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A Preliminary Study on the Reliability of the Malay Version of the Quality of Life Inventory™ Version 4.0 (PEDSQL) Generic Core Scales among Children with Disabilities in Kelantan, Malaysia: Parent-Proxy Report

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ABSTRACT

Introduction: Little is known about the quality of life of children with disabilities (CWD). To the best of our knowledge, there is no validated instrument to measure the quality of life of CWD in Malaysia.

Objective: The objective of this cross sectional study was to determine the reliability of the Malay version of the Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales among CWD in Kelantan.

Methods: A cross sectional study was conducted in September 2009 among CWD aged between two to eighteen years old, registered with the Kelantan Foundation for the disabled. Parent-proxy report was used. The test for Cronbach's alpha was performed to determine the internal consistency reliability

Results: There were a total of 78 CWD involved in this study. The internal consistency reliability was good as the Cronbach's alpha of all domains were above 0.6, ranging from 0.65 to 0.85.

Conclusions: The Malay Version of the Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales shows good internal consistency reliability. However, future study with bigger sample size is necessary before it may be recommended to be used as a tool to measure the quality of life of CWD whose parents understand the Malay language.

Keywords: Reliability, Malay version, PEDSQL, quality of life, children with disabilities

Background

Health was defined by the World Health Organization (WHO) as a state of complete physical, mental and social well-being, and not merely the absence of disease or illness [1]. This definition implies that health consists of multiple dimensions, including physical, emotional, social, economic, and spiritual aspects [2], and its qualities can be measured. Health-related quality of life (HRQOL) refers to “the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person’s experiences, beliefs, expectations, and perceptions”[3]. HRQOL has emerged as an essential outcomes indicator in health and clinical practice [4]. It can be used in evaluating health-care interventions and treatments, understanding the burden of disease and identifying health inequalities. Furthermore, it is essential in identifying and prioritizing health problems for individual patients, facilitating communication between patients and health-care staff, identifying hidden or unexpected health problems, monitoring changes in patients’ health state or detecting responses to treatment as well as aids to decision making [5].

Little is known about the quality of life of children with disabilities (CWD) [6]. A study conducted in six European countries revealed that the quality of life of children with cerebral palsy was similar with normal children except for schooling [6]. The children’s characteristics, family structure and the disability services available in Malaysia may be different from those countries where the prior study was done and as such the quality of life may be different in nature and magnitude.

There are various instruments, comprising the generic and disease-specific instruments available to measure the HRQOL of children

including CWD. These instruments include the Children Life Quality Index (CLQI), Generic Children’s Quality of Life Measure (GCQ), Cerebral palsy (CP) QOL Child, Attention-deficit/hyperactive disorder (ADHD) Impact Module and The Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales [5].

The Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales measure the HRQOL in children and adolescents ages two to eighteen years old. Besides the availability of age appropriate versions, other advantages include brevity and parallel forms for children and parents [4, 7, 8]. The scales are applicable in clinical trials, research, clinical practice, school health settings, and community population [2]. The Malay version of the Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales has been validated among Malaysian children with Thalassaemia [9].

To the best of our knowledge, there is no validated instrument to measure the HRQOL among CWD in Malaysia.

Therefore, the objective of this study was to determine the reliability of the Malay version of the Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales among Malaysian parents with CWD.

Methods

The Malay version of Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales and setting

This study was conducted in Kelantan, situated in the north-east of Peninsular Malaysia.

Consent from original authors of The Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales was sought to use this module and validate the Malay version of it. It consists of parent-proxy report that measures physical (8 items) and psychosocial functions including emotional (5 items), social (5 items) and schooling (5 items) function of children aged two to eighteen years old. A 5-point response scale is utilized (0 = never a problem; 4 = always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0); so that higher scores indicate better functioning (better HRQOL) [4]. (The instrument is attached).

The original English version of The Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales has been validated among 1,629 parents of chronically ill children, acutely ill children and healthy children, recruited from paediatric health care settings. The internal consistency of proxy-report was very good as the Cronbach's alpha ranged from 0.76 to 0.88[4]. The internal consistency of the Malay version of it was also very good as the Cronbach's alpha ranged from 0.77 to 0.86. However it was administered among children with Thalassaemia themselves (self-report) [9].

Study design, Study population and data collection

A cross sectional study was conducted in September 2009 among CWD aged between two to eighteen years old, registered with the Kelantan Foundation for the disabled. Non-probability sampling technique was used select the respondents during a special event conducted by the foundation. Parent-proxy report was used in which the caregivers of CWD answered the questionnaire. Parent

proxy-report instrument is essential when children are too young, too cognitively impaired, too ill or fatigued to complete the instrument or when they are unwilling to respond for themselves [10, 11]. Only care givers who were able to understand the Malay language were included.

The sample size was calculated using *ssalpha* command based on Stata software [12]. For a domain with the least number of items, that was 5, with the expected Cronbach's alpha at 0.8 and the lower bound of Cronbach's alpha at 0.73 with 95% confident, the required sample size was 69.

During the collection, the caregivers were explained about the study rationale and informed consent was obtained before they answered the self administered questionnaires. The authors were present during the collection of data to ensure any doubt and enquiry was clarified.

Statistical analysis

Data entry and statistical analysis was done using Statistical Packages for Social Sciences (SPSS) version 12.1. The demographic profiles of the children and their caregivers were described using mean, SD, frequency and percentage. We examined the mean and SD of each domain to assess the item analysis. To determine the internal consistency reliability of the domains, the analysis for Cronbach's alpha was performed. The item's item-total correlation was assessed. The Cronbach's alpha above 0.7 [13- 15] was deemed to show acceptable internal consistency reliability.

This study was approved by the Research and Ethics Committee, Universiti Sains Malaysia (USM).

Results

Profile of children and caregivers

There were a total of 78 CWD involved in this study. All belonged to the Malay race. The gender was equally distributed. More than half of them were those in the age group between 13 to 18 years old (51.3%) with different types of disability (Table 1).

The majority of caregivers were female (61.5%) and attended formal education until secondary schools (59.0 %). Their mean age was 47 years old (SD = 9.6). More than half of them earned about RM 1000 or less monthly. The majority of them (87.2%) had one disabled child in their family (Table 2).

Means and Standard Deviations

Table 3 shows the mean total score was 71.7 (SD=3.39). The highest mean score was the mean score for physical health domain (mean=74.1; SD=3.05), while the lowest mean score was the mean score for school functioning domain (mean=65.6; SD=6.24).

Internal Consistency Reliability

The internal consistency reliability based on the Cronbach's alpha of all domains was above 0.6 (ranging from 0.65 to 0.85). The highest Cronbach's alpha was the Cronbach's alpha for the physical health domain, while the lowest was the school functioning domain. In general, the corrected item-total correlation for all domains was acceptable as it was 0.4 and above except for the item 'miss school due to doctor's appointment '(schooling function domain), (item-total correlation was 0.140).

The detailed analyses are shown in Table 3.

Discussions

This study reveals the preliminary reliability of the Malay version of the Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales in measuring the HRQOL of CWD. The results showed good internal consistency with Cronbach's alpha values ranging from 0.65 to 0.85 across four domains. It is suggested that a Cronbach's alpha of 0.7 or 0.8 is an excellent internal consistency [13-15]. Varni et al also found in their study of the original version of the Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales that all scales exceeded the minimum reliability standard of 0.7, ranging from 0.75 to 0.88[4]. Good internal consistency (exceeded 0.7) was also reported for proxy-report of the Norwegian version [6] and the UK-English version [7]. The internal consistency of the Malay version which was validated among children with Thalassaemia was also good as the Cronbach's alpha ranged from 0.77 to 0.86 [9].

Our study showed that the highest Cronbach's alpha was from the physical health domain with Cronbach's alpha of 0.85. Similarly, [7] and [8] found the Cronbach's alpha from the physical health domain scored the highest (Cronbach's alpha 0.88 and 0.83 respectively). Our finding also concurs with the UK-English version [7] where the school functioning domain had the lowest Cronbach's alpha value.

In general, the corrected item-total correlation for all domains was acceptable as it was 0.4 and above except for the item 'miss school due to doctor's appointment '(school functioning domain), (item-total correlation

was 0.140). [4, 9] found that all items met or exceeded the 0.4 standard for the corrected item-total correlation.

The HRQOL among children in our study was poorer as compared to those reported by [4, 7, 8], indicated by lower mean score of all domains. Healthy children were included in the prior studies [4, 7, 8]. Better quality of care and support provided in more developed countries might explain the better quality of life. In addition, half of our respondents were from poor socioeconomic background (monthly income was RM 1000 or less). The mean score of most of the domains in our study was higher than those reported by [9] except for social functioning. The need for regular blood transfusion and the presence of medical complications among children with Thalassaemia in the prior study [9] might affect their physical health, emotional functioning and school functioning.

The present findings in this preliminary study have several potential limitations. Test-retest reliability was not performed. No comparison was analyzed between normal children and CWD as well as between different types of disability. The correlation between children and parent-proxy report was not reported. The consistency between children and parent-proxy reports was also not tested. A proxy rater's estimate may be insufficiently accurate [4]. In addition, the sample size in this study was relatively small compared to prior studies [4, 7, and 8]. Non-probability sampling technique and small sample size might affect the external validity of the findings. Therefore, we recommend future study with larger samples comparing the findings with normal healthy control as well as among different types of disability and test retest analysis to be carried out.

Since the caregivers were all coming from a single state within Peninsular Malaysia, it is

not certain that the findings may be generalized to the rest of Malaysia. However, the standard Malay language was used and it is likely that there are no major differences with other states in Malaysia. The Malay language is also used in other countries in Southeast Asia (Indonesia, Brunei and Singapore). Therefore, this Malay version may benefit a large number of CWD in this region.

Conclusion

In conclusion, the Malay Version of the Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) Generic Core Scales shows good internal consistency reliability. However, future study with bigger sample size is necessary before it may be recommended to be used as a tool to measure the HRQOL of CWD whose parents understand the Malay language.

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Table 1: Socio-demographic characteristic of CWD

Variables	n	%
Age		
2 to 4	4	5.1
5 to 7	11	14.1
8 to 12	23	29.5
13 to 18	40	51.3
Gender		
Male	39	50.0
Female	39	50.0
Types of disability		
Vision problems	2	2.6
Hearing problems	3	3.8
Physical disabilities	1	1.3
Cerebral palsy	3	3.8
Down syndrome	1	1.3
Attention Deficit Hyperactive Disorder	2	2.6
Learning problems	11	14.1
Mental retardation	7	9.0
Autism	3	3.8
Combination of different types	45	57.7

Table 2: Socio-demographic characteristic of caregivers

Variable	n	%	Mean	SD
Age			46.9	9.61
Ethnic				
Malay	78	100.0		
Gender				
Male	30	38.5		
Female	48	61.5		
Marital status				
Married	68	87.2		
Unmarried / divorced	10	12.8		
Job				
Not working	38	48.7		
Self employed	18	23.1		
Government servant	15	19.2		
Private sectors	7	9.0		
Educational level				
Not schooling	6	7.7		
Primary school	18	23.1		
Secondary school	46	59.0		
College/University	8	10.3		
No of children in family			5.7	2.57
No of disabled children in family			1.2	0.47
Family income				
RM 0 to RM 1000	50	64.1		
RM 1001 to RM 2000	11	14.1		
>RM 2000	17	21.8		

Table 3: Scale descriptive, Internal Consistency Reliability & Corrected total item correlation

Domains/items	Mean	SD	Corrected total item correlation	Cronbach's alpha
Total score	71.7	3.39		
Physical health	74.1	3.05		0.85
Hard to walk more than one block			0.635	
Hard to run			0.742	
Hard to do sports or exercise			0.654	
Hard to lift something heavy			0.638	
Hard to take bath or shower			0.638	
Hard to do core around house			0.587	
Hurt or ache			0.393	
Low energy			0.445	
Psychosocial health	69.3	3.37		
Emotional functioning	70.1	10.22		0.76
Feel afraid or scared			0.635	
Feel sad or blue			0.742	
Feel angry			0.654	
Trouble sleeping			0.638	
Worry about what will happen			0.638	
Social functioning	72.2	7.49		0.76
Trouble getting along with peers			0.602	
Other kids not want to be friend			0.630	
Teased			0.435	
Doing thing other peers do			0.433	
Hard to keep up when play with others			0.542	
School functioning	65.6	6.24		0.65
Hard to concentrate			0.479	
Forget things			0.498	
Trouble keeping up with school work			0.498	
Missed school - not well			0.443	
Missed school- doctor appointment			0.140	