

Quality of life:

what does it mean for general practice?

There is no doubt that maintenance or improvement of health-related or disease-related quality of life (QoL) is the ultimate goal of general practice. When keeping this in mind it focuses practice not only on the physical aspects of disease, but also on how patients perceive their illnesses. Defining general practice as 'comprehensive personal care'¹ implies that therapies should be balanced between evidence and patient preferences, which are influenced by their present and anticipated future QoL. This is especially relevant in treating chronic and palliative patients, when shared decisions should be made about surgery, medication and pain relief, withholding of treatment, and even some forms of euthanasia.

In the last few decades many studies have examined the concept of QoL and methods to gain a clear view of this aspect of history-taking. Symptoms only partially reflect the perceived burden of the disease. Ferrans² showed that in patients with cancer, QoL instruments provide additional information about side effects and the impact on other aspects of life that cannot be captured by measures targeted at key symptoms.

There is a considerable discrepancy between patients' assessment of their own health and their doctor's judgement.^{3,4,5,6} So it is vital for GPs to ask questions about the commonly distinguished QoL domains of physical, mental, social, and psychological consequences of disease. Instruments to overcome bias in the perceptions of healthcare providers might be helpful in determining QoL. The content, the phrasing, and ways of administering of the instruments is the subject of many studies validating generic or disease-specific instruments. Generic instruments (such as the SF-36,⁷ EQ-5D,⁸ SF-6D,⁹ WHOQOL-100,¹⁰ Sickness Impact Profile,¹¹ Nottingham Health Profile,¹² and the COOP/WONCA¹³ charts) and disease-specific instruments have to meet criteria

for validity, reliability, sensitivity to change, and applicability.¹⁴

Recent reviews have emphasised the difficulties of choosing between the large number of QoL instruments available. For instance, one study on QoL instruments for children and adolescents found 30 generic and 64 disease-specific instruments.¹⁵ Great efforts have been made to cross-validate QoL instruments for various diseases, nationalities, cultures, and target populations.

Often researchers are advised to use a generic as well as a disease-specific instrument to cover all methodological criteria. But for integration in daily practice the key issue is measuring QoL in a way that provides relevant information for patients' and practitioners' decision-making; focuses the practitioners' attention on the patients' concerns; and is easy to administer during routine care. Major questions to ask are whether we can use these instruments in clinical practice and for (economic) decisions in the area of public health.

In the present issue of the *BJGP* two studies are published from the Respiratory Research Group in Manchester.^{16,17} Both studies are based on postal surveys carried out in the registered population of two general practices. The surveys included the EQ-5D: a generic QoL instrument covering the five dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, from which an index score is calculated. In the first study¹⁶ a cross-sectional analysis showed how comorbidity affects the EQ-5D index. In the second study¹⁷ the changes in the EQ-5D scores were calculated for patients who had three consecutive measurements over a 5-year period. The researchers found that QoL decreases with increasing numbers of chronic conditions, and that in a cohort of about 2500 participants the quality of life declined significantly over 5 years after adjusting for age, education level and duration, sex, and smoking behaviour.

Although the studies were performed 5 years ago and were locally restricted, these results may have implications for clinical practice and public health in general.

The various QoL measures can be used for research purposes, economic decision making, and for decision making in clinical practice, but need to be tailored to these goals.¹⁵

In clinical practice QoL measures are currently used for needs assessment and monitoring purposes. Chronic disease management systems, with the aim of delivering systematic multidisciplinary care that is also targeted at individual needs, often incorporate disease-specific instruments to assess needs and/or to monitor changes in perceived disease consequences.

Older patients are often included in several disease management systems because they have more than one chronic condition. They often have to complete several QoL instruments thus increasing the 'load of care' for themselves and the burden for the health professionals. The use of one generic instrument, like the EQ-5D which shows a decrease in QoL with an increase in number of diseases, may reduce this load. This presents a dilemma, as generic instruments provide less information on the perceived effects of particular conditions than disease-specific ones, and specific instruments are more responsive to changes in disease conditions than the corresponding domains of generic instruments.¹⁸

For clinical practice, QoL measures should be easily incorporated into the daily routine. Different ways of administering tests (interview or questionnaire, by telephone or computer, the frequency and time intervals of administering) affect patient scores, as does the type of questioning. To illustrate how type of questioning can have an impact patient scores, a study on patients with HIV1 infection showed that they

evaluated their QoL significantly worse when the questioning was retrospective compared to prospective, and that the retrospective scores showed better associations with change in clinical indicators than the prospective questioning.¹⁶

QoL instruments are also needed as outcome indicators to calculate quality-adjusted life years and cost-effectiveness of therapy and care-delivery interventions. The study by Hazell *et al* showed¹⁷ an autonomous decrease in QoL over a 5-year period, indicating the difficulty of taking a point of reference. Questions arise around the validity of health-related QoL measures; for example, which cultural and economic influences interfere with health related QoL? These questions around validity and reliability gain prominence when QoL measurements are used as patient outcome parameters in quality assessment and pay-for-performance systems.

Although much focus is put on hard clinical outcome measures like reducing blood pressure or HbA1c, it is understandable that those responsible for public finances and for safe and effective health care are looking for measures related to the ultimate goal of care. But a rule of thumb should be that performance indicators are related to those aspects of care delivery that can be controlled and changed by healthcare professionals.¹⁹ It is a challenge for research and practice to find ways and instruments to base quality assessments on how patients evaluate their quality of life related to the care that they received.

A key issue for general practice is taking into account patients' needs and preferences and the context of the patient. Health professionals' views often differ from patients' perceptions. GPs differ in their routine questioning. The systematic incorporation of QoL measures in

consultations may be helpful to get a clearer picture of how patients perceive their health-related QoL and its course.

QoL measures can also be helpful as a stimulus for practice improvement when used as patient outcomes in quality assessment procedures. The use of QoL measures as indicators in pay-for-performance systems is unlikely in the near future; still, it is a challenge for research and clinical practice to find ways to increase patient centredness by using QoL instruments in general practice.

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Provenance

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