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Measuring Relatives' Perspectives on the Quality of Palliative Care: The Consumer Quality Index Palliative Care

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ABSTRACT

Context: A Consumer Quality Index (CQ-index) is a questionnaire assessing the actual care experiences and how important the recipient finds certain care aspects, as well as the priorities for improving quality. A CQ-index Palliative Care (CQ-index PC) for bereaved relatives was developed to measure the quality of palliative care.

Objectives: This article provides insight into the development and psychometric characteristics of this questionnaire, as well as quality improvement priorities.

Methods: The content of the CQ-index PC was based on existing questionnaires, literature, and interviews and focus group discussions with relatives, patients, and caregivers. The questionnaire was tested in 31 care facilities providing palliative care. Close relatives/contact persons of patients who died non-suddenly six weeks to six months earlier were eligible for inclusion. Psychometric analyses were performed to shorten the questionnaire and to assess its reliability. "Need for improvement scores" also were computed to identify care aspects with the highest priority for quality improvement.

Results: Three hundred ninety-two bereaved relatives were eligible for inclusion. The net response was 52% (n = 204). Psychometric analyses resulted in six scales (Cronbach's alphas ranging from 0.71 to 0.90). The quality aspects relatives considered most important were dying peacefully, getting help in good time in acute situations, and personal attention. Aftercare was the aspect with the highest priority for quality improvement.

Conclusion: The CQ-index PC for relatives can be used to assess the quality of palliative care from the perspective of bereaved relatives. This instrument gives health care professionals insight into care aspects with the highest priority for quality improvement.

INTRODUCTION

There is increasing interest in making the quality of palliative care transparent. Transparent information about the quality of care is considered important for health care providers who seek to realize improvements in quality. In addition, information about the quality of care can be used by patients or relatives who want to make a well-founded choice of a health care provider. Furthermore, external parties such as governments and health care inspectorates attach great importance to information about the quality of care from individual health care providers.

Several definitions exist for the quality of care,^{[1], [2] and [3]} but most definitions concern two dimensions, namely whether individuals receive the care that they need and whether the care received is effective.¹ Regarding the first dimension, in particular, it is important to gain insight into the user's perspective on the quality of care. As patients are the main target group of health care, they are appropriate persons to judge the quality of care. However, when patients near the end of life, they may no longer be cognitively or physically able to respond to quality questionnaires. Therefore, bereaved family members are also important sources of information about the care received.⁴ They often have a good overview of the care given during the dying phase. Moreover, relatives also can report on the quality of support and aftercare provided to them. This is important because aftercare is a key element in palliative care, as is indeed acknowledged in the World Health Organization definition of palliative care.⁵

In recent years, a variety of measurement instruments for palliative care have been developed dealing with a range of topics.^{[6], [7] and [8]} A systematic review by Hudson et al. described 62 instruments to be completed by the relatives of patients receiving palliative care.⁷ Hudson et al. concluded that the primary focus of existing instruments includes: satisfaction with service delivery (n = 14), psychiatric disorders (n = 6), quality of life (n = 6), needs (n = 5), grief and bereavement (n = 5), burden (psychological and/or social impact of the carer role; n = 4), preparedness/competence (n = 3), family functioning (n = 3), and other (n = 15). Less than half of these 62 instruments were developed specifically for the palliative care context. In addition, existing instruments often focused on a very specific target group, such as relatives of patients with dementia,⁹ or on only one specific care setting, such as palliative care at home.¹⁰ There was no information on the psychometric characteristics of approximately a quarter of the 62 instruments mentioned in the review.

The review by Hudson et al. also shows that instruments administered to family caregivers of palliative care patients often include questions about satisfaction of relatives with the service delivered. A definition of satisfaction is "fulfilling expectations, needs or desires."^{[11] and [12]} Satisfaction with care, therefore, involves health care users comparing their expectations with the actual care delivered, which leads to either a positive or negative feeling. If health care users have low expectations, they will be more easily satisfied than health care users with high

expectations. Satisfaction is, therefore, a result of both expectations and actual care experiences. Consequently, variations in satisfaction scores can result from differences in either expectations or experiences.¹³ This ambiguity is an important problem in satisfaction measurement.^{[14] and [15]} In addition, the fact that health care users often feel dependent and grateful to their care providers may result in people giving socially desirable answers, expressed in skewed satisfaction score distributions (the majority reporting “excellent” or “good” care).

Measuring the experiences of care users rather than their satisfaction, and relating these to their expectations, therefore, may better reflect the quality of care and also may provide clearer action points for improving the quality.^{[13], [16] and [17]} To make use of these advantages, a “new generation” of questionnaires has been developed for measuring care experiences and expectations from the perspective of care users. This new generation includes the Consumer Quality-index (CQ-index®) for measuring the quality of health care in The Netherlands since 2006. The structure of the various indices is largely based on the American Consumer Assessment of Healthcare Providers and Systems questionnaires¹⁸ (CAPHS) and the Dutch Quality Of care Through the patient's Eyes questionnaires^{[13] and [19]} (QUOTE).

In the last five years, approximately 23 CQ-indices have been developed for various target groups (see www.centrumklantervaringzorg.nl).^{[20], [21] and [22]} CQ-indices are often used to measure “subjective” quality indicators that reflect the experiences of care users with the care received in a certain care facility or setting. In The Netherlands, these quality indicators are often published on web sites or in publications, giving patients and relatives an opportunity to make a well-founded choice between different health care providers. Besides, CQ-index data can be used to provide transparent accountability information for the Health Care Inspectorate, health care insurers, governmental bodies, or other “third parties.” Data from CQ-indices provide quality information for health care providers seeking to improve the quality of care within their own organizations.

The development of various CQ-indices has been strongly promoted by the Dutch Ministry of Health. In 2008, this ministry produced a policy document,²³ among other things, stating that a CQ-index also was needed in palliative care to improve transparency and encourage improvements in the quality of care. In response to this, we developed such a CQ-index for palliative care (CQ-index PC). This new instrument, which can be used in various palliative care settings, consists of separate versions for patients and for bereaved relatives. The patients' version is useful for patients who are still physically and cognitively capable of completing this structured questionnaire. However, this implies that dying patients cannot be included as they are no longer physically and cognitively capable. Therefore, there is a separate version for bereaved relatives asking about the quality of palliative care in the last week of the life of the patient and about the quality of support and aftercare for relatives.

This article focuses on the version of the CQ-index PC for relatives. The details of the patient version have been described elsewhere.²⁴ This article aims to present this new instrument for measuring relatives' experiences of palliative care. In particular, it emphasizes the care experiences of relatives in the last week before death of the patient and in the aftercare phase.

In addition, the instrument assesses which quality aspects the relatives find important, and which are the priorities for the improvement of quality.

METHODS

Construction of the Questionnaire

The construction phase of a CQ-index always involves several stages.²⁵ In the first stage, interviews and/or focus group discussions are conducted. In the development of the CQ-index PC, our research group had conducted interviews in a previous study with 19 patients, and 23 relatives provided input for the pilot questionnaire.²⁶ These interviews with relatives and patients focused on what relatives and patients thought as important for good palliative care.²⁶ In mid-2008, one focus group discussion with three relatives, one interview with a relative, and two focus group discussions with 18 health care providers were conducted to gather extra data about quality aspects of palliative care that are important for patients and relatives. In addition, three individual interviews with patients were conducted to refine and validate the earlier interview data. We started the focus group discussions and interviews with open-ended questions, such as “Describe some positive and negative care experiences” and “According to you, what makes good quality care?” The focus group discussions were summarized by the researchers in consultation with the participants. The individual interviews were recorded and typed out verbatim. The interviews and focus group discussions were analyzed qualitatively and inductively. The first author (S. J. J. C.) read and reread the material and used inductive coding to categorize the aspects of care that were mentioned as crucial for high-quality palliative care. The process and outcomes of the analysis were discussed by S. J. J. C. with the co-authors (A. L. F. and L. D.). Important quality aspects that emerged from the analysis, and which were mentioned frequently in the interviews, were “taking wishes and needs into consideration,” “autonomy,” “personal/warm attention,” “expertise,” and “continuity of caregivers.”

Another standard element in the process of constructing a CQ-index is a literature study. For the development of the CQ-index PC, relevant literature on existing quality research, CQ-indices, and quality questionnaires were studied.²⁴ No existing questionnaires were found that were completely suitable for measuring the quality of palliative care in various settings and which contained all dimensions of palliative care (physical, psychosocial, and spiritual). Some of the items were derived from existing Dutch questionnaires.^{[21], [27] and [28]}

Further, a steering committee with sixteen experts and stakeholders provided input for constructing the draft questionnaire. The Ministry of Health, national umbrella organizations, health care providers, and representatives of patient organizations were represented in the steering committee. These parties assessed the content validity of the questionnaire and the comprehensibility of the draft questionnaire. This resulted, for example, in a clearer introduction to the questionnaire.

The first draft of the CQ-index PC for relatives was pre-tested among twelve relatives for comprehensibility and time required to complete the questionnaire, and to check whether questions were missed. This resulted in some minor revisions, for example, adding the option “not applicable” to some questions.

Content of the Questionnaire

The relatives' version of the CQ-index PC consisted of questions on background characteristics such as age and gender, experience items (questions about actual experiences regarding specific aspects of care), and importance items (questions about how important specific aspects of care are for relatives). It addresses physical, psychosocial, and spiritual care aspects.

The questionnaire also contained questions on the support provided for the patient in the last week before death. The reason why we only focused on the week before death is that this is a period in which dying patients themselves will no longer be physically and cognitively able to complete a questionnaire, whereas close relatives often have a very good overview of the care in the period shortly before death. In addition, the questionnaire contained questions on the support provided for the relative in the last week before the patient's death. Finally, questions were asked about aftercare.

The answer categories for most of the experience items were "never," "sometimes," "usually," and "always" (an ordinal four-point scale), sometimes combined with "not applicable." A few experience items had answer options of "yes" or "no." The answer categories for the importance items were "not important," "fairly important," "important," and "extremely important" (also an ordinal four-point scale).

Sample and Recruitment Process

The sample consisted of care facilities recruited partly from within the research team's existing professional networks. In addition, care facilities participating in a parallel project on the development of quality indicators²⁹ were invited to participate in this project on the development of the CQ-index PC. Once a care facility agreed to participate, a central contact person within this facility was assigned. This person was responsible for recruiting all bereaved relatives who met the inclusion criterion of "being a bereaved relative and contact person of a patient who died not suddenly six weeks to six months earlier."

At the end of 2008, the CQ-index PC version for relatives was sent to 392 bereaved relatives of patients cared for in a total of 31 health care facilities in The Netherlands (five high-care hospices, one low-care hospice, one hospital, five nursing homes, 11 homes for the elderly, six home care organizations, and two mental health care organizations). After two weeks, a reminder was sent to the nonrespondents.

Statistical Analysis

Several psychometric analyses were performed to shorten the questionnaire by removing items and to assess the questionnaire's reliability. The analyses involved calculating the distribution of scores, item-response analyses, calculating scores for the importance items, Pearson's correlation analyses, factor analysis (principal component analysis with oblique rotation), and calculating Cronbach's alpha. When deciding on the items to be removed from the questionnaire, we took account of

- Extremely skewed items. We considered items extremely skewed if more than 90% of answers were in the most positive category (“always” or “yes”) or in the most negative category (“never” or “no”)
- Items with a high percentage of missing values (defined as more than 10% missing values) and/or a high percentage of “not applicable” answers
- Items with relatively low scores for “perceived importance.” A relatively low score is defined as having a mean score for an item on “perceived importance” in the bottom 10 of all the mean scores
- Items with a strong mutual relationship (Pearson's correlation $r > 0.70$)
- Items not fitting into scales (according to the factor analysis)
- Items not contributing to the scale reliability (if Cronbach's alpha < 0.7 and item-total correlation < 0.40)

In addition to the psychometric analyses, the mean scores (for all respondents) were calculated for the importance items. Moreover, “need for improvement” scores were calculated to obtain an initial indication of which quality aspects have the highest priority for improvement. Need for improvement scores are calculated by multiplying the mean score for a question on the importance of a care aspect by the percentage of respondents with a “negative experience” for this care aspect, and then dividing this number by 100. A negative experience means that a respondent has answered “never” or “sometimes” or “no” to a question about an actual experience with a certain aspect of care. A high need for improvement score means that most respondents attach considerable importance to a care aspect but their experiences of it are often negative. The higher the need for improvement score, the higher the priority an aspect should be given for improvement.

Ethics

The Medical Ethics Committee of the VU University Medical Center in Amsterdam approved this study.

RESULTS

Response

Two hundred four of the 392 included bereaved relatives completed the questionnaire (52.0% response). Most respondents were relatives of patients who died at home (27.9%), in a nursing home (27.5%), home for the elderly (17.2%), or relatives of patients receiving care in a hospice facility (23.5%), hospital (1.5%), or mental health care organization (2.5%). The mean age of the relatives was 60 years; 65% were women. The majority (66%) were relatives of a patient who died of cancer. The biggest group of relatives (45%) was sons or daughters of the deceased patient; 39% were the partner.

Psychometric Results

Three items were extremely skewed: the item on whether the patient had died peacefully; the item on “the politeness of caregivers;” and the item on “knowing who is the contact person for treatment.”

There were no items that had more than 10% missing values. However, there were three items where about 60% of the relatives had answered “not applicable;” these items, therefore, were not included in the subsequent factor analysis.

There were 10 importance items with relatively low scores, varying between 2.33 and 3.23 (within a range of 1–4). For instance, an item concerning help with household activities was omitted.

Moreover, some items had strong correlations ($r > 0.70$). This could be a reason for the omission of one of the two correlated items (e.g., the items on information about the life expectancy and information about the approaching death were highly correlated; the first item, therefore, was omitted). However, sometimes highly correlated items were not deleted because, for example, strong correlation does not always imply a large overlap in the content of the item. In addition, arguments and remarks made by relatives in the drafting and testing phase, as well as recommendations of the steering committee, were taken into account when deciding on the omission of items.

[TABLE 1.]

Six reliable scales were distinguished based on the factor analyses and reliability analyses. Each scale comprises three or four items. These scales and their items are presented in [Table 1.]

In addition, eleven stand-alone experience items were distinguished in the questionnaire (Table 2). These items did not fit in a reliable scale. Nevertheless, these items were not removed from the questionnaire because relatives considered them to be “very important” for palliative care and/or because they scored relatively high as candidates for improvement. In the sections below, we will discuss the scores for importance items and also the need for improvement scores.

[TABLE 2.]

Scores for Importance Items

Table 3 lists the five importance items with the highest mean scores. As shown, relatives consider “dying peacefully,” “offer of help in good time in acute situations,” and “attention” to be most important.

[TABLE 3.]

Need for Improvement Scores

Table 4 shows the five care aspects addressed in the questionnaire that were given the highest priority for improvement. The need for improvement score is shown in the left-hand column. This score is obtained by multiplying the figures in the next two columns and dividing the product by 100. The corresponding percentage of

respondents who scored experience items negatively by answering “never,” “sometimes,” or “no” is displayed in the middle column, and the mean scores and standard deviations for the importance items are presented in the right-hand columns.

[TABLE 4.]

The items concerning “being informed about the possibility of aftercare,” a “final conversation or discussion in which the care and treatment were evaluated,” and “receiving information about options concerning the funeral” have the highest need for improvement scores.

The relatively high need for improvement scores in Table 4 indicate that health care providers should prioritize these aspects if they want to improve palliative care. For example, “being informed about the possibilities of aftercare” has a need for improvement score of 1.597, with a 58.3% negative score for the experience item and a mean score of 2.74 for the importance item. This score indicates that more than half of the bereaved relatives (58.3%) answered that they were not informed about this (the answer options were “yes” or “no”).

The importance score of 2.74 (in a range from 1 to 4) indicates that relatives consider it “fairly important” to “important” that they are informed about the possibilities of aftercare.

DISCUSSION

This article shows that the CQ-index PC for relatives is an instrument that contains six reliable scales addressing the quality of palliative care. The CQ-index PC for relatives contains questions about the care for the patient in the last week of life and about the support for relatives in this final week before death. It addresses physical, psychosocial, and spiritual care aspects. In addition, aftercare for relatives is an important aspect of the CQ-index PC for relatives.

A key characteristic of the CQ-index PC is that the instrument asks about actual care experiences, whereas most other quality instruments addressing the user perspective directly ask about satisfaction,^{[7] and [28]} with a higher risk of getting socially desirable and skewed answers. Although there are a few other instruments addressing actual experiences of palliative care (for instance, the toolkit³⁰), the CQ-index PC differs from these instruments, as it also includes items addressing how important respondents find certain care aspects. This means that the importance that patients and relatives attach to certain quality aspects can be taken into account when quality improvements are planned. For example, if a care user has a bad experience with a certain quality aspect but does not find this quality aspect very important, this is less crucial than when care users have bad experiences with a quality aspect they consider extremely important. Combining actual care experiences with importance scores produces need for improvement scores. If professionals want to improve the quality of their palliative care, they should focus on the highest need for improvement scores. In this study, it turned out that aftercare had the highest need for improvement, as reflected in the scores for the aspects “being informed about the

possibilities of aftercare” and “final conversation or discussion in which the care and treatment were evaluated.”

Because aftercare has the highest priority for improvement, health care providers should be made aware of the importance of aftercare, for example, through training and clinical supervision. In addition, managers in palliative care have the responsibility to arrange satisfactory provision of aftercare for the closest relatives. To gain a complete picture on the quality of palliative care within a specific care facility, the patients' version of the CQ-index PC²⁴ must also be used, besides the version for bereaved relatives. Some questions in the relatives' version correspond to questions in the patients' version (e.g., an item concerning the expertise of caregivers and an item concerning respect for the patient's life stance). Asking bereaved relatives about their perspectives on the quality of palliative care will always be valuable, even when the patients themselves are able to complete the patients' version of the questionnaire. Bereaved relatives are particularly appropriate respondents for questions on the final period as they have a good overview of the care in the very last days of the patient and can provide information on the aftercare they themselves have received.

As already stated in the introduction, CQ-indices may be used for several purposes and also may function as practical instruments for measuring quality indicators from the care users' perspective.²⁹ Internationally, there is an increasing interest in quality indicators in palliative care.^{[31] and [32]} Some quality indicators can be relatively objective in nature, such as the percentage of patients suffering from specific problems or symptoms in the palliative phase,^{[29] and [31]} whereas other quality indicators reflect care users' subjective appraisals of the quality of care. CQ-indices are appropriate instruments for measuring the latter type of quality indicators.²⁹ One limitation is that no items about care for the physical well-being of the patient were included in the CQ-index PC for relatives. This was a deliberate choice, as relatives do not always know what specific interventions there have been to relieve pain and other physical suffering. However, this aspect is covered in depth in the patients' version of the CQ-index PC. Moreover, in a parallel project, we developed several quality indicators addressing physical symptoms, measured using numerical rating scales.²⁹ These quality indicators concern the percentages of patients with (moderate to severe) pain, constipation, fatigue, and shortness of breath. We recommend, therefore, also measuring these kinds of more objective quality indicators in addition to measurements of subjective experience with the CQ-index PC.

In the study presented, we used the CQ-index PC in various palliative care settings such as the patient's home, hospice facilities, nursing homes, homes for the elderly, hospitals, and mental health institutes. However, the ability of the CQ-index PC to discriminate between settings has not yet been determined. Future research will shed light on whether the CQ-index PC can detect quality differences over time or between health care organizations, for example, with regard to aftercare. Some care facilities, particularly hospices, have a longer tradition of specialized palliative care than others. Hence aftercare, for example, might be expected to be a regular part of the care given in hospices but not necessarily in general hospitals. We are currently preparing a study with larger samples, which will enable comparisons between settings and the testing of such hypotheses.

As a result of this development process, a CQ-index PC for relatives is now available to obtain insights into the quality of palliative care from the perspective of bereaved relatives. This questionnaire differs from other quality instruments in palliative care because it examines relatives' actual care experiences as well the importance relatives attach to various care aspects. Combining actual experiences with importance scores allows priorities for quality improvement to be established.

At the moment, the CQ-index PC has only been tested in Dutch. However, an English translation has been produced for informational purposes for foreign researchers (available on request). It is recommended that the CQ-Index PC also should be tested and validated by researchers in other countries who want to measure the quality of palliative care from a user perspective and who are interested in priorities for quality improvement.

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TABLES

Table 1
Scales and Their Reliability Scores (Cronbach's alpha)

| Scale | Cronbach's Alpha | Experience Items (Translated From Dutch) |
|---|------------------|---|
| Care for the psychosocial/spiritual well-being of the patient | 0.88 | Did the caregivers respect your relative's life stance? Were the caregivers accessible for discussions about your relative's approach to the end of life? Did the caregivers pay attention to your relative? |
| Care for the relative's own psychosocial/spiritual well-being | 0.90 | Did the caregivers take personal wishes of your relative into account? Did the caregivers pay attention to your anxiety? Did the caregivers pay attention to your depression? Did the caregivers respect your life stance? Could you talk to the caregivers about what it meant to care for your sick relative? |
| Attitude to the relatives | 0.81 | Were the caregivers polite to you? Did the caregivers listen carefully to you? Did the caregivers have enough time for you? Did the caregivers take you seriously? |
| Autonomy | 0.80 | Did the caregivers involve you in decisions about the care for your sick relative? Could you decide what your own task was in the care for your sick relative? Did the caregivers take your personal wishes into account with regard to the care for your relative? |
| Information for the relative in the last week before death | 0.71 | Did the caregivers explain things to you in a way that you could understand? Did the caregivers give you contradictory information? Did you receive information about the approaching death? Did you receive information about the options concerning the funeral? |
| Expertise | 0.78 | Did the caregivers have the necessary expertise? Was there a good match between the care provided by the different caregivers involved in looking after you? Were you offered help in good time in acute situations? |

Table 2
Overview of Stand-Alone Experience Items in the Questionnaire

1. Did your relative have access to a counselor for spiritual problems (e.g., a minister/priest or humanist counselor)?
2. Did your relative have the opportunity to be alone if he/she wanted to be?
3. Did your relative receive support from the caregivers with preparations for saying goodbye to relatives?
4. Did your relative accept his/her approaching death?
5. Did your relative die peacefully?
6. Did you have the opportunity to be alone with your relative if you wanted to be?
7. Did you know who the contact person was for the care?
8. Did you receive information about the advantages and disadvantages of various types of treatment?
9. Did you feel supported by the caregivers immediately after the death of your relative?
10. Were you informed about the possibility of aftercare after the death of your relative?
11. Was there a final conversation or discussion in which the care and treatment were evaluated?

Table 3
Top Five Items of Importance (Highest Mean Scores)

| Item | Mean Score ^a | Standard Deviation |
|---|-------------------------|--------------------|
| Do you think it is important that | | |
| People in the last stage of life can die peacefully? | 3.87 | .391 |
| Help is offered in good time in acute situations? | 3.82 | .420 |
| Caregivers pay attention to people in the last stage of life? | 3.74 | .513 |
| Caregivers have the necessary expertise? | 3.73 | .479 |
| Caregivers take personal wishes into account of people in the last stage of life? | 3.73 | .477 |

^aThese score range was from 1 (not important) to 4 (extremely important).

Table 4
Five Highest "Need for Improvement" Scores With Corresponding Scores for Experience Items and Importance Items

| Item About: | Need for Improvement Score | % With Negative Score for Experience Item | Mean Score for Importance Item | Standard Deviation for Importance Item |
|--|----------------------------|---|--------------------------------|--|
| Being informed about the possibility of aftercare after the death of the relative | 1.597 | 58.3 | 2.74 | 0.935 |
| Final conversation or discussion in which the care and treatment are evaluated with the relative | 1.444 | 53.1 | 2.72 | 1.020 |
| Receiving information about options concerning the funeral | 1.275 | 48.1 | 2.65 | 1.085 |
| Receiving support with preparations for saying goodbye to the relative | 0.837 | 24.2 | 3.46 | 0.701 |
| Receiving information about the approaching death | 0.763 | 21.2 | 3.60 | 0.638 |