Thames Valley Children's Centre

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Research Program, TVCC
779 Base Line Road East
London ON N6C 5Y6
519.685.8680 www.tvcc.on.ca

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What is "Quality of Life"

and How Can Research Identify the Factors that Optimize Life Quality for Children and Youth with Chronic Conditions?

Introduction

Optimization of **quality of life (QOL)** for children and youth with chronic conditions is becoming a primary goal of pediatric rehabilitation services and a central focus of health research (King, Tucker, Baldwin, & LaPorta, 2006). However, **little is yet known** about which factors can best enhance QOL for this group of young people (Rosenbaum, 2008).

A primary concern in the area of pediatric QOL research has been a lack of clarity about what QOL means. Although people have a general understanding of what QOL is, it is very important that this concept be **accurately conceptualized and measured** when conducting research so that the factors that impact it can be identified and then targeted for service.

The **purpose of this summary** is: 1) to briefly **consider the major conceptual and methodological issues** surrounding pediatric QOL research; and 2) to **identify areas for future research** that can help to inform policy and practice about the factors that are most important for optimizing QOL for children and youth with chronic conditions.

Defining Quality of Life

There are numerous ways to think of QOL. In 1995, there were **more than 100 definitions** in the literature (Cummins, 1995), and this number has increased since then. However, few definitions are based on a conceptual theory or framework of QOL (Renwick, Fudge Schormans, & Zekovic, 2003).

Despite the plethora of definitions and the lack of conceptual theories or frameworks, two primary approaches have emerged for thinking about QOL: a **health-related approach** and a **holistic approach** (Zekovic & Renwick, 2003). QOL has often been evaluated in terms of health-related concepts, like physical symptoms, functional status, or general health. However, many researchers suggest that health-related QOL should not be differentiated from a broader, holistic notion of QOL (Davis et al., 2006; Wallander, Schmitt, & Koot, 2001). That is, QOL does not depend primarily on a child's health status; rather, **health status is only one of several factors related to QOL** (King, Schwellnus, Russell, Shapiro, & Aboelele, 2005).

Issues for Quality of Life Research

Zekovic and Renwick (2003) identify **four issues** important to consider in pediatric QOL research: 1) **applicability** (is QOL the same for children despite their health status?); 2) **nature** (is QOL a subjective or objective phenomenon?); 3) **dimensionality** (is QOL a unidimensional or multidimensional concept?); and, 4) **information source** (whose perspective should be sought on children's QOL?).

Applicability. The general consensus in the literature on disability is that **QOL has basically the same meaning for all people** (Zekovic & Renwick, 2003). Moreover, the QOL of children and youth with chronic conditions is often comparable to those without chronic conditions. For example, recent studies of children with cerebral palsy indicate that half or more report their QOL to be similar to children without cerebral palsy (Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007; Dickinson et al., 2007).

Nonetheless, it is important to examine why some individuals enjoy a higher QOL than others, and to **take certain health-related factors into consideration** when examining QOL for children and youth with chronic conditions. For example, one could measure the age of onset of a condition and assess its impacts on QOL.

Nature. QOL has been evaluated using **objective** (e.g., socioeconomic status, presence or absence of a chronic condition) and **subjective or perceived** measures (e.g., perceptions of self-esteem, perceptions of social support).

The World Health Organization Quality of Life Group (1995) defines QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns." Indeed, QOL is often defined as an individual's overall perception of life satisfaction/enjoyment (Anderson & Burckhardt, 1999). For example, Renwick and Brown (1996) define QOL as "the degree to which the person enjoys the important possibilities of his or her life."

These definitions reflect the point of view that **QOL may be best understood as a subjective evaluation by a person of the overall degree of positivity in his/her life that can be influenced by the interplay of multiple subjective and objective factors**.

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While there may never be complete agreement about how to conceptualize, measure, and study a concept as abstract as QOL, **an approach that views QOL as a subjective phenomenon may provide a better fit with a client autonomy model** where clients are viewed as experts with respect to their own life quality (Dijkers, 1999).

Dimensionality. QOL is generally considered to be a multidimensional concept. The primary dimensions of QOL that are most often identified include **physical, psychological, and social functioning/well-being.** Others extend upon these core dimensions to include domains such as personal development, spirituality, material well-being, and human rights (Verdugo, Schalock, Keith, & & Stancliffe, 2005). In addition, particular dimensions have been identified as perhaps more important at certain points in life. For example, autonomy and body image may be especially important in adolescence (Eiser, 2007).

However, measures that are used in studies to identify correlates of QOL often include **life dimensions that overlap** with those included in the actual measures of QOL. One approach that avoids confounding the measurement of QOL with the measurement of potential correlates is to measure QOL as a unidimensional concept, in terms of a person's ***overall*** **life satisfaction or** ***global*** **perceived QOL (PQOL),** and then to examine its association with the multiple factors hypothesized to be influencing it.

Indeed, studies of children and youth in the general population that have taken this approach have found significant positive correlations between **personal** and **interpersonal** factors (e.g., self-esteem, hope, extroversion) and global PQOL (Huebner, Gilman, & Suldo, 2007).

Information Source. Research indicates that **school-aged children can self-report** on their health and well being (Riley, 2004), and that it is important for them to do so because their subjective feelings about themselves and their life quality can only be known to them (Topolski, Edwards, & Patrick, 2004). However, **the perspectives of both children and their families can be helpful** for making decisions related to interventions since each is likely to have unique knowledge about, and place different values on, various life dimensions (Feldman, Grundland, McCullough, & Wright, 2000).

In addition, **objective information** (e.g., amount of service utilization) collected from both families and other sources can contribute to a comprehensive assessment of the factors impacting PQOL and can help inform decision-making.

Areas for Future Research

- **Qualitative studies** with children and families would facilitate the development of new theories and frameworks of QOL and extend upon existing frameworks. For example, a qualitative study by Renwick and colleagues (2003) led to the conception of a framework of QOL specifically for children with developmental disabilities where the fundamental elements of QOL are: 1) the child; 2) his/her family environment; and 3) the broader environment. Additional qualitative work could focus closely on factors (e.g., spirituality) within each fundamental element to examine their unique contribution to QOL.
- **Development and testing of short, easy-to-complete instruments** that measure the multiple life dimensions associated with children's and youths' PQOL, and that measure global PQOL, would be useful for substantiating the relationships between these concepts in population-based studies.
- **Longitudinal studies** that obtain information from multiple sources would be helpful for identifying the the relative contribution of personal, interpersonal, and environmental factors to global PQOL over time. These studies would also help identify which factors are most influential at important transition periods for children and youth with chronic conditions. Such research **could assist policy makers, administrators, and service providers** in designing and providing services that will optimize QOL throughout childhood and adolescence.

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For more information, contact:

Janette McDougall, Ph.D.
Researcher
Research Program
janette.mcdougall@tvcc.on.ca

779 Base Line Road East
London ON N6C 5Y6
Phone: 519-685-8680, Ext. 53377
Fax: 519-685-8696

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