



Quality of Life as an Innovative Health Technology

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KEY FINDINGS

Between about 1975 and 1995 'quality of life' (QoL) emerged as the most important measure of success in clinical practice. This process has been studied through an analysis of the main QoL literature over the last few decades. From virtually no reference to QoL in the early 1970s, papers, letters and editorials are now accumulating in Medline, the main international medical database, at the rate of over 5,000 new references per annum.

- The origins of QoL measurement do not lie in an empirical search for better ways by which to capture it but in various political solutions advanced to address social 'problems' that appeared after WWII
- QoL measurement evolved through a number of stages over a period of about 20 years. This process can be characterised as having advocacy, promotional, acceptance and questioning phases.
- The standard QoL instrument was basically constructed from four contemporary questionnaire-based measures of aspects of health covering symptom checklists, physical function (Activities of Daily Living), mental health function and social function
- In the mid 1990s new 'reflexive' items were introduced into quality of life instruments that asked about the meaning of the symptom for the patient as well as about its presence.
- The emergence of QoL in the last two decades of the 20th century disturbed the long association between pathology and symptoms. Now, symptoms (and harm to functioning that is implied by the presence of symptoms) can be used to indicate both the presence of disease and/or a state of QoL
- The measurement of QoL needs to change as the underlying construct must reflect (changing) social views of the 'good life' but it is held back by the success of past measures and the need to ensure comparability of measurement procedures especially for longitudinal studies.

RESEARCH TEAM

Dr David Armstrong and Dr Jane Ogden, King's College London

Prof Simon Wessely, Department of Psychiatry, Institute of Psychiatry

Prof Richard Lilford, Dep of Epidemiology and Public Health, University of Birmingham

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What is Quality of Life?

Until about 30 years ago health care interventions were evaluated according to 'biomedical' criteria. The most salient was mortality: did the intervention decrease the number of deaths amongst patients with the specified condition? Other biological measures such as reduction in blood pressure in hypertension or increase in haemoglobin in anaemia were used to indicate that treatments 'worked'. But then, in the mid 1970s a new outcome measure emerged that apparently celebrated the patient's perspective over the doctor's. This new indicator of medical success was called 'quality of life' (hereafter, QoL). It provided an answer to an increasing medical conundrum that often the biomedical outcome indicators showed success but the patient seemed little improved. This problem seemed particularly relevant for the new 'heroic' technologies, such as renal dialysis and organ transplantation, in which the success of survival seemed a mixed blessing for patients who seemed often to suffer more misery from the intervention than from the underlying disease. From the mid 1970s QoL measurement grew to become, arguably, the most important indicator of medical outcome in the opening years of the 21st century. The concept of QoL now dominates formal health care evaluations.

Yet while QoL has taken such a central place in medicine and health care over the last few decades the nature of QoL is less clear. What is 'quality of life'? And how can it be operationalised in formal instruments? The existence of over 800 different QoL instruments attests to the diversity and fruitfulness of the concept but also its contested nature. The purpose of this project was to explore this central 'technology' of modern medicine how it came into existence, how it manifested itself, and how it affected health care, an innovative health technology so important that it dominates so much of contemporary medical research and practice yet at the same time so elusive that its exact nature and definition remain unclear.

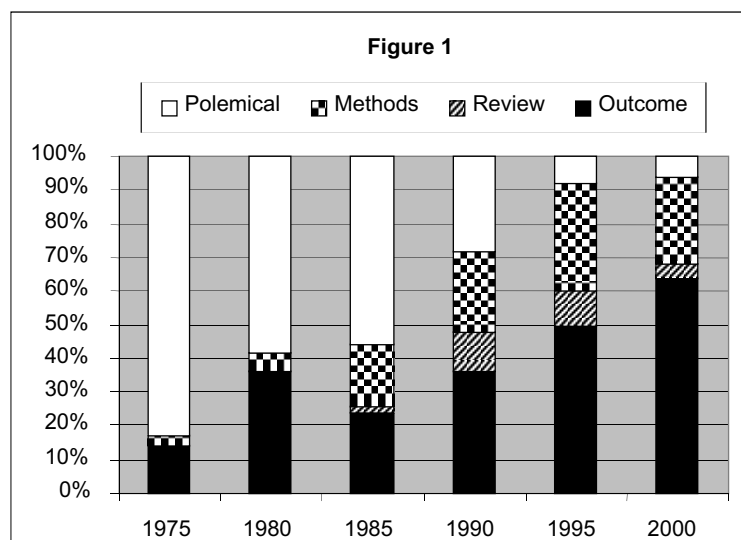
Origins of QoL Instruments

Analysis of the earliest discussions of QoL identified three main sources for the interest in the concept. One was the general idea that

QoL could be used to mediate between those who believed that recent times were characterised by social progress and those who believed they were characterised by social crisis. The second source was the parallel medical debate about the personal costs of new and often heroic medical technologies. Treatments such as renal dialysis often seemed to save lives but only at considerable cost to the patient in terms of the quality of their life. Third, the growing problem of chronic disease burden and the rising number of elderly, particularly in residential homes, meant that new more sensitive indicators of therapeutic success were needed beyond the traditional measures of lives saved or lives extended. These three factors acted as the initial engine for QoL measurement and justified the subsequent attempts to operationalise this socially vital concept.

How Instruments Develop

The process of developing QoL measures was also studied through the types of papers that gave it voice and form. Papers were broadly classified into four categories: Outcome or Empirical papers that reported QoL assessments of particular groups of patients; Review papers that collated and analysed the empirical data from previous papers reporting outcome data; Methodological papers that were concerned with further development of measurement procedures; and finally, Polemical papers that did not clearly fit any of the above three categories. The latter, as will be shown, were much more important in the early years. The distribution of papers according to this classification is shown below



During the 1970s the main focus was on 'advocacy' as polemical papers promoted the value of the concept and its use in practice and research. The 1980s and early 1990s then marked a period of development and consolidation of many instruments. The contemporary QoL literature was therefore characterised by methodological accounts of the development and testing of new measures together with their deployment in the evaluation of health care interventions. Finally, the period since the mid 1990s has involved a more confident use of QoL instruments together with the beginnings of 'head-to-head' comparisons of instruments in this proliferating field.

The Construction of QoL Instruments

A study of the 'internal structure' of QoL instruments revealed their precursors in mental health measures, symptom checklists, and physical function inventories (so-called Activities of Daily Living ADLs). To these were added explicit recognition of social function (which was often seen as a simple extension of physical function). Between about 1980 and 1995 the new generic QoL instruments appeared embodying these four key dimensions even though many expressed these underlying structures in different terms and, of course, usually used their own distinct range of individual items.

In the mid 1990s a new reflexivity emerged in the measurement of QoL. This manifested itself in the appearance of 'personalised' instruments in which individual patients were invited to construct their own measures of QoL through identifying and scoring their own choice of dimensions (taking the form of 'What areas of life are important to you?', 'Which of these are most important to you?' and 'How would you rate each at the moment?'). Reflexivity also appeared in the more traditional formal instruments as they began asking about the personal implications of symptoms as well as their existence (for example, adding to the question: 'Do you have impaired mobility?' the supplementary

enquiry: 'Does it bother you?'). Finally, a further component of this reflexive turn is the discovery over the last decade that QoL is not only influenced by illness (thereby making them useful means of assessing illness severity) but also by prior expectations. The latter anchorage places the concept of QoL more firmly in the social world.

Stabilising Instruments

Because QoL instruments attempt to capture the patient's world they can never be 'stabilised': as criteria of the good life change so what is meant to be a 'good quality life' changes. This instability is particularly important for the 'instrument industry'. Inevitably there have been suggestions that some instruments are better than others and that focusing on only a few will aid cross study comparisons; indeed, some instruments have already become virtual standards. But if, say the SF-36 becomes established as a market leader the fact that it was created in 1992 (before the reflexive turn) means that its vision of QoL is fixed in time (very few instruments go into newer versions, precisely because they lose the claim to stability). In effect the hand of the past weighs more heavily on QoL measurement than other less mutable medical outcome measures such as mortality or biomedical/laboratory measures.

The Transformation of Symptoms

The foregoing observation on the development and evolution of QoL into so many areas of clinical practice can also be read as part of a more fundamental shift in the logic and nature of very late 20th century clinical work. Whereas for two centuries symptoms (in the form of patients' experience/reports) were held to derive from an underlying pathological lesion within the body (and in a reciprocal gesture allow the diagnosis of that lesion), QoL extended symptoms from their immediate bodily manifestations to their 'downstream' implications for physical, mental and social function (and, as with the lesion, enabled calculation of QoL by aggregation of these various measurements of function).

The recent 'discovery' that QoL is affected by prior patient expectations as much as by the illness has further challenged the historical link between symptoms and pathology. The new medical framework emphasises improvement in QoL (and its attendant 'distal' symptoms) rather than simply treatment of the underlying pathology (that might, at best, relieve proximal symptoms). Ironically, although it is difficult to 'stabilise' the measurement procedures surrounding QoL, the concept has been increasingly stabilised within a reconfigured medical framework that makes QoL the new medical goal. In this sense QoL has been both a restraining and transformative technology.

In summary, QoL represents a new emphasis on the patient's voice in place of the traditional dominance of the voice of biomedicine. But QoL also begins to usurp at both a conceptual and practical level, the centrality of pathology in medicine. The task of medicine had been the treatment of pathology to relieve symptoms; now it has the joint goal of improving QoL both by improving extended symptoms and by improving QoL. And given the recent shifts towards a conceptualisation of QoL based on the personal, on reflexivity, and on expectations, QoL changes the very purpose of medical activity.

Conclusion

This research project has mapped the emergence of QoL over the last few decades as a major new outcome for clinical practice and research. In part it has been an illustration of how innovative technologies emerge: the conceptual phase in which the idea gains acceptance, the development phase in which instruments are developed, the empirical phase when they are used and evaluated on different populations, and the consolidation phase when

their value and use is further crystallized. In part, however, this project also provides an account of a revolutionary new medical technology that is not only instrumentally applied by medicine but comes to change the very nature of clinical practice itself.

About the Project

The project used both quantitative and qualitative analysis of published evaluative studies that have used QoL measures (and related instruments such as subjective health measures). Medical databases provide a readily accessible and comprehensive coverage of published medical research over the last three or four decades (which encompasses the period during which QoL has been used in technology evaluation)

The data base was used to classify studies that use QoL measures. The classification included year of publication, the diseases/medical problems addressed, the type of technology being evaluated, the country in which the research was carried out, citation impact scores, etc. This enabled the spread of QoL measures to be mapped. Further, through study of accompanying articles and editorials that promote QoL measurement the history of the struggle to achieve legitimacy for this new way of evaluating success can be better understood.

Copies of QoL instruments used in these studies were subjected to an analysis to identify the underlying structure of the instruments together with their content items. Changes in these features of QoL measure design provide an overview of changing ways in which quality of life has been realised over the last three decades as well as enabling these to be related to their deployment in the field of biomedical technology assessment.

For further information contact:

Professor Andrew Webster, IHT Programme Director

Department of Sociology, University of York, Heslington, York YO10 5DD

Tel: +44 1904 43 3064/4740 ♦ Fax: +44 1904 43 4702/3043 ♦ E-mail: iht@york.ac.uk

Web site: <http://www.york.ac.uk/res/iht/>