

clinical governance is to transform the culture and service delivery of NHS organisations throughout the United Kingdom. This revolution has begun.

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## Measuring quality of life

### Who should measure quality of life?

Julia Addington-Hall, Lalit Kalra

One of the reasons behind the rapid development of quality of life measures in health care has been the growing recognition of the importance of understanding the impact of healthcare interventions on patients' lives rather than just on their bodies. This is particularly important for patients with chronic, disabling, or life threatening diseases who live without the expectation of cure and have conditions that are likely to have an impact on their physical, psychological, and social wellbeing.

Health professionals frequently make quality of life judgments when making decisions about the care of disabled patients,<sup>1</sup> and the professional's view on expected quality of life is often the key factor in determining whether effective treatment for a life threatening condition will be given or withdrawn.<sup>2</sup> Professionals' perceptions may, however, be at odds with those held by their patients.<sup>3</sup> It is therefore important to ask patients to assess their own quality of life using one of a growing number of reliable and valid measures.

Choosing an appropriate measure and using it in clinical practice can be problematic.<sup>4</sup> Deciding to use a measure, however, presupposes that patients are able to assess their own quality of life and complete a quality of life measure. Some patients—and in some conditions many patients—are unable to do this because of cognitive impairments, communication deficits, severe distress caused by their symptoms, or because the quality of life measure is too burdensome physically or emotionally.<sup>5</sup> These may be precisely the patients for whom information on quality of life is most needed to inform clinical decision making. Rather than lose all information on that patient, someone else (a family member or health professional) may be asked to act as a proxy or surrogate.

In this paper the use of proxies to measure quality of life is addressed. We consider the advantages and dis-

#### Summary points

Some patients cannot complete quality of life measures because they have cognitive impairments, communication deficits, are in severe distress, or because the measures are too burdensome

It is precisely these patients for whom information on quality of life is most needed to inform decision making

Proxies—both healthcare professionals and lay caregivers—can provide useful information particularly on the more concrete, observable aspects of quality of life

Scores from proxies may be influenced by their own feelings about and experiences of caring for the patient

When a clinician's assessment of quality of life is at odds with that of the patient, the patient should have the final word

advantages of using proxies to rate quality of life, debate the reasons why a proxy's view and a patient's view may differ, and suggest directions for future research.

#### Can proxies provide useful information on quality of life?

Quality of life tools measure subjective experience. Completing a quality of life measure on behalf of someone else requires proxies to put themselves in another person's shoes, to imagine what it feels like to

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be them, and to speculate about the impact of their health and health care on their experience of life. Proxies are often good at this. There is usually moderate agreement between individual patients and their proxies, although lower levels of agreement may be reported for psychosocial functioning.<sup>5-6</sup> For example, 41% of ratings made by patients with cancer on seven domains measuring quality of life on a five point scale (physical fitness, feelings, daily and social activities, overall health, pain, and overall quality of life) agreed exactly with those of their significant other (usually a spouse), doctor, and nurse; ratings were within one point for 43% of comparisons, and only 17% of comparisons identified more profound discrepancies.<sup>7</sup>

Proxies are almost as good as patients in detecting changes in some quality of life domains over time.<sup>8</sup> As a group, proxies tend to rate a patient's quality of life as

more impaired than the patient.<sup>5</sup> This depends, however, both on the domain and on the type of proxy. Nurses<sup>6</sup> and lay caregivers<sup>9</sup> are particularly likely to overestimate patients' depression, anxiety, and distress, and a number of studies have shown that doctors consistently underestimate the severity of symptoms.<sup>10-11</sup> Although ratings by proxies and patients do not agree exactly, there seems to be sufficient agreement between their assessments of quality of life to make the information that proxies provide useful when the patient cannot be asked directly.<sup>6</sup>

A number of factors have been identified that affect the degree of agreement between patients and proxies. These are reviewed in the box. Although characteristics of both the patient and the proxy can affect agreement, they have small effects. For example, in a study comparing scores on the quality of life questionnaire of the European Organisation for Research and Treatment into Cancer (EORTC QLQ-30) from cancer patients and their proxies, characteristics of the patient and proxy accounted for less than 15% of the variance between them.<sup>5</sup> This suggests that the important determinants of agreement between the ratings of a proxy and a patient have yet to be identified. Although more research is needed, it is more likely that random errors in the ratings of both patients and their proxies account for most of the difference between the two—for example, from a lack of precision in the tools used and situational factors such as mood.

### Determinants of quality of life scores

Understanding the determinants of individuals' assessments of their quality of life may help clarify why the scores of proxies and patients differ. There is no direct correspondence between objective functioning and an

#### Factors affecting agreement in quality of life assessments

##### General factors

Agreement depends on the concreteness, visibility, and importance of the aspects of quality of life under consideration.<sup>6</sup> Agreement is better for concrete, observable aspects and less good for more subjective domains, such as emotional health

Agreement may improve over time, but evidence is contradictory<sup>10</sup>

##### Factors related to the patient

Patients may not complete quality of life measures in ways that accurately reflect their feelings. For example, patients may seek to answer questions in ways that present themselves favourably. This may be related to findings of lesser agreement between patients and proxies<sup>4</sup>

Proxies have a better chance of accurately reflecting quality of life if patients are open with them about their problems and feelings<sup>5</sup>

Agreement between patients and proxies seems to be greater when quality of life is either very good or very poor<sup>5</sup>

##### Factors related to the proxy

The lay caregivers' experience of caring, the amount of time they spend with the patient, and their own distress may influence their assessment of the patient's quality of life.

Lower quality of life scores have been associated with increases in the burden on the caregiver,<sup>24-25</sup> time spent together,<sup>26</sup> and the carer's distress,<sup>15</sup> and with the carer having a lower quality of life<sup>5</sup>

Extent of agreement may be influenced by the relationship between the patient and proxy, although the evidence for this is limited<sup>5</sup>

Health professionals may project their own feelings of hopelessness and distress on to the patient when assessing their quality of life<sup>27-28</sup>

The psychometric properties of the measure are important: if the measure is unreliable, then high agreement cannot be expected<sup>5</sup>

individual's quality of life nor between the perceptions of patients and healthy people, professionals, or others with similar disabilities.<sup>12 13 14</sup> Patients may rate their quality of life highly despite obvious problems or may show significant improvement in scores that do not correlate with objective measures of disease or physical function.

Clinicians may find it difficult to accept patients' ratings of quality of life. This can be an important issue when working with patients with severe disabilities or with those who are dying because clinicians may hold expectations about quality of life that are not supported by patients' assessments. For example, it is often presumed that dying is a time of great suffering and severe problems<sup>15</sup> and that quality of life scores will therefore decline as death approaches. Indeed, in a study comparing quality of life measures in patients with advanced cancer it was argued that the fact that one measure identified greater deterioration over time than another meant that it was more sensitive.<sup>16</sup>

### Functional status

The functional status of patients with cancer declines as death approaches and is a good prognostic indicator.<sup>17</sup> Scores on other quality of life domains in patients with cancer are neither necessarily lower than in other people nor do they necessarily deteriorate. In one study, patients in hospice had lower scores than apparently healthy adults on two quality of life domains (psychophysiological wellbeing and functional wellbeing) but not on a third (social and spiritual wellbeing).<sup>18</sup> The implications of this "disability paradox" for comparative measurement of quality of life, using methods such as quality adjusted life years, was discussed in the second paper in this series.<sup>4</sup>

### Changes in priorities

Patients' priorities may change at the end of life. It has been argued that existential, spiritual, and social issues become more important.<sup>19</sup> In a study using an individualised quality of life measure—the schedule for the evaluation of individualised quality of life (SEIQoL)—in patients with advanced, incurable cancer, patients almost universally rated concerns about their family as more important than health in determining quality of life.<sup>20</sup> Of a possible score of 100, the median global quality of life score was 61, challenging the belief that terminally ill patients invariably have a poor quality of life.

It has been argued that the changes in quality of life that occur in chronic and life threatening illnesses result in part from patients adapting to the situation in which they find themselves (box).<sup>21</sup> Patients change their internal standards, values, or conceptualisation of quality of life and therefore assess it differently than they would have if they had not adapted to their situation. This phenomenon of internal adaptation is called "response shift" and may explain the apparently paradoxical quality of life scores obtained from these patients. A reverse response shift is shown by the finding that patients awaiting a kidney transplant had a mean rating of quality of life of 5.23 on a 10 point scale; this rose to 7 after transplantation.<sup>22</sup> However, when at 5 months, 12 months, and 18 months after transplantation these patients were asked to rate what their quality of life had been before surgery the mean retrospective scores were 3.27, 3.14, and 3.05,

### Future research

New research should focus on

- Investigating those characteristics of the patient, proxy, and measure that affect the degree of agreement between them
- Discovering the ways in which proxies' own experiences of caring for the patient (or similar patients) influence their judgment of the patient's quality of life
- Determining how expectations and adaptation influence individuals' assessments of their quality of life
- Developing theoretical models that further our understanding of the assessment of quality of life. Sprangers and Schwartz's model of determinants of change in assessment, incorporating the phenomenon of response shift, is a good example of an attempt to explain findings rather than just describe them.<sup>21</sup> This model needs further testing

respectively. Before transplantation these patients had successfully adapted to their condition, and thus had rated their quality of life more highly than when they later re-evaluated it from the vantage point of improved health after the operation. Proxies tend to rate patients' quality of life as being worse than patients. Response shift may account for this.

Response shift has received little attention until recently, but it has important implications for measuring changes in quality of life. Having a greater understanding of how patients' and proxies' evaluations change over time could help explain why their ratings do not always agree and might help us more meaningfully interpret changes in scores. Some of the problems posed by response shift in measuring changes in quality of life were highlighted in the first paper in this series.<sup>23</sup>

### Implications for the future

Quality of life measures are designed to enable patients' perspectives on the impact of health and healthcare interventions on their lives to be assessed and taken into account in clinical decision making and research. Some patients are unable to complete these measures as a result of cognitive impairments, commu-

### Determinants of changes in self assessment of quality of life<sup>21</sup>

According to a theoretical model developed by Sprangers and Schwartz,<sup>21</sup> changes may result from an interaction between

- A catalyst, such as a change in health status
- Antecedents—that is, stable characteristics or the individual's disposition, for example personality traits
- Mechanisms—that is, behavioural, cognitive, and affective processes that accommodate changes in health status, for example comparing oneself to others, adjusting goals, adopting different routines, and
- Response shift—that is, "changes in the meaning of one's evaluation of quality of life resulting from changes in internal standards, values, or conceptualisation"<sup>21</sup>

nication deficits, severe distress, or because the measures are too burdensome. It is precisely these patients, however, for whom information on quality of life is most needed to inform decision making. The evidence on using proxies suggests that both healthcare professionals and lay caregivers can provide useful information, particularly on more concrete, observable aspects of quality of life. Proxies' scores may be influenced by their own feelings about and experiences of caring for the patient, and the extent to which patients normally talk about their feelings to their proxies seems important. It is likely that agreement will be greater when reliable measures are used, although this has not been empirically tested. Further research is needed to fully understand how the characteristics of the patient, proxy, and measure influence agreement. In particular, greater understanding is needed of how expectations and adaptation influence patients' assessment of their quality of life. In the meantime, clinicians would do well to remember that when their assessment of quality of life is at odds with that of the patient, it is the patient who should have the final word.

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## An urgent fax

Recently, four faxes arrived in my office within 24 hours asking for urgent psychiatric community assessments. They all told separate stories of human misery and asked for emergency psychiatric consultations. It was clearly impossible to see all the patients immediately as I was the only senior psychiatrist covering the team. I therefore tried to call the referring doctors in order to prioritise the patients but could locate only one.

A fax is easy to send. Firstly, you dictate a letter (an illegible scrawl will also do). Then, you give it to your secretary. End of story. Or is it?

A fax is equally difficult to receive. It may get lost or submerged by other papers in an in-tray. It may go to the wrong number, with the risk of confidential material going astray (the police headquarters, social services, or estranged husband come to mind). When safely filed away in the notes, the fax will then slowly fade, making it a useless long term record. A posted copy is therefore essential.

Sending a fax is no guarantee that the recipient will act. There is no dialogue or communication. There is no sharing of clinical information. There is no discussion of safety. There is often no

mention of how to locate the patient or what to do if they are out (keep ringing up or visiting until the urgency has passed is one tactic to ensure exhaustion). The letter may not mention whether the referral has been discussed with the patient. Worse, there is no agreement over who has clinical responsibility for the patient.

I may be a technological dinosaur, but I have never got into the habit of using the fax to refer patients. I prefer to pick up the telephone instead. I remember the bulk of my clinical teaching at medical school, as a house officer, and as a psychiatric trainee was geared at presenting a patient to a tutor or colleague. This is a high order skill, perfected after years of training, presumably for the purpose of distilling the salient points of history and examination and communicating them to other colleagues. To communicate in emergencies by fax negates all these skills. Perhaps clinical exams should be replaced with essays that are faxed to the examiners after the patient is assessed.

I am seriously considering throwing the fax machine out of the window. No, better still, I will fix it to work for outgoing calls only.

Robert Chaplin *consultant psychiatrist, London*