



NIH Toolbox

Assessment of Neurological and Behavioral Function

USE OF THE NIH TOOLBOX TO ASSESS QUALITY OF LIFE IN OUTCOMES RESEARCH

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NIH Blueprint

for Neuroscience Research



Tools, Resources and Training

For more information, please visit www.nihtoolbox.org
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Credits:



Marcia Grant, RN, DNS and the Education Committee of ISOQOL (June, 2005)

Topics for Organizing Quality of Life Educational Quality of life definitions, theory and conceptual issues

1. Quality of life definitions, theory and conceptual issues



- ◆ Theories and Conceptual
- ◆ Related Concepts
- ◆ Utility Measures
- ◆ Functional Status
- ◆ Patient Reported Outcomes

Functional Status in QOL Research



- ◆ Rarely assessed beyond whether basic cognitive functioning is high enough to undergo informed consent (or at least high enough to understand the text in a QOL measure)



Cognition

Executive Function

Inhibitory Control
Cognitive Flexibility

Episodic Memory

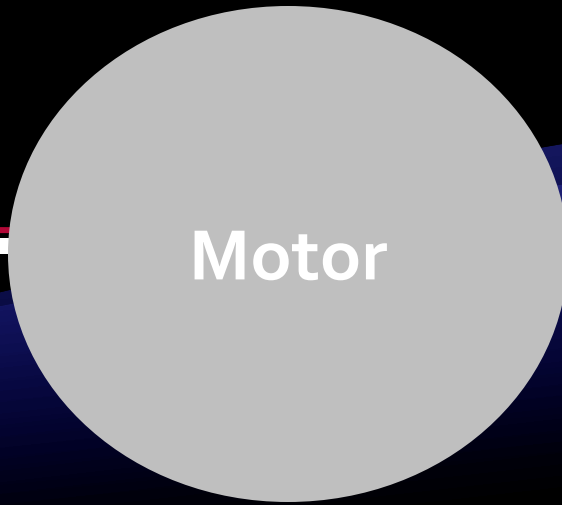
Working Memory

Language

Vocabulary Comprehension
Reading Decoding

Attention

Processing Speed



Endurance

Locomotion

Strength

Dexterity

Balance

Upper Extremity
Lower Extremity

(Non-vestibular)



Sensation

Olfaction

Odor Identification

Taste

Preference

Intensity

Bitter Perception

PROP Sensitivity

Vestibular Balance

Vestibular-ocular Reflex

Vestibulospinal Function

Audition

Hearing Threshold

Speech Processing

Hearing Loss

Somatosensation

Texture Discrimination

Proprioception

Pain

Touch Discrimination

Touch Perception

Vision

Visual Acuity

Visual Function HRQOL

Peripheral Vision



Emotional Health

Psychological Well-Being

*Positive Affect
Life Satisfaction
Meaning and Purpose*

Negative Affect

*Sadness
Fear
Anger
Apathy*

Stress and Self-Efficacy

*Perceived Stress
Self-Efficacy
Coping Strategies*

Social Relationships

*Social Support
Companionship
Social Distress
Social Network Integration*



2. Quality of Life in Children

3. Quality of Life in Adults

4. Quality of Life in Special Populations (Elderly, co-morbidities, disabled, etc.)

5. Research Issues in QOL

6. QOL Measurement Issues



- a. Where to find specific measures (www.nihtoolbox.org)
- b. How to select a scale
- c. Generic versus disease specific scale
- d. Scales for adults
- e. Scales for families
- f. Scales for children and adolescents
- g. Economic/utility measurements
- h. Functional measures
- i. Item response theory
- j. Cross cultural adaptation/ translation and validation

7. Scoring and Interpretation Issues



- a. Intent to treat analysis
- b. Missing Data
- c. Response Shift
- d. Norm reference
- e. Clinical versus Statistical Significance



8. Quality of life issues in relation to specific populations

9. Learning Resources for QOL education

10. Quality of life and economic issues (use of health care resources)

11. Using QOL Assessment in clinical practice

Toolbox Abstract



There is little uniformity among the measures used to assess neurological function and behavioral health. The NIH Toolbox initiative seeks to assemble brief, comprehensive assessment tools that will be useful to clinicians and researchers in a variety of settings. . . such measures are rarely included in studies of this type, due in part to the lack of brief, well-validated instruments.



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