

Quality of Life measurement in Children with Epilepsy.

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ABSTRACT

Epilepsy is the most common chronic neurological condition in childhood. However, minimal attention has been paid to the child's concerns about epilepsy in relation to the everyday but important parts of the child's life for example: school career, family holidays and personal relationships. Recent research with adults suggests that subjective measurement methods should be incorporated in quality of life (QoL) test batteries. Up to now such methods have not been developed for children with epilepsy.

In this research we survey the methods and instruments which can be used to measure the quality of life of children with epilepsy. We examine health related QoL instruments which have been used both in the study of children with epilepsy and other handicaps and examine the aims and dimensions of these instruments in relation to epilepsy. The results of this theoretical study are summarised into specific hypotheses concerning the measurement of QoL relevant to children with epilepsy. Practical questions for the project have been how the measurement of QoL can be related to medical variables and the criteria for measurement related to children of different ages.

Quality of Life measurement in Children with Epilepsy

Introduction

The need to measure childrens' perceptions of the intensity of symptoms associated with different treatments and quality of life has been neglected.

In this poster, some of the possibilities and problems for the measurement of Quality of Life (QoL) in children will be explored.

1. Why measure QoL in children?

- As a basis for interventions.
- As issues of importance to the child are identified, it should be possible to optimise outcomes by developing more appropriate interventions.
- To compare clinical trials
- Accurate measures that reflect the impact of treatment from the child's perspective are urgently needed.

2. Why child-specific measures?

- Developmental differences
- Child development is rapid and the social and behavioural effects of a diagnosis of epilepsy are dependent on the age at diagnosis.
- Age dependent interpretations of QoL.
- "Getting on at school" may have a social meaning to the young child and an academic meaning to the adolescent.
- Friendship patterns change with age.
- "Good health" for younger children can mean the ability to perform 'Superman acts'.

3. Methodological problems

a) Reliability

The argument for a reliable instrument needs to be balanced against the inevitable change that accompanies the development of any child.

b) Positive / negative self-presentation

Children may wish to present a more positive image or alternatively socially undesirable behaviour and defiance.

c) Parent vs. self-ratings

● **Limitations of parents' ratings are:**

- 1) reflects parents' own anxiety;
- 2) unreliable on emotions.

Even reports of external factors may not be accurate e.g. concerning difficulties at school or in interactions with friends.

● **Limitations of self-rating are:**

- 1) limited cognitive and linguistic skills
- 2) Expression of symptoms is highly dependent on parental influence.

4. Symptoms

a) Subjective measurement problems.

- Child not able to understand or explain internalisation of social/health problems.
- Distress may be sub-conscious and difficult to express or even recognise for younger children.

b) Objective measurement problems.

Validity doubtful when scales need to be simplified and danger of experimental bias where scales need to be explained.

5.1 Scales completed by the child

(Generic scales are printed in italics)

Age range	Objective QoL	Subjective QoL
up to 6 years	<ul style="list-style-type: none"> ● <i>Relationships 5-6 years (with pictures)</i> 	
6 to 12 years	<ul style="list-style-type: none"> ● <i>DUCATQOL</i> ● <i>What worries you most</i> ● <i>Coping Health Inventory for Children</i> ● <i>'I want to be like that' -Computer Qn.</i> ● <i>Self-worth interview</i> 	<ul style="list-style-type: none"> ● <i>Three wishes</i> ● <i>How are you?</i> ● <i>Focus groups</i>

12 to 16 years	<ul style="list-style-type: none"> ● Young people & epilepsy ● <i>DUCATQOL</i> ● <i>KINDL</i> ● <i>Piers CSCS</i> ● <i>Standing in front of the mirror</i> ● <i>Self-image</i> ● <i>Child Health Questionnaire</i> ● <i>Child Behaviour Checklist</i> ● <i>Self-rating scales >9 years</i> ● <i>TAAQOL</i> 	<ul style="list-style-type: none"> ● <i>Thematic Apperception Test</i> ● <i>How are you?</i>
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5.2 Scales completed by the parent

(Generic scales are printed in italics)

Age range	Objective QoL	Subjective QoL
up to 6 years	<ul style="list-style-type: none"> ● Hague Restrictions in Childhood Epilepsy Scales (HARCES) 	<ul style="list-style-type: none"> ● Hague Seizure Severity Scale (HASS) ● Hagues Side Effects Scale (HASES)
6 to 12 years	<ul style="list-style-type: none"> ● Limitation & Stigma Scale ● Quality of life in children ● Hague Restrictions in Childhood Epilepsy Scale (HARCES) ● Impact Scale ● <i>Child Behaviour Checklist</i> 	<ul style="list-style-type: none"> ● Hague Seizure Severity Scale (HASS) ● Hagues Side Effects Scale (HASES) ● Walton Child Severity Questionnaire
12 to 16 years	<ul style="list-style-type: none"> ● Adolescent Psychosocial Seizure Inventory ● Quality of life in children ● Hague Restrictions in Childhood Epilepsy Scale ● <i>Impact Scale</i> ● <i>Child Health Questionnaire</i> 	<ul style="list-style-type: none"> ● Hague Seizure Severity Scale (HASS) ● Hagues Side Effects Scale (HASES)

6. Discussion

In selecting a scale, consideration needs to be given to:

- 1) the purpose of assessment,

2) the time available and

3) whether or not it is possible to elicit information directly from the child.

There is very little reliability or validity data available for epilepsy-specific measures.

All measures should consider developmental differences in QoL and how concerns change with maturity.

There is a need for a more theoretical approach, probably based on normative developmental psychology.

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