MEASUREMENT OF QUALITY OF LIFE IN CHILDREN

DIVISION OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA
MEASUREMENT OF QUALITY OF LIFE IN CHILDREN

Report of a WHO/IACAPAP Working Party

London, UK, 3-4 June 1993

This is the report of a meeting held in 1993, which examined the need for an instrument to assess quality of life in children and which reviewed the possible methods for doing so. In particular, the meeting examined whether the existing methodology being used by WHO in the development of the WHOQOL for adults, was appropriate for developing an instrument for use in childhood.

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A meeting was convened on 3-4 June 1993 at the Institute of Child Health, London, co-sponsored by the World Health Organization (WHO) and the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) to consider the purpose for which quality of life measures in children may be required, and the extent to which any single measure needs to be applicable in a very broad range of countries around the world. The meeting was to review existing measures and to examine whether the existing methodology being employed by WHO in the development of the WHOQOL was appropriate for developing an instrument for use in childhood. The meeting was then to recommend further activities to the WHO and IACAPAP with regard to instrument development and use. A list of participants and the terms of reference for the meeting are attached.

WHO and IACAPAP had, in addition to the above objectives, certain specified requirements with regard to a possible measure of QOL in children.

WHO Requirements

For WHO, the scope of the instrument has to encompass a comprehensive description of quality of life and should not focus on certain limited or very focused aspects of life. Nevertheless, for practical reasons, the instrument might not be able to cover every relevant issue and some comprehensiveness might have to be sacrificed for utility. The areas covered by the instrument need to be appropriate for well children as well as those who are sick or disadvantaged. The instrument should take a very child-centred approach.

IACAPAP Requirements

For IACAPAP this project is part of the work of a task force on quality of life in children (a second task force is working on a bill of rights for institutionalized children). The report of this meeting and of any work resulting from it will be presented at the San Francisco IACAPAP Congress in July 1994.

IACAPAP has for some time been concerned to broaden its work to encompass more than the regularly held congresses. This task force is seen as important in its multidisciplinary nature and in the possibility of developing a universally valuable instrument.
General Issues determining the form of an assessment instrument

1. Purposes for which it may be required

- To aid clinical decision-making
- As an end point in clinical trials
- To screen patients/families and then apply prophylactic intervention
- To develop and evaluate supportive interventions within and between countries
- Monitoring and evaluating health and social policies.

2. Focus

- Health-related QOL
- QOL in general
- Health status measure

There was advocacy for the development of a general QOL measure, albeit one that could appropriately be applied in health care settings.

QOL can be seen as one extra dimension, albeit an important one, along which the results of health interventions and policies could be measured. Outcomes can be assessed according to physician reported signs, patients' reports of symptoms, measures of impairment, disability or handicap, etc. A QOL measure should explore a broad range of issues relating to a person's personal and social life and should concentrate on how these persons feel about themselves and their position in life. Quality of Life (as defined in the WHOQOL project) is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment. Such a measure of perceived QOL would therefore need to be used in conjunction with other measures that assess for instance physician observed variables.

There is some demand from those assessing health outcomes for a single index outcome score derived from all relevant variables, such as signs and symptoms of disease, disabilities, side effects of treatment, etc. Some attempts have been made to develop such an index, which has been referred to (probably incorrectly) as a QOL Index. Convenient though it may be to work with such a single outcome score, this must be seen as something very different from the measure of perceived QOL referred to earlier.
Issues related to measurement in children

1. Possible lack of validity of self-report by children
2. Use of proxy judgements made by carers or professionals
3. Because of the rapid changes in children due to development (cognitive, psychological, physical), measures of QOL may require adjustment for the age of the child
4. Premorbid functional and cognitive abilities cannot be established in the very young child, so making it difficult to obtain a longitudinal perspective.

It was acknowledged that some children are too young or too disabled to complete self reports and that some proxy judgements will have to be made. The two approaches were not, however, seen as mutually exclusive.

General characteristics proposed for an instrument

- child centred
- employ subjective self-report wherever possible
- be age-related or at least developmentally appropriate
- be cross-culturally comparable
- have a generic core and specific modules
- put an emphasis on health enhancing aspects of quality of life rather than merely negative aspects as do many other instruments

There was much debate on the format of the instrument. It was agreed that pilot work is needed to establish the validity and reliability of various techniques, e.g. visual analogues and categorical scales using schematic drawings.

Specific characteristics of an instrument

It is likely that an instrument will contain items (questions) probing a number of domains and that the instrument would yield numerical scores for each domain of at least interval measurement. The domains with subdomains (facets) and items could be generated during a development phase using:

- a focus group approach
- free-response interviews with children
- interviews (semi-structured) with children, asking them to comment on domains and facets generated by parents, teachers, health professionals, other children and the existing literature.

It would probably be sensible that work would start using children within a fairly narrow age band.

The group, by a process of "brain storming" suggested a list of facets which are certainly not exhaustive, but provide a discussion point for developing an instrument. The facets have been grouped fairly arbitrarily into a number of domains. They are certainly not mutually exclusive at this stage.
Suggested list of domains and facets

Family/Social relations

Role in family
Valuable adults
Parental relationships
Family dynamics
Family lifestyle
Pets
Friendships

Physical function

Mobility
Function
Sleep

Psychological (internal)

Self-worth
Perceived control
Guilt
Mood
Confidence

Physical appearance

Body image
Hair
Size

Psychosocial relations to social and material environment

Safety
Future prospects
Value to important others
Play
Choices
Options
Acceptance

Environment

School
Food
Chores
Space
Material comfort
Although the domains/facets to be included should be those which children say are important, it was recognized that health care professionals and parents would need to provide additional facets of relevance to the agencies wishing to monitor quality of life. For example, a totally child-centred instrument might be very heavily weighted on, say, material possessions, sweets and toys, and this would be of little value to a clinician who wished to monitor quality of life in a clinical trial.

**Data collection**

As far as questionnaire completion was concerned, it was hoped that this would be done primarily by children whenever possible. However, it seemed likely that some additional assessments would have to rely on primary caregiver’s reports of children’s functioning, although it was felt that these should not be used in a direct way to describe the child’s quality of life.

It is not clear what method of measurement would yield the most valid and reliable responses. It was agreed that pilot work will have to be done to establish appropriate questionnaires and response methods. For example visual analogue scales or categorical scales using schematic drawings all have their merits and proponents. These would have to be compared during a developmental phase.

**Recommendations**

1. The group agreed that starting work in this area was important due to the inadequacy of current measures.

2. Substantial pilot work would be necessary, perhaps utilizing the focus group approach of the adult WHOQOL research groups, and using some of the centres within that study.

3. Funding must be adequate for sensible development of a more satisfactory instrument to measure the quality of life of children.
WHO/IACAPAP Working Party
on the Measurement of Quality of Life in Children
London, UK, 3-4 June 1993

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Terms of Reference

1. To consider the purpose for which quality of life measures in children may be required with reference to economically under-developed as well as economically developed countries

2. To review existing measures and, in particular, the appropriateness of the WHO Quality of Life instrument (WHOQOL) for modification for use with children

3. To make recommendations to WHO, IACAPAP and any other relevant governmental or non-governmental agencies.