Original Article

A Preliminary Study on the Reliability of the Malay Version of PedsQL™ Family Impact Module among Caregivers of Children with Disabilities in Kelantan, Malaysia

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Abstract

Background: **No previous study has assessed the impact of childhood disability on parents and family in the context of Malaysia, and no instrument to measure this impact has previously been available. The objective of this cross-sectional study was to determine the reliability of a Malay version of the PedsQL™ Family Impact Module that measures the impact of children with disabilities (CWD) on their parents and family in a Malaysian context.**

Methods: **The study was conducted in 2009. The questionnaire was translated forward and backward before it was administered to 44 caregivers of CWD to determine the internal consistency reliability. The test for Cronbach's alpha was performed.**

Results: **The internal consistency reliability was good. The Cronbach's alpha for all domains was above 0.7, ranging from 0.73 to 0.895.**

Conclusion: **The Malay version of the PedsQL™ Family Impact Module showed evidence of good internal consistency reliability. However, future studies with a larger sample size are necessary before the module can be recommended as a tool to measure the impact of disability on Malay-speaking Malaysian families.**

Keywords: *caregivers, disabled children, public health, psychometrics, quality of life, questionnaires, reliability and validity*

Introduction

With the advancement of treatment modalities, more children survive severe acute illnesses but, often, not without sequelae causing some form of chronic morbidity or disability. The care of chronically ill and disabled children is complex. Follow-up by a multidisciplinary team is often desirable, but in many places in Malaysia, such services are not available. The need for multiple visits to medical care facilities and the problems faced by these children in carrying out their daily activities may have a significant impact on the family.

Several studies evaluating the impact of children's chronic morbidity and disability on the family have shown the presence of negative outcomes. Problems include social stigma, altered family dynamics, emotional disturbance (1), and psychosocial impact (2). However, the patient's characteristics and family structure and the disability services available in Malaysia may differ from the countries where these studies were conducted; as such, the impact on the families may differ in nature and magnitude.

For English-speaking populations, there are various instruments available to measure the impact of a child's disability on parents

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and the family. These instruments include the Beck Depression Inventory, State-Trait Anxiety Inventory, the Nottingham Health Profile Part 1 (3), and the PedsQL™ Family Impact Module. The PedsQL™ Family Impact Module was designed to measure the impact of paediatric chronic health conditions on parents and the family. It measures parents' self-reported physical, emotional, social, and cognitive functions, communication, worry, parent-reported family daily activities, and family relationships (4).

To the best of our knowledge, there is no validated instrument for the Malaysian population that measures the impact of paediatric chronic illness or disability on parent and family functioning. This study was performed to determine the reliability of the Malay version of the PedsQL™ Family Impact Module, which measures the impact of children with disabilities (CWD) on their parents and family in a Malay-speaking population.

Materials and Methods

PedsQL™ Family Impact Module and setting

This study was conducted in Kelantan, which is situated in the northeast of Peninsular Malaysia. Consent from the original authors of the PedsQL™ Family Impact Module was sought to use this module and to create and validate a Malay version of it. This module measures parents' self-reported physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (4 items), communication (3 items), and worry (5 items). It also measures parent-reported family daily activities (3 items) and family relationships (5 items). A 5-point response scale is utilised (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 (less negative impact). The original version of the PedsQL™ Family Impact Module was validated in San Diego among 23 families of medically fragile children with complex chronic health conditions who either resided in a long-term care convalescent hospital or resided at home with their families. The internal consistency was very good, as the Cronbach's alpha ranged from 0.82 to 0.97 (4).

Procedure

This study was approved by the Research and Ethics Committee, Universiti Sains Malaysia. The process of validation during the current study involved translation of the questionnaire and a cross-sectional field study among the caregivers of CWD. The original PedsQL™ Family Impact Module was translated from English to the Malay language independently by a medical doctor and a linguist who were fluent in both languages. The translations were revised and reconciled by the authors to produce a forward-translated version of the questionnaire. This version was back-translated into English by another medical doctor and linguist. The authors then compared the forward-translated and backward-translated versions and reconciled the questionnaire accordingly. The back-translated version was compared with the original PedsQL™ Family Impact Module to ensure its similarity. The authors agreed on the final version, and the face validity was determined to be acceptable.

The cross-sectional field study was conducted in September 2009 among caregivers of CWD and adolescents, aged 2 to 18 years old, who were registered with the Kelantan Foundation for the Disabled. Only participants who were able to understand the Malay language were included. The sample size was calculated using the ssalpha command based on Stata software (5). For a domain with the least number of items (3), with an expected Cronbach's alpha of 0.7 and a lower bound of Cronbach's alpha at 0.60 with 95% confidence, the required sample size was 95.

During the field study, the study rationale was explained to the caregivers, and informed consent was obtained before the caregivers answered the self-administered questionnaires.

Statistical analysis

Data entry and statistical analysis were conducted using SPSS version 12.1 (SPSS Inc., Chicago, IL). The demographic profile of the respondents was described using mean, SD, frequency, and percentage. We examined the mean and SD of each item in each domain to assess the item analysis. To determine the internal consistency reliability of the domains, the analysis for Cronbach's alpha was performed, and the item-total correlation was assessed. Cronbach's alpha above 0.7 was deemed to show acceptable internal consistency reliability (6–8).

Results

Profile of caregivers and children

A total of 44 caregivers were involved in this study; their demographic characteristics are listed in Table 1. All participants were Malay, and the majority of them were female (75.0%) and attended formal education until secondary school (58.1%). Many of the participants were the parents of CWD (65.1%). The participants had a mean age of 48 years old (SD 10.6), and their median total monthly household income was RM900. The mean age of their CWD was 14 years old (SD 5.4). The children's types of disability included vision problems (*n* = 2), hearing impairment (*n* = 5), cerebral palsy and other physical disabilities (*n* = 8), learning problems including dyslexia (*n* = 13), and mental retardation including autism and Down syndrome (*n* = 17).

Means and standard deviations

Table 2 shows that the highest mean score was for the family relationship domain (82.6, SD 23.74), while the lowest mean score was for the physical domain (65.1, SD 22.88). The mean score of items ranged from 23.3 (SD 31.18) to 88.4 (SD 25.21). Among the items analysed, the highest mean score was for the item assessing the lack of communication among family members (family relationship domain). The lowest mean score was for the item assessing parents' worries about the future of their children (worry domain).

Internal consistency reliability

The internal consistency reliability based on the Cronbach's alpha of all domains was above 0.7 (ranging from 0.730 to 0.895). The highest Cronbach's alpha was for the family relationship domain, while the lowest was the communication domain. In general, the corrected item-total correlation for all domains was acceptable, at 0.4 and above, with the exception of the item "do not understand my family situation" (communication domain, item-total correlation 0.383). The corrected item-total correlation for the family relationship domain gave the highest Cronbach's alpha, ranging from 0.623 to 0.854. The detailed analyses are shown in Table 2.

Table 1: Demographic characteristics of caregivers and children

Characteristic	*n*	(%)
Sex of caregivers		
Male	11	(25.0)
Female	33	(75.0)
Age of caregivers	48	(10.6) [a]
Monthly household income	RM900	(1200) [b]
Marital status [c]		
Married	37	(88.1)
Divorced	5	(11.9)
Caregiver's level of education [d]		
No formal education	3	(7.0)
Primary school	14	(32.6)
Secondary school	25	(58.1)
Collage/university	1	(2.3)
Number of children	6	(2) [a]
Number of children with disabilities	1	(0.5) [a]
Age of children with disabilities	14	(5.4) [a]
Sex of children with disabilities		
Male	24	(54.5)
Female	20	(45.4)

[a] Results are expressed in mean (SD).
[b] Result is expressed in median (IQR), skewed to the right.
The total number of subjects is 44.
[c] Marital status unknown for 2 subjects.
[d] Level of education is unknown for 1 subject.

Table 2: Item analysis and internal consistency reliability

Domains	Mean (SD)	I-T co	Cb's A
Physical functioning	65.1 (22.88)		0.845
Tired during the day	58.1 (31.21)	0.683	
Tired when waking up in the morning	59.3 (29.90)	0.646	
Too tired to do favourite things	66.3 (32.22)	0.591	
Headaches	61.6 (29.55)	0.680	
Physically weak	65.1 (32.80)	0.621	
Sick to the stomach	77.3 (27.72)	0.530	
Emotional functioning	71.9 (24.30)		0.850
Anxious	72.7 (33.55)	0.673	
Sad	65.1 (28.94)	0.679	
Angry	62.8 (26.9)	0.517	
Frustrated	78.5 (30.20)	0.783	
Helpless or hopeless	80.2 (33.91)	0.661	
Social functioning	76.6 (25.66)		0.822
Isolated from others	86.0 (25.18)	0.642	
Trouble getting support from others	74.4 (33.85)	0.633	
Difficult to find time for social activities	70.9 (34.50)	0.723	
Inadequate energy for social activities	75.0 (33.20)	0.613	
Cognitive functioning	69.3 (23.89)		0.823
Difficulty paying attention	68.0 (26.35)	0.405	
Difficulty remembering things people say	68.0 (28.00)	0.704	
Difficulty remembering things just heard	62.8 (34.23)	0.797	
Difficulty thinking quickly	78.5 (29.20)	0.715	
Communication	74.6 (23.14)		0.730
Others do not understand my family's situation	66.3 (29.32)	0.383	
Difficult to talk about the child's health	73.8 (29.40)	0.640	
Difficult to tell doctors and nurses their feeling	83.7 (27.21)	0.662	
Worry	63.4 (23.09)		0.788
The child's medical treatment is working or not	74.4 (30.61)	0.504	
Side effects of the medications/medical treatment	82.0 (26.90)	0.565	
Reaction of others to the child's condition	59.3 (34.10)	0.658	
The child's illness is affecting other family members	77.9 (34.60)	0.644	
The child's future	23.3 (31.18)	0.473	
Daily activities	69.3 (27.36)		0.771
Family activities take more time and effort	68.6 (38.22)	0.667	
Difficulty finding time to finish household tasks	74.4 (30.61)	0.546	
Feeling too tired to finish household tasks	66.9 (29.74)	0.629	
Family relationships	82.6 (23.74)		0.895
Lack of communication among family members	88.4 (25.21)	0.682	
Conflicts among family members	82.6 (29.65)	0.728	
Difficulty making decisions together as a family	82.6 (28.10)	0.854	
Difficulty solving family problems together	82.0 (30.53)	0.832	
Stress or tension among family members	77.3 (27.72)	0.623	

The total number of subjects is 44.
Abbreviations: I-T co = item-total correlation, Cb's A = Cronbach's alpha.

Discussion

This study demonstrates the preliminary reliability of the translated Malay version of the PedsQL™ Family Impact Module for measuring the impact of CWD on the parents and family. The results showed good internal consistency, with Cronbach's alpha values ranging from 0.730 to 0.895 across 6 domains. It is suggested that a Cronbach's alpha of 0.7 or 0.8 indicates excellent internal consistency (6–8). Varni et al. (4) found that all scales exceeded the minimum reliability standard of 0.7. This finding is similar to the findings of a study conducted among 97 parents of children with sickle cell disease in Wisconsin in the United States (9). However, a similar study conducted among 66 Brazilian families of outpatient children diagnosed with malignant neoplasm and receiving chemotherapy found that the internal consistency for some items (emotional, communication, and worry) was less than 0.7 (10).

Our study showed that the highest Cronbach's alpha was for the family relationship domain (0.895). Similarly, Varni et al. (4) and Panepinto et al. (9) found that the Cronbach's alpha for the family relationship domain had the highest score (Cronbach's alphas of 0.97 and 0.96, respectively). Our findings were also consistent with other studies (9,10) that found the lowest Cronbach's alpha value for the communication domain. In general, the corrected item-total correlation for all domains was acceptable, with the exception of the item "do not understand my family situation". This finding could be explained by the difference between this item and the other 2 items in the communication domain, which directly indicate communicable words such as "talk" and "tell".

The mean score of all functions in our study was higher than those reported by Varni et al. (4) for the outpatient samples, except for the cognitive function. This finding indicates that the caregivers in our study functioned better than those in the previous study. This finding might be explained by a possibly higher acceptance among the Malay population of the fate of having children with chronic illnesses, although the facilities available in Malaysia are relatively limited.

A limitation of this cross-sectional study with no comparison group is that it may not be sufficient to fully demonstrate the external validity of the questionnaire. Because the caregivers were all from a single state within Peninsular Malaysia, it is uncertain whether the findings can be generalised 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 children and caregivers in this region. Due to time constraints, the test–retest, which demonstrates the stability of the information, was not conducted. Therefore, we recommend that future studies should compare the findings with normal, healthy controls and among different types of disabilities, and that a test–retest analysis be conducted with a larger sample size.

Conclusion

The Malay version of the PedsQL™ Family Impact Module has excellent internal consistency. However, future studies with a larger sample size are necessary before it can be recommended as a tool to measure the impact of disabilities on Malay-speaking Malaysian families.

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Authors' Contributions

Conception and design: AAR, AAA
Obtaining of funding: AAR, WPWI, MII
Collection and assembly of the data: AAR, SH, NHA, MII, AO
Analysis and interpretation of the data: AAR, MKI
Drafting of the article: AAR, NM
Critical revision and final approval of the article: HVR
Statistical expertise: MKI
Administrative, technical, or logistic support: AAR, WPWI,MII

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