Fact Sheet
Quality of Life Considerations in School-Age Children with Cerebral Palsy

The TRIPSCY Evidence-based Journal Club is a means for Vermont Pediatric Physical and Occupational Therapy Practitioners and others to stay abreast of the research literature and integrate it in their practice to benefit children and their families.

Introduction:
Quality of life (QoL) is a person’s perception of their “life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1997, p. 1). The term ‘health-related quality of life’ (HRQL) is a narrowing of QoL to the parts that can be influenced by a person’s health and/or diagnosis (Wood-Dauphinee, 1999). Thus, HRQL is children’s feeling about the impact of their conditions and services on different aspects of their life and is more related to functioning (De Civita et al., 2005; Majnemer, Shevell, Law, Poulin & Rosenbaum, 2008). Quality of life and HRQL are priority outcomes for health and rehabilitation services (Majnemer et al., 2008).

Articles reviewed:
There have been many studies of QoL and HRQL in school-age children with cerebral palsy. Articles that covered the breadth of available information were selected for this review including the comparison of QoL of children with and without CP, viewpoints of children and parents about children’s QoL, and identification of factors related to improving or hindering QoL of children (Dickinson et al., 2007; Gates et al., 2010; Rosenbaum et al., 2007; Russo et al., 2008; Shelly et al., 2008; Varni et al., 2007). As a group, the studies reviewed had strong methodology and had similar findings although they were conducted in different countries. Thus their results can be trusted.

Key information learned from the studies:
• The QoL of Children with CP is similar to that of typical developing children (Dickinson et al., 2007). This may seem counter-intuitive. This may be explained by a well-studied phenomenon referred to as ‘response shift’, which refers to a person’s own evaluation of their QoL being altered by experiencing a disability or illness. A response shift is a: change in the person’s own criteria for measuring their QoL; change in the person’s values; and/or, a redefinition of the meaning of disability or illness by the person (Schwartz et al., 2007).
• Neither the degree of motor impairment nor the specific types of impairments of children is associated with their QoL (Dickinson et al., 2007; Rosenbaum et al., 2007). However the degree of motor impairment is related to children’s perceived HRQL (Rosenbaum et al., 2007; Varni et al., 2007). With increased degree of impairment HRQL decreases.
• The QoL of most children with CP is similar to other children and is associated with social and environmental factors (Dickinson et al., 2007).
• There are differences between parental and child perceptions of children’s QoL (Gates et al, 2010; Shelly et al., 2010). Parents relate their children’s QoL to the activities the child can do, or their child’s physical function (Shelly et al., 2010). They associate difficulties performing activities to components of QoL such as social well-being and acceptance, emotional wellbeing, feelings about functioning, participation and physical health (Shelly et al., 2010). In contrast, children report that they can experience high QoL in these same components regardless of their level of physical functioning (Shelly et al., 2010). It should be noted that difference between children and parental ratings of children’s QoL does not indicate that either are wrong or that either are inaccurate raters of QoL. Instead, it represents the fact that they perceive QoL and HRQL differently (White-Koning et al., 2005). Also of note, health professionals’ estimates of children’s QoL is consistently lower than that of parents, and most different from the children’s own self-estimate (White-Koning et al., 2005).

• Children with CP who experience pain have poorer quality of life as rated by parents and the children (Dickinson et al., 2007; Russo et al, 2008). Pain does not appear related to degree of impairments (Dickinson et al., 2007). These children, regardless of age, perceive themselves to be less scholastically and behaviorally competent (Russo et al, 2008). Older children with pain had worst self-perception of athletic competence, self-worth and physical appearance and younger children with pain had worst self-perception of physical competence (Russo et al, 2008).

• Russo and colleagues (2008) found that pain is a common problem in children with CP since 48% of children in their study reported having pain. The pain was primarily on the affected side either the leg or the arm and the leg. The pain had generally an aching quality and mild severity for 2/3 of children, and was moderate to severe for 1/3 of the children. Pain was intensified by movement, immobility and fatigue. It is important to note that pain could be relieved by massage, rest, sleep and analgesia although the latter tends to be underused (Russo et al, 2008). Pain is a present an/or capable of emerging variable that can impact HRQOL (Schwartz et al., 2007).

Take Home Message...

Quality of Life (QoL) and Health Related Quality of Life (HRQL) are based on the perceptions of individuals who experience disability or illness and should not be confused with labels, symptoms or diagnoses. QoL for children with CP is an important outcome of treatment and intervention for education, health and rehabilitation professionals. HRQL includes the individual’s perceptions of a wide range of physical, emotional and participation factors. Therapists should be cautious about their tendency to attribute a greater impact of the disability on QoL than either children or their parents do, and should avoid imposing their own judgments and values. As professionals, we can and should explore QoL issues with children and families using valid tools and methods (see resources), including scales developed for children with intellectual disabilities. It is important to share resources to improve our ability to assess QoL and assure that children and their families are involved in the discussion of intervention priorities that impact their QoL.

Degree and type of impairment can explain differences between perceptions of HRQL of children with CP. While physical functioning, or the ability to perform specific activities, is positively correlated with QoL perception, it also important to acknowledge and share with teachers and parents that children can have a good QoL regardless of what they can and can’t do. Therapists are usually focused on impairment issues and have an important role in improving and developing functional skills. Professionals also need to consider and ask about the presence and impact of pain. Pain has a direct impact on QoL and functioning in children with CP. Therapist have a role in educating families and other professionals about the need to actively relieve and manage pain through various strategies (e.g. massage, rest and sleep), and should be alert to the fact that medication to treat pain is generally underused and may be needed. Rehabilitation personnel may be able to help teachers and parents interpret problematic behaviors that could be the results of pain, other health and/or sensory issues and may be able to suggest environmental modifications in the classroom or at home that can decrease pain. As a group, we might explore the usefulness of a pain protocol for use in schools.

Finally, the literature related to QoL of children with disabilities is not limited to children with CP. We need to consider the QoL perceptions of children with other disabilities as well, including those with anxiety, depression and other behavioral challenges. Whenever possible, health care providers should seek input form both parent and child when making decisions about treatment priorities. Clinicians should also support changes in the attitudes of society about children with disabilities, moving from pity and sorrow toward efforts to address acceptance and full participation in society, which can positively impact QoL of all children.
Resources: Assessing Children’s QoL in the clinical and at school

- Pediatric QoL measures (American College of Rheumatology QoL Questionnaire). http://www.rheumatology.org/practice/clinical/forms/index.asp

Resources: Pain Questionnaires

- Non-Communicating Children’s Pain Checklist measures - http://pediatric-pain.ca/content/Measures

Reference List:


