quick to point out that there is nothing like contentment with the accident of this diagnosis, but out of acceptance of what is, one gains contentment with the current state of life.

When asked about any potentially useful content that should be added, only one respondent suggested including some phrases gratitude to God and people patients interact with. None of the statements was considered irrelevant.

I: For the time we have been talking, is there a question that has been inappropriate or irrelevant?

R: No. All the questions have been good, they are educative and informative UG-31-2021

The scale was rated as appropriate and clear and all respondents could differentiate between the response option of

strongly disagree, disagree, neither agree or disagree, agree, and strongly agree.

Mapping of the NIH-HEALS on to The Patient Description of Spiritual/Psycho-social Healing

Having mapped all the patient descriptions of the term spiritual/psycho-social healing on to the NIH-HEALS factors, (i) Connection—belief in and connection to a higher power, religion, religious community, and family; (ii) Reflection and Introspection—finding meaning, purpose, gratitude and joy in nature, activities including those that connect mind and body, interconnectedness, present moment orientation, and an increased sense of awareness about the fragility of life; and (iii) Trust and Acceptance—accepting what is, feeling resolved, feeling at peace, and trusting that caregivers, friends, and family will respond to needs as they arise. We confirmed cross-cultural equivalence of the construct as the themes mapped on to the factors, we however noted scant mention of friends, family and caregivers under the Trust and Acceptance factor. We also noted that to some patients healing means physical cure or change of illness status (see [Supplementary file 1](#) for details).

Discussion

We aimed to assess the face and content validity properties of the NIH-HEALS and culturally adapt the measure for the Ugandan context using the cognitive interview and standard piloting methods. The cognitive interview approach is powerful for establishing the nature and any root cause of problems with items or statements in a given measure.²⁰ We preferred to use the think aloud and probe methods as retrospective questioning is associated with recall bias, which occurs when patients have difficulty recalling the thinking process at the point, they gave their responses.²⁰

The study participants noted that the measure’s content was relevant, and of the 35 items, 5 were difficult to comprehend, but considered relevant. As such explanatory notes were added as recommended by the participants, making these items easier to comprehend. This input further justifies the need to engage and involve patients in research which shapes the care they receive, a practice which is gaining

increasing attention in palliative care.²³ The cognitive interview approach was useful for identifying issues with the NIH-HEALS measure for spiritual and psycho-social healing, which may be missed by traditional piloting. This is especially important in self-report measures where users must be able to understand the meaning intent of each of the questions before the self-rating.²⁴

The measure's response scale was rated appropriate, as patients could distinguish between the various response options. This could be explained by the long time use of Likert scales in palliative care settings to measure palliative care outcomes.²⁵ The median time for completion of the NIH-HEALS was 20 minutes, which is slightly longer than the commonly used 10–15 minutes,²⁶ and as such a shorter version of the NIH-HEALS should also be considered for situations where quick integration within clinical care is required. It has been noted that time required for completion can be a barrier to integration of measures within routine clinical care, hence, the need for a shorter version.²⁷

Our findings further highlight the theme of difficult conversations, for example, the statements on possibility of dying and grief were highlighted as sensitive topics by three of the study participants. This finding lends credence to the evidence base on difficult conversations in palliative care.²⁸ Conversations about death and dying or even accepting the terminal nature of terminal illnesses is a taboo in most African cultures.²⁹ Many patients and families prefer to keep hope for physical cure alive. This has also been cited as a barrier to the initiation of advance care planning in palliative care in Africa. The need to train health workers on how to break bad news and how to engage in difficult conversations has been emphasized in palliative care³⁰ and this finding reinforces this desired practice.

The use of cognitive interviewing further highlighted the importance of taking a broader view on spiritual/existential care, which goes beyond religion to include, meaning, beliefs, purpose, relationship with self and others and nature.³¹ Misinterpreting religion for spirituality may result into failure to meet the needs of patients and families who may not necessarily be religious but have spiritual/existential concerns, resulting into spiritual/existential distress which negatively impacts on patient and family quality of life.³²

On the side of the factor structure of measure, the patient themes on spiritual/psycho-social healing, mapped on to the NIH-HEALS three factor structure, proving evidence for construct equivalence. We, however, noted that in the African context, the theme on family, friends, and caregivers under factor 3 (trust and acceptance) were not commonly mentioned, possibly because African patients commonly live with communities and families during the illness,³³ making them part of the social network, and thus this may lean more towards the social domain of well-being. This is further supported by the fact that over 70% reported having a primary caregiver. We also noted that for several patients healing meant physical cure or changes of illness status, which links into the domain of normalcy. This can only be achieved if

they learn to get on with life as it is, feel normal in the new normal.³⁴ Given that shorter measures are preferred in palliative care,³⁵ considering an open-ended question may be preferred to adding more statements to the measure.

Based on the findings, we note that the NIH-HEALS has sufficient face and content properties and with the minor adaptations, it can be used for assessing spiritual/psycho-social healing in cancer palliative patients in Uganda. Assessing Psycho-Social-Spiritual healing is now recognized as an important outcome of palliative care and if delivered appropriated it can contribute to the best practice of delivering person-centered care to patients living with cancer. This field is expanding and is being increasingly recognized as part of the quality of care improvement framework.³⁶ As such this research contributes to building the evidence base for measuring outcomes in palliative care as a pathway to stimulating the development of person-centered care.³⁷ More so, such interviews may be therapeutic and may facilitate further self-reflection and introspection, which may be an easy pathway to empower patients to identify new perspectives and participate in their psycho-social and spiritual healing. Further studies to explore its appropriateness in African settings which are different from Uganda are warranted to further assess the face and content properties and hence appropriateness for use within those settings Africa. We also recommend further studies in African settings to examine other psychometric properties of the NIH-HEALS using quantitative approaches.

This study has some limitations, palliative care should be provided based on need and many other conditions can benefit from the services to alleviate health-related suffering,³⁸ however, this study only focused on patients with cancer, further studies in other populations are thus recommended.

Acknowledgments

We are grateful to Hospice Africa Uganda for allowing us to conduct this study at their facility and the African Field Epidemiology Network for coordinating the implementation. The authors thank Lawrence Matovu for supporting the data collection, the patients who took part in the study and the clinical staff that supported the recruitment of patients.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by the National Institutes of Health Clinical Center (grant number: 6019-S17).

ORCID iD

Eve Namisango  <https://orcid.org/0000-0001-5032-4714>

Supplementry Material

Supplemental material for this article is available online.

References

- Globocan. *The Global Cancer Observatory*. 2020. <https://gco.iarc.fr/today/data/factsheets/populations/903-africa-fact-sheets.pdf> (accessed July 2021).
- Sleeman KE, Gomes B, de Brito M, et al. The burden of serious health-related suffering among cancer decedents: Global projections study to 2060. *Palliative Med*. 2020;35:231-235. doi:10.1177/0269216320957561.
- Shah SC, Kayamba V, Peek RM Jr, et al. Cancer control in low- and middle-income countries: is it time to consider screening? *J Glob Oncol*. 2019;5:1-8. doi:10.1200/jgo.18.00200.
- TGC Observatory. <https://gco.iarc.fr/today/data/factsheets/populations/800-uganda-fact-sheets.pdf>. <https://gco.iarc.fr/today/data/factsheets/populations/800-uganda-fact-sheets.pdf> Uganda: TGC Observatory. (Published September 2021, accessed 2021).
- Jin F, Poynten IM, Grulich AE. HIV treatment and anal cancer: emerging clarity. *Lancet HIV*. 2020;7:e220-e221. doi:10.1016/s2352-3018(20)30027-8.
- Stefan DC. Cancer care in Africa: an overview of resources. *J Glob Oncol*. 2015;1:30-36. doi:10.1200/JGO.2015.000406.
- Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306:639-645. doi:10.1056/nejm198203183061104.
- Van Lancker A, Velghe A, Van Hecke A, et al. Prevalence of symptoms in older cancer patients receiving palliative care: a systematic review and meta-analysis. *J Pain Symptom Manage*. 2014;47:90-104. doi:10.1016/j.jpainsymman.2013.02.016.
- Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996;12:237-252. doi:1996/05/01.
- Luna MJ, Ameli R, Sinaii N, et al. Gender differences in psycho-social-spiritual healing. *J Womens Health (Larchmt)*. 2019;28:1513-1521. doi:10.1089/jwh.2019.7837.
- Steinhorn DM, Din J, Johnson A. Healing, spirituality and integrative medicine. *Ann Palliat Med*. 2017;6:237-247. doi:10.21037/apm.2017.05.01.
- Sloan DH, BrintzenhofeSzoc K, Kichline T, et al. An assessment of meaning in life-threatening illness: development of the healing experience in all life stressors (HEALS). *Patient Related Outcome Measures*. 2017;8:15-21. doi:10.2147/prom.S118696.
- Mokkink LB, Prinsen CA, Bouter LM, et al. The consensus-based standards for the selection of health measurement instruments (cosmin) and how to select an outcome measurement instrument. *Braz J Phys Ther*. 2016;20:105-113.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care J Int Soc Qual Health Care*. 2007;19:349-357. doi:10.1093/intqhc/mzm042.
- Willis G. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. Thousand Oak: Sage Publications; 2005.
- Murtagh FE, Addington-Hall JM, Higginson IJ. The value of cognitive interviewing techniques in palliative care research. *Palliat Med*. 2007;21:87-93. doi:10.1177/0269216306075367.
- Ameli R, Sinaii N, Luna MJ, et al. The National Institutes of Health measure of healing experience of all life stressors (NIH-HEALS): factor analysis and validation. *PLoS One*. 2018;13:e0207820. doi:10.1371/journal.pone.0207820.
- Sacktor NC, Wong M, Nakasujja N, et al. The international HIV dementia scale: a new rapid screening test for HIV dementia. *Aids*. 2005;19:1367-1374.
- Sørensen JB, Klee M, Palshof T, et al. Performance status assessment in cancer patients. An inter-observer variability study. *Br J Cancer*. 1993;67:773-775. doi:10.1038/bjc.1993.140.
- Willis GB. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. USA: SAGE Publications; 2005.
- Tourangeau R. Cognitive sciences and survey methods. In: Jabine TB, Miron SL, Tanur JM, et al., eds. *Cognitive aspects of survey methodology: Building a bridge between disciplines*. USA: National Academy Press, 1984, 73-101.
- O’Cathain A, Thomas KJ. Any other comments? Open questions on questionnaires – a bane or a bonus to research? *BMC Med Res Methodol*. 2004;4:25. doi:10.1186/1471-2288-4-25.
- Cook N, Siddiqi N, Twiddy M, et al. Patient and public involvement in health research in low and middle-income countries: a systematic review. *BMJ open*. 2019;9:e026514. doi:10.1136/bmjopen-2018-026514.
- Murtagh FEM, Addington-Hall JM, Higginson IJ. The value of cognitive interviewing techniques in palliative care research. *Palliat Med*. 2007;21:87-93. doi:10.1177/0269216306075367.
- Blum D, Selman LE, Agupio G, et al. Self-report measurement of pain & symptoms in palliative care patients: a comparison of verbal, visual and hand scoring methods in Sub-Saharan Africa. *Health Qual Life Outcomes*. 2014;12:118. doi:10.1186/s12955-014-0118-z.
- Harding R, Selman L, Agupio G, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African palliative outcome scale. *Health Qual Life Outcomes*. 2010;8:10. doi:10.2010/01/2710.1186/1477-7525-8-10.
- Antunes B, Harding R, Higginson IJ, et al. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med*. 2014;28:158-175. doi:10.1177/0269216313491619.
- Zhou G, Stoltzfus JC, Houldin AD, et al. Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer. *Oncol Nurs Forum*. 2010;37:E400-E410. doi:10.1188/10.Onf.E400-e410.
- Ekore RI, Lanre-Abass B. African cultural concept of death and the idea of advance care directives. *Indian J Palliat Care*. 2016;22:369-372. doi:10.4103/0973-1075.191741.
- Parry R, Land V, Seymour J. How to communicate with patients about future illness progression and end of life: a systematic

- review. *BMJ Supportive & Palliative Care*. 2014;4:331-341. doi:[10.1136/bmjspcare-2014-000649](https://doi.org/10.1136/bmjspcare-2014-000649).
31. Puchalski CM, Vitillo R, Hull SK, et al. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med*. 2014;17:642-656. doi:[10.1089/jpm.2014.9427](https://doi.org/10.1089/jpm.2014.9427).
 32. Delgado-Guay MO, Hui D, Parsons HA, et al. Spirituality, religiosity, and spiritual pain in advanced cancer patients. *J Pain Symptom Manage*. 2011;41:986-994. doi:[10.1016/j.jpainsymman.2010.09.017](https://doi.org/10.1016/j.jpainsymman.2010.09.017).
 33. Sepulveda C, Habiyambere V, Amandua J, et al. Quality care at the end of life in Africa. *BMJ (Clinical research ed)*. 2003;327:209-213. doi:[10.1136/bmj.327.7408.209](https://doi.org/10.1136/bmj.327.7408.209).
 34. Zimmermann C, Swami N, Krzyzanowska M, et al. Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ (Can Med Assoc J)*. 2016;188:E217-E227. doi:[10.1503/cmaj.151171](https://doi.org/10.1503/cmaj.151171).
 35. Antunes B, Harding R, Higginson IJ. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med*. 2014;28:158-175. doi:[10.1177/0269216313491619](https://doi.org/10.1177/0269216313491619).
 36. Donabedian A. The quality of care. How can it be assessed? *J Am Med Assoc*. 1988;260:1743-1748.
 37. Bausewein C, Daveson BA, Currow DC, et al. EAPC white paper on outcome measurement in palliative care: improving practice, attaining outcomes and delivering quality services - Recommendations from the European association for palliative care (EAPC) task force on outcome measurement. *Palliat Med*. 2016;30:6-22.
 38. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet commission report. *Lancet*. 2018;391:1391-1454. doi:[10.1016/s0140-6736\(17\)32513-8](https://doi.org/10.1016/s0140-6736(17)32513-8).