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Validation of the QUAL-EC for assessing quality of life in patients with advanced cancer ☆

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ABSTRACT

Objective: Improving quality of life is the main goal of palliative cancer care. However, there is a lack of measures validated specifically for advanced cancer. The purpose of this study was to validate the Quality of Life at the End of Life (QUAL-E) measure in a sample of patients with advanced cancer.

Methods: Data were analysed for 464 patients with advanced cancer who were participating in a randomised controlled trial of early palliative care intervention versus routine care. Patients completed the 26-item QUAL-E, the Functional Assessment of Cancer Therapy (FACT-G) quality of life measure and measures of spiritual well-being, performance status, symptom burden, satisfaction with care and communication with health care providers. We conducted a confirmatory factor analysis on the QUAL-E to test for the hypothesised four-factor structure and examined construct validity by calculating correlations with relevant scales.

Results: A 17-item reduced version of the QUAL-E, the QUAL-E-Cancer (QUAL-EC) achieved an acceptable fit to a four-factor model. Both the full and reduced versions of the QUAL-E were internally reliable and showed good construct validity. Symptom Control was correlated with other measures of physical functioning; Relationship with Healthcare Provider was correlated with satisfaction with care and better physician and nurse communication; Preparation for End of Life was strongly associated with emotional well-being; and Life Completion was strongly associated with social and spiritual well-being.

Conclusions: Due to its good factor structure and sound psychometrics, we recommend the reduced QUAL-EC scale to assess quality of life in patients with advanced cancer.

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1. Introduction

Improvement of quality of life is the central goal of palliative cancer care.[1] However, quality of life is a challenging construct to measure and to improve in palliative care populations, given the decline in general function that occurs in the last months of life.[2,3] Several validated measures of quality of life exist that are specific for cancer[4,5] or for palliative care populations.[6,7] More recently, general cancer measures have been modified or extended to evaluate patients with advanced cancer.[8,9] However, the latter measures were not originally developed for palliative care populations and may be incomplete in their content[8] or too long to be routinely feasible.[9] In this study, we validate a palliative quality of life measure in a sample of patients with advanced cancer.

The Quality of Life at the End of Life (QUAL-E) measure was designed to assess quality of life in patient populations nearing the end of life[10] and is unique in that its development was based on qualitative research concerning perceptions of a good death.[11] Participants in this research included patients with cancer and other life-threatening diseases, as well as healthcare professionals and bereaved family members. The instrument was subsequently validated in a mixed sample of patients with advanced cancer, heart failure, chronic pulmonary obstruction and renal disease, although the sample size was not large enough to compare factor models across disease type.[12] There were also unexpected challenges regarding the QUAL-E's subscale correlations and convergent validity. Specifically, one of the subscales unexpectedly was negatively correlated with two others, and only modest correlations were observed between the QUAL-E and the Functional Assessment of Cancer Treatment (FACT) measure of quality of life,[5] which was used in this mixed disease sample despite being a cancer-specific measure. Although a recent review of quality of life instruments identified the QUAL-E as one of the most promising measures for use in palliative care settings, more investigation was recommended into its psychometric properties.[13]

The purpose of the present paper was to clarify the psychometric properties of the QUAL-E in a sample of patients with advanced cancer and to validate the measure in this population of patients. Specifically, we hypothesised that: (1) the QUAL-E would possess a four-factor structure; (2) Symptom Impact or Control would be positively correlated with other indicators of physical well-being and functioning; (3) Relationship with Healthcare Provider would be positively correlated with satisfaction with care and good communication with physicians and nurses; and (4) Preparation for End of Life and Life Completion would be positively correlated with social, emotional and spiritual well-being.

2. Patients and methods

2.1. *Participants and Procedure*

Approval for this study was granted by the University Health Network Research Ethics Board. The participants were patients with advanced cancer enrolled in an ongoing cluster randomised controlled trial of early palliative care intervention versus routine oncology care. Patients were recruited from 24 outpatient oncology clinics at Princess Margaret Hospital, Toronto, Canada, and were randomised either to immediate consultation and follow-up by a palliative care team or to conventional cancer care. Inclusion criteria were: (i) metastatic gastrointestinal, genitourinary, breast, lung or gynaecological cancer (for lung, oesophageal and pancreatic cancers, patients with Stage 3 disease were also included); (ii) age $\geqslant$ 18 years; (iii) Eastern Cooperative Oncology Group performance status from 0 to 2; and (iv) a prognosis of 6 months to 2 years (estimated by the primary oncologist). Patients with metastatic breast or prostate cancer were refractory to hormonal therapy. Exclusion criteria included insufficient English literacy to complete questionnaires, and inability to pass a cognitive screen, the Short Orientation-Memory-Concentration Test.[14] Participants were asked to complete measures of quality of life, symptom burden and satisfaction with care each month for 4 months. Between 1st December 2006 and 1st May 2010, 468 patients returned baseline questionnaires and of those 464 completed the QUAL-E.

2.2. *Measures*

The QUAL-E is a 26-item self-report measure of quality of life with four subscales assessing symptom severity or impact, quality of relationship with healthcare provider, preparation for end of life and feeling of life completion.[10] When completing the QUAL-E, individuals provide three symptoms that were most bothersome during the last month and complete four items regarding the frequency and severity of the most bothersome symptom. These four items are reverse-scored, such that a higher subscale score indicates greater symptom control. This subscale was originally named Symptom Impact[10]; we have relabelled it Symptom Control, to better reflect the scoring direction. The 5-item Relationship with Healthcare Provider subscale assesses the extent to which individuals feel informed and actively involved in their medical treatment. The 5-item Preparation for End of Life subscale assesses the extent to which individuals are worried about impending issues, such as financial strain, death and dying and their families' abilities to cope. The 7-item Life Completion subscale assesses the extent to which individuals have felt able to care for others and feel cared for and the degree to which they feel a sense of meaning and peace. Respondents also provide 1-item assessments of the importance of each subscale domain to their quality of life and a single-item rating of overall quality of life.

The Eastern Cooperative Oncology Group (ECOG) scale is a 6-point measure ranging from 0 (fully active) to 5 (dead) that assesses the patient's ability for self-care and ambulation.[15] The Edmonton Symptom Assessment System (ESAS) is a validated, self-administered tool to measure the severity of common symptoms in patients with advanced disease.[16,17] The scale assesses nine main symptoms (pain, fatigue, drowsiness, nausea, anxiety, depression, appetite, dyspnoea and sense of well-being) and one 'other' symptom. Because no time frame is stipulated on the ESAS form, we added instructions that symptoms were to be rated based on the previous

24-h period.[18] The ESAS Distress Score (EDS) is the sum of the nine main symptom ratings and may range from 0 to 90, with higher scores indicating greater symptom severity.

The Functional Assessment of Cancer Therapy (FACT-G) is a 27-item measure of quality of life with subscales assessing physical, social, emotional and functional well-being.[5] Higher scores in each case indicate greater well-being. The Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT-Sp)[19] is a 12-item measure of feelings of meaning and peace and the comfort derived from one's faith or spiritual beliefs. The scale produces an overall spiritual well-being score with subscale scores concerning meaning/peace and comfort from faith.

The Communication with Health Care Providers (CARES) Medical Interaction Subscale is an 11-item measure derived from the Cancer Rehabilitation Evaluation System.[20] CARES assesses negative patient experiences when communicating with doctors and nurses. The FAMCARE P-16 is a 16-item validated scale assessing patient satisfaction with outpatient oncology care.[21,22]

2.3. *Statistical analyses*

The baseline measures are the subject of this report and were analysed in SAS 9.1. We multiply imputed missing values to make maximum use of the dataset in the estimation of parameters.[23] We report the results from a single imputation because the pattern of results was consistent across multiple imputations. The findings did not change substantively when analysing patients with only complete data.

We conducted a confirmatory factor analysis (CFA) on the 21 QUAL-E items amenable to such analysis, testing for the hypothesised four-factor structure. A good fit is indicated by a Comparative Fit Index (CFI) $\geqslant 0.95$, Non-Normed Fit Index (NNFI) $\geqslant 0.95$ and Root Mean Square Error of Approximation (RMSEA) $\leqslant 0.06$. An acceptable fit is indicated by CFI and NNFI between 0.90 and 0.95 and RMSEA between 0.06 and 0.10.[24] In the event of poor fit, modification indices were consulted and items that were overly complex (i.e. associated with other factors) or redundant were eliminated, producing a reduced scale.[25,26]

We then examined the measure's construct validity by calculating correlations between the full and reduced subscales and related measures of physical functioning, satisfaction with care, physician and nurse communication and quality of life.

3. Results

Table 1 shows the descriptive statistics of the sample. Our initial CFA found an unsatisfactory fit for a four-factor model, CFI = 0.85, NNFI = 0.82 and RMSEA = 0.08. The modification indices revealed that the three most complex items were Items 23, 4 and 13. Item 23 (I feel at peace) was supposed to be an indicator of Life Completion but was overly associated with Symptom Control, Preparation for End of Life and Relationship with Healthcare Provider. Item 4 (How worried are you about this symptom occurring in the future) was meant to assess Symptom Control but was overly associated with Preparation for End of Life. Item 13 (I have regrets about the way I have lived my life) was meant to measure Preparation for End of Life but was overly associated with Life Completion.

We removed these items and re-ran our CFA testing for four factors. Goodness of fit was improved but remained just shy of satisfactory, CFI = 0.90, NNFI = 0.89 and RMSEA = 0.07. Examination of the modification indices suggested that difficulties remained in the Life Completion subscale; specifically, the error terms of some items remained inter-correlated even after the extraction of a common factor. This may occur when items are overly redundant in content. The most problematic item was Item 20 (I have been able to help others through time, gifts, or wisdom), which remained overly associated with Items 19 (I have been able to say important things to those close to me), 24 (There is someone in my life who I can share my deepest thoughts) and 18 (I have been able to say important things to those close to me). After removing this item, a four-factor model achieved an acceptable fit, with CFI = 0.93, NNFI = 0.91 and RMSEA = 0.06. We refer to the

Table 1 – Sample characteristics (*N* = 468).

Variable	*n* (%)	Mean (SD)	Min–Max
Age	468	61 (12)	28–88
Female	256 (55)		
Married/common-law	337 (72)		
Primary tumour			
Gastrointestinal	143 (31)		
Lung	101 (22)		
Genitourinary	86 (18)		
Gynaecological	71 (15)		
Breast	67 (14)		
Full QUAL-E			
Symptom Control	417	11 (3.5)	4–20
Relationship with Healthcare Provider	458	18 (4.1)	6–25
Preparation for End of Life	457	18 (4.0)	5–25
Life Completion	457	26 (5.1)	13–35
Reduced QUAL-EC[a]			
Symptom Control	416	8.1 (2.8)	3–15
Preparation for End of Life	456	14 (3.5)	4–20
Life Completion	456	19 (3.8)	8–25
ECOG	468	0.78 (0.6)	0–2
ESAS Distress Score (EDS)	468	25 (16)	0–78
FACT-G			
Physical well-being	466	18 (5.9)	0–28
Social well-being	460	22 (4.5)	3–28
Emotional well-being	464	17 (4.9)	2–24
Functional well-being	463	16 (6.0)	1–28
FACIT-Sp			
Spiritual well-being	456	33 (9.1)	0–48
Faith	439	9.9 (5.0)	0–16
CARES	459	0.37 (0.5)	0–3
FAMCARE P-16	456	66 (9.7)	25–80

[a] No change was made to the Relationship with Healthcare Provider subscale in the reduced QUAL-E scale, therefore the subscale data from the full measure holds. ESAS = Edmonton Symptom Assessment Scale.

Table 2 – Standardised factor loadings for the reduced QUAL-EC scale.

Subscale and item	Loading
F1, Symptom Control	
Symptom 1: frequency during the last week[a]	0.74
Symptom 1: severity during the last week[a]	0.86
Symptom 1: interference with ability to enjoy life[a]	0.78
F2, Relationship with Healthcare Provider	
I have a sense of control about my treatment decisions	0.78
I participate as much as I want in the decisions about my care	0.76
Beyond my illness, my doctor has a sense of who I am as a person	0.58
In general, I know what to expect about my illness	0.63
As my illness progresses, I know where to go to get answers to questions	0.57
F3, Preparation for End of Life	
I worry that my family is not prepared to cope with the future[a]	0.73
At times, I worry that I will be a burden to my family[a]	0.67
Thoughts of dying frighten me[a]	0.53
I worry about the financial strain caused by my illness[a]	0.59
F4, Life Completion	
I have been able to say important things to those close to me	0.72
I make a positive difference in the lives of others	0.67
I have been able to share important things with my family	0.82
Despite my illness, I have a sense of meaning in my life	0.68
There is someone in my life with whom I can share my deepest thoughts	0.58

[a] These items are reverse-scored.

Table 3 – Subscale inter-correlations for the full and reduced versions of the QUAL-E.

Subscale	1	2	3	4
Full QUAL-E				
1. Symptom Control	1	0.04	0.26[*]	0.16[*]
2. Relationship with Healthcare Provider		1	0.19[*]	0.43[*]
3. Preparation for End of Life			1	0.24[*]
4. Life Completion				1
Reduced QUAL-EC				
1. Symptom Control	1	0.03	0.16[*]	0.15[*]
2. Relationship with Healthcare Provider		1	0.18[*]	0.40[*]
3. Preparation for End of Life			1	0.13[*]
4. Life Completion				1

Note: The items of the Relationship with Healthcare Provider subscale were unchanged across both the full and reduced versions of the QUAL-E.

[*] $p < 0.01$

reduced scale as the QUAL-E-Cancer (QUAL-EC); Table 2 shows the standardised factor loadings of its items.

Table 1 provides descriptive statistics for the QUAL-EC. No change was made to the item content of the Relationship with Healthcare Provider subscale and so the data for this variable remains the same in the full and reduced versions of the QUAL-E. Table 3 shows the factor inter-correlations of the full and reduced measures. The internal reliabilities (Cronbach's alpha) for the full and reduced subscales were respectively: 0.83 and 0.83 for Symptom Control, 0.73 and 0.73 for Preparation for End of Life and 0.86 and 0.83 for Life Completion; the internal reliability for the Relationship with Healthcare Provider subscale was 0.80.

Finally, in Table 4, we describe the correlations assessing the construct validity of the full and reduced subscales. Greater Symptom Control was associated with greater physical and functional well-being and with less overall symptom burden. Relationship with Healthcare Provider was associated with less negative interactions with doctors and nurses and more satisfaction with care. Preparation for End of Life was positively and strongly associated with emotional well-being and also positively associated with social and spiritual well-being and faith. Life Completion was positively and strongly associated with social and spiritual well-being and also positively associated with emotional well-being.

Of note, there is item overlap between the Life Completion subscale and the meaning/peace subscale of the FACIT-Sp, resulting in a possible inflation of the correlation between Life Completion and overall spiritual well-being. We, therefore, report the correlations between the Life Completion full and reduced subscales and the faith subscale of the FACIT-Sp, which are not subject to this interpretative issue and which were found to be in the expected directions.

4. Discussion

In this study, we examined the psychometric properties of the QUAL-E measure of quality of life in a large sample of patients with advanced cancer and validated a reduced version of the scale, the QUAL-EC. Both the full and reduced versions of the QUAL-E were internally reliable and showed good construct validity. Symptom Control was correlated with other measures of physical functioning; Relationship with Healthcare Provider was correlated with satisfaction with care and better physician and nurse communication; Preparation for End of Life was strongly associated with emotional well-being; and Life Completion was strongly associated with social and spiritual well-being. We recommend the reduced QUAL-EC scale for use in patients with advanced cancer due to its good factor structure; the full scale may still be used in this population, though the subscales should be interpreted with greater caution.

Our results differ in important ways from those of the previous QUAL-E validation study conducted in a sample of heterogeneous disease groups.[12] In that study, one of the Preparation for End of Life items (Item 15: Thoughts of dying frighten me) unexpectedly loaded in the opposite direction from the other items in this subscale. It was, therefore, recommended to eliminate this item from the scoring system,

Table 4 – Correlations between full and reduced QUAL-E subscales and related measures.

Variable	PWB	FWB	ECOG	EDS
Symptom control (full)	0.62*	0.50*	−0.23*	−0.60*
Symptom control (reduced)	0.58*	0.46*	−0.23*	−0.56*
	CARES	FAMCARE P-16		
Relationship with Healthcare Provider	−0.37*	0.57*		
	EWB	SWB	SpWB	Faith
Preparation for End of Life (full)	0.61*	0.23*	0.34*	0.15*
Preparation for End of Life (reduced)	0.60*	0.19*	0.30*	0.14*
Life Completion (full)	0.35*	0.53*	0.66*	0.47*
Life Completion (reduced)	0.28*	0.54*	0.60*	0.43*

PWB = physical well-being; FWB = functional well-being; EDS = ESAS Distress Score; EWB = emotional well-being; SWB = social well-being; and SpWB = spiritual well-being.

* $p < 0.01$.

although it was retained in the QUAL-E because of clinical interest and to allow for continued testing of its associations within the scale. In contrast, we found that the fear of death item loaded appropriately on the Preparation for End of Life subscale, associating positively with items regarding worries related to the family and financial strain. The association in this cancer population between the personal fear of death and social concerns about dying may be due to the more predictable functional decline in cancer compared with other illnesses.[27] In our study, concerns about preparation for the end of life were also associated with worries about developing a specific symptom in the future. This may reflect differences between cancers, where there is cumulative symptom burden at the end of life[28] and other illnesses, where death can occur suddenly during a period of slow decline.[29]

We also found differences from the previous validation study in the correlations of the QUAL-E with the FACT-G and FACIT-Sp measures and in the subscale inter-correlations. In our study, correlations for the full measure were stronger than those in the previous validation study between the QUAL-E Symptom Control subscale and the FACT-G physical well-being (0.62 versus 0.23) and functional well-being (0.50 versus 0.27) subscales; and between the Preparation for End of Life subscale and the FACT-G emotional well-being (0.61 versus 0.21) and spiritual well-being (0.34 versus 0.13) subscales. In addition, our subscale inter-correlations were all in the expected directions: greater Preparation for End of Life was associated with a greater sense of Life Completion and a better Relationship with Healthcare Providers, as hypothesised – but not demonstrated – in the previous validation.[12] The greater sample homogeneity in our study may have allowed for closer associations. In addition, the FACT-G is a cancer-specific measure and the subscales may better reflect the relevant constructs in a cancer population.

Quality of life in patients with advanced cancer has generally been measured using cancer-specific,[4,5] domain-specific[30] or palliative care-specific measures.[3,6,7] Palliative care-specific versions have also been developed for cancer quality of life measures.[8,9] The EORTC QLQ-C15-PAL is a shortened version of the EORTC QLQ-C30 measure. It was developed from the latter using importance ratings of individual items, which were completed by patients with advanced cancer receiving specialised palliative care and by palliative care health care professionals.[8] Although this questionnaire is appropriate as a core measure, participants identified a number of additional items that they considered relevant, including existential and spiritual issues, worries related to relatives and the future and issues related to information and satisfaction with care. Of note, all of these items are included in the QUAL-E.

Another palliative care instrument developed based on an existing cancer measure is the FACIT-Pal. This measure consists of a 19-item palliative care subscale for use together with the 27-item FACT-G general cancer quality of life measure. The entire 36-item scale has been validated in a sample of patients with advanced cancer enrolled in a randomised trial of a palliative care psychoeducational intervention.[9] Although the 19-item subscale was developed through interviews with terminally ill patients with cancer and their family members,[31] the core FACT-G itself was not and the overall measure is quite long for a palliative care population. The QUAL-E is briefer and is unique in that the entire scale was developed using qualitative interviews with patients, family members and care providers at the end of life. Unlike other measures of quality of life for cancer patients, it also has subscales assessing Preparation for End of Life and Life Completion.

A limitation of our approach to developing the QUAL-EC for patients with advanced cancer is that we did not investigate whether new items could be added to improve the specificity of the measure for use in cancer; instead we were limited to reducing the pool of original items. However, in previous QUAL-E validations, approximately 60% of the patients had cancer[10,12]; the scale has face validity for use in patients with cancer; and in our study, both the original and reduced measures correlate closely with appropriate subscales of the cancer-specific FACT-G. Another limitation is that the minimally important change for the QUAL-E and the reduced measure has not yet been established. Therefore, in intervention studies, either measure is best used in combination with other instruments for which there has been sufficient longitudinal evaluation of sensitivity to change. Establishing values for minimally important change for the

QUAL-E and QUAL-EC are important directions for future research.

In conclusion, we have validated a reduced version of the QUAL-E for use in assessing quality of life in patients with advanced cancer (see Appendix). The measure assesses aspects of quality of life at the end of life that are not as commonly assessed by other related measures, namely end of life preparation, feelings of life completion and quality of the relationship with the healthcare team. Based on its sound psychometric properties, we recommend the QUAL-EC for clinical and research purposes in patients with advanced cancer.

Conflict of interest statement

None declared.

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Appendix. The QUAL-E-Cancer measure (QUAL-EC)

I'd like you to think back over the last month. Please tell me the three physical or emotional symptoms that have bothered you the most during that time. Some examples are pain, nausea, lack of energy, confusion, depression, anxiety and shortness of breath.

Symptom #1: ________________________
Symptom #2: ________________________
Symptom #3: ________________________

If you have had no physical or emotional symptoms that bothered you over the last month, then skip to question #4

Of the symptoms listed above, which one symptom has bothered you the most this past week? ________________________
Please answer the following 3 questions based on this one symptom:

1. During the last week, how often have you experienced this symptom?[a]
2. During the last week, on average, how severe has this symptom been?[a]
3. During the last week, how much has this symptom interfered with your ability to enjoy your life?[a]

Below is a list of statements that other people with an illness have said may be important. Please tell me how true each statement is for you.

4. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions
5. I participate as much as I want in the decisions about my care
6. Beyond my illness, my doctor has a sense of who I am as a person
7. In general, I know what to expect about the course of my illness
8. As my illness progresses, I know where to go to get answers to my questions
9. I worry that my family is not prepared to cope with the future[a]
10. At times, I worry that I will be a burden to my family[a]
11. Thoughts of dying frighten me[a]
12. I worry about the financial strain caused by my illness[a]
13. I have been able to say important things to those close to me
14. I make a positive difference in the lives of others
15. I have been able to share important things with my family
16. Despite my illness, I have a sense of meaning in my life
17. There is someone in my life with whom I can share my deepest thoughts

Notes: Items 1–3 assess Symptom Control. Items 4–8 assess Relationship with Healthcare Provider. Items 9–12 assess Preparation for End of Life. Items 13–17 assess Life Completion. Items are summed to produce relevant subscale scores. All items, except Items 1 and 2, are rated using the following scale: 1, not at all; 2, a little bit; 3 a moderate amount; 4, quite a bit; and 5, completely. Item 1 is rated using the scale: 1, rarely; 2, a few times; 3, fairly often; 4, very often; and 5, most of the time. Item 2 is rated using the scale: 1, very mild, 2, mild; 3, moderate; 4, severe; and 5, very severe.

[a] These items are reverse-scored.

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