

## Quality of Life, Self-Determination, and Spirituality: What Youth with Chronic Conditions Have to Say

### Introduction

This summary outlines findings of a qualitative study conducted as part of a mixed-methods research project titled, *The Impact of Personal, Interpersonal, and Environmental Factors on Changes in Quality of Life for Youth with Chronic Conditions*.

Objectives of the qualitative study were to explore what the terms '**quality of life,**' (QOL) '**self-determination,**' (SD) and '**spirituality**' mean to youth with chronic health conditions. Youth were also asked to think about what factors contribute to these three concepts, and what connections might exist between QOL and SD, and QOL and spirituality. A purposive sample of 18 youth aged 11-20 years with various conditions, such as cerebral palsy, other central nervous system disorders, and Asperger's syndrome participated in semi-structured interviews which were analyzed using a qualitative descriptive methodology (Sandelowski, 2000). Transcripts were coded line-by-line, codes were collapsed into categories, and themes were identified.

### What does Quality of Life Mean to Youth?

Youth described QOL as an **overarching personal evaluation** of their life. In their descriptions, youth included terms such as feeling 'satisfied,' 'happy,' 'good,' and 'enjoying life.' One participant said, "*The value of your life and how much you think you are enjoying your life, or how good your life is for you.*"

Having feelings of **purpose in life** and **self-determination** were also spontaneously included in some youths' definitions of QOL. For one youth, QOL was about "*Waking up and feeling happy...having a sense of purpose...*", while another participant stated that "*You live life to the fullest and you never give up.*"

### Factors Affecting Quality of Life

**Relationships** with family, friends, and professionals were consistently described as important to QOL. Youth talked about the positive impact of close relationships in terms of the provision of support and acceptance. Some youth said they would like to see changes in their relationships to improve their QOL (e.g., gaining more friends, becoming less dependent on parents).

**Supportive environments** included aspects of home, school, and community that impact youth's QOL. Youth discussed the availability of resources, physical accessibility, and experiences of social supportiveness. Examples include receiving career planning support at school, getting a wheelchair accessible van, and expanding one's social network at university.

**Doing things** that youth enjoy and find meaningful was described as enhancing QOL. Participation in leisure and recreational activities were seen to contribute positively to well-being, and youth spoke about the significance of their involvement in sports,

clubs, and more casual activities, such as going to the mall.

**Personal growth and moving forward** was framed in terms of learning inside and outside of school, as well as reflecting on impactful life experiences, such as attending camp. Doing well at school and planning for post-secondary education and future employment were considered especially important by older youth.

**Self-understanding** was rooted in an **acceptance of disability** that was thought to positively impact QOL. Youth talked about personal advantages and strengths that they have developed through living with a disability. For example, one youth described her compassion toward others who are living in “worse off” situations. (See McDougall, Baldwin, Evans, Nichols, Etherington, & Wright [2015] for a full discussion of participants’ QOL definitions and factors related to QOL).

### What does Self-Determination Mean to Youth?

SD was described in terms such as ‘independence,’ ‘freewill,’ ‘believing in yourself,’ and ‘goal achievement.’ One youth described SD as *“Being determined, like not backing down. Standing up for what you want, and what you need as a person.”*

### Contributors to Self-Determination

**Personal strengths**, intrinsic to each youth, were noted as important factors leading to SD. These included characteristics such as willpower, perseverance, confidence, motivation, not being afraid to ask for help, and a desire to achieve.

**Interdependence**, both giving and receiving emotional and tangible support helped youth become independent and make their own choices. When asked what needed to be in place to be self-determined, one youth said, *“Probably the support of my family and friends, and them, like helping me with*

*whatever goal that I’m doing, or just being supportive of what I want to do and not telling me that I can’t do it, and the support of the people at school.”*

**Functional independence**, including taking care of one’s needs and getting around on one’s own, facilitates self-determination. Youth talked about the importance of accessing transportation, resources, and developing life skills such as cooking and earning money.

The link between SD and QOL was made clear: **SD leads to good QOL**. As one youth said, *“You need to have self-determination in order to improve yourself and improve the circumstances around you for you to have a quality life.”* (See McDougall et al. [2015] for further detail on how youth define SD and its contributors).

### What Does Spirituality Mean to Youth?

Many of the youth defined spirituality within a religious context, describing their relationship with God or a higher power. Others described spirituality more philosophically in terms of purpose in life, or used broad statements such as “having a life that’s unique” or that “everything happens for a reason.”

### Key Spiritual Themes

**Importance of beliefs:** Youth discussed a diversity of beliefs, ranging from belief in God, to more general ideas about the self, for example: *“You have to believe in yourself to have your dreams and goals.”*

**Sources of strength and comfort:** Beliefs were also discussed in terms of personal strengths that facilitate living well, for example, having compassion and a sense of humour. Participants provided specific examples of practices that foster strength and comfort including: prayer, artistic self-expression, time alone or time with others, meditation, and following routines.

**Finding purpose in helping others:** Youth talked about the reciprocal benefits that come from helping others, being kind and compassionate, and accepting differences. As one youth said, *“I guess I feel better about myself when I help someone. When I’m helping others I feel closer to God.”*

**Personal connections and perspectives on disability** were factors contributing to both QOL and spirituality. Youth spoke about the importance of personal connections with family, friends, and professionals, as well as being connected with self and with God. Relationships with others provided love, emotional and practical support, guidance, and encouragement. Youth talked about their understanding of disability in ways which highlighted both the realities of their limitations and the insights and advantages gained through living with a disability. One youth affirmed that *“Having a disability drives you more than another person ...disability makes your sense of purpose strong.”*

Youth spoke about the various ways that **spirituality is linked with QOL**, with one participant stating that, *“If you're on the right path and you feel like you're in a good spot wherever that might be then you probably have the perception that your quality of life is pretty good.”* (See Baldwin et al. [2015] for a full discussion of spiritual themes).

### Implications and Conclusion

Exploring the rich descriptions of QOL, SD, and spirituality given by youth with chronic conditions illustrates the significance of these concepts in their lives. Youth have made clear connections between SD and improving QOL, as well as the role of spirituality in having good QOL. The breadth of factors contributing to QOL, SD, and spirituality lend support for a shift in rehabilitation toward a more **holistic approach to service delivery**, extending beyond a focus on improving physical impairments and functional limitations.

With a common goal of optimizing QOL, health and other professionals should also consider SD and spirituality and other contributing factors, such as relationships, supportive environments, participation, personal growth, and self-understanding as critical elements of taking a **strengths-based approach** toward supporting youth.

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### For more information, contact:

**Janette McDougall**, PhD  
 Thames Valley Children’s Centre  
 779 Base Line Road East, London ON, N6C 5Y6  
 Phone: 519.685.8700 ext 53377  
 Email:janette.mcdougall@tvcc.on.ca

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