Quality of Life

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Introduction

Quality of Life is defined as “an individual’s perception of the position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns.” (The WHOQOL Group, 1998; Skevington et al., 2004)

HRQOL measures an individual’s perception of how a chronic health condition (CHC) impacts on his or her physical or psychosocial functioning (Waters at al., 2009; Bakanience et al 2016).
Introduction

Recommendation from the literature indicate that HRQOL should be measured by condition and age-related instruments, that both the parent and child/adolescent perception be measured and that the child perception be valued. The literature would indicate that children as young as 8 can report on their QOL. New age and SB-specific instruments have recently been created but not used extensively. If time is limited the adolescent self-report should be used over the parent report. Use of HRQOL measures has been found in other conditions to be helpful in clinical practice and to impact health care providers clinical practice. (Varni et al., 2007, Sawin & Bellin, 2010). In SB, Improvements in the social domain of HRQOL have been reported with age.
Overall HRQOL and general QOL/HRQOL assessments of children and adults with spina bifida are consistently lower in the physical domain (Sawin & Bellin, 2010; Waters et al., 2009; Flanagan et al., 2011). Parent and provider feedback indicate the items in the physical domains of many HRQOL measures are unhelpful or even offensive if the items measure physical function that most children with spina bifida cannot achieve (i.e. walking up-stairs, running a distance).

The work group feels it is important to avoid use of QOL/HRQOL instruments that have items in the physical domain that automatically disadvantage the measurement and interpretation of QOL/HRQOL in individuals with SB.
Introduction

• Pain is consistently related to QOL/HRQOL in all ages, by both parent and self-report and across varied instruments. (Oddson, 2006; Wood, et al., 2009; Bellin et al., 2013). Although pain has the largest relationship, the studies that addressed other secondary conditions found UTI and pressure ulcers in children as well as pressure ulcers and latex allergy in adults related to HRQOL and ability to participate fully in the community (Wood et al., 2009; Lala et al., 2014).

• LOL ambulation and shunt status are infrequently and inconsistency related to QOL/HRQOL. The relationship is most consistent in physical domain. However, in adults there is some evidence that level and lesion and full-time wheelchair use are associated with reduced QOL (Schoemakers, 2005; Dicianno et al., 2009, Bellin et al., 2001, Young et al 2013).

• Functional status inconsistently related to overall QOL/HRQOL (Ledger, 2005, Sahin et al., 2014).
Introduction

• Scoliosis was not related to QOL/HRQOL (Mercado et al., 20087; Khoshbin et al., 2014).

• In the older literature, urinary continence problems were inconsistently related to QOL/HRQOL and most often by parent report. There is more evidence that bowel continence (Choi et al., 2013; Rocque et al., 2015) or satisfaction with bowel program (Sawin et al., 2006) impacts HRQOL.

• Recently in studies of adults (Liu et al., 2015) there was more support for urinary continence contributing to overall HRQOL. Using a tool that specifically measures the impact of continence on HRQOL, any bowel incontinence and amount of urinary incontinence were supported as related to the HRQOL bladder and bowel scale (Szymanski et al., 2015, 2016).

• Executive function has been significantly related to QOL (Barf et al., 2010)

• Both adolescent resilience factors and family factors are strongly related to HRQOL (Sawin et al., 2003, 2006, Bellin et al., 2013)
Outcomes

Primary: Improve QOL in individual with SB across the lifespan.

Secondary: With the info provided in this guideline, HCP have a better understanding of QOL and HRQOL measurement, potential issues related to available tools or tool development, and factors related to QOL or HRQOL. Increase quality of life assessments in clinical practice.

Tertiary: Clinicians of every specialty integrate assessment of QOL and intervention to address QOL into clinical practice.
Clinical Questions Overall

1. What factors are related to QOL?
2. What might QOL assessment and improvement activities look like in clinical practice?
3. What measures of QOL and HRQOL are the most efficient and useful?
Prenatal/Infancy (through age 1 year)

Clinical Questions
1. What factors are related to QOL?

Guidelines
1. Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines)
2. Address constipation as long-term constipation impedes the development of an effective bowel program (see bowel guidelines)
Toddler (1-3 years)

Clinical Questions
1. Clinical Questions
2. What factors are related to QOL?

Guidelines
1. Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines)
2. Address constipation as long-term constipation impedes the development of an effective bowel program (see bowel guidelines)
Preschool (3-5 years)

Clinical Questions
1. What factors are related to QOL?
2. What measures of QOL/HRQOL are the most efficient and useful?

Guidelines
1. Assist families in their efforts to facilitate the development of protective psychosocial behaviors (e.g. showing affection, bouncing back when things don’t go his or her way, showing interest in learning new things) See Mental Health Guidelines.
2. Target strategies to optimize bowel program as bowel incontinence is consistently related to HRQOL (especially social).
3. Address assessment of executive function (see neuropsychological guidelines)
School Age

Clinical Questions

1. What factors are related to QOL?
2. What might QOL assessment and improvement activities look like in clinical practice?
3. What measures of QOL and HRQOL are the most efficient and useful?
Guidelines - Psychosocial/Cognitive

1. Promote psychosocial well-being. (See mental health -- Assist families in their efforts to facilitate the development of protective beliefs (hope, optimism, attitudes, future expectations, active coping strategies) and behaviors (e.g. showing affection, bouncing back when things don’t go his or her way, showing interest in learning new things; handling negative situations; establishing and maintaining friendships) (see mental health—especially peer relationships)

2. Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines)

3. Refer to community resources that enhance protective factors (sports, camps, scouts, community programs).

4. Address assessment of executive function (see neuropsychological guidelines)
School Age

Guidelines- *Continence*

1. Target strategies to optimize bowel program effectiveness as any bowel incontinence is the type of incontinence most negatively related to (especially social)

2. Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency.
School Age

Guidelines - Pain

1. Evaluate presence and characteristics of any pain experienced
2. Develop strategies to address pain and its impact on school/work, recreation and social activities
School Age

Guidelines- Measurement

1. Use a systematic approach to evaluating QOL/HRQOL.
2. Consider using both self and parent-report instruments.
3. Omit the physical domain for any instrument that uses items beyond the ability of most children with SB (e.g. walking long distances, climbing stairs, jumping). Emotional, social and school domains of most generic QOL instruments are reliable and valid.
4. Use an age and condition-specific instrument to assess HRQOL (see instrument appendix).
5. Consider using a single-item QOL question with follow up assessment if needed.
Teenage

Clinical Questions
1. What factors are related to QOL?
2. What might QOL assessment and improvement activities look like in clinical practice?
3. What measures of QOL and HRQOL are the most efficient and useful?
Teenage

Guidelines – *Psychosocial*

1. Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines).

2. Consider strategies to optimize peer relationships (see mental health guidelines).

3. Consider the unique priorities important in quality of life for each individual.

4. Refer to community resources that enhance protective factors (sports, camps, scouts, community programs).

5. Address strategies to compensate for executive functioning challenges.
Teenage

**Guidelines – Continence/mobility**

1. Target strategies to optimize bowel program effectiveness as any bowel incontinence is the type of incontinence most negatively related to HRQOL in adults (especially social).

2. Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency in adults.

3. Investigate the adolescent’s satisfaction with her/his bowel program. Address concerns to optimize program.

4. Consider functional mobility options that optimizes societal participation (see mobility and function guidelines).
Teenage

Guidelines – Pain

1. Evaluate presence and characteristics of any pain experienced
2. Develop strategies to address pain and its impact on school/work, recreation and social activities
Teenage

**Guidelines – Measurement**

1. Use a systematic approach to evaluating QOL/HRQOL.
2. Consider using both self and parent-report instruments.
3. Omit the physical domain for any instrument that uses items beyond the ability of most children with SB (e.g. walking long distances, climbing stairs, jumping). Emotional, social and school domains of most generic QOL instruments are reliable and valid.
4. Use an age and condition-specific instrument to assess HRQOL (see instrument appendix).
5. Evaluate both self and parent-report of QOL/HRQOL. If assessment time is limited choose self-report of QOL/HRQOL.
6. Consider using a single-item QOL question with follow up assessment if needed.
Adult

Clinical Questions
1. What factors are related to QOL?
2. What might QOL assessment and improvement activities look like in clinical practice?
3. What measures of QOL and HRQOL are the most efficient and useful?
Adult

Guidelines - Psychosocial

1. Identify strategies or resources to facilitate the development of protective beliefs (hope, optimism, attitudes, future expectations, active coping strategies) and behaviors.
2. Explore satisfaction with relationships/sexuality (see sexuality section).
3. Consider strategies to optimize peer relationships (see mental health guidelines).
4. Consider the unique priorities important in quality of life for each individual.
5. Refer to community resources that enhance protective factors (sports, camps, scouts, community programs, universities with a strong support program for students with disabilities).
6. Address strategies to compensate for executive functioning challenges.
Adult

Guidelines – Continence/mobility

1. Target strategies to optimize bowel program effectiveness as any bowel incontinence is the type of incontinence most negatively related to HRQOL in adults (especially social).

2. Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency in adults.

3. Investigate the adult’s satisfaction with her/his bowel program. Address concerns to optimize program.

4. Consider functional mobility options that optimizes societal participation (see mobility and function guidelines)
Adult

Guidelines – *Pain*

1. Evaluate presence and characteristics of any pain experienced
2. Develop strategies to address pain and its impact on school/work, recreation and social activities
**Guidelines - Measurement**

1. Use a systematic approach to evaluating QOL/HRQOL.
2. Consider using both self and parent-report instruments.
3. Omit the physical domain for any instrument that uses items beyond the ability of most children with SB (e.g. walking long distances, climbing stairs, jumping). Emotional, social and school domains of most generic QOL instruments are reliable and valid. Instruments like the WHOQOL-BRIEF avoid this issue using questions such as “Do you have enough energy for everyday activities? Or To what extent do you feel that physical pain prevents you from doing what you need to do?”
Adult

Guidelines – Measurement (cont’d)

4. Use an age and condition specific instrument to assess HRQOL (see instrument appendix).

5. Consider evaluating both self and parent-report of QOL/HRQOL if adult living with parents. If assessment time is limited choose self-report of QOL/HRQOL.

6. Consider using a single-item QOL question with follow up assessment if needed.
Family Quality of Life

• An emerging concept, Family QOL may have usefulness in the care of individuals and families with SB. FQOL has been defined as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (Hu et al, 2011) and “A summary appraisal of domains of life important to the family” (Ridosh, et al., 2016).

• FQOL has been measured with domain-specific instruments (Beach FQOL Tool) and a generic FQOL tool (see Appendix). There is not enough experience with the concept or the tools used to measure FQOL to include it in the guidelines but future investigation is warranted.
Research Gaps

1. Continued refinement of HRQOL and QOL measurement including the relationship of individual and parent proxy reports is needed.
2. Continued research is needed to identify the factors related to HRQOL and how change in these factors across time impacts HRQOL.
3. Research is needed to determine if measuring HRQOL in clinical practice actually leads to activities that improve HQOL.
4. Further research on the emerging concept of Family QOL and its association with child outcomes is needed.
5. Implementation research is needed to evaluate if emerging evidence on QOL/HRQOL is integrated into practice. If the emerging evidence is not integrated into practice, the barriers to implementing the finding needs to be identified and addressed.
Research Gaps

6. What resources or programs are available to increase physical activity at different life stages?

7. Are there any treatments to increase physical activity in PT or OT that are being developed or researched?

8. Which types of exercise are best for certain age groups? For example, if an adult has not tried any exercises, are there recommendations for where to start out? Or, are the recommendations the same as for the general population?


References


References


References

Sawin, K. J., Buran, C. F., & Brei, T. J. (2007) Factors Related to Quality of Life (HRQOL) in Adolescents and Young Adults with Spina Bifida. *SCI Nursing*, 23(4).


References


