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

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Abstract

Background

Improving value in healthcare means optimizing outcomes while minimizing costs. The emerging pay-for-performance era requires understanding the impact of healthcare services on health-related quality of life (HRQoL). Pediatric and surgical subspecialties have yet to fully integrate HRQoL measures into practice. This study aims to review and characterize the HRQoL outcome measures across various pediatric neurosurgical diagnoses.

Methods

A literature review was performed by searching PubMed and Google Scholar with search terms such as “health-related quality of life” and “pediatric neurosurgery” and then including the specific pathologies for which a HRQoL instrument was found (for example: “health-related quality of life” + “epilepsy”). Each measurement was evaluated based on content and purpose, relative strengths and weaknesses, and validity.

Results

68 articles were reviewed. Epilepsy, brain tumor, cerebral palsy, spina bifida, hydrocephalus, and scoliosis were diagnoses with published studies using disease-specific HRQoL instruments. General HRQoL instruments were also reported. Internal, test-retest, and/or inter-rater reliability varied across instruments, as did face, content, concurrent, and/or construct validity. Few instruments have been tested enough for robust reliability and validity. Significant variability exists in usage of these instruments in clinical studies within pediatric neurosurgery.

Conclusions

HRQoL instruments reported in pediatric neurosurgery are currently without standardized guidelines and thus exhibit high variability in use. Clinicians should support the development and application of these methodologies to optimize these instruments, promote standardization of research, improve performance measures to reflect clinically modifiable and meaningful measures, and ultimately lead the national discussion in healthcare quality and patient-centered care.

Title

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Introduction

The concept of clinical outcomes research in healthcare is evolving. Outcomes should not be measured only by clinicians. Patients and caregivers are those most affected by healthcare services. Increasing attention is being placed on understanding the impact and value of healthcare services on health-related quality of life (HRQoL). Outcome measures should include a measure of HRQoL outcome. Pediatric and surgical subspecialties have yet to fully understand and integrate HRQoL measures into practice. For instance, our group found that 46 different instruments have been used between 2005 and 2014 to measure HRQoL in pediatric neurosurgery.[1] In addition, there was no standardization for which measure was appropriate in different clinical settings.[1]

The first steps toward understanding HRQoL measurements and incorporating them into clinical practice are to identify available measures, to describe their content and purpose, and to describe their strengths, weaknesses, and validity. While these steps have been undertaken for quality of life (QoL)

measures in children with chronic illnesses,[2] such a literature review is lacking in pediatric neurosurgery. Here, we review HRQoL outcome measures used in pediatric neurosurgery.

Why measure QoL?

Since the patient protection and affordable care act (PPACA) was signed into law in 2010, there has been a new emphasis on physician reimbursement via pay-for-performance. Currently, pay-for-performance relies on the physician's cost-effectiveness and evidence-based treatments. However, it is unclear if such measures have any reflection on patient outcomes. Traditionally, clinical studies have reported objective measures such as clinical events, radiographic measurements, operative time, and mortality rates. Subjective measures, such as HRQoL outcomes, are also important in evaluating the impact of a certain intervention by understanding the patient's and/or family's perception of their outcome.[1,3-4] Incorporating both objective and subjective measures of outcomes may guide evaluation of physician performance, especially in this evolving healthcare climate. Fundamentally, healthcare is not something done to patients, but rather, it should involve shared decision-making. In order to inform patients' perceptions of outcomes, data on HRQoL is essential.

As an example, epilepsy is a complex disorder affecting millions of lives in the US, not only with respect to their physical health but also to their psychosocial well-being. Many patients with childhood-onset epilepsy suffer problems with social adjustment and competence as adults, regardless of their seizure frequency. While significant progress has been made in the management of seizures, with improved seizure control, a greater focus on patients' psychosocial health is necessary.[4-6] Thus, measurement of HRQoL in childhood epilepsy may better identify patients at risk for social adjustment issues and competency problems in the future.

How to measure QoL? (current methods used – general vs disease-specific)

There are two methods to assess QoL: using a generic measure or a disease-specific measure.[3,5,7] While the former has the advantage that it can be applied in many different situations and that the results can be compared across various demographics or clinical populations, it may lack the sensitivity or selectivity to detect subtle disease-specific psychosocial impairments. On the other hand, disease-specific measures can detect these subtle changes within a certain patient population, but they cannot be compared to other measures and lack the well-documented psychometric properties of generic instruments.[3,5,8, 84]

Another issue is that there is no consensus on measuring HRQoL, partly because of varying definitions of "quality of life".[1,8-9] This is reflected in the fact that many measures have variability in their definitions and number of domains tested, suggesting that these measures may not be truly assessing the same underlying construct.[2] The World Health Organization defines QoL as "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".[10] Likewise, definitions of HRQoL are nebulous, such as "a rubric, encompassing various aspects of personal experience, including physical and psychological health, cognitive factors, social role performance, and general life satisfaction".[11] Simpler definitions of HRQoL have been proposed, such as an individual's perception of his or her health.[12] Health as defined by the World Health Organization encompasses physical, mental and social components of well-being.[8.13] Well-being denotes a self-reported reflection on a person's experience including a synthesis of mental, physical and emotional states.[14]

However, as clinicians become more cognizant of the importance of QoL measures, and the utilization of these measures increases, their ease of use and accuracy in identifying subtle psychosocial impairments will improve. In order to achieve this, there must be metrics to properly evaluate the QoL

instruments. Currently, a QoL measure is judged by its reliability, validity, responsiveness to change, and its ease of interpretation and administration.[15] Internal reliability is the ability of different items within one instrument that assess the same domain to produce similar results. Test-retest reliability refers to the reproducibility of the results; in other words, if the same patient were to take the test in the same exact situation on different days, the scores would be more or less the same. Inter-rater reliability refers to the extent to which different raters agree in their assessments; for instance, different raters may disagree on how well certain responses reflect the domain being assessed.[15-16]

Validity is defined as the ability of the test to measure what it sets out to measure.[15,17] Several types of validity exist: content validity refers to whether an instrument samples all the relevant and important domains in question; face validity reports the patients' perception of the items, the instrument itself and the experience the patients will have during completion of the instrument; concurrent or criterion validity refers to how the instrument compares to the "gold standard"; construct validity refers to whether an instrument actually measures what it is intended to measure.[15-16] Responsiveness to change refers to the ability of an instrument to detect small but important changes over time: typically condition-specific measures are much better equipped to detect subtle changes over time than generic measures.[8,15]

Strengths/weaknesses of HRQoL measures

Several limitations of pediatric HRQoL measures include discrepancies between parents' and children's ratings, limited availability of disease-specific measures and limited availability of measures for self-completion by children, although often proxy measures are necessary in this patient population.[2] Moreover, children's viewpoints differ from those of adults in that they place greater value in their physical attributes, activities and social life as opposed to basic functional tasks or self-sufficiency.[3] In

table 1 below, we briefly summarize the purpose, strengths, weaknesses, accuracy, and target population of various generic QoL instruments that have been used in pediatric neurosurgery over the past 10 years. In greater detail we describe the various disease-specific instruments currently available.

List of pediatric neurosurgery-specific instruments

There are multiple pediatric neurosurgery-specific instruments available, with some tested for reliability and validity, while others are still in need of this testing.[18] A complete list of QoL instruments available can be found at the Quality of Life Instruments Database (www.proqolid.org).[19] Below we describe in greater detail the various condition-specific measures available in pediatric neurosurgery.

Epilepsy

Although several instruments for assessing HRQoL in adults have been created, assessing HRQoL in adolescents is more complex secondary to the wide range of maturity within this age group, differences in independence and experience, and potential volatility of emotions.[20]

Quality of life in Epilepsy – 89 (QOLIE 89)

Although QOLIE 89 is geared towards adults, it has been adapted for children with good results.[21] The questionnaire is based upon the Epilepsy Surgery Inventory (ESI-55), has long been used as a measure of surgical outcome with strong evidence of reliability and validity, and is well suited for descriptive studies and clinical trials.[22]

It is composed of 89 questions forming 17 sub-scales that represent four domains: epilepsy-targeted, cognitive, mental health and physical health domains.[22,23] It incorporates the Short Form Health Survey (SF-36) with an additional 53 questions appropriate for adults with epilepsy, and its reliability and validity in epilepsy patients have been demonstrated.[22,23]

QOLIE 31

This is an abbreviated version of the QOLIE 89 consisting of 31 questions comprising 7 sub-scales.[24] The subscales were divided into two broad categories: emotional/psychological effects (including seizure worry, overall QoL, emotional well-being, and energy/fatigue subscales) and medical/social effects (including medication effects, work-driving-social limits, and cognitive function subscales).[24] Its reliability and validity have been demonstrated, and it has been translated into 9 other languages, allowing its use in multi-national clinical trials after validating in each respective language, many of which have been performed.[24-29]

QOLIE 10

This is an abbreviated version of the QOLIE 89 consisting of 10 questions and encompassing all seven sub-scales in QOLIE 31. One question was taken from each of the following domains: seizure worry, emotional worry, energy/fatigue, cognition, and overall QoL. Two questions were taken from the medication effects domain to sample the physical and mental effects of medications; three items were taken from the social function scale to provide individual questions for driving, social and work limitations. This tool has high reliability and validity in screening QoL in adult epilepsy patients with good correlation with QOLIE 89.[30] This questionnaire has not been adapted to a pediatric population.

QOLIE-AD-48

An adolescent version of QOLIE 89 has been created: the QOLIE-AD-48. This instrument contains 48 items over 8 sub-scales (epilepsy impact, memory/concentration, attitudes toward epilepsy, physical function, stigma, social support, school behavior, and health perceptions), targets epilepsy patients 11-17 years old and was developed by a panel of seven epilepsy experts by a compilation of some generic instruments plus input from focus groups, health professionals and literature review. It has proven validity, internal consistency, reliability and test-retest reliability.[20]

Impact of Childhood Illness scale (for epilepsy)

This scale consists of 30 items covering 4 domains: impact of illness and treatment, impact on child development and adjustment, impact on parents, and impact on the family. It is geared towards children 6-17 years old and completed by the parent. It has good face validity, but reliability is unproven.[2] Moreover, although developed to be epilepsy-specific, its questions are generic, and this instrument can be applied across different illnesses.[31-32]

Impact of Childhood Neurologic Disability Scale (ICND)

The ICND is a 44-item questionnaire measuring four domains: epilepsy, cognition, behavioral and physical/neurologic function. It is completed by parents of children with epilepsy aged 2-18 years, with excellent internal consistency and test-retest reliability.[32-33]

Epilepsy Surgery Inventory (ESI-55)

The ESI-55 is designed specifically to measure QoL in patients who have had epilepsy surgery. It evaluates twelve domains: health perceptions, energy/fatigue, overall QoL, social function, emotional well-being, cognitive function, physical function, pain, role limitations due to physical, emotional or memory problems, and change in health. It consists of 55 total questions, with 19 epilepsy-specific questions added to the SF-36. It has good psychometric properties but suffers from an excess ceiling effect.[34]

Quality of Life in Children with Epilepsy Questionnaire (QOLCE)

This is a 76-item questionnaire that is completed by parents of children with epilepsy. A score of 0-100 is formed by an unweighted average of 16 subscales, covering 5 domains: physical function, emotional well-being, cognitive function, social function and behavior. This questionnaire has been

found to be reliable and valid and is sensitive to epilepsy severity, with lower scores evident in children with more severe epilepsy.[7,35]

Quality of Life in Childhood Epilepsy Questionnaire 55 (QOLCE-55)

This 55-item questionnaire is an adaptation of the original 76-item QOLCE, created to address the issue of measurement equivalence. This principle examines the extent to which different questions are interpreted in a similar fashion across different groups; although often taken for granted, measurement equivalence can lead to biased comparisons. The QOLCE-55 is parent-reported and intended for children 4-18 years old. It assesses the following four domains: cognitive, emotional, social and physical. It has very good internal consistency as well as measurement equivalence when groups are stratified by age or gender or longitudinally if patients are assessed at diagnosis and 24 months post-diagnosis, supporting the validity of this tool.[36]

Epilepsy and learning disabilities quality of life (ELDQOL) scale

This scale consists of 70 items covering the following domains: seizure severity, seizure-related injuries, antiepileptic drug side effects, behavior, mood, physical, cognitive, and social functioning, parental concern, communication, overall QoL and overall health. This scale has demonstrated strong reliability and validity in assessing QoL in children with epilepsy.[37]

Other scales were developed specifically to address certain aspects of epilepsy. The Washington Psychosocial Seizure Inventory (WPSI) focuses on psychosocial concerns of epileptic patients; the Neurologic Disorders Depression Inventory for Epilepsy (NDDI-E) aims to diagnose depression in those with epilepsy; the Liverpool QoL Batteries takes a composite approach, combining multiple subscales that can be selected to tailor an instrument to a specific patient.[34] These scales however are geared towards adults with epilepsy with little application in pediatric settings.

Hague Restrictions in Childhood Epilepsy Scale (HARCES)

HARCES consists of 10 items that measure the amount of disability resulting from restrictions imposed by seizure burden. This instrument is geared towards assessing the physical function of children with epilepsy, is completed by the parents, and includes questions concerning the frequency with which the child participates in functional activities such as swimming, riding a bicycle, staying elsewhere overnight and participating in physical education. HARCES has good internal reliability, high test-retest reliability and good validity.[32]

Brain Tumor

Pediatric Functional Assessment of Cancer Therapy – Childhood Brain Tumor Survivor (pedsFACT-BrS)

As survival for childhood cancer patients has risen dramatically, the quality of this increased survival time period is important. However, limited data on measuring HRQoL in childhood cancer survivors exists, with instruments to date focusing on adult survivors only, combining adult and childhood survivors, having small sample sizes, including only one type of cancer or combining many types of cancers together, and having no controls or using sibling controls.[38] In fact, brain tumor patients are often excluded from QoL studies as their experiences are viewed as atypical. Addressing the lack of an adequate instrument for childhood brain tumor survivors, the Pediatric Functional Assessment of Cancer Therapy – Childhood Brain Tumor Survivor (pedsFACT-BrS) was created. This instrument contains 34 items total, 22 of which are generic and 12 disease-specific. It covers four domains: physical well-being, emotional well-being and illness experiences, social well-being, and brain tumor-specific concerns. While its internal consistency/reliability and face and content validity have been demonstrated in some sub-populations, such as Korean children or children surviving at least 1 year

post-treatment, much more extensive testing must be performed to validate it in other sub-populations and across different life spans.[39-40]

Pediatric Quality of Life Inventory (PedsQL) Brain Tumor module

The PedsQL is a generic measure with extensive validation across various diseases. The brain tumor module was adapted from this. It consists of 24 items encompassing six domains (although some domains are excluded on the proxy-report while others are excluded on the self-report): cognitive problems, pain and hurt, movement and balance, procedural anxiety, nausea and worry. It can be completed by self-report, typically for children over 5 with adequate cognitive function, or by parent-proxy for others. Good internal consistency and construct validity have been demonstrated for this instrument.[41]

Chiari Malformation

Chiari Health Index for Pediatrics (CHIP)

Not to be confused with the Child health and illness profile – child/adolescent editions (CHIP-CE and CHIP-AE, respectively), the Chiari Health Index for Pediatrics (CHIP) is a recently developed, 45-question instrument assessing two domains: physical and psychosocial. The physical domain consists of pain frequency, pain severity and non-pain symptoms. This instrument is designed such that it can be completed by the parent, child or both. When validated against the Health Utilities Index Mark 3 (HUI3), it has demonstrated construct validity in assessing pain-, cognitive-, and emotion-related QoL as well as symptomatic features specific to Chiari malformation type I patients. While it has good test-retest reliability, internal consistency requires further development as the psychosocial component has some redundancy.[42]

Cerebral Palsy

Outcomes research in cerebral palsy management has previously involved spasticity rating scales, tests of gross and fine motor skills, and gait analyses. Recently, more attention has been paid to health-related QoL outcomes in such patients.[8] Both generic and condition-specific measures have been used to measure QoL in children with cerebral palsy, although condition-specific measures have the advantage of also assessing domains unique to this disorder, such as physical functioning, need for adaptive equipment and psychosocial factors.[43] Condition-specific measures include the following: Care and Comfort Hypertonicity Questionnaire (C&CHQ), the 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, Lifestyle Assessment Questionnaire (LAQ), and the Pediatric Outcomes Data Collection Instrument (PODCI).[8,43] The development process for CP QOL-Child and DISABKIDS included discussions with children with cerebral palsy. All of these measures were designed as parent-report questionnaires, although CP-QOL-Child, DISABKIDS and PedsQL 3.0 Cerebral Palsy Module have child-report versions for patients over 8 years old. CP-QOL also has an adolescent version administered to patients 13-18 years old. A modified CanChild Outcome Measures Rating Form and Guidelines approach was used to assess the clinical utility and psychometric properties of each measure and to analyze the quality of the publications each instrument used as a source. This analysis rates the CPCHILD and CP QOL-Child as high quality, the DISABKIDS and PedsQL 3.0 as moderate quality and the C&CHQ as poor quality. Completion times were provided for three of the measures: 20-30 minutes for CPCHILD; 15-25 minutes for CP QOL-Child; and 5 minutes for PedsQL 3.0. All five measures had construct validity. All except PedsQL 3.0 reported content validity, and both CPCHILD and CP QOL-Child reported concurrent validity. All the measures except C&CHQ reported internal reliability of the domains,

CPCHILD and CP QOL-Child reported retest reliability, and only DISABKIDS reported inter-rater reliability.[43]

The LAQ evaluates physical independence, clinical burden, mobility, schooling, economic burden and social integration. Although little research has been conducted on this instrument and despite lacking a child-report version, some small analyses have shown good reliability, over a four-year gap, and validity, when a measure of disability is used as a benchmark.[8]

The PODCI assesses comorbidity index, upper extremity and physical function, transfers and basic mobility, sports and physical function, pain/comfort, expectations and happiness. It is reliable and valid when using the Child Health Questionnaire (CHQ) as a benchmark.[8] However, both the LAQ, which measures the impact of disability, and the PODCI, which measures functional status and capabilities rather than their well-being, have been inappropriately used by researchers to assess HRQoL in cerebral palsy patients. This reflects the ambiguity of the definition of HRQoL.[8]

Spina Bifida

Increasing focus on health-related outcomes in the management of spina bifida has led to better psychosocial outcomes, signifying the importance of tracking these outcomes.[44] The spina bifida HRQoL instrument, generated from the viewpoint of the children and their parents rather than the healthcare provider, has a child version for those 5-12 years old and an adolescent version for those 13-20 years old. The child version has good internal reliability while the adolescent version has good test-retest reliability; both have good construct validity. The final questionnaire has 44 questions in the child version, which is proxy-report, and 47 in the adolescent version, which is self-report. Both versions test the following ten domains: social, emotional, intellectual, financial, medical, independence, environmental, physical, recreational, and vocational.[2,45-46]

Hydrocephalus

Hydrocephalus Outcome Questionnaire (HOQ)

The HOQ is a 51-item questionnaire that provides a quantitative measure of HRQoL in hydrocephalus patients. This instrument was created by input from health professionals such as pediatric neurosurgeons and neurosurgical nurses who care for hydrocephalus patients as well as input from parents of these patients via focus group discussions. A literature review of previous clinical hydrocephalus research as well as past pediatric health status instruments was also performed. Good test-retest reliability, inter-rater reliability and construct validity were demonstrated, and it evaluates the following domains: physical, social-emotional and cognitive.[47]

Spine

Quality of life profile for spine deformities (QLPSD)

This 21-item questionnaire is geared towards assessment of HRQoL in adolescents with spine deformities. During development, it was administered to patients 10-20 years old covering five domains: psychosocial functioning, sleep disturbances, back pain, body image, and back flexibility. The QLPSD has good internal consistency, test-retest reliability and construct validity.[48]

Scoliosis Quality of Life Index (SQLI)

Initially, HRQoL in adolescent scoliosis was measured via the Scoliosis Research Society (SRS)-24, a 24 item questionnaire assessing seven domains: pain, general self-image, self-image after surgery, function after surgery, general function, function-activity, and satisfaction with surgery. However, the SRS-24 suffered from lack of internal consistency in the function domain, unknown test-retest reliability, and unknown criteria and discriminant validity. Thus, the SRS-22 was created using a combination of the

SRS-24 and SF-36.[49] However, during the creation of this instrument, the mean age of patients in that study was 25 years. This detracted from its relevance in the adolescent, 10-18 year-old population, and thus the SQLI was developed as a modification of the SRS-22. The SQLI is a 22-item self-reported instrument with good reliability and validity in measuring HRQoL in adolescent idiopathic scoliosis patients that covers five domains: physical function, back pain, self-esteem, moods and feelings, and satisfaction of treatment.[50]

Discussion

As noted above, numerous measures are available to pediatric neurosurgeons to assess HRQoL, especially for epilepsy and cerebral palsy. While incorporating HRQoL measures into routine clinical practice can advance our understanding and quantification of patients' or their families' perceptions of their outcomes, choosing an appropriate instrument to administer to a certain patient can be daunting. Understanding some basic characteristics of these measures can help in the selection process: is it patient or parent-reported? Is it good for post-operative patients? Can it be used longitudinally over a long age range? Is it quick and/or easy to complete? A comprehensive list of questions the clinician can consider in selecting a certain instrument has been described previously.[84] Briefly, the disease-specific measures presented above are summarized below to aid practitioners in choosing the most appropriate instrument for their practice.

For epilepsy, self-reported questionnaires include QOLIE89, QOLIE 31, QOLIE10, QOLIE-AD-48, and ESI-55. The QOLIE10 may be used as a quick, initial screening measure for older pediatric epilepsy patients, although its use has been validated only in the adult setting at this point. Then, the QOLIE31 or QOLIE89 may be used for a more in-depth analysis of HRQoL in select patients, with QOLIE31 reserved

for busier practices and QOLIE89 otherwise. The QOLIE-AD-48 may be appropriate for those ages 11-17 years old, although its limited age range and concern for longitudinal HRQoL monitoring as patients age detract from its applicability. Lastly, the ESI-55 may be more suitable for post-operative patients.

If an epileptic patient suffers severe cognitive deficits to the point of being incapable of completing an HRQoL instrument, a parent- or proxy-reported instrument may be indicated. These include the ELQDOL, impact of childhood illness scale, ICND, QOLCE, QOLCE-55, and HARCES. The ELQDOL was specifically created for patients with both epilepsy and learning disabilities, specifically Lennox-Gastaut syndrome.[85] The impact of childhood illness scale evaluates the impact of the patient's epilepsy on their parents and family and thus may be better equipped to evaluate HRQoL for patients requiring more attention and care from their family members. On the contrary, HARCES may be more appropriate for higher functioning kids, as it is geared towards analysis of their physical function, such as riding a bike, swimming, etc. QOLCE is reliable and valid with good sensitivity for epilepsy severity, making it the most robust, parent-reported tool for assessing HRQoL across a broad range of epileptic patients. QOLCE-55, a truncated version of QOLCE, however has only proven results in patients assessed at diagnosis and at two years postdiagnosis, making it difficult to apply in patients with poor longterm follow-up, as encountered frequently in non-surgical epileptic patients.

For brain tumors, out of the two options, the PedsQL Brain Tumor module represents the better option at this time; it can be patient or parent-reported, is 24 questions only, and has good internal consistency and construct validity. The pedsFACT-BrS has only been validated in Korean children and those surviving at least 1 year post-treatment. For chiari, spina bifida and hydrocephalus patients, only one disease-specific instrument is available, and greater incorporation of these into routine clinical practice can continue to improve them. For spine patients, the two major instruments are QLPSD and SQLI that are both short with good reliability and validity; SQLI may be more appropriate for post-operative patients as it includes a measure of satisfaction with treatment.

Multiple measures for cerebral palsy HRQoL exist, with all designed to be parent-reported, while CP QOL-CHILD, DISABKIDS and PedsQL 3.0 have child-report versions for those over 8 years old. The CanChild outcomes measures rating form and guidelines approach has been used to assess the clinical utility and psychometric properties of the cerebral palsy HRQoL tools, rating CPCHILD and CP QOL-Child as high quality, DISABKIDS and PedsQL 3.0 as moderate quality and C&CHQ as poor quality. In addition, only CPCHILD and CP QOL-Child have demonstrated good construct, content and concurrent validity as well as internal and retest reliability. Their completion times are also similar, ranging from 15-30 minutes. Thus, both CPCHILD and CP QOL-Child may be the more robust HRQoL instruments, with the latter have a child-report version for those over the age of 8.

These measures above represent the disease-specific measures used within pediatric neurosurgery; however, in some clinical practices, generic measures may be more appropriate. As noted previously, generic measures have the advantage of broad applicability to various disease populations but may lack sensitivity to detect certain problems specific to a certain pathology; disease-specific measures in contrast are more specific and sensitive for disease-specific problems but make comparisons between different patient populations difficult.[3,5,8,84]

Once a certain instrument has been selected, the next hurdle is incorporating them into routine clinical practice; the steps necessary to accomplish this have been well described previously.[84]

Future directions

While clinicians have always valued high patient satisfaction and good clinical outcomes, quantifying HRQoL is a formidable task. Various measures of HRQoL have been introduced, which

continue to develop as our understanding grows. Recognizing the importance of HRQoL instruments, the medical field, including pediatricians and pediatric neurologists, is increasingly adopting them. Pediatric neurologists are more commonly administering disease-specific questionnaires with respect to epilepsy, spinal dysraphism, sequelae of prematurity, brain tumors and headaches.[1,3] Despite the progress seen in general pediatrics and pediatric neurology, pediatric neurosurgery has not followed suit, with little change in HRQoL usage over the past 10 years.[1] Moreover, many of these publications created their own, unvalidated instruments.[1] Physicians are unlikely to administer HRQoL instruments in their daily practice unless it becomes as familiar to them as clinical measures, such as blood pressure readings.[3] As quantification of HRQoL begins to play a role in outcomes analysis and the concept of value, administration of these instruments should be adopted. While numerous disease-specific instruments are available in pediatric neurosurgery, significant development is still required. Standardizing the usage of these instruments and tailoring them to the appropriate clinical setting is a necessary first step in their development. Next steps include incorporation into standardized disease management or treatment algorithms.

Conclusion

There are many HRQoL instruments reported in pediatric neurosurgery without standardized guidelines and with high variability in use. Clinicians should support the development and optimization of these instruments and eventually adoption of standardization of HRQoL measures in patient care workflow and clinical research. The impact can be positive if we use clinically modifiable and meaningful measures together across the field of pediatric neurosurgery, and ultimately lead the national discussion in healthcare quality and patient-centered care.

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