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QOLLTI-F: measuring family carer quality of life

Robin Cohen Departments of Oncology and Medicine, McGill University, McGill University Health Centre and Lady Davis Research Institute, Jewish General Hospital, Montreal, **Anne M Leis** Saskatchewan Cancer Control Research Program, Department of Community Health & Epidemiology, University of Saskatchewan, Saskatoon, **David Kuhl** St. Paul's Hospital and Centre for Practitioner Renewal, Providence Health Care, and Department of Family Practice, Faculty of Medicine, University of British Columbia, Vancouver, **Cécile Charbonneau** Maison Michel Sarrazin and Department of Management, Pavilion Palais-Prince, Laval University, Quebec City, **Paul Ritvo** School of Kinesiology and Health Sciences, York University, Toronto and **Fredrick D. Ashbury** Department of Health Policy, Management and Evaluation, University of Toronto, and PICEPS Consultants, Inc, Toronto

Background: The primary goal of palliative care is to optimize the quality of life (QOL) of people living with a life-threatening illness and that of their families. While there have been important advances in measurement of the QOL of palliative care patients, little attention has been paid to the QOL of their carers (family caregivers). To develop and deliver the most effective services to these carers, their QOL needs to be measured with acceptable and psychometrically sound instruments that have content validity. **Methods**: This study reports three phases of the development and testing of such a measure: QOLLTI-F, Quality of Life in Life Threatening Illness – Family Carer Version, simultaneously in English and French. Participants were carers from 12 Canadian palliative care services who were asked to complete QOLLTI-F on three occasions. **Results**: The final version of QOLLTI-F consists of 16 items. It was deemed acceptable by the vast majority of carers and a longer, 24-item version was completed in a median of 12 min. Content validity was assured by inclusion of all domains reported by carers to be important to their QOL: state of carer, patient wellbeing, quality of care, outlook, environment, finances and relationships. Construct validity was demonstrated, as principal components analysis indicated that the 16 items did indeed reflect these seven domains. Furthermore, the seven domain scores predicted 53% of the variance in global QOL, although the QOLLTI-F Total score predicted less well (43%). The test–retest reliability for the QOLLTI-F Total score was 0.77–0.80 and ranged from 0.50 to 0.79 for the seven domain scores. All QOLLTI-F scores were shown to be significantly different between days the carers considered bad, average and good, demonstrating responsiveness to change, with the exception of the Financial Concerns submeasure, which did not distinguish between average and good days. **Conclusions**: QOLLTI-F is unique in that in measuring one person's QOL (the carer's) it includes their perception of the condition of another (the patient). This attests to the close relationship between the two. It is also unique in that its content is derived from a qualitative study asking carers what is important to their own QOL, rather than focusing on the changes or burdens related to caregiving. QOLLTI-F also has the advantage of being briefer than other carer QOL measures. It contains measures of seven different domains that are determinants of carer QOL, in addition to a summary score. All these measures are valid, reliable and responsive to change in QOL. *Palliative Medicine* 2006; **20:** 755–767

Key words: cancer; carer; end-of-life; family carer; palliative care; quality of life

Introduction

The goal of palliative care is optimizing quality of life (QOL) in patients and their families by preventing problems, delaying their onset and reducing their severity. QOL is defined as *subjective* wellbeing, reflecting differences or gaps between hopes and expectations and current experiences.[1–3] QOL must therefore account for expectations as well as objective conditions and ultimately represent the sum of positive and negative factors, rather than simply the presence/absence of QOL detractors.[4,5] For example, being a carer can strengthen one's sense of purpose in life and provide the opportunity to

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Address for correspondence: Robin Cohen, Palliative Care Research, Jewish General Hospital, Pavilion H, 3755 Côte Ste. Catherine, Montreal, QC, Canada H3T 1E2.
E-mail: robin.cohen@mcgill.ca

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deepen important relationships.[4,6,7] Therefore QOL measures in palliative care should not solely reflect burden.

Moreover, the QOL literature in palliative care has primarily focused on patients.[4] Yet carer QOL is inevitably woven into the care of palliative patients, a point particularly obvious in the recent trend towards home care for terminally ill patients. Although this trend is congruent with the desire of most people to die at home,[8,9] terminal home care places heavy burdens on carers, which can add to their distress at facing a loved one's death.[7,10] Reciprocally, burden on the family and its wellbeing is often one of patients' most important concerns.[11]

The true cost/benefit ratio for society of transferring care to the home, or providing excellent palliative care in an institutional setting, cannot be evaluated without assessing its impact on the QOL of carers. As family members are understandably painfully affected by a life-threatening illness in a member, they may be viewed as second-order patients in their own right.[7,10,12] Research documents the increase of demands and the peaking of carer stress during the palliative stage.[13] Carers of palliative care patients not only endure physical strains and increased responsibilities, but their mental health and social participation decline.[10,12,14] Furthermore, carers of palliative care patients often report more psychological distress than do the patients,[14–16] all of which obligates society to provide interventions that help carers maintain optimal QOL and health while caring for terminally ill loved ones. Therefore, we need to measure the outcome of interventions on carer QOL. The purpose of this article is to report the results of a multimethod study conducted over three phases to design a psychometrically and conceptually valid instrument to measure the QOL of carers of cancer patients receiving palliative care.

Domains relevant to QOL of carers of palliative care cancer patients

Two past studies focused on defining QOL domains relevant to carers of cancer patients, based on self-report. Weitzner and colleagues developed the content of their Caregiver QOL Index-Cancer (CQOLC) Questionnaire from a qualitative study focused primarily on how the patient's illness impacted the carer's physical, emotional, family and social functioning.[6] As this study did not explore what domains the carers felt were important and the method used presupposed domains,[6] it may have limited the carers' answers. The sample interviewed was also unlikely to include carers of people in the last few months of life, as carers of patients unable to participate due to poor condition were excluded, as were those where 'substances known to affect the central nervous system (i.e., narcotic analgesics, antiemetics, or steroids) were administered to the carer or patient one week or less before entry into the study'. In Weitzner *et al*.'s study, carers mentioned several issues as important to their QOL: increased responsibilities; interference with normal routine, social isolation; worry and fear of the unknown; need to protect loved one; decreased orientation to the future; increased communication and emotional closeness.

The second study was performed by this investigative group in order to define domains for a new measure of the QOL of carers. Interviews were undertaken with 59 carers of palliative care patients from two large and one small Canadian city, who were caring for loved ones at home or in hospital. The carers were asked to describe what was important to their QOL, with responses reflecting the following seven domains: state of carer, patient wellbeing, quality of care, outlook, environment, finances and relationships.[4,5]

Existing QOL instruments for carers

Some have used adaptations of QOL instruments originally designed for patients to measure carer QOL.[17] Two instruments, the Caregiver QOL Index (CQLI) and LASAS, were specifically designed for carers of hospice patients and consist of four or five single-item indicators.[18,19] Neither was based on interviews with carers regarding important contributors to their QOL. The CQLI items cover emotional, social, financial and physical domains selected on the basis of a literature review and confirmed to be relevant by only five former carers of patients. In these instruments, important domains are missing, including those concerned with patient wellbeing and quality of care. Furthermore, it has not yet been determined whether these single-item measures of domains will demonstrate adequate test–retest reliability.

The 35-item CQOLC, the content of which is based on the qualitative study reviewed above,[6] was tested for reliability and validity in the anticancer treatment setting, where its psychometric properties appeared to be appropriate,[20,21] and in a home hospice setting, with similarly positive results.[21] Factor analysis revealed factors representing mental/emotional burden, lifestyle disruption, hopefulness, social support and financial concerns.[20] These overlap but do not match areas found important to carer QOL in their qualitative study[6] and in our qualitative study,[4,5] as described above. Therefore, while CQOLC has good psychometric qualities, it is probably not sufficiently comprehensive and is lacking in content validity.

Although a single summary score representing overall QOL is useful in some situations, for many purposes, more detailed information is required. It is important to

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assess carer status in multiple domains, given the distinct potential for important changes in some domains that would remain unrecognized if only summary scores are used. For example, it is possible to observe significant improvement in some domains (eg, outlook, relationships) and deterioration in others (eg, patient condition, environment) but no change in summary scores.

Purpose

The purpose of this reported study series was development of an acceptable, psychometrically valid self-report instrument measuring QOL in carers of people with terminal cancer. The content of this instrument, the Quality of Life in Life-Threatening Illness – Family carer version (QOLLTI-F), was based on a qualitative study wherein carers responded to the question “What is important to your QOL?” described previously.[4,5] Phases 1 and 2 developed the initial items and carers judged their importance, comprehensiveness, redundancy and acceptability. This data and frequency distributions were used to refine QOLLTI-F and establish content validity. In Phase 3 the questionnaire was consolidated based on each domain derived from the qualitative work, and subsequently the items and each subscale were tested for validity and reliability to obtain a final psychometrically sound 16-item version. English and French language versions were developed and validated simultaneously.

Method

Ethics

Approval was obtained from the ethics committees of each participating clinical institution, as well as McGill University and the Universities of Saskatchewan, British Columbia and Toronto. All participants gave written informed consent and competent patients gave verbal assent to involve their carer in the study.

Sites and settings

Participants who were caring for a patient at home or in hospital were recruited in five Canadian cities (Montreal, Quebec City, Saskatoon, Toronto, Vancouver). Services included inpatient palliative care and consultation in tertiary and secondary care hospitals, a free-standing hospice and home care.

Participants

Primary carers were defined as the person who provided the most care for a person who was followed by a participating service and for whom the primary goal of care was optimization of QOL rather than cure or prolongation of life, and who was not paid to provide care. The carer had to be at least 18 years of age and speak either English or French fluently. No more than one carer per patient participated. They were identified by the patient wherever possible. In cases where the patient was unable to identify the primary carer due to cognitive or physical incapacity, the patient’s palliative care doctor or nurse made the identification. Many strategies were implemented to recruit consecutive eligible carers of patients admitted to the participating services. However, due to clinical staff not having the time to determine eligibility for the carer of every patient admitted, the result is a convenience sample.

Phase 1 method and results

Content development

SRC, AL and Terry Bunston, PhD developed a preliminary set of items to represent the seven domains they found to be important to carer QOL in their qualitative study: Environment, State of the Patient, Carer’s Own State, Carer Outlook, Relationships, Quality of care and Financial worries.[4,5] These were then circulated to the whole team, the members of which were asked for suggestions for rewording, suggestions for additional items if domains were not properly covered, and to indicate which questions were redundant in an effort to reduce the length of the questionnaire. Several items were reworded and 40 items (plus 2 regarding global QOL) were retained, translated and tested. Some seemingly redundant items were included in order to select those with the best distribution (ie, least skewed, mean and median were similar, a wide range of the 0–10 scale was used) for the final questionnaire.

Translation

The items were generated in English, then translated into French by a professional translator. As much of the population in Montreal is bilingual, we are able to use palliative care staff to comment on the translations by having them compare both language versions. This was done by five staff members in addition to SRC and AL. A few words were changed.

Acceptability and content validity

As a preliminary check, six English-speaking and one French-speaking carer were then asked to read over the questionnaires with a research assistant and to indicate whether the instructions or any of the items were unclear. Most were clear and one needed clarification. This item originally read: “The location of (patient name) was right for me”. It was reworded as “The place (patient name) was staying was right for me”.

Next, 10 carers from each of Montreal, Saskatoon and Toronto (total $n = 30$) rated the importance of each of the

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40 items to their QOL on a scale from 0 = not important at all to 10 = extremely important. In addition, they were asked to indicate whether any aspect of the questionnaire was unclear, upsetting or unimportant, and whether any questions were redundant or missing. Explanations were gathered each time a part of the questionnaire was unacceptable in any of these ways. A total of 6 palliative care professionals completed the same exercise. Based on the importance ratings and the comments concerning redundancy, relevance and clarity, 10 items were deleted. The 30 items retained had an importance rating from the carers ranging from 7.3 to 9.5.

Format

QOLLTI-F was designed to be read aloud, in order to allow those with low literacy or physical impairment that precludes them from completing the questionnaire unassisted to participate. The response scales were 11-point numerical rating scales (range of scoring options from 0 through to and including 10), with a descriptive anchor at each end. We chose to use an 11-point scale because we have found it intuitively easier for those with less formal education to understand compared to 7-point scales, eg, they effortlessly realize that 5 is the midpoint.

A two-day timeframe was used. Especially near the end of life, situations change rapidly for palliative care patients, and therefore also for the carer. We did not want to use a longer timeframe as this would require the carer to answer by averaging over potentially very different QOL. We feel that the two-day timeframe captures more than the brief snapshot of a single day. In addition, QOLLTI-F was created to be used in conjunction with our McGill Quality of Life Questionnaire that measures patient QOL, which has a two-day time-frame.

The 30 carers participating in this phase were asked which of two formats was preferred: one where items were grouped according to domain, and one where items having the same response options (eg, not at all, completely) were grouped together. The carers were asked to look at both versions before carrying out the importance ratings and to choose the one they wanted to use. There was a clear preference for the format with items grouped according to content domain (22/30 = 73%) rather than that grouped according to response option.

Back-translation

The revised 30 (+2 global)-item questionnaire was then back-translated by two bilingual volunteers, whose first language is English, and who had not seen the English version of the questionnaire. One was a lawyer and the other a professional who had recently been a carer. Both individuals have spent much of their work life communicating in French, and together they brought both precision in language and meaning to the back-translation. The back-translation matched the original English version with one exception. The item reading ‘I coped very poorly/well’ required clarification to ‘I coped with my situation very poorly/well’.

Phase 2 method

Item reduction and further evidence of acceptability

The 30 (+2 global)-item questionnaire was then completed by a new sample of 60 carers (20 in each of Montreal, Saskatoon and Toronto). In addition, time to complete the questionnaire was noted, and participants were asked whether any items were unclear or upsetting. The distribution of each item was determined, with particular focus on skewness, range of the 0–10 scale used and evidence of bimodality.

Phase 2 results

Participants

As intended, approximately half the participants were a family member caring for a patient living at home (28 or 47%) and the other participants were caring for patients who were hospitalized (32 or 53%). The patients had been followed by a palliative care service for between 1 week and 22 months, with the exception of one who was followed for 47 months. Two-thirds of the carers were female and most were the spouse (38 or 63%) or daughter (12 or 20%) of the patient. Carer age was fairly evenly distributed among those over 30: 17 (28%) were aged 31–50, 15 (27%) were aged 51–65 and 23 (38%) were over 65. Only 4 (7%) were aged 18–30. The highest level of education was also fairly evenly distributed: 5 (8%) attended only primary school, 21 (35%) attended or completed high school, 14 (23%) attended or completed college or trade school, and 18 (30%) attended or completed university (2 were ‘other’). Income was similarly distributed. Most participants lived with a spouse (48 or 80%). Almost one quarter (14 or 23%) had children under 18 living at home.

Acceptability

Clarity. Asked directly if the instructions were clear, 93% answered ‘yes’. Two commented that it was difficult for them to be so precise when choosing a response option on the 11-point scale. While 14/55 (25%) indicated that at least one item was unclear, no item was described as unclear by more than 2/55 people (4%). According to a participant, if it was the first time going through this experience, it was hard to answer questions related to the quality of care as one does not know what kind of care can be expected and what you

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need to know. Another said clarification was required regarding the meaning of 'care for yourself'.

Upsetting items. When asked if any questions were upsetting, 6/56 (11%) answered 'yes' for 1–3 items. No items were listed by more than two people (4%). The items that two people said were upsetting concerned whether the condition of the patient was distressing, whether being ready for the future was a problem and whether they felt financially secure.

Time to complete. When asked directly if the questionnaire was too long, only 2 participants (4%) answered 'yes'. The mean time to complete the 30 + 2 general items was 21 min (median = 20, range 10–35).

Content validity

Importance. As the questionnaire asks participants to respond according to their situations within the past two days, four respondents felt this timeframe problematic in terms of assessing the importance of the questionnaire content. Four said the questions regarding the quality of health care in the past two days were not applicable as they had not interacted with the health care system during that time. Two people considered the item regarding having time to take care of yourself irrelevant. One said the item regarding being comforted by their spirituality was irrelevant. Another felt she could not judge whether others she cared about were managing well.

Redundancy. Participants were also asked whether any items appeared redundant. Pearson correlation coefficients were also examined to determine redundancy. Three pairs of questions were said to be redundant, one of them by two participants. The redundant pair mentioned by two participants concerned the quality of relationships with people they cared about and the quality of communication with them ($r = 0.86$). Items regarding feeling supported and whether they had all the help they needed were mentioned as redundant by one participant ($r = 0.64$). The other pair mentioned as redundant asked the extent to which they could attend to their daily tasks and responsibilities and how often they had time to take care of themselves, with a lower correlation ($r = 0.23$). Items not mentioned by participants as redundant but which we had expected to be redundant and did indeed have high correlations included relationship with the health care team and quality of care ($r = 0.97$) and whether the carer thought the patient had what he/she needed and whether the patient was content ($r = 0.59$). A question on how well the carer was coping correlated fairly highly with 4/5 of the items concerning the respondent's own state ($r = 0.48$–0.66), and 0.73 with their sense of meaning in life.

Missing content. Seven people (7/55 or 13%) suggested content that they felt should be added. These concerned finding out how the patient and family feel about death; more items regarding their social support system, including whether they were supported by their children; and more specific questions regarding health care received (eg, home care; availability of assistance; continuity of care; separate medical, nursing, and other care).

Phase 2 changes to QOLLTI-F

Following discussion of the results reported above, the investigative team decided to delete six items. All items retained had a mean importance rating of 7.2/10 or higher. Because many of the distributions of items regarding relationships and quality of care were highly skewed towards answers that indicated the best situation, several of the end anchors were changed in hopes of a better distribution in Phase 3.

Although we realize that for some people, especially those caring for patients at home and who are more stable, the two-day timeframe appears too short, we left it as it is for the following reasons. First, our experience with this patient population indicates that their status can change from day to day, especially as death approaches, and QOLLTI-F is intended to be used throughout the final months of life. Second, while we will not capture the whole carer experience by administering a questionnaire once to a single person (as was the experience of the participants in this study), in any study we are measuring across people and/or across time, and will therefore have a more complete experience represented by the total dataset.

The items concerning whether the patient's condition was distressing, preparation for the future and feeling financially secure were listed as upsetting by two participants (4%) and only when specifically asked if any questions were upsetting (possible answers: yes, no). However, we decided to retain them as they were clearly important to QOL based on our qualitative study. We feel these items may have been upsetting because they may have reflected important factors that contributed to the QOL of these carers but which were not going well. While one person suggested that we add questions concerning carer and patient feelings regarding death, the mention of death was avoided as the questionnaire should not be the means through which family is apprised, through inference, that the patient is dying. We expect that the question about preparation for the future (which in itself was upsetting to two participants) is interpreted within the context of the imminence of the patient's death for those who are aware of it. While some participants suggested adding more specific items, they were not added to QOLLTI-F because it is impossible to assess QOL by measuring very specific contributors to QOL, as these differ from person to person and even for the same person over time. Therefore, at any given time of measurement, the inclusion of very specific items would result in having many irrelevant questions (thereby adding noise to the data) and would make the questionnaire too long to be feasible.[4]

Phase 3

Acceptability

In this phase acceptability was determined by: recording the time it took the carer to complete QOLLTI-F; adding a question asking carers to rate how tiring the questionnaire was, from 0 = not at all to 10 = very much; noting any respondent comments about the questionnaire regarding clarity and applicability of items; and noting the amount of missing data for each item.

Data collection

Primary carers completed the two-item global measure of QOL and the 24-item version of QOLLTI-F arrived at in Phase 2, along with a single item rating how tiring it was to complete the questionnaires. In order to determine test–retest reliability, and also whether QOLLTI-F scores change when the carer reports that their QOL has changed, they were asked to complete the questionnaires three times. The first two times were scheduled two days apart, with the expectation that for most their QOL would not change very much in that time, allowing us to determine test–retest reliability. Time 3 was scheduled with a larger gap in time from Time 2 in hopes of observing a change in QOL, but not so far in time that the patient was likely to have died. Because patients being cared for at home tended to be more stable, if the patient they were caring for was at home, Time 3 was approximately three weeks after Time 1, whereas for carers of hospitalized patients Time 3 was approximately one week after Time 1. At Time 1 carers also completed a demographic sheet and provided some information about patient characteristics. Carers were given the option of choosing to complete the questionnaires in English or in French.

Construct validity

Measuring the seven domains. Principal components analysis with varimax (orthogonal) rotation was conducted to further assess construct validity by domain. Items that decreased the interpretability of the principal components analysis or that had a poor distribution were eliminated. This was followed by an oblimin (oblique) rotation to determine if the resulting components would be the same and the extent of their correlation with each other. The resulting seven measures representing the seven domains were used in all further analyses. The final questionnaire resulting from the studies reported here is in Appendix A.

Distinguishing between days known to be of differing quality. In order to have a measure of change external to QOLLTI-F, prior to completing QOLLTI-F carers rated their QOL during the past two days as: very bad, bad, average, good or very good. Because few people rated their day quality as 'very bad' or 'very good', the 'very bad' and 'bad' days were collapsed into one category, the 'very good' and 'good' days were collapsed into another category, and days rated as 'average' formed the third category of scores. For this analysis, QOLLTI-F questionnaires completed at Time 1, Time 2 and Time 3 were all used. The significance of the difference in scores between days rated by the carers as good, average or bad was determined using ANOVAs followed by post-hoc testing with Tukey's Honestly Significant Difference (HSD) Test.[22]

Concurrent validity

Concurrent validity for the overall scale was assessed by determining its correlation with a two-item scale measuring overall QOL. This latter scale always preceded QOLLTI-F so that the answers would not be influenced by the content of QOLLTI-F, as order effects can inflate such correlations.[23]

Reliability

Internal consistency. The internal consistency of the QOLLTI-F items is of some interest in order to allow the scale to be compared to others. However, because we are trying to measure seven different determinants of QOL with very few items, it is not necessarily a problem if internal consistency is not above the standard Cronbach's alpha of 0.70. This is especially true when we calculate the internal consistency of the subscales, as they have very few items. However, for those scales with more than two items, determining whether internal consistency is increased or decreased by removal of each item provides more information to help understand the subscale.

Reproducibility. In order to know whether QOL had changed between two times of measurement, carers were directly asked to rate the change in overall QOL and in each domain since the last time they completed QOLLTI-F using a set of 'Change Scales' created for each domain measured in this study. The Change Scales ranged

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from -5 = tremendously worse to $+5$ = tremendously improved. When the carer indicated no or little change in QOL in a domain (ie, a difference score of -1, 0 or $+1$ for the Change Scale), his/her data was used to determine test–retest reliability. This was evaluated by calculating an intraclass correlation coefficient for the QOLLTI-F Total score and for each subscale.[24] A separate analysis of test–retest reliability was done for Time 1–Time 2 and for Time 2–Time 3.

Scoring

In order to maintain ease of interpretation, QOLLTI-F and each of its subscales are scored from 0 to 10, with 10 representing the best possible situation. First, scores of items where 10 is the worst possible situation are transposed (10-raw score). Subscale scores are calculated by taking the mean of the items comprising that subscale. The QOLLTI-F Total Score is the mean of the subscale and single-item indicator scores. This scoring method also ensures that the number of items in each subscale is irrelevant to the QOLLTI-F Total Score, and that each submeasure contributes equally. Item responses that appeared to be missing at random were replaced by the group mean for that item if there were no more than two items unanswered, they were not from the same subscale and they were not left out by that participant on more than one of the three occasions when QOLLTI-F was completed, unless an explanation was given that they were left out because the carer found it not applicable. In this way there is no effect on the group mean, however the variance is reduced. We chose this method rather than replacing the missing score with the mean of the individual respondent's answers to other items in that subscale because our subscales have so few items, often covering quite different concepts, that we do not believe this would necessarily be a more representative way of imputing missing data. In any case, as so few items were missing, this procedure should have minimal impact on the results. The Global QOL score was the mean of the two global QOL items which preceded QOLLTI-F. These were also rated on a 0–10 scale, with 10 being the best QOL possible.

Interpretation of differences in scores

The differences in QOLLTI-F scores between days the carers rated as 'very good/good', 'average' and 'bad/very bad' help us to interpret differences in QOLLTI-F scores in other situations. For example, this information helps us understand if a difference created by an intervention is similar to changing a bad day into a good day, or a bad day into an average day, and so forth.

Results

A total of 245 carers completed QOLLTI-F + the two global items. One hundred and forty-nine carers completed the questionnaires on all three occasions, 51 completed them twice and 45 completed them only once. A total of 594 questionnaires were completed. A total of 36 missing items (0.003% of all items) were replaced by the group mean. All data available were used for each analysis.

Respondent profile

Most of the carers were female (182 or 75%), married or living as married (195 or 81%) and were the spouse (138 or 61%) or daughter (56 or 25%) of the patient. People of all ages were well represented, with the exception of carers aged 18–30, who numbered only 12 (5%). Most were Catholic (127 or 54%) or Protestant (58 or 25%). Most of the carers were not yet retired (116 or 58%). Income was fairly evenly distributed, with a median of 31 000–40 000 Canadian dollars.

Fifty-nine percent of the patients being cared for were living at home, while the others were hospitalized. The most prevalent cancer was lung (46 or 22%), followed by gastrointestinal (37 or 18%) and genitourinary (32 or 15%). The majority of patients were able to communicate (155 or 76%), but an important minority were able to communicate only sometimes (42 or 20%) or not at all (8 or 4%). They were evenly split between male (123 or 51%) and female (119 or 49%). The majority of patients were over age 65 (141 or 58%) although an important minority were aged 51–65 (72 or 30%) or 31–50 (28 or 12%).

Language version

The English version of QOLLTI-F was completed 439 (74%) times, while 155 (26%) completed the French version. There were four items that had significantly different scores on the English and French versions (ANOVA, $P < 0.01$). Those completing the questionnaire in French indicated significantly more distress due to the patient's condition, feeling more helpless, having less time to care for themselves and finding less meaning in life. The data collected did not allow us to determine whether this was due to differing situations, different cultural perceptions or problematic translation. However, if problematic translation was the cause, we would not expect to find all the differences between language groups to be in the same direction (French indicates a worse situation), as was the case.

Acceptability

The mean time to complete the 24 + two items was 13.4 min (median 12 min). When asked how tiring it was to complete QOLLTI-F, on a scale from 0 = not at

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all to 10 = very much, the mean score was 1.3 and the median was 0, indicating that the length of the questionnaire was acceptable.

There were very few missing answers over all items. No item had more than 3% of the data missing. The question that had the most missing data asked the carer how satisfied s/he felt the patient was. Several carers of patients able to communicate said that they could not judge for the patient, while several caring for an unresponsive patient said that it was not applicable. This item was subsequently removed.

Construct validity

As the primary goal of the study was to select the items that would best form subscales to represent the seven domains found in the qualitative study, exploratory principal components analysis was performed with all 24 items and with and without items that had a skewed distribution, or the carers found difficult to answer (the one concerning patient satisfaction), or that made the factor analysis more interpretable when removed. This was achieved with the 16 items and their factor loadings shown in Table 1, with those forming each submeasure bolded. Of these 16 items, only the one regarding *the amount of control the carer has over his/her life* remained problematic. This item loaded most heavily on the 'Environment' factor, whereas it was intended to load on the 'Carer's Own State' factor. Seven domain scores (five subscales and two single-item indicators) were therefore created with the items that loaded most heavily on each factor, with the exception that the *control* item was included in the 'Carer's Own State' subscale. When an oblique rotation was performed (allowing the components to be correlated with one another), the results were the same. The correlations between the seven components were not high: the highest was a correlation of 0.36 between the Relationships and Outlook subscales.

Construct validity for the overall scale was studied by separately regressing a) the 16 items, b) the seven domain scores and c) the QOLLTI-F Total score (the mean of the seven domain scores) on the mean of the two items assessing global QOL. The 16 items predicted 55% of the variance in global QOL and the seven domain scores predicted 53% of the variance, indicating that little information is lost when condensing the items to domains. In contrast, the QOLLTI-F Total score predicted much less of the variance (43%), indicating that more information is lost when the Total score is calculated.

Reliability

Internal consistency. Cronbach's alpha was 0.857 for the 16-item QOLLTI-F. While the patient's condition is clearly important to carer QOL, it is also different from the other determinants of carer QOL, in that only removal of this item from the analysis resulted in a slightly higher (rather than the usual lower) Cronbach's alpha (0.860). The internal consistency for the subscales was lower, with the lowest being the 2-item Environment and Relationships subscales, not unexpectedly, as each of these subscales contain only two items, which cover quite different content (eg, relationship with patient and relationship with others). Cronbach's alphas for the subscales were: Environment 0.48, Carer's Own State 0.81, Outlook 0.65, Quality of Care 0.71, Relationships 0.54).

Reproducibility. The test–retest reliability for the QOLLTI-F Total score was 0.77 between Time 1 and Time 2, and 0.80 between Time 2 and Time 3 as

Table 1 Factor analysis on the final 16 QOLLTI-F items; items comprising each submeasure are bolded in the column for that submeasure

Item	Carer's Own State	Environment	Carer's Outlook	Quality of Care	Relationships	Patient Condition	Financial
1. Place	−0.05	**0.65**	0.06	0.39	−0.02	0.32	−0.03
2. Privacy	0.26	**0.76**	0.04	0.03	0.11	−0.21	0.23
3. Patient condition distressing	0.26	0.06	0.00	0.01	0.06	**0.85**	0.03
4. Control	**0.39**	0.55	0.22	0.05	0.09	0.25	−0.15
5. Time to care for self	**0.59**	0.51	−0.01	0.11	−0.03	0.04	0.34
6. Thinking clear	**0.76**	0.12	0.18	0.13	0.17	−0.05	−0.07
7. Physical wellbeing	**0.75**	0.11	0.16	0.13	0.07	0.18	0.14
8. Emotional wellbeing	**0.71**	0.15	0.20	0.06	0.04	0.37	0.11
9. Feelings re: being a carer	0.16	0.35	**0.49**	0.25	0.37	0.02	−0.19
10. Spirituality comforting	0.13	0.03	**0.73**	0.20	0.09	−0.05	0.26
11. Meaning in life	0.23	0.06	**0.80**	0.07	0.11	0.07	0.09
12. Relationship to patient	0.02	0.06	0.16	0.10	**0.85**	0.18	0.16
13. Relationship to others	0.32	0.04	0.11	0.33	**0.59**	−0.27	0.14
14. Decision-making	0.17	0.18	0.28	**0.72**	0.20	0.06	0.04
15. Quality of health care	0.12	0.09	0.08	**0.88**	0.10	−0.02	0.08
16. Financial worries	0.14	0.10	0.28	0.10	0.23	0.03	**0.80**

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measured by an intraclass correlation coefficient. For the seven domain scores, the intraclass correlation coefficients ranged from 0.50 to 0.79 (Table 2).

Distinguishing between days known to be of differing quality. There was a significant difference in QOLLTI-F Total score and all domain scores between each of the three categories of day quality (very good/good, average, bad/very bad) with one exception (ANOVA followed by Tukey's HSD, $P < 0.05$). The Financial Concerns domain score was not significantly different on days rated 'very good/good' and those rated as 'average'. The means for each type of day, the differences between them, and the number of standard deviations and percentage of the scale range that these differences represent are shown in Table 3.

Discussion

This study describes the process of designing and testing a research instrument to measure the QOL of carers of palliative care patients at the end of life that is conceptually and psychometrically sound. On the basis of the results from this study, the number of items in QOLLTI-F was reduced from 10 to 16 and grouped in five subscales and two single-item indicators representing the seven domains found important to carer QOL in our preceding qualitative study. We also established that psychometric properties for each subscale, each single-item indicator and the Total score were acceptable in this initial study.

To our knowledge QOLLTI-F is unique among QOL instruments in that it includes an important domain not found in others, namely the perceived condition of someone other than the person whose QOL is being evaluated (ie, the palliative patient). As noted in our qualitative study,[4,5] the carer's life is so entwined with that of the patient that they seem in many ways inseparable, and in some cases the carer seems to lose any identity other than that of carer.

Table 2 Test–retest reliability for QOLLTI-F Total and submeasure scores using Deyo *et al.*'s intraclass correlation coefficient (ICC)[24]

Scale or submeasure	No. items	ICC Time 2–Time 1	ICC Time 3–Time 2
QOLLTI-F Total	Mean of the 7 submeasure scores	0.77	0.80
Carers Own State	5	0.67	0.73
Relationships	2	0.60	0.69
Carers Outlook	3	0.57	0.77
Quality of Care	2	0.64	0.64
Patient Condition	1	0.58	0.50
Finances	1	0.79	0.72
Environment	2	0.55	0.68

Of the domains measured, 'Patient Condition' was rated the worst (ie, lowest), followed by 'Carer's Own State', whether the period being rated was described as good, average or bad. Given that the patients are dying, and the literature shows conclusively the huge toll that caregiving in this situation takes on the carer, this is expected and supports the construct validity of QOLLTI-F. 'Quality of Care' followed by 'Relationships' were the domains rated the best (ie, highest) on all three types of days. Similarly, support is rated consistently high by palliative care patients.[22,25] The relative lack of variance in Quality of Care and Relationships scores, clearly limited by a ceiling effect, makes these subscales less predictive of global QOL than they might otherwise be. This ceiling effect occurred despite our attempts to change the wording of items many times in order to better reach a normal distribution. It is debatable whether this reflects problematic items or clinical realities. A limitation of this study is that distributions of all ratings probably do not reflect what would be found were we able to recruit carers of patients at the end of life who were not receiving fairly high quality palliative care. Such patients and their families are extremely difficult for researchers to identify prior to death. It is also reassuring that most carers rate their relationships with the patient and others very highly. Again, we do not know if this reflects problematic items or realities. Many people report growing closer through the crisis of a terminal illness in the family, therefore relationships may be particularly close. Alternatively, it may be socially undesirable to report poor relationships, and data was often collected in the presence of the patient (for ethical reasons we decided it was not warranted to insist that the patient not be present), which may have biased the answers to the 'Relationships' questions.

The design of this study allows us to calculate the difference in QOLLTI-F scores corresponding to the difference between days the carers considered good, average and bad. This will help those using QOLLTI-F in the future to attach some clinical meaning to any changes or differences in scores observed between groups or in a group of carers over time. A group of experts in QOL measurement have concluded that the literature suggests that a change of 0.5 standard deviations, usually corresponding to 5–10% of the scale range, represents a minimal clinically important difference.[26–28] The difference in QOLLTI-F scores between average and bad days, and between average and good days for each QOLLTI-F measure is 7–18% of the scale range, representing 0.2–1.1 standard deviations. The differences in QOLLTI-F scores between good and bad days are, as expected, larger: 14–36% of the scale range, representing 0.5–2.1 standard deviations.

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Table 3 Differences between QOLLTI-F scores on days known to be of different quality

Scale, subscale or single-item indicator	Bad mean (SD)	Average mean (SD)	Good mean (SD)	Average – bad (% of scale range), no. SDs	Good – average (% scale range), no. SDs	Good – bad (% scale range), no. SDs
Global QOL	3.7 (1.8)	5.5 (1.7)	7.3 (1.7)	1.8 (18%), 1.0	1.8 (18%), 1.1	3.6 (36%), 2.1
QOLLTI-F Total	5.6 (1.4)	6.7 (1.3)	7.6 (1.3)	1.1 (11%), 0.8	0.9 (9%), 0.7	2.0 (20%), 1.5
Carer's Own State	4.3 (1.7)	5.9 (1.8)	7.1 (1.9)	1.6 (16%), 0.9	1.2 (12%), 0.6	2.8 (28%), 1.6
Relationships	7.0 (2.2)	7.8 (2.0)	8.4 (1.7)	0.8 (8%), 0.4	0.6 (7%), 0.3	1.4 (14%), 0.7
Carer's Outlook	6.4 (2.0)	7.4 (1.8)	8.1 (1.6)	1.0 (10%), 0.5	0.7 (7%), 0.4	1.7 (17%), 0.9
Quality of Care	7.2 (2.3)	8.0 (1.8)	8.6 (1.6)	0.8 (8%), 0.4	0.6 (6%), 0.4	1.4 (14%), 0.7
Patient Condition	2.8 (2.5)	3.8 (2.6)	5.4 (3.1)	1.0 (10%), 0.4	1.6 (16%), 0.6	2.6 (26%), 0.9
Finances	6.1 (3.2)	6.8 (2.8)	7.5 (2.6)	0.7 (7%), 0.2	0.7 (7%), 0.3	1.4 (14%), 0.5
Environment	5.9 (2.6)	7.2 (2.3)	7.9 (2.2)	1.3 (13%), 0.5	0.7 (7%), 0.3	2.0 (20%), 0.8

Good, mean for days rated 'very good' and 'good'; average, mean for days rated 'average'; bad, mean for days rated 'very bad' and 'bad'.

As always when developing psychometric instruments, further studies are required to confirm the psychometric properties reported here. It would be useful to compare the QOLLTI-F subscales with other measures of similar concepts, to further establish construct validity. Whether or not QOLLTI-F is relevant for carers caring for other types of patients remains to be determined. However, a review of factors important to the QOL of carers of stroke survivors found many of the same factors to be important.[29]

QOLLTI-F's acceptability to carers and its psychometric properties reported here encourage its use together with measures of palliative care patient QOL (such as the McGill QOL Questionnaire).[22,26] This may lead to better understanding of the relationship between patient and carer QOL, and the impact of our interventions on both. QOLLTI-F may also be used to study the relationship between carer QOL while the patient is alive and the carer's grief experience. Unless attention is directed to finding and implementing ways of maintaining carer wellbeing, their own health, already at risk,[30,31] will possibly be at unacceptably high risk. QOLLTI-F provides a means of measuring the QOL of carers of people at the end of life, allowing us to proceed to design and test interventions to provide them with the care required for sustained health.

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Appendix

QOLLTI-F©: Quality of Life During Serious Illness – Family Carers

STUDY IDENTIFICATION #: ___________ DATE: ____________

Day/Month/Year

PLEASE READ THESE INSTRUCTIONS BEFORE ANSWERING THE QUESTIONNAIRE

There are no right or wrong answers. Honest answers will be most helpful.
This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.
These numbers extend from one extreme answer (for example, 'not at all') to its opposite (for example, 'completely').
Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank in a sentence refers to the person you are caring for, but please do not write any name to keep this confidential.

1. Over the past two days (48 hours) I wondered if the place _____ was staying (home, hospital, other) was the right place to be:

never 0 1 2 3 4 5 6 7 8 9 10 always

2. Over the past two days (48 hours) I had the privacy I wanted:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

3. Over the past two days (48 hours) the condition of _____ was distressing to me:

not often 0 1 2 3 4 5 6 7 8 9 10 always

4. Over the past two days (48 hours) the amount of control I had over my life was:

not a 0 1 2 3 4 5 6 7 8 9 10 a huge
problem problem

5. Over the past two days (48 hours) I had time to take care of myself:

never 0 1 2 3 4 5 6 7 8 9 10 always

6. Over the past two days (48 hours) I was able to think clearly:

not often 0 1 2 3 4 5 6 7 8 9 10 always

7. Over the past two days (48 hours) physically I felt:

extremely 0 1 2 3 4 5 6 7 8 9 10 extremely
poor good

8. Over the past two days (48 hours) emotionally I felt:

extremely 0 1 2 3 4 5 6 7 8 9 10 extremely
poor good

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9. Over the past two days (48 hours) being able to provide care or company for_____ made me feel good:

rarely or 0 1 2 3 4 5 6 7 8 9 10 always

never

10. Over the past two days (48 hours) I was comforted by my outlook on life, faith, or spirituality:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

11. Presently I feel that my life has meaning:

very little 0 1 2 3 4 5 6 7 8 9 10 very much

meaning meaning

For questions 12 and 13, if you did not make important decisions or need health care in the past two (2) days, please answer for the last few times you did.

12. Over the past two days (48 hours) I agreed with the way decisions were made for _____:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

13. Over the past two days (48 hours) the quality of health care we received was:

unsatisfactory 0 1 2 3 4 5 6 7 8 9 10 extremely

good

14. Over the past two days (48 hours) I felt my interaction with _____ was:

very comfortable 0 1 2 3 4 5 6 7 8 9 10 stressful

15. Over the past two days (48 hours), overall, I felt my interactions with the other people most important to me were:

very comfortable 0 1 2 3 4 5 6 7 8 9 10 stressful

16. Over the past two days (48 hours) my financial situation has been stressful:
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

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