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The EORTC approach to quality of life (QL) assessment: An update

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The EORTC QLSG has pursued a modular approach to the development of QL measures throughout the 1990's. The core instrument, the EORTC QLQ-C30 (currently version 3.0), developed by this Group has proved a reliable, valid and cross-culturally applicable means of assessing the QL of cancer patients in a variety of settings worldwide. The instrument is now available in 33 languages and there is a library of documentation (scoring manual, reference values, translation guidelines, guidelines for assessing QL in clinical trials) to support its use in international clinical trials. 14 supplementary modules are available or in development (according to standard procedures) to address disease- and/or treatment specific issues insufficiently covered by the QLQ-C30. A computerised item bank has been developed to facilitate the process of instrument development. The QLSG is increasingly focusing on issues arising from the implementation of QL measures both by training others in how to design and conduct QL studies in their clinical trials and itself undertaking projects to address methodological questions in the analysis and interpretation of QL data. QLSG also supports the work of individual members e.g. in using QL assessment in routine practice and is collaborating with others in the development of alternative strategies for QL assessment for the future.

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Abstract not received.

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Quality of life issues in the palliative care setting

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Palliative care is complex and involves a broad spectrum of health services, treatment and other types of interventions. It is stated that palliative care is the active total care of patients whose disease is not responsive to curative or life prolonging treatment. In palliative medicine it is important to focus on symptom control, patient and family support and optimal organisation of the health care system.

In most clinical trials in palliative care, methodological problems have been experienced related to patient recruitment, assessment of subjective phenomena at decreased sample size ad subsequent assessment points, primarily due to early death after study entry or patient impairment due to progressive disease.

Cognition and physical deterioration may effect patients' ability to carry out self-assessment of health related quality of life (HRQOL). There is no consensus on how to measure HRQOL in this patient population, neither how to measure such a common symptom as pain. Within the field of palliative care criticism has been raised against the content of the cancer specific HRQOL instruments. The main criticism has been that these instruments are lacking indicators of the spiritual domain.

A future strategy might be to combine the cancer specific quality of life instruments, such as the EORTC QLQ-C30 with new scales or modules specifically developed for palliative care.

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Assessing quality of life in clinical practice in oncology

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During the past several decades major strides have been made in developing brief, multi-dimensional, self-report questionnaires for assessing the health-related quality of life (HRQL) of patients with cancer. To date, these questionnaires have been used primarily in clinical research settings e.g., (descriptive epideiomologic studies, clinical trials, etc.). More recently, interest has been expressed in incorporating such HRQL assessments in daily clinical oncology practice.

Particularly in the palliative treatment setting, health care providers need to be well-informed about the range of physical, functional and psychosocial problems confronting their patients. The available literature suggests, however, that physicians vary widely in their ability to elicit relevant information from their patients, and that patients vary in their ability to articulate their problems and concerns. The time constraints operating in the typical outpatient care setting represent an additional structural barrier to optimal doctor-patient communication. Routine assessment of patients' HRQL may increase the likelihood that relevant, patient-centered issues are both discussed and acted upon during medical consultations.

In this paper we will present the preliminary results of a randomized, controlled study (N = 200) of the value of standardized HRQL assessments (the EORTC QLQ-C30) in outpatient palliative chemotherapy treatment settings, in terms of: (1) facilitating doctor-patient communication; (2) increasing physicians' awareness of their patients' physical and psychosocial health problems; (3) increasing both patients' and physicians' satisfaction with their medical encounters; and (5) improving patients' HRQL over time.

Additionally, recent trends in the field of health status and quality of life assessment, including the use of touch-screen technology and computer-adaptive testing, will be discussed briefly as they relate to the incorporation of HRQL measures in daily clinical oncology practice.

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Health-related quality of life assessment – Priorities for the 21st century

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The assessment of health-related quality-of-life (HRQL) as part of randomized, controlled trials (RCTs) in oncology is becoming common in Europe and North America. In most current RCTs HRQL is still a secondary outcome, but as interest in measuring the effects of palliative treatments expands, it is gaining importance as a primary outcome.

Now that measuring HRQL in clinical trials is established, HRQL measurement also needs to move into routine clinical practice. Better questionnaires (higher internal consistency and responsiveness) of known sensitivity and specificity, using individualized approaches (e.g., based on item response theory) and modern technology (laptop or palm computers with touch-sensitive screens) are already either available or being developed.

Statistically significant changes are insufficient, by themselves, to completely evaluate the importance of changes in HRQL over time or of differences between groups. We also need to ascertain the magnitude of changes in HRQL scores that have subjective and clinical meaning and are of relevance to patients and clinicians.

New and simple methods for analyzing data with missing information must continue to be explored. Utility-measurement and psychometrically-based camps of thought should seek and find common ground.

It is now time for the science and application of HRQL measurement in medicine to be taught in medical schools.

These priorities are important if health care practitioners wish to place the same value on quality of survival as on length of survival.

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Contemporary methodological issues in quality of life assessment

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The methodology of quality of life (QL) assessment is developing rapidly. In the last decade, patient self-assessment questionnaires have been developed, tested, and refined. The validity and reliability of these instruments have been investigated in detail. It is clearly demonstrated that is possible to measure the impact of cancer and cancer treatment on the patient's wellbeing in a scientifically acceptable way, that it is feasible to collect QL data in clinical trials, and to use these data as end-points in trials. This presentation will discuss current issues related to instrument development and to the analysis and interpretation of QL data in clinical trials. Concerning instrument development, the EORTC QL Study Group has established detailed procedures ensuring that new QL questionnaire modules are of high quality. In the coming years this approach is likely to be supplemented with alternative ways of using items across questionnaire and modules.

A problem frequently encountered in the analysis of longitudinal QL data is that – due to the fact that many different aspects of QL were measured repeatedly – there is a problem of multiple hypothesis testing. To some extent this can be prevented by specifying a limited number of analyses in the research protocol. In some cases, data from health care professionals can be used to identify additional 'post hoc hypotheses' which can be tested in the QL data. Examples of this will be given.