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Review

Quality of life in palliative care: principles and practice

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Abstract: In healthcare, most researchers and clinicians agree that quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably to a lesser extent to meaning and fulfilment. This multidimensional health-oriented concept has been named health-related quality of life (HRQOL). However, during end-of-life care spirituality and existential issues become more prominent, as well as family members' perception of quality of care. Outcome measures in palliative care require constructs that reflect the specific goals of palliative care, such as improving QOL before death, symptom control, family support and satisfaction, as well as patients' perceptions of 'purpose' and 'meaning of life'. It is generally recommended that internationally developed and validated patient-rated multidimensional questionnaires should be used when assessing HRQOL in research. However, 'multidimensionality', with often more than 10 possible outcomes, is a threat both to statistical analysis and clinical interpretation of data. Preferentially, a more limited number of outcomes based upon the research question(s) should be defined prior to data collection in the study protocol. The researcher needs to carefully evaluate the content of the questionnaire, in addition to other properties, such as the validity and reliability, before the final decision is made with regards to which instrument to use in a given study. *Palliative Medicine* 2003; **17:** 11–20

Editors note
We shall continue to publish high quality reviews or papers 'for discussion', but in general these will be commissioned. We begin with a review which has been condensed from Quality of life in palliative medicine: principles and practice, by Stein Kaasa and John Håvard Loge, in the Oxford Textbook of Palliative Medicine, 3rd Edition, due in the autumn of 2003. We are most grateful to Oxford University Press for granting permission to publish this condensed version of the chapter.

Introduction

Quality of life (QOL) is a central concept in palliative care and in healthcare in general. It is not a new idea; one of the main goals of the healthcare system in ancient Greece was to improve patients' QOL.[1]

Despite the widespread use of the term 'quality of life', no precise common definition exists. Two general approaches are used for understanding the concept: QOL as a broad concept encompassing 'how is your life, everything taken into consideration', and QOL as a health-oriented concept encompassing aspects of health or healthcare, such as symptoms and functioning. These are not mutually exclusive concepts, but rather a continuum between two extremes allowing an intuitive flexibility in defining QOL.

Overall quality of life

In sociological, psychological and medical contexts, QOL has been used as a broad concept. To find indicators of this abstract phenomenon, satisfaction, happiness, morale, positive and negative affects have been put forward as important components. Some put an emphasis on normality, viewing QOL as fulfilment of life and the possibilities to live a normal life, while others focus more on mental capacity, to think clearly, to see, to love and be loved, to make decisions for oneself, to maintain contact with family and friends, to live at home and/or to be physically active.

Used as described above, QOL is strongly linked to normality, including normal function or that a minimum of human needs are met. Such a minimum of needs were also described by Maslow,[2] often referred to as 'Maslow's needs hierarchy', consisting of biological needs, needs for close relationships, needs for meaningful occupation and

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needs for change. This concept has been further elaborated in viewing QOL as the level of a person's activity, the quality to relate to others, self-esteem and a basic mood of happiness.[3]

The concept of normality and biological fulfilment is challenged empirically in that many patients with major physical and/or psychological limitations may report a high degree of overall QOL.[4] These empirical findings fit well with another theory, the so-called gap theory by Calman.[5] He described QOL as the inverse relationship of the difference between an individual's expectations and their perceptions of a given situation, 'the smaller the gap the better quality of life'.

Quality of life in medicine

In healthcare as in life in general, QOL may have different meanings to different people. Despite the ongoing discussion on how to define QOL, most researchers and clinicians probably agree that QOL in medicine is related to symptoms, functioning, psychological well-being and probably to a lesser extent to meaning and fulfilment (existential and spiritual issues). This multidimensional health-oriented concept has been named health-related quality of life (HRQOL).[6–10]

The World Health Organization (WHO) definition of health captured in 1947 the multidimensionality of health: 'Health is not only the absence of infirmity and disease, but also a state of complete physical, mental and social well-being'.[11] In 1948, Karnofsky described another important step in the same direction. He evaluated the palliative effect of nitrogen mustard on various malignant tumours by means of subjective improvement, objective improvement and performance status.[12]

During the 1970s, standardized questionnaires were developed in co-operative groups and in university settings. 'Linear analogue self assessment scales' (LASAs) were used to capture the subjective health status (i.e., wellbeing, mood, anxiety, activity, pain and social activity) of specific groups of cancer patients.[6,7] Others developed measures of health status in order to capture the subjects' general perception of their health (Sickness Impact Profile,[8] Nottingham Health Profile,[13] SF-36[14,15]). Some more physically oriented scales, such as the Barthel Index, may also be placed in this latter tradition.[9] Other measures, sometimes classified as QOL measures, focus purely on psychological aspects of health, such as the General Health Questionnaire (GHQ)[10] and the Profile of Mood States.[16] A similar development of measures took place within the area of pain assessment based upon the International Association for the Study of Pain (IASP) definition of pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'.[17] This definition is conceptually similar to most definitions of QOL. A 'language of pain' was developed, which is well illustrated by the McGill Pain Questionnaire (MPQ).[18] More simple tools were also used to assess pain intensity, such as Verbal Rating Scales (VRS), Numerical Rating Scales (NRS) and Visual Analogue Scales (VAS).[19]

Most of the HRQOL and pain measures are built upon utilized questionnaires, which are variably suited to palliative care patients. For severely ill patients, assessment by means of interview is probably more appropriate. Interviews are flexible and provide detailed information but are time consuming (and therefore expensive). Further, their usefulness can be limited in multicentre trials in which HRQOL is often assessed at several time points. Assessment by use of questionnaires has therefore become a commonly used approach. Questionnaires are often in paper format, but can also be administered electronically.

The enormous increase in publications indexed under the subject heading QOL in Medline reflects the increased focus on patients' QOL. The rapidly increasing number of papers and newly developed questionnaires are a reminder of the ambiguity of the concept of QOL. Different wordings of the same phenomena across different questionnaires, e.g., fatigue versus vitality or psychological functioning versus mental health, underline the lack of precision, both on the level of single items and scales, and hampers communication across studies.

Quality of life in palliative care

The goals of palliative care are acknowledged to include HRQOL as well as spirituality, loss and grief, family involvement and coping. Many of the most commonly used HRQOL tools have been criticised for being too narrow by only including physical, psychological and social aspects of a patient's life. Thus, outcome measures in palliative care require constructs that reflect the specific goals of palliative care,[20] such as improving the QOL before death, controlling symptoms and supporting the family. It has been proposed that meaning should also be included, as well as purpose, spirituality and grief.[21–23] During end-stage disease, patients will often not be able to complete HRQOL instruments and proxies will be the only possible source of information, either by means of interviews (open, semistructured or structured) or questionnaires.

What is a palliative care population?

A palliative care population is not a well-defined group of patients. In some programmes most patients are dying while in others the majority of the patients have a longer life expectancy. To choose the optimal methodology for collection of HRQOL data in palliative care practice and research, the patient population in question should be

Table 1 Patient populations in palliative care

A suggestion for classification		
	Expected survival	Karnofsky
Primary palliation	> 6 months	70–90
Early palliation	2–3 months	50–60
Late palliation	B 1 month	20–40
Imminently dying	B 1–2 weeks	B 10

specified, e.g., by expected survival, type of tumour directed treatment, do not resuscitate (DNR) status, symptom burden, type of oncological treatment and so on. A suggestion for a common classification is proposed in Table 1. The category 'imminently dying' can be divided into a group of cognitively intact and cognitively impaired patients (Table 1). The content of the assessment tools, their length and the use of proxy raters are some of the important issues to consider in relation to the patient population being investigated.

Compliance and patient population

Missing data are a potential source of selection bias in cancer research and quality assurance programmes.[24] Missing data are not generally missing by random. The patients in poorest health, with shortest life expectancy are the noncompliers.[25] When data are missing for some patients, basic questions arise as to whether the patients with missing data differ from those with complete data sets. In order to evaluate the scientific report and to compare cohorts between studies, a standard reporting system of compliance, including all available information, should be required. Compliance is often defined as the number of questionnaires completed as a proportion of the number expected. The issue of compliance is described in more detail in textbooks[26] and in statistical literature.[27]

Proxy ratings

Proxies may be considered as an alternative or complementary source of information, especially during end-of-life care, when the patients are no longer able to respond to the traditional data collection procedures.[28] However, there has been a general negative attitude towards the use of proxy ratings in the HRQOL literature because it has been repeatedly agreed that assessment directly from the patient is the most valid way of collecting subjective data.

Review articles[29,30] and commentaries[31,32] have evaluated caregivers and significant others as raters. The findings of the published studies are not consistent but can be summarized as follows:

- Healthcare providers tend to overestimate patients' anxiety, depression and psychological distress.
- Agreement between healthcare providers' and patients' ratings was better in the absence of distress than in the presence of distress.
- Pain and other symptoms are underestimated.
- Proxy ratings seem to be more accurate when the domains are concrete and observable.

Questionnaires for measurement of HRQOL

The rapidly increasing number of questionnaires represents a challenge for the user. The first step in the selection procedure is to specify the aims of the project or clinical problems in question and to compare these with the content of questionnaires.

It is generally recommended to assess HRQOL with multidimensional instruments because such measures are more comprehensive than unidimensional scales.[33] The HRQOL measures are commonly divided into *generic*, *disease specific* and *domain specific*. The *generic* measures are not specific to any population or disease. They are therefore applicable to subjects with more than one condition, and they make comparisons across populations and conditions possible.

The *disease-specific* measures are developed for specific groups of patients, such as the EORTC-QLQ-C30 (European Organization for Research and Treatment of Cancer) and the Functional Assessment of Cancer – General Version (FACT-G)[34,35] or instruments specifically developed for palliative care. Most of the instruments include various aspects of functioning, such as physical, role and social functioning and subjective appraisal of symptoms and wellbeing.[36] Most recent generic and disease-specific instruments also assess positive health, i.e., good health and wellbeing and not merely the absence of problems.[37]

The *domain-specific* instruments assess specific domains within the overall concept of HRQOL, such as fatigue, pain or psychological distress.

Assessments of QOL will often include combinations of generic, disease-specific and domain-specific instruments based upon the specific purpose of the study. For example, if one wants to compare the effects of single fraction irradiation with multiple fractions in a population with painful bone metastasis, a disease-specific questionnaire such as the EORTC-QLQ-C30 in combination with domain-specific questionnaires for measurement of pain might be relevant. The questionnaires must fit the purpose for the assessment, but their number must also be balanced against the burden upon the respondents and the costs of the data collection. The increased amount of information gained by including domain-specific measures is not always obvious and is clearly dependent on the psychometric properties, the content and the sensitivity of the instruments. For example, if a fatigue instrument does not have better measurement qualities than the fatigue scale within a generic or disease-specific instrument, it is probably best not to be included because of the increased burden to the patient.

Comparative data on various instruments measuring the same constructs are relatively scarce. The researcher might be best off choosing instruments that are commonly used and found relevant within similar populations and settings. By choosing commonly used instruments, findings can more easily be evaluated in a broader perspective. The psychometric properties of an instrument might vary across populations, therefore applying a questionnaire for the first time within a 'new population', generally requires retesting of the psychometric properties of the instrument.

Disease-specific measures

The following disease- and domain-specific instruments have been commonly used. Most of these have been applied in several settings, including palliative care populations.

EORTC QOL-C30

The development of the cancer-specific questionnaires, the EORTC QLQ C-30 started in 1980, and the first 30-item version was finalized in 1993.[34] Modified versions have been published and the group recommends version 3.0 of the questionnaire.[38] The questionnaire covers five functional scales, general quality of life, three symptom scales and six single items.

The questionnaire is translated and validated in 38 languages and has been used in more than 1500 studies worldwide. The instrument has good psychometric properties including test/retest reliability.[39,40] The instrument has also been used for other purposes, such as studying the communication between patient and physician.[41]

The so-called modular approach adopted by the EORTC Quality of Life Group is designed so that the core questionnaire can be supplemented with additional questionnaires designed for specific cancer sites, such as lung cancer (LC13),[43] breast cancer (BR23)[44] and head and neck cancer (H&N35).[45,42] Several questionnaires for other cancer sites are under development. At present, no specific module for palliative care exists. Updates on the latest development of the EORTC questionnaires are found on the website,[38] www.eortc.be/home/qol/eortc

FACT-G

The Functional Assessment of Cancer – General Version (the FACT-G) is part of a measurement system called Functional Assessment of Chronic Illness Therapy (FACIT) intended for use in chronic diseases. The FACT-G was first published in 1993 and includes 27 items arranged in subscales covering four dimensions: physical wellbeing, social/family wellbeing, emotional wellbeing and functional wellbeing.[35] The psychometric properties are reported as comparable with the EORTC QLQ C30.[35]

For an update on the FACIT measurement system refer to the study group's net-site,[46] www.facit.org/facitquestionnaire.htm

Domain-specific measures

Generic or disease-specific instruments might not be sensitive enough for detection of differences in some of the components of HRQOL. For example, in a study of patients with advanced prostate cancer, the EORTC QLQ-C30 fatigue scale did not detect variations in fatigue over time, whereas two fatigue-specific instruments captured group differences.[47] Similar findings were reported in another study.[48] Domain-specific instruments have been designed to assess specific symptoms, such as pain, fatigue and anxiety. Numerous instruments are available and for a more comprehensive description the reader is referred to relevant textbooks.

Symptoms of anxiety and depression

Most of the domain-specific instruments for measurement of anxiety and depression can be regarded as 'first-generation' instruments. For example, the Hospital Anxiety and Depression Scale (the HADS) was constructed in 1983, but it has relatively recently been recommended for use in oncology and in palliative care.[49–51]

For instruments measuring anxiety and depression in palliative care it is important to screen for somatic items (fatigue, weight-loss, loss of appetite, etc.). Such symptoms are valid symptoms of anxiety and depression in psychiatric and healthy populations, and they are included in the present diagnostic criteria for these disorders.[52] However, these symptoms are probably not valid in palliative care because they may reflect the underlying physical disease.[53]

In spite of the relatively extensive research literature addressing this methodological challenge, published papers still do not pay attention to the consequences of including somatic items in assessments of anxiety and depression in the physically ill.

Fatigue

Fatigue is the most frequent symptom in palliative care and is experienced by nearly all patients with advanced disease.[54,55] In palliative care, as opposed to healthy populations, fatigue only weakly correlates with psychological distress and probably reflects the subjective experience of being ill.[55]

Instruments specifically designed for measuring fatigue were first published in the late 1980s. At present, several instruments are available[56,57] and most of these should be classified as ‘first-generation’ instruments. Most researchers agree that fatigue is a multidimensional phenomenon, but the number and types of dimensions is debated. All present fatigue measures include physical fatigue, which corresponds to the subjective feeling of being exhausted and lacking energy.

Pain

Pain is the second most prevalent symptom in palliative care, and for the majority of patients it is the most distressing symptom. It is well documented that pain is underdiagnosed and often undertreated when diagnosed.[58] Pain is also the main target for pharmacological interventions during palliative care. In general, pain is included as a single item or as a separate subscale in existing generic and disease-specific instruments. It is also important to underscore that pain is a complicated and controversial area for assessment, although some of the problems reflect general challenges for HRQOL assessments.

Domain-specific tools for measurement of pain, such as the McGill Pain Questionnaire, measure pain as a multidimensional phenomenon, but it is rather extensive and thereby often difficult to apply in debilitated palliative care patients.[59] A shorter version of this instrument has been developed and validated.[60] Others, e.g., the Brief Pain Inventory (BPI),[61] measure the impact of pain upon physical functioning in addition to measuring pain intensity. There is reason to question whether the functional consequences of pain can be separated validly from functional limitations due to other factors.[62] This point is of particular relevance in palliative care because of the complexity of the disease process, functional limitations and the appearance of several symptoms at the same time.

Use of single items

The use of single items either as self-constructed items or as items borrowed from a complete instrument is generally not recommended. The rationale for this is however debatable. The validity of self-constructed items is generally uncertain and moving an item from its context might affect the responses. However, if one wishes to measure sleep, for example, very few instruments include item(s) on this important aspect of health and disease. Instead of constructing single items, it is preferable to use items that have been developed and validated as part of multidimensional questionnaires.

Cognitive impairment

Cognitive impairment as part of dementia, amnesic disorder or delirium is prevalent in palliative care.[63] Among patients with terminal cancers, 20–40% develop delirium or other neuropsychiatric conditions.[64] Cognitive impairment affects completion rate, data quality and possibly the validity of HRQOL studies in palliative care. It is, therefore, often necessary to screen for cognitive impairment prior to collection of HRQOL-data in palliative care. This needs to be done by structured clinical interviews.

Palliative care-specific instruments

Some instruments developed specifically for use in palliative care are presented in the following. The selection of instruments is pragmatic and not comprehensive.

A short form individual quality of life questionnaire (SEIQOL)

The SEIQOL was originally designed for use in patients undergoing major orthopaedic procedures. subsequently, it has been clinically evaluated in palliative care. The schedule for the evaluation of individual quality of life (SEIQOL) was designed specifically to assess three questions: what areas of life are important, how is the individual doing in each of these areas and what is the importance of the area?[65]

The SEIQOL is a complex measure and its use in routine clinical practice may prove impractical. An abbreviated form has been developed recently, the SEIQOL – direct weighting (SEIQOL-DW)[66] and validated in a population of advanced cancer patients.[23] One limitation of the study was the high number of exclusions of terminally ill patients. It was concluded that the SEIQOL-DW seems most appropriate for routine clinical settings, while the original SEIQOL is more suitable for an indepth exploration of QOL.

Therapy Impact Questionnaire

The Therapy Impact Questionnaire (TIQ) is a 36-item questionnaire assessing both disease and therapy impact, and divided into four dimensions – physical symptoms, functional status, emotional and cognitive domains and social interaction.[67]

The questionnaire has been validated in Italy in a population with advanced cancer. To our knowledge the questionnaire is not extensively used outside Italy.

McGill Quality of Life Questionnaire

The McGill Quality of Life Questionnaire (MQOL) is a 17-item questionnaire derived from patient interviews, literature review and existing instruments.[68,69] The instrument consists of five distinct subscales, physical wellbeing, physical symptoms, psychological symptoms, existential wellbeing and support (or relationships).[21,70]

The questionnaire was validated in a multicentre study with patients recruited from palliative care services and later in a combined population consisting of oncology outpatients and palliative care services.[71]

The Missoula – vitas quality of life index

The subjective experience of an individual living with the interpersonal, psychological and existential or spiritual challenges accompanying advanced diseases was used as the basic definition when this instrument was developed, focusing on the terminal phase of life.[22] The instrument is composed of 25 items and has been validated in a hospice setting. It covers five domains: symptoms, function, interpersonal, wellbeing and spirituality. Most questions are of a global nature, including the assessment of symptoms. The instrument seems most suitable for use in the planning of care and probably in quality control. The validity of the questionnaire needs to be explored in more detail.

The Life Evaluation Questionnaire

The Life Evaluation Questionnaire (LEQ) is a 45-item questionnaire developed to evaluate aspects of life that are relevant to patients with incurable cancer and that are not measured by established questionnaires.[72] The content is based upon indepth interviews with patients and carers. The instrument consists of five main domains: freedom versus restrictions, appreciation of life, contentment, resentment and social interaction.

McMaster Quality of Life Scale

The McMaster Quality of Life Scale (MQLS) was developed to assess QOL from the palliative care patients' perspective.[73] It is a 32-item questionnaire measuring physical, emotional, social and spiritual domains. Each domain is subdivided into scales with low (0.09) to moderately high (0.79) internal consistency. A parallel form is used for family and staff ratings. The inter-rater reliability was satisfactory within the patient population, while the agreement between patient and family ($r = 0.64$) and patient and staff ($r = 0.50$) was moderate.

HRQOL during end-of-life care or for the dying

Research on QOL for the dying patient is sparse and is probably related to several factors, such as a lack of focus on dying patients and the dying process in general.

There are several methodological challenges related to HRQOL assessment in the dying, including the rapid change in most biological processes and loss of cognition, which is highly relevant to the ability to collect subjective data. In most palliative care programmes the aim is to support the family to care for the dying at home as well as providing specialist professional care. Consequently, the team is caring for the patient in a family network. These points have led assessment tool developers to recommend that outcomes should be patient focused and family centred, clinically meaningful, administratively manageable and psychometrically sound.[74]

In summary, it appears that this kind of patient-focused assessment is very similar to the strategy developed for assessing patients at earlier stages of disease, which has focused on symptom control and how to relieve patient burden. During end-of-life care, spiritual and existential issues need to be addressed, as well as family members' perception of quality of care.

Family satisfaction, HRQOL, grief and other domains may be used as an outcome of quality of death. A variety of instruments have been used in the published studies to examine different aspects and models of care,[75–78] although no consensus on content nor on type of instruments has been achieved. In several studies, a general high level of satisfaction with care has been observed and only minor differences between various palliative care programmes, which may indicate a poor ability of the existing instruments to discriminate between groups when measuring satisfaction with care and HRQOL.[79–84]

The complexity, length and content of most HRQOL instruments seem inappropriate for use during the dying process. To our knowledge there is no single instrument widely used for this purpose, but simple numerical rating scales (NRS) have been developed. The Edmonton Symptom Assessment Schedule (ESAS) is a short 10-item instrument[85] and has been used extensively in several scientific reports by the Edmonton Group.[86] Other symptom assessment schedules are also used, such as the Memorial Symptom Assessment Scale – Short Form (MSAS-SF).

Some aspects of analysis and interpretation of data

Clinical significance

What is the clinical relevance of a summary score on a single item when comparing groups of patients or individuals? This is one basic question to ask both in daily clinical practice, in interpreting clinical research and in sample size calculation in the planning process of a clinical trial. The clinical significance is related to the importance of the symptoms or the sign.

In pain assessment, a numerical rating scale ranging from 0 to 10 is often used as a simple unidimensional outcome. When discussing the clinical significance of a pain score, two important questions need to be answered. What score indicates a need for some intervention? What is the minimum improvement on a pain measure, say on a

0–10 scale, in a randomized trial, comparing two different pain medications, which is of clinical importance?

Change in any clinical variable, independent of the nature of the variable, i.e., physiological (blood pressure), psychological (anxiety), performance (physical ability) and so on, needs to be interpreted in a clinical framework. It is not a statistical question whether a change of 20 on a scale from 0 to 100 is of clinical significance. In order to be able to make a valid judgement on the magnitude of a measure in order to regard it as 'clinically significant', the clinician needs at least to understand the nature of the measure, including insight into the content of the composite score, the clinical meaning of the measure and how it relates to individual patients.

Multidimensionality

The strength of the HRQOL concept is its multidimensionality, however during analysis and in the interpretation of the outcomes, the multidimensionality is a challenge. Based upon a careful clinical consideration, it is recommended that the primary outcomes are identified, i.e., the domains of most importance, before the study is launched. Outcomes should to be limited to two or three, and the remaining data from the HRQOL questionnaire must be considered as additional information, and should not be used as an indicator for change of practice.

The lack of a common metric between scales within the same instrument is also a problem. How much this phenomenon also influences the size of what is a clinically significant change in the instrument is still an unresolved question.

In a recent systematic review of HRQOL in palliative care, no clear pattern was found in how various researchers address the issue of clinical significance.[87] In some reports, a group mean change of 10 on a 0–100 scale has been proposed as a clinically significant difference.[88] Others have said that half a standard deviation is a clinically significant difference, which is close to 10 on a 0–100 scale.

Final comments

Most HRQOL instruments are developed for use in research and may not be suited for use in daily clinical practice. However, in the future one may expect to have instruments which are computer based and well suited for use in both the clinic and in research. In the meantime, a reasonable strategy is to choose one of the commonly used HRQOL instruments for use in research. The content of the questionnaire needs to be investigated to ensure that it fits the research questions addressed in each specific project.

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