Asian J Gerontol Geriatr 2008; 3: 17–26

ORIGINAL ARTICLE

Applicability of the modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E) for frail older people

HYL Chan[1] BSN, RN, **SMC Pang**[2] PhD, RN

[1] PhD candidate and Clinical Instructor, School of Nursing, The Hong Kong Polytechnic University
[2] Professor and Head, School of Nursing, The Hong Kong Polytechnic University

ABSTRACT

Objectives. Quality of life (QOL) has emerged as an outcome measure, since merely achieving longevity is no longer the goal of medicine. Older people, especially those who are frail, are more prone to morbidity and mortality. This study aimed at determining a specific QOL measurement for the frail elderly residing in long-term care facilities.

Methods. Quality-of-life Concerns in the End of Life Questionnaire (QOLC-E) was derived from an ethnographic study of patients with advanced chronic obstructive pulmonary disease and terminal cancer. It was adapted for the frail elderly in this study based on the assumption that they shared similar concerns in the last phase of their lives. A total of 313 frail older people from a geriatric outpatient clinic and 10 nursing homes were recruited for testing the psychometric status of the modified QOLC-E (mQOLC-E).

Results. The 23 items in the mQOLC-E entailed six factors for analysis. The factor structure resembled that of the original QOLC-E. Its internal consistency and inter-rater reliability of the mQOLC-E were acceptably high. Significant differences were noted between the frail and non-frail groups in terms of the mQOLC-E mean scores, thus demonstrating the test's discriminative validity.

Conclusions. The findings provide evidence that the mQOLC-E was a valid and reliable instrument for assessing the quality-of-life concerns of frail older people. The findings also reveal that they share similar concerns to patients in need of palliative care. Knowledge from this study will be useful for designing care to address the concerns for this vulnerable group.

Key words: Frail elderly; Quality of life; Questionnaire

Correspondence to: HYL Chan, School of Nursing, The Hong Kong Polytechnic University, Hung Hom, Hong Kong. E-mail: hsylchan@inet.polyu.edu.hk

INTRODUCTION

Frailty is a transitional stage from independence to in need of assistance. Although advancing age is not in itself a causative factor for becoming frail, to a certain extent, age-related physiologic changes in reserves of organ function and the advent of diseases place older people at risk of frailty.[1] Often, frail older people experience slow progressive health deterioration and functional impairment over a long period before death. Generally speaking, generic and disease-specific quality-of-life instruments fail to capture their specific concerns during this period of time.

Study aim

This was part of a larger study, which aimed to develop an advance care planning programme for frail older people. Specifically, it reports the process of adapting the Quality-of-Life Concerns in the End of Life Questionnaire (QOLC-E) to assess the quality-of-life concerns of frail older people and the psychometric properties of this modified instrument.

Quality-of-Life Concerns in the End of Life Questionnaire

The QOLC-E was empirically derived from a local ethnographic study.[2] Twenty advanced chronic obstructive pulmonary disease (COPD) and 20 metastatic cancer inpatients from two public hospitals were interviewed to assess primary determinants of their quality of life during the last chapter of their lives. After the interviews, field observations were conducted regularly to observe the condition of the interviewees and the care they received during hospitalisation.

Major themes pertinent to quality of life were inductively derived from their verbatim transcripts. The thematic analysis yielded 16 positive and 17 negative issues perceived by the patients as important constituents in evaluating quality of life.[3] These descriptors covered aspects of physical, emotional, relational and existential well being and were regarded as the 'quality-of-life concerns in the end of life'. They were then compiled into a questionnaire known as the QOLC-E.

In the QOLC-E, each item was scored on a 0-to-10 numeric scale with descriptors anchor at the two ends. Since some of the questions were negatively phrased, conversion of scores was needed so that a higher score indicated a higher level of satisfaction. The psychometric properties of the QOLC-E were then tested on 108 advanced COPD patients and 41 terminal cancer patients from three local hospitals. Of the 33 items, five were excluded from further analysis because their factor loadings were lower than 0.5 and they depressed internal consistency. These items were about the financial worries, perceived severity of illness, fear of dying and control over life. The fifth item which was the overall quality-of-life single-item scale (SIS) was taken out from the QOLC-E as an independent item for overall evaluation.

The remaining 28 items yielded seven factors explaining 63% of the total variance. For the sake of better interpretation, one of the factors was split into two subscales. The eight subscales were: (1) value of life, (2) health care concerns, (3) food-related concerns, (4) support, (5) negative emotions, (6) sense of alienation, (7) physical discomfort, and (8) existential distress. The first four subscales measured positive aspects of quality-of-life concerns, while the last four measured negative aspects. Good internal consistency was reported, with an overall Cronbach's alpha of 0.87. The alpha values of the eight subscales ranged from 0.57 to 0.83. Convergent and divergent validity were demonstrated by studying the correlations between the QOLC-E subscales and the overall quality-of-life SIS, the activities of daily living (ADL) and the Hospital Anxiety and Depression Scale.

METHODS

Subjects

The validation process employed a cross-sectional design, in which both community-dwelling older people and nursing home residents were recruited to enhance the generalisability of the findings. One geriatric outpatient clinic of an acute hospital and 10 nursing homes agreed to take part in the study. Patients attending for follow-up visits in the clinic and as well as nursing homes residents were asked to participate in the study.

The criteria of frailty were adapted from the definition proposed by the American Medical Association.[4] Eligible subjects were aged 65 years or more, mentally competent and able to communicate in Cantonese. Moreover, they had to be partially dependent in terms of functional ability (i.e. scored <17 in the instrumental activities of daily living [I-ADL]) and had at least one moderate-to-severe health-impairing problem (i.e. scored ≥3 in the Cumulative Illness Rating Scale [CIRS]). Those who had known psychiatric illness or communication difficulties were excluded.

Instruments

Overall Quality of Life Single Item Scale

This was included to measure the overall subjective quality of life on a numeric scale from 0-to-10. It was significantly correlated with the McGill Quality of Life Questionnaire, with a coefficient of 0.48.[5] Pang et al[6] reported that its correlation with the overall QOLC-E was significant, with a correlation coefficient of 0.60.

Activities of Daily Living

Physical functional ability was evaluated in two dimensions: personal ADL (P-ADL) and I-ADL.[7] In this study, each dimension included eight items assessed on a three-grade scale. The higher the score, the less the limitation experienced in performing the task. The Chinese version translated by Chi and Leung[8] was employed in this study, for which the Cronbach's alphas of the P-ADL, the I-ADL and the overall scale were 0.92, 0.87 and 0.93 respectively.

Cumulative Illness Rating Scale

This aimed to quantify health problems in terms of the level of impairment.[9] Health problems were classified into six categories according to the body systems, and rated as 0 to 4 on a 'degree of severity' scale. Rochon et al[10] found that the CIRS score was better than chronological age in predicting survival and length of hospital stay among patients with chronic comorbidity. This scale was translated into Chinese, with some common geriatric health problems listed out to ease administration. It was then given to two geriatricians for content validation. The inter-rater reliability of the Chinese CIRS was tested, and its intraclass correlation coefficient ranged from 0.77 to 0.99.

Procedures

The study was approved by the ethics committee of the School of Nursing, The Hong Kong Polytechnic University and the care facilities involved. Prior to the survey, a pilot test was conducted with a convenience sample of 30 frail nursing home residents to ensure that the QOLC-E was understood by frail older persons. The questionnaire was generally well received, but the interview experiences also suggested the need for refinement in two aspects.

The major adaptation needed was the response format of the QOLC-E. The 11-point numeric rating scale used in the QOLC-E can help to reflect the degree of variation between individuals in a more precise manner. In reality, many respondents found it difficult to quantify their perceptions. They often described these in response to the questions, rather than giving the rating. Since they were not familiar with using a rating scale to represent their perceptions, they often had to be prompted to do so. Although the sophistication entailed in the numeric scale enhances the tool's sensitivity in detecting differences, it hampered the interview. Many of the respondents also failed to appreciate the preciseness of the scale, tending to dichotomise their answers into two extremes or rate them as neutral.

In addition, inconsistency in the direction of the questions due to positive and negative descriptors further complicated the rating process. Thus, the rating of 10 did not always represent the most desirable state. For example, the item about feeling worried was negatively framed according to the frequency of the negative emotions, for which 0 denoted never having had such feelings, while 10 denoted being overwhelmed by them. By contrast, the item about the sense of worthiness of life was positively framed according to the level of satisfaction, for which 0 denoted that the respondent found their life completely worthless while 10 denoted that the respondent found their life very worthwhile. This further increased the response burden for the respondents in understanding the rating scale.

To avoid making the respondent feel overwhelmed, the response format of the QOLC-E was changed to a 4-point Likert scale with a short descriptor attached to each option. Instead of asking the respondents to give a score to represent their own perceived situation, the options were read out for them to choose.

Another concern was the clarity of the items. Three items in the existential distress subscale and one about life's goal appeared difficult for these older people to comprehend without elaboration. Explanations were added to clarify their meaning and ensure consistency in questionnaire administration.

One issue noted in the health care concern subscale was that there were two items about perceptions regarding the care they received in hospital. Since the QOLC-E was initially derived from hospitalised patients, the focus was more on hospital care. To adapt it for frail older people generally, the focus of the questions was shifted to either the care offered in the clinic or the nursing home.

Despite these changes, one item 'satisfied with the control of symptoms' on the health care concern subscale still appeared less than clear. Many respondents said that they were suffering from a number of health problems. Of these discomforts, some were persistently distressing, while others were under control. It was difficult to evaluate symptom management in one question. This was an inherent problem of the item, not about how it was phrased. It appeared that the item was not able to reflect the full picture regarding perceptions of symptom management. Since the responses to this question were inconclusive, it was omitted.

The questionnaire was revised mainly according to the frail older people's level of understanding. The revisions aimed to improve its clarity and appropriateness for the target group. It was renamed as the modified QOLC-E (mQOLC-E). Apart from changing the response format, there was no other substantial change to the questionnaire in terms of content. After the revision, the mQOLC-E, together with the overall quality of life SIS, the ADL and the CIRS, were administered to a larger group of frail older people to explore the validity of its psychometric properties.

The purpose of the study, the individual's rights to privacy, confidentiality and withdrawal were explained to all potential subjects. Since most such older people had difficulty in reading and writing, the questionnaires were administered in face-to-face interviews. Emotional responses were closely observed and interviewees were not forced to answer if they showed any signs of unease. Counselling was provided if they seemed to have any negative psychological reactions, and institutional staff and/or their family members were notified for follow-up observations. No adverse reactions were noted and most of the respondents appeared to appreciate the interviews. The duration of the interviews ranged from 20 minutes to an hour, depending on the individual's likelihood to share his/her own experiences related to quality-of-life concerns.

Data analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (Windows version 14.0; SPSS Inc, Chicago [IL], US). Before factor analysis, the Kaiser-Meyer-Olkin (KMO) and the Bartlett test of sphericity were performed to justify the suitability of the data set for the analysis. Exploratory factor analysis was used to reveal patterns of relationships among the questions. A principal component extraction with varimax rotation was performed to examine the constructs of the scale. Factor rotation was a way to maximise the orientation of variables near one of the axes. The most common rotation approach was the varimax rotation, which generally presented the clearest factor structure.[11] The number of factors was determined from the scree plot and eigenvalues greater than one. Items with the highest loading on a particular factor were grouped as a subscale.

Construct validity reflects the ability of an instrument to measure an abstract construct.[12] The construct validity of the mQOLC-E was evaluated by comparing its various subscales with other instruments measuring similar or different constructs. Convergent validity is demonstrated if the subscale is closely correlated with another instrument that measures a similar phenomenon. Divergent validity is demonstrated if the subscale has low correlations with another instrument that is intended to assess different characteristics. In this study, the convergent and divergent validity of the mQOLC-E were demonstrated by assessing Pearson's correlation coefficients among the subscales in the mQOLC-E and between the mQOLC-E and the overall quality of life SIS, the ADL scales as well as the CIRS.

Known groups comparison was also performed to examine whether the mQOLC-E was able to differentiate frail older people from their non-frail counterparts. Differences between frail and non-frail groups in terms of mean scores of the mQOLC-E and its subscales were analysed, based on the assumption that the former had more pressing quality-of-life concerns than non-frail older people.

The reliability of the mQOLC-E was assessed in terms of the internal consistency and the inter-rater reliability. Cronbach's alpha coefficients were calculated to determine the internal consistency of the overall mQOLC-E and each of its subscales. Inter-rater reliability was assessed using the intraclass correlation coefficient on 15 consecutively recruited respondents to evaluate the agreement on ratings between raters.

RESULTS

Respondents' characteristics

From a geriatric outpatient clinic and 10 nursing

Table 1
Demographic characteristics of the frail and non-frail elderly

	Non-frail group (n=197)	Frail group (n=313)	p Value
Age (years), mean±SD (range)	82.25±6.09 (67-99)	82.47±6.73 (65-99)	0.706*
Gender, No. (%)			<0.001†
Male	57 (28.9)	98 (31.3)	
Female	140 (71.1)	215 (68.7)	
Marital status, No. (%)			0.013†
Single	16 (8.1)	30 (9.6)	
Married	35 (17.8)	95 (30.4)	
Separated/divorced	5 (2.5)	3 (1.0)	
Widowed	138 (70.1)	177 (56.5)	
Education level, No. (%)			0.115†
No formal education	118 (59.9)	202 (64.5)	
Primary school	60 (30.5)	79 (25.2)	
Junior secondary	11 (5.6)	12 (3.8)	
Senior secondary	5 (2.5)	7 (2.2)	
Tertiary	2 (1.0)	9 (2.9)	
Cumulative Illness Rating Scale, mean±SD			
No. of categories endorsed (0-6)	2.44±1.35	3.04±1.23	<0.001*
Total score (0-24)	4.52±2.65	7.00±2.72	<0.001*
No. of categories impaired at moderate or severe level (0-6)	0.12±0.45	1.32±0.59	<0.001*
Personal activities of daily living	19.52±4.59	16.64±4.21	<0.001*
Instrumental activities of daily living	13.42±4.44	10.88±2.37	<0.001*
Quality-of-life single-item scale	6.12±2.26	5.41±2.65	0.012*

* *t* test
† Chi-square test

homes, 313 respondents who met the inclusion criteria of frailty were recruited for instrument validation. As shown in **Table 1**, their mean age was 83 (standard deviation [SD], 7) years. The majority were female (69%), widowed (57%), and had not received any formal education (65%). More than half were living in a nursing home, 79 (25%) were living with a family, and 73 (23%) were living alone. The mean number of moderate to severe health-impairing problems they had was 1.3 (SD, 0.6). The mean I-ADL score were 10.9 (SD, 2.4).

Appropriateness of the items

To determine whether the items were able to reflect the concerns of frail older people, the response pattern to each item was examined. Skewness, meaning clustering of scores at one end of the distribution, was observed for three items, indicating that such items might be less appropriate for analysis in the frail older population. The first item was 'participation in healthcare decisions'; 75% (n=236) of the respondents said that they usually were not involved in the decision making process. The second was 'fear to look into the future'; 60% (n=187) said they took each day as it comes. Concerning the third item 'regarding religion as important', 28% (n=88) did not have religious beliefs. The major religious belief among the respondents was ancestral worship (n=137, 61%). Of those who had religious practices, 34% (n=76) did not consider them to be important. In addition, the missing rate of the item 'feels that life goals have been achieved' was high (43%), because many of them replied that they had grown up in hard times and thus had never planned any goals for their lives. Thus, these four items were inferred to be less likely quality-of-life concerns of frail older people.

The item-to-total correlation was calculated for both the overall questionnaire and the subscales to examine how each correlated with the sum of all other items in the questionnaire. The abovementioned four

Table 2
Varimax rotated factor structure and factor loadings of the modified Quality-of-Life Concerns in the End of Life Questionnaire (n=313)

	Factor*					
	1	2	3	4	5	6
Items						
Nervous	0.830					
Low mood	0.769					
Sad	0.762					
Worried	0.748					
Lonesome	0.478					
Feels a burden to others	0.423	0.405				
Powerless		0.847				
Helpless		0.806				
Hopeless		0.721				
Feels that life is meaningful			0.806			
Feels good about him/herself as a person			0.808			
Feels that life is worthwhile			0.790			
Feels that life is a gift	0.432		0.330†			
Second most troublesome discomfort				0.822		
Third most troublesome discomfort				0.727		
General physical discomfort				0.707		
Most troublesome discomfort				0.696		
Feels that health care providers can meet his/her needs					0.826	
Satisfied overall with the health care received					0.793	
Perceives the world as full of love and caring					0.678	
Feels supported					0.472	
Satisfied with the food provided						0.871
Has a good appetite						0.825
Eigenvalue	6.544	2.458	1.706	1.567	1.293	1.240
% of variance explained	28.452	10.687	7.418	6.813	5.620	5.392
Cumulative % of variance explained	28.452	39.139	46.557	53.369	58.990	64.382

* Factor loadings <0.40 are not displayed
† Factor loading in the factor to which the item originally belonged

items correlated less well with others and lowered the Cronbach's alpha of the overall questionnaire and the subscales to which they belonged. These four items, together with the item 'satisfied with control of symptoms', were omitted from further analysis, with a view to increasing the instrument's relevance for the frail older population.

Factor analysis

Prior to factor analysis, the KMO and Bartlett's test of sphericity were performed to assess the sampling adequacy and item correlation. The KMO value was 0.84 (Chi-square=1888.97, df=253, p=0.000), indicating that the sample was extremely powered to detect correlations among the remaining 23 items in the mQOLC-E. The p value was less than 0.000 meaning that the relationships between variables were large enough for factor analysis.

Factor analysis of the 23 items in the mQOLC-E yielded a six-factor solution, which cumulatively accounted for 64% of the total variance. The factor structure is shown in **Table 2**. Principle-axis factoring using the quartimax rotation with Kaiser-Normalisation was also performed to determine the factor structure of the mQOLC-E. A similar factor structure was shown as that resulting from varimax

TABLE 3
Pearson's correlation coefficients among the modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E) and its subscales*

	SIS	P-ADL	I-ADL	CIRS score
Overall mQOLC-E	0.589†	0.281†	0.219†	-0.140§
Negative emotions	0.428†	0.303†	0.213†	-0.066
Physical discomfort	0.502†	0.102	0.098	-0.288†
Value of life	0.363†	0.157‡	0.108	-0.013
Existential distress	0.477†	0.217†	0.190†	-0.071
Care and support	0.220‡	0.106	0.090	-0.017
Food-related concerns	0.428†	0.187†	0.183†	-0.190†

* SIS denotes quality-of-life single-item scale, P-ADL personal activities of daily living, I-ADL instrumental activities of daily living, and CIRS Cumulative Illness Rating Scale

† $p \leq 0.001$

‡ $p \leq 0.01$

§ $p \leq 0.05$

rotation factor analysis.

The factor structure resembled that of the original QOLC-E as most of the items loaded onto their respective factors as they had existed in the factor structure of the original QOLC-E,[6] except that in the current analysis the items in the health care concerns subscale and the support subscale aggregated into one factor. Notably, the item 'feels that life is a gift', which originally belonged to the value of life subscale, had a higher factor loading on factor 1 (negative emotions subscale) than on factor 3 (value of life subscale). Since a factor loading greater than 0.30 is generally considered indicative of a certain degree of relationship,[13] the item was retained in factor 3, which is the construct the item intended to measure.

For the sake of interpretation, in the original factor analysis of the QOLC-E, one of the factors was split into two subscales—negative emotions and sense of alienation. This was not done in the current analysis. Therefore, there were six subscales in the mQOLC-E, namely: (1) value of life, (2) care and support (3) food-related concerns, (4) negative emotions, (5) physical discomfort, and (6) existential distress. The first three subscales measured positive aspects, while the last three addressed negative quality-of-life aspects.

Construct validity

TABLE 3 shows the Pearson's correlation coefficients between the mean scores of the overall mQOLC-E, its subscales, the overall quality of life SIS, the P-ADL, the I-ADL and the CIRS. The overall mQOLC-E was significantly associated with the overall quality of life SIS, providing evidence of concurrent validity (r=0.589, $p \leq 0.001$). The correlation between the overall mQOLC-E and the CIRS was weak but significantly negative (r= –0.140, p=0.013). This indicated that the comorbid condition was inversely related to the overall quality of life, but not necessarily a determinant factor.

Stronger association was noted between the CIRS and the physical discomfort subscale (r= –0.288, $p \leq 0.001$). This also helped to demonstrate convergent validity as they measure similar constructs. Divergent validity was demonstrated by examining the correlations between scales that measure different constructs. These were revealed by the insignificant correlations between the CIRS and negative emotions, value of life, existential distress, and care and support subscales.

TABLE 4 shows that all the subscales were positively and significantly correlated with each other, but were of different magnitude. For example, a moderate correlation was found between the negative emotions subscale and the existential distress subscale, but that between the negative emotions scale and the care and support subscale was comparatively weaker. The close relationship between the negative emotions and the existential distress subscales shows that these two kinds of psychological attributes are distinct but influence each other mutually, whereas the association between negative emotions and care and support concerns was weaker.

Table 4
Pearson's correlation coefficients among the modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E) and its subscales

	Negative emotions	Physical discomfort	Value of life	Existential distress	Care and support	Food-related concerns
Overall mQOLC-E	0.819*	0.588*	0.654*	0.784*	0.501*	0.500*
Negative emotions		0.407*	0.424*	0.578*	0.241*	0.303*
Physical discomfort			0.205*	0.311*	0.130†	0.305*
Value of life				0.451*	0.435*	0.273*
Existential distress					0.320*	0.273*
Care and support						0.181*
Food-related concerns						

* p≤0.001
† p≤0.05

Table 5
Known groups comparison

	Mean ± SD			p Value
	Total (n=510)	Non-frail (n=197)	Frail (n=313)	
mQOLC-E*	3.00 ± 0.53	3.19 ± 0.43	2.95 ± 0.50	0.000†
Negative emotions	3.28 ± 0.81	3.39 ± 0.87	3.21 ± 0.75	0.017‡
Physical discomfort	2.95 ± 0.73	3.12 ± 0.68	2.81 ± 0.73	0.000†
Value of life	2.86 ± 0.73	2.88 ± 0.66	2.84 ± 0.77	0.692
Existential distress	2.55 ± 1.11	2.78 ± 1.04	2.40 ± 1.12	0.000†
Care and support	3.25 ± 0.54	3.32 ± 0.50	3.22 ± 0.57	0.095
Food-related concerns	2.60 ± 0.84	2.73 ± 0.78	2.52 ± 0.87	0.011‡
Mean single-item scale	5.69 ± 2.52	6.12 ± 2.26	5.41 ± 2.65	0.013‡

* The score of the modified Quality-of-Life Concerns in the End of Life Questionnaire ranged from 1 to 4 (1 representing the least and 4 the most satisfaction towards the condition); the score of the overall quality-of-life single-item scale ranged from 0 to 10 (0 representing the least and 10 the most desirable condition)
† p≤0.001
‡ p≤0.05

Known groups comparison

The 313 frail respondents were compared with 197 elderly respondents recruited from the clinic and nursing homes who did not meet the criteria for frailty. The mean scores of the overall mQOLC-E and its subscales in the frail and non-frail respondents are shown in **Table 5**. The frail group on average had a lower score in the overall mQOLC-E and all six subscales than their non-frail counterparts. Statistically significant differences were noted in the mean overall mQOLC-E (p≤0.001) score, the negative emotions subscale (p=0.017), the physical discomfort subscale (p≤0.001), the existential distress subscale (p≤0.001) and for food-related concerns (p=0.011).

Reliability

The internal consistency of the mQOLC-E and its subscales were examined using Cronbach's coefficient alpha. As shown in **Table 6**, the whole scale had good internal consistency, with a value of 0.89 for the overall scale. The Cronbach alphas of the six subscales ranged from 0.71 to 0.86.

Inter-rater reliability was examined to assess the variation in rating between two raters. The intra-class correlations of agreement of ratings for all items in the mQOLC-E were greater than 0.83. This is above the suggested acceptable level.

DISCUSSION

This study attempted to validate an instrument for assessing the quality-of-life concerns of frail older people. The applicability of the QOLC-E, which was originally developed to assess the quality-of-life concerns of terminally ill patients with COPD or metastatic cancer, was applied to frail older people.

Table 6
Internal consistency of the overall modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E) and its subscales

	No. of items	Cronbach's alpha
Overall mQOLC-E	23	0.891
Negative emotions	6	0.841
Existential distress	3	0.856
Value of life	4	0.801
Physical discomfort	4	0.775
Care and support	4	0.713
Food-related concerns	2	0.768

This was based on the assumption that the latter also face the fact of life's finite nature was imminent. They therefore shared similar quality-of-life concerns as patients with advanced or terminal diseases. Since the QOLC-E was developed in our local setting, translation and cultural issues were resolved.

Psychometric properties of the modified Quality-of-Life Concerns in the End of Life Questionnaire

The pilot test experience suggested three ways to enhance the appropriateness and sensitivity of the instrument in assessing quality-of-life concerns of frail older people. These modifications were in the areas of response format and question clarity. Five items were eliminated from further analysis because of skewed response patterns, suggesting that they were less likely to reflect the concerns of frail older people.

In the principal factor analysis, the factor structure of the remaining 23 items in the mQOLC-E resembled that of the original QOLC-E in Pang et al's study.[6] The Cronbach's alphas of the overall mQOLC-E and its subscales were acceptably high, suggesting that the instrument was internally consistent. The only difference was that in the current analysis, items in the health care concerns and support subscales were loaded onto one factor. One possible explanation was that frail older people and hospitalised patients have different healthcare expectations. Hospitalised patients might deliberately differentiate the health professional from their informal health care providers, whereas frail older people might perceive health professionals in the long-term care facility as one of their sources of support. Hence, the difference between the two subscales was less distinct for the frail elderly. Particularly for nursing home residents, as many had lived there for several years, they might have developed intimate relationships and a strong rapport with the nursing home health care providers. For this reason, the items in the health care concerns subscale and the support subscale very likely measure similar constructs, and thus in the present study they were aggregated into one factor.

Yet, the sensitivity of the mQOLC-E to change over time cannot yet be assumed, as the findings were only drawn from a cross-sectional survey. Monitoring the subjects over time may help to overcome this constraint.

Implications

Apart from demonstrating the applicability of the mQOLC-E among frail older people, this study substantiates the need to affirm the life value of older people. Existential distress was the least satisfied domain among the respondents, regardless of their level of frailty. In Pang et al's study,[3,6] existential distress was rated as the second undesirable domain. Thus, existential concern is not the privilege of patients with terminal or advanced illness, and needs to be integrated into all palliative care services for the elderly.

Missing values in the data averaged less than 5%. The high response rate indicates that older people were willing to share their thoughts about how they perceived their lives and their current concerns. Obviously, their own values and beliefs were shaped by their experiences, but were not used to incorporate them into their health care planning. Such experiences shed light on the direction of advance care planning in any larger study. The main theme would therefore be to encourage older people to articulate their values and beliefs, and these would be rich resources in the process of formulating their future care plans.

CONCLUSION

As yet there was no instrument for assessing the quality of frail older people's last chapter of life. This study therefore attempted to adapt the QOLC-E, which was originally developed for patients with advanced or terminal diseases, to this particular vulnerable group. The findings provide evidence that the mQOLC-E is a valid, reliable and culturally appropriate instrument for assessing the quality-of-life concerns of frail Chinese older people. The findings also substantiate the notion that people who are near the end of life share similar quality-of-life concerns. The importance of attending to the concerns of frail older people is thus underscored.

Acknowledgements

This is part of a larger study investigating the impact of advance care planning on the quality of life of frail older residents in long-term care facilities. It was funded in part by The Hong Kong Polytechnic University (A-PG78). We sincerely thank all the respondents and staff in the study venues for their support. We would also like to thank Wendy Lee and KL Chan for helping with data collection.

References

1. Walston JD, Fried LP. Frailty and its implications for care. In: Morrison RS, Meier DE, Capello C, editors. *Geriatric palliative care*. Oxford: Oxford University Press; 2003:93-109.
2. Pang SM, Tse CY, Chan KS, Chung BP, Leung AK, Leung EM, et al. An empirical analysis of the decision-making of limiting life-sustaining treatment for patients with advanced chronic obstructive pulmonary disease in Hong Kong, China. *J Crit Care* 2004;19:135-44.
3. Pang MC, Chan KS, Chung PM, Lau KS, Leung MF, Leung WK, et al. Validation of a Chinese instrument for assessing the quality of life of persons with advanced chronic disease. *Journal of Modern Nursing Education and Research* 2005;2:9-19.
4. American Medical Association white paper on elderly health. Report of the Council on Scientific Affairs. *Arch Intern Med* 1990;150:2459-72.
5. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med* 1997;11:3-20.
6. Pang SM, Chan KS, Chung BP, Lau KS, Leung EM, Leung AW, et al. Assessing quality of life of patients with advanced chronic obstructive pulmonary disease in the end of life. *J Palliat Care* 2005;21:180-7.
7. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969;9:179-86.
8. Chi I, Leung EM. *Towards healthy ageing in Hong Kong*. Hong Kong: St. James' Settlement; 1995.
9. Linn BS, Linn MW, Gurel L. Cumulative illness rating scale. *J Am Geriatr Soc* 1968;16:622-6.
10. Rochon PA, Katz JN, Morrow LA, McGlinchey-Berroth R, Ahlquist MM, Sarkarati M, et al. Comorbid illness is associated with survival and length of hospital stay in patients with chronic disability. A prospective comparison of three comorbidity indices. *Med Care* 1996;34:1093-101.
11. Thompson B. *Exploratory and confirmatory factor analysis: understanding concepts and applications*. Washington DC: American Psychological Association; 2004.
12. Portney LG, Watkins MP. *Foundations of clinical research: applications to practice*. 2nd ed. Upper Saddle River, N.J.: Prentice Hall Health; 2000.
13. Tabachnick BG, Fidell LS. *Using multivariate statistics*. Boston: Pearson/Allyn & Bacon; 2007.