QUALITY OF LIFE
SPINA BIFIDA HEALTHCARE GUIDELINES

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Introduction and synthesis of the evidence:
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" (Group, 1998; Skevington, Lotfy, & O'Connell, 2004). HRQOL measures an individual's perception of how a chronic health condition (CHC) impacts on his or her physical or psychosocial functioning (Bakaniene, Prasauskiene, & Vaiiciene-Magistris, 2016; Waters et al., 2009).

Recommendations from the literature indicate that HRQOL should be measured by condition and age-related instruments, both the parent and child/adolescent perception be measured and that the child perception be valued. Parent report is often but not always lower than child/adolescent report (Flanagan, Gorzkowski, Altiok, Hassani, & Ahn, 2011; Murray, Dwyer, Rubin, Knighton-Wisor, & Booth-LaForce, 2014). The literature would indicate that children as young as 8 can report on their QOL. New age and spina bifida-specific instruments have been recently created but not been used extensively (Szymanski, 2017; Szymanski et al., 2015; Szymanski et al., 2016). If time is limited, the adolescent self-report should be used over parent report (Flanagan et al., 2011; K. J. Sawin & Bellin, 2010). Use of HRQOL measures has been found in other conditions to be helpful in clinical practice and to impact health care providers clinical practice (Sawin & Bellin, 2010; James W Varni, Limbers, & Burwinkle, 2007). Improvements in the social domain of HRQOL have been reported with age (Murray et al., 2014).

Overall HRQOL and general QOL assessments of children with spina bifida are consistently lower in the physical domain (Flanagan et al., 2011; Sawin & Bellin, 2010). 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 instruments that have items in the physical domain that are beyond the capabilities of most individuals with SB.

We do not know if measuring of QOL actually improves QOL. We do know some factors that are related to HQOL and clinically addressing those factors is important. The focus of this guideline is to mitigate the factors that negatively impact HRQOL and enhancing the factors positively related to HRQOL.

The measurement of HRQOL is in its infancy and available measures may or may not be the primary mode for collecting HRQOL data from individuals and families.
assessment by the clinician of factors important to the individual and interventions important in achieving these goals remain central to the HRQOL assessment. For example, we know that pain, bowel incontinence, lack of optimism, and depression are negatively related to HRQOL, and thus it would be important for the clinicians to assess these areas comprehensively. Further, we do not know what the impact of repeated measurement of HRQOL has on HRQOL and this needs to be explored. These guidelines are a synthesis of the preliminary literature available and expert opinion.

QOL or HRQOL should not be measured in isolation. There may be components of HRQOL that are not measured by current instruments. If clinicians are going to address HRQOL they also need to address the factors important to the individual/family. A series of questions might be clinically useful (e.g., How would you rate your quality of life? What makes up QOL for you? For you what would make your QOL better?)

While QOL instruments cue the provider to address things that might have been overlooked and measure change over time, the critical issue is that clinicians need to query patients about QOL and HRQOL and assess the factors identified in the literature that are related to these constructs. Clinicians also need to be aware of measurement issues in QOL.

Factors related to QOL/HRQOL

- Pain is consistently related to QOL/HRQOL in all ages, by both parent and self-report and across varied instruments (Bellin et al., 2013; Oddson, Clancy, & McGrath, 2006; Wood, Watts, Hauser, Rouhani, & Frias, 2009). 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 (Lala, Dumont, Leblond, Houghton, & Noreau, 2014; Wood et al., 2009).

- Physical QOL/HRQOL is the most consistently lower in those with SB. However, many QOL and HRQOL tools have items in their physical domains that automatically disadvantage the measurement and interpretation of QOL in individuals with SB (Sawin & Bellin, 2010; Waters et al., 2009).

- LOL ambulation and shunt status are infrequently and inconsistency related to QOL/HRQOL (Padua et al., 2002). The relationship is most consistent in physical domain (Bartonek, Saraste, & Danielsson, 2012; Young, Sheridan, Burke, Mukherjee, & McCormick, 2013). However, with adults there is some evidence that level of lesion and full-time wheelchair use are associated with reduced HRQOL (Bellin et al., 2011; Dicianno, Bellin, & Zabel, 2009; Schoenmakers, Uiterwaal, Gulmans, Gooskens, & Helders, 2005; Young et al., 2013).


- Scoliosis was not related to QOL/HRQOL (Khoshbin et al., 2014; Mercado,
Alman, & Wright, 2007)

- Hydrocephalus/presence of a shunt has been related to reduced HRQOL especially in adults (Flanagan et al., 2011; Rocque et al., 2015)
- In the older literature, urinary continence problems were inconsistently related to QOL/HRQOL (Dodson et al., 2008) and most often by parent report. There has been more evidence that bowel continence (Choi, Shin, Im, Kim, & Han, 2013; Rocque et al., 2015) or satisfaction with bowel program (Sawin, Buran, & Brei, 2007) may be related to HRQOL. Recently in studies of adults (Liu et al., 2015) there is more support for urinary continence contributing to overall QOL. Using a new instrument (Szymanski et al., 2015) that specifically measures the impact of continence on HRQOL, any bowel continence and amount of urinary incontinence were related to the bladder and bowel HRQOL subscale but not to relationship or esteem/sexuality HRQOL subscales (Szymanski et al., 2016). There is little literature on sexuality and QOL and using generic measures there was no relationship (Lassmann, Garibay Gonzalez, Melchionni, Pasquariello, & Snyder, 2007).
- Obesity (most often quantified as BMI) was most often not related to QOL in children/adolescents with SB unlike the peers where there is a relationship (Abresch, McDonald, Widman, McGinnis, & Hickey, 2007; Buffart, van den Berg-Emons, van Meeteren, Stam, & Roebroek, 2009; Flanagan et al., 2011; Tezcan & Simsek, 2013).
- Family variables such as family satisfaction and family resources have been related to QOL for adolescents and young adults (Bellin et al., 2013; Sawin, Buran, Brei, & Fastenau, 2003; Sawin et al., 2006)
- Adolescent resilience variables (e.g., attitude to SB, hope, future expectations, coping), lack of optimism and depression have been strongly related to HRQOL and QOL (Sawin et al., 2007; Sawin et al., 2003)
- Executive function was significantly related to QOL (Barf, Post, Verhoef, Gooskens, & Prevo, 2010).

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**

a. What factors are related to QOL?

b. What might QOL assessment and improvement activities look like in clinical practice?

c. What measures of QOL and HRQOL are the most efficient and useful?

- **Infancy**
  Clinical Questions
  
a. What factors are related to QOL?

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

- **Toddler**
  Clinical Questions
  
a. What factors are related to QOL?

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

- **Preschool**
  Clinical Questions
  
a. What factors are related to QOL?
  
b. What measures of QOL/HRQOL are the most efficient and useful?
Guidelines

• 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.
• Address assessment of executive function (see neuropsych guidelines)
• Target strategies to optimize bowel program as bowel incontinence is consistently related to HRQOL (especially social)

Schoolage Clinical Questions

• What factors are related to QOL?
• What might QOL assessment and improvement activities look like in clinical practice?
• What measures of QOL and HRQOL are the most efficient and useful?

Guidelines

Psychosocial/Cognitive

• Promote psychosocial well-being. (Omit if in the MH section-- 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)
• Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines)
• Refer to community resources that enhance protective factors (sports, camps, scouts, community programs)
• Address assessment of executive function (see neuropsych guidelines)

Continence

• Target strategies to optimize bowel program effectiveness as any bowel incontinence is the type of incontinence most negatively related to (especially social).
• Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency.

Pain
• Evaluate presence and characteristics of any pain experienced
• Develop strategies to address pain and its impact on school/work, recreation and social activities

Measurement

• Use a systematic approach to evaluating QOL/HRQOL.
• Consider using both self and parent-report instruments.
• 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.
• Use an age and condition specific instrument to assess HRQOL (see instrument appendix).
• Consider using a single-item QOL question with follow up assessment if needed.

Teenage Clinical Questions

a. What factors are related to QOL?
b. What might QOL assessment and improvement activities look like in clinical practice?
c. What measures of QOL and HRQOL are the most efficient and useful?

Guidelines

• Promote psychosocial well-being
  (OMIT if in the MH section-- 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)
• Consider strategies to assess and strengthen family functioning which can be of critical importance in child outcomes such as QOL (see family guidelines)
• Consider strategies to optimize peer relationships (see mental health guidelines).
• Consider the unique priorities important in quality of life for each individual.
• Refer to community resources that enhance protective factors (sports, camps, scouts, community programs)
• Address strategies to compensate for executive functioning challenges
Continence/mobility
- 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).
- Investigate the adolescent’s satisfaction with her/his bowel program. Address concerns to optimize program.
- Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency in adults.
- Consider functional mobility options that optimizes societal participation (see mobility and function guidelines).

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

Measurement
- Use a systematic approach to evaluating QOL/HRQOL.
- Consider using both self and parent-report instruments.
- 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.
- Use an age and condition specific instrument to assess HRQOL (see instrument appendix).
- Evaluate both self and parent-report of QOL/HRQOL. If assessment time is limited choose self-report of QOL/HRQOL.
- Consider using a single-item QOL question with follow up assessment if needed.

- Adult
  Clinical Questions

Guidelines
- Promote psychosocial well being. Identify strategies or resources 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).
- Explore satisfaction with relationships/sexuality (see sexuality section).
- Consider strategies to optimize peer relationships (see mental health).
• Consider the unique priorities important in quality of life for each individual.
• Refer to community resources that enhance protective factors (sports, camps, scouts, community programs, Universities with a strong support program for Students with Disabilities)
• Address strategies to compensate for executive functioning challenges

Continence/mobility
• 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)
• Investigate the adult’s satisfaction with her/his bowel program. Address concerns to optimize program
• Assess both volume and frequency of urinary incontinence as volume may be more distressing than frequency in adults
• Consider functional mobility options that optimizes societal participation (see mobility and function guidelines)

Pain
• Evaluate presence and characteristics of any pain experienced
• Develop strategies to address pain and its impact on school/work, recreation and social activities

Measurement
• Use a systematic approach to evaluating QOL/HRQOL.
• Consider using both self and parent-report instruments.
• 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?”
• Use an age and condition specific instrument to assess HRQOL (see instrument appendix).
• Evaluate both self and parent-report of QOL/HRQOL. If assessment time is limited choose self-report of QOL/HRQOL
• Consider using a single-item QOL question with follow up assessment if needed.
Note: 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, Summers, Turnbull, & Zuna, 2011) and “A summary appraisal of domains of life important to the family” (Ridosh, Sawin, Schiffman, & Klein-Tasman, 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**

  Continued refinement of HRQOL and QOL measurement including the relationship of individual and parent proxy reports is needed.

  Continued research is needed to identify the factors related to HRQOL and how change in these factors across time impacts HRQOL.

  Research is needed to determine if measuring HRQOL in clinical practice actually leads to activities that improve HQOL.

  Further research on the emerging concept of Family QOL and its association with child outcomes is needed.

  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.
## QOL Appendix 1: Summary and assessment of QOL/HRQOL/FQOL instruments

Summary and Analysis of QOL instrument used in Children, Adolescents and Adults with CHC - and their potential use in the SB population

<table>
<thead>
<tr>
<th>Name and authors</th>
<th>Short Description age range</th>
<th>Subscales</th>
<th>Assessment using parameters of Waters et al, 2009</th>
<th>Recommendation</th>
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<tr>
<td><strong>Generic instruments</strong></td>
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<tr>
<td><strong>PedsQL™</strong> (Varni) (child or parent SR) (J. W. Varni et al., 2006)</td>
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<tr>
<td>Scales for children (5-12) Adolescents (13-18) and young adults (18 and older). Well-established series of QOL measures. Relatively strong psychometrics across youth with many CHC and their typically developing peers. Parent and child versions</td>
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<td>Physical, emotional, social, cognitive (school/work)</td>
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<td>3</td>
<td>2</td>
<td>1</td>
<td>3 (5+)</td>
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<tr>
<td>Do not use physical scale</td>
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<tr>
<td>Emotional, social and cognitive scales may be useful especially if comparing to typically developing youth. However, heavy focus on functioning.</td>
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<td><strong>CHQ</strong> Child (187) or parent (50) SR (Raat, Landgraf, Bonsel, Gemke, &amp; Essink-Bot, 2002)</td>
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<tr>
<td>Parent and child version Developed by experts using literature and other instruments.</td>
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<tr>
<td>Behavior, bodily pain, general pain, mental health, parent impact-emotional, physical functioning, parent impact-time, role-emotional/behavioral, role-physical and self-esteem. Physical and Psychosocial summary scores.</td>
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<td>1</td>
<td>1</td>
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<td>1 (13+)</td>
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<td>Long, may be useful in specific circumstances or if specific subscales are of interest. No data on sensitivity to change. Multiple items with floor and ceiling effects. Not used extensively in SB (CP comparison indicated it was outperform</td>
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<td>Name and authors</td>
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<tr>
<td>KIDSSCREEN 52, -27, and 10 item versions. (Ravens-Sieberer et al., 2010)</td>
<td>Validated in 12 European countries using over 22,000 children aged 8 and 18 years of age. 10-item version supported with internal and test re-test reliability. Not used to date with children with SB.</td>
<td>Focus groups, cognitive interviews and pilot testing 52 and 27 versions include=5 domains Physical well being, psychological well-being, support and peers and financial resources.</td>
<td>3 3 3 3 3 *</td>
<td>Only child generic instrument rated as 3 in all categories by Waters et al, 2009 No known use in US to date in SB.</td>
</tr>
<tr>
<td>WHOQOL-BRIEF The WHOQOL Group, 1998</td>
<td>26 items in 6 domains. The WHOQOL-BREF is a shorter version of the 100 item original instrument. 1997 USA version available at: <a href="http://depts.washington.edu/seaqol/docs/WHOQOL-BREF%20with%20scoring%20instructions_Updated%2001-10-14.pdf">http://depts.washington.edu/seaqol/docs/WHOQOL-BREF%20with%20scoring%20instructions_Updated%2001-10-14.pdf</a></td>
<td>Physical health, psychological health, social relationships, and environment. Reference period: Last 2 weeks Questions positively worded and flexible for all conditions: (e.g., Do you have enough energy for everyday life?)&quot;</td>
<td>3 3 3 3 3 2 (2 6)</td>
<td>Preferred generic scale for adults with SB. Physical scale-while assessing the impact of physical status on QOL does so with items that does not automatically disadvantage individuals with a specific mobility-related impairment.</td>
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**SB-specific Instruments**

<p>| HRQOL-SB | Items positively phrased. Reflects many domains but no factor analysis or | 3 3 2 1 (only) 3 2 (4 5) 1 | Many items with ceiling effects. No |</p>
<table>
<thead>
<tr>
<th>Name and authors</th>
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<tbody>
<tr>
<td>Parent and teen report (Parkin et al., 1997)</td>
<td>test-retest reliability. Strong internal reliability Many items with ceiling effects</td>
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<tr>
<td>HOQ (Kulkarni, Rabin, &amp; Drake, 2004)</td>
<td>For children with hydrocephalus measures functional status. No factor analysis. Limited psychometric properties</td>
<td>Originated from focus groups</td>
<td>1 2 1 1 3 2 2</td>
<td>Factor structure. Strong internal reliability. May be more appropriate for general assessment of younger child by parent. Only total score supported so no domain assessment possible. Use with caution or if a longitudinal study with previous use.</td>
</tr>
<tr>
<td>Quality of Life Assessment (C, T, A) QUALAS – C 8-12 years (Szymanski et al., 2015)</td>
<td>A family of instruments (child, teen, adult) created to evaluate living with SB. Strong input from families/ those with SB. Qualitative interviews to develop instrument. Psychometrics assessed for each of the 3 instruments Child version for 8-12 years old. Time frame: last 4 weeks.</td>
<td>Two scales 1. Esteem and Independence 2. Bladder and Bowel Response pattern for all instruments in this family ranged from never to always (5 options) plus a alternative statement (e.g, Did it annoy you if you could not do what other teenagers could do -- in addition to the never to always response</td>
<td>3 3 3 3 (8+) 2 3 (1 0) 2</td>
<td>Based on qualitative and cognitive interviews. Assessed using appropriate ly large enough samples to assess construct validity. Good factor structure, internal and test-retest reliability. Some negative wording</td>
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<td>Name and authors</td>
<td>Short Description</td>
<td>Subscales</td>
<td>Assessment using parameters of Waters et al, 2009</td>
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<tr>
<td>QUALAS-T (Szymanski, 2017)</td>
<td>Teen version with 10 items and 2 scales. (ages 13-17)</td>
<td>Two scales 1. Family and Independence 2. Bladder and Bowel</td>
<td>HF/QOL Family Perso Focus OP Sel-Est # R V</td>
<td>(upset, embarrasse d, bother you) but generated from qualitative interviews and affirmed by cognitive interviews. No physical scale (could be a asset or liability). Child: Useful to assess how self-esteem and bowel and bladder status is perceived Teen: Useful to assess the two domains. May not be a useful measure of overall HRQOL.</td>
</tr>
<tr>
<td>QUALAS-A (Szymanski et al., 2015)</td>
<td>Adult version with 15 items and 3 scales for ages 18 and above. All items in health and relationships positively worded. Bowel and Bladder scale same for teens and adults so can use same scale for those 13 or older</td>
<td>Two scales 1. Health and relationships 2. Esteem and sexuality 3. Bladder and Bowel</td>
<td>First scale allows for assessment of health and relationships. Important inclusion on items on sexuality (only Instrument that does ). Sexuality items might be also appropriate</td>
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was “I could do what other teens do”
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<td></td>
<td>HF/QOL</td>
<td>Famil y/ Perso n</td>
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<td>alpha ≥ 0.70, ICC ≥ 0.77). Correlations between QUALAS-A and WHQOL-BREF were low except for high correlations with Health and Relationships domain (0.63 ≤ r ≤ 0.71).</td>
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<tr>
<td>SBPQ Quality of life questionnaire for children with spina bifida (Velde et al., 2016)</td>
<td>Dutch scale Developed by using existing items from other instruments (PedsQL and Fecal Incontinence QoL survey, n=10) and qualitative interviews yielded additional 25 items for total of 35 items for children 6-18 years mental age. Questions address last 3 months 11 minutes to complete</td>
<td>Physical functioning, social functioning, emotional functioning, school, home and hospital. Child and parent versions available with picture book for children</td>
<td>Physical functioning</td>
<td>3</td>
</tr>
<tr>
<td>Name and authors</td>
<td>Short Description age range</td>
<td>Subscales</td>
<td>Assessment using parameters of Waters et al, 2009</td>
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<tr>
<td>Development of a tool to describe .......... (Deroche et al., 2015)</td>
<td>QOL instrument for adolescents with a disability Used 174 adolescents with spina bifida, (38%); muscular dystrophy, and fragile x syndrome to develop tool</td>
<td>Emotional health, physical health, independence, Activity limitation, and Community participation.</td>
<td>HF QOL Famil y Perso n Focus OP Sel f Est # R V</td>
<td>The physical scale addresses specific tasks (vigorous activities, running heavy lifting) and should be avoided. The community participation scale is useful and the activities scale would be more useful if stated in a positive manner (what the individual can do rather than focus on limitations).</td>
</tr>
<tr>
<td>Single item QOL</td>
<td>A part of many instruments. Overall how would you rate your QOL</td>
<td>Allows individual to determine domains important to</td>
<td>HF QOL Famil y Perso n Focus OP Sel f Est</td>
<td>Does not help the HCP identify what</td>
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<tr>
<td>Name and authors</td>
<td>Short Description</td>
<td>Subscales</td>
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<tr>
<td>(Sawin &amp; Bellin, 2010)</td>
<td></td>
<td>her/him self and prioritize domains based on personal perception</td>
<td>HF / QOL</td>
<td>determines QOL for the individual. Would need a FU question to identify domains important to particular pt.</td>
</tr>
<tr>
<td>Faecal Incontinence (FIC) QoL survey not included here as it addresses only one aspect of HRQOL. Those who wish additional information on this scale are referred to Nanigian et al., 2008 and Sawin &amp; Bellin, 2009</td>
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<tr>
<td>FAMILY QOL (for full discussion of FQOL scales see Hu et al, 2011)</td>
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<tr>
<td>PedsQL™ Family Impact Model (parents SR) (Varni et al., 2006)</td>
<td>1. Impact of pediatric chronic health conditions on parents functioning</td>
<td>1. Problems with physical, emotional, social, and cognitive functioning, communication, and worry. 2. Problems with family activities and relationship</td>
<td>3 1 1 1 2(3 6 ; 2 8 &amp; 8)</td>
<td>Some have used for FQOL and the authors do indicate it can be used for QOL assessment. It indeed is an assessment of impact on the family but may not be assessment of QOL. Heavy function emphasis.</td>
</tr>
<tr>
<td>FQOL Generic tool (Ridosh et al., 2016)</td>
<td>Created for use with family with AYA with SB</td>
<td>Items allows the responder to include domains important to them and to rank the domains according to their own priorities. Rated from 0-100; summed and added</td>
<td>3 2 3 3 3 3 (3 )</td>
<td>Has been evaluated in sample of adolescents/young adults with SB (n=120) and a comparison sample (n=98). Found to have strong preliminary psychometrics including one factor,</td>
</tr>
<tr>
<td>Name and authors</td>
<td>Short Description age range</td>
<td>Subscales</td>
<td>Assessment using parameters of Waters et al, 2009</td>
<td>Recommendation</td>
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<tr>
<td>Beach Family Quality of Life Scale (FQOL) (Hu et al., 2011) (Hoffman, Marquis, Poston, Summers, &amp; Turnbull, 2006)</td>
<td>Purpose: measure several aspects of families' perceived satisfaction in 5 domains: Family Interaction, Parenting, Emotional Well-being, Physical / Material Well-being, and Disability-Related Support.</td>
<td>25-item questionnaire; 5 point Likert-type response pattern</td>
<td>Very dissatisfied to very satisfied. Available from <a href="http://www.midd">http://www.midd</a> ss.org/sites/default/files/fqol_survey.pdf</td>
<td>high internal reliability.</td>
</tr>
</tbody>
</table>

Waters et al framework for assessing QOL and HRQOL measures

1. **HF/QoL**: Original purpose of instrument. Health/functioning =1; midrange =2; QoL 3;  
2. **Family**: Origin of items Low involvement of family =1; midrange =2; High involvement of family =3  
3. **Focus**: Actual focus of the instrument Functioning =1; midrange=2; well-being=3  
4. **OPP**: Opportunity to self-report No opportunity to self-report=1 midrange =2; self-report version available =3  
5. **Self-Est**: Potential threat to self-esteem Negative working =1; midrange=2; Positive wording=3  
6. **# items**: Length Large number of items =1; midrange =2; small number of items =3  
7. **R & V**: Psychometric properties Poor or not demonstrated=1; midrange=2; excellent and demonstrated adequately


