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Janette McDougall

Western University, jmcdoug6@uwo.ca

Gary Bedell

Tufts University

Virginia Wright

Bloorview Research Institute

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The youth report version of the Child and Adolescent Scale of Participation (CASP): assessment of psychometric properties and comparison with parent report

J. McDougall,* G. Bedell† and V. Wright‡

*Thames Valley Children's Centre, London, ON, Canada

†Tufts University, Medford, MA, USA, and

‡Bloorview Research Institute, Toronto, ON, Canada

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Abstract

Objective The Child and Adolescent Scale of Participation (CASP) parent report is a brief and valid measure for use with children and youth with chronic conditions/disabilities that has been shown to have good coverage at the chapter level of the 'Activities and Participation' component of the International Classification of Functioning, Disability and Health. The purpose of this research was to assess the psychometric properties of a CASP youth self-report version, to further validate the parent report, and to compare parent and youth reports of youths' activity and participation.

Methods Baseline data from a longitudinal study examining predictors of changes in quality of life for youth with chronic conditions/disabilities were used. CASP data were collected on 409 youth aged 11–17 with various conditions/disabilities using youth and parent reports. Internal consistency and factor structure were examined for both versions using Cronbach's alpha and exploratory factor analyses. Inter-rater agreement and magnitude of differences between youth and parent report were evaluated using intraclass correlation coefficients and paired *t*-tests respectively. Gender, age and condition/disability group differences in youth report CASP scores were examined using independent *t*-tests or analyses of variance.

Results Strong internal consistency and internal structure validity was demonstrated for the CASP youth and parent report. The youth report factor structure was similar to the parent report in this and other studies. Youth reported their activity/participation to be significantly higher than did their parents. Significant differences in CASP scores were found among condition/disability groups. **Conclusions** Findings show that, from a psychometric standpoint, the youth version of the CASP is a promising new self-report measure of activity and participation. As youth perceive their activity and participation levels differently than their parents, it is important to collect data from both sources to obtain a more comprehensive understanding of this aspect of youths' lives.

Keywords

adolescence, childhood disability, ICF-CY, measurement, participation, self-report

Correspondence:

Janette McDougall,
Thames Valley Children's
Centre, 779 Base Line
Road East, London, ON,
Canada, N6C 5Y6
E-mail:
janette.mcdougall@
tvcc.on.ca

Introduction

The concept of participation, and its measurement, has received increased attention in the area of health and disability research

since the publication of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO 2001), and the more recent International Classification of Functioning, Disability and Health –

Child & Youth Version (ICF-CY) (WHO 2007). In addition to each providing a classification system for coding and documenting health and disability, the ICF and the ICF-CY share a conceptual framework for understanding functioning and disability. In this framework, 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 situations (WHO 2001). On the positive side, 'body functions' and 'body structures' are the physiological functions and anatomical parts of the body respectively; 'activity' is considered the execution of a task by a person; and 'participation' is defined as an individual's involvement in a life situation. A person's functioning and disability, including his/her participation, is considered to arise from the interaction among health conditions, and contextual or environmental factors (e.g. air quality, accessibility of the environment, peer relationships, service availability, etc.) and personal factors (e.g. age, gender, values, beliefs, lifestyle, etc.) (WHO 2007).

Within the 'Activities and Participation' component of the ICF/ICF-CY, there are nine domains or chapters considered to be 'Level One' codes within the classification system: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life. These chapters break down into increasingly smaller coded categories from levels two through four. Although the ICF and ICF-CY provide distinct definitions of activity and participation, they do not clarify how to separately operationalize the two concepts. Instead, four options are provided: (1) sets of activities and participation domains are distinct (no overlap); (2) partial overlap exists between sets of activities and participation domains; (3) activities as detailed categories and participation as broad categories, with or without overlap; and (4) use of the same and total overlap of domains for both activity and participation (see WHO 2001 for greater detail).

Prior to the ICF and the ICF-CY, few measures existed for assessing the participation of children and youth with chronic conditions/disabilities. A 2005 review (Morris *et al.* 2005) of instruments that might be feasible for use in a postal survey of families of children with cerebral palsy to describe their activity and participation as defined by ICF-CY revealed only seven potential measures. The researchers concluded that none of the

instruments reviewed could adequately measure activity and participation in terms of the ICF-CY. They, however, recommended the 64-item Assessment of Life Habits of Children (LIFE-H) (Fougeyrollas *et al.* 1998) as the most appropriate instrument for use by its content, but cautioned that psychometric testing had not been yet conducted.

A 2006 review (McConachie *et al.* 2006) of measures of participation appropriate for children in general identified five instruments and also examined them in terms of their correspondence with chapters in the 'Activities and Participation' component of the ICF. Two measures, the LIFE-H and the more recently developed and briefer 20-item Child and Adolescent Scale of Participation (CASP) (Bedell 2004), were identified as including items that covered all ICF chapters. A limitation of the CASP was identified as its being completed by a parent rather than a child him/herself.

Most recently, a 2011 review (Adolfsson *et al.* 2011) of instruments that purport to assess either children's performance (i.e. activity) or participation identified six claiming to measure performance and six claiming to measure participation and linked them to the chapters in the 'Activities and Participation' component of the ICF-CY using linking rules by Cieza and colleagues (Cieza *et al.* 2005). The CASP was included among the participation measures and once again identified as being the most brief, yet still with good coverage of, and distribution of items across the chapters of the 'Activities and Participation' component of ICF-CY.

The CASP

The CASP was originally designed as part of the *Child and Family Follow-up Survey* to monitor outcomes and needs of children and youth with acquired brain injuries (ABI) (Bedell 2004). Reference to the 'Activities and Participation' component of the ICF helped steer the development of the measure. In addition to the ICF, the CASP was informed by research examining the participation of children and youth with a variety of conditions/disabilities, expert clinicians, researchers and families of children and youth with ABI (Dumas *et al.* 2003; Bedell 2004; Bedell *et al.* 2005).

The CASP is described as measuring 'children's extent of participation and restrictions in home, school and community life situations and activities compared with same age peers, as reported by family caregivers' (Bedell 2009, p. 343). Twenty items are divided into four subsections: (1) home participation; (2) school participation; (3) community participation and; (4) home and community living activities. Items pertaining to the 'Activities and Participation' chapters of the ICF/ICF-CY are

Table 1. Examples of CASP parent report items corresponding to chapters in the 'Activity and Participation' component of the ICF/ICF-CY

ICF/ICF-CY chapter	CASP item example	CASP subsection
	<i>Compared to other children your child's age, what is your child's current level of participation in the following activities. . .</i>	
Learning and Applying Knowledge	Using educational materials and equipment that are available to other children in his or her classroom that have been modified for your child (e.g. books, computers, chairs and desks)	School participation
General Tasks and Demands	Family chores, responsibilities and decisions at home (e.g. involvement in household chores and decisions about family activities)	Home participation
Communication	Communicating with other children and adults at home	Home participation
Mobility	Moving around the neighbourhood and community (e.g. public buildings, parks, restaurants, movies) [<i>Please consider your child's primary way of moving around, NOT his or her use of transportation</i>]	Neighbourhood and community participation
Self-Care	Self-care activities (e.g. eating, dressing, bathing, combing or brushing hair, using the toilet)	Home participation
Domestic Life	Household activities (e.g. preparing some meals, doing laundry, washing dishes)	Home participation
Interpersonal Interactions and Relationships	Social, play or leisure activities with friends in the neighbourhood and community	Neighbourhood and community participation
Major Life Areas	Educational activities with other children in his or her classroom	School participation
Community, Social and Civic Life	Structured events and activities in the neighbourhood and community (e.g. team sports, clubs, holiday or religious events, concerts, parades and fairs)	Home and community living activities

CASP, Child and Adolescent Scale of Participation; ICF, International Classification of Functioning, Disability and Health; ICF-CY, International Classification of Functioning, Disability and Health – Child & Youth Version.

dispersed among the four subsections (see Bedell 2009 for full item descriptions within each subsection). Table 1 includes examples of CASP items that correspond to the nine chapters in the 'Activities and Participation' component of the ICF/ICF-CY, as identified in the McConachie and colleagues (2006) review of participation measures for children with disabilities. Also shown in Table 1 are the various subsections of the CASP that the items correspond to.

Limitations of the CASP have been noted, including: (1) its focus on children's level of participation/ability to take part compared with same age peers, and omission of questions about frequency and enjoyment of participation; (2) the lack of individual items asking about specific types of activities/participation (e.g. watching TV, going to the movies, playing sports, etc.); (3) not making a conceptual distinction between activity and participation; and (4) the reliance on parent report (McConachie *et al.* 2006; Bedell & Coster 2008; Adolfsson *et al.* 2011).

Studies have indicated that youth with chronic conditions/disabilities are more likely than other children and youth to experience restricted participation at home, school and in the community (Eriksson & Granlund 2004; King *et al.* 2009, 2010). Therefore, the CASP's comparison to same-age peers to assess participation restrictions may indeed be a useful metric.

Given that reviews (McConachie *et al.* 2006; Adolfsson *et al.* 2011) have found the CASP to have good overall coverage at the

chapter level of the 'Activities and Participation' component of the ICF, and recent testing (Bedell 2009) of the CASP has identified three factors: one that may be considered to have a primary focus on activity (i.e. basic daily activities/mobility); a second with a primary focus on participation (i.e. social, leisure participation/communication); and a third where activity and participation appear to overlap (i.e. advanced daily activities) (see Measures section below), it might be more accurate to consider the CASP as a measure of both activity and participation. Indeed, despite original reference to the CASP as a measure of participation, Bedell (2009) has more recently suggested that the CASP may in fact be measuring both activity and participation. As Bedell (2009) explains, a measurement challenge exists because the same nine ICF/ICF-CY domains are used to classify both activity and participation.

Despite its limitations, and given that the operationalization of both activity and participation is an ongoing and unresolved issue, the CASP remains a very brief, relatively easy-to-complete tool that offers good global coverage at the chapter level of the 'Activities and Participation' component of the ICF-CY. Given that the measure is based on the ICF, it adopts the ICF/ICF-CY definitions of activity and participation and has operationalized those concepts in terms of overlap between the 'Activities and Participation' domains; one of four approaches endorsed by the ICF/ICF-CY. Because of its brevity and simplicity, it is useful clinically and for both programme evaluation and population-based research.

The CASP author has addressed the need for a youth report version of the CASP by recently designing one. In doing so, the CASP is the one of very few measures of activity and participation at home, school and in the community for children and youth with chronic conditions/disabilities that provides both a parent and youth report.

Evidence for children's competency supports the position that children should become the preferred reporters of their disabilities, including activity limitations and participation restrictions (Young *et al.* 1995). It is important for school-aged children and youth to self-report on their health, functioning and well-being because the subjective feelings of children and youth about themselves and their lives can only be known to them (Topolski *et al.* 2004). In taking part in the measurement of their functioning, they may be more motivated to change it. Moreover, children and youth may have a broader knowledge of their activity and participation at home, school and in the community than would proxy reporters (Young *et al.* 1995). At the same time, the perspectives of both children and parents are important for making decisions related to interventions and policy decisions (Eiser & Morse 2001; Helders 2001; Livingstone *et al.* 2007) as children and parents are likely to place different values on health and life states (Feldman *et al.* 2000).

Purpose of paper

This paper is the first to assess psychometric properties for the youth report version of the CASP. In addition, the parent report version of the CASP is further validated using data from this same sample of youth and parents. Finally, this paper compares the parent proxy reports to youth self-reports in terms of their factor structure and ratings of youths' activity and participation. Although much research has been performed comparing ratings of youth with chronic conditions/disabilities and their parents on quality of life and health-related quality of life measures (e.g. Majnemer *et al.* 2008; Upton *et al.* 2008; Morrow *et al.* 2012) scant work has been done that compares the ratings of these parents and youth on measures of activity or participation (Morris *et al.* 2005).

Methods

Baseline data from a random sample of 430 youth aged 11–17 with a variety of chronic conditions/disabilities, and one of their parents, were used to assess the youth and parent report of the CASP. The data were from a longitudinal study examining predictors of changes in quality of life for youth with chronic conditions/disabilities (see McDougall *et al.* 2011 for detail

about the original study). A prospective cohort design (Bijleveld *et al.* 1998) is being used for the longitudinal study, with a 3-year follow-up of each participant (and four key data collection time points).

Youth were recruited from eight children's treatment centres. To achieve a random sample, a study Research Assistant at each centre used computer-generated random numbers to select youth to contact about taking part in the study from a list of potential participants who met eligibility criteria (criteria described below). If families had more than one eligible child, only one was selected to participate in the study also using a randomization method.

Participants

A non-categorical approach to illness was adopted, combining children with different chronic conditions/disabilities into a total group for data analysis purposes (Stein & Jessop 1984). Youth were eligible to be included in the study if they were cognitively able to answer the questionnaire items, and if they had any one or more of the following chronic conditions/disabilities: cerebral palsy, spina bifida, autism spectrum disorder, non-progressive muscular disorders, ABI, developmental delay, cleft lip and/or palate, Down syndrome, arthritis, communication disorder, amputation, or any other central nervous system disorder.

The mean age of the study youth was 14 (SD = 2.2). There were slightly more males (55%) than females in the sample. Cerebral palsy was the largest disability group ($n = 142$, 35%) (see Table 1). Parents' average age was 45 (SD = 6.5), with more female (88%) than male parents. Eighty-three per cent of parent respondents were birth mothers to the youth, 10% were birth fathers, 4% were adoptive mothers and 3% were another type of relationship (e.g. step father, grandmother). English was spoken in 90% of families' homes, French in 2% and various other languages in 8% of homes.

Measures

Questionnaires measuring youths' perceived quality of life and the hypothesized predictors of changes in quality of life (including activity and participation measured via the CASP) are administered to youth and their parents shortly after entry to the study and then again every 12 months over the course of 3 years. At the time of writing this paper, the baseline interviews have been completed, and investigators are continuing to collect data for the additional time points.

The 20 items of the CASP are rated using a four-point scale: (4 = aged expected; 3 = somewhat limited; 2 = very limited; 1 = unable), or as 'not applicable'. A not applicable option is provided because some of the questions may not pertain to very young children. A higher score on the CASP represents a higher level of children's participation in home, school and community life situations and activities compared with same age peers. The youth report CASP varies very little from the parent report in terms of language and not at all in terms of the measurement scale and scoring used, making them easily comparable. Both the new CASP youth report and the CASP parent report can be accessed for use free of charge at: <http://sites.tufts.edu/garybedell/measurement-tools/>.

Initial psychometric testing of the parent report CASP using data from 60 children and youth with ABI demonstrated evidence of test-retest reliability [intraclass correlation coefficient (ICC) = 0.94], internal consistency [Cronbach's alpha (α) = 0.98] and construct validity (Bedell 2004). Exploratory factor analysis identified a two-factor solution, with 73% variance explained: (1) mobility, self-care, home and community living activities; and (2) social, communication, leisure, school-based activities (Bedell 2004).

Further testing using a sample of 313 children and youth aged 3–22, without and with (i.e. developmental disabilities, ABI, learning, attention or sensory disorders) conditions/disabilities also showed the CASP to have high internal consistency (α = 0.96) (Bedell 2009). Factor analytical testing indicated that the items loaded onto three factors identified as: (1) social, leisure participation/communication; (2) advanced daily activities; and (3) basic daily activities/mobility, with a large degree of variance (63%) explained (Bedell 2009). Significant differences in CASP scores were found to be related to type of disability ($F = 35.67$; $P < 0.001$), but not to age ($F = 0.66$, $P = 0.65$) or gender ($t = 1.7$, $P = 0.09$) (Bedell 2009). Children with a developmental disability (i.e. mental retardation, cognitive/intellectual disability, cerebral palsy, Down syndrome, autism spectrum disorder), on average, had significantly lower CASP scores ($P < 0.001$) than all other groups (i.e. those children with no disability, ABI, or learning, attention, sensory disorders).

Procedures

Baseline data collection occurred either in the privacy of the respondent's home or in a private office at the youth's treatment centre. The parent and youth made the choice of location. Interviewers obtained written informed consent in person from youth and parents just prior to conducting the assessment. Following a standardized introduction to the questionnaire, each

youth took part in a face-to-face interview (30–60 min) with additional support as required from a study interviewer (e.g. further explanation of questions, provision of additional time). The parent questionnaire (each 30–60 min) was self-completed and was done at the same time as the youth interview. The primary caregiver, most often the youth's mother completed the questionnaire in a separate room. The youth and parent were not given access to each other's responses.

Data analyses

Descriptive analyses of the CASP youth report were conducted. Cronbach's alpha was computed to examine the internal consistency of the youth and parent report versions of the CASP. Exploratory factor analyses were used to examine the structure of the youth and parent report versions. Principal components analyses were used for the initial extraction and varimax rotation was applied to shift the items so that they would correlate more strongly with one factor than another. Cronbach's alpha was also used to examine the internal consistency of the subscores of the CASP found with the factor analyses. ICCs (two-way random effects, absolute) were computed to evaluate inter-rater agreement, and paired *t*-tests were conducted to assess mean differences between the youth and parent reports on the CASP total score and factor subscores. Independent *t*-tests or analyses of variance were carried out to determine mean differences in CASP total scores for the youth report in relation to gender, age and disability groups.

It should be noted that the 'not applicable' answer option for individual items of the CASP was not offered in this study, as the sample included school-aged children who it was anticipated all of the items would pertain to. Very few data were missing, therefore, the generation of summary scores that have been created in past testing of the CASP to be able to include those participants who answered 'not applicable' to several items was not necessary. Instead, total scores based on the summation of all CASP items were used. Any respondents without full data were excluded from the analyses using listwise deletion.

Results

Full CASP data were available for 409 of the 430 youth in the original sample. CASP youth total scores ranged from 28.0 to 80.0 out of a possible 80.0. The mean score was 69.5 (SD = 8.2), and the median score was 71.0. No floor effects were found. Ceiling effects were found for 5% ($n = 23$) of the sample. Table 2 provides CASP score descriptive statistics for age, gender and disability groups on the youth report. Significant differences in

Table 2. Descriptive statistics: sample characteristics and CASP scores for youth report

Characteristics	n (%)	CASP scores	
		M (SD)	Minimum–maximum
Age			
11	96 (23)	70.2 (8.2)	28–80
12	58 (14)	69.7 (7.8)	48–79
13	53 (13)	67.9 (8.6)	41–80
14	45 (11)	70.0 (7.9)	49–80
15	40 (10)	69.6 (9.1)	43–80
16	54 (13)	69.3 (7.9)	50–80
17	63 (16)	69.1 (8.2)	51–80
Gender			
Female	185 (45)	70.2 (7.8)	41–80
Male	224 (55)	68.9 (8.5)	28–80
Disability			
Cerebral palsy	142 (35)	68.3 (8.9)	28–80
Acquired brain injury	58 (14)	70.3 (7.4)	48–80
Communication/cleft lip-palate	44 (11)	72.1 (7.3)	43–80
Spina bifida	32 (8)	68.6 (8.2)	49–80
Autism spectrum disorder	30 (7)	65.3 (7.8)	48–79
Developmental delay	25 (6)	69.9 (6.5)	50–80
Amputation	16 (4)	76.7 (2.7)	71–80
Other	62 (15)	69.5 (8.2)	41–80

Sample ($n = 409$).

CASP, Child and Adolescent Scale of Participation.

CASP scores existed for disability groups ($F = 4.33$; $P < 0.0001$), but not for age ($F = 0.50$; $P = 0.81$) or gender ($t = 1.56$; $P = 0.12$). *Post-hoc* analyses (Tukey tests) were used to examine where differences existed between each of the disability groups. Youth with an amputated limb had significantly higher scores than those with cerebral palsy ($P < 0.01$) or autism spectrum disorder ($P < 0.0001$), and youth with communication disorders/cleft lip and/or palate, had significantly higher scores compared with youth with autism spectrum disorder ($P < 0.01$).

Results of internal consistency and scale structure analyses

The internal consistency of the CASP items for both the youth and parent report total scale was high ($\alpha = 0.87$ and 0.95 respectively). In the principal components analyses, a solution for the youth report in which two of five factors had an eigenvalue slightly greater than one (1.04 and 1.01) was discarded as they were uninterpretable factors (only one or two variables with a significant factor loading). Therefore, an eigenvalue of 1.05 was set as the threshold for the youth report. Three conceptually similar factors were identified for both versions of the CASP and contributed 44% of the variance in the youth report and 65% in the parent report: (1) social, leisure participation/communication (17% and 22% respectively); (2) advanced daily activities (14% and 17% respectively); and (3) basic daily

activities/mobility (13% and 26% respectively). There were items with shared variance in each of the reports based on their loading on more than one factor. Tables 3 and 4 identify the factors, the degree to which items loaded onto these factors (i.e. the correlation coefficients between the items and the factors), and the proportion of variance explained by each factor for the youth and parent report respectively.

Comparative analyses for youth and parent reports

Child and Adolescent Scale of Participation mean youth total scores ($M = 69.5$, $SD = 8.2$) were compared with CASP mean parent total scores ($M = 63.5$, $SD = 12.8$). ICC analysis indicated moderate agreement between youth and parent reports ($ICC = 0.63$, 95% $CI = 0.41$ to 0.75) and the t -test analysis showed that the youth score was significantly higher than the parent score ($t = 10.93$, $P < 0.0001$).

Child and Adolescent Scale of Participation items were combined to form factor subscores based on the combined factor analyses results of the youth and parent report: (1) items 1, 2, 6, 7, 8, 10, 12 and 15 formed the social, leisure participation/communication subscore; (2) items 11, 14, 17, 18, 19 and 20 formed the advanced daily activities subscore; and (3) items 3, 4, 5, 9, 13 and 16 formed the basic daily activities/mobility subscore. The rationale for assigning items to a scale when they shared variance with other factors was to be able to make exact

Table 3. Factor analyses for CASP youth report

	CASP items	Social, leisure participation/ communication	Advanced daily activities	Basic daily activities/ mobility
1.	Home: social/leisure (family)	0.491*	0.253	0.058
2.	Home: social/leisure (friends)	0.736*	0.021	0.099
3.	Home: chores/responsibilities	0.265	0.128	0.661*
4.	Home: self-care	0.155	0.131	0.748*
5.	Home: mobility	0.078	0.150	0.625*
6.	Home: communication	0.490†	0.469†	-0.082
7.	Community: social/leisure (friend)	0.719*	0.003	0.278
8.	Community: structured activities	0.603*	0.091	0.264
9.	Community: mobility	0.441†	0.303†	0.323†
10.	Community: communication	0.668*	0.266	0.106
11.	School: educational activities	0.036	0.697*	0.096
12.	School: social/leisure (students)	0.423†	0.398†	0.215
13.	School: mobility	0.023	0.411†	0.424†
14.	School: using educational materials	-0.015	0.400†	0.377†
15.	School: communication	0.379†	0.580†	-0.023
16.	HCLA: household activities	0.348	0.079	0.684†
17.	HCLA: shopping managing money	0.353†	0.362†	0.210
18.	HCLA: managing daily schedule	0.247	0.548*	0.171
19.	HCLA: using transportation	0.067	0.463*	0.171
20.	HCLA: work activities and responsibilities	0.194	0.639*	0.168
	Variance explained (total = 44%)	17%	14%	13%

*Item loaded more strongly on this factor.

†Item shared variance with this factor.

CASP, Child and Adolescent Scale of Participation; HCLA, home and community living activities.

Table 4. Factor analyses for CASP parent report

	CASP items	Social, leisure participation/ communication	Advanced daily activities	Basic daily activities/ mobility
1.	Home: social/leisure (family)	0.572*	0.327	0.250
2.	Home: social/leisure (friends)	0.768*	0.226	0.259
3.	Home: chores/responsibilities	0.231	0.426	0.658*
4.	Home: self-care	0.122	0.323	0.777*
5.	Home: mobility	0.051	0.138	0.803*
6.	Home: communication	0.577†	0.471†	0.042
7.	Community: social/leisure (friend)	0.683†	0.178	0.517†
8.	Community: structured activities	0.501†	0.102	0.631†
9.	Community: mobility	0.436	0.123	0.672*
10.	Community: communication	0.732*	0.287	0.309
11.	School: educational activities	0.447	0.638*	0.099
12.	School: social/leisure (students)	0.648*	0.171	0.464
13.	School: mobility	0.377	0.135	0.658*
14.	School: using educational materials	0.272	0.528*	0.319
15.	School: communication	0.671†	0.506†	0.011
16.	HCLA: household activities	0.177	0.388	0.755*
17.	HCLA: shopping managing money	0.343†	0.570†	0.470†
18.	HCLA: managing daily schedule	0.145	0.740*	0.399
19.	HCLA: using transportation	0.314†	0.344†	0.584†
20.	HCLA: work activities and responsibilities	0.268	0.703*	0.318
	Variance explained (total = 65%)	22%	17%	26%

*Item loaded more strongly on this factor.

†Item shared variance with this factor.

CASP, Child and Adolescent Scale of Participation; HCLA, home and community living activities.

Table 5. Parent and youth CASP items for each factor

Compared to other children your child's age, what is your child's current level of participation in the following activities. . ./Compared to other children your age, what is your current level of participation in the following activities. . .

Social, leisure participation/communication	Advanced daily activities	Basic daily activities/mobility
Social, play, leisure activities with family members at home (e.g. games, hobbies, 'hanging out')	Educational (academic) activities with other children in his or her/your classroom or school	Family chores, responsibilities and decisions at home (e.g. involvement in household chores and decisions about family activities)
Social, play, leisure activities with friends at home (can include conversations, on the phone or internet)	Using educational materials and equipment that are available to other children in the classroom/s or that have been modified for you/your child (e.g. books, computers, chairs, desks)	Self-care activities (e.g. eating, dressing, bathing, combing or brushing hair, using the toilet)
Communicating with other children and adults at home	Shopping and managing money (e.g. shopping at stores, figuring out change)	Moving about in and around the home
Social, play, leisure with friends in the neighbourhood and community (e.g. casual games, 'hanging out', going to public places like a movie theatre, park or restaurant)	Managing daily schedule (e.g. doing and completing daily activities on time; organizing and adjusting time and schedule when needed)	Moving around neighbourhood and community (e.g. public buildings, parks, restaurants, movies) [<i>Please consider your child's/your primary way of moving around, NOT his or her/your use of transportation</i>]
Structured events and activities in the neighbourhood and community (e.g. team sports, clubs, holiday or religious events, concerts, parades and fairs)	Using transportation to get around in the community (e.g. to and from school work, social or leisure activities) [<i>Driving or using public transportation</i>]	Moving around at school (e.g. to get to and use the bathroom, playground, library or other rooms and things that are available to other children his or her/your age)
Communicating with other children and adults in the neighbourhood or community	Work activities and responsibilities (e.g. completion of tasks, punctuality, attendance and getting along with others)	Household activities (e.g. preparing some meals, doing laundry, washing dishes)
Social, play and recreational activities with other children at school (e.g. 'hanging out', sports, clubs, hobbies, art, lunchtime or recess activities)		
Communicating with other children at school		

CASP, Child and Adolescent Scale of Participation.

Table 6. Internal consistency for items in the youth and parent report CASP total scores and in subscores derived from factor analyses

Scores	Cronbach's alpha	
	Youth	Parent
CASP total score	0.87	0.95
Social, leisure participation/communication	0.80	0.90
Advanced daily activities	0.67	0.86
Basic daily activities/mobility	0.74	0.89

CASP, Child and Adolescent Scale of Participation.

comparisons between the youth and parent reports. Table 5 presents the CASP parent and youth items for each factor. Cronbach's alpha was computed to assess the internal consistency of the resulting three CASP subscores for both the youth and parent reports. The α ranged from 0.67 (youth report) for the advanced daily activities subscore to 0.90 (parent report) for the social, leisure participation/communication subscore (see Table 6).

Youth and parent subscores were then compared using ICCs and *t*-test analyses. For each of the three subscores, there was

moderate agreement according to the ICCs, and significant differences between youth and parent reports on the *t*-tests (see Table 7).

Discussion

This paper is the first to assess the psychometric properties for the youth self-report version of the CASP. Moreover, it is one of the first to compare the ratings of parents and youth on a measure of activity and participation for youth with chronic conditions/disabilities, specifically in this case, the CASP. Finally, the paper further validates the CASP parent report.

This research provides preliminary evidence of the internal consistency and factor structure of the CASP youth report. Internal consistency for the total youth score and two of the subscores (i.e. social, leisure participation/communication and basic daily activities/mobility) was good to excellent. The moderate value of Cronbach's alpha for the advanced daily activities subscore (0.67) may be due to shared variance across factors for some items. The factor structure of the youth report was virtually the same as the parent report, taking into account the

Factor	Youth		Parent		t	P	ICC	95% CI	
	M	SD	M	SD				LL	UL
CASP total score	69.5	8.2	63.5	12.8	10.93	0.0001	0.63	0.41	0.75
Social, leisure participation/ communication	27.6	4.1	25.9	5.2	7.26	0.0001	0.63	0.50	0.71
Advanced daily activities	21.2	2.8	18.7	4.5	12.52	0.0001	0.51	0.23	0.67
Basic daily activities/mobility	20.7	3.0	19.3	4.3	9.00	0.0001	0.70	0.57	0.79

CI, confidence interval; LL, lower limit; UL, upper limit; CASP, Child and Adolescent Scale of Participation.

shared variance for some items. In addition, this study identified the same three-factor solution within the CASP that was found in another study assessing the CASP parent report (Bedell 2009), providing further verification of the factor structure of the parent report.

This finding also provides strength to the assertion by Bedell (2009) that the CASP might be more accurately described as a measure of both activity and participation. The 'basic daily activities/mobility' subscore could be considered to have a primary focus on activity, and includes items that past reviews (McConachie *et al.* 2006; Adolfsson *et al.* 2011) have identified as mapping onto the 'General Tasks and Demands', the 'Self-Care', the 'Domestic Life' and the 'Mobility (i.e. personal mobility at home, school and in the community)' chapters of the ICF/ICF-CY. The 'social, leisure, participation/communication' subscore could be seen as having a primary focus on participation, and includes items identified in the reviews as covering the 'Communication', the 'Interpersonal Interactions and Relationships' and the 'Community, Social and Civic Life' chapters of the ICF/ICF-CY. Finally, there seems to be some overlap between activity and participation in the 'advanced daily activities' subscore, which includes items identified in reviews as representing the 'Learning and Applying Knowledge', the 'Major Life Areas' and the 'Mobility' (i.e. using transportation to get around in the community) chapters in the ICF/ICF-CY. The advanced daily activities subscore appears to include activities that involve more complex social interactions and/or skill acquisition than the basic daily activities/mobility subscore. For example, self-care or household activities at home are generally more solitary and less complex and than shopping and managing money in the community or taking part in educational (academic) activities with other children at school. Further examination of internal consistency and structure of the CASP in additional samples of youth with various conditions/disabilities will determine whether the three-factor structure of the youth and parent reports is accurate.

This research has provided further evidence that youth can report on their functioning, in particular their ability to take part in basic, advanced and social activities across home, school

and community environments. Significant mean differences were found between youth and parent reports for the CASP total score and all three factor subscores, indicating that youth view their activity and participation differently than their parents. The finding that youth reported their level of activity and participation to be higher than did their parents reflects other studies that have determined that youth with chronic conditions/disabilities report higher scores than their parents with respect to their health-related quality of life/quality of life (White-Koning *et al.* 2007; Upton *et al.* 2008; Morrow *et al.* 2012).

Several possibilities may contribute to youth reporting higher levels of activities and participation: (1) youth may have a more accurate view of what they do across multiple environments; (2) youth may be participating more than their parents realize; or (3) response shift bias (i.e. youth could be idealizing their level of activity and participation to the interviewer). Parents complete the study questionnaire independently, whereas the youth completes the questionnaire as part of an interview. Youth may be less likely to tell another person they have limitations in activity and participation. Efforts were made to minimize response shift bias in this study by training interviewers to conduct the interviews using a standardized protocol.

However, researchers argue that differences between parents' and children's reports are unlikely to indicate that either is right or wrong, but rather a reflection of each individual's beliefs about the child's health, functioning and well-being (Upton *et al.* 2008). What is more important than which is a closer reflection of reality is what each report contributes to an understanding of a youth's outcomes (Parsons *et al.* 1999).

The largest proportion of the study sample in this research was composed of children with cerebral palsy. Past studies testing the CASP have included only or mostly children with ABI (Bedell 2004; Bedell 2009). This work provides an initial indication that, although the CASP was originally created for use with children with ABI, it may also be used reliably and validly with youth with cerebral palsy, and other youth included in the sample, such as those with spina bifida or communication disorders. As has been found in past research

Table 7. Comparative analyses for total score and factor subscores on youth and parent reports

assessing the CASP parent report (Bedell 2009), the youth report appears to also be able to discriminate among groups of youth with different conditions/disabilities. In this and other work (Bedell 2009), children and youth with developmental conditions/disabilities score significantly lower on the CASP than children and youth with other types of conditions/disabilities. It may be of benefit for future research to look more closely at these associations using larger samples of each type of condition/disability, and at the factors that might lead groups of youth with developmental conditions/disabilities to report lower activity and participation scores than youth with other types of conditions/disabilities.

The findings of this study indicated that the overall sample was scoring towards the higher end of the CASP scale. Similar results have been found in past research evaluating the CASP (Bedell 2009). However, ceiling effects were found for only 5% of individuals. This is well within the 15–20% range that is considered acceptable for being able to assess sensitivity to change (Andresen 2000).

Limitations and future research directions

This study was limited in that it included a largely English-speaking sample of youth aged 11–17 with chronic conditions/disabilities. In previous research, the parent report CASP has been shown to be appropriate for assessing the activity and participation of children and youth aged 3–22 (Bedell 2009). Future testing will show whether the youth report is also useful across a larger age span, and with ethnically diverse samples. Further psychometric testing of the youth report CASP using larger, more diverse samples includes: assessing test–retest reliability, concurrent and convergent validity; confirming a three-resolution factor structure; and further examining discriminant validity and youth–parent reliability/mean differences. In addition, the responsiveness of both the youth and parent report needs to be studied. Currently, the CASP author is collecting data on such samples for these purposes.

Conclusion

The initial work conducted here suggests that the youth self-report version of the CASP is a promising measure for assessing the activity and participation of youth who have chronic conditions/disabilities. The CASP youth and parent versions appear to be measuring activity and participation similarly enough to warrant use of the youth report alone when youth perspectives are of primary interest, parent report when youth reports are not possible (i.e. because of a youth's cognitive

limitations), or parallel use when nuances between parent and youth viewpoints are important to understand.

Key messages

- Interest in measures of participation has increased since the publication of the ICF and ICF-CY.
- The CASP parent report has been identified as a brief, easy-to-complete and valid measure for use with children and youth with chronic conditions/disabilities that has good coverage at the chapter level of the 'Activities and Participation' component of the ICF-CY.
- It is important for school-aged children and youth to self-report on their own health, functioning and well-being. At the same time, comparisons of youth and parent reports are useful for providing a more complete picture of youths' strengths and needs.
- This study assessed a youth self-report version of the CASP, further validated the CASP parent report, and compared parent and youth ratings of youths' activity and participation.
- In terms of psychometric properties, the youth self-report version was indicated to be a promising measure for assessing personal perceptions of activity and participation that can be used alone or in conjunction with the CASP parent report; further testing is required to assess all aspects of reliability and validity for both versions of the CASP.

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