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A “Positive” Focus for Pediatric Rehabilitation Research

Janette McDougall, PhD



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”**

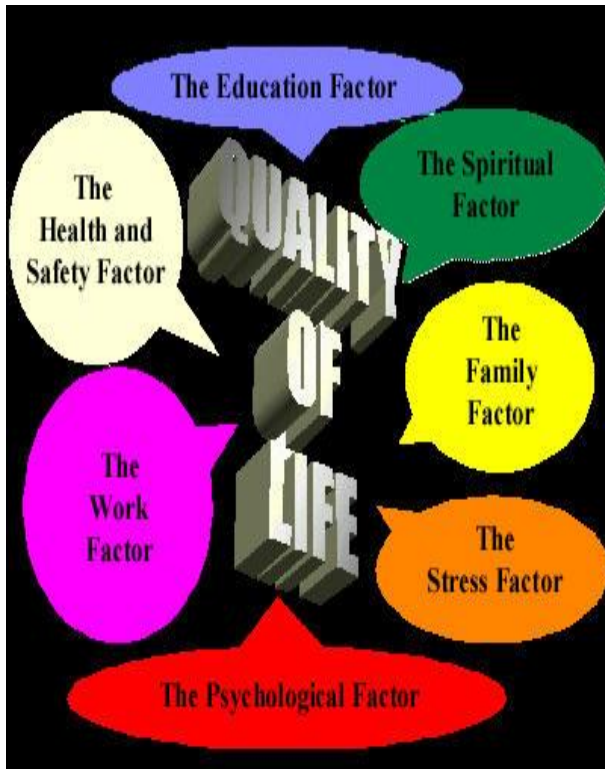


Introduction

- 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 including positive constructs when estimating predictors of **positive outcomes**

Introduction

- Optimizing quality of life (QOL) for children and youth is a **primary goal** of children's rehabilitation services
- Many supports and interventions are said to be directed toward this goal
- It is important to understand the **key factors** that influence QOL and **changes** in QOL for children and youth with chronic conditions



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Investigators/Funding

- **Janette McDougall, PhD**
 - Principal Investigator
 - Researcher,
 - Thames Valley Children's Centre
- **Virginia Wright, PhD**
 - Co-Principal Investigator
 - Research Scientist,
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- **Linda Miller, PhD**
 - Co-Investigator
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- Funded by:
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What is “Quality of Life”?



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Conceptual Approach to QOL

- QOL in pediatric health and rehabilitation has often been evaluated 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

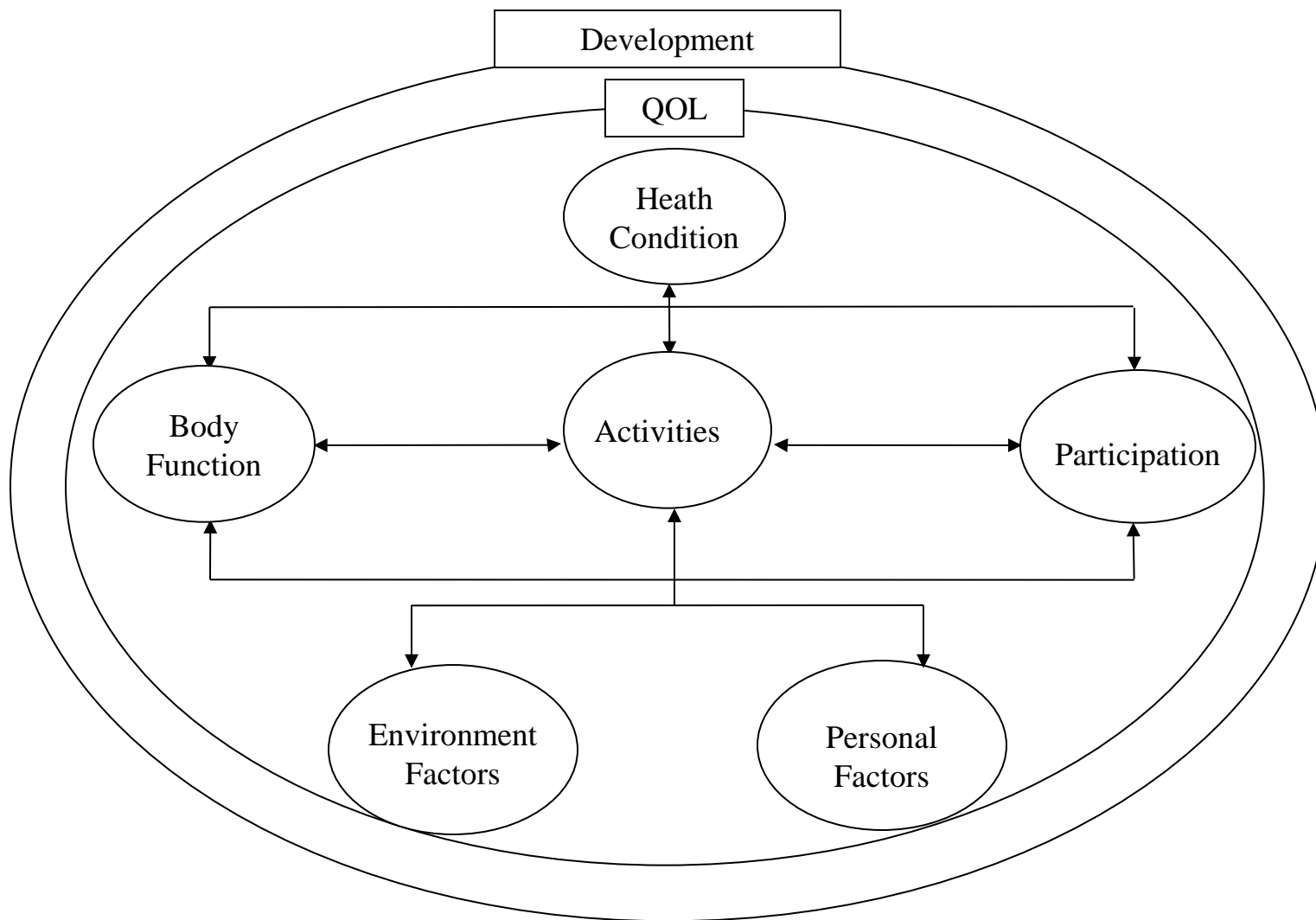
Study Focus/Aims

- This study is addressing **two unexplored research areas:**
 - **1) the changing nature** of perceived QOL for youth with chronic conditions over a three-year period, and
 - **2) the factors that influence QOL and change in perceived QOL** for youth
- **Both** youth and parent perspectives are being gathered
 - **439 youth** (and their primary caregivers) joined the study at baseline
 - Recruited from **8 Ontario children's treatment centres** (London, Toronto, Ottawa, Sudbury, Chatham-Kent, Windsor, Kingston, Simcoe-York)

- The **factors** to be included in the study model to be tested were identified from:
 - **Past research** that has identified correlates of perceived QOL for children and youth in the general population and for children, youth, and adults with chronic conditions (e.g., Edwards, Patrick, & Topolski, 2003)
 - **Conceptual models of QOL** (e.g., Felce & Perry, 1997; Renwick, Fudge Schormans, & Zekovic, 2003; Schallock, 1996)
 - World Health Organization's International Classification of Functioning, Disability, and Health (**ICF**) (WHO, 2001)
 - And TVCC's **Life Needs Model of Pediatric Service Delivery** (King, Tucker, Baldwin, Lowry, LaPorta, & Martens, 2002)

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Revised WHO ICF Model

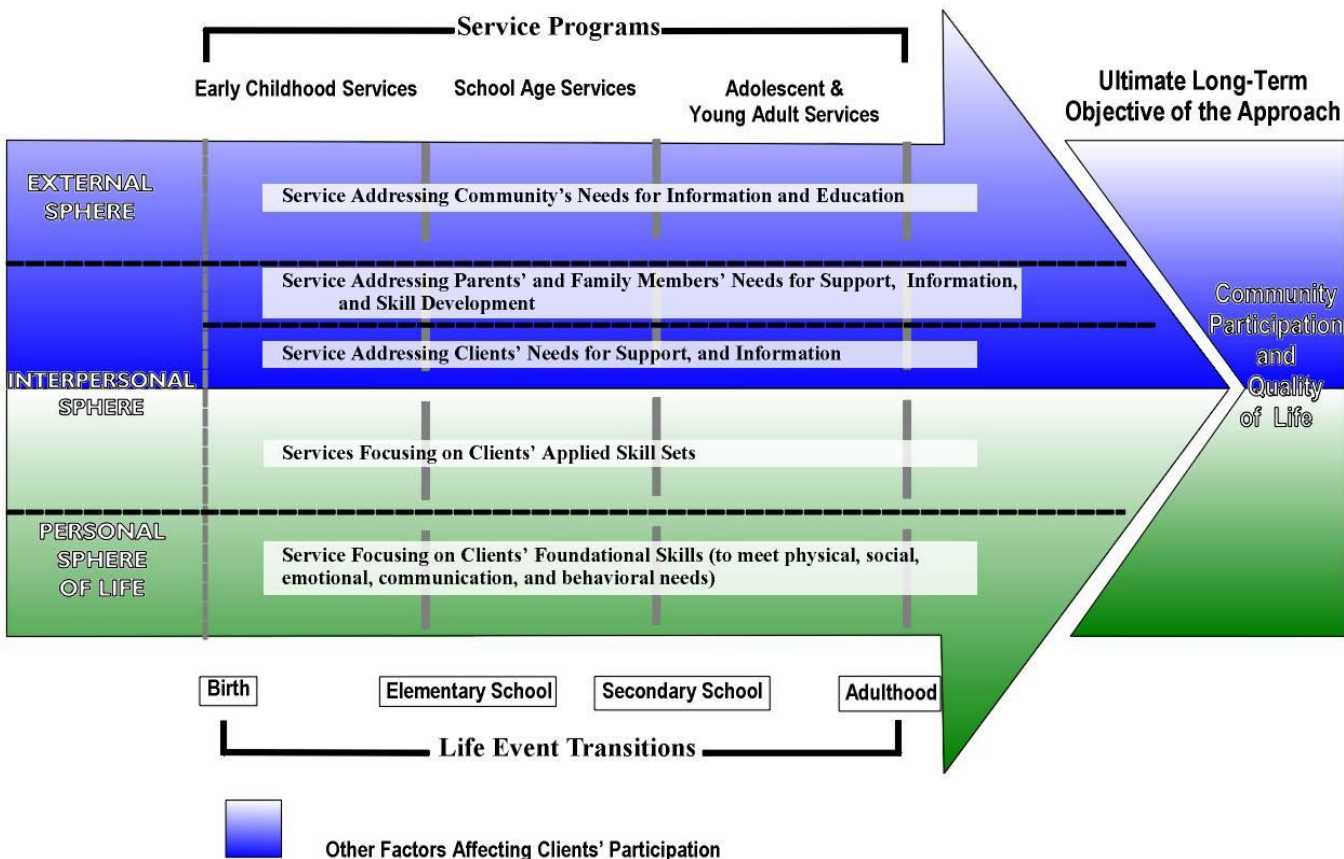


A Life Needs Model of Service Delivery

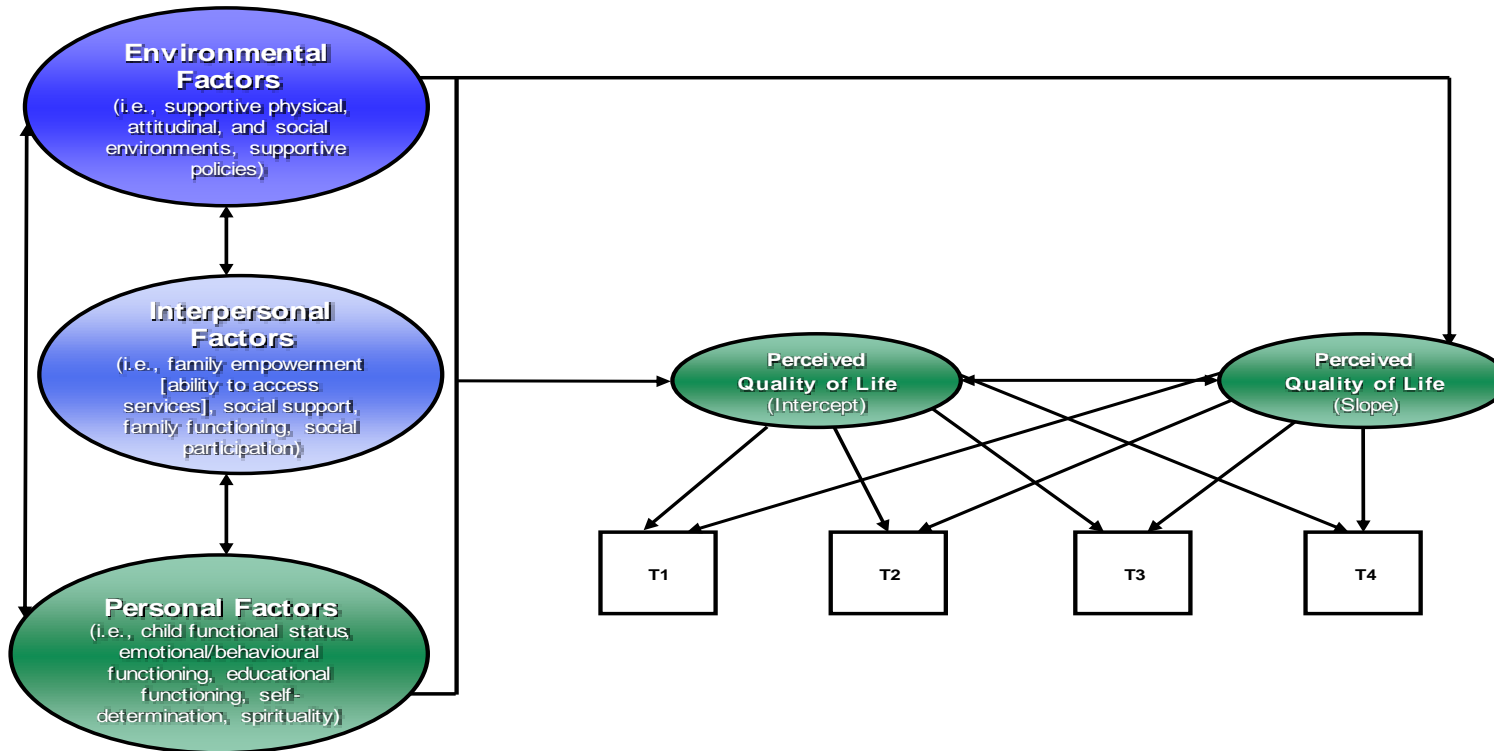
Service to Support Community Participation and Quality of Life for Children and Youth with Disabilities

Short-Term Goals of Services

- To foster positive attitudes
 - To reduce environmental restrictions
 - To encourage availability of programs and services in the community
 - To foster policies and legislation that support people with disabilities
-
- To encourage supportive relationships and environments for child, parents, and other family members
 - To foster competencies of families (e.g., Advocacy, parenting, and negotiating skills)
-
- To improve clients' function and competence in real-world settings (e.g., Home, school, and community)
-
- To improve physical, social, emotional, communication, and behavioral skills



Study Model



Study Participants



- Youth participants were between 11 and 17 years old age (14 on average) when they entered the study
- 56% are male
- 35% (153) have **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 are primarily birth mothers (83%)

Study Methods

- Questionnaires were/are being 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 takes part in **a face-to-face interview** (30-60 minutes)
- The parent questionnaire (30-60 minutes) is **self-completed** at the same time and place as the youth interview



- **Outcome (Perceived Quality of Life)**
 - **Student Life Satisfaction Scale (SLSS)** (Huebner, 1991)
 - Parent report and youth self-report - domain-free overall life assessment
 - 7 items using 6-point rating scale from 1 = strongly disagree to 6 = strongly agree
 - **My life is going well**
 - **My life is just right**
 - **I would like to change things in my life**
 - **I would like to have a different kind of life**
 - **I have a good life**
 - **I have what I want in life**
 - **My life is better than most kids**

- ***Personal or Child-Related Factors***

- **Physical/Cognitive Functioning** - The Child and Adolescent Factors Inventory (Bedell, 2004)
- **Functioning in Daily Activities** - The Child and Adolescent Scale of Participation (Bedell, 2004)
- **Emotional/Behavioural Functioning** - Strengths and Difficulties Questionnaire (Goodman, 1997); Social Anxiety Scale for Children –Revised (LaGreca & Stone, 1993)
- **School Productivity/Engagement** - School Productivity Measure (McDougall, 2008)
- **Self-Determination** - ARC-Brief Version (The ARC's Self-Determination Scale -adapted with permission) (Wehmeyer & Kelcher, 1995)
- **Spirituality (defined as deep feelings/beliefs)/Religiousness** - Spiritual Transcendence Index (Seidlitz et al., 2002); Index of Religious Behaviours (McDougall, 2008)

- ***Interpersonal Factors***

- **Social Support from Parents, Close Friends, Teachers, and Classmates** - Social Support Appraisals Scales (Dubow & Ullman, 1989)
- **Family Functioning** - Family Functioning Scale (National Longitudinal Survey of Children and Youth, 1998)
- **Home, School, and Community Participation** - Child and Adolescent Scale of Participation (Bedell, 2004)
- **Family Empowerment (Assessing/Knowledge about Services)** - Family Empowerment Scale (Koren et al., 1992)

- ***Environmental Factors***

- **Home, School, Community Environment (Physical, Attitudinal, Social, and Policy Barriers)** – Child/Adolescent Scale of Environment (Bedell, 2004)
- **School Belongingness/Safety** - (HBSCS, 2005)
- **Neighbourhood Cohesion/Safety** - (NLSCY, 1994)



Initial Analyses of Key Factors - Controls

- Basic **health** and **socio-economic variables** were controlled for in analyses (i.e., youths' chronic condition, age at diagnosis, youth age, youth gender, language spoke in home, family income, parent age, parent gender, parent education, parent marital status, number of siblings, population density)

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Initial Baseline Findings

Key Factors Related to QOL - Youth Report

Factor	<i>B</i>	<i>t</i>
Pain/Other Physical Symptoms	-0.07	-3.27****
Emotional Symptoms	-0.14	-2.96***
Spirituality	0.18	2.85***
School Productivity/Engagement	0.11	2.34**
Self-Determination (goal orientation)	0.11	1.93*
Social Support from Family	0.24	2.06**
School Belongingness/ Safety	0.19	3.38****

* $p < 0.10$; ** $p < 0.05$; *** $p < 0.01$; **** $p < 0.001$ $R^2=0.46$; $F=0.0001$

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Initial Baseline Findings

Key Factors Related to QOL – Parent Report

Factor	<i>B</i>	<i>t</i>
Pain/Other Physical Symptoms	-0.10	-4.12****
Emotional Symptoms	-0.13	-2.46**
Social Anxiety (fear of peer rejection)	-0.09	-1.96**
Spirituality	0.08	2.41**
School Productivity/Engagement	0.18	5.15****
Family Functioning	0.12	2.76***
School Barriers	-0.07	-2.47**
Home and Community Barriers	-0.18	-2.44**

* $p < 0.10$; ** $p < 0.05$; *** $p < 0.01$; **** $p < 0.001$ $R^2=0.39$; $F=0.0001$

- As a separate frame of reference for interpretation of the factors that arise from the quantitative analyses, a **qualitative study component** was undertaken in Year 2 of the study
 - A series of individual interviews, followed by a focus group, were conducted with 18 youth by two Clinician/Researchers
 - The purpose of the interviews and focus group was to obtain youths' views on what QOL means to them and the factors related to QOL through another method of data collection

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The Qualitative Piece

Quality of Life means....

- “How enriched and fulfilling your life is.”
- “How you enjoy life and get the best out of life.”
- “That you live life to the fullest and you never give up.”
- “How satisfied you are with living.”
- “Be a useful person and be happy.”
- “How good your life is for you.”
- “Making sure everyone has a good life.”
- “Being as independent as possible and relying on others but not being completely reliant on others.”
- “Having a sense of purpose.”
- “Having fun.”
- “Doing the best you can with your circumstances and abilities.”
- “To be alive.”



The Qualitative Piece

Factors youth most frequently identified as being important to their quality of life...

- Family
- Friends
- Being independent/having a job
- Support
- Participation in leisure and recreation
- Social interaction
- School/knowledge/learning
- Personal attitude/beliefs
- Accessibility/mobility
- Helping others
- Health
- Safety
- Basic needs



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Benefits of Study



- Findings can **help guide program/policy development**
 - Policy development should be guided by QOL issues meaningful to youth and families (Zekovic & Renwick, 2003)
- Initial findings suggest a **holistic, positive approach** would be beneficial that **goes beyond** reducing physical symptoms and improving function to providing supports and family-centred services designed to **enhance other life dimensions and personal strengths** like:
 - emotional well-being, school productivity, self-determination, social support, and community participation, as well as providing additional supports like spiritual care and self-advocacy support, and advocating for supportive school and community environments where **youth can thrive and develop** to their full potential

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Questions/Comments?

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To access QOL Study webpage:

<http://www.tvcc.on.ca/qol.htm>