

lesson: after all it is a mistake that any junior doctor is at risk of making.

A critical incident review would have shared this knowledge with others and enabled those involved to take part in a full and frank discussion about what had happened.³ The danger in the senior consultant's approach is that the message may have been, "When things go wrong, falsify medical records" rather than "When things go wrong, deal with an error in as open a manner as the situation allows." A proper internal

review would also ensure that when things do go wrong changes are made to systems to minimise the risk of the mistake being repeated. This would go some distance towards ensuring that lessons are learnt from medical errors.

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Measuring quality of life

Is quality of life determined by expectations or experience?

Alison J Carr, Barry Gibson, Peter G Robinson

This is the first in a series of five articles

Academic
Rheumatology,
University of
Nottingham,
Nottingham City
Hospital,
Nottingham
NG5 1PB

Alison J Carr
*ARC senior lecturer
in epidemiology*

Guy's, King's
College, and St
Thomas's Hospitals
School of Medicine
and Dentistry,
London SE1 9RT
Barry Gibson
lecturer in sociology

Guy's, King's
College, and St
Thomas's Hospitals
School of Medicine
and Dentistry,
London SE5 9RW
Peter G Robinson
*senior lecturer in
dental public health*

Correspondence to:
A J Carr
alison.carr@
nottingham.ac.uk

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Carr, I J Higginson,
P G Robinson

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The way we think about health and health care is changing. The two factors driving this change are the recognition of the importance of the social consequences of disease and the acknowledgement that medical interventions aim to increase the length and quality of survival. For these reasons, the quality, effectiveness, and efficiency of health care are often evaluated by their impact on a patient's "quality of life."

There is no consensus on the definition of quality of life as it is affected by health (health related quality of life). Definitions range from those with a holistic emphasis on the social, emotional, and physical well-being of patients after treatment¹ to those that describe the impact of a person's health on his or her ability to lead a fulfilling life.² This article assumes it to be those aspects of an individual's subjective experience that relate both directly and indirectly to health, disease, disability, and impairment. The central concern of this paper is the tendency to regard the quality of life as a constant. We contend that perceptions of health and its meaning vary between individuals and within an individual over time. People assess their health related quality of life by comparing their expectations with their experience. We propose a model of the relation between expectations and experience and use it to illustrate problems in measuring quality of life. The implications of these concepts for the use of quality of life as an indicator of the need for treatment and as an outcome of care are discussed.

Definitions and determinants of quality of life

Measures of the quality of life summarise the judgments people make to describe their experiences of health and illness. This is what distinguishes them from measures of disability that ask about an ability to complete specific tasks, such as climbing stairs or dressing oneself. Quality of life is a broader concept and is concerned with whether disease or impairment limits a person's ability to fulfil a normal role (for example, whether the inability to climb stairs limits a person at work). However, the measures do not consider how people arrive at these judgments. Understanding the mechanisms through which health, illness, and healthcare interventions influence the quality of life (that is, understanding the deter-

Summary points

Health related quality of life is the gap between our expectations of health and our experience of it

Perception of quality of life varies between individuals and is dynamic within them

People with different expectations will report that they have a different quality of life even when they have the same clinical condition

People whose health has changed may report the same level of quality of life when measures are repeated

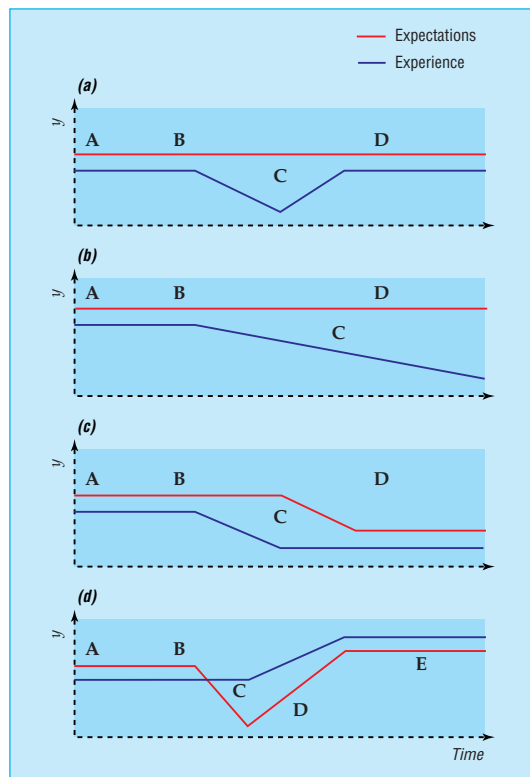
Current measures do not take account of expectations and cannot distinguish between changes in the experience of disease and changes in expectations of health

minants of quality of life) may highlight ways in which it can be maximised.

A primary aim of treatment, particularly in chronic disease, is to enhance the quality of life by reducing the impact of the disease. Yet patients with severe disease do not necessarily report having a poor quality of life.³ Therefore the relation between symptoms and quality of life is neither simple nor direct. Considering quality of life as the discrepancy between our expectations and our experience provides a way of explaining how we evaluate it.⁴

Expectations, experience, and quality of life

Our everyday lives are complex. When we are asked about them we need ways to simplify our thoughts to provide answers. We do this by using sets of stable assumptions (expectations) to inform our observations. A haematologist uses reference values in the same way. Patients with back pain, for example, may expect that consulting a doctor will solve their problem. Patients have expectations about how they



Four models of back pain occurring in a 35 year old woman at different times (A-E). In the figure (a) shows an acute episode; (b) shows a chronic episode; (c) shows her acceptance of a chronic condition; and (d) shows different effects of expectations and experience over time

will be treated, the amount of pain they will have, and how effective their treatment will be.

A model of quality of life

In the figure (a) shows a model of an acute episode of back pain occurring in a 35 year old woman over time (A-D). It represents the relation between her expectations and her experience of her quality of life. When expectations are matched by current experience, there is no quantifiable impact on quality of life (period A, before the onset of symptoms). Whenever the experience of health falls short of expectations (after the onset of symptoms at point B) there is an impact (period C). The model shows a number of possible trajectories in illness (a-d). During a chronic episode of back pain (b) the woman may believe that at her age she should have no pain. Because her expectations remain unchanged she may have difficulties at work and in relationships with family and friends. She may also feel depressed and anxious. Thus the gap between expectations and experience persists during period C.

In (c) her initial expectation that her pain will resolve is replaced by her acceptance that she will have to function within the constraints of her illness. Thus the discrepancy in period C is reduced when she revises her expectations, and in period D homeostasis is re-established.

In (d) the woman has had back pain with functional limitations for two years, but her expectations match her experience (period A) because she has adapted to the change in her health. If she is then referred to a pain management programme but has low expectations of its efficacy, and two weeks into the programme

feels that she is better able to control her pain and feels positive about her future, her experience is better than her expectations (period C). If she then revises her expectations in the light of her experiences (period D) homeostasis is reached at a higher level than before she attended the programme (period E).

The model illustrates how the impact of an illness may resolve as the experience of health returns to its original level, how illness may persist with continued disappointment, or how a patient may be pleasantly surprised by the effectiveness of treatment. Most measures of quality of life detect the negative impact of disease or treatment on a patient's quality of life (period C, a-c).

Implications for measuring quality of life

The model illustrates three problems with measuring health related quality of life: people have different expectations; people may be at different points on their illness trajectory when their quality of life is measured; and the reference value of their expectation may change over time.

The first problem occurs because expectations are learnt from experiences and therefore are highly specific. They vary between individuals and are subject to differences in social, psychological, socioeconomic, demographic, and other cultural factors. Expectations about quality of life are closely related to people's relationships with their environment. This may lead to structural variations in evaluations of the impact on quality of life. For example, older people have described the need to adapt to their changing circumstances as a means of successfully coping with ageing.⁵

These variations in evaluating the impact of the disease or treatment on a person's quality of life can be incorporated into the model on the y axis and would be represented by something that classified people on the basis of their expectations and experiences, such as health needs. People's evaluations of their quality of life are made within horizons of possibilities that they see for themselves and therefore are a fundamental component of their identity. These horizons are determined by factors such as social class, age, sex, ethnic group, sexuality, disability, and personal biography.

Existing measures of quality of life do not account for expectations of health: they do not incorporate the boundaries within which levels of expectation and experience are measured. The result is that someone with an experience of poor health who has low expectations might not evaluate the experience as having an impact on their quality of life because their expectations are correspondingly low. Conversely someone who generally has good health might experience a significant impact on their quality of life from a relatively minor illness, such as tonsillitis, because they have high expectations of their health. This problem may have profound implications if measurements of quality of life are to be used to prioritise and plan services, as has been proposed in dentistry.^{6,7}

The second problem highlighted by the model is that the magnitude of the impact depends on when the measurement is made. With existing measures it is impossible to ascertain at what point on the individual's disease trajectory the measurement has been made. Moreover, responses to illness are highly individual: there is no standardised pattern followed by

all patients. This means that even in a clinical trial where quality of life might be measured at equal intervals (and after the same duration of treatment) for all patients, they may still be at different points on their disease trajectories, for example at points A, C, or D in the model.

The third problem arises because experiences constantly change expectations: people constantly move towards an ever changing point of equilibrium. Psychological, sociological, and health services research all provide evidence that quality of life is a dynamic construct. The mechanisms by which people evaluate or quantify their quality of life change over time and in response to many factors.⁸⁻¹³ The result is an inherent instability in its meaning.

This problem of “response shift” (the idea that the terms of reference by which quality of life is judged change over time) is compounded if repeated measures are made, such as when an intervention is evaluated. For example, in *c* in the figure if the woman's quality of life were measured during period A and again during D using existing measures, no change would be detected. This is because the period during which the impact occurred and her expectations changed has been missed. Therefore someone may have experienced an impact on their quality of life (period C) and, although they have adapted to the change in their health by altering their expectations, they may still be considered to have a poorer quality of life during period D than before their illness (period A). Specific examples of response shifts in chronic disease are discussed in a later paper in this series.¹⁴

The model helps to understand how healthcare interventions may improve health related quality of life



Perception of quality of life varies between individuals

Later papers in this series will evaluate the clinical utility of quality of life measures, whether these measures are patient centred, who should measure the quality of life, and whether there is such a thing as a life not worth living

and may allow us to increase the effect of treatment on it. In the traditional model of health care, interventions restore impairments so that the experience of health returns to the level of original expectations.

Adaptation

The impact of chronic disease on patients' quality of life can be minimised by helping them adjust their expectations and adapt to their changed clinical status. This approach has already been adopted in many healthcare strategies, including some psychological interventions, self management programmes, and patients' education groups. For example, one aim of assistive technology is to allow people to continue in their normal roles and meet their expectations of life despite their physical impairment and disability. Devices such as dentures and guide dogs help people bridge the gap between what they want to do and what their physical health allows them to do.

Expectations of treatment

Expectations are learnt from experience. If previous episodes of back pain have settled after two days of sleeping on the floor, an individual will expect that a new episode will resolve in the same way. Likewise, experiencing ineffective interventions may generate the expectation that new interventions will also be ineffective. These observations can be used to enhance the efficacy of treatment. Significant success has been achieved in generating a response to both active and placebo interventions by changing negative expectations or creating positive expectations of treatment and health services.¹⁵⁻¹⁹

Conversely, unmet expectations are likely to result in dissatisfaction. Dissatisfied patients are more likely to experience a poor outcome by not adhering to treatment regimens, by not attending follow up appointments, and because their symptoms respond less well to treatment.^{20 21}

Implications for health promotion

Helping people adapt to irreversible changes in their health may be beneficial, but what should be done for those people whose expectations of health are unrealistically low? Health promotion is the process of helping people to take control over and improve their own health. Changing people's expectations of health is the core of health promotion. Some people's experiences cause them to have low expectations of their health; they then tolerate significant levels of disease and disability. It is possible for patients to achieve the level of autonomy necessary to engage in health promotion activities only if they are aware of the possibilities. Raising expectations of health is therefore an essential part of the “critical consciousness” of improving community health. In the drive to improve health, health promotion might increase the expectations of people with poor health and seemingly reduce their quality of life. Reflecting on aspects of reality is part of the process of empowerment

and provides the force that allows people to take action to change that reality.²²

Implications for the future

The model discussed here uses Calman's definition of quality of life as being the gap between expectations and experience.⁴ It takes account of the fact that people see different possibilities for themselves when they evaluate different factors that have an impact on their quality of life. Applying this model highlights some of the limitations of current methods of measuring quality of life in terms of their ability to assess accurately the impact of illness or treatment and to quantify and understand changes in the evaluation of an impact over time. Further work is required to test the model, but the implications for measuring quality of life are that existing measures need considerable modification, that new measures need to be developed, and that the role of expectations and experience in evaluations of quality of life need to be analysed.

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Don't say the W word

Having been admitted to hospital with a deep vein thrombosis and pulmonary embolism for the second time in a couple of years, I was feeling a little discouraged about my immediate future. One thing that started to bother me was the realisation that I had made no will: I had the idea that for me to die intestate would cause all sorts of horrible complications for my wife.

So, trying to find a practical solution to what seemed to me to be a worrying problem, I jotted down what sounded like a reasonable, basic will in the back of a paperback book and asked the patient in the next bed to witness it. (Apparently just one witness signature is not enough, so my will would not have worked anyway, but I did not know this at the time.) I then mentioned it to the nurse who was looking after me—what I had done and where it was. When my wife came in to see me I told her about it and asked her to take the book home just in case. From both of these people I got a certain amount of the inevitable “Come off it, Neville, you won't be needing that,” which was kind, but I felt vaguely that I had done the right thing.

A few hours later the worst very nearly came to the worst. I collapsed, was resuscitated, struggled for a bit, and was moved to the intensive care unit and then to another hospital. During the noise and bustle of the immediate post-resuscitation phase, while I was still on the ward, I was a little surprised to hear someone say, in slightly coded language, “This might be a good time to find out what he did with that document, you know, the one about his wishes.”

I thought, “Blimey, it'll keep won't it,” but through a bit of a haze I said quite loudly, “It's OK, it's gone home.” There was a pause then: “Do you remember what you put in there?” I grumpily replied, “No, not really, just the usual stuff.” Was this some sort of intelligence test, I wondered—how could this possibly be relevant now?

A couple of months later I found out. I was making the usual round of tracking people down with wine and chocolates, thanking the crash team who had attended me, and so on. One of the people I ran to earth for a chat was the nice chest senior registrar who had looked after me on admission and who had broken the increasingly bad news as it developed. After a while, we got onto the subject of my will, and he laughed and said, “Did you hear what a fuss that caused?” Baffled, I asked him what he meant. It turns out that the crash team, on arrival at the ward, had been told that I had written a living will and apparently did not want to be resuscitated. They couldn't now find the document, but it was believed that that was what was in it.

Fortunately, this piece of news had been met with complete disbelief by the crash team. The doctor leading it later told me he thought it was nonsense, in a 38 year old man with three children and previous general good health, and even if he had seen it himself he would have ignored it, treating it as little more than a suicide attempt, and only worrying about the consequences later. He felt strongly that it was not even worth discussing for a moment. I'm grateful for this. I'm also grateful that no one decided to be a bit of a patients' rights radical and give it a few extra minutes before calling the crash team, just to make sure that poor old Neville got the dignified exit he wanted.

I have toyed with having “Please DO resuscitate” tattooed across my chest just in case.

The last word came from the senior registrar. Wagging a finger in my face, he said solemnly, “Let this be a lesson to you. Never, never mention the word ‘will’ in a hospital again.” So I haven't.

Neville Young *database manager, Wolfson Institute for Preventive Medicine, St Bartholomew's and the Royal London Hospital School of Medicine and Dentistry, London*