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Self-generated Domains of Quality of Life in Children with and Without Cerebral Palsy

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Abstract

This study was conducted to demonstrate feasibility of utilizing a modified SEIQoL-DW with children by examining self-generated domains of quality of life in children with and without cerebral palsy. Study samples were children, ages 6–12, (mean 8.9, SD 1.8) including 41 children with cerebral palsy (CP) and 60 children who were age and gender matched peers without disability. Quality of life was assessed with a modified Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW). Group differences in overall ratings of quality of life were not significant; however, there were significant group differences in the frequency and hierarchy of self-generated domains. Within the group with CP, functional ability was not associated with quality of life.

Keywords

Individual quality of life; Quality of life; School-age children; Cerebral palsy

The definition of quality of life (QoL) has changed dramatically since its conception during the 1940s. Previously, thought of as a construct measuring physical health, a more contemporary definition incorporates the notion of subjective reports of overall well being (Livingston et al. 2007). The construct of quality of life now includes what a person can do and is no longer just an assessment of health status. Additionally, the current definition of QoL, as defined by the World Health Organization, stresses the importance of considering the individual's cultural context when examining the construct (Bjornson et al. 2008).

Quality of life is, therefore, a multi-dimensional, dynamic and person-centered construct (Murrell 1999) which includes an assessment of subjective well-being (Murrell 1999; Ring et al. 2007). Determinants of well-being are age-specific, developmentally derived, and experiential (Moore and Keyes 2003). The dimensions of well-being in children are posited as physical, social, emotional, and cognitive (Zaff et al. 2003). Children's views about their quality of life domains were not encouraged until recently (House of Commons Health Committee 1999). Previous research has identified key domains of subjective well-being for children as

including family, friends, school, social activities with peers, physical play, and quiet time (Bedell and Dumas 2004; Buysse 2002; Eisenberg et al. 1997; King et al. 2003; Simeonsson et al. 2001).

The constructs of quality of life (QoL) and health-related quality of life (HRQoL) are often used interchangeably in the literature. However, HRQoL was developed to assess aspects of health status and one's response to medical treatment and illness outcomes, while QoL assumed to be used to evaluate issues unrelated to the context of health care (Drotar 1998; Hunt 1997; Bjornson et al. 2008). Health-related quality of life measures are primarily for the purposes of discrimination, prediction, and evaluation to improve the health outcome (Bjornson and McLaughlin 2001). Health-related quality of life assessments also have the potential to improve clinical decision-making by including child and adolescent perspectives on the consequences of illness (Levi and Drotar 1997). However, results of HRQoL assessment measures also run the risk of contributing to the perceived dysfunction of an individual or the discrimination of a person simply because one has a physical disability (Hunt 1997; Levi and Drotar 1997).

Typically, subjective quality of life is assessed with instruments that include Likert ratings of predetermined content (Varni et al. 2001; Ravens-Sieberer and Bullinger 1998). The Schedule for Evaluation of Individual Quality of Life (SEIQoL) (McGee et al. 1991; O'Boyle 1994), however, utilizes a procedure in which the individual first identifies content of self-perceived importance and then ranks and rates the status of self-generated domains. Thus, the SEIQoL was developed to assess an individual's perspective of quality of life and to overcome the possible limitations of standardized measures of QoL with predetermined domains for evaluation. Therefore, the SEIQoL, in concordance with the WHO definition, allows for a more culturally sensitive assessment of QoL. The SEIQoL scores are derived from a judgment analysis (Hammond et al. 1975; Stewart 1988). The SEIQoL is a person-centered quality of life measure which was revised to a more clinically useful and user-friendly version—The Schedule for the Evaluation of Individual Quality of Life—Directed Weighted (SEIQoL-DW) (O'Boyle et al. 1996).

The SEIQoL-DW has been used in a broad range of disorders including HIV (Hickey et al. 1996), malignant cord compression (Levack et al. 2004), patients disabled with a serious psychiatric illness (Prince and Gerber 2001) and with healthy individuals (McGee et al. 1991). The SEIQoL-DW is also believed to be suited for use with patients who are cognitively impaired (Browne et al. 1997; Dijkers 2003; Joyce et al. 2003; Murrell 1999) and those with severe neurological disability such as multiple sclerosis (Murrell and Kenealy 1999). The SEIQoL-DW has also been found to be a valid tool in adult populations of stroke survivors (LeVasseur et al. 2005).

The SEIQoL-DW has not been extensively studied in children. Wagner (2004) used the SEIQoL-DW to study youth between the ages of 8–17 years with diabetes. Seventy-seven youth with type 1 diabetes were given the SEIQoL—DW during diabetes camp. The domains nominated by this sample were Family, Friends, Diabetes, School, and Hobbies, in this order of importance. Data from ten of the study participants, all below age 12, were deemed invalid due to difficulty understanding the standard instructions; in total, one third of these children surveyed under the age of 12, (10 out of 30), had difficulty completing the forms. The researchers hypothesized that children younger than 12 years, who had difficulties completing the SEIQoL-DW, were more likely to have had academic problems or parents with lower levels of education. No research to date has utilized the SEIQoL-DW to assess quality of life in children with CP.

In recent years, there has been increasing interest in research on the QoL of children with CP. In a recent review of the QoL and CP literature (Livingston et al. 2007), it was noted that

measuring the QoL construct in children with CP is difficult due to the heterogeneity of the population, including a variety of physical, communicative, and intellectual impairments. The review also addressed frequent methodological concerns including the utilization of measures which look at health status as opposed to QoL and the completion of QoL measures by parents due to the above mentioned impairments. When the construct of QoL is assessed in children with CP, several studies reported conflicting findings between children with CP and typically developing children on one of the QoL domains. Dickinson et al. (2007) compared 1,174 children with CP, ages 8–12, to typically developing children on a measure of QoL. No difference in QoL was found between the two groups. Similarly, Chow et al. (2005) found that in children with physical disabilities, including CP, subjective quality of life did not differ from typically developing peers. However, other researchers have found significant differences in certain QoL domains when comparing the two populations; children with CP reporting lower levels of physical, emotional, social, and school functioning than their typically developing peers (Varni et al. 2005). A consistent finding in the literature has been that poorer physical well being is associated with lower levels of gross motor function (Livingston et al. 2007). Livingston et al. (2007), recommended at the conclusion of their review that future research should assess children of varying motor functioning and utilize self report measures of QoL.

The current study was conducted to demonstrate feasibility of utilizing a modified SEIQoL-DW with children by examining self-generated domains of quality of life in children with and without cerebral palsy. The study included children of varying gross motor functioning and utilized child self report as opposed to parent report in the measurement of QoL. It was hypothesized that: (1) Children, ages 6–12, would be able to self-generate QoL domains using a modified SEIQoL-DW procedure; supported by previous research which has found that children with CP under the age of 12 are able to respond to questions regarding QoL when IQ is greater than 70 (Dickinson et al. 2007); (2) Group differences in SEIQoL Total Index scores would not be statistically significant; supported by previous research (Dickinson et al. 2007; Livingston et al. 2007); and, (3) Group differences in frequency, ranking and status of domains would not be statistically significant.

Method

Sample

A correlational descriptive design was used to study a nonprobability, volunteer sample of 101 school-age children between the ages of 6–12 years in grades 1–6. Data were collected as part of a large study of social integration of children with disabilities (Cunningham et al. 2007; Thomas et al. 2008). The children comprised two groups: 41 children diagnosed with cerebral palsy (CP) and 60 typically developing (TD) children. Inclusion criteria for all children included: 1) IQ greater than 70; 2) functional oral communication skills; 3) public or private schooling; 4) absence of current psychiatric diagnoses (e.g., schizophrenia); and, 5) absence of any recent medication changes that could affect cognition. In addition to these general inclusion criteria, the group with CP included only a history of congenital CP with no history of post-neonatal acquired brain injury (i.e., Traumatic Brain Injury, stroke, encephalitis or injury secondary to status epilepticus). The TD children were included if they had no history of cognitive, functional, or physical impairments, no special education certification, and no diagnosis of CP.

Chi-square analysis found no significant differences between the TD and the CP groups in age, grade, SES, gender, and ethnicity. Significant differences were found between the groups for gestational period, birth weight, and history of seizures. Table 1 summarizes demographic variables for the two groups.

Within the CP group there were 41 children, mean age 8.76 years, SD=1.81. Spasticity was diagnosed in 82.7% of the sample. Twenty-seven percent of participants reported positive seizure history. Functional status was categorized using the Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997), with GMFCS levels as follows: Level I (5), Level II (1), Level III (17), Level IV (5), Level V (1) and 12 children classified as having no restrictions and no limitations.

This study was conducted in accordance with Institutional Review Board (IRB) guidelines. Families were recruited from outpatient hospital clinics, summer camps, and community sports teams in the Midwest. Written consent was obtained from parents and written or oral assent from children.

Instruments and Procedures

Quality of life was measured using a modification of the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (McGee et al. 1991; O'Boyle et al. 1996). The SEIQoL-DW (Hickey et al. 1996) is a semi-structured interview designed to explore the most important areas in life from the individual's perspective. The interview is comprised of three stages allowing the individual to identify areas of personal importance (domains), level of satisfaction/functioning in these domains, and relative importance of each domain selected. In the first stage, the individual nominates five life domains that are considered personally the most important. Stage two consists of a status/satisfaction rating of each domain using a visual analogue scale ranging from 0 (worst possible) to 100 (best possible). The third and final stage provides a relative importance of each nominated life domain using a five-stacked, interlocking, laminated circular disk. The respondent determines the proportion of each labeled domain out of 100%. Each domain disk is rotated over the other domains producing a pie chart. The relative size of each disk represents the weight attached to the nominated domain. An overall score, SEIQoL Index, can be calculated by the sum of domain levels multiplied by the domain weights.

Previous studies have reported altering the method of eliciting information during stages two or three based on the study sample. In a previous study of adults with dementia (Coen et al. 1993), the researchers utilized five intervening labels ("very bad" to "very good") to substitute for the use of the visual analogue scale (stage two). Murrell and Kenealy (1999) reported, also, using intervening labels during stage two with adults diagnosed with multiple sclerosis. Tovbin et al. (2003) reported asking hemodialysis patients to rate the importance of each nominated life domain using a ranking scale 1 to 5 rather than determining proportions from the original interlocking pie disk (stage three).

Good construct validity of the SEIQoL and SEIQoL-DW has been demonstrated in previous studies (LeVasseur et al. 2005; O'Boyle et al. 1992; Prince and Gerber 2001). Internal and re-test reliability results have been found to be sufficient (Atkinson and Zibin 1996; Browne et al. 1997; Moons et al. 2004). SEIQoL-DW has been shown to demonstrate stability (Browne et al. 1997).

In this study the development of a modified version for children of the SEIQoL was derived from the SEIQoL-DW. In addition to following the manual of instruction (O'Boyle et al. 1996), stages two and three of the interview process were altered to a 5-point Likert scale. It was felt that the concepts utilized in stage two (satisfaction/status) and stage three (importance) were too abstract; and, understanding proportions may be too difficult for younger children (6–12 years). Each interview with the child was conducted by a trained research assistant. Stage one consists of asking the child to "think about" the five most important factors that contribute to their quality of life. The researchers modified some of the words in the instructions to make them more understandable to the child. Children were asked "What are the things about your

life that really make it good? What is really important to you? What do you really like to do?" If the child was unable to list an area of importance, than a standard "cue" was volunteered by the interviewer in such a way not to influence the response. Stage two consists of a 5-point Likert scale rather than the 100 mm visual analogue scale to assess the status/satisfaction of each factor/domain that the child lists as contributing to their individual quality of life "at the moment." (e.g., 5 = going as well as possible; 1 = not going well). Stage three consists of a 5-point Likert ranking scale, rather than the five disk proportional pie chart, in which the child ranks the selected domains in order of salience to their quality of life (e.g., 1 = most important; 5 = least important). A Total SEIQoL Index score was calculated by multiplying each domain's importance ranking by its satisfaction score and then summing the products. The result is a total score with a potential range from 15 to 75. The higher scores indicate a perceived better quality of life.

Functional mobility was measured using the Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997). The GMFCS assesses gross motor functioning and activity limitations with a five level ordinal scale. The GMFCS was originally designed for use with children with CP, thus the scale is differentiated between levels by functional limitations and need for assistive technology for mobility. Interrater reliability is 0.75 and content and predictive validity are well-demonstrated in child and adult populations (Palisano et al. 1997; Sandstrom et al. 2004; Wood and Rosenbaum 2000).

Results

In this study, 11 quality of life domains were self-identified using the modified version of the SEIQoL-DW. These domains were categorized into the following: Family, Friends, Pets, Hobbies, Physical Play, Physical Health/Physical Needs, School/Education, Religion, Electronics/Entertainment, Travel, and Other. Interrater reliability was established with blind ratings by two undergraduates, yielding a kappa of .80. Examples of these domains from verbatim phrases of the children are listed in Table 2.

All children ($n=101$) generated at least two domains that were important to their quality of life. Ninety-one children (90%) generated five domains, as instructed.

Group differences in mean SEIQoL Total Index scores, TD 65.98 (7.72) vs. CP 67.70 (7.27), were not statistically significant, $t(1, 98) = -1.04$, ns. In the CP group, the associations between GMFCS and SEIQoL Total scores were not statistically significant. Mean frequencies with which SEIQoL domains were generated were examined (Table 3). There were statistically significant group differences in the frequency of the Health/Needs domain, generated more frequently by the TD group, $t(1, 100) = 2.37$, $p < .05$. The groups generated the same three most frequent domains (Family, Physical Play, Friends).

Frequency with which domains were ranked as most important in determining the child's quality of life differed between groups (Table 4). Both groups identified Family most frequently; however, this was followed by Health/Needs and Friends in the TD group, and by Physical Play and Electronics in the CP group.

The group differences in mean status/satisfaction ratings of domains were not statistically significant (Table 5).

Discussion

This study examined self-generated hierarchies and status of domains that determine subjective quality of life in children with and without cerebral palsy. Although previous work found that the standard SEIQoL-DW procedure is not fully accessible to younger children, current

findings demonstrate that a modified SEIQoL-DW procedure is largely accessible to children, ages 6–12, IQ>70. Ninety percent of the children ($n=91$) listed five domains of importance and only 10% ($n=10$) limited their listing to two domains.

As for between-groups differences, the group difference in the SEIQoL-DW Total Index scores was not significant and there were no significant group differences in the status/satisfaction of specific domains. This is supported by previous research which has found when children under the age of 12 with CP rate their QoL, it does not differ significantly from the ratings of typically developing peers (Dickinson et al. 2007; Chow et al. 2005). However, there were subtle group differences in the frequency with which domains were generated. The five most frequently generated domains selected by both groups were: Family, Physical Play, Friends, Electronics, and Hobbies. Typically developing peers, however, self-identified the Health/Needs domain more often than children with CP. This perhaps counterintuitive finding may reflect the extent to which health and physical status are assumed by TD children to determine QoL, while children with CP, who have lived with physical impairments, have found that there are other more salient determinants.

There also were group differences in frequency with which domains were identified as the single most important determinant of QoL. Family was the domain most frequently ranked as most important by both groups; however, that is where the similarities stopped. Consistent with general frequency differences, again, children with CP did not identify Health/Needs as the most important determinant of QoL nearly as often as TD peers. Interestingly, children with CP identified the domain of Physical Play more important than their typically developing peers. Again, this may reflect the extent to which groups differ in taking certain activities for granted, but further research is needed.

The study findings have theoretical and practical implications. In this study, self-generated domains of quality of life can be categorized into the three dimensions of well-being reported by Zaff et al. (2003): physical, social/emotional and cognitive. The Physical dimension could include the domains of Physical Play, Health/Needs, and Travel. The domains of Family, Friends, Pets, Religion and Electronic/Entertainment can be categorized into the Social/Emotional dimension. The dimension of Cognitive could include Hobbies and School/Education domains. These self-selected domains of quality of life also provide further support for the key dimensions of subjective well-being reported by Eisenberg et al. (1997) and others; i.e., family, friends, school, social activities with peers, physical play, and quiet time. At the practical level when caring for school-age children with cerebral palsy, findings support the perspective that children, irrespective of disability and functional status, value and need the social and emotional network of family and friends. Children also desire to experience physical play. Play and physical activity are necessary for a child's development of mental capacity and sense of well-being (Connor 2003; Erikson 1963, 1980). Finally, findings support the recommendation that healthcare clinicians consider utilizing a combination of subjective quality of life instruments and a specific health-related quality of life measure when assessing the well-being of children with cerebral palsy.

Findings of this study contribute to the literature in several areas. First, the population utilized included children with various gross motor functioning which provides additional evidence that difficulties with gross motor functioning are not related to an overall negative QoL. Additionally, by utilizing self report assessments as opposed to parent report, the hope is that a true subjective measure of QoL was obtained in this population. Previous research has demonstrated a significant discrepancy between parent and self report of QoL in the CP population (White-Koning et al. 2007).

There are methodological limitations that qualify the interpretations of the findings. These limitations include the relatively small sample and the method of recruitment. This study was not able to identify the specific needs associated with domain frequency differences, including physical play and health/needs. It would be beneficial to explore what specific types of physical play are important to a child with cerebral palsy and what aspects of physical health needs and concerns are relevant to all school-age children. Further research in this area can include qualitative studies to determine greater specificity of needs and concerns.

This study demonstrates that using a generic, individual quality of life measure, children between ages 6–12 years are able to list areas of importance based on their experience and developmental stage. These school-age children, irrespective of a diagnosis of cerebral palsy, indicated that family, physical play, friends, and hobbies/electronics are salient social/emotional, physical, and cognitive dimensions in their life. Chronic health conditions can create a unique life experience for developing children; however, this experience does not radically alter their psychosocial and emotional needs.

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Table 1

Sample characteristics

	Cerebral Palsy (CP) (n=41)	Typically Developing (TD) (n=60)
Age (years)	8.8 (1.8)	8.9 (1.7)
Gender		
Male	27	30
Female	14	30
Grade		
1–3	26	28
4–6	15	32
SES		
Unskilled laborer, menial service workers	0%	0%
Machine operators, semiskilled workers, skilled craftsman	4.9%	2.1%
Skilled craftsman, clerical, sales workers	17.1%	6.4%
Medium business, minor professional, technical	56.1%	51.1%
Major business and professional	17.1%	40.4%
Ethnicity		
Caucasian	31	32
African-American	3	15
Hispanic	0	2
Asian	1	0
Native American	1	1
Other	5	10
Seizure history	27% positive **	0% positive **
Birth weight (grams)	2113.72 (1097.68) **	3468.56 (513.0)
Gestation (weeks)	30.6 (6.4) **	37.7 (1.1) **

*
 $p < .05$;

**
 $p < .01$

Table 2

Self-generated domains

Domain category	Example
Family	“going on the boat with my family”
Friends	“being with my friends”
Pets	“my dog”
Hobbies	“collecting trains or legos”
Physical play	“recess at school”
Physical health/physical needs	“medicine, getting shots”
School/education	“my teachers”
Religion	“prayers...praying”
Electronics/entertainment	“playing video games”
Travel	“going places”
Other	“getting my ears pierced.”

Table 3

Comparisons SEIQOL domain frequency by group

	CP (n=41)		TD (n=60)		t	p
	Mean	SD	Mean	SD		
Friends	.585	.547	.783	.524	1.83	<.10
Pets	.366	.623	.200	.403	-1.63	n.s.
Family	.829	.738	.85	.778	.134	n.s.
Hobbies	.488	.746	.483	.701	-.031	n.s.
Physical play	.878	.899	.833	.717	-.277	n.s.
Health/needs	.098	.300	.467	.965	2.369	<.05
School/education	.293	.461	.367	.609	.659	n.s.
Religion	.073	.469	.017	.129	-.888	n.s.
Electronics	.561	.673	.67	.252	-.690	n.s.
Travel	.146	.358	.067	.252	-1.315	n.s.
Other	.366	.623	.333	.542	-.279	n.s.

Table 4

Frequency of domains ranked as most important by group

Cues	CP (<i>n</i> =41)		TD (<i>n</i> =60)	
	Frequency	Percent	Frequency	Percent
Friends	2	4.9%	6	10.0%
Pets	3	7.3%	1	1.7%
Family	18	43.9%	32	53.3%
Hobbies	2	4.9%	2	3.3%
Physical play	8	19.5%	1	1.7%
Health/needs	1	2.4%	9	15.0%
School/education	1	2.4%	1	1.7%
Religion	1	2.4%	1	1.7%
Electronics	4	9.8%	3	5.0%
Travel	0	0.0%	1	1.7%
Other	1	2.4%	3	5.0%

Table 5

Mean status/satisfaction ratings of SEIQOL domains by group

	CP (n=41)		TD (n=60)	
	Mean	SD	Mean	SD
Friends	4.72	.16	4.39	.11
Pets	4.54	.88	4.25	.87
Family	4.29	1.01	4.23	.85
Hobbies	4.59	.61	4.17	1.00
Physical play	4.54	.57	4.28	.80
Physical health/physical needs	4.5	.58	4.60	.15
School/education	4.00	1.21	4.13	.74
Religion	5.00	–	5.00	–
Electronics/entertainment	4.47	.89	4.14	1.14
Travel	4.67	.52	3.75	1.26
Other	4.38	.77	4.03	1.09