Review article

Quality of life assessment in children: a review of conceptual and methodological issues in multidimensional health status measures

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Abstract

Study objective – To clarify concepts and methodological problems in existing multidimensional health status measures for children.

Design – Thematic review of instruments found by computerised and manual searches, 1979-95.

Subjects – Nine health status instruments.

Main results – Many instruments did not satisfy criteria of being child centred or family focussed; few had sufficient psychometric properties for research or clinical use; underlying conceptual assumptions were rarely explicit.

Conclusions – Quality of life measures should be viewed cautiously. Interdisciplinary discussion is required, as well as discussion with children and parents, to establish constructs that are truly useful.

(J Epidemiol Community Health 1996;50:391-396)

The focus on mortality and morbidity as outcomes in health is being steadily superseded by broader considerations of quality of life. Since Karnofsky's trials of cancer chemotherapy¹ and the World Health Organization (WHO) definition of health in 1958 - 'a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity'² - the traditional clinical agenda has been changing to accommodate economic and consumer concerns.³

The 1989 Convention on the Rights of the Child stressed the child's right to adequate circumstances for physical, mental, spiritual, moral, and social development.⁴ Moreover, a child has the right to express his or her opinion freely, and have that opinion taken into account, and has a special place in the caring, protective, responsibility of his family. This view of health and wellbeing is especially apposite to the multidisciplinary approach to child health services in many parts of the world.

The possible applications of quality of life measures span public health research and everyday clinical practice - audit, clinical trials, outcome evaluation, economic analyses, surveys of populations and subgroups - and have been summarised recently.⁵ Quality of life

measures are very new in paediatrics but it is probable that their use will become commoner in view of the proportion of children who already have special needs,⁶ chronic illness, attend hospital, or are in the care of a statutory authority. This paper aims to present a thematic review of the published reports in order, firstly, to clarify concepts of health, childhood, and disability in existing instruments, secondly, to outline methodological problems in measurement, and, thirdly, to encourage informed discussion in the choice and use of outcome measures in child health.

There is some confusion with regard to common terminology. Subtle differences distinguish quality of life and health related quality of life. The former term is the concept most attuned to the WHO definition, broadly encompassing all the spheres of human existence. Health related quality of life refers only to those dimensions which can be affected by health service intervention. Health status, health function, and health attribute are broadly synonymous.

Guyatt has proposed a taxonomy for instruments based on their scope and applicability.⁷ Specific instruments focus on a single condition, disease, function, or population. Generic instruments, such as health profiles and utility measures, cover a broad range of function, disability, and distress and are intended for use in a wide range of conditions. Health profiles are single instruments that measure different aspects of quality of life, using a single psychometric approach and sharing a common scoring system. These scores can be aggregated into a small number of scores or a single score referred to as an index. Many such indices assign a value, derived from statistical theory, for a health state scaled to lie on a continuum from zero (death) to one (perfect health).

Method

DATA COLLECTION

Terms that seemed useful for a computer search using Medline, Embase, and SciSearch were used for the period 1979-95. Articles were retrieved on the basis of their title and abstract. In the articles found, cited references with appropriate titles were retrieved, and text-

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Accepted for publication
February 1996

Table 1 Child quality of life instruments

Authors	Age group (y)	Dimensions	Publication
Eisen and Ware ¹²	0-4; 5-13	Physical, mental, general, satisfaction with development	1979
Stein and Jessop ²⁵	0-16	Communication, mobility, mood, energy, sleeping, eating, toileting	1990
Lewis and Pantell ¹⁶	0-16	—	1989
Feeny ¹⁴	—	Sensation, mobility, emotion, cognition, self care, pain fertility	1992
Schmidt ¹⁸	7-27	Productive activity and functioning, health status and treatment related physical symptoms, qualitative aspects of daily life	1993
Lindstrom ¹¹	2-18	External-socioeconomic conditions; inter-personal-social networks; personal-activity, self esteem, mood	1993
Starfield ¹⁰	11-17	Activity, comfort, satisfaction with health, disorders, achievement, resilience	1993
Austin ¹⁷	—	Physical, psychological, social, school	1994
Graham ¹⁵	10-14	Activities, appearance, communication, continence, depression, discomfort, eating, family, friends, mobility, school, sight, self care, sleep, worry	1995

books were also screened for useful references. Finally, some references were obtained after correspondence with authors in the field.

EVALUATIVE CRITERIA

Instruments were assessed using four conceptual criteria:

- They had to be *child centred*, related to development or age, relevant to children’s experiences, and asking children for their opinions;
- They had to consider the child as part of a *family unit within a social network*;
- They had to be *generalisable*; and
- The *assumptions* underlying the instrument had to be appropriate.

The five methodological properties examined were *method of administration, psychometric characteristics, scoring, statistical issues, and practicality*.

Instruments

Several hundred articles were found on this subject but most did not mention quality of life in the specific context of measurement. Searching the published reports on this subject is difficult in Europe and it is likely that some eligible studies were missed. Some references were difficult to locate as they were not published in peer reviewed journals but as reports for health insurance companies and state governments in North America. There were many disease specific instruments, for example for asthma, allergic rhinitis, epilepsy, arthritis, and cystic fibrosis etc. Only one relevant article was located by computer search. Only two papers came from Europe, probably reflecting differences in health care financing priorities.

Many behavioural scales exist in the psychological reports for assessing aspects of child functioning⁸⁻⁹ and distress, and some of which, for example self percept scales for teenagers, ask the child’s opinion. Most, however, do not detail physical function.

Most quality of life instruments use a simple functional concept of health, a list of activities grouped in physical, psychological, and social domains, as in published reports that consider adults. There are alternative constructs, Starfield, for example, integrates these components into six domains; activity, comfort, satisfaction with health, disorders, achievement, and resilience, based on the conviction that mind and body are inseparable and that biological, social,

and environmental correlates of health are inextricably interrelated.¹⁰ Lindstrom includes three life spheres in his model: *external*, describing social, economic, and housing conditions from the child’s viewpoint; *interpersonal*, describing the structure and function of social networks surrounding the child; and *personal*, describing activity, self esteem and the basic mood of the child.¹¹

In the present survey, there were five broad groups of paediatric quality of life instruments, the RAND Corporation,¹² functional status FS-II(R),¹³ utility group,¹⁴ Nordic,¹¹ and WHO-associated.¹⁵ One shorter instrument had origins in both the RAND and FS-II(R) instruments.¹⁵ One instrument was specifically developed for adolescents,¹⁰ one was a collection of several existing scales,¹⁶ and a further one had been slightly modified to allow simultaneous use on adult and child subjects.¹⁷ In some cases instrument development had taken several years. Details of quality of life instruments are given in table 1.

The utility measures are based on a multi-attribute framework,¹⁸ modified¹⁹ and weighted to derive utility scores for different health states.²⁰ Techniques for deriving valuations for states of health have been described. These include the *standard gamble* in which probabilities are ascribed to various health states until they seem equally acceptable, and the *time trade off* in which alternative health states are valued by comparing varying amounts of time spent in these states until they seem equivalent. Volunteers for these statistical games are usually healthy adults without experience of the health states in question. For a fuller discussion of this highly controversial topic see Torrance²¹ and others.²²⁻²³

CHILD ORIENTATION

Instruments vary according to the degree to which they are oriented towards children and their experiences. The two main issues are whether to ask children directly, and how to allow for developmental level and age. Some do not ask the child for their opinion. The utility models employ clinician’s assessments, while earlier instruments¹²⁻²⁴ depend primarily on the parent, usually the mother, responding on behalf of the child; sometimes asking the mother to attribute outcomes to illnesses. In recent instruments, for example Lindstrom’s,¹¹ children from as young as 2 are involved in

reporting, and participation increases progressively with age. Austin¹⁶ involves children in the psychological and school sections, while Graham *et al*¹⁵ have a separate questionnaire for child and for parent. Starfield's questionnaire¹⁰ is exclusively for teenagers. Schmidt¹⁷ makes no allowance for either age or development, simply substituting the word 'school' for 'occupation' in the adult questionnaire. The FS-II(R)²⁴ asks about days missed from school, which is inappropriate for preschool children. Many instruments have separate questions for those under 5 and for the 6-13 year age group.

FAMILY FUNCTION AND SOCIAL RELATIONS

Family function is important. Children are not independent beings and the family comprises the supporting persons who will most affect the child's quality of life, and who are in turn affected by the child's disease and outcome. Social relations are important determinants of wellbeing in chronic disease. Interventions in the family and the child's social environment are commonplace in child health and welfare services. Most of these instruments do not enquire about the family. The two most concerned with teenagers ask how the child is getting on with the family^{10 15} and one author enquires in detail about family function and quantity and quality of social relations.¹¹

ASSUMPTIONS AND GENERALISABILITY

Perceptions of health and illness are culturally determined and accordingly may differ considerably. Further variations may occur within cultures, for example in immigrant, socioeconomic, and geographical subgroups. An instrument validated among health insurance subscribers need not necessarily be valid among non-subscribers; similarly, one validated among children with chronic asthma may not be useful for children with learning disability. An instrument validated or intended for use among disabled children might be inappropriate for use in a healthy population. This being the case, what can be called 'cultural' differences pose a challenge to the validity of an instrument.

Cultural generalisability is a difficult matter to judge – perhaps the simplest criterion is whether the instrument has been tested in a sample representative of the populations in which its use is intended. Generalisability is, of course, only an issue if a method or results are extended to a population different to that used in validation. A clinic validated instrument may be quite satisfactory if its use is restricted to audit within that clinic. Most of the North American instruments, where details were available, were tested in multicultural samples, often the urban poor. Lindstrom used a random sample of 10 290 children from five Nordic countries.

Intrinsic to the construction of the 'quality' concept are socioculturally bound assumptions about what kinds of being and doing have value. The tacit model of 'quality' betokens an obverse model of disability. The issue of validity for different cultures holds equally true for disabled people. The constructs and value

judgements of the non-disabled, and especially 'experts' may result in bias in outcome measurement. This is illustrated most dramatically in utility measures where general population weightings of health states can result in utility scores for disabled children of less than zero, that is worse than death.²¹ Most authors operationalise their models of quality as activities of daily living. Few authors explicitly define their constructs of health or quality of life for children.

Ziebland identifies four non-exclusive models in reports concerning adults.²⁵ The 'functional' model reflects a view that disability is a medical concern and emphasises functions which lie within the clinician's sphere of influence. For example, the question in the RAND instrument¹² – '*Does this child's health limit him in any way in using public transport or a bicycle?*' This question does not permit environmental constraints, such as poverty or access, to explain individual limitation. This is a fundamental issue of confounding, challenging the validity of the response obtained. Neither does this type of question identify the cost of performing the task in terms of pain or energy. Graham's instrument¹⁵ contains this latter refinement, qualifying dysfunction with upset and satisfaction on a Likert scale, in what is referred to as the 'subjective distress' model. It also contains elements of the 'comparative' model. For example in the item – '*Understanding things and making your needs known*', the scale ranges from – '*Better than any other child of the same age*' to '*Totally unable to let people know what you need*'. This can be heavily influenced by circumstance, for example a child might underestimate their ability in relation to a more impaired child in a special school. Habitual comparisons can also underestimate impairment partially overcome by circumvention, development, or time.

The 'dependence' model focuses on help used rather than help needed, for example, '*Is this child unable to walk, unless assisted by an adult or by crutches, artificial limb or brace?*'¹² There is likely to be variation in local availability of support and in the individual threshold for requesting it. Aids and appliances might be a better reflection of wealth or degree of adaptation than disability.

The emphasis in the utility models on capacity rather than performance significantly decreases the reporting of disability. Feeny refers to performance as 'the level at which the patient chooses to function'.¹⁴ This wording reflects a libertarian, individualistic world view. The view that disability is a property of an individual and can be investigated outside social and environmental contexts has come under strong criticism.^{26 27}

PRACTICAL APPLICATION

Four instruments were explicitly for clinical use,^{14 15 17} two of which had not had their psychometric properties assessed.^{14 17} Of the four remaining research instruments, one was to test clinical hypotheses,¹⁶ one was to test hypotheses about financing,¹² and two were for epidemiological and public health research.^{10 11}

METHOD OF ADMINISTRATION

One instrument was administered by a research assistant.²⁸ The utility models used structured clinicians' assessments which were then compared at a consensus meeting. Most were questionnaires for parents and/or children. Three of these were administered by telephone. One of them was expressly designed to follow up patients who had not returned for follow up.¹⁷ Telephone response carries its own types of bias, the most obvious are telephone ownership and having available time. Respondents may be less likely to discuss sensitive emotional topics over the phone and be less frank in their responses.

VALIDITY

The desirable psychometric properties of a questionnaire have been well documented.²⁹ Validity is the strength with which inferences can be drawn about subjects within (internal) or outside a study (generalisability), and is really a mark of appropriateness. The foregoing comments on conceptual issues have direct implications for validity. Nevertheless, an instrument that lacks acceptable face validity might well pass tests of construct and content validity by comparison with previously published scales and assessment by experts.

Few of these instruments were subjected to tests for validity, internal consistency, test-retest reliability, and responsiveness to change. The latter two properties are especially important if an instrument is to be used to infer real change before and after an intervention. Austin used scales from existing instruments but did not recheck psychometric properties for them in combination. Schmidt compared responses from different family members as a method of validation. Only one author tested responsiveness to change.

Pantell has identified several important sources of systematic error in measurement of health status in child subjects.²⁸ Proxies such as parents and teachers agreed fairly well in reporting on child functioning but markedly less well for recent functional status, certain types of subjective feelings in regard to illness, information needs, emotional states, and family functioning. Other issues included position bias; the tendency to choose the first answer; acquiescence response bias, the tendency to agree with the interviewer; limited understanding of negatively worded items; and differences in time perception. These may all be related to developmental age. These differences in response pattern leave open the question of whether low parent-child concordance in some areas of response is due to limitations in abstract reasoning or a true difference in perspective or opinion.

Few authors calculate the standard error around scores arising from random sampling variation. Fitzpatrick has highlighted several important basic statistical principles for the construction of rating scales, which are still the subject of debate.⁵ Most children in these reports have a quality of life score of 90 or more out of 100. Clearly some ceiling effect could be at work, and this leaves little room for

improvement in status. The same might occur in the opposite direction - a floor effect. A target outcome might be static, for example social relations might not change because of lack of intervention from health services. A treatment that merely sustains life, not improves it, leading to a static (or even declining) quality of life index may still have a benefit for the individual. This might be the case in a degenerative condition in which the deterioration in quality of life might be expected to be greater without intervention. Grades in scales may be too large for an effect to appear in either direction. Generic scales may include items that are not relevant for the group under investigation.

SCORING SYSTEM

The problems of scoring generate as much controversy as those of construct. The main choices are on whether to aggregate scores from separate domains or to keep them separate. Aggregation allows groups to be compared easily but has the disadvantage of missing contradictory trends in domains, leading to a loss of sensitivity. These instruments are equally split in their approaches to scoring. Another decision is whether equal weight should be given to each domain. If quality of life is truly subjective, should measurement not reflect the importance each individual puts on different spheres? The problem then arises on how to compare subjects. Some of these problems can be overcome by statistical techniques such as multilevel modelling.

Some have questioned whether illness should necessarily be attributed as an adverse event. Facing illness with courage can be construed by children as an experience of positive emotional development.³⁰ Similarly, others have argued that the experience of disability itself may have positive effects. Chronic disorders in childhood are often complex and can have an impact on more than one function or domain. Should having more than one functional limitation have a simple additive effect on quality of life therefore, or is some degree of synergy involved?

Discussion

Existing quality of life instruments for children clearly differ considerably in their orientation towards children. They accord different importance to family function and social relations in children's wellbeing. Interviews with children show that their concepts of health and illness are completely separate and not at opposite ends of a spectrum.¹⁰ Health in children is much more about positive attributes such as healthy behaviour and attitudes than in adult life. Health care interventions play a much smaller part in their welfare than they do for example in the elderly population.³¹ Another problem is that there is much less agreement on the normal roles and functions of children at each age, both within and between social contexts, than there is for adults.¹³

In adults, health has been conceived in terms of relative self sufficiency and productive activity. Utility models also depend on a material view of existence. In contrast, complete self

sufficiency is not expected in children and youth whereas age appropriate cognitive, psychological, social, and physical development are important considerations. Ill health may be manifested by decelerations in the rate of attainment of normal features rather than by evidence of abnormal form or function.¹⁰ It becomes difficult to determine whether failure of a child to achieve independent function is part of the normal developmental process, a result of an environment that fosters dependency, or loss of ability secondary to illness.¹³ Deviations in development may be hard to assess since normative sequences have barely been worked out for general populations of healthy children. Moreover, children with impairments may have unique developmental sequences and their life experiences may be quite different to those of other children.

Quality of life measurements allow patients to report their opinions. However, these opinions can easily be distorted or misrepresented by the method of seeking information. From a methodological point of view, varying models of disability can explain varying results from similarly labelled domains between different instruments. This has implications for using existing instruments to test the construct validity of new instruments. We have seen how the wording of questionnaires reveals assumptions about the model builder and how instrument validity can be affected by slight differences in wording. In the published reports on quality of life, the 'personal tragedy' view of disability still outweighs that of disability as a consequence of social organisation. The concepts and assumptions underlying quality of life instruments need to be made explicit.

A recurring maxim in the adult literature is that quality of life is a subjective phenomenon. This raises the question of exactly whose subjectivity should be sought, especially for young children. Infants obviously cannot be questioned about their preferences for neonatal care. The strong relations between the welfare of the family and the child complicate the judgement on whose opinion should be sought.²³ The complexity of these issues has led to some scepticism about the feasibility of measuring functional status in children under 2 years old. Parents and health professionals can differ markedly in their perspectives about children's health status³² and significant areas of discordance also exist between children and their parents,^{28 32} not to mention between mothers and fathers. These differences match those found in adults³³ and impede the use of co-respondents to validate quality of life data.

Effects of disease and intervention have been identified in new areas. The World Bank's global disease burden project illustrated the importance of neuropsychiatric conditions, relative to more visible conditions, as causes of disability hitherto underestimated by conventional measures.³ These types of insight lend impetus to research in new areas of prevention and intervention. By the same token, failure to detect social and family impacts of childhood disability can impair adult adjustment. It follows that these new areas can only be

explored if outcome measures are not merely restricted to domains believed to be important to clinicians. The opportunity to effect beneficial change is wholly dependent on closing the information loop between research and practice. There is evidence that clinicians find this type of feedback informative but it does not lead to a change in clinical decisions.³⁴

Attempts have been made to compare chronic disorders,^{11 16} and to answer economic hypotheses concerning equity and efficiency. Cost utility analyses seek to demonstrate the comparative merit of interventions in early life and health service purchasers will increasingly seek this sort of economic justification. However, such analyses are heavily based on assumptions about human preference and can be misleading if the principles underlying such methods are not understood.

There is need for further research in four major areas. The fundamental constructs of life quality for children deserve discussion with representative groups of health and welfare professionals, with both healthy children and those with chronic disorders, and their parents. It is hoped that some consistent valid themes would emerge from such discussion. The quality of a child's family and social environments needs further systematic measurement as these can exert both positive and negative influences on the child. At the level of the individual child, practical solutions to the administration of quality of life instruments to children of differing developmental levels, and of adjusting definitions of quality of life for those levels, need to be devised. It also behoves us to study healthy children in order to define the range of physical, psychological, and social experiences that might be expected to occur and how these are affected by the course of time. This would aid the interpretation of results from ill children and guide efforts at intervention.

Experience is also required to address the question of which approach to use for children with different impairments – whether a core instrument with disorder-specific modules or totally separate instruments for each disorder is more suitable. The corollary to this is how to approach the child with multiple impairments.

Conclusion

In future clinical practice, broader definitions of health and measurements of outcome must be considered. Their impact has been amply demonstrated in the adult literature and their use should be seen as complementary to the 'holistic' tradition in child health. However, childhood is qualitatively different to adulthood and this fact coupled with a number of methodological problems should make clinicians wary of quality of life measurements as they stand.

In research, there is a notable lack of debate over concepts of childhood, health, and disability. There is need for interdisciplinary discussion of how we are to define and operationalise such concepts. The methodology of questionnaires needs thoughtful refinement. Most health care activity for children is not directed at disease cure but at prevention and educa-

tion. We must use broader measures to illuminate wider causal frameworks and to create better multidisciplinary health promoting strategies. The emphasis on positive aspects of health in childhood might lead in turn to an instructive model informing strategies for adult public health.

This work is supported by a Wellcome Research Training Fellowship.

I am grateful to Dr Helen McConachie and Dr Astrid Fletcher for critical comments in drafting this paper.

- Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: Macleod CM ed. *Evaluation of chemotherapeutic agents*. New York: Columbia University Press, 1949: 191-205.
- World Health Organisation. *Constitution of the WHO*. Geneva: WHO, 1958; Annex I.
- World Bank. *World development report 1993*. New York: Oxford University Press, 1993: 329.
- Centre for Human Rights, United Nations. *Convention on the rights of the child*. Geneva: United Nations, 1989.
- Fitzpatrick R, Fletcher A, Gore S, Jones D, Spiegelhalter D, Cox D. Quality of life measures in health care. I: Applications and issues in assessment. *BMJ* 1992;305:1074-7.
- Report of the Committee of Enquiry into the Education of Handicapped Children and Young People (Warnock report). *Special educational needs*. London: Department of Education and Science, 1978.
- Guyatt G, Feeny D, Patrick D. Issues in quality-of-life measurement in clinical trials. *Controlled Clinical Trials* 1991;12:81S-90S.
- Achenbach TM. The child behaviour profile: an empirically based system for assessing children's behaviour problems and competences. *Int J Mental Health* 1979;7:24-42.
- Goyette CH, Conners CK, Ulrich RF. Normative data on revised parents and teacher rating scales. *J Abnorm Child Psychol* 1978;6:221-36.
- Starfield B, Bergner M, Ensminger M, et al. Adolescent health status measurement: development of the child health and illness profile. *Pediatrics* 1993;91(2):430-5.
- Lindstrom B. Quality of life for children with disabilities. *Soz Präventivmed* 1993;38:83-9.
- Eisen M, Ware JE, Donald CA, Brook RH. Measuring components of children's health status. *Med Care* 1979;16(9):902-21.
- Stein REK, Jessop DJ. A noncategorical approach to chronic childhood illness. *Public Health Rep* 1982;97(4):354-62.
- Feeny D, Furlong W, Barr RD, Torrance GW, Rosenbaum P, Weitzman S. A comprehensive multiattribute system for classifying the health status of survivors of childhood cancer. *J Clin Oncol* 1992;10(6):923-8.
- Graham P, Flynn D. A new measure of health related quality of life: preliminary findings. *Psychology and Health* 1996 (in press).
- Lewis C, Pantell R, Kieckhefer G. Assessment of children's health status. Field test of new approaches. *Med Care* 1989;27(3):S54-S65.
- Austin JK, Shelton Smith M, Risinger MW, McNelis AM. Childhood epilepsy and asthma: comparison of quality of life. *Epilepsia* 1994;35(3):608-15.
- Schmidt GM, Niland JC, Forman SJ, et al. Extended follow up in 212 long-term allogeneic bone marrow transplant survivors. *Transplantation* 1993;55(3):551-7.
- Torrance GW, Boyle MH, Horwood SP. Application of multiattribute utility theory to measure social preferences for health states. *Operational Research* 1982;30:1043-69.
- Cadman D, Goldsmith C, Bashim P. Values, preferences and decisions in the care of children with developmental disabilities. *J Dev Behav Pediatr* 1984;5:60-64.
- Saigal S, Feeny D, Furlong W, Rosenbaum P, Burrows E, Torrance G. Comparison of the health related quality of life of extremely low birth weight children and a reference group of children at age eight years. *J Paediatr* 1994;125(3):418-25.
- Torrance G. Measurement of health state utilities for economic appraisal. *J Health Econ* 1986;5:1-30.
- Carr-Hill RA. Background material for the workshop on QALYS. Assumptions of the QALY procedure. *Soc Sci Med* 1989;29(3):469-77.
- Stevenson R. The Oregon formula: health economists' dream or Stalinist nightmare? *Arch Dis Child* 1991;66:990-3.
- Stein REK, Jones DJ. Functional status II(R). A measure of child health status. *Med Care* 1990;28(11):1041-55.
- Ziebland S, Fitzpatrick R, Jenkinson C. Tacit models of disability underlying health status instruments. *Soc Sci Med* 1993;37(1):69-75.
- Oliver M. Changing the social relations of research production? *Disability, Handicap and Society* 1992;7(2):101-14.
- Abberley P. Counting us out: a discussion of the OPCS disability surveys. *Disability, Handicap and Society* 1992;7(2):139-156.
- Pantell R, Lewis C. Measuring the impact of medical care on children. *J Chronic Dis* 1987;40(S1):99S-108S.
- Fletcher A, Gore S, Jones D, Fitzpatrick R, Spiegelhalter D, Cox D. Quality of life measures in health care. II: Design, analysis, and interpretation. *BMJ* 1992;305:1145-48.
- Danilowicz DA, Gabriel HP. Post-operative reactions in children: Normal and abnormal responses after cardiac surgery. *Am J Psychiatry* 1971;128(2):185-8.
- James J. Community involvement towards community objectives. *Soz Präventivmed* 1992;37:218-22.
- Rosenbaum P, Cadman D, Kirpalani H. Assessing quality of life. In: Spilker B ed. *Quality of life assessment in clinical trials*. New York, NY: Raven Press, 1990: 205-215.
- Slevin ML, Plant H, Lynch D, Drinkwater J, Gregory WM. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988;57:109-12.
- Rubenstein L, Calkins D, Young R, Cleary PD, Fink A, Koseoff J. Improving patient function: a randomised trial of functional disability screening. *Ann Intern Med* 1989;111:836-42.