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## RESEARCH PAPER

# ICF-based functional components and contextual factors as correlates of perceived quality of life for youth with chronic conditions

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### Abstract

**Purpose:** To explore International Classification of Functioning, Disability and Health (ICF)-based functional components and contextual factors associated with perceived quality of life (QOL) for youth with chronic conditions from the perspective of youth and parents. **Method:** Baseline data were obtained from a longitudinal study examining predictors of changes in perceived QOL for youth with chronic conditions. 439 youth aged 11–17 (and one of their parents) completed a questionnaire. Standardized tools were used to measure youth functioning, contextual factors and perceived QOL. Multivariate linear regression analyses, controlling for socio-demographic and health information, were conducted to explore correlations among youth functioning/contextual factors and youth and parent perceptions of youth QOL. **Results:** Significant ( $p \leq 0.05$ ) negative correlates with both youth and parent perceptions of youth QOL included pain/other physical symptoms and emotional symptoms. Significant factors positively correlated with youth and parent perceptions of youth QOL included school productivity and spirituality. Other significant positive correlates of youth perspectives were family social support and school belongingness/safety. Family functioning was positively correlated, and youth social anxiety and environmental barriers were negatively correlated, with parent perceptions of youth QOL. **Conclusions:** This study provides preliminary evidence of factors upon which services aimed at improving perceived QOL of youth with chronic conditions could be based.

### Keywords

Chronic conditions, ICF, perspectives, quality of life, youth

### History

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### ► Implications for Rehabilitation

- This study supports the utility of clinicians assessing the QOL of youth with chronic conditions in terms of youths' and their families' perspectives.
- This is the first study to identify key factors that impact perceived QOL at one point in time across a group of youth with chronic conditions, offering clinicians a main starting-point for considering youths' strengths and needs and the supportiveness of the environment.
- Findings suggest youth and families would benefit from the availability of services that encompass the full scope of the ICF.

### Introduction

Optimization of quality of life (QOL) for children and youth with chronic conditions is a primary goal of pediatric rehabilitation services and a central focus of child health and rehabilitation research [1]. In child health and rehabilitation research, QOL has typically been evaluated in terms of concepts like physical symptoms, functional status or health utility. Most measures purporting to assess QOL that have been used in this field include multiple subdomains, most typically physical, emotional and social functioning, and often calculate overall QOL as the sum of

subdomain scores. Moreover, in many studies examining the correlates of QOL, the measures of correlates frequently include items/subdomains that overlap with those items/subdomains included in the actual measures used to assess QOL [2]. This practice can lead to confounding results. For example, gross motor functioning of children and youth with cerebral palsy has repeatedly been found to correlate with QOL when it is measured in terms of physical functioning, but rarely when it is measured as emotional or social functioning [2].

A recent review [3] of patient-reported outcome measures concluded that many QOL instruments were developed prior to the clarification of conceptual differences between functioning, disability, and health and QOL, provided by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) [4], and the WHO-QOL Group [5]. According to the WHO-QOL Group [5], QOL is

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defined as, “individuals’ *perceptions* of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns” (p. 1570).

There is growing consensus that QOL may be best perceived as a subjective phenomenon [3]. Indeed, several concept analyses of QOL suggest that the concept should be defined in terms of overall life satisfaction, as opposed to concepts like functioning, utility, happiness, etc. [6–8]. Moreover, the WHO Regional Office for Europe [9] has most recently proposed overall satisfaction with life as the core indicator of subjective wellbeing. It is recommended by the WHO that their member countries include a single-item measure of general life satisfaction in national surveys [9], indicating their support for overall life satisfaction as relevant for monitoring and policymaking.

In view of all this, one approach that evaluates QOL subjectively and avoids confounding the measurement of QOL with the measurement of its potential correlates in population-based research is to measure QOL as a unidimensional construct, in terms of a person’s *overall* life satisfaction or *global* perceived QOL, and then to examine its association with multiple hypothesized correlates [10].

Recently, McDougall et al. [11] proposed a modified version of the ICF Model of Functioning and Disability based on a systems perspective that offers a framework for understanding how functioning and contextual factors contribute to people’s QOL (see McDougall et al. [11] for a description/visual of the modified model). The modified model expands upon the original ICF Model to depict a person’s QOL, and development over time, as an ever-changing composite in which the whole 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) [11].

The modified model reflects the idea that all of the components included in the ICF Model could potentially affect a person’s QOL and contribute to changes in QOL [11]. This modified model acknowledges the importance of subjective wellbeing, and encourages researchers/clinicians to collect QOL information from individuals themselves (i.e. perceived QOL), as well as from other sources. A recent study found support for this model when exploring the relationships between personal factors, environmental factors, and activity participation variables and QOL among young adults with disabilities, aged 18 to 30 years old [12].

To date, there has been no empirical evidence about the contribution of functioning and other potentially important contextual factors to the global perceived QOL of children and youth with chronic conditions [10]. Yet, identifying correlates of QOL in this group of young people *from their (and their families’) perspective* is considered chief among the number of research directions to pursue when moving forward to improve the understanding of what makes children’s and youths’ lives better [13].

Thus, the objective of this study was to use baseline data from a longitudinal study [10] to conduct an initial exploration of aspects of functioning and contextual factors associated with global perceived QOL for youth with chronic conditions, from the perspective of both youth and their parents. A proper assessment of youth wellbeing should take into account youths’ own perspectives [2,14]. At the same time, perspectives of both youth and parents are important for making intervention-related and policy decisions since each party is likely to place different values on life states [2].

The hypothesized correlates of perceived QOL included in the study were chosen to reflect the functional components and contextual factors of the ICF Model of Functioning and Disability [4], and are supported by conceptual models of QOL [15,16]

as well as past research regarding correlates of perceived QOL for children and youth in the general population [17–20] and for children, youth and adults with chronic conditions [21–24] (reviewed in McDougall et al. [11]). The overall approach to studying QOL is reflected in the modified ICF model as presented by McDougall and colleagues [11].

## Methods

This research utilized baseline data for a random sample of 439 youth with various chronic conditions, ages 11 to 17 who are participating in a longitudinal study examining predictors of changes in perceived QOL (see McDougall et al. [10] for a full description of the longitudinal study). Youth were recruited from eight children’s treatment centers. At the time of writing this paper, only baseline data collection has been completed and investigators are continuing to collect data for the additional time points. A prospective cohort design [25] is being used for the longitudinal study, with a three-year follow-up of each participant. Ethical approval for the study was obtained from the Health Sciences Research Ethics Board, Western University, London, Ontario, Canada.

## Participants

This study focuses on youth with the kinds of physical, developmental and communicative conditions for which rehabilitation services are typically provided in children’s treatment centers. A non-categorical approach to illness was adopted for the study, combining children with different conditions into a single group for data analysis purposes [26]. For each youth enrolled, one parent (most often the birth mother) also participated. Youth had one of the following as a primary condition: cerebral palsy, spina bifida, autism spectrum disorder, acquired brain injury, developmental delay, cleft lip and/or palate, Down syndrome, arthritis, communication disorder, amputation or any other non-progressive muscular or central nervous system disorder. To be eligible for the study, a youth also needed to live within 100 km of the youth’s treatment center and to be able to cognitively understand and answer the study questionnaire with guidance from a study interviewer (i.e. trained health professional).

## Procedures

Baseline data collection occurred either in a private office at the youth’s treatment center or in the youth’s home. Study interviewers obtained written informed consent from youth and parent before the baseline assessment. After a standardized introduction from the interviewer to the questionnaire, each youth took part in a face-to-face guided questionnaire completion process (30–60 min) with additional support as required from the interviewer (e.g. further explanation of questions). The parent questionnaire (30–60 min) was completed independently in a separate room by the parent at the same time as the youth interview. The youth and parent were not given access to each other’s responses.

## Measures

The parent and youth questionnaires were each made up of a series of validated measures. Additional measures were developed and tested as part of this research, where tools of suitable length/content were not available. Youth perceived QOL was measured in the youth and parent questionnaires using the Students’ Life Satisfaction Scale (SLSS) [27]. This tool was originally developed for use with, and has been extensively tested with, children and youth in the general population [28]. A parent version was adapted for this study with permission from the measure’s authors.

The SLSS contains seven context-free items rated using a six-point scale: (6 = strongly agree; 5 = moderately agree; 4 = mildly agree; 3 = mildly disagree; 2 = moderately disagree; 1 = strongly disagree). Five items are positively worded (i.e. My 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). Two items are negatively worded (i.e. I would like to change things in my life; I wish I had a different kind of life) and require reverse coding in the scoring.

The adapted parent version uses the same six-point scale and includes the following reworded items: My child feels his/her life is going well; My child feels his/her life is just right; My child feels he/she has a good life; My child has what he/she wants in life; My child feels his/her life is better than most kids; My child would like to change things in his/her life; My child wishes he/she had a different kind of life.

The SLSS was evaluated by our team prior to use in this research and was found to perform differently with youth who have chronic conditions compared to youth in the general population [29] (see McDougall et al. [29] for a description of the testing of the SLSS). Specifically, both youth and parent versions were found to have two factors (as opposed to one found in general population research): one consisting of the five positive items representing "satisfaction with overall life quality"; the other consisting of two negative items representing "desire for life change". Comparable findings were reported when the SLSS was used in another study involving children with cerebral palsy, where a discrepancy was found in responses between positive and negatively worded items [30].

Additional analyses were conducted to assess reliability and factor structure of the SLSS when only positively worded items were included. Cronbach's alpha improved for both youth and parent versions ( $\alpha = 0.82$  and  $0.88$ , respectively), and a one-factor structure was indicated, accounting for 61% of variance in the youth version, and 69% in the parent version. Correlations with another validated measure of youth life satisfaction, the Brief Multidimensional Students' Life Satisfaction Scale [31] also improved between both youth and parent versions ( $r = 0.67$ ,  $p \leq .001$ ;  $r = 0.72$ ,  $p \leq .0001$ , respectively) when only positive items were included, indicating good concurrent validity of the abbreviated versions. The five-item positively worded youth and parent versions of the SLSS were used in this research.

Each of the hypothesized correlates of perceived QOL used in this research was measured in either the parent or the youth questionnaire. Correlates that were measured within the youth questionnaire consisted of: (1) functioning (i.e. activities and participation, using the Child and Adolescent Scale of Participation (CASP)) [32] and (2) contextual factors (i.e. emotional/behavioral functioning, using the Strengths and Difficulties Questionnaire [33] and the Social Anxiety Scales for Children – Revised [34]; self-determination via an adapted/abbreviated version of Arc's Self-Determination Scale [35], developed with permission; religiosity, using an Index of Religious Behaviors, developed for this study; spirituality, using the "spirit" subscale of the Spirituality Index, adapted for youth with permission [36]; school belongingness/safety and neighborhood cohesion/safety, using items from the 2005/06 Health Behavior of School Aged Children Survey [37] and the 1994/95 National Longitudinal Survey of Children and Youth (NLSCY) [38], respectively; and youths' social support from family, close friends, classmates and teachers, via the Social Support Appraisals Scale) [39].

Hypothesized correlates of perceived QOL that were measured within the parent questionnaire included: (1) functioning (i.e. impairments via a checklist of youths' impairments, the Child and Adolescent Factors Inventory (CAFI)) [40], and (2) contextual factors (i.e. youths' personal effort/success at school using the

School Productivity Measure, developed for this study; family functioning, using the Family Functioning Scale from the 1994/94 NLSCY [38]; parents' empowerment related to their knowledge of and ability to obtain services for their child, using the "knowledge" sub-scale of the Family Empowerment Scale [41]; and supportive physical, attitudinal and social environments for youth, using the Child and Adolescent Scale of Environment (CASE)) [40].

The CAFI, CASP and CASE measure impairments, activity and participation, and environmental factors, respectively, and were chosen for use because they were originally developed based on the ICF framework [40]. Table 1 lists all study measures, their sub-scales (constructs), whether the measure is a parent or youth report, number of items for each subscale, examples of item content, and Cronbach's alpha for each subscale.

Basic socio-demographic and youth health information was gathered by the parent questionnaire and included as control variables in this research. Research in children and youth in the general population has shown socio-demographic variables (i.e. age, sex, ethnicity/race, marital status, sibling relationships, socio-economic status, community size) to be weakly to modestly correlated with perceived life satisfaction [17,18]. Recent research has also found modest differences in SLSS youth report scores for chronic condition groups [18] and correlations have been found between QOL scores and age at diagnosis for childhood cancer survivors [42], see Table 2 for the control variable list.

### Statistical analyses

Two multivariate linear regression analyses were performed: one exploring correlates associated with youths' own perceptions of their QOL; another exploring correlates associated with parents' perceptions of youths' QOL. Prior to this, preliminary multivariate analyses for each outcome (i.e. youth perceived QOL and parent perceptions of youth perceived QOL) were conducted separately for each study measure with multiple sub-scales, examining the sub-scales as correlates (e.g. Strength and Difficulties Questionnaire). Two additional preliminary multivariate analyses for each outcome were also conducted; one that included the remaining single-scale personal factor variables as correlates (e.g. Spirituality Index, School Productivity Measure) and one, the remaining single-scale environmental factor variables as correlates (e.g. Family Empowerment Scale, Family Functioning Scale). The purpose of this approach was to eliminate scales and sub-scales that were not significant ( $p < 0.05$ ) in the preliminary analyses from inclusion in the two final analyses. This approach was taken to reduce the number of independent variables included in the final models.

All of the 12 study control variables listed in Table 1 were incorporated into the preliminary and final regression analyses. First, bivariate correlations between control variables were examined to identify any possible collinearity concerns. The magnitude of the correlation coefficients between any of the control variables was less than 0.5, indicating no collinearity concerns [43].

All variables in the multivariate analyses were treated as continuous except for nominal level variables, which were dummy-coded. Nominal level variables were dummy-coded in order to treat them as continuous.

Multivariate regression analyses were conducted using Mplus statistical software (version 6) [44]. Multiple imputation was used to fill in values for missing data on study variables. On average, there was less than 5% missing data across all variables. Five fully imputed data sets were created and analyzed in Mplus. Parameter estimates and standard errors were averaged over the five data sets. The cluster option in Mplus was invoked to account for the

Table 1. Measures and their subscales/constructs used as correlates or outcomes.

Measures	Subscales/constructs and examples of item content	Report	# Items	$\alpha$
<i>Correlates – youth functioning/personal factors</i>				
Child and Adolescent Factors Inventory [40]		Parent		
	Cognition (e.g. problems understanding or learning new things; difficulty problem solving)		4	0.85
	Movement/strength (e.g. balance problems; coordination problems)		2	0.71
	Sensory (e.g. speech problems; vision problems)		3	0.50
	Pain/other physical symptoms (e.g. physical symptoms such as headaches, dizziness, discomfort)		2	0.60
Child and Adolescent Scale of Participation [32]		Youth		
	Basic daily activities/mobility (e.g. self-care; moving around at home)		6	0.74
	Advanced daily activities (e.g. managing daily schedule; using educational materials)		6	0.67
	Social, leisure participation/communication (e.g. fun activities with family at home such as games; structured activities in community such as sports)		8	0.80
Strengths and Difficulties Questionnaire [33]		Youth		
	Peer problems (e.g. other kids bully; gets on better with adults)		5	0.54
	Pro-social behavior (e.g. nice to others; shares with others)		5	0.67
	Conduct problems (e.g. loses temper; fights a lot)		5	0.51
	Hyperactivity (e.g. restless; easily distracted)		5	0.68
	Emotional symptoms (e.g. worries a lot; often unhappy)		5	0.71
Social Anxiety Scale for Children – Revised [34]		Youth		
	Fear of peer rejection (e.g. feels others kids talk behind back; feels other kids make fun)		9	0.91
	Generalized anxiety (e.g. quiet in a group of kids; hard to ask kids to do things)		3	0.72
	Fear of new situations (e.g. nervous when talks to new kids; shy around new kids)		4	0.84
Self-Determination Scale (adapted/abbreviated from Arc's Self-Determination Scale) [35]		Youth		
	Goal orientation (e.g. if wants to do something finds a way to do it; makes plans for the future)		6	0.69
	Personal autonomy (e.g. chooses own clothes; chooses how to spend own money)		5	0.65
	Social autonomy (e.g. chooses free time activities; makes friends on own)		3	0.57
	Self-assurance (e.g. tells others new or different ideas; expresses feelings to others)		4	0.69
Spirituality Index [36] (adapted for youth)		Youth		
	Spirituality - defined as deep feelings/beliefs (e.g. spirituality helps to understand purpose in life; even when there are problems, feels spiritual peace inside)		4	0.85
Index of Religious Behaviors*		Youth		
	Religious behaviors (e.g. how often goes to church; how often prays/meditates)		5	0.84
School Productivity Measure*		Parent		
	Personal effort/success at school (e.g. how often completed homework in last month; how often tried to do personal best at school in last month)		4	0.86
<i>Correlates – environmental factors</i>				
Social Support Appraisal Scale [39]		Youth		
	Close friend support (e.g. thinks friends care; can tell friends problems)		5	0.75
	Classmate support (e.g. thinks classmates care; feels left out by classmates)		3	0.72
	Family support (e.g. family listens to ideas; thinks family cares)		6	0.83
	Teacher support (e.g. can count on teachers for help with problems; thinks teachers care)		6	0.78
Family Functioning Scale [38]		Parent		
	General family functioning (e.g. able to make decisions to solve problems; members accepted for who they are)		6	0.78
Scale of School Environment [37]		Youth		
	School belongingness/safety (e.g. feels like belongs at school; school is safe)		3	0.77
Scale of Neighborhood Environment [38]		Youth		
	Neighborhood cohesion/safety (e.g. safe to walk alone after dark; there are good parks and play spaces)		3	0.50

(continued)

Table 1. Continued

Measures	Subscales/constructs and examples of item content	Report	# Items	$\alpha$
Family Empowerment Scale [41]	Parental knowledge/ability to obtain services (e.g. good understanding of child's service system; able to get information to help child)	Parent	10	0.91
Child and Adolescent Scale of the Environment [40]	School barriers (e.g. people's attitudes toward child; lack of support and services for child)	Parent	4	0.85
	Physical barriers (e.g. physical design of buildings, lack of equipment; lack of transportation)		5	0.76
	Home and community barriers (e.g. family stress, community attitudes toward child; lack of support, services, and funding)		9	0.85
<i>Outcomes</i>				
Students' Life Satisfaction Scale [27] Youth – Revised [29]	Overall perceived quality of life of youth from youths' perspective (e.g. my life is going well; my life is just right)	Youth	5	0.82
Students' Life Satisfaction Scale Parent – Revised [29]	Overall perceived quality of life of youth from parents' perspective (e.g. my child feels his/her life is going well; my child feels his/her life is just right)	Parent	5	0.88

\*Measures developed for this study.

possibility of design effects associated with the nested structure of the data (i.e. youth nested within centers).

## Results

Youth were randomly selected (with replacement) from initial lists of potential participants compiled at each center using a computerized randomization method. The overall initial list across centers consisted of 3188 youth. Three hundred and ninety-three families could not be contacted. Of those contacted, 1372 were deemed ineligible (see criteria above) and 984 declined to participate (no interest, busy, youth acutely ill, other), leaving the 439 who agreed to participate. In general, participating families did not differ significantly on a number of socio-demographic characteristics from those who declined to participate, with the exception of parent age (44 years 6 months and 46 years 7 months, respectively,  $p \leq 0.05$ ).

### Sample characteristics

Table 2 summarizes basic socio-demographic characteristics and health information of the sample (i.e. study controls). The mean age of youth was 13 years. There were more males (56%) than females. Cerebral palsy was the largest condition group (35%) followed by acquired brain injury (13%). Eighty-three percent of parent respondents were birth mothers to youth, 11% were birth fathers, 4% were adoptive mothers, and 2% were another type of relationship (e.g. grandmother).

### QOL scores

Youth total scores on the revised SLSS varied from 8.0 to 30.0 out of a possible 30.0 points; parent total scores varied from 5.0 to 30.0. Youths' mean score was 25.33 (SD = 4.47), compared to parents' mean score of 23.24 (SD = 4.69) (see McDougall et al. [29] for a full comparison of youth and parent scores on the SLSS).

### QOL correlates

The models of both youth and parent correlates of QOL were significant and accounted for a significant amount of variance

( $p \leq 0.001$ ,  $R^2 = .46$ ;  $p \leq 0.001$ ,  $R^2 = 0.39$ , respectively). As seen in Tables 3 and 4, statistically significant ( $p \leq 0.05$ ) negative correlates with both youth and parent perceptions of QOL for youth included pain/other physical symptoms and emotional symptoms. Significant factors positively correlated with both youth and parent perceptions of youth QOL included school productivity and spirituality. Other significant positive correlates of youth perspectives were family social support and school belongingness/safety. Family functioning was positively correlated, and youth social anxiety (fear of peer rejection), home/community barriers and school barriers were all negatively correlated, with parent perceptions of youth QOL. In terms of magnitude of effects, family social support, school belongingness/safety, and spirituality were indicated to have the largest effects in the youth analysis ( $\beta = 0.24$ , 0.19 and 0.18 respectively). In the parent analysis, school productivity and home and community barriers appeared to have the greatest effect ( $\beta = 0.18$  and  $-0.18$ , respectively).

To assess what variance the control variables accounted for in the models, both models were run with the controls excluded. The variance explained for the models of both youth and parent correlates of QOL without the control variables changed very little from the original models ( $p \leq 0.001$ ,  $R^2 = 0.44$ ;  $p \leq 0.001$ ,  $R^2 = 0.35$ , respectively).

## Discussion

This research was the first to comprehensively explore ICF-based functional components and contextual factors associated with global perceived QOL for youth with chronic conditions from the point of view of both youth and parents. Both perspectives were obtained because it was thought that youth and parents might place different values on what is important to youth QOL. Surprisingly, for both youth and parents, the same or related factors were associated with facilitating or hindering QOL for youth. That the same or related aspects of life were linked with youth QOL from both perspectives provides added support for these as *key* factors. Functional, personal and environmental factors were all significantly related to youth perceived QOL, indicating the benefits of a biopsychosocial approach to both

Table 2. Description of socio-demographic and health-related sample characteristics (study controls).

Characteristics	#Items	n	(%)	M	SD	Min–Max
Youth sex	1					
• Female		193	44.0	–	–	–
• Male		246	56.0	–	–	–
Youth age (years)	1	439	–	13.8	2.2	11–17
Parent sex	1					
• Female		386	87.9	–	–	–
• Male		53	12.1	–	–	–
Parent age (years)	1	439	–	44.8	6.5	29–71
Parent marital status	1					
• Married		294	67.0	–	–	–
• Living common law/partner		38	8.7	–	–	–
• Separated/divorced		61	13.9	–	–	–
• Single (never married)		27	6.2	–	–	–
• Widowed		15	3.4	–	–	–
• Missing data		4	0.8	–	–	–
Parent education	1					
• Secondary school or less		28	6.4	–	–	–
• Completed secondary school		65	14.8	–	–	–
• Some college or university		85	19.4	–	–	–
• Completed college or university		257	58.5	–	–	–
• Missing data		4	0.8	–	–	–
Family income	1					
• Under \$25 000		62	14.1	–	–	–
• \$25 000 to \$34 999		32	7.3	–	–	–
• \$35 000 to \$44 999		32	7.3	–	–	–
• \$45 000 to \$54 999		29	6.6	–	–	–
• \$55 000 to \$64 999		28	6.4	–	–	–
• \$65 000 to \$74 999		42	9.6	–	–	–
• \$75 000 or more		161	36.7	–	–	–
• Missing data		53	12.0	–	–	–
Language spoken at home	1					
• English		393	89.5	–	–	–
• Other		46	10.5	–	–	–
Number of children in home	1	439	–	2.6	1.2	1–9
Population density	1					
• Rural (less than 3000)		62	14.1	–	–	–
• Town (3000 to 19 999)		68	15.5	–	–	–
• Small city (20 000 to 49 999)		33	7.5	–	–	–
• Medium city (50 000 to 99 999)		39	8.9	–	–	–
• Large city (100 000 or more)		231	52.6	–	–	–
• Missing data		6	1.4	–	–	–
Youth primary chronic health condition	1					
• Cerebral palsy		153	34.9	–	–	–
• Spina bifida		36	8.2	–	–	–
• Autism spectrum disorder		38	8.6	–	–	–
• Brain injury		59	13.4	–	–	–
• Cleft lip-palate/communication		41	9.4	–	–	–
• Amputee		18	4.1	–	–	–
• Developmental delay		29	6.6	–	–	–
• Other condition (i.e. arthritis, Down syndrome, other central nervous system or neuromuscular disorder)		65	14.8	–	–	–
Youth age at diagnosis	1					
• Before birth		32	7.3	–	–	–
• At birth		117	26.7	–	–	–
• Within first year of life		78	17.8	–	–	–
• 1 to 2 years old		60	13.7	–	–	–
• 3 to 4 years old		49	11.2	–	–	–
• Five years of age or older		102	23.3	–	–	–

ns are before multiple imputation for missing values.

assessment and enhancement of QOL for youth with chronic conditions. In addition, the types of factors identified were aspects of life that are amenable to change.

The key functional and personal factors associated with both youth and parent perspectives were for the most part identical,

with somewhat varying strengths of association and magnitude of effects. Both youth and parent analyses indicated that pain/other physical symptoms were negatively associated with youth perceived QOL. Research has indicated that long-lasting pain among children and youth with chronic conditions is often not sufficiently treated [45,46]. In addition, emotional symptoms were negatively correlated with both youth and parent perceptions of youth QOL. Mental health can also often be overlooked in children and youth with chronic conditions [47,48]. These findings, in conjunction with past research, suggest that questions about pain/other physical symptoms and mental health should always be included in initial and follow-up assessments of youth.

Correlates representing activities and participation, a major component of the ICF, were significant positive correlates of perceived QOL in preliminary analyses that included only the CASP sub-scales. However, they were not significantly related to perceived QOL in the final analyses that included a greater number of competing correlates. It could be speculated that the ability to carry out activities of daily living and to participate socially may be of less significance to perceived QOL, while youth are dealing with physical and emotional issues. However, the importance of engaging in activities and in social participation to the development of mental and physical health should not be disregarded [48].

Spirituality, described as any deep feelings or beliefs youth may have, was positively correlated with perceived QOL in both the youth and parent analyses, with a larger magnitude of effect in the youth analysis. Although rarely a part of standard care, the value of listening to youth and understanding the importance of personal meaning in their lives, and attending to associated needs as well as building on strengths within the context of pediatric rehabilitation, is supported within the literature [49]. Researchers recommend adopting a holistic approach to rehabilitation services that encompasses mind, body and spirit and is explicitly reflected in the practice of family-centered service [49].

Indeed, this research supports the position that the provision of family-centered service, with an emphasis on including parent and family wellbeing within the scope of pediatric rehabilitation services, is integral to the wellbeing of youth with chronic conditions [50]. Positively correlated with youth perceptions of perceived QOL and with the largest magnitude of effect was family social support, while overall functioning of the family was positively correlated with parent perspectives of youth perceived QOL. Barriers at home such as family stress and community barriers such as lack of support and encouragement also had considerable effect on and were negatively associated with parent perspectives of QOL for youth.

School productivity, in terms of personal effort and success at school was also positively associated with perceived QOL in both the youth and parent analyses; the magnitude of effect being larger in the parent analysis. It is also noteworthy that self-determination in terms of goal-orientation was moderately and positively correlated ( $p \leq 0.10$ ) with perceived QOL in the youth analysis. These findings suggest that having a chronic condition is not a detriment to youths' desire for personal development and achievement. Findings also support past work that has emphasized the importance of goal setting at home and in the school setting for youth who receive rehabilitation services [51].

Indeed, school life appeared to be a very important context to the life quality of youth. Specifically, a sense of school belongingness/safety was a significant positive correlate of perceived QOL with a substantial effect in the youth analysis, and school barriers, such as poor attitudes and lack of programs were negatively associated with perceived QOL in the parent analysis. Social anxiety, in terms of fear of peer rejection was moderately and negatively correlated ( $p \leq 0.10$ ) with poorer



Table 3. Multivariate linear regression correlates of youth perceived quality of life – youth report.

Variables	<i>B</i>	<i>SE B</i>	95% CI ( <i>B</i> )	$\beta$	<i>t</i>
Youth functioning/personal factors					
Pain/other physical symptoms	-0.27	0.08	-0.43;-0.11	-0.07	-3.27***
Carrying out advanced daily activities	0.08	0.08	-0.08;0.24	0.05	1.01
Social/leisure participation/communication	0.06	0.06	-0.06;0.18	0.05	1.00
Social anxiety (fear of peer rejection)	0.02	0.02	-0.02;0.06	0.05	1.48
Emotional symptoms	-0.27	0.09	-0.45;-0.09	-0.14	-2.96**
Peer problems	-0.02	0.14	-0.24;0.25	-0.01	-0.15
Pro-social behavior	-0.18	0.16	-0.49;0.13	-0.07	-1.14
Self-determination (goal orientation)	0.15	0.08	-0.01;0.31	0.11	1.93
Self-determination (self-assurance)	0.01	0.07	-0.13;0.15	0.01	0.17
Spirituality	0.19	0.07	0.04;0.32	0.18	2.85**
School productivity	0.18	0.08	-0.05;0.27	0.11	2.34*
Environmental factors					
Social support from family	0.27	0.13	0.02;0.52	0.24	2.06*
Social support from classmates	0.10	0.07	-0.04;0.24	0.06	1.59
School belongingness/safety	0.31	0.09	0.13;0.49	0.19	3.38***
Home and community barriers	-0.02	0.04	-0.10;0.06	-0.02	-0.56
$R^2 = 0.46$					
$F = 0.001$					

\* $p \leq 0.05$ .\*\* $p \leq 0.01$ .\*\*\* $p \leq 0.001$ .

Table 4. Multivariate linear regression correlates of youth perceived quality of life – parent report.

Variables	<i>B</i>	<i>SE B</i>	95% CI ( <i>B</i> )	$\beta$	<i>t</i>
Youth functioning/personal factors					
Pain/other physical symptoms	-0.42	0.10	-0.63;-0.23	-0.10	-4.12***
Carrying out basic daily activities	0.01	0.05	-0.04;0.11	0.01	0.26
Social anxiety (fear of peer rejection)	-0.04	0.02	-0.14;0.06	-0.09	-1.96*
Emotional symptoms	-0.25	0.10	-0.45;-0.05	-0.13	-2.46*
Self-determination (goal orientation)	-0.03	0.04	-0.11;0.05	-0.02	-0.81
Self-determination (self-assurance)	0.04	0.07	-0.16;0.24	0.03	0.61
Spirituality	0.09	0.04	0.00;0.16	0.08	2.41*
School productivity	0.31	0.06	0.19;0.43	0.18	5.15***
Environmental factors					
Social support from family	0.05	0.05	-0.05;0.15	0.04	1.02
Family functioning	0.18	0.06	0.06;0.30	0.12	2.76**
Family empowerment for accessing services	0.04	0.03	-0.02;0.10	0.06	1.34
School barriers	-0.17	0.07	-0.31;-0.03	-0.07	-2.47*
Home and community barriers	-0.21	0.08	-0.37;-0.05	-0.18	-2.44*
$R^2 = 0.39$					
$F = 0.001$					

\* $p \leq 0.05$ .\*\* $p \leq 0.01$ .\*\*\* $p \leq 0.001$ .

perceived QOL in the parent analysis. Health and education professionals and policy makers need to be aware of the importance of school productivity and the supportiveness of the school environment to perceived QOL and support youths' desire to be successful and included. Recently, health care professionals, policy makers and youth service providers have been encouraged to advocate for school-based health centers (SBHS) to address the health needs of all students, including those with chronic conditions [52]. Positive findings in medical, mental health and educational outcomes for students who use SBHCs show promise for positioning youth on positive developmental trajectories [52].

#### Study limitations and directions for future research

Caution should be used when generalizing findings to youth with chronic conditions who are not receiving services from a children's treatment center and who do not fit the socio-demographic and health-related profile of study participants.

A limitation of this research was that it used cross-sectional data derived from a longitudinal study. The longitudinal study, when data are available, will examine the factors that influence changes over time in perceived QOL for youth with chronic conditions. Testing the longitudinal data using statistical methods such as structural equation modeling and latent growth curve modeling will be useful for unraveling the complex inter-relationships among functioning, contextual factors and perceived QOL over time and will allow researchers to look at within-person change and development [53]. For example, the longitudinal analyses may help us to better understand the associations among activities and participation and perceived QOL.

#### Conclusion

This study supports the utility of assessing global perceived QOL for youth with chronic conditions and then identifying related functional, personal and environmental factors as a way of

understanding what is important to the life quality of youth. The ICF framework, and the modified ICF model that was applied to study global perceived QOL of youth with chronic conditions in this research, go well beyond consideration of the physical impairments and functional limitations of individuals with chronic conditions, yet pediatric rehabilitation services still tend to focus on these aspects of children's and youths' lives [48]. In addition to working toward alleviating physical impairments and functional limitations, findings help to justify the provision of services designed to enhance other life dimensions, like youth emotional wellbeing and family wellbeing, as well as providing additional supports such as spiritual care for youth and their families, and advocating for supportive school and community environments where youth can thrive and develop to their full potential.

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