

Agreement between Saudi children with cerebral palsy and their parents on the perception of quality of life using the PedsQL™ 3.0: A pilot study.

Afrah Almuwais, Nada Alzahrani, Meznah Almuhalhil, Shaima Adossary, Sara Alyagoot, Samiah Alqabbani*

Rehabilitation Department, College of Health and Rehabilitation Sciences, Princess Nourah Bint Abdulrahman University. Riyadh, Saudi Arabia

Abstract

Background: Child involvement in health care decision-making is essential during health planning. Additionally, perspectives of parents about children's Quality of Life (QOL) could influence healthcare utilization.

Objectives: Our goal was to assess the level of agreement between children with CP and their parent's perception of QOL by using the PedsQL™ 3.0 instrument in Arabic.

Materials and Methods: A cross-sectional study of 29 children with CP (mean age of 10.3 ± 1.5 years old) and their parents/caregivers filled the electronic version of the PedsQL™ 3.0 Cerebral Palsy Module in Arabic. The data was analysed via Pearson's Correlation Coefficient (PCC) and Intraclass Correlations Coefficient (ICC).

Results: We found a strong to moderate positive correlation between children self-reports and parent proxy-reports in the Daily Activity, Eating Activity, Movement and Balance, and Speech and Communication scales of PedsQL™ 3.0. There was no significant correlation in the School Activity, Fatigue, and Pain and Hurt scales. The parents/caregivers significantly underestimated their children's QOL in the School Activity, Pain and Hurt, and Movement and Balance scales.

Conclusion: An acceptable level of agreement was found in certain PedsQL™ 3.0 scales. However, we found a trend for parents/caregivers to underestimate their children's QOL. Future studies should include a larger sample size and validate the Arabic translation of the PedsQL™ 3.0.

Keywords: Quality of life, Cerebral palsy, Saudi, Children.

Accepted on February 27th, 2021

Introduction

Cerebral Palsy (CP) is a neurological disorder that affects the developing brain and involve movement and developmental impairments which leads to activity limitation CP is the second greatest cause of disability among children in the Kingdom of Saudi Arabia (KSA), with a prevalence rate of 23.4 per 10,000 children and 14% of CP cases are located in the central province [1,2]. Children with CP experience a wide range of motor impairments, which places heavy demands on health, education, and social services. The condition may be accompanied by additional impairments that affect people with CP's daily life and participation in society, such as neuroimpairments, which include spasticity, muscle weakness, and limited range of motion that affects gross and fine motor function [3]. In addition, it may affects cognitive and sensory impairments, such as a learning disability, epilepsy, and speech and visual impairments [2,3]. This condition could adversely affect the Quality of Life (QOL) of children with CP.

The involvement of children in health care decision-making during health planning demonstrates respect for their capabilities and promotes a sense of control and cooperation with health professionals. Children could report their QOL when provided with a tool suitable to their age and cognitive

level age [4]. Varni, Limbers, and Burwinkle demonstrated that 5-year-old children could report QOL if provided with the appropriate tool [5]. Parents also have an essential role in the decision for their child's health care process. Their role enhances physician-parent-child communication and reflects positively on patient satisfaction and compliance [5,6]. Children who are too young or have intellectual disabilities, such as children with CP, may not reliably self-report their QOL. Hence, to optimally assess outcomes in such cases, parent proxy-report instruments must be incorporated [7]. Additionally, perception of parents regarding their children QOL could influence health care utilization [5]. For this reason, QOL instruments that involve both perspectives of children and parents should be used to provide comparable results between self-reports and proxy-reports [5]. The PedsQL™ 4.0 Generic Core Scales is a valid and reliable self-report instrument to measure QOL outcomes (14), and it includes both a child self-report and a parent proxy-report [5]. An earlier version, the PedsQL™ 3.0 Cerebral Palsy Module, was designed for children and adolescents with CP and translated into different languages, including Arabic, according to the standardized procedures of the MAPI Research Trust [6,14-20].

Recent studies show a high agreement between child self-reports and parent proxy-reports in the perception of QOL among children with attention deficit hyperactivity disorder and epilepsy [9,10]. However, other studies in the literature report that parents of children with CP tended to underestimate their child's Quality of Life (QOL), since the quality of life was rated significantly higher by the children than by their parents [5,11,12]. In addition, culture and society could influence parents' perspectives on quality of life [13]. Therefore, it is important to investigate the agreement level between children with CP and their parents according to their culture and the country they live in.

However, to the best of our knowledge, no studies have tested the agreement between children with CP and their parents using the PedsQL 3.0 Cerebral Palsy Module. Therefore, the aim of the study was to assess the level of agreement between children with CP and their parent's perception on their children's QOL using the Arabic PedsQL™ 3.0 Cerebral Palsy Module. The study was conducted in Riyadh, KSA.

Materials and Methods

Participants

The study has a cross-sectional design utilizing non-probability sampling techniques. A convenient sample of 29 children with CP and their parents/caregivers participated. Participant's age ranged from 8 to 12. Children who were diagnosed with other neuromuscular disorders, intellectual disabilities, visual or hearing impairments, or behavioural disorders were excluded from this study.

Instrument

The MAPI research trust allowed the authors to use the translated Arabic version of the PedsQL™ 3.0 Cerebral Palsy Module. The tool is a valid and reliable tool to assess quality of life in children with CP [15,16].

The child self-report is identical to the parent proxy-report, except for the identifier "you", which was changed to "your child". Both reports are comprised of 35 items divided into seven scales: nine items in daily activities, four in school activities, five in movement and balance, four in pain and hurt, four in fatigue, five in eating activities, and four in speech and communication [15,16].

The participants rate the items on a five-point Likert scale from 0 (Never) to 4 (Almost always); thus, higher scores indicate lower problems in QOL. The resulted score was transformed to a scale from 0-100. There is no total score. Instead, the mean score was calculated through dividing the total score of the scale by the number of items answered in each scale [15,16].

Procedures

The participants were recruited from four different paediatric rehabilitation outpatient clinics in Riyadh: The prince Sultan bin Abdulaziz Humanitarian City (SBAHC), the Disabled Children's Association (DCA), the Stand-Out rehab centre, and

the Bedayah Specialist Center for Physical Therapy. The data collection process was based on a face-to-face interview with the parents/caregivers and their children.

Children and parents were separated from each other and asked to fill out the PedsQL™ 3.0 Arabic version on two iPads. Two researchers were available to provide further explanation to ensure that all parties reached full understanding of the process. Before the data collection process, certain general questions such as "what do you like to do at school/home" were asked to establish a good rapport with the children in order to increase their comfort during interactions and their level of engagement [22].

Additionally, this was a helpful way to determine whether the cognitive level of the children was appropriate enough and if they understood the task before filling out the questionnaire. Subsequently, demographic data were collected from both the children and their parents/caregivers by using a simple questionnaire designed by the researchers to collect data on sex, age, social status, parents' level of education, the child's current school grade, and how many hours a day the parents spent with their children on average.

Ethical consideration

The study was approved by the IRB committee of the Princess Nourah bint Abdulrahman University (PNU) (IRB log number 18-0252). Informed consent from parents/caregivers and informed assent from the children were obtained.

Data Analysis

All data collected on the participants is confidential. The statistical analysis was performed using the SPSS v.17.0 (SPSS Inc., Chicago, IL, USA) package for MacOS. Sample characteristics were averaged using mean and standard deviation for quantitative variables and percentages for qualitative variables.

Internal consistency was assessed using Cronbach's alpha coefficient for both child self-report and parents proxy-report. The correlation between the child self-report and parent proxy-report was analysed *via* Pearson's correlation coefficient.

The level of agreement between child self-report and parent proxy-report was analysed *via* the Intraclass Correlation Coefficient (ICC) as follows: ≤ 0.4 =poor; 0.41-0.60=moderate; 0.61-0.80=good; and 0.81-1=excellent [23]. Differences in parent and child perception of QOL were assessed using the independent samples t-test. The significance level was set to ≤ 0.05 .

Results

Twenty-nine children with CP (mean age 10.3 ± 1.5) and twenty-nine parents/caregivers (mean age of 37.7 ± 9.46) participated in the study. 55% of participants were male, and 69% of proxy-reports were from mothers. The sample data are shown in Table 1.

Agreement between Saudi Children with cerebral palsy and their parents on the perception of hrqol using the pedsql™ 3.0 parent proxy-reports and self-reports: A pilot study.

Children (n=29)		Caregivers (n=29)	
Variable	n (%)	Variable	n (%)
Sex:		Caregiver relation:	
Male	16 (55%)	Mother	20 (69%)
Female	13 (45%)	Father	5 (17%)
		Other	4 (14%)
Mean age:	10.3 ± 1.50	Mean age:	37.7 ± 9.46
Education:		Level of education:	
1st grade, Elementary	5 (17%)	Elementary	6 (21%)
2nd grade, Elementary	2 (7%)	Intermediate	3 (10%)
3rd grade, Elementary	5 (17%)	High school	7 (24%)
4th grade, Elementary	7 (24%)	Diploma	1 (3%)
5th grade, Elementary	1 (3%)	Bachelor	12 (41%)
6th grade, Elementary	6 (21%)	Social status:	
1st grade, Intermediate	2 (7%)	Single	4 (14%)
None	1 (3%)	Married	25 (86%)
		Average hrs spent with child:	17.45 ± 7.18
		1 - 6 hrs	3 (10%)
		7 - 12 hrs	7 (24%)
		13 - 18 hrs	5 (17%)
		19 - 24 hrs	14 (48%)

Table 1. Sociodemographic characteristics of the sample.

The Arabic version of PedsQL™ 3.0 for parent proxy-reports demonstrated an overall good to acceptable internal consistency in all seven scales (0.69-0.85). However, for child self-reports, only two scales achieved good internal consistency: Daily Activities and Eating Activities (0.82 and 0.85 respectively). The remainder of child self-report scales demonstrate poor to unacceptable consistency (0.39-0.63).

A strongly positive correlation was found between parents' and children's reports in three scales: Daily Activities ($r=0.58$, $p<0.001$); Movement and Balance ($r=0.61$, $p<0.001$); and Eating Activities ($r=0.58$, $p<0.001$). A moderately positive correlation was found in the Speech and Communication scale ($r=0.48$, $p<0.001$). No association was found between the reports in three scales: School activities; Pain and Hurt; and Fatigue. Results also show a good level of agreement between PedsQL™ 3.0 parent proxy-reports and child self-reports in three scales: Eating Activity (ICC=0.74); Daily Activity (ICC=0.72); Speech and Communication (ICC=0.64). A moderate agreement was found in the Movement and Balance scale (ICC=0.49). However, poor agreement was found in the

Fatigue, School Activity, and Pain and Hurt scales (ICC=0.41, 0.15, 0.08 respectively). Data on correlation and agreement can be found in Table 2.

PedsQL™ Scales	ICC	Pearson's correlation
Daily Activities	0.72**	0.58**
School Activities	0.15	0.1
Movement and Balance	0.49**	.61**
Pain and Hurt	-0.08	-0.05
Fatigue	0.41	0.28
Eating Activities	0.74**	0.58**
Speech and Communication	0.64**	0.48**

** Significant at $p<0.001$.

Table 2. Correlation between the PedsQL™ 3.0 CP parent proxy-reports and child self-reports.

The results of the t-test when comparing the mean and Standard Error (SE) scores of the PedsQL™ 3.0 parent proxy-reports and child self-reports indicate that QOL values in parent proxy-reports were lower than in child self-report across almost all scales. Parents significantly underestimated their child's QOL in the School Activities (65.7 ± 4.8 vs. 81.47 ± 3.8 , $p=0.01$), Movement and Balance (53.8 ± 5.1 vs. 80 ± 3.0 , $p<0.001$), and Pain and Hurt (69.4 ± 4.7 vs. 91.9 ± 3.2 , $p<0.001$) scales. These results are presented in Table 3.

PedsQL™ Scales	Child	Parent	P-value
Daily activities	57.9 (5.04)	50.67 (5.08)	0.32
School activities	81.47 (3.8)	65.7 (4.8)	0.01**
Movement and balance	80 (3.0)	53.8 (5.1)	<0.001**
Pain and hurt	91.9 (3.2)	69.4 (4.7)	<0.001**
Fatigue	72.84 (4.3)	63.36 (5)	0.16
Eating activities	80 (4.6)	77.76 (4.8)	0.74
Speech and communication	87.28 (3.3)	90.09 (2.9)	0.53

Table 3. Mean and Standard Error (SE) comparison of the PedsQL™ 3.0 CP parent proxy-reports and child self-reports.

Discussion

The study assessed the level of agreement between children with CP and their parents when using the PedsQL™ 3.0 Cerebral Palsy Module instrument to assess HRQOL. The Arabic version of PedsQL™ 3.0 Cerebral Palsy Module showed good internal consistency in all scales for parent proxy-reports and only two scales (Daily activities and Eating activities) for child self-reports.

The results indicate a moderate to good agreement between children self-reports and parent proxy-reports of the Arabic

version of PedsQL™ 3.0 Cerebral Palsy Module in four scales: Daily Activities; Eating Activities; Movement and Balance; and Speech and Communication. Similarly, Majnemer et al. demonstrated that the level of agreement between parents and children with CP varies depending on the scale [25].

The highest level of agreement reported in their study was with respect to physical health and well-being and the lowest agreement, to School Activities. The agreement between the child and the parent could be attributed to the proxy-report rater relationship; mothers usually are the primary caregivers for their children and thus they are more aware of their children's HRQOL [26,27]. In this study, mothers represented 69% of caregivers and 80% of mothers spent about 12-24 hrs a day with their children. Moreover, Daily Activities, Movement and Balance, and Eating Activities can be more easily observed and assessed by parents than other scales [27,28]. Eiser et al. similarly indicate that the physical functions that could be observed, therefore, showing higher agreement is not observed [27]. On the other hand, three scales demonstrated poor agreement: School Activity, Pain and Hurt, and Fatigue. Additionally, parents reported significantly lower QOL scores compared to their children in these scales. This result was consistent with several studies that indicate that parents tend to underestimate their children's QOL [6,12,13]. White-Koning et al. demonstrated that parents OD children with CP tend to underestimate their children's performance in most of the health-related quality of life [12].

Several factors could justify the discrepancy between parent proxy-reports and children self-report in specific scales. Since the pain and hurt and the fatigue scales are subjective measurements, parents may be less accurate when assessing this problem [28,29]. For example, children may interpret that fatigue is a result of a certain activity or exertion, or that it may be linked to their mood. On the other hand, the parents/caregiver may interpret fatigue as a medical condition [29,30].

For the pain and hurt scale, children may think of one specific event while their parents/caregivers consider several events when answering the questions. Moreover, this result could be due to children's limited ability to understand the concept of pain when compared to their parents. In this study, children were not consistent in responding to questions in the Pain and Hurt and Fatigue scales similarly to their parents, which raises the issue of reliability of those scales in the Arabic version of PedsQL™ 3.0. In the Arabic translation, there was an overlap between the concept of pain and fatigue with most participants, and interpretation of these words may vary according to each participant.

The School Activity scale achieved poor agreement, similar to Varni et al. who obtained a low level of agreement in the school functioning scale on PedsQL™ 4.0 Generic Core Scales [8]. Evidently, some parents are unavailable when their children are performing certain activities at school. Thus, the parent/caregiver might be unaware of their child's capability at school [29,30].

The results from this pilot study show that parent proxy-reports achieved acceptable to good internal consistency in all scales

of the PedsQL™ 3.0 Cerebral Palsy Module in Arabic. Nevertheless, child self-reports demonstrated acceptable internal consistency only in the daily activities and eating activities scales. As for the level of agreement, results indicate a good agreement between parents and children in the scales that demonstrated good internal consistency (Daily activity and eating activity). Additionally, those scales were observable functions therefore, contributing the good agreement [28]. The scales that showed poor agreement were those reached unacceptable internal consistency. This may influence the level of agreement among them, suggesting that a higher ICC may result in a higher level of agreement.

The Arabic version of PedsQL™ 3.0 Cerebral Palsy Module should be culturally adapted to accommodate the needs of the population. In this case, the School Activities scale has two questions about keyboards and mouse usage, which are rarer in schools nowadays. Therefore, replacing them with other items that might be more common in their daily lives, such as tablets, video game consoles, and smartphones is recommended. Moreover, in the Eating Activities scale, the type of cutting-whether by knife or by hand-was not specified. This question needs to be modified since in Saudi Arabia, it is culturally acceptable to use one's hands while eating. Thus, although translated, the PedsQL™ 3.0 is not yet culturally adapted for the Saudi population.

This study has several limitations; the first of which is that the level of GMFCS was not assessed, since the functional level of the children may affect the level of agreement. Therefore, further studies should evaluate the functional level of participants. Furthermore, it is recommended that future studies assess the psychometric characteristics of the Arabic version of the PedsQL™ 3.0 Cerebral Palsy Module on a larger sample size, in order to gather enough data to culturally adapt the instrument for the Saudi population.

Although the Arabic version of PedsQL™ 3.0 shows promise, similar studies with larger sample sizes should be conducted to assess the properties of the instrument within Saudi culture. Additionally, further studies are warranted to analyse the psychometric properties of the Arabic version of PedsQL™ 3.0 on a larger scale. For future studies, it is recommended to address the agreement on HRQOL between parents/caregivers and their children in a large sample size with different age groups and disability levels. In addition, further investigation of the factors that may influence this type of agreement is recommended.

Conclusion

The study demonstrates a good agreement between parent proxy-reports and child self-reports across most of the PedsQL™ 3.0 scales. However, other scales show discrepancies. In their reports, parents estimated that their children had a lower level of QOL than the children's self-reports. This indicates the importance of relying on child self-reports to assess their involvement and access to health care.

Acknowledgment

This research was funded by the Deanship of Scientific Research at Princess Nourah bint Abdulrahman University through the Fast-Track Research Funding Programme.

References

1. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy. *Dev Med Child Neurol Suppl* 2007; 49: 8–14.
2. Al Salloum AA, Al Mouzan MI, Al Omar AA, Al Herbish AS, Qurashi MM. The prevalence of neurological disorders in Saudi children: a community-based study. *J Child Neurol* 2011; 26: 21–4.
3. Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Dev Med Child Neurol* 2002; 44: 309–16.
4. McCabe MA. Involving children and adolescents in medical decision making: developmental and clinical considerations. *J Pediatr Psychol* 1996; 21: 505–16.
5. Longo E, Badia M, Orgaz MB, Gómez-Vela M. Comparing parent and child reports of health-related quality of life and their relationship with leisure participation in children and adolescents with Cerebral Palsy. *Res Dev Disabil* 2017; 71: 214–22.
6. Varni JW, Limbers CA, Burwinkle TM. Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQLTM 4.0 Generic Core Scales. *Health Qual Life Outcomes*. 2007; 5: 2.
7. Varni JW, Limbers CA, Burwinkle TM. Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQLTM 4.0 Generic Core Scales. *Health Qual Life Outcomes*. 2007; 5: 43.
8. Arnaud C, White-Koning M, Michelsen SI, et al. Parent-reported quality of life of children with cerebral palsy in Europe. *Pediatrics* 2008; 121: 54–64.
9. Marques JC, Oliveira JA, Goulardins JB, et al. Comparison of child self-reports and parent proxy-reports on quality of life of children with attention deficit hyperactivity disorder. *Health Qual Life Outcomes* 2013; 11: 186.
10. Haneef Z, Grant M, Valencia I, et al. Correlation between child and parental perceptions of health-related quality of life in epilepsy using the PedsQL.v4.0 measurement model. *Epileptic Disord* 2010; 12: 275–82.
11. White-Koning M, Arnaud C, Dickinson HO, et al. Determinants of child-parent agreement in quality-of-life reports: a European study of children with cerebral palsy. *Pediatrics* 2007; 120: 804–14.
12. Upton P, Lawford J, Eiser C. Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Qual Life Res* 2008; 17: 895–913.
13. Alwhaibi RM, Zaidi U, Alzeiby I, et al. Quality of life and socioeconomic status: A comparative study among mothers of children with and without disabilities in Saudi Arabia. *Child Care Pract* 2020; 26: 62–80.
14. Varni JW, Seid M, Kurtin PS. PedsQLTM 4.0: reliability and validity of the Pediatric Quality of Life InventoryTM version 4.0 Generic Core Scales in healthy and patient populations. *Med Care* 2001; 39: 800–12.
15. Varni JW, Burwinkle TM, Sherman SA, et al. Health-related quality of life of children and adolescents with cerebral palsy: hearing the voices of the children. *Dev Med Child Neurol* 2005; 47: 592–7.
16. Varni JW, Burwinkle TM, Berrin SJ, et al. The PedsQLTM in pediatric cerebral palsy: reliability, validity, and sensitivity of the generic core scales and cerebral palsy module. *Dev Med Child Neurol* 2006; 48: 442–9.
17. Felder-Puig R, Frey E, Proksch K, et al. Validation of the German version of the Pediatric Quality of Life InventoryTM (PedsQLTM) in childhood cancer patients off treatment and children with epilepsy. *Qual Life Res* 2004; 13: 223–34.
18. Reinfjell T, Diseth TH, Veenstra M, et al. Measuring health-related quality of life in young adolescents: reliability and validity in the Norwegian version of the Pediatric Quality of Life InventoryTM 4.0 (PedsQLTM) generic core scales. *Health Qual Life Outcomes* 2006; 4: 61.
19. Gkoltsiou K, Dimitrakaki C, Tzavara C, et al. Measuring health-related quality of life in Greek children: psychometric properties of the Greek version of the pediatric quality of life inventoryTM 4.0 generic core scales. *Qual Life Res* 2008; 17: 299–305.
20. Jafari P, Forouzandeh E, Bagheri Z, et al. Health related quality of life of Iranian children with type 1 diabetes: Reliability and validity of the Persian version of the pedsqTM generic core scales and diabetes module. *Health Qual Life Outcomes* 2011; 9: 104.
21. Ji Y, Chen S, Li K, Xiao N, et al. Measuring health-related quality of life in children with cancer living in Mainland China: feasibility, reliability and validity of the Chinese Mandarin version of PedsQL 4.0 Generic Core Scales and 3.0 Cancer Module. *Health Qual Life Outcomes* 2011; 9: 103.
22. Bell J, Condren M. Communication strategies for empowering and protecting children. *J Pediatr Pharmacol Ther* 2016; 21: 176–84.
23. Bartko JJ. The intraclass correlation coefficient as a measure of reliability. *Psychol Rep* 1966; 19: 3–11.
24. Majnemer A, Shevell M, Law M, et al. Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. *Qual Life Res* 2008; 17: 1163–1171.
25. Landgraf JM, Abetz LN. Functional status and well-being of children representing three cultural groups: Initial self-

- reports using the CHQ-CF87. *Psychol Health* 1997; 12: 839–54.
26. Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. *Qual Life Res* 2001; 10: 347–57.
27. Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioural and emotional problems: implications of cross-informant correlations for situational specificity. *Psychol Bull* 1987; 101: 213–32.
28. Jokovic A, Locker D, Guyatt G. How well do parents know their children? Implications for proxy reporting of child health-related quality of life. *Qual Life Res* 2004; 13: 1297–307.
29. Davis E, Nicolas C, Waters E, et al. Parent-proxy and child self-reported health-related quality of life: using qualitative methods to explain the discordance. *Qual Life Res* 2007; 16: 863–71.

***Correspondence to**

Samiah Alqabbani

Rehabilitation Sciences Department,

College of Health and Rehabilitation Sciences

Princess Nourah Bint Abdulrahman University

Riyadh

Saudi Arabia

Tel: + 0500016946

Email: sfalqabbani@pnu.edu.sa