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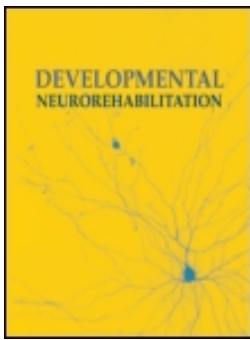
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## Applying the ICF framework to study changes in quality-of-life for youth with chronic conditions

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### Abstract

**Objective:** The objective of this paper is to describe how the ICF framework was applied as the foundation for a longitudinal study of changes in quality-of-life (QoL) for youth with chronic conditions.

**Method:** This article will describe the study's aims, methods, measures and data analysis techniques. It will point out how the ICF framework was used—and expanded upon—to provide a model for studying the impact of factors on changes in QoL for youth with chronic conditions. Further, it will describe the instruments that were chosen to measure the components of the ICF framework and the data analysis techniques that will be used to examine the impact of factors on changes in youths' QoL.

**Conclusions:** Qualitative and longitudinal designs for studying QoL based on the ICF framework can be useful for unraveling the complex ongoing inter-relationships among functioning, contextual factors and individuals' perceptions of their QoL.

**Keywords:** ICF, ICF-CY, youth, disability, quality-of-life, longitudinal research

### Resumen

**Objetivo:** El objetivo de este trabajo es describir como el marco ICF se aplicó como base de un estudio longitudinal sobre cambios en la calidad de vida en jóvenes con enfermedades crónicas.

**Método:** En este artículo se describe el objetivo del estudio, métodos, medidas y técnicas de análisis. Se señalará como fue utilizado el marco ICF – y cómo se amplió – hasta proveer un modelo para estudio del impacto de factores en cambios en la calidad de vida de jóvenes con enfermedades crónicas. Además, describirá los instrumentos utilizados para medir los componentes del marco ICF y las técnicas de análisis de información que se utilizarán para examinar el impacto de factores en los cambios de calidad de vida de los jóvenes.

**Conclusiones:** Los diseños longitudinales y cualitativos para estudio de la calidad de vida basados en el marco ICF pueden ser útiles para descifrar las complejas interrelaciones en curso entre los factores funcionales, contextuales y la percepción del individuo sobre su calidad de vida.

**Palabras clave:** ICF, ICF-CY, jóvenes, discapacidad, calidad de vida, investigación longitudinal

### Introduction

Population-based studies have indicated that ~30% of school-aged children and youth have at least one chronic physical health condition [1, 2]. Moreover, the prevalence of chronic physical health conditions among children and youth is increasing [1].

Children and youth with chronic conditions are more likely than other children and youth to experience multiple problems that could affect their quality-of-life (QoL). These include: secondary impairments [3]; limitations in daily activities [2, 4, 5]; emotional

and behavioural problems [2, 4, 6]; under-developed self-determination [7]; social isolation and peer neglect [8, 9]; decreased social participation at home, school and in the community [4, 10, 11]; school difficulties [4]; and unsupportive physical, social and attitudinal environments [12, 13].

#### *The ICF and QOL*

Optimizing children and youths' QoL has become a central focus of programme development and service delivery in paediatric rehabilitation [14, 15]. Over

the last decade, rehabilitation programmes and services have refocused to address aspects of children and youths' lives beyond physical health [16]. Expanded definitions of health and functioning, such as that of the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) [17], have encouraged consideration of the impact of contextual factors on a person's functioning and well being, in addition to the impact of health [18]. In the ICF framework, 'health conditions' are defined as diseases, disorders, injuries, etc. Functioning is an umbrella term that encompasses all body functions and structures, activities and participation, while disability is an overarching term for impairments, activity limitations and participation restrictions. 'Impairments' are defined as problems in body function or structure; 'activity limitations' are difficulties a person may have in carrying out daily activities; and 'participation restrictions' are problems a person may experience when involved in life or social situations [17]. According to the ICF, a person's functioning and disability are considered to arise from the interaction among health conditions and contextual factors, namely environmental factors (e.g. community attitudes, accessibility of the environment, peer relationships, service availability, etc.) and personal factors (e.g. age, gender, values, beliefs, lifestyle, etc.) [17]. A visual model of functioning and disability that depicts the interactions among these concepts is provided in the ICF (see Figure 1).

One of the related changes associated with the emergence of expanded definitions of health and functioning like the ICF and, more recently, the International Classification of Functioning, Disability and Health—Children and Youth (ICF-CY) [19], is a reconsideration of the conceptualization and operationalization of QoL. In general, most QoL conceptual models and measures have included a number of domains that focus on aspects of the following five life dimensions: material, physical, emotional, and social well-being, and productivity [20]. A model of QoL by Schalock [21] expanded on past conceptual work and further sub-divided these five basic life dimensions to eight even more distinct dimensions: material, physical, emotional well-being, personal development, social inclusion, interpersonal relations, self-determination and human rights.

The World Health Organization Quality of Life Group (WHO-QOL) [22] 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' (p. 1570). Accordingly, an increasing number of researchers are defining QoL as an individual's perception of life satisfaction/enjoyment [23–25]. For example, Renwick and Brown [26], as cited in Zekovic and Renwick [27], define QoL as 'the degree to which a person enjoys the important possibilities of his or her life' (p. 24). These definitions reflect a growing sense that QoL may

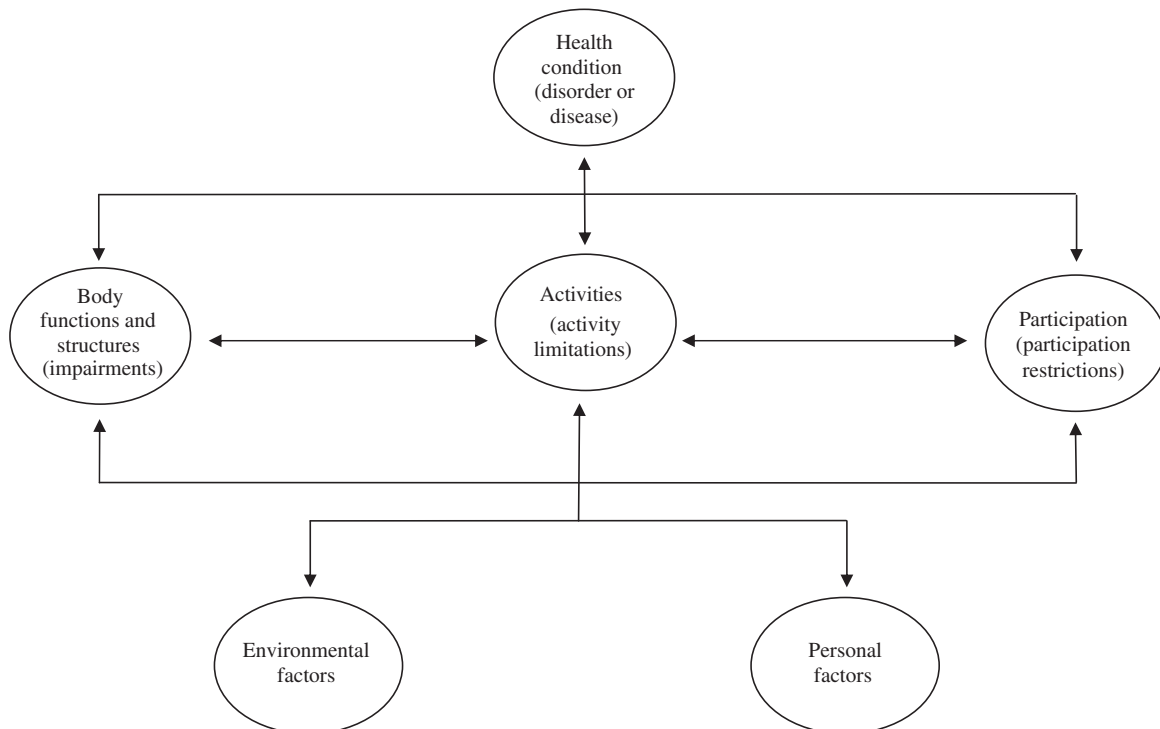


Figure 1. The World Health Organization's model of functioning and disability [17].

ultimately be best understood as a subjective phenomenon [23, 28]. Assessment of persons' perceived QoL (PQoL) provides a view of life conditions through the eyes of individuals themselves [29] and a sense of the value that individuals place on various aspects of life [30].

To avoid confounding a person's health status, functioning and contextual factors with QoL, it has been suggested that the best approach may be to measure these various factors distinctly and examine their relationship to a person's PQoL [23]. Most recently, McDougall et al. [31] have proposed a modified version of the ICF Model of Functioning and Disability based on a systems perspective that offers researchers a framework for understanding how functioning and contextual factors contribute to the quality of people's lives (see Figure 2). Prior to the introduction of this proposed modified model, no recommendations for how to include QoL in the ICF Model had been put forth, although establishing links with QoL concepts and the measurement of subjective well-being was mentioned in Annex 8, an addendum of the ICF [17], as an area for future work.

The proposed modified model expands upon the original ICF Model to depict a person's QoL and ultimately his/her development over time, as an

ever-changing composite whole that is more than the sum of its parts (i.e. functioning at the body, individual and social levels, a person's health condition and contextual factors). It is thought that all of the factors included in the ICF Model could potentially affect a person's QoL and could contribute to changes in QoL as the person develops over time. This proposed modified model acknowledges the importance of subjective well-being and encourages researchers to collect QoL information from the perspectives of individuals themselves (i.e. PQoL), as well as from other sources. McDougall et al. [31] recommend that an individual's perceived satisfaction with various aspects of life and overall life quality be included as codes in the personal factors component of both the ICF and ICF-CY, when codes for that component are developed (see McDougall et al. [31] for a complete explanation of the proposed modified model).

*Past research*

Cross-sectional studies of children and youth in the general population have found significant correlates of PQoL, including emotional and behavioural functioning, relationships with parents and peers and social participation [32–35]. A number of cross-

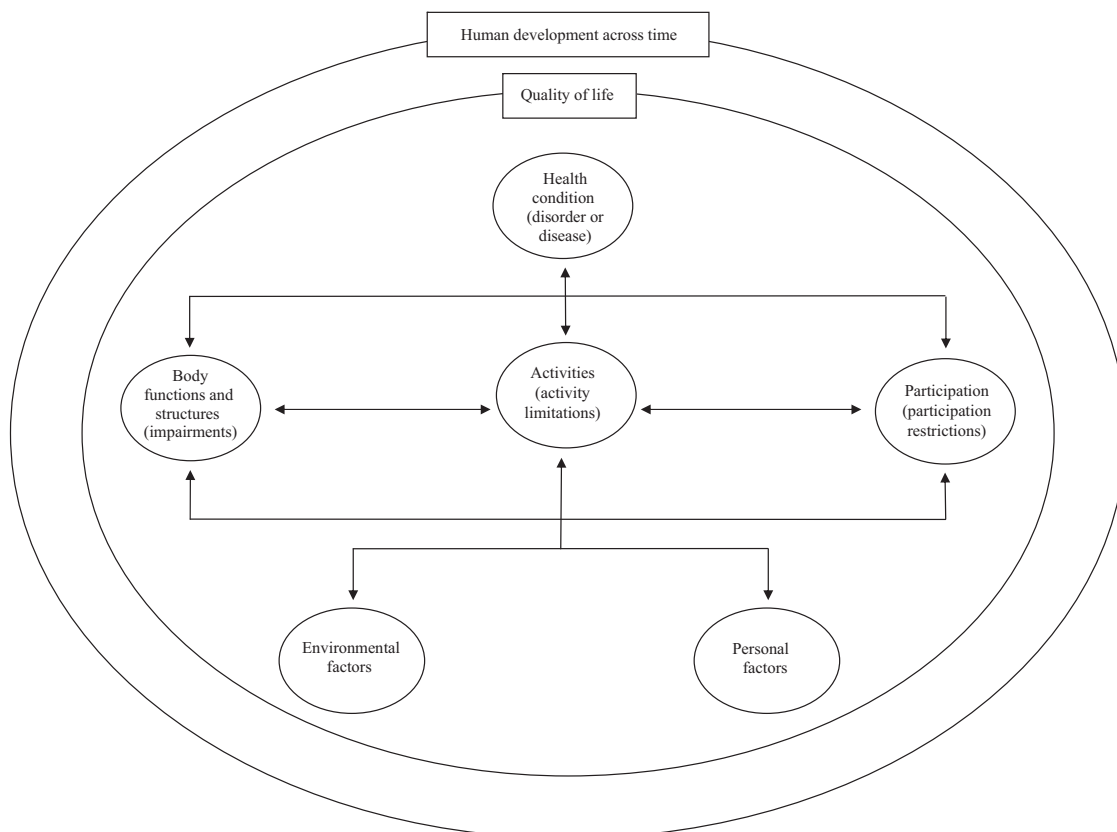


Figure 2. A modified version of World Health Organization's model of functioning and disability.

sectional studies have identified significant correlates of PQoL for adults with chronic conditions, such as physical and emotional functioning and support from others [24, 36–39]. Research has identified self-determination as being positively related to QoL for adults with chronic conditions [40] and spirituality as being important to QoL for families of children with chronic conditions [41]. Very little is known, however, about the role that self-determination and spirituality play in PQoL, specifically for children and youth with chronic conditions.

Indeed, there is little empirical evidence about the contribution of functioning and any other potentially important contextual factors on the PQoL for children and youth with chronic conditions. One unique exception is a cross-sectional study of 2801 7th–12th grade students in a rural area of the US [42]. Nine hundred and sixty children and youth were identified as having a chronic condition in the sample. It was found that, on average, children and youth with chronic conditions and disabilities (i.e. activity limitations) reported lower PQoL than those who had chronic conditions without disabilities. Moreover, self-rating of health, depressive symptoms and contextual variables accounted for a significant portion of the variance in PQoL between the two groups.

To date, it appears that no longitudinal studies have examined predictors of changes in PQoL for children and youth with chronic conditions. Moreover, no studies have examined the variables that may mediate or moderate the impact of predictor variables on PQoL for children and youth with chronic conditions. Understanding change is of paramount importance when children and youth are considered within the context of rehabilitation service provision. Knowing the important combinations of predictors and mechanisms of change in PQoL over time can assist in the development and continuation of preventive strategies, programmes and policies to enhance PQoL.

One cross-sectional study examined the effects of age on PQoL for 1274 German children and youth aged 6–11 years in the general population and found a significant decrease in PQoL as age increased [43]. However, it should not be assumed that this similar direction or magnitude of change would occur for children and youth with chronic conditions. Indeed, a study by Feldman et al. [30] of children with arthritis and their families asked study participants about their PQoL at two points in time and found PQoL improved slightly, despite the average disease severity score staying the same. A cross-sectional study in Europe is currently collecting follow-up data for a sample of 818 youth with cerebral palsy to examine changes in PQoL across two time points as well as to explore the influence of contextual factors

on children's PQoL [44]. At baseline, this study found that children with cerebral palsy had, on average, similar PQoL to children of the same age in the general population.

The idea of looking at temporal variation in QoL through longitudinal studies is emerging in other health-care areas as a superior approach to cross-sectional designs [45]. Relationships among variables may be quite different when change is considered compared to when associations are examined at a single point in time [46]. The proposed modified ICF model by McDougall et al. [31] with its developmental component supports the use of longitudinal designs for unravelling the complex ongoing inter-relationships among functioning, contextual factors and QoL. Longitudinal studies of PQoL for children and youth are needed in both the general population and in clinical populations [43]. Identifying the unique functional aspects and contextual factors that predict PQoL over time for children and youth with chronic conditions can assist policy-makers, administrators and service providers to tailor rehabilitation and allied services to support these individuals in optimizing their life quality.

#### *Purpose of this paper*

The purpose of this paper is to describe a longitudinal study currently underway that aims to identify and examine predictors of changes in PQoL for youth who have chronic conditions; this study demonstrates how the ICF framework can be applied to the evaluation and understanding of PQoL. The hypothesized predictors of change that are included in the study were chosen to reflect the functional components and contextual factors of the ICF Model of Functioning and Disability [17] and are supported by conceptual models of QoL [20, 21] as well as past research regarding correlates of PQoL for children and youth in the general population and for children, youth and adults with chronic conditions (reviewed above). The overall approach to studying PQoL is reflected in the proposed modified ICF model as presented by McDougall et al. [31].

#### **Study description**

This study has been funded by the Canadian Institutes of Health Research (Grant # 191232). It is a longitudinal investigation to identify and examine determinants of changes in PQoL for ~575 youth aged 11–17 years who have chronic conditions. Individuals in this age span are expected to encounter a number of key life transitions during the course of a 3-year-follow-up period (e.g. changes in school, changes in expectations regarding



independence, changes in health and mobility, changes in role within the family and in the community) [47–49]. At the time of writing this paper, the investigators are partway through enrolment of the study sample and completion of the baseline interviews.

The study is addressing two unexplored areas of research: (1) the changing nature of PQoL for youth with chronic conditions; and (2) the factors hypothesized to predict change in PQoL for these youth.

Specific objectives of the study are as follows:

- *Objective 1.* To examine changes in PQoL over a 3-year period for youth between the ages of 11–17 years inclusive who have chronic conditions;
- *Objective 2.* To determine key factors which contribute to measured changes in PQoL, giving particular attention to the functional components and contextual factors identified by the ICF;
- *Objective 3.* To identify mechanisms (*mediational pathways*) through which effects on changes in PQoL occur; and
- *Objective 4.* To determine changes in PQoL for youth with differing personal socio-demographic and health-related factors (e.g. age, gender, household income, age of onset of youth's condition, etc.) (*moderating influences*).

#### *Study design*

A prospective cohort design [50] is being used, with a 3-year follow-up of each participant (and four key data collection time points). The use of four time points allows the examination of the possibility of non-linear growth patterns. Over the course of 15 months, 575 youth and their primary caregivers who receive services from one of several children's rehabilitation centres in Ontario, Canada, are being recruited to participate. Questionnaires measuring youths' PQoL and the hypothesized predictors of PQoL are being administered to youth and their parents shortly after entry to the study and then again every 12 months over the course of 3 years.

A non-categorical approach to illness has been adopted, combining children with different chronic conditions into a total group for data analysis purposes [51]. Much research supports including distinct chronic conditions because of the great commonality in their psychological, psychosocial and social implications [51–54]. There appears to be as much variation in disease severity within condition categories as there is between categories [51]. Epidemiological studies have found condition-related factors that cut across diagnoses, particularly activity limitations, are better indicators of problems than the presence of chronic conditions [2, 4].

Youth are eligible to be included in the study if they have any one or more of the following chronic conditions: cerebral palsy, spina bifida, autism, Asperger's syndrome, non-progressive muscular disorders, acquired brain injury, developmental delay, cleft lip and/or palate, Down syndrome, arthritis, communication disorder, amputee or any other central nervous system disorder.

As a separate frame of reference for interpretation of the predictors that arise from the quantitative analyses, a qualitative study component will be undertaken in Year Two of the study. A series of interviews, followed by focus groups, will be conducted with youth and led by two Clinician Researchers at the children's rehabilitation centre in London, Ontario. The purpose of the individual interviews and subsequent focus groups will be to obtain youths' views on factors related to QoL through another method of data collection and examine these alongside the quantitative findings. The value of focus groups lies in the group interaction that occurs among individuals with shared concerns [55], providing opportunities to build upon the themes identified during the individual interviews [56].

Youth who take part in the interviews and focus groups will meet the study's enrolment criteria as described below (randomly selected in Year Two after the enrolment for the quantitative study is complete) but will not have been enrolled in the quantitative arm of the study so that their views of possible predictors of QoL will not be influenced by exposure to the study's questionnaire.

#### *Recruitment procedures*

At each centre, an administrative Research Contact has generated a list of all clients between the ages of 11–17 years. Using computer-generated random numbers, a Research Assistant at each centre is in the process of randomly selecting youth from the lists as potential participants. A Letter of Information is sent to families asking them to send back a postage paid form to the centre Research Assistant if they do not want to be contacted about the study. A follow-up recruitment phone call is made by the centre Research Assistant to potential study participants. If the youth and parent verbally agree to participate, a Study Interviewer (a trained health professional hired from each participating centre) then contacts the family to set up a convenient time for the baseline interview. Families that decline involvement are asked to provide general background information (e.g. age, gender, education, etc.) that will allow Study Investigators to compare participants to non-participants.

*Data collection and management*

Study interviewers contact families and administer the questionnaire packages to youth and parents at each 12-month interval over a 3-year period (12, 24 and 36 month follow-ups). Data collection occurs either in the privacy of the respondent's home or in a private office at the youth's rehabilitation centre. The parent and youth make the choice of location. Interviewers obtain written informed consent in person from youth and parents just prior to conducting the baseline assessment. Following a standardized introduction to the questionnaire, each youth takes part in a face-to-face interview (30–60 minutes) with additional support as required from the Study Interviewer (e.g. further explanation of questions, provision of additional time). The parent questionnaire (each 30–60 minutes) is self-completed and is done at the same time as the youth interview. The primary caregiver of the youth completes the questionnaire. The youth and parent are not given access to each other's responses. The importance of independent responses is explained in the Information Letter.

*Measures*

There are two study questionnaires: a youth face-to-face questionnaire and a parent self-administered questionnaire. These questionnaires are each made up of a series of validated measures. PQoL is defined as an individual's perception of life satisfaction/quality that emerges and changes due to the impact of an individual's functioning, as well as contextual factors. Appropriate measures were identified to capture PQoL and the various factors hypothesized to influence it over time. Health conditions, impairments, activity limitations, participation restrictions and environmental factors were all defined based on the distinct definitions provided by the ICF. Measures representing these constructs were identified for use in the study. Measures of other relevant contextual factors were also identified for use. All measures are described below. While the youth and parent questionnaires are similar overall in their content, there are a number of important differences that are noted below.

*Youth questionnaire.* The primary outcome, youth PQoL, is being measured in the youth questionnaire using two distinct measures that were designed to assess PQoL: the Students' Life Satisfaction Scale (SLSS) [57], a seven-item global measure (using a six-point rating scale) that is context free (e.g. 'I have a good life', 'I have what I want in life'); and the Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS) [58], a seven-item general measure

(using a seven-point rating scale) that aggregates responses across specific life domains and life overall (i.e. satisfaction with family, friends, school, self, living environment and life overall). The authors decided to use both measures of PQoL to capture this construct in two distinct ways: globally and domain specifically. Other research has found a global measure to be simpler and more direct and a domain-specific measure to capture greater detail [59].

Both of these PQoL measures have been tested with children and youth in a number of different countries, including the US and Canada, and have documented reliability (high internal consistency (alphas ranging from 0.80–0.88 for the SLSS and from 0.75–0.85 for the BMSLSS across samples, and test-re-test reliability — 0.91 for the BMLSS and 0.74 for the SLSS over a 2-week time period) and validity [32, 57, 60–66]. Responsiveness to change over a 9-month period has also been found for the SLSS [67].

Hypothesized predictors and potential mediators (see Data analyses section below for a description of mediating and moderating analyses) are being measured through youth reports of (1) functioning, (i.e. activities and participation, using the Child and Adolescent Scale of Participation (CASP)) [68] and (2) contextual factors (i.e. emotional/behavioural functioning, using the Strengths and Difficulties Questionnaire (SDQ) [69] and the Social Anxiety Scales-Revised (SASC-R) [70]; self-determination, using an adapted and abbreviated version of the ARC's Self-Determination Scale (ARC) [71]; spirituality, using the Spiritual Transcendence Index (STI), adapted for youth [72]; youths' social support from family, close friends, classmates and teachers, using the Social Support Appraisals Scale (APP) [73]; and supportive physical, attitudinal and social environments for youth), using the Child and Adolescent Scale of Environment (CASE) [68]. Moderators and control variables are measured by a demographic questionnaire for youth and include youths' gender, age and self-rated health.

*Parent questionnaire.* Parents' perspectives of youth outcomes (PQoL) will be measured in the parent questionnaire using the same two measures (SLSS and BMSLSS) as in the youth questionnaire, but with parent wording. This wording was adapted with permission from the measures' authors.

Hypothesized predictors and potential mediators will be primarily measured in the parent questionnaire using the same measures as in the youth questionnaire, but with parent wording. The measures were either available as parent-report or have been adapted with permission from the original



authors. The parent questionnaire also includes the following additional measures of functioning and contextual factors: a checklist of youths' secondary impairments, the Child and Adolescent Factors Inventory (CAFI) [68], a measure of youths' educational functioning, the School Productivity Measure (SPM) [74], a measure of family functioning, the Family Functioning Scale [75] and a subscale from the Family Empowerment Scale (FES) [76] to measure parents' empowerment related to their confidence and ability to obtain services for their child.

Moderators and control variables are measured by a parent demographic questionnaire and include family socioeconomic status (i.e. parent education, occupation, income), marital status, family

structure, language spoken in the home, place of residence (rural vs urban), child's primary health condition (measured using a 'chronic conditions list') [18], age of onset of child's condition, number of years receiving rehabilitation services, number of services received, type of school youth attends, amount of assistance the youth requires, measures of parent mental and physical health and parent social support (see Table I for a list of measures and individual variables).

The CAFI, CASP and CASE [68] measuring impairments, activity and participation, and environmental factors, respectively, were specifically chosen for use in this study because they were originally developed based on the ICF framework. The CAFI consists of 10 items that reflect a child's cognitive,

Table I. Study measures and variables/constructs.

Measure	Variables/constructs
<i>Predictors and potential mediators</i>	
Child and Adolescent Factors Inventory (CAFI)	Impairments (single items measuring attention, memory, problem-solving, learning, motivation, seeing, hearing, speech, movement, strength, sensory function, and physical symptoms)
Child and Adolescent Scale of Participation (CASP)	Basic daily activities/mobility Advanced daily activities
Strengths and Difficulties Questionnaire (SDQ)	Social participation at home, school and in the community Child emotional functioning (emotional problems scale) Child behavioural functioning (conduct problems scale) Child hyperactivity Child peer problems Child prosocial behaviour
Social Anxiety Scales-Revised (SASC-R)	Fear of negative evaluation Fear of new situations Generalized anxiety Self-determination
Adapted/Abbreviated Version of ARC's Self-Determination Scale	
Adapted/Abbreviated Spiritual Transcendence Index (STI)	Spirituality
School Productivity Measure (SPM)	School productivity
Social Support Appraisals Scale (APP)	Family support Close friend support Teacher support Classmate support
Family Functioning Scale (FFS)	Family functioning
Child and Adolescent Scale of the Environment (CASE)	Supportive, physical, social and attitudinal aspects of the environment
Abbreviated Version of Family Empowerment Scale (FES)	Parental confidence and ability to obtain services for child
<i>Potential Moderators</i>	
Demographic Questionnaire	Single items measuring youth's gender, age and self-rated health, family socioeconomic status (i.e. parent education, occupation, income), marital status, family structure, language spoken in the home, place of residence (rural vs urban), youth's primary health condition, age of onset of youth's condition, number of years receiving rehabilitation services, number of services received, type of school youth attends, amount of assistance the youth requires, parent mental and physical health
<i>Outcomes</i>	
Students' Life Satisfaction Scale (SLSS)	Global perceived quality-of-life
Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS)	Domain specific/overall quality-of-life

behavioural, psychological and physical function. Internal consistency has not been tested since this measure was designed as an inventory of impairments, not as a unidimensional construct. The CASP includes 20 individual items that link to all domains of the activity and participation component of the ICF [77]. It has been shown to have high internal consistency ( $\alpha = 0.98$ ) [69]. Factor analytic testing of the measure indicates that the items load onto three distinct factors identified as: basic activities, advanced activities and participation and a large proportion of variance (63%) is explained [78]. The CASE is adapted from the Craig Hospital Inventory of Environmental Factors [79], an instrument designed for adults. The CASE inquires about problems experienced with supportive, physical, social and attitudinal aspects of the environment. Evidence of high internal consistency has been found ( $\alpha = 0.91$ ). Preliminary factor analysis is not clear as to whether the measure is multidimensional. This study aims to conduct factor analytic testing. However, if the measure does not prove to be multidimensional, it will be used as a unidimensional scale.

As listed above, additional measures were included in the study to capture relevant contextual factors. It should be noted that, in some cases, it was difficult to define a factor as an aspect of functioning or as a personal factor. For example, behavioural functioning appears to be identified as both an aspect of functioning (i.e. d7202, regulating behaviours within interactions) and as a possible personal factor (i.e. overall behaviour pattern) in the ICF and ICF-CY. As another example, spirituality is found in the ICF and ICF-CY in the activities and participation component (d930) and includes the process of 'finding meaning'. The authors would argue that spirituality is a personal factor that emerges as an individual interacts within his/her environment. Clarifying the difference between aspects of functioning and certain personal factors is felt to be an area for further ICF work.

In addition, the authors, in their original grant proposal, refer to social participation, social support and family functioning as 'interpersonal factors'. Developmental theorists [80, 81] have distinguished human interaction conceptually from the environment. The former is regarded as an interactive process between a particular individual and significant others and the environment is regarded as the surrounding physical, social and attitudinal setting in which such interaction takes place. For example, a school's overall social culture would be considered an environmental factor, whereas the personal relationship a child engages in with his teacher or a classmate would be considered an interpersonal factor. 'Interpersonal interactions and relationships'

are classified in the activities and participation component of the ICF, while 'support and relationships' are classified in the environmental factors component. Since almost all relationships involve some degree of reciprocity, this may be another area for further clarification and delineation within in the ICF.

#### *Data analyses*

*Statistical procedures.* Study objectives will be tested in M-Plus Software [82] using latent growth curve modelling (LGM) [83]. LGM estimates change (i.e. growth trajectory) on one or more outcomes over time. It is viewed as the most appropriate technique for analysing change [84] and is useful for testing hypotheses about theoretically relevant predictors of how quickly change occurs [85].

Change is represented by two latent (unobserved) factors that are conceptualized as having an underlying continuous scale: a latent intercept and a latent slope. The latent intercept specifies the initial status or starting point of the growth trajectory. The latent slope specifies the rate of change. The slope may increase or decrease over time. Study growth models will be estimated using youth and parent reports of youth PQoL. Two models will be estimated based on youth report, one with PQoL measured using the SLSS (the context free 7-item global measure) and the other with PQoL measured using the BMSLSS (the 7-item measure aggregating responses across specific life domains and life overall). Two additional models will be estimated that capture parent reports of youth PQoL using parent versions of the SLSS and BMSLSS.

Unconditional growth models (i.e. models without predictors) will first be estimated to identify the presence of growth and to find the best shape of the trajectory (e.g. linear, quadratic) (Objective 1). Then, the latent intercepts and slopes will be regressed on the predictors using single process conditional growth modelling (Objective 2). Positive coefficients will represent accelerating growth in PQoL and negative coefficients will represent decelerating growth. Predictors will first be included as fixed covariates measured at the start of the growth process. In the models that follow, this restriction will be relaxed and the values of the predictors will be allowed to change over time (time variant predictors). General growth mixture modelling [86] will be used if PQoL (i.e. study outcome) displays significant individual variation (heterogeneity) around the group mean growth process (i.e. if two or more discrete groups of individuals each share a unique growth trajectory) in any of the four study models to be estimated. The procedure will assess

which predictors best discriminate between different trajectory groups.

The goodness of fit of the models will be estimated using two standardized indices (RMSEA and TLI) and the chi-square statistic. Full Information Maximum Likelihood (FIML) will be used to deal with missing data. FIML generates unbiased parameter estimates and is more efficient for longitudinal data than other missing data techniques, such as mean imputation [87, 88]. Due to the nested structure of the data (children nested within centres), model estimates of standard errors will be adjusted for non-independence of observations.

If one or more hypothesized predictors (fixed covariates) are found to contribute to significant growth in youth PQoL, mediation analysis will be conducted using parallel process growth modelling to examine how effects are transmitted (Objective 3) [89]. In the absence of empirical research, a range of possible mediators will be explored. For example, if youth emotional functioning is found to be a significant predictor of change in PQoL, authors will test whether the effect occurs directly or is transmitted indirectly through change in family functioning (i.e. mediator). Statistical moderation (Objective 4) of the model pathways estimated above will be assessed using the multiple groups procedure in M-plus. The plausibility of pathways will be evaluated for categories of key youth and parent socio-demographic and health-related variables (e.g. ages 11–14 years vs 15–17 years; boys vs girls; early vs late age of onset of condition).

*Statistical power.* Due to the absence of longitudinal studies of predictors of PQoL for youth with chronic conditions, empirically-based judgements could not be made regarding expected effect sizes. However, low-to-mid-range effect size values falling in the range of 0.30–0.50 are considered to signify modest improvements in children’s psychosocial and behavioural functioning [90]. To calculate the sample size requirements for the LGC analyses, Monte Carlo simulations were performed using M-plus statistical software. With power set at 0.80 and type one error at 0.05, a sample of 425 participants is required to detect a standardized effect size of 0.40 (mid-point effect size identified as meaningful). This estimate assumes four equally-spaced data collections, linear growth, no missing data and a normally distributed outcome.

*Expected attrition and potential bias.* Based on a longitudinal study that included children receiving services from Ontario children’s treatment centres (less than 5% attrition over 3 years) [91] and on a meta-analysis of retention in longitudinal designs

involving youth (30% attrition over 27 months) [92], an attrition rate of 25% was estimated between baseline assessment and the final follow-up. To account for attrition, 575 youth will be recruited, resulting in a sample size of 430 participants. This number is close to the 425 participants needed to detect a standardized effect size of 0.40.

*Qualitative methods and analyses.* Study investigators and two Clinician researchers developed a semi-structured interview schedule for the initial individual interviews with youth in the qualitative component of the study. The primary method of exploring QoL in the focus groups will be through use of constructed life scenarios as a focal point for discussion. These scenarios are being developed by the two Clinician researchers and will be enhanced by topics and ideas arising from the individual interviews that precede the focus groups. Use of scenarios helps to stimulate discussion and de-personalize the situations, making it easier for youth to express their views about these potentially sensitive issues [93].

Initial coding of transcripts will involve data horizonalization, that is taking short statements verbatim from the text [94]. NVivo software [95] will be used for data coding and summarization. The transcripts will first be coded and then the study team will review the coding framework (peer debriefing) [94]. Colaizzi’s [96] steps for phenomenological data analysis will guide the movement of codes into categories and sub-themes [94, 97]. As the purpose of the focus groups is to expand upon the information gained in the interviews, coding will be done first with the interviews and then the resulting code structure will be applied to the focus groups and expanded as necessary. Embedded quotes from the interviews and focus groups will be included in each sub-theme’s summaries, which will be connected into an overarching theme. A final check of thematic structure will occur at an investigator meeting. Descriptions of themes will be mailed to the participants, requesting feedback on how well the summary reflects their experiences (member checking) [94].

#### *Knowledge translation*

The study team will develop a comprehensive knowledge dissemination plan. Study results will be provided to key stakeholders, interest groups and the general population through several mediums including family newsletters and easy-to read summaries, websites, community presentations, manuscript submissions to peer-reviewed journals, conference presentations, interviews and newspaper and magazine articles. Workshops will be held with youth, parents,

administrators and health ministries towards the end of Year Four to share and exchange ideas around study findings. These key stakeholder discussions are expected to provide information on the implications of findings for more effective and efficient services, policy development, collaboration between rehabilitation and allied services for youth and gaps in clinical practice and research that could lead to further improvements in youths' PQoL.

### Summary

This research is based on the ICF Model of Functioning and Disability, in addition to past research and QoL conceptual models, in an effort to identify the functional and contextual factors beyond a youth's health condition that be impacting their PQoL. As a way of understanding how functioning and contextual factors impact changes in a person's PQoL, the authors conceived a modified version of the ICF Model, which incorporates QoL and development.

Optimization of QoL for children and youth with chronic conditions represents a high-priority long-term goal for paediatric rehabilitation services. Identifying the unique factors that influence the PQoL of children and youth with chronic conditions will help to inform policy decisions about how and where to allocate funds and is vital for ensuring the provision of suitably-targeted and effective rehabilitation services for children and youth with chronic conditions.

The ICF goes well beyond physical symptoms in its framework, yet rehabilitation services tend to focus on physical symptoms. The findings from this study may provide evidence that services should be broadened to encompass the scope of the ICF. Findings could help to justify services designed to enhance other life dimensions, like emotional well-being, social support and community participation for children and youth, as well as providing additional supports like spiritual care and self-advocacy support for children and youth and their families and advocating for positive societal attitudes and physically accessible environments. In addition, findings could help identify the kinds of services that may be beneficial to provide at key transition points throughout youths' lives. Moreover, identification of the relative impact of various functional and contextual factors on QoL, from the perspective of youth and parents—those individuals whose opinions matter most—will provide an opportunity for collaboration among clients, health-care and other allied professionals toward the goal of optimizing the QoL for children and youth with chronic conditions.

No studies exist that have examined the factors that influence changes over time in PQoL for children and youth with chronic conditions. The findings of this study will generate new knowledge and future research directions in the area of QoL and, more generally, in the field of child health.

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### Notice of correction

Please note that the following amendments have been made to this paper, first published Early Online 31 October 2010. Alteration of references 10 and 42. Alteration to citations on pages 48 and 49. The authors would like to apologise for the errors in the original publication.

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