Quality of life measurement: bibliographic study of patient assessed health outcome measures

Andrew Garratt, Louise Schmidt, Anne Mackintosh, Ray Fitzpatrick

ELPS

The full version of this article appears on bmj.com

Abstract

Objectives To assess the growth of quality of life measures and to examine the availability of measures across specialties.

Design Systematic searches of electronic databases to identify developmental and evaluative work relating to health outcome measures assessed by patients.

Main outcome measures Types of measures: disease or population specific, dimension specific, generic, individualised, and utility. Specialties in which measures have been developed and evaluated.

Results 3921 reports that described the development and evaluation of patient assessed measures met the inclusion criteria. Of those that were classifiable, 1819 (46%) were disease or population specific, 865 (22%) were generic, 690 (18%) were dimension specific, 409 (10%) were utility, and 62 (1%) were individualised measures. During 1990-9 the number of new reports of development and evaluation rose from 144 to 650 per year. Reports of disease specific measures rose exponentially. Over 30% of evaluations were in cancer, rheumatology and musculoskeletal disorders, and older people's health. The generic measures—SF-36, sickness impact profile, and Nottingham health profile—accounted for 612 (16%) reports.

Conclusions In some specialties there are numerous measures of quality of life and little standardisation. Primary research through the concurrent evaluation of measures and secondary research through structured reviews of measures are prerequisites for standardisation. Recommendations for the selection of patient assessed measures of health outcome are needed.

Introduction

Clinical trials and similar forms of evaluative study should incorporate the patient's perspective of outcome.[1] For complete assessment of the benefits of an intervention it is essential to provide evidence of the impact on the patient in terms of health status and health related quality of life. These terms refer to experiences of illness such as pain, fatigue, and disability and also broader aspects of the individual's physical, emotional, and social wellbeing.[2 3] Unlike conventional medical indicators, these broader impacts of illness and treatment need, wherever possible, to be assessed and reported by the patient.

Several reviews have criticised researchers for their failure to use appropriate measures of health related quality of life in evaluations purporting to address the impact of interventions by assessing outcomes of concern to patients.[3–7] We undertook an extensive review to describe the extent to which patient assessed outcome measures have been developed and applied and examined whether such instruments are available for all aspects of clinical research.

Methods

Search strategy—We retrieved reports relating to the development and evaluation of patient assessed measures. We based our search terms on terminology applicable to the development and evaluation of patient assessed health outcomes and terminology used in structured reviews.[3 8] We searched the following from their inception to 2000: AMED, Biological Abstracts, British Nursing Index, Cinahl, Econlit, Embase, Medline, PAIS International, PsycInfo, Royal College of Nursing database, Sigle, and Sociological Abstracts.

Assessment of reports—The inclusion criteria comprised the development and testing of patient assessed measures including aspects of health status and quality of life, summary items, and symptoms. We excluded reports that related solely to the use of measures. We assessed the reports for the different types of measure (box) and specialties using a classification based on that used in a review of quality of life measures within randomised clinical trials, supplementing where necessary.[2]

Results

Search strategy

After we removed duplicates the initial download from the electronic databases produced 23 042 records. Of these, 3921 (17%) met the inclusion criteria and reported on the development and testing of patient assessed measures of health outcome. The 3921 reports cited 1275 identifiable measures. The number of reports increased from 144 new records in 1990 to 650 in 1999 (figure). At the time of our search the databases were incomplete for 2000.

There was considerable overlap between the types of measure because a large number report the concur-

National Centre for Health Outcomes Development, Unit of Health-Care Epidemiology, Institute of Health Sciences, University of Oxford, Oxford OX3 7LF

Andrew Garratt
research officer

Louise Schmidt
research officer

Anne Mackintosh
database manager

Department of Public Health, Institute of Health Sciences, University of Oxford, Oxford OX3 7LF

Ray Fitzpatrick
professor

Correspondence to:
A Garratt
andrew.garratt@uhce.ox.ac.uk

BMJ 2002;324:1417–9

Types of measure

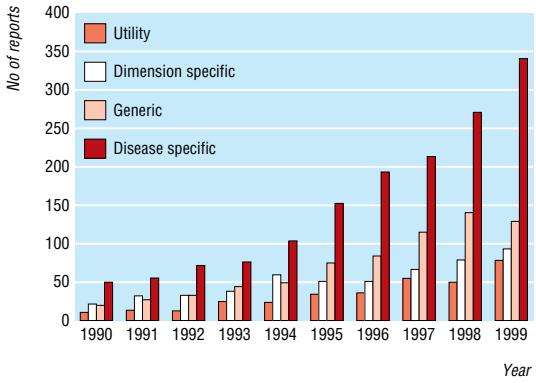
Dimension specific measures focus on particular aspects of health such as psychological wellbeing and usually produce a single score—for example, Beck depression inventory[9]

Disease or population specific measures include aspects of health that are relevant to particular health problems and may measure several health domains—for example, asthma quality of life questionnaire[10]

Generic measures can be used across different patient populations; they usually measure several health domains—for example, SF-36[11]

Individualised measures allow respondents to include and weight the importance of aspects of their own life; they usually sum to produce a single score—for example, patient generated index[12]

Utility measures have been developed for economic evaluation, incorporate preferences for health states, and produce a single index—for example, EuroQol EQ-5D[13]



Number of reports for four main types of measure by year

rent validation of measures. Most (1819) reported the development and evaluation of measures specific for a disease or population; 865 reported generic measures; 690 reported dimension specific measures; 409 reported utility measures; and 62 reported individualised measures (see bmj.com).

The largest number of evaluations were for rheumatology and musculoskeletal medicine, cancer, and older people; these three accounted for 31% of the 3921 reports. Mental health, neurological diseases, paediatrics-child health, and respiratory diseases were the only other specialties that accounted for more than 5% of records each. There were also a large number of reports (6%) for generic and utility measures that have been evaluated within general populations (for more detail see bmj.com).

The arthritis impact measurement scales,[14] health assessment questionnaire,[15] and European Organisation for Research into the Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30)[16] were the three disease specific measures reported most frequently (table). However it was the generic measures, including the SF-36,[11] sickness impact profile,[17] and Nottingham health profile[18] that had undergone the largest number of evaluations. These three measures accounted for 16% of the total number of reports; they have been evaluated across numerous patient populations and have been translated into several languages. Population norms are also widely available for these measures. Of the utility measures, the EuroQol[13] and health utilities index[19] have undergone the largest number of evaluations.

Discussion

The application of patient assessed measures of health outcome has become increasingly important to evaluation of health care.[1] We have shown considerable growth in the production of measures to support this trend. Growth has not been consistent across specialties or health problems and has been concentrated around the development of measures specific for diseases or populations.

Selection of measures

The different types of measure are all potentially useful for evaluating health outcomes from the perspective of the individual patient, and there are now multiple measures available within these individual categories. Those wishing to select a measure for a specific application face quite a daunting task. Although there is some evidence for the standardisation of generic measures with a few measures achieving widespread application, this is not the case for disease specific measures. For many patient populations there are several specific measures. It is perhaps not surprising that there is evidence of a lack of consistency in the selection of measures for clinical trials which hinders comparisons between studies.[2] In a study of 67 clinical trials, 48 were found to use 62 different existing measures and 13 reported new measures.[2]

The selection of measures can be informed through primary research that compares measures against recommended criteria,[3] recommendations

Most widely evaluated measures within 3921 reports

Instrument	No of records
SF-36	408
Sickness impact profile	111
Nottingham health profile	93
EORTC QLQ-C30	82
QALY	79
EuroQol	77
Health assessment questionnaire	62
Arthritis impact measurement scales	59
Quality of wellbeing scale	53
General health questionnaire	43
Health utilities index	41
COOP charts	33
Functional assessment of cancer	32
WHOQOL	24
Healthy years equivalent	24
Beck depression inventory	23
Asthma quality of life questionnaire	21
McGill pain questionnaire	19
WOMAC	18
Hospital anxiety and depression scale	18
Duke health profile	17
SF-12	15
Psychological general wellbeing index	15
St George's respiratory disease questionnaire	15
MOS-HIV	14
Rotterdam symptom check list	14

based on expert consensus, and structured reviews that assess the evidence for different measures. The concurrent evaluation of measures within primary research typically involves the comparative evaluation of reliability, validity, and responsiveness. Recommendations have been produced for the use of patient assessed measures in rheumatoid arthritis and back pain.[20 21] Our search strategy identified 314 reviews of instruments. The quality of the reviews was variable with just 47 using the words comprehensive, structured, or systematic within the title or abstract. Most reviews compared measures for reliability, validity, and responsiveness to change. However several other important considerations relating to the selection of patient assessed measures have been described,[3 22] the most pertinent being the relevance of the content of a measure to the proposed application.

Conclusions

The huge growth in the number of patient assessed measures of health outcome has obvious benefits in terms of the availability of measures for specific populations. However, potential users require guidance particularly when faced with multiple measures. Structured reviews together with recommendations based on patient and professional consensus are required for the effective application of measures. Concurrent evaluation can also help to determine the most suitable measure for a particular application. Finally, researchers should undertake comprehensive literature searches to ascertain whether a suitable measure is available before they decide to develop a new one.

We thank Elizabeth Oram and Monique Raats, who helped with data management and literature searches.

Contributors: See bmj.com

Funding: AG, AM, and LS are funded by the Department of Health as part of its funding of the National Centre for Health Outcomes Development. The views expressed in this paper are those of the authors and not necessarily those of the Department of Health.

Competing interests: None declared.

1 Fitzpatrick R, Davey C, Buxton M, Jones DR. Criteria for assessing patient based outcome measures for use in clinical trials. In: Stevens A, Abrams K, Brazier J, Fitzpatrick R, Lilford R, eds. *The advanced handbook of methods in evidence based healthcare*. London: Sage, 2001:181-94.
2 Sanders C, Egger M, Donovan J, Tallon D, Frankel S. Reporting on quality of life in randomised controlled trials: bibliographic study. *BMJ* 1998;317:1191-4.
3 Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess* 1998;2:1-74.
4 Hayes JA, Black NA, Jenkinson C, Young JD, Rowan KM, Daly K, et al. Outcome measures for adult critical care: a systematic review. *Health Technol Assess* 2000;4:1-111.
5 Baker GA, Hesdon B, Marson AG. Quality of life and behavioral outcome measures in randomized controlled trials of antiepileptic drugs: a systematic review of methodology and reporting standards. *Epilepsia* 2000;41:1357-63.
6 Stewart A, Cummins C, Gold L, Jordan R, Phillips W. The effectiveness of the levonorgestrel-releasing intrauterine system in menorrhagia: a systematic review. *Br J Obstet Gynaecol* 2001;108:74-86.
7 Duncan PW, Jorgensen HS, Wade DT. Outcome measures in acute stroke trials: a systematic review and some recommendations to improve practice. *Stroke* 2000;31:1429-38.
8 Garratt AM, Schmidt L, Fitzpatrick R. Patient-assessed health outcome measures for diabetes: a structured review. *Diabet Med* 2002;19:1-11.
9 Beck A, Ward C, Medelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;4:561-71.
10 Juniper EF, Guyatt GH, Ferrie PJ, Griffith LE. Measuring quality of life in asthma. *Am Rev Respir Dis* 1993;147:832-8.
11 Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. conceptual framework and item selection. *Med Care* 1992;30:473-83.
12 Ruta DA, Garratt AM, Russell IT. Patient centred assessment of quality of life for patients with four common conditions. *Qual Health Care* 1999;8:22-9.
13 EuroQol Group. EuroQol—a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199-208.
14 Meenan RF, Mason JH, Anderson JJ, Guccione AA, Kazis LE. AIMS2. The content and properties of a revised and expanded arthritis impact measurement scales health status questionnaire. *Arthritis Rheum* 1992;35:1-10.
15 Fries JF, Spitz PW, Young DY. The dimensions of health outcomes: the health assessment questionnaire, disability and pain scales. *J Rhuematol* 1982;9:789-93.
16 Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365-76.
17 Bergner M, Bobbitt RA, Carter WB, Gilson BS. The sickness impact profile: development and final revision of a health status measure. *Med Care* 1981;19:787-805.
18 Hunt SM, McEwen J, McKenna SP. Measuring health status: a new tool for clinicians and epidemiologists. *J R Coll Gen Pract* 1985;35:185-8.
19 Feeny D, Furlong W, Boyle M, Torrance GW. Multi-attribute health status classification systems. Health utilities index. *Pharmacoeconomics* 1995;7:490-502.
20 Fried BJ, Boers M, Baker PR. A method for achieving consensus on rheumatoid arthritis outcome measures: the OMERACT conference process. *J Rheumatol* 1993;20:548-51.
21 Bombardier C. Outcome assessments in the evaluation of treatment of spinal disorders. *Spine* 2000;25:3097-9.
22 Higginson IJ, Carr AJ. Measuring quality of life: using quality of life measures in the clinical setting. *BMJ* 2001;322:1297-300.

(Accepted 9 January 2002)

What is already known on this topic

Quality of life measures are increasingly used for measuring health outcomes in evaluative research

There is little standardisation in the use of such measures within clinical trials

What this study adds

There has been exponential growth in reports relating to the development and evaluation of quality of life measures

The number of reports varies considerably according to the health problem

One hundred years ago

How to be happy though a doctor

There are those who when asked to select the most eligible, satisfactory, and enjoyable position in the whole range of medical practice have chosen the life of a country doctor in what the advertising agents call "a pleasant neighbourhood." He must, of course, occupy a first-rate position; his emoluments must be sufficient to enable him to live in a good house, to hold his own in entertaining and in general social life, to educate his children fashionably and well, and to take a sufficient holiday every year in Scotland or in some accredited health resort. Under those circumstances, if he steers clear of politics and does not trouble himself too much with local affairs, his lines will be cast in pleasant places. If he is a sportsman and a good shot he will find his place at the cover side or on the river bank, and if golf flings its seductive spell over him, he will never be without the chance of joining a good team for a foursome. Far happier is his lot on the average than that of the London consultant, who may fail outright, or drop out of the course on the way to the goal, or when success is attained, can only hold his own in the face of the strenuous competition of modern times by equally strenuous exertion. (*BMJ* 1902;i:1371)