

## How Can Perceived Quality of Life be Optimized for Youth with Chronic Health Conditions Throughout Adolescence?

### Introduction

In recent years, there has been growing interest in health and disability research to explore quality of life in terms of **individuals' own perspectives** of their life in general, and what factors or aspects of life influence those perspectives. There is increasing emphasis for public policy to be more closely aligned with **what really matters to people** as far as what they think of their life quality and what might make it better (Helliwell, Layard, & Sachs, 2011). Countries, governments, and organizations are seeing the importance of collecting information about individuals' perceptions of their own subjective well-being. Asking people if they are satisfied with their QOL and collecting information about what may be related to that satisfaction can **reveal underlying strengths** and **critical hidden issues** about individuals and the society they live in (Helliwell et al., 2011). It can suggest the **need for change**, such as the need for new or different types of supports, services, or attitudes.

Recently, the Office of the Provincial Advocate for Children and Youth in Ontario conducted the *I Have Something to Say* (IHSTS) project where they collected online submissions from children and youth with special needs and their caregivers to understand what aspects of these children's lives, and the government services they receive, could be improved. **Four overarching themes** emerged: family and home, school and education, supports and

services, and transitions across the lifespan (Provincial Advocate for Children and Youth, 2016).

At the same time the IHSTS project was taking place, a study (McDougall et al., 2016) funded by the Canadian Institutes of Health Research (CIHR) was being done that followed a group of youth who were receiving care from the Ontario Association of Children's Rehabilitation Services (OACRS) centres to understand how they perceived their QOL over the course of three years, and what factors influenced those perceptions.

### Purpose of this Summary

This summary describes the CIHR-funded 'QOL' study and its results, and highlights key areas where service providers and policy makers can focus their efforts in order to **optimize QOL for youth with chronic health conditions** as they develop throughout adolescence.

### What was Done

This multi-centre, longitudinal study examined **two unexplored research areas**: 1) the changing nature of perceived QOL for youth with chronic conditions; and 2) the personal, interpersonal, and environmental factors associated with changes in their perceived QOL.

Four hundred and thirty-nine youth, aged 11 to 17 years were recruited from eight OACRS centres to participate in the study. In order to

obtain a comprehensive picture of youths' QOL, one parent for each youth also participated. Both the youth and parent (or primary caregiver) completed a study **questionnaire at four time points over a three-year period**. The youth and parent questionnaires measured personal, interpersonal, and environmental variables related to everyday life at home, school, and in the community. Perceived QOL was assessed using abbreviated youth and parent versions of the Student Life Satisfaction Scale (SLSS) (Huebner, 1991) that includes six items such as "My life is just right"; "My child's life is just right."

Advanced statistical techniques were used to identify unique QOL **change trajectories** within the study sample across the four assessment points, and to ascertain the factors associated with those trajectories (for details, see McDougall et al., 2016).

### Study Findings

Two QOL trajectories were identified from the youth data: 86% of youth reported 'high and stable' (i.e., unchanging) QOL and 14% reported 'moderate/low and stable' QOL.

Three trajectories were found from the parent data: 36% reported their youths' QOL to be 'high and stable,' 46% reported it to be 'moderate and stable,' and 18% reported it to be 'moderate/low and stable.'

Relative to the 'high and stable' groups, youth with more reported pain/other physical symptoms, emotional symptoms, and home/community barriers were **more likely** to be in the 'moderate and stable' or 'moderate/low and stable' groups. Also, youth with higher reported self-determination, spirituality, family social support, family functioning, school productivity/engagement, and school belongingness/safety were **less likely** to be in the 'moderate and stable' or moderate/low and stable' groups, compared to the 'high and stable' groups.

### Discussion and Implications

All trajectories appeared **stable over three years** of follow-up. The **majority of youth reported high QOL** over time. Yet, distinct groups existed within the study sample, with lower levels of QOL. Researchers have demonstrated that when resources are lacking and excessive demands are placed on an individual or groups of individuals, subjective well-being can be overwhelmed (Cummins, 2016). Moreover, when such circumstances are ongoing, perceptions of low QOL can become a **stable and ongoing phenomenon**.

For individuals who experience ongoing perceptions of low QOL, research suggests that **interventions can serve to restore their subjective well-being** to a high and stable state (Tomyn, Weinberg, & Cummins, 2015). In this 'QOL' study, multiple contextual factors were related to membership in the 'moderate and stable' and 'moderate/low and stable' trajectory groups. Although universal prevention efforts for all youth are important, **this evidence highlights the need for targeted programs** for those experiencing the greatest threats to their QOL to try to shift them to a higher trajectory. Moreover, it appears these individuals benefit most from additional resources and supports (Tomyn et al., 2015).

#### *Key Factors Associated with QOL over Time*

Emotional symptoms were associated with membership in other trajectory groups compared to the 'high and stable' groups. Pain/other physical symptoms were associated with 'moderate and stable' and 'moderate/low and stable' group membership. This study suggests **emotional and pain/other physical symptoms** can have longstanding effects on QOL for a significant number of individuals and should always be inquired about in initial assessments and **carefully monitored and treated** throughout childhood and adolescence.

Youth with higher **spirituality**, described in the study questionnaire as ‘**any deep feelings or beliefs**’ were less likely to be in the ‘moderate/low and stable’ groups. **Listening to youth** and communicating effectively to understand the importance of personal meaning in their lives may prove helpful for identifying those youth who are experiencing ongoing poor QOL (King et al., 2012).

Moreover, like the IHSTS project, this research indicates the importance of focusing on home, school, and community environments, family, education, supports and services, as well as transitional periods in youths’ lives. Youth with higher **family social support** and higher **family functioning** were less likely to be in the ‘moderate/low and stable’ groups. More **barriers at home** (e.g., family stress) and **community barriers** (e.g., lack of supports and services) were both associated with membership in the ‘moderate and stable’ and the ‘moderate/low and stable’ groups.

**Routine assessment of family well-being** and **community barriers** in childhood and adolescence by service providers could help to identify those children and their families who require additional supports and resources.

Youth with higher **school productivity/engagement** were less likely to be in the ‘moderate and stable’ and ‘moderate/low and stable’ groups. Similarly, youth with a greater sense of **school belongingness/safety** and higher **self-determination** were less likely to be in the ‘moderate/low and stable’ groups. **Universal prevention programs** may be important for promoting inclusive school cultures and for maintaining high QOL for youth who are functioning well at school, while the QOL of those who are experiencing difficulties with learning and motivation may benefit most from **targeted interventions** at school that are available from early childhood and during important transitional periods.

## Summary

**To optimize perceived QOL** for youth with chronic health conditions as they move through adolescence, service providers and policy makers may want to ensure the use of a comprehensive, biopsychosocial, strengths-based approach and focus their efforts on:

- Youths’ physical health, including pain prevention and management;
- Youths’ emotional well-being, including a sense of purpose and meaning in life;
- Family support for youth and overall family functioning;
- Youths’ school productivity/engagement and self-determination in terms of goal orientation;
- Physical and social barriers in the school and community environments; and
- Availability of ongoing supports and resources at home, school, and in the community and during important transitions.

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