Measures of health-related quality of life outcomes in pediatric neurosurgery: literature review

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Conflicts of interest

• No financial disclosures
• HRQoL

• Peds HRQoL

• How to measure HRQoL?

• Evaluating QoL Measures

• Specific examples

• Conclusions
Health-Related Quality of Life (HRQoL)

- Healthcare moving to a pay-for-performance era

| Cost effectiveness | Evidence-based treatment |

- Outcomes measured by objective data (demographics, clinical data, operative data)

- Outcomes should also include subjective measures like health-related quality of life
Health-Related Quality of Life (HRQoL)
Health-Related Quality of Life (HRQoL)

• Engel class outcome measures

• Patients also suffer from the psychosocial implications of their condition
  – Sexual function?
  – Driving?
  – Swimming/bathing alone?
Health-Related Quality of Life (HRQoL)

• Many scales are regularly used in adults which have been validated across institutions and populations.

• HRQoL tools may help identify patients at risk for social adjustment and competency issues in the future.

• Many scales are used and modified
  – Standardized, validated instruments for evaluating pediatric HRQoL are lacking.
• HRQoL

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Pediatric HRQoL

- 46 scales used for pediatric HRQoL from 2005-2014
  - Most general and broad while some are neurosurgery-specific

- Use in pediatrics has been steadily increasing
  - Used less frequently in pediatric neurosurgery and use is not increasing relative to other areas
Pediatric HRQoL

• No standardization for different clinical settings

• Literature generally incorporates multiple instruments, often custom-designed and unvalidated

• Many tools in use today are a subjective measure of outcomes based on parent reporting
• HRQoL

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# General vs Disease-Specific Measures

<table>
<thead>
<tr>
<th>General</th>
<th>Disease-specific</th>
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<tbody>
<tr>
<td>Results can be compared across demographics or populations</td>
<td>Detect subtle changes</td>
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<tr>
<td>Lack the sensitivity to detect disease-specific impairments</td>
<td>Unique, cannot be compared to other measures</td>
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How to Measure QoL?

- No consensus on the definition of “quality of life”

**WHO**: “the individual’s **perception** of their position in life, in the **context of culture** and **value** systems in which they live and in relation to their goals, **expectations**, standards and concerns”
How to Measure HRQoL?

- HRQoL with a similarly nebulous definition:

  “a rubric, encompassing various aspects of personal experience, including physical and psychological health, cognitive factors, social role performance, and general life satisfaction”
Evaluating QoL Measures

• Adaptations for quality of life measures
  – Reliability, validity, ease of interpretation and ease of administration
  – Internal reliability
  – Test-retest reliability
  – Inter-rater reliability
  – Responsiveness to change
Evaluating QoL Measures

• Validity
  – Content validity: the instrument samples all the relevant and important domains in question
  – Face validity: patient’s perception of the items, and their experience while completing the items
  – Concurrent/criterion validity: how the instrument compares to the ‘gold standard’
  – Construct validity: whether the test measures what it is intended to measure
Limitations

• Differences in parents’ and children’s responses
• Limited availability of measures with components for the child to complete
• Nature of disease limits ability to respond
• Many scales exist, but are often customized to the diagnosis and have not been validated across populations and conditions
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Epilepsy
Quality of Life in Epilepsy (QOLIE)

• Initially designed for adults, and reliability validated in these patients
  – Adapted for children with good results
• Initial and abbreviated versions
  – QOLIE 89
  – QOLIE 31
  – QOLIE 10
  – QOLIE-AD-48
Additional tests

- Epilepsy Surgery Inventory (ESI-55)
  - Designed for children who have had epilepsy surgery
  - 55 questions, 19 epilepsy-specific questions
  - Twelve domains (table)
  - Excess ceiling effect
  - Good validity, reliability unproven
  - Questions are generic, can be applied to many conditions

<table>
<thead>
<tr>
<th>health perceptions</th>
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<tbody>
<tr>
<td>energy/fatigue</td>
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<td>overall quality of life</td>
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<tr>
<td>social function</td>
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<td>emotional well-being</td>
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<td>cognitive function</td>
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<td>physical function</td>
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<td>pain</td>
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<tr>
<td>role limitations</td>
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<tr>
<td>change in health</td>
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Additional tests

• Impact of Childhood Illness Scale
  – Designed for children 6-17
  – Questions are generic, can be applied to many conditions

• Quality of Life in Children with Epilepsy Questionnaire (QOLCE)
  – Score 0-100, 76 questions, 16 subscales
  – Sensitive to severe epilepsy

• Epilepsy and learning disabilities quality of life (ELDQOL)
  – demonstrated strong reliability and validity

• Impact of Childhood Neurologic Disability Scale (ICND)
Tumor
Pediatric Functional Assessment of Cancer Therapy – Childhood Brain Tumor Survivor (Peds-FACT-BrS)

• Created to address the lack of an adequate instrument to measure QOL in pediatric brain tumor survivors
• 34 items, 12 are disease-specific
• Internal consistency/reliability have been demonstrated in a specific sub-population, much more extensive testing is needed to validate it in other populations
PedsQL Brain Tumor module

• Generic measure with extensive validation across various diseases
• 24 items, encompassing 6 domains (Table)
  – Good internal consistency and construct validity has been demonstrated

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<th>Cognitive problems</th>
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<tr>
<td>Pain and hurt</td>
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<td>Movement and balance</td>
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<td>Procedural anxiety</td>
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<td>Nausea</td>
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<td>Worry</td>
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Cerebral Palsy
QoL in CP

• Outcomes have previously involved spasticity rating scales, tests of gross and fine motor skills, gait analysis
• Both generic and condition-specific measures have been used to measure quality of life
  – Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD)
  – Cerebral Palsy Quality of Life child version (CP QOL-Child)
  – DISABKIDS
  – PedsQL 3.0 Cerebral Palsy Module
  – Care and Comfort Hypertonicity Questionnaire (C&CHQ)
Spina Bifida
Condition-specific measures

- Designed by Parkin et al
  - Children 5-12, Adolescents 13-17
  - Ten domains (table)
  - good internal reliability, test-retest reliability, and construct validity
Hydrocephalus
Condition-specific measures

• Designed by Kulkarni et al
  – Created from input from pediatric neurosurgeons, nurses, patients and parents
  – Three domains (table)
  – Good test-retest reliability, inter-rater reliability and construct validity
Spinal Deformities
• HRQoL

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Condition-specific measures

- **Quality of life profile for spine deformities (QLPSD)**
  - 88 questions
  - Directed at adolescents with spinal deformities

- **Scoliosis Quality of Life Index (SQLI)**
  - Self reported tool
  - Used to measure HRQoL in adolescent idiopathic scoliosis patients
Future Directions

• Measures which currently exist need further investigation and standardization

• Pediatric neurosurgery should prioritize the use of HRQoL and implementing its role in patient care

• Implementing new outcome measures can be challenging, but by increasing use it will soon become as familiar as a GCS or cranial nerve exam


