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Validation of the Missoula-Vitas Quality-of-Life Index Among Patients with Advanced AIDS in Urban Kampala, Uganda

Eva Namisango, MSc, Elly Katabira, PhD, Charles Karamagi, PhD, and Peter Baguma, PhD

Departments of Clinical Epidemiology and Biostatistics (E.N., C.K.) and Medicine (E.K.), Faculty of Medicine (E.K.), and Institute of Psychology (P.B.), Makerere University, Kampala, Uganda

Abstract

The Missoula-Vitas Quality-of-Life Index (MVQOLI) is a unique tool specifically designed to measure quality of life (QOL) in advanced illness in a palliative care setting. The aim of this study was to explore its cross-cultural validity. We used a culturally adapted version in a local language, Luganda, and tested the MVQOLI-M in 200 patients with advanced AIDS in urban Kampala, Uganda. Content validity was assessed using the content validity ratio approach. Reliability was assessed using Cronbach's alpha (α), and test-retest reliability was evaluated using the intraclass correlation coefficient. All items and domains were rated content valid and there was good construct validity. The instrument demonstrated good internal consistency (α = 0.83). The transcendence domain was the best predictor of overall QOL. The MVQOLI-M is an acceptable, valid, and reliable measure of QOL for people with advanced AIDS and findings demonstrate the importance of measuring the transcendence domain in QOL in advanced illness. J Pain Symptom Manage 2007;33:189−202. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Introduction

Despite the development of new pharmaceutical interventions for persons with human immunodeficiency virus, few HIV-infected patients in the developing world can access these drugs. As a result, most patients progress to AIDS, which makes the need for palliative care services paramount in the health care system. In 1990, the World Health Organization emphasized that the ultimate goal of palliative care is achievement of the best quality of life (QOL) for patients and their families.[1] Clinch and Schipper have suggested that QOL is the most appropriate outcome measure in terminal care because it is focused on what happens to the patient, measuring the effect of physiological change rather than only the fact of physiological change.[2] It is, however, generally recognized that it is difficult to define and measure QOL.[3,4] Notwithstanding the challenges, progress has been made in recent years in understanding and measuring QOL in palliative care. It is recognized that QOL is multidimensional in that it involves various domains, such as the physical, functional independence,

psychological, social, spiritual, and existential.[5] It is subjective in that it should reflect the impact of a disease from the patient's perception rather than what professionals or even carers perceive.[6] It is dynamic in that it may change with time and disease progression.[3] These are the minimal common denominators in conceptualizing QOL as a heuristic model that can guide investigations of this construct.

Although there is no recognized gold standard for measurement of QOL,[7] over the past decades, two classes of complementary health status measures have emerged to fill this information gap—objective measures of functional health status and subjective measures of health and well-being.[5] Various QOL measurement tools have been designed but most may not be ideal for use in palliative care patients, whose QOL assessment should focus on areas for which palliative care is most effective, such as psychosocial and spiritual problems.[8,9] The Medical Outcomes Study-HIV (MOS-HIV), HIV/AIDS-Targeted Quality of Life (HAT-QOL), Functional Assessment of Human Immunodeficiency Virus Infection (FAHI), and MQOL-HIV are relevant tools in measuring QOL in HIV but are not suitable for use in a terminally ill population in a palliative care setting because none of them capture the existential domain, which has been found to be very important in predicting QOL of patients with advanced illness.[10−12]

With increasing research in palliative care, it is important that the measurement tools used should be valid and reliable. The Missoula-Vitas Quality-of-Life Index (MVQOLI) was developed and validated in the United States especially for patients with advanced illness in a palliative care setting.[9] The MVQOLI has been demonstrated to have good acceptability and validity within the U.S. population.[9] Other scales are also available in palliative care, but the MVQOLI is preferred because the transcendence/existential domain can be measured, it focuses on the terminal phase of illness, it uses categories of responses and scoring that allow for weighting of each QOL dimension according to the patient reported importance, and uses subjective language to reflect and measure the evolving nature of patients' experience and adaptation to circumstances.

One limitation to the use of the instrument, as with any other QOL instrument, is its validity and reliability in different cultures, considering the view that perceptions and valuations of the QOL domains may vary from culture to culture. This is an important research issue as it questions the extent to which a QOL scale developed in one country can be uncritically applied in another.[10,13] This study used a cross-sectional design to explore the validity and reliability of the MVQOLI in terminally ill AIDS patients receiving palliative care in Uganda, Africa.

Methods
Measurement and Measurement Tools

The MVQOLI. A review of literature and informal interviews of hospice professionals, patients, and their families were used to determine the dimensions and items of QOL to be measured for the MVQOLI.[9] The MVQOLI is a 25-item index based on a developmental model for understanding the experience of life at end of life, as described by Byock.[14] The model suggests that persons retain an inherent opportunity for further development or growth at the end of life. Such growth is marked by subjective sense of well-being and an enhanced sense of meaning that can occur despite declining function. It was against this background that we hypothesized that among patients with advanced AIDS, there will be a divergence, reflecting the lack of a causal relationship between self-reported QOL and the patients' functional status as evaluated by clinical observers. The instrument focuses on five dimensions of a person's subjective experience: symptoms, functional status, interpersonal relations, emotional well-being, and transcendence. Each of the five dimensions contains five items eliciting three types of information from the patients: 1) an assessment of perceived status with respect to the experience encompassed by the dimension; 2) the degree of satisfaction or dissatisfaction with the status; and 3) a rating of the importance of the dimension to the patient's overall QOL.

Each item uses a five-point Likert scale recorded so that the lowest score always

indicated the least desirable situation and vice versa. The questions are general, which means that the MVQOLI provides information about the domains that detract from or augment the patient's QOL. The MVQOL also incorporates a single item quality-of-life status question, which was used to assess the convergent validity of the MVQOLI-M.

The Karnofsky Performance Status Scale. The Karnofsky Performance Status Scale is designed to quantify the patient's functional performance. The scale is observer rated and scores range from 0, corresponding to death, to 100, or complete independent functioning. Observer-rated functional performance status was measured to determine its relationship to patient-rated QOL. The Karnofsky Performance Status Scale was used because it is the most widely used measure of functional performance in HIV/AIDS.[15]

Sociodemographic Questionnaire. A sociodemographic questionnaire was used to collect information on the respondent's age, sex, education, marital status, religion, and primary occupation.

Adaptation and Translation of the MVQOLI

Adaptation and translation of the MVQOLI was done according to the criteria for translation and adaptation of generic health-related QOL measures.[16] The instrument was slightly modified to enhance its face validity and content validity. Item 7 was made clearer by replacing the term "do the things I like to do" to hobbies. Item 16 was considered quite idiomatic and it was clarified as having connection to a concept larger than, and outside, the self, for example, a connection to God or a supernatural being. Item 24 was also improved by briefly explaining what is meant by things getting out of control, such as losing control over situations or life (Appendix). The content experts also noted the need to be more specific concerning symptoms by renaming the "physical "domain as the "physical symptom" domain. The scaling of the global item was adjusted to suit the target culture and language as follows: "worst possible" was changed to "very poor" and "best possible" was changed to "very good."

The modified version was then translated from the source language (English) to the target language (Luganda). Translation was done according to the guidelines for adapting instruments in multiple languages and cultures.[17] Translators who were conversant with both the source and target languages, and had skills in cross-cultural adaptation of instruments, made two independent forward translations and two independent backward translations. The final version was independently reviewed and translated by a bilingual clinical psychology student without previously seeing the original MVQOLI. The back-translated version had very close concordance with the original MVQOLI, as verified by a professional linguist fluent in both the English and Luganda languages. A social scientist conversant with both languages carried out the final step of smoothing out the language. This involved editing the target language version of the instrument in a consistent writing style. This helped to ensure that patients could easily understand the modified version of the MVQOLI. A palliative care expert reviewed the final instrument to check for omissions.

Addition of Items

Based on informal interviews with hospice professionals, AIDS patients and a review of the literature,[8–12] two experimental items on stigma and sexuality were included, as they are often perceived to be important components of the African culture, which may influence the patients' QOL.

Recruitment and Completion of Questionnaires

Informed Consent. The Faculty of Medicine Ethics & Research Committee, Makerere University and the National Council of Science and Technology, Uganda, approved the study. Following verbal explanation of the study's purpose, risks/benefits, and the participant's rights, patients indicated informed consent by signing a consent form.

Selection of Subjects. All the study subjects were participating in a community/home and outpatient clinic related to their HIV care. All terminally ill patients aged 18 years and above were considered eligible for the study and

were only excluded if they fulfilled one of the following exclusion criteria: 1) weakness that prevents completion of questionnaires; 2) impaired mental status precluding completion of the questionnaires and rendering informed consent meaningless; or 3) unable to understand and communicate in English or Luganda. Terminally ill was defined as patients in whom the disease is so advanced that the focus of treatment has moved from the curative to palliative, and who spend at least 50% of the day in bed.

A consecutive sampling method was used for subject recruitment. Participants were recruited from any service center they used for accessing HIV care (the home, outpatient clinic, or hospital). Personnel collecting the data read the instructions to patients and clearly explained the details. Respondents were asked whether they were satisfied with the clarity of the instructions and any queries on the questionnaire items were handled accordingly. The questionnaires were answered by respondents unaided if possible or otherwise read to respondents by the research assistants. For hospitalized and very sick patients at home, the instrument was administered to patients at the bedside. At the clinic based home care center, facility, the instrument was administered to patients in a side room, which was free from public interference. For the patients seen at home, the instrument was administered in the most convenient place as long as it was free from public interference.

Statistical Analysis

Data were analyzed using EPINFO, STATA, and SPSS software.

Screening Data. The MVQOLI-M data were screened for appropriateness of parametric statistics by examining for each item and subscale: the mean, range, skewness, kurtosis, frequency distribution, and box-whisker plot. Multivariate outliers were detected using the regression of all MVQOLI-M items on a dummy variable containing random numbers. The influence of extreme scores on the mean was evaluated by comparing the original and trimmed mean values.

Scoring of the Instrument. Data from the self-administered and interviewer-administered questionnaires were pooled together. Dimensional subscores and total subscores were calculated according to the following formulas:

$$\text{Domain scores} = [DA_1 + DA_2 + DS_1 + DS_2]/2 \times (DI)$$

$$\text{Total score} = [\text{sum of weighted dimensional subscores}]/10 + 15$$

where D is one of the five dimensions, A is an assessment item in the specified dimension, S is a satisfaction item in the specified dimension, and I is the importance item for the specified dimension. Subscripts indicate the first (1) or second (2) item of that type.

Interpretation. Domains that were below zero diminish QOL and domains that were above zero augment QOL. A separate scoring algorithm was used for the experimental items on sexuality and stigma. The experimental questions were rated on a 1−5 Likert scale (variable score = the sum of the points for all five items); the higher the score for stigma, the more stigma, and the higher the score for sexuality, the better the patient's sexuality.

Content Validity. To quantify content validity, the content validity ratio (CVR) was computed for each ith item or domain in the instrument based on the form developed by Lawshe as follows:[18]

$$\text{CVR}_i = \frac{n_e - N/2}{N/2}$$

where CVR_i = CVR value for the ith measurement item or domain; n_e = number of subject matter experts indicating a measurement item is essential; N = total number of subject matter experts on the panel.

The Lawshe table gives the minimum CVR needed to retain the item on the scale. A minimum CVR value of 0.62 was necessary for statistical significance at $P < 0.05$ based on 10 panelists. The feedback from all panelists was examined to identify areas of major concern and to determine whether there was general agreement and support for the scale.

Results

Participant Characteristics

A total of 200 patients were recruited over a period of four months. Of all the eligible patients, four could not participate due to severe weakness and five died before being contacted. All patients contacted agreed to participate in the study and completed questionnaires. Seventy-five percent of the patients were receiving care at home, 15% at the outpatient clinic, and 10% from the inpatient units. Respondents were predominantly female ($n = 122$; 61%); the mean age was 37 years (range, 18−64 years). Details of the sociodemographic characteristics are shown in Table 1.

Table 1
Sociodemographic Characteristics of 200 Subjects and Comparison of the Total MVQOLI-M Scores

Characteristic	Frequency	%	MVQOLI Total Score, Mean (SD)	P
Age (years)				
18−29	39	19.5	15.63 (4.34)	0.148
30−39	97	48.5	15.79 (4.32)	
40+	64	32.0	16.96 (3.61)	
Religious affiliation				
Catholic	74	37.0	15.99 (3.76)	
Anglican	58	29.0	15.32 (3.28)	
Pentecostals	41	20.5	18.51 (4.92)	
Muslim	25	12.5	14.57 (4.22)	**<0.0005**
SDA	2	1.0	15.30 (3.39)	
Education				
Primary	87	43.5	16.75 (4.27)	
Secondary	85	42.5	16.04 (3.66)	0.93
Informal	16	8.0	14.40 (5.59)	
Tertiary	12	6.0	14.64 (3.29)	
Employment				
Informal sector	135	67.5	16.06 (4.48)	
Unemployed	38	19.0	16.39 (2.95)	0.91
Formal sector	26	13.0	16.02 (3.82)	
Student	1	0.50	18.55 (2.27)	
Sex				
Female	122	61.0	16.52 (4.16)	0.97
Male	78	39.0	15.53 (4.00)	
Marital status				
Married	56	28.0	15.13 (4.07)	
Widowed	83	41.5	16.63 (4.36)	
Divorced/ separated	38	19.0	15.88 (4.07)	0.70
Single	23	11.5	17.25 (3.30)	

Bold number indicates statistically significant data; SDA = Seventh Day Adventist.

Screening the Data

Examination of the mean, range of answers, skewness, kurtosis, and frequency of distributions indicated that all MVQOLI-M questions were appropriate for parametric analysis. Means, standard deviations (SDs), and range are shown in Table 2. The average QOL of the sample of 200 terminally ill AIDS patients as represented by the global item was 2.68. The domain with the lowest mean score was function, while interpersonal well-being had the highest mean score.

In the total sample, seven items were not completed (one MVQOLI-M global item, six sexuality). The missing data seemed to be randomly distributed and were, therefore, replaced by the sample mean of the respective items. Two multivariate outliers were detected; further examination of the questionnaires indicated that they were part of the target population. We ran a univariate analysis by removing the top and bottom 5% of the cases and recalculating the new mean to determine how much of a problem the outliers were to be. The influence of these extreme scores on the mean was evaluated by comparing the original and trimmed mean values. The two mean values were not sufficiently different to affect the remaining distribution. The two outliers were, therefore, retained in the data set for analysis. For all preliminary assumption testing performed, only the equality of variance assumption was violated for multiple variable comparisons and thus a more conservative alpha of level 0.007 was adopted for significance in the univariate F test.

Acceptability

MVQOLI-M items were acceptable to the study participants. Seven of the 200 patients found the sexuality item embarrassing but rated it. On the whole, the average time required to complete the instrument was 15−20 minutes for patients with Karnofsky scores above 50% and 30−35 minutes for those with Karnofsky scores below 50%.

Content Validity Index of the Items and Domains

All items were judged content valid with recommendations made to rephrase Items 7, 16, and 24 to suit the cultural context. These

Table 2
Range of Responses, Mean, and SD of the MVQOLI-M

Dimension	Number of Items	Possible Range	Respondent's Range	Mean	SD
Interpersonal	5	−30 to 30	−30 to 30	17.44	13.03
Transcendence	5	−30 to 30	−30 to 30	16.08	12.99
Symptoms	5	−30 to 30	−30 to 30	1.70	9.83
Psychological	5	−30 to 30	−30 to 30	−1.39	12.90
Function	5	−30 to 30	−30 to 22.5	−2.05	10.81
Total score	25	0 to 30	8 to 24	16.27	3.38
Global score	1	1 to 5	1 to 5	2.68	0.95

changes were incorporated in the modified version. All domains reached an acceptable content validity index (CVI) level, as rated by the content experts.

Convergent and Divergent Validity

Correlation analysis between the overall QOL, as measured by the global item, and the MVQOLI-M total score revealed a strong positive relationship between the two variables, demonstrating convergent validity ($r = 0.580$, $n = 200$, shared variance $= 33.6\%$, $P < 0.0005$). The instrument also demonstrated divergent validity as demonstrated by the low correlation between the MVQOLI-M total scores and the Karnofsky Performance Status score, a dissimilar variable ($r = 0.25$, $n = 200$, shared variance $= 6.3\%$, $P < 0.0005$). This suggests that the instrument discriminates among dissimilar variables.

Reliability

The internal consistency of the MVQOLI-M was good, with a Cronbach's alpha value of 0.85. Inclusion of experimental items on sexuality and stigma did not meaningfully affect the internal consistency of the instrument. The interpersonal domain reflected the best internal consistency (Table 3).

The test-retest intraclass correlation coefficient between the MVQOLI total scores, as rated by 50 patients who reported their overall QOL had not changed at 11 days post-baseline, was 0.6. This value was statistically significant ($n = 50$, shared variance $= 37.2\%$, $P < 0.0005$, 95% CI: 0.4012−0.7581). Findings indicate that the MVQOLI is fairly stable over short time periods considering that QOL is a dynamic construct.

Predicting MVQOLI-M Scores

To determine whether sociodemographic characteristics were predicting MVQOLI-M

scores, analysis of variance (ANOVA) was performed. Results of the ANOVA showed that religion was predictive of MVQOLI-M scores (Table 1). Further examination of the mean plot showed that the Pentecostals recorded the highest total QOL scores. One-way between-groups multivariate ANOVA was performed to further investigate religious differences in QOL, with religious affiliation as the independent variable. There was a statistically significant difference between the religious groups on the combined dependent variables (Wilks' Lambda $= 0.818$, $P = 0.029$; partial eta squared $= 0.049$). The effect of religion was meaningful only on the transcendence and psychological well-being domains (eta squared $= 0.108$ and 0.101, respectively) (Table 4).[19]

Partial correlation analysis was used to further explore the relationship between patient self-rated overall QOL (global item), and the transcendence and psychological well-being domains while controlling for religion. There was a strong positive partial correlation between the global item and transcendence ($r = 0.510$, $n = 200$, $P < 0.0005$), with high levels of transcendence being associated with higher scores of overall well-being. Findings were similar for

Table 3
Assessment of Internal Consistency of the MVQOLI-M

	Cronbach's Alpha Score
MVQOLI	**0.84**
MVQOLI with experimental items	**0.88**
Subscales	
Interpersonal	0.76
Function	0.67
Psychological well-being	0.69
Transcendence	0.70
Physical symptom	0.56

Bolded numbers show the overall internal consistency of the instrument without additions of new items, and when experimental items are added.

Table 4
Results of Multivariate ANOVA of the Differences between Religious Groups

Source Variable	Dependent Variable	F	P	Eta Squared
Religion	Psychological well-being	**5.915**	**<0.0005**	**0.108**
	Transcendence	**5.580**	**<0.0005**	**0.101**
	Global item	3.802	0.005	0.072
	Total QOL score	3.730	0.006	0.071
	Function	1.648	0.164	0.033
	Interpersonal	1.611	0.173	0.032
	Physical symptom	1.027	0.395	0.021

Bolded numbers highlight the domains in which the various religious sects differed significantly, which is shown by the *P*-value, the eta square, and F-value.

a similar analysis on the psychological well-being domain ($r = 0.385$, $n = 200$, $P < 0.0005$). An inspection of the zero-order correlation for transcendence ($r = 0.528$, $n = 200$, $P < 0.0005$) and psychological well-being ($r = 0.411$, $n = 200$, $P < 0.0005$) suggested that controlling for religion had very little effect on the strength of the relationship between these two variables (Δ in $r = 0.002$ and Δ in $r = -0.026$, respectively). The changes in the coefficients were below the 10%−15% change recommended to confirm presence of confounding.[20] Further analysis thus did not control for the effect of religion.

The transcendence domain had the highest correlation with the global item, which represents the patient's self-rated overall QOL ($r = 0.53$, shared variance $= 28.0\%$, $P < 0.0005$). All the MVQOLI-M subscale scores have statistically significant positive correlation with the global item.

Standard multiple regression analysis also confirmed that transcendence was the most important subscale in the regression equation for predicting patient self-rated overall QOL, with the highest standardized beta coefficient

Table 5
Results of Multiple Linear Regression Analysis of QOL on the MVQOLI Subscales

Variable	Unstandardized Beta	Standardized Beta	P
Transcendence	0.075	**0.240**	**0.004**
Function	0.016	0.180	0.006
Psychological well-being	0.013	0.180	0.013
Physical symptom	0.016	0.165	0.010
Interpersonal	0.007	0.101	0.134

Bolded numbers highlight the most important domain in explaining the variation in quality of life of the patients. We use the standardized beta for uniform comparison and then its *P*-value for statistical significance.

of 0.24 (Table 5). This explained 24% of the variance in QOL when the variance explained by all other variables in the model was controlled for. All variables made statistically significant unique contribution to the equation except the interpersonal domain. The model explained 36.8% of the variance in self-rated overall QOL (R squared $= 0.368$, $n = 200$, $P < 0.0005$).

Discussion

Findings from this study provide preliminary evidence that the MVQOLI-M is an acceptable, valid, and reliable means of measuring QOL in terminally ill AIDS patients receiving palliative care. The QOL domains represented in the MVQOLI-M are applicable and can be understood by Ugandans. The poorest QOL was found in the domains of function, psychological well-being, and physical symptoms. This further supports the need for a holistic approach to care for people with advanced illness, since the effect of HIV extends across all the important domains of QOL.[21]

In this study, transcendence was found to be the best QOL predictor, as it made the strongest unique contribution to explaining QOL. The findings support previous overall observations concerning the importance of transcendence issues in people with advanced disease.[10,11] It also provides more evidence for QOL having culturally robust constructs. Our findings support the notion advanced by Cohen and Mount:[8] as physical condition deteriorates, spiritual issues may tend to gain as determinants of QOL. There is, therefore, evidence for a possibility of growth at the terminal phase of life.

The transcendence dimension is a purely spiritual domain. In being spiritual, it is less affected by things like pain and discomfort commonly experienced by the patients. This detachment may explain some comfort derived by those with spiritual, religious, or personal beliefs at times of suffering.[21] This notion is further supported by the effect of religion on the transcendence and psychological well-being domains found in this study.

The results of the study support our hypothesis that observer-rated functional performance rated by a trained observer is neither a reliable predictor nor proxy for QOL in the terminally ill. This is evidenced by the very low correlation between the overall QOL score and the Karnofsky Performance Status score. The MVQOLI-M function dimension shows a higher correlation with the overall QOL rating ($r = 0.41$) than does the Karnofsky Performance Status score ($r = 0.25$). This suggests that QOL is a very subjective construct and the person's adaptation and reevaluation of their situation affects their QOL. Notably, these elements are integral to the MVQOLI-M construct for the terminally ill. These findings further lend support to the notion that to describe functional status instruments as QOL measures is a misnomer that should be resisted. Such instruments cannot supply a comprehensive answer about QOL since various important areas are ignored.

Study findings confirm that stigma is a relevant factor and probably belongs to the psychological well-being domain since it is an interpersonal concept. This makes sense in that less stigma greatly improves the quality of relationships, that is, improves psychological well-being of a patient. Remple and Hilton reported similar findings in a study conducted in Canada among HIV-infected women.[22] The second experimental variable assesses the effect of illness on the patient's normal sex life. Sexuality had the lowest correlation with the overall QOL item and was not very useful in predicting overall QOL. Sexuality explained only 6.8% of the variance in overall QOL, which is very low compared to stigma, which explained 17.3% of the variation in overall QOL. This may indicate that terminally ill AIDS patients in urban Kampala do not derive good sexual satisfaction in the advanced stages of illness. Alternatively, patients could have

been embarrassed by the item, and simply rated it indifferently or in a resentful and defensive manner with an overall low score.

In terms of reliability, the physical symptom domain had weakest internal consistency. A possible explanation for this finding is inferred from the interviewers' recommendation to rephrase Item 5, as the term physical discomfort was quite weak and, therefore, not able to bring out the importance of physical symptoms to the patients' physical symptom domain and overall QOL. When this item was dropped and internal consistency recalculated in a secondary analysis, this domain achieved a Cronbach's alpha of 0.77, lending support to this notion. For function and psychological well-being, the Cronbach's alphas missed the level of 0.7 by low levels (0.03, 0.01), suggesting the possibility that acceptable internal consistency does exist.

Measuring QOL is problematic in the terminally ill population, since it is common to find patients who cannot complete a questionnaire. With this inherent and unavoidable limitation, debilitated patients could not be interviewed, yet the QOL issue is critical in such difficult situations to enhance holistic care even for such patients. This could have introduced selection bias in the study. Nonetheless, bias is not likely to affect the generalizability of the findings. This is because only four of the eligible participants could not be interviewed because their debilitated physical state limited their ability to complete the MVQOLI-M.

Despite the limitations, we strongly believe that our central conclusions remain valid. There is preliminary evidence that the MVQOLI-M is an acceptable, valid, and reliable QOL measure among patients with advanced AIDS disease. Study results also provide more evidence for the need to reflect on the patient's sense of personhood and meaning of life in advanced illness, in the African setting.

Acknowledgments

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Appendix
Modified Version of the Missoula-Vitas Quality-of-Life Instrument

Today's Date: _____Patient No:_____

PATIENTS' INSTRUCTIONS
**INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE WITH THE
FOLLOWING STATEMENTS BY MARKING IN ONE OF THE BOXES BELOW THE
QUESTION. FOR ITEMS WITH TWO STATEMENTS, INDICATE AGREEMENT WITH ONE
OR THE OTHER; OR IF THEY ARE EQUALLY TRUE, CHOOSE "NEUTRAL." IF YOU
MAKE A MISTAKE OR CHANGE YOUR MIND, PLACE AN X THROUGH THE WRONG
ANSWER AND MARK THE BOX INDICATING YOUR CORRECT ANSWER.**

__INTERVIEWER INSTRUCTIONS__
*ALL QUESTIONS SHOULD BE ASKED EXACTLY AS WRITTEN; UNCLEAR ITEMS SHOULD
BE CLARIFIED TO RESPONDENT'S SATISFACTION BEFORE THEY GIVE A RESPONSE TO
THE STATEMENT WHERE NECESSARY. PLEASE KEEP READING OUT ALL THE SCALE
RESPONSES AND ALLOW THE PATIENT TO RATE WHAT IS APPLICABLE TO THEM.*

**PHYSICAL SYMPTOM (experience of the physical discomfort associated with progressive illness;
perceived level of distress)**

1.   My physical symptoms are adequately controlled.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

2.   I feel sick all the time.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

3.   I accept my physical symptoms as a fact of life.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

4.   I am satisfied with the current control of my physical symptoms.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

5.   Despite physical   Physical discomfort
        discomfort, in general   OR   over shadows any
        life goes on.   opportunity for life to go on.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

FUNCTION (perceived ability to perform accustomed functions and activities of daily living; experienced in relation to expectations)

6.   I'm still able to attend
      to most of my personal care   OR   I am dependent on others
      needs like dressing by myself**.**   for personal care needs, like dressing.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

7.   I am still able to do
      many of my   OR   I am no longer able to do
      hobbies.   many of my hobbies.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

8.   I am satisfied with my ability to take care of my basic needs of personal care.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

9.   I accept the fact that I
      cannot do many of the   OR   I am disappointed that I cannot
      things that I used to do.   do many of the things
                                                        that I used to do.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

10.   My contentment with life depends upon being active and being independent in my personal care.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

INTERPERSONAL (degree of investment in personal relationships and the perceived quality of one's relations with family and friends)

11.   I have recently been able to say important things to the people close to me.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

12.   I feel closer to others
      in my life now than I   OR   I feel increasingly distant
      did before my illness.   from others in my life.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

13.   In general, these days I am satisfied with relationships with family and friends.

□   □   □   □   □
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

14.   At present, I spend as much time as I want to with family and friends.

□   □   □   □   □
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

15.   It is important to me to have close personal relationships.

□   □   □   □   □
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

TRANSCENDENCE (Experienced degree of connection with an enduring construct; degree of experienced meaning or purpose in life)

16.   I have a greater sense   OR   I feel more disconnected to the supernatural
        of connection to the   being I believe in than I did before my illness
        supernatural being I believe in
        than I did before my illness

□   □   □   □   □
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

17.   I have a better sense   I have less of a sense of
        of meaning in my life   OR   meaning in my life now
        now than I have had   than I have had in the past.
        in the past.

□   □   □   □   □
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

18.   It is important to me to feel that my life has meaning.

□   □   □   □   □
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

19.   As the end of my life   As the end of my life
        approaches, I am   OR   approaches, I am uneasy with
        comfortable with the   the thought of my own death.
        thought of my own death.

□   □   □   □   □
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

20.   Life has become more
      precious to me; every   OR   Life has lost all value for
      day is a gift.   me; every day is a burden.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

PSYCHOLOGICAL WELL-BEING (self-assessment of an internal condition; subjective sense of wellness or disease; experience of contentment)

21.   My affairs are in order;   My affairs are not in order;
      I could die today with   OR   I am worried that many
      a clear mind.   things are unresolved.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

22.   I feel generally at peace   I am unsettled and
      and prepared to leave   OR   unprepared to leave this
      this life.   life.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

23.   I am more satisfied with myself as a person now than I was before my illness.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

24.   The longer I am ill,   The longer I am ill, the more
      the more I worry about   comfortable I am with the
      everything "getting out   OR   idea of "letting go"
      of control" (losing control   (having control over situations).
      over situations).

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Agree   Agree
Strongly   Strongly

25.   It is important to me to be at peace with myself.

☐   ☐   ☐   ☐   ☐
Agree   Agree   Neutral   Disagree   Disagree
Strongly   Strongly

GLOBAL

How would you rate your overall quality of life?

☐   ☐   ☐   ☐   ☐
Very poor   Poor   Fair   Good   Very good

Please use the space below for any additional comments you may have to make on the subject matter.
……………………………………………………………………………………………………

PLEASE MAKE SURE THAT YOU HAVE ANSWERED ALL THE QUESTIONS