Beyond disability

Quality of Life for Youth with Chronic Conditions:

A Longitudinal Study

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Funding

- Funded by:
  Canadian Institutes of Health Research ($742,340)

  2009-2017

Research Team Acknowledgement

- **Co-Principal Investigator**
  - Virginia Wright, Bloorview Research Institute
- **Co-investigator**
  - Linda Miller, Western University
- **Across 8 OACRS Centres**
  - 2 Clinician/Researchers
  - 2 Project Coordinators
  - 7 Research Assistants
  - 18 Study Interviewers
  - 8 Collaborators
- **Centres** (London, Toronto, Ottawa, Sudbury, Chatham-Kent, Windsor, Kingston, Simcoe York)

Introduction

- **Positive psychology** has been referred to as a **component** of an **'emerging disability paradigm'** because of its implications for considering conceptions of **well-being** in people with chronic health conditions (Schalock, 2004)
- Until recently, research in pediatric rehabilitation, as in traditional psychology, primarily focused on **repairing what is considered 'dysfunctional'**

Introduction

- Changes in thinking have led to a shift in the field from this traditional perspective to **a broadened perspective** that sees health and functioning as resulting from the **interaction** between a **person** and the **environment**
- In addition, this broadened perspective has come to include a focus on **enhancing individuals' intrinsic strengths** to promote well being
- In pediatric rehabilitation research, there is increased interest in focusing on **positive outcomes,** such as **quality of life**

What is ‘Quality of Life’?

Conceptual Approach to QOL

- QOL in pediatric health and rehabilitation has often been evaluated as health-related QOL by proxy (parent/clinician) in terms of **physical, emotional, social functioning/well-being**
- In many studies, measures of correlates of QOL often overlap with measures of QOL itself - can lead **to confounding results**
- Some suggest it should be defined/measured in terms of an individual's **life satisfaction or overall perceived QOL** (Beckie & Hayduk, 1997; Ferrans, 1996; Moons et al., 2006), and then concepts such as physical, emotional, social functioning/well-being, environment, etc. could be examined as correlates

Conceptual Approach to QOL

- Increasingly, countries, governments, and institutions are coming to believe collecting information about individuals' perceptions of their **subjective well-being** (e.g., life satisfaction, happiness) is equally as important for assessing QOL as collecting information about their **objective well-being**

- It is now recommended by the **World Health Organization** that countries include a measure of **overall life satisfaction** in their national surveys
  - This indicates the WHO's support for overall life satisfaction as being **relevant to people's QOL** and as **important for policymaking and societal improvement**

Study Focus/Aims

- This study addressed **2 unexplored research areas:**
  - **1) <u>the changing nature</u>** of overall **perceived QOL** for youth with chronic conditions over a 3-year period (4 time points spaced 12 months apart), and
  - **2) <u>the factors</u>** that influence **change** in overall perceived QOL for youth
- **Both** youth and parent perspectives were gathered
  - Recruited from the **8 OACRS centres**
  - **439 youth** (and their primary caregivers) joined the study at baseline

Study Participants

- Youth participants were between 11 and 17 years old age (13, 10 months on average) when they entered the study
- 56% male
- 35% (153) **cerebral palsy**, 13% (59) **acquired brain injury**, 9% (41) **communication disorders**, 8% (38) **autism spectrum disorders**, 8% (36) **spina bifida**, and 26% (112) **another condition** (e.g., developmental delay, Down syndrome, amputee, etc.)
- Parent participants primarily birth mothers (83%)

Study Methods

- Questionnaires were administered to youth and their primary caregiver shortly after **admission to the study and then again every 12 months for 3 years** (4 time points)
- Each youth took part in **a face-to-face interview** (30-60 minutes)
- The parent questionnaire (30-60 minutes) was **self-completed** at the same time and place as the youth interview

Measures

- ***Outcome (Perceived Quality of Life)***
  - **Abbreviated Student Life Satisfaction Scale (SLSS)**

    (Huebner, 1991)
    - Youth self-report and parent report - domain-free overall life assessment
    - 5 items using 6-point rating scale from 1 = strongly disagree to 6 = strongly agree
      - **My life is going well (my child feels his/her life is going well)**
      - **My life is just right**
      - **I have a good life**
      - **I have what I want in life**
      - **My life is better than most kids**

Measures …

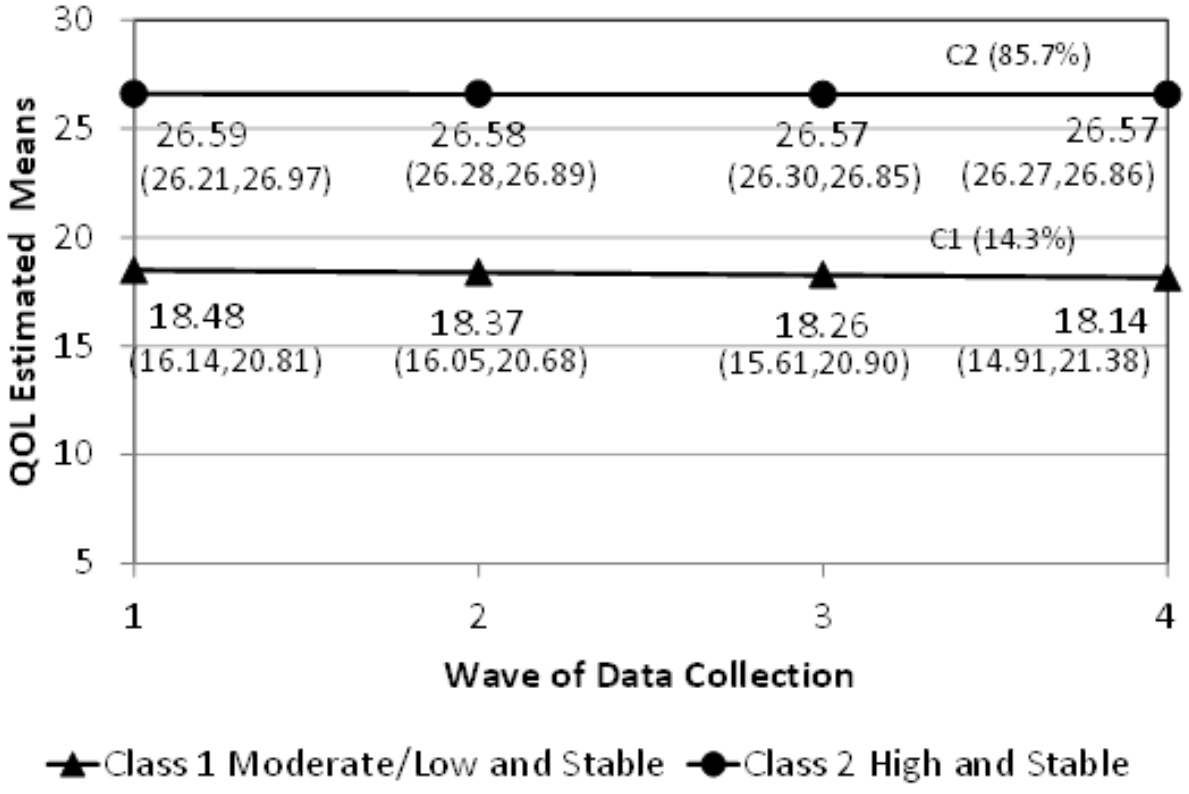
- ***Youth Functioning/Personal Factors***
  - **Pain/Physical Symptoms -** The Child and Adolescent Factors Inventory (Bedell, 2004)
  - **Emotional Functioning -** Strengths and Difficulties Questionnaire (Goodman, 1997)
  - **School Productivity/Engagement -** School Productivity Measure (McDougall, 2008)
  - **Self-Determination (i.e., having the power and will to make choices) -** ARC-Brief Version (ARC's Self-Determination Scale - adapted) (Wehmeyer & Kelcher, 1995)
  - **Spirituality (defined as deep feelings/beliefs) -** Spiritual Transcendence Index (Seidlitz et al., 2002)
- ***Interpersonal/Environmental Factors***
  - **Social Support from Parents -** Social Support Appraisals Scales (Dubow & Ullman, 1989)
  - **Overall Family Functioning -** Family Functioning Scale (NLSCY, 1998)
  - **Home and Community Environment (Physical, Attitudinal, Social, and Policy Barriers) -** Child/Adolescent Scale of Environment (Bedell, 2004)
  - **School Belongingness/Safety -** (HBSCS, 2005)

Longitudinal Data Analysis

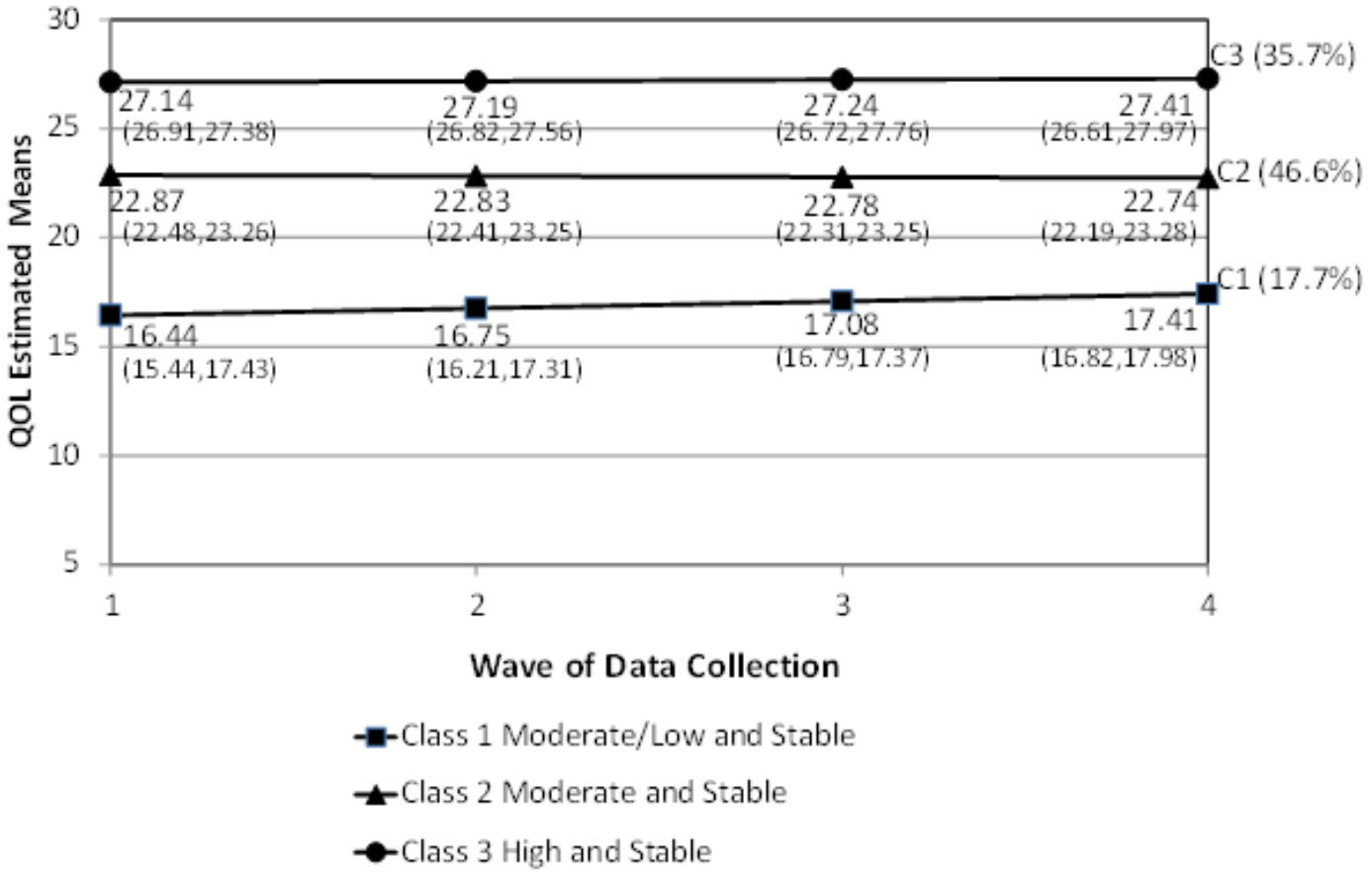
- ***Latent Class Growth Analysis***
  - Latent Class Growth Analyses (LCGA) were conducted to identify groups of youth with **unique trajectories** of global perceived QOL from both youth and parent perspectives

- ***Multinomial Regression Analyses***
  - Multinomial logistic regression analyses were then conducted to determine the influence of a given covariate predicting the **likelihood of belonging to one group** in relation to being in a reference group, typically the largest normative group
  - Basic health and socio-economic variables were included to **control** for their effect for in analyses (i.e., age at diagnosis, youth and parent age, youth and parent gender, family income, parent education, parent marital status)

Unconditional Model of Distinct Trajectories for Youth Report



Unconditional Model of Distinct Trajectories for Parent Report



Interpreting Longitudinal Findings

- Based on youth and parent reports **most youth are faring well** in terms of their perceived QOL
- However, there is a **significant percentage** of youth in both reports with moderate/low perceived QOL scores, and a good number of youth who parents view as having moderate perceived QOL
- Surprisingly, **all trajectories were stable** in nature

Interpreting Longitudinal Findings

- Yet, distinct groups exist within the study population with **varying levels of stability**
- Cummins (2010) has put forth and demonstrated a theory of homeostasis that posits humans have a subjective wellbeing **'set-point'**, with individual set-points normally ranging from 70 to 90 out of 100, with a mean of 80
- If groups within a population drop below this set-point, it represents **homeostatic failure**, that is, when excessive demands are placed on groups of individuals, homeostasis can be overwhelmed
- Moreover, when demands are ongoing, the homeostatic drop can become **a stable and ongoing phenomenon**

Interpreting Longitudinal Findings

- For individuals operating below their set-point, **interventions** may serve to restore homeostasis
  - A study by Tomyn et al. (2015) tested predictions based on Homeostasis Theory about intervention outcome
  - They hypothesized youth functioning within a normal set-point range would achieve a small increase from an intervention; alternatively, those experiencing **homeostatic failure** would **raise their subjective well-being** substantially
  - Their study results confirmed these hypotheses

Predictors of Group Membership for Youth QOL (Youth Report)

	Estimated Odds Ratios C1 (vs C2)
Correlates	
Youth functioning/personal factors	
Emotional symptoms (YR)	1.32**
Pain/other physical symptoms (PR)	1.38
Self-determination (YR)	0.88***
Spirituality (YR)	0.86***
School productivity/engagement (PR)	0.80*
Interpersonal/Environmental factors	
Youth social support from family (YR)	0.84***
Overall family functioning (PR)	1.04
School belongingness/safety (YR)	0.88*
Home and community barriers (PR)	1.03

YR = Youth Report; PR = Parent Report

C2 = high and stable quality of life (reference group) (84.3% *n* = 367)

C1 = moderate/low and stable quality of life (15.7% *n* = 68)

**p* < .05; ***p* < .01; ****p* < .001

n = 435 youth; 8 youth treatment centres

Note: Results adjusted for youth and parent age, youth and parent gender, youth age at diagnosis, marital status, education, income. Results adjusted for design effects.

Predictors of Group Membership for Youth QOL (Parent Report)

	Estimated Odds Ratios	
	C2 (vs C3)	C1 (vs C3)
Correlates		
Youth functioning/personal factors		
Emotional symptoms (YR)	1.20***	1.55***
Pain/other physical symptoms (PR)	1.38**	1.54**
Self-determination (YR)	0.99	0.94
Spirituality (YR)	0.96	0.88*
School productivity/engagement (PR)	0.69***	0.67***
Interpersonal/Environmental factors		
Youth social support from family(YR)	0.97	0.89
Family functioning (PR)	0.96	0.87***
School belongingness/safety (YR)	1.16	1.15
Home and community barriers (PR)	1.16***	1.34***

YR = Youth Report; PR = Parent Report

C3 = high and stable quality of life (reference group) (36.2%*n* = 158)

C2 = moderate and stable quality of life (48.1% *n* = 210)

C1 = moderate/low and stable quality of life (15.7% *n* = 69)

*$p < .05$; **$p < .01$; ***$p < .001$

n = 437 parents; 8 youth treatment centres

Note: Results adjusted for youth and parent age, youth and parent gender, age, youth age at diagnosis, marital status, education, income. Results adjusted for design effects

Implications of Study

- Findings support a **holistic, positive approach** to service delivery to optimize perceived QOL for youth that considers the influence of **physical and mental health**, **personal strengths**, and **interpersonal and environmental factors**
  - Service providers should inquire about these **key factors** when conducting **initial and ongoing assessments** to ensure **'at-risk' youth** are identified for the services, supports, and resources they need
  - policy makers should consider theses factors in the development of **universal prevention initiatives to safeguard resilience for all youth** and **targeted interventions** to improve adverse developmental trajectories of QOL for youth with unmet needs as they progress through adolescence

Questions/Comments?

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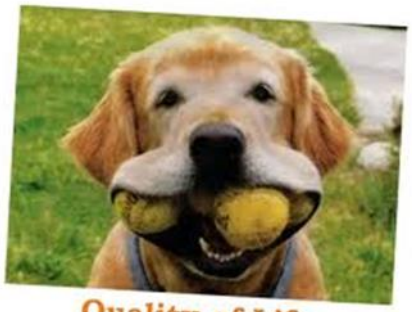

To access QOL Study webpage:

http://www.tvcc.on.ca/qol