

## Measuring quality of life for patients with terminal illness: the Missoula–VITAS<sup>®</sup> quality of life index

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**Key words:** palliative care, terminal illness, quality of life, patient-centred, outcomes measurement

Quality of life (QOL) is an important outcome measure in caring for terminally ill patients. The Missoula–VITAS<sup>®</sup> Quality of Life index (MVQOLI) has been developed to provide a measure of quality of life that is meaningful to both clinicians and patients. Unique features of the instrument include its focus on the terminal phase of life, the item structure and a scoring system that allows the weighting of each dimension of QOL by the respondent, and the subjective wording of the items that allows respondents to interpret the measured elements according to their own experience. The validity and reliability of the patient-reported survey instrument were tested by administering the 25-item questionnaire to 257 patients in 10 community-based hospices. Participants were incurably ill with predicted survival of six months or less. Exclusion criteria included inability to communicate, dementia, or psychological symptoms that might be intensified by completing the index. Reliability and validity of the new index were examined using standard statistical and psychometric analyses. The MVQOLI demonstrated internal consistency (Cronbach's alpha = 0.77). MVQOLI total scores were correlated with scores on the Multidimensional Quality of Life Scale – Cancer 2 and with patient-reported global QOL ratings. MVQOLI scores did not correlate with observer-rated functional status scores indicating divergent validity. The MVQOLI could be completed by patients of varied educational level, age, functional status, and length of time with a terminal illness. The instrument is designed to contribute to the task of planning care by evaluating patient-identified sources of distress, strength and satisfaction, including issues of life closure. This information contributes to crafting highly specific interventions. Further studies are necessary to determine the usefulness of the instrument in measuring outcomes of end-of-life care in nonhospice settings, and for racial and diagnostic groups under-represented in this sample.

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**Mots clés:** soins palliatifs, maladie terminale, qualité de vie, centré sur les patients, la mesure des deulements

La qualité de vie (QOL) est une mesure de deulement importante dans les soins de patients en phase terminale. Le 'Missoula-VITAS® Quality of Life Index' (MVQOLI) a été développé pour fournir une mesure de la qualité de vie qui est à la fois significative aux infirmières et patients. Les caractéristiques uniques de l'instrument incluent son foyer sur la phase terminale de vie, la structure d'article et le système de marquer qui permettent la possibilité de donner du poids à chaque dimension de QOL par le répondant et les termes subjectifs des articles qui permettent aux répondants d'interpréter les éléments mesurés selon leur propre expérience. La validité et la solidarité de l'instrument de la sondage rapportée par les patients étaient essayées par administrer la sondage de 25 articles aux 257 patients dans 10 hospices centrés sur la communauté. Les participants étaient incurablement malades avec une survivance prédite de 6 mois ou moins. Les critères d'exclusion ont inclus l'incapacité de communiquer, la démence ou les symptômes psychologiques qui pourraient être intensifiés par terminer l'index. La solidarité et la validité du nouvel index étaient examinées utilisant les analyses statistiques et psychométriques standardes. Le MVQOLI a démontré la consistance interne (Cronbach's alpha = 0.77). Les scores totaux de MVQOLI ont été mis en corrélation avec les scores de l'échelle de la Qualité de Vie à Multi-dimensions – Cancer 2 et avec les évaluations globales de QOL rapportées par les patients. Les scores de MVQOLI n'étaient pas en corrélation avec les scores de la situation fonctionnelle évalués par les observateurs ce qui indique la validité divergente. Le MVQOLI pourrait être complété par les patients d'une niveau de l'éducation, l'âge, la situation fonctionnelle et la durée de la maladie terminale variés. L'instrument est dessiné pour contribuer à la tâche de planifier les soins par évaluer les sources de détresse, la force, et la satisfaction identifiées par les patients, y compris les questions de la fermeture de vie. Cette information contribue à inventer les interventions extrêmement précises. Il faut exécuter plus d'études pour déterminer l'utilité de l'instrument en mesurant les deulements de soins en fin de vie, dans les cadres non-hospices et pour les groupes raciaux et diagnostiques qui sont sous-représentés dans cet échantillon.

## Introduction

Improving quality of life (QOL) is recognized as an important goal of palliative care.<sup>1,2</sup> Thus, QOL assessment has become an important measure for clinical care planning, for programmatic quality improvement, and for research in the comparison of existing therapies and clinical trials of new therapies. Clinch and Shipper<sup>3</sup> have suggested that QOL could be the most appropriate outcome measure of terminal care because it is focused on what happens to the patient, measuring the effect of

physiological change (such as pain reduction that enables greater freedom of ambulation) rather than only the fact of physiological change. In addition, well-constructed QOL measurement tools evaluate the comprehensive outcomes of all interventions.<sup>3-5</sup> The recent SUPPORT<sup>6</sup> study of terminal care revealed the need for new methods to enhance communication, decision-making, and symptom control in terminal care. When combined with established function and symptom assessment scales, information derived from a patient-reported QOL assessment tool could provide the basis for

improved goal definition. The recognition of meaningful and achievable goals may, in turn, facilitate communication and improved sharing of decision-making and care planning by physicians and their terminally ill patients.

Gill and Feinstein<sup>4</sup> reviewed 75 articles that reported QOL measurement during clinical trials of therapeutic interventions and found that in 85% of them, 'QOL' was not defined and targeted domains of QOL were generally not identified. Published instruments for measuring QOL, as a group, often focus on physical status and functional capacity, reflecting either an intentional construct or an assumption that lower functional levels are determinative of lower QOL.<sup>5,7-9</sup> Even within the field of end-of-life care, this orientation is frequently adopted without critical evaluation.<sup>3</sup> Cohen, Mount and colleagues<sup>9-11</sup> have discussed the limitations of measures for patients receiving palliative care, and have documented the importance of an existential or 'life meaning' domain.<sup>11</sup> Importantly, few instruments allow for the potential for positive experiences that might enhance QOL in the terminal phase.<sup>7,12</sup>

Considering the unique context of advanced incurable illness and the attributes of QOL assessment tools outlined by other authors,<sup>4,5,7,9</sup> an idealized instrument for use in a palliative care setting would encompass specific features, such as those listed in Table 1. Tools recently developed for use in advanced cancer and palliative care populations

have incorporated many of these, although Hearn and Higginson conclude in a recent review<sup>13</sup> that no one measure sufficiently covers the domains relevant to palliative care. The McGill QOL questionnaire (MQOL)<sup>9,10</sup> is notable for its well-defined construct, multidimensional structure, patient self-reporting, inclusion of both negative and positive contributions to QOL, and excellent psychometric properties. The MQOL and several other instruments<sup>16</sup> (Ferrans and Powers<sup>4,15</sup>) are designed, however, for patients with cancer or other diseases at all phases of the illness, including those undergoing aggressive curative therapy and those with no evidence of disease-following therapy. These instruments may not, therefore, address the unique concerns of patients who are terminal and may be aware of their terminal status. In addition, the MQOL does not allow for weighting of the measured dimensions according to their importance to the respondent.<sup>9-11</sup> Instruments that do allow weighting, often weight every item<sup>14,15,17,18</sup> making them overly long for patients to complete, and they may include different numbers of items in each dimension so that the total score reflects an unequal weighting of dimensions.<sup>9</sup>

The Missoula-VITAS QOL index (MVQOLI) was developed to incorporate the features identified in Table 1 and differs from existing instruments in (1) its focus on the terminal phase of illness; (2) the use of categories of responses and scoring that allow for the weighting of each QOL dimension according to the patient-reported importance; (3) the use of subjective language to reflect and measure the evolving nature of the patients experience and adaptation to circumstances; and (4) its clinical utility as an assessment tool to aid in designing care plans and interventions. The theoretical framework for the MVQOLI builds upon Cassell's<sup>19</sup> multidimensional model of personhood and the model of lifelong human development as applied to the terminally ill.<sup>20,21</sup> The potential for human development remains throughout life; and in addition to the obvious potential for suffering, the circumstance of progressive, incurable illness includes the possibility for positive experiences and presents an opportunity for personal growth.<sup>20-23</sup> The construct measured in the MVQOLI can be stated as follows:

QOL in the context of advanced, progressive, incurable illness, is defined as the subjective experience of an individual living with the interpersonal,

**Table 1** Critical features of a quality of life assessment tool

- A well-defined construct that has clinical applicability.
- Self-reported rather than observer-rated; a subjective assessment.
- Multidimensional, assessing relevant spheres of personhood including those related to health and function, as well as psychological, emotional and spiritual dimensions of self.
- Scoring of the instrument provides for weighting of dimensions by the person.
- The tool measures changes experienced by the person in both negative and positive directions from pre-illness status ('baseline') within each dimension.
- Both the total score and component dimensional scores are clinically meaningful.
- 'Sensibility' which includes measures of validity as well as 'real world' applicability and utility,\* including ease of administration and scoring.
- Use as both a discriminative tool, measuring differences between groups of persons, and an evaluative tool, measuring changes in an individual over time.

\*Feinstein AR. *Clinimetrics*. New Haven, CT: Yale University Press, 1987: 141-66.

psychological, and existential or spiritual challenges, that accompany the process of physical and functional decline and the knowledge of impending demise. A person's QOL can range from suffering, associated with physical distress and/or a sense of impending disintegration, to the experience of wellness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks.

This construct forms the basis for one central hypothesis of the MVQOLI validation study described here. The hypothesis is that among patients with advanced, incurable illness there will be a divergence, reflecting the lack of causal relationship between self-reported QOL and the patients' functional status as evaluated by clinical observers.<sup>24</sup>

The MVQOLI was administered to over 300 hospice patients in order to assess its psychometric properties. Results indicate that the MVQOLI

exhibits reliability, and both concurrent and construct validity within a population of terminally ill patients receiving hospice care.

## Methods

### Development of the instrument

A review of the literature<sup>3,7,9,10,14-17,19,25-27</sup> and informal interviews of hospice professionals, patients and their families were used to determine the dimensions of QOL to be measured. Five dimensions were chosen for measurement – symptom (Sx), functional (F), interpersonal (IP), well-being (WB) and transcendent (T). These are defined in Figure 1A.

Thirty-one items were drafted for pilot testing. Items were either a single statement to which patients were asked to indicate agreement or dis-

(A)	
<b>SYMPTOM (S):</b>	the level of physical discomfort and distress experienced with progressive illness.
<b>FUNCTION (F):</b>	perceived ability to perform accustomed functions and activities of daily living and the emotional response, experienced in relation to the person's expectations.
<b>INTERPERSONAL (IP):</b>	degree of investment in personal relationships and the perceived quality of one's relations/interactions with family and friends.
<b>WELL-BEING (WB):</b>	self-assessment of the individual's internal condition. A subjective sense of wellness or unease, contentment or lack of contentment (the intrapersonal).
<b>TRANSCENDENT (T):</b>	experienced degree of connection with an enduring construct, and of meaning and purpose of one's life (the transpersonal).
(B)	
<b>ASSESSMENT (A):</b>	subjective measurement of actual status or circumstance. <b>Example:</b> I feel sick all the time.
<b>SATISFACTION (S):</b>	feelings or emotions in response to actual circumstances. <b>Example:</b> I accept my symptoms as a fact of life.
<b>IMPORTANCE (I):</b>	the degree to which a given dimension has an impact on quality of life. <b>Example:</b> Despite my physical discomfort, I can enjoy my days.

**Figure 1** (A) The five dimensions of quality of life assessed by the MVQOLI. (B) The three categories of items used to assess each dimension of quality of life.

agreement, or two opposing statements with which patients indicated a greater or lesser degree of agreement by placing a mark along a linear scale anchored at each end by one of the statements. The item structure reflected the goal of measuring both positive and negative contributions to QOL. Single statements were used when the converse was obvious and unambiguous. Two-sided items were used whenever it was necessary to clarify the converse and in order to avoid 'leading' the respondent by including only the positive or negative statement. On the questionnaire presented to respondents, numerical scores assigned to each answer are not identified. Both the item structure and the lack of a numerical scale were designed to increase subjectivity and allow patients to define their own arbitrary scale.

Each of the items elicited one of three different types of responses, called response categories (defined in Figure 1B) which were assessment, satisfaction and importance. The items were randomized. One additional item was added to provide an overall or global QOL assessment for validity testing.<sup>25</sup>

Content validity of the instrument was assessed by a group of hospice professionals,<sup>14</sup> including four nurses, two chaplains, three nurse managers, three administrators, and one quality improvement specialist. This group was provided with definitions for the five dimensions and was asked to comment on the MVQOLI content and to assign each item to one of the five dimensions on the basis of the definitions provided.

Lastly, a scoring algorithm was devised. Assessment (A) and satisfaction (S) responses (in each dimension) are scored on scales ranging from negative to positive (as suggested by Ferrans and Powers<sup>14</sup>) and the average (A) plus the average (S) scores provided the unweighted dimensional scores which range from -6 to +6. Assessment items are scored from -2 to +2 and satisfaction items are scored from -4 to +4. Different scales were assigned based on the greater role of satisfaction (reflecting mastery and adaptation) in the underlying construct, above.<sup>28</sup> Weighted dimensional subscores are calculated by multiplying the sum of the average assessment plus the average satisfaction score by the importance (I) score (an integer between 1 and 5) in that dimension (see 'Data analysis' section, below); weighted subscores range from -30 to +30. Total scores are a modified sum of the weighted dimensional subscores and,

therefore, reflect the multidimensional QOL weighted according to the individual patient's identification of the most important dimensions. The total is calculated by summing the five weighted dimensional scores, dividing the sum by 10, and then adding 15, so that the resulting total falls between 0 and 30. The conversion to a positive score facilitates analysis of aggregate population data.

The 31-item questionnaire was pilot tested with 58 hospice patients from south Florida, Chicago and Houston. All of the surveys were administered by two researchers (Dr Merriman and a master's level nurse trained by her) in order to eliminate protocol variability. During a home visit, the study was explained to the patient in detail, an informed consent signature was obtained, and the MVQOLI was left with the patient and collected the next day. All questionnaires were coded and returned in sealed envelopes to protect patient identity. The data from the pilot study was used to refine a 25-item version of the MVQOLI. Items most frequently left unanswered or marked as 'not applicable', along with items that correlated poorly with their intended dimensions, or that correlated equally well with more than one dimension (and, therefore, lacked discrimination), were revised or eliminated from the subsequent version of the MVQOLI.

The 25-item version of the MVQOLI reported here contained five items in each dimension (two assessment, two satisfaction, and one importance; see the Appendix). The items were presented in a random order with the global item in the middle of the questionnaire.

#### **Informed consent**

The study was approved by two institutional review boards, one jointly sponsored by St Patrick's Hospital and Community Medical Center in Missoula, Montana, and one administered by VITAS Healthcare Corporation, Miami, Florida. Following verbal explanation of the study's purpose, risks, and benefits as well as the participant's rights, patients indicated informed consent by signing a disclosure document. The document conformed to the guidelines outlined in HHS Regulations on the Protection of Human Subjects, 45CFR §§46.116-46.117.

## Protocol for reliability and validity testing of the 25-item version of the MVQOLI

### Selection of research sites and training of research assistants

Ten hospices were chosen to participate, based on census and personnel requirements of the study protocol. At each site, a research co-ordinator was identified and social work personnel were enlisted as research assistants. Research assistants were trained by one of the principal investigators (Dr Merriman) in methods for unbiased selection, enrolment and coding of subjects, steps to be followed in administering the MVQOLI and providing collateral data, and techniques for Karnofsky performance scale (KPS) scoring of subjects.<sup>24</sup>

### Selection of subjects

Patients were considered eligible for the study if they could understand and respond to the questionnaire on their own. Guidelines for administering the tool, allowed for items to be read verbatim (without explanation) to subjects, if necessary. Patients were excluded if they (1) were unable to understand and communicate in English; (2) exhibited dementia upon clinical evaluation by the research assistant; or (3) were experiencing psychological symptoms that, in the judgement of the clinicians involved, might be exacerbated by items within the MVQOLI.

### Administration of the MVQOLI

The research assistants were provided with pre-coded packets containing the MVQOLI, the Multidimensional QOL Scale-Cancer 2 (MQOLS-CA2) by Padilla and Grant,<sup>26,27</sup> a previously validated instrument that was used for analysis of concurrent validity, consent forms, and a form for recording both demographic information and the KPS score that the research assistant assigned to the patient during the visit in which the MVQOLI was delivered. In conjunction with regularly scheduled visits, the research assistants offered the eligible patients the opportunity to participate in the study of the MVQOLI, obtained informed consent from those willing to participate, and completed the demographic data sheets. The questionnaires were left with the patients for up to one week so that they could be completed and sealed within the envelopes provided. The envelopes were returned to the office

by the hospice staff. All survey envelopes were returned to the authors unopened, for data analysis.

### Data analysis

The MVQOLI questionnaire forms were created using the Survey Network™ Design Software (version 1.4) from National Computer Systems (NCS) and were printed onto specialized, scannable, 'bubble sheet' paper. Completed surveys were scanned into a personal computer using the Survey Network™ Data Collection Software (version 3.0b) and an OPSCAN5 Model 30 optical scanner, both from NCS. A pre-assigned numerical score for each response is recorded in the computer database upon an electronic scan of the questionnaire, along with a unique identifier code for the questionnaire.

Data files were transferred into Paradox® (version 4.0) database files. Standard Paradox queries were used to identify incomplete records or records with 'not applicable' answers. These were manually scored if possible. Records that contained missing data for any 'importance' item, or for which both 'assessment' or both 'satisfaction' items in any one dimension were missing, were removed from the database and counted as unscorable.

Dimensional subscores and total scores were calculated according to the following formulas using custom paradox calculation scripts:

Unweighted dimensional subscore = average assessment + average satisfaction =

$$\frac{DA_1 + DA_2}{2} + \frac{DS_1 + DS_2}{2} = \frac{DA_1 + DA_2 + DS_1 + DS_2}{2}$$

Weighted dimensional subscore =

$$\left[ DA_1 + DA_2 + DS_1 + DS_2 \right] / 2 \times (DI)$$

Total score = [(sum of weighted dimensional subscores)/10] + 15; This is a mathematical conversion to generate total scores between 0 and 30.

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.

Statistical analyses were carried out using Parastat® (version 2.5), a statistical package designed for use with Paradox databases. For some analyses, including internal consistency and Spearman cor-

relations, data files were transferred to SPSS for Windows, Statistical Package for Social Sciences (version 6.1).

## Results

### Respondent population

For testing of the final version of the MVQOLI, 257 hospice patients agreed to participate in the research study and 224 (87%) completed the questionnaire. For this study, conducted in multiple sites using clinical staff as research assistants, the data on the total number of patients approached and the number who refused were not consistently reported. In the pilot study (see Methods), six patients out of 58 (10%) refused to participate. In current practice in one hospice setting (VITAS Healthcare Corp.), 43 of 877 patients (5%) refused to complete the MVQOLI. With respect to eligibility for the reported study, the research assistants were instructed to list all eligible patients (see Methods) and to randomly select those to be offered the questionnaire. In current hospice practice, all newly admitted patients are evaluated for their ability to complete the MVQOLI and we find that 55% of patients (482/877) are unable to complete the questionnaire; those who are unable include patients who are unable to communicate (in general, patients in this group are moribund), exhibit dementia, or have severe psychosocial symptoms that may be exacerbated by completing the tool.

Of the 224 returned questionnaires, the 173 (77%) that could be completely scored served as the population for statistical and psychometric analysis. (Note that an additional 13 of the questionnaires that could not be scored with sufficient accuracy for research purposes, nevertheless did provide adequate information for clinical planning.) Only 42 (24%) of respondents reported that they had help in reading the questionnaire and 131 (76%) filled out the survey independently.

Demographic information was available for 165 participants. In eight cases, demographic data was not recorded. Patients who were able to complete the survey represented a wide range of ages (29–91 years) and educational levels (eight years to over 16 years of formal education) but only a limited mix of racial/cultural heritage (92% Caucasian), diagnoses (68% cancer, 11% end-stage lung disease, 8% end-

stage heart disease), and location of living (79% private home). In addition, the majority of respondents reported that their hospice care was paid for by Medicare (67%) or Medicaid (14%), both of which are government-funded health insurance programmes. Additional demographic characteristics for these 165 patients are displayed in Table 2.

The demographic characteristics of the patients whose MVQOLI forms could not be scored, were similar to those of patients whose forms could be scored. In addition, the MVQOLI scores for the eight patients without demographic information were not different from those of the 165 with demographic information (data not shown), therefore, they are included in the analyses.

### Range and variance of responses

The range of dimensional subscores and total scores is shown in Table 3. The range of observed scores for the respondent population was large (Table 3); the dimension with the smallest observed range was the interpersonal, where scores were skewed toward higher levels. The full range of possible scores was reached for the functional and the well-being dimensions. Total scores covered 71.5% of the possible range (0–30); the mean total score was 19.91 (SD = 3.97) (Table 3).

To determine whether any independent variables were predictive of the MVQOLI score, demographic groups were compared using a *t*-test and ANOVA. No significant differences in total scores were observed based on gender, educational level, marital status, reported religious affiliation, or hospice reimbursement source (Table 2). Mean scores for respondents who filled out the questionnaire on their own versus those who had help reading the items were not statistically different (data not shown). The 26 (16%) respondents who reported that their health had generally not been good for their adult life had statistically lower MVQOLI scores than those who reported generally good health during their adult years ( $P = 0.04$ ) (Table 2). Comparisons of racial or diagnostic groups, or groups based on living arrangement (private home, with or without family, versus nursing home) or on hospice reimbursement source, were not performed due to the relative demographic homogeneity of the study sample (see Respondent population).

**Table 2** Selected characteristics of the demographic subpopulation (165 patients) and comparison of MVQOLI total scores

Characteristic	Value	Number*	Percent	MVQOLI total score (mean $\pm$ SD)	P value <sup>†</sup>
Mean age	63	165			
Gender	Female	93	56	19.72 $\pm$ 3.93	NS
	Male	72	44	20.08 $\pm$ 3.94	
Religious affiliation	Protestant	84	51	19.97 $\pm$ 4.01	NS
	Catholic	45	27	18.89 $\pm$ 3.83	
	Other	22	13	21.98 $\pm$ 3.61	
	None	12	8	21.18 $\pm$ 4.34	
Marital status	Married	72	44	19.78 $\pm$ 3.49	0.08 0.016 NS
	Widowed	49	30	20.94 $\pm$ 3.67	
	Divorced	28	17	18.30 $\pm$ 4.83	
	Single	11	7	19.30 $\pm$ 4.58	
Educational level	Grade school	33	20	19.75 $\pm$ 3.97	NS
	High school	89	54	20.01 $\pm$ 4.09	
	Assoc. degree	18	11	18.86 $\pm$ 3.59	
	Bachelor degree	14	8	20.59 $\pm$ 3.34	
	Graduate degree	7	4	18.77 $\pm$ 4.19	
Report on overall adult health status	Good	136	82	20.22 $\pm$ 3.76	0.04
	Not good	26	16	18.05 $\pm$ 4.33	
Length of time patient has been aware of terminal diagnosis	< 1 month	19	12	20.24 $\pm$ 3.38	NS
	1–3 months	23	14	20.61 $\pm$ 3.97	
	4–6 months	34	21	20.13 $\pm$ 3.55	
	7–12 months	11	7	19.80 $\pm$ 3.85	
	> 12 months	71	43	19.33 $\pm$ 4.45	
Mean Karnofsky Performance Score	59.2				

\*Numbers may not add to 165 because some patients did not answer all questions.

<sup>†</sup>NS: Not significantly different (at a level of  $P < 0.05$ ) from other values within a given characteristic.

**Table 3** Range of responses and means

Dimension	Possible range	Respondent range	Mean	Standard deviation	Median
Symptom	-30 to 30	-25 to 25	6.19	7.32	6.00
Function	-30 to 30	-30 to 30	6.09	15.27	7.50
Interpersonal	-30 to 30	-17.5 to 30	17.64	10.92	20.00
Well-being	-30 to 30	-30 to 30	5.01	14.45	7.50
Transcendent	-30 to 30	-20 to 30	14.10	13.00	16.00
Total score	0–30	6.5–27.95	19.91	3.97	20.45
Global score	1–5	1–5	3.39	1.07	3.00

### Reliability

Reliability of the MVQOLI was measured by calculating internal consistency which yielded a Cronbach's alpha of 0.77 (standardized alpha = 0.79). Test-retest reliability was not evaluated for two reasons. First, the possibility that completing the MVQOLI itself may have an effect on QOL would render test-retest results misleading. Planned studies will test this hypothesis. Second, it was not practical to implement a test-retest protocol in the context of our resources and the short lengths of stay for many subjects.

While not a formal statistical measure of reliability, mean scores for each of the different data collection sites were compared. Analysis of variance showed that the mean scores at the sites were not significantly different ( $f = 1.09$ ). These data indicate that the MVQOLI can provide similar scores for similar groups of patients, even when administered by different researchers in different geographical locations.

### Validity testing

Content and face validity were analysed based on



the review of the instrument by hospice professionals. When 14 hospice professionals were asked, during development of the MVQOLI, to assign the randomly arrayed items to one of the five dimensions (definitions provided), the items were correctly assigned 77% of time, indicating that items can be reliably sorted to their intended dimensions.

Concurrent validity was tested via concurrent administration of the MQOLS-CA2.<sup>26,27</sup> The total scores on the two questionnaires exhibit very good correlation with a coefficient of 0.63.

Construct validity was examined by analysing the correlation of the MVQOLI with convergent and divergent constructs. In the analysis of convergence, MVQOLI total scores and ratings on the global QOL item were compared and the Pearson's coefficient of correlation was 0.43.

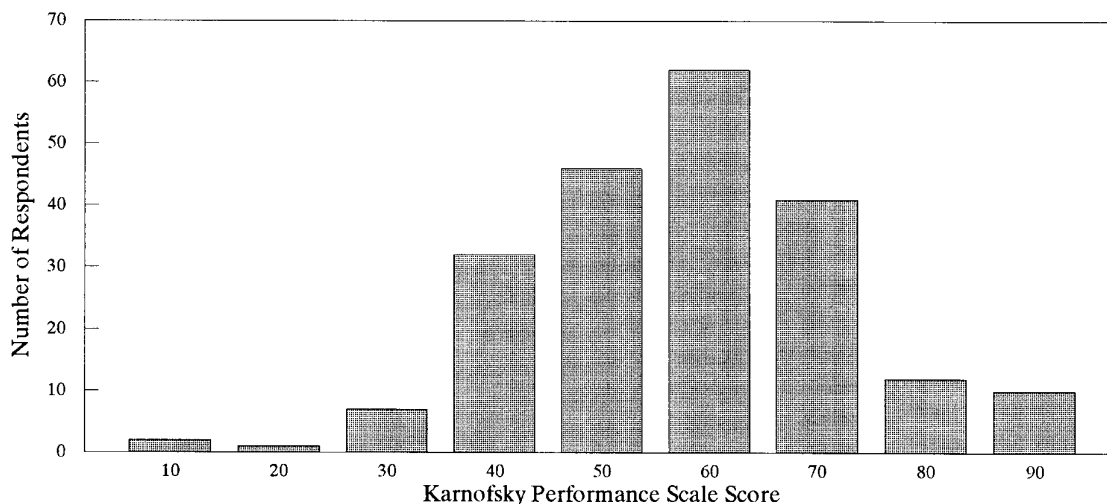
Analysis of the correlation between total scores on the MVQOLI and ratings on the KPS, an observer-rated measure of functional performance and not of QOL,<sup>24,27</sup> indicated that the two scales are divergent (coefficient = 0.19). Similarly, there was very low correlation between the KPS and scores on the MQOLS-CA2 (coefficient = 0.18) and the global QOL item (coefficient = 0.13). It can be noted that KPS scores of the respondent population were distributed between 30 and 80 with a peak at 60 (skewness = 0.23; kurtosis = 0.07) (Figure 2). The correlation between the MVQOLI functional dimension subscore and the MQOLS-CA2 total score

was 0.53; the correlation between the MVQOLI functional score and the global QOL item was 0.39.

## Discussion

The MVQOLI was specifically designed for use with patients at an advanced, terminal phase of illness due to any underlying disease. The multisite study design and limited exclusion criteria were implemented to ensure a varied population of respondents within this group. Participants were selected at random from lists of eligible patients prepared by the research assistants (and/or the entire interdisciplinary team). There is a potential for bias in the preparation of the original lists of eligible patients. Although the instructions provided urged the inclusion of every patient who met inclusion criteria, they are inevitably subject to individual interpretation and could not ensure inclusion of all appropriate patients.

With respect to age, gender, and KPS score, the respondents are well distributed and the results are generalizable. The MVQOLI was comprehensible to, and completed by, respondents of various educational levels and religious backgrounds, and by patients who had recently learned of their terminal diagnosis as well as those who had known of their diagnosis for longer than a year. None of these independent variables affected total MVQOLI scores.



**Figure 2** Distribution of Karnofsky Performance Scale scores for respondents in the demographic subset.

The interesting fact that respondents who report generally good adult health had higher MVQOLI scores than those reporting generally poor adult health, may attest to the importance of overall attitude in determining QOL, but more research is needed.

The study group was predominately Caucasian, with cancer as the terminal diagnosis, limiting the generalizability of the study to other racial and diagnostic groups. It is interesting to note that in a recent study of 6451 hospice patients in the US, 92.4% were Caucasian<sup>29</sup> suggesting that this is characteristic of the population served by US hospice programmes. Another limitation of the current research is that it involved only patients enrolled in hospice programmes. Ongoing and future studies with the MVQOLI will address other racial and diagnostic groups and will be extended to patients being cared for in nonhospice settings who understand that they are incurably ill and that care is of a palliative nature.

The MVQOLI demonstrated concurrent validity, as measured by correlation of the total score with the score on the MQOLS-CA2<sup>26,27</sup> (coefficient = 0.63), and reliability, as measured by internal consistency ( $\alpha = 0.77$ ). Future studies will include evaluation of test-retest reliability and will examine our hypothesis that the experience of completing the MVQOLI may have an effect on QOL for terminally ill respondents.

Convergent validity was assessed by comparing the MVQOLI total score with a global QOL rating (single item). The level of correlation (coefficient = 0.43) was somewhat lower than expected, though consistent with an earlier study by Cohen *et al.*<sup>10</sup> One interpretation of these data is that, contrary to a recent analysis by Donnelly and Walsh,<sup>30</sup> the single-item global QOL rating is insufficient to capture the full 'lived experience' of the terminal patient. Consistent with this view, it may be that the MVQOLI more accurately measures 'QOL closure' (a term suggested by T Ryndes, personal communication), than QOL as evaluated by the single global item. In any case, it should be noted that placement of the global item in the middle of the questionnaire may affect the reliability of this data since the response can be influenced by the items that precede the global item, as was shown by Cohen *et al.* (10th International Congress on Care of the Terminally Ill, 1994, personal communica-

tion). Future studies will place the global item in front of all the other items.

MVQOLI total scores showed no correlation with KPS scores (coefficient = 0.19). Previous reports emphasize the importance of QOL score correlation with the KPS score as a measure of convergent validity. That interpretation, however, reflects the view that observer-rated functional performance is a fundamental predictor of QOL, that is, that the two elements always vary in direct proportion. This concept, however, has been refuted by several authors.<sup>7,9,10</sup> The results of the present study indicate that functional performance rating by a trained observer is neither a reliable predictor, nor a proxy for QOL in this terminally ill population, as evidenced by the low correlation between the KPS score and either the global QOL item or the MQOLS-CA2 score. The lack of correlation between the MVQOLI total score and the KPS score thus provides evidence of divergent validity.

It is worth noting that the MVQOLI functional dimension score shows a higher correlation with both the global item (coefficient = 0.39) and the MQOLS-CA2 score (coefficient = 0.53) than does the KPS score. These data suggest that patient-evaluated functional status, which includes measures of satisfaction and importance, is an element of QOL for the terminally ill. This interpretation is consistent with Calman's concept that QOL is determined by the difference between a person's expectations and their lived experience,<sup>28</sup> and comprises the elements of mastery and adaptation that are integral to our QOL construct for terminal patients.

The survey item structure, which is composed of three types of subjective information – assessment, satisfaction and importance – within each dimension of experience, is unique to the MVQOLI and contributes to its clinical relevance. For example, an examination of the scores in the symptom dimension provides evidence of the need for more than physical symptomatic relief. Notably, the unweighted symptom score (assessment plus satisfaction) is negatively correlated with the symptom importance score; that is, the better the control and/or adjustment to symptoms, the less important the dimension becomes to the person's overall QOL. Of interest, our findings suggest that adequate symptom management, while necessary, is by itself insufficient to improve the patient's subjective QOL, and that with adequate symptom control,

attention to the other dimensions becomes increasingly important.

Primarily because the MVQOLI provides these patient-weighted dimensional subscores, it may offer considerable clinical utility for the design and implementation of patient-focused care that other tools have been unable to provide.<sup>31</sup> The MVQOLI incorporates both multidimensional assessment and respondent ratings of the importance of each dimension, providing patient-reported information in a structured and quantifiable manner. Graphic displays of the dimensional scores, such as those in Figure 3, are simple to read and visually display which dimensions are adding to, and which are detracting from, QOL. Under the unique scoring protocol, the importance item influences the magnitude of the score in each dimension, and the patient's assessment and satisfaction responses determine whether the score is positive (improving QOL) or negative (detracting from QOL). The MVQOLI is potentially a powerful tool for framing discussions with patients about treatment goals, as well as for joint patient-clinician care planning. Importantly, the MVQOLI is intended to supplement relevant physiologic data and subjective assessments of symptom intensity, such as visual analogue scales, providing more comprehensive data for appropriate quality assurance and oversight. Clinicians can apply the MVQOLI dimensional scores as an evaluative tool to assess individual patients, localizing the critical domains and measuring the degree of distress and, thereby, enable clinical intervention

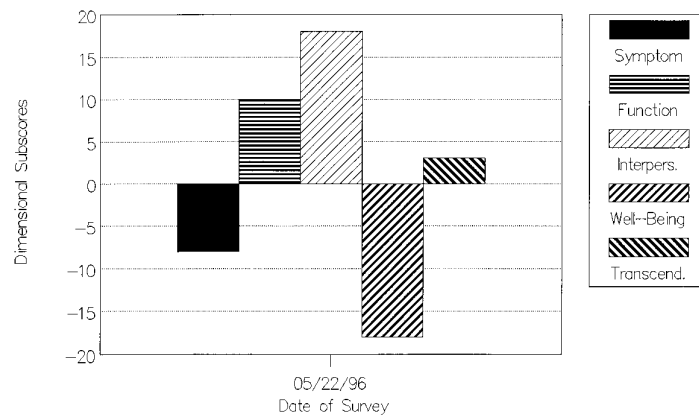
to be directed with increased specificity and efficiency. Total scores may enable researchers to apply the MVQOLI as a discriminative tool in prospective trials of physical (including pharmaceutical), psychosocial, and supportive (such as music or art therapy) interventions. We are developing and testing shorter versions of the MVQOLI which may be even more appropriate for use in therapeutic trials.

One desired feature of a QOL assessment tool is the capacity to measure differences in QOL over time. This feature was not examined in the present study due to time and resource constraints. The tool is being currently used to study the QOL in hospice patients over the course of their care. A serious methodologic challenge is presented by the currently short length of stay in hospices in the US,<sup>29</sup> which makes it difficult to find patients who are able to complete the survey two or more times.

The emerging era of health care reform presents a challenge to identify the most appropriate care for each patient. For patients who are dying, appropriate care must respond to the patient's subjective, and often changing quality of experience and needs. Both the art and science of medicine should be brought to bear in improving the patient's QOL. Tools such as the MVQOLI provide valuable assistance in meeting this challenge.

**Acknowledgements**

This study was partially supported by funding from the American Academy of Hospice and Palliative



**Figure 3** Bar graph representation of MVQOLI weighted dimensional subscores. The group of five bars represents one administration of the MVQOLI. Dimensions with longer bars are more important to the patient; positively scored dimensions enhance quality of life and negatively scored dimensions diminish quality of life.

Medicine. The authors are also grateful for the invaluable participation of and provision of travel funds by the following hospices: Hospice of the Florida Suncoast, Hospice of the Bluegrass, Hospice of Louisville, HealthEast Hospice, Hospice of Southeastern Michigan, Hospice of Southern Illinois, Hospice of Northern Virginia, VITAS – San Fernando, VITAS – Inland Empire, and Hospice of Rhode Island. VITAS hospices in Houston, Texas, Broward County, Florida, and Chicago, Illinois participated in the preliminary study.

Special thanks go to Barry Kinzbrunner for his early recognition of the potential value, application, and implications of the MVQOLI and for his ongoing intellectual and practical support of the work.

We also thank Jim Gouaux for discussions concerning the research protocol, Carolyn Schwartz for helpful suggestions regarding statistical analysis, Barbara Miller for assistance with data collection, Joanne Martin for assistance with computerized scoring and data analysis, and Mary Molloy Beaulieu for administrative assistance.

Finally, we thank the reviewers for their time and valuable constructive criticism that significantly improved the final version of the manuscript.

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

Agree ← → Disagree

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

Agree ← → Disagree

**Well-being**

16. My affairs are in order; I could die today with a clear mind.

← →

My affairs are not in order; I am worried that many things are unresolved.

17. I feel generally at peace and prepared to leave this life.

← →

I am unsettled and unprepared to leave this life.

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

Agree ← → Disagree

19. The longer I am ill, the more I worry about things 'getting out of control'.

← →

The longer I am ill, the more comfortable I am with the idea of 'letting go'.

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

Agree ← → Disagree

**Transcendent**

21. I have a greater sense of connection to all things now than I did before my illness.

← →

I feel more disconnected from all things now than I did before my illness.

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

← →

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

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

← →

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

24. Life has become more precious to me; every day is a gift.

← →

Life has lost all value for me; every day is a burden.

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

Agree ← → Disagree

Did you complete this questionnaire by yourself?

YES  NO

