

## Conference Paper

# A Psychometric Evaluation of The Malay Version of PedsQL<sup>TM</sup> Family Impact Module among Caregivers of Children with Learning Disabilities

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## Abstract

Parenting a child with learning disability can be a source of significant stress and affects the quality of life of the parents and families. The aim of this study was to evaluate the psychometric properties of the Malay version of PedsQL<sup>TM</sup> Family Impact Module that measure the impact of children with learning disabilities on their caregivers' health-related quality of life (HRQoL) and family functioning. A cross-sectional study was conducted involving 383 caregivers of children with learning disabilities in Kelantan, a state of Peninsular Malaysia. Internal consistency reliability, construct validity and construct reliability were evaluated using Cronbach's alpha and confirmatory factor analysis (CFA). The Malay version of PedsQL<sup>TM</sup> Family Impact Module showed good internal consistency reliability (Cronbach's alpha > 0.7). Second order CFA showed that the instrument had acceptable construct validity after modification with Goodness-of-fit indices reached the standard indicating acceptable model fit ( $\chi^2(426) = 878.842, p < 0.001; RMSEA = 0.053; CFI = 0.918; \chi^2/df = 2.063$ ). Average variance extracted and composite reliability achieved minimum acceptable value for main construct and all subconstructs except Physical Functioning subconstruct. The Malay version of PedsQL<sup>TM</sup> Family Impact Module with eight subscales and 31 items had adequate construct validity and reliability and could be used to assess the impact of pediatric disability on parent HRQoL and family functioning in Malay-speaking Malaysian families.

**Keywords:** PedsQL<sup>TM</sup> Family Impact Module; psychometric; confirmatory factor analysis; caregivers; disability

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## 1. INTRODUCTION

Disability and developmental problems in childhood have become important problems to improvements in health care (Amar-Singh 2008). Disabilities not only affect significantly on the children's development, but also on the lives of their family members, especially parents who are their long-term caregivers. There is growing evidence that caring a child with disability or chronic condition affects the parents' health and quality of life [4, 6, 7].

The assessment of the impact of pediatric chronic conditions and disabilities on parental health status and functioning is undoubtedly useful. This assessment is also valuable for health care professionals and policy makers in the effort to improve the health-related quality of life (HRQoL) of children and their families. Many survey instruments have been used to measure the impact of pediatric chronic conditions on parents and the family for English-speaking population. These instruments include Pediatric Quality of Life (PedsQL<sup>TM</sup>) Family Impact Module [15, 18], Short Form 36 (SF-36) Health Survey [16], WHOQOL-BREF [11] and General Health Questionnaire-28 (GHQ-28) [10].

Based on the Malaysian population, some studies have been conducted examining the impacts of caregiving children with spina bifida, Down syndrome, mental retardation and other types of disabilities on the parents and family. The researchers have adopted different well-established instruments from Western to measure these impacts, such as Parenting Stress Index [13], Parental Stress Scale [12], PedsQL<sup>TM</sup> Family Impact Module [8] and General Health Questionnaire [13, 17]. A central issue that guides this study is that the different instruments will yield variability in findings and different estimates of the values of health outcomes. Thus, the quality of life outcomes of parents cannot be completely assessed without a well-developed and validated instrument that specifically measures the impact of children's disability on parental HRQoL in our population.

In order to improve the assessment of the impact of pediatric chronic diseases on the parent HRQoL in the context of Malay culture, we decided to introduce and use the PedsQL<sup>TM</sup> Family Impact Module (FIM). A preliminary study on reliability of the Malay version of the PedsQL<sup>TM</sup> FIM has been conducted by Azriani et al. (2011) among caregivers of children with disabilities. Although it was tested on reliability, it is considered insufficient evidence of construct validity and reliability, thus further validation should be conducted in larger samples to confirm its validity and reliability. The objective of the current study was to evaluate the psychometric properties of the Malay version

of the PedsQL<sup>TM</sup> FIM using confirmatory validity approach in the sample of caregivers of children with learning disabilities.

## 2. METHODS

### 2.1. Participants and Settings

This cross-sectional study was conducted in community-based rehabilitation (CBR) centres and schools with special education integration program in Kelantan, the most northeastern state of Peninsular Malaysia. The data was collected in February to September 2015. One-stage cluster random sampling method was employed to select the study samples. The participants were parents or guardians (herein "caregivers") of children with learning disabilities who registered with Department of Social Welfare Malaysia and attending the CBR and schools. The inclusion criteria as follows: (1) those who are primary caregivers, (2) have a child with the diagnosis of Down syndrome, autism spectrum disorder (ASD), attention-deficit hyperactive disorder (ADHD), global developmental delays, intellectual disability, or specific learning disabilities, (3) their child aged of 18 years old and below, and (4) their child lives at home. Caregivers who were absent during the study period and/or demonstrated a severe mental illness were excluded from the study.

This study was approved by the Universiti Kebangsaan Malaysia Research Ethics Committee (Research Code: NN.109-2014), Department of Social Welfare Malaysia, Ministry of Education Malaysia and Kelantan State Education Department. A self-administered and guided questionnaire which consisted of background information sheet and the Malay version of the PedsQL<sup>TM</sup> FIM.

### 2.2. Instrument: PedsQL<sup>TM</sup> Family Impact Module

PedsQL<sup>TM</sup> FIM which was introduced by Varni et al. (2004), is a parent-reported measure for the impact of paediatric chronic medical conditions on the parent HRQOL and family functioning. This multidimensional instrument consists of 8 subscales: Physical Functioning (6 items), Emotional Functioning (5 items), Social Functioning (4 items), Cognitive Functioning (5 items), Communication (3 items), Worry (5 items), Daily Activities (3 items) and Family Relationships (5 items). A 5-point Likert 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 FIM was translated into the Malay version by Azriani et al. (2011). The previous study involved forward and backward translation process, preliminary test and field test. The authors agreed on the final version, and the face validity was determined to be acceptable. The field study on 44 caregivers of children with disabilities showed the internal consistency reliability based on the Cronbach's alpha of all domains of the Malay version was above 0.7 (ranging from 0.730 to 0.895).

### 2.3. Statistical Analysis

Descriptive and reliability analyses were done using IBM SPSS version 22 software and confirmatory factor analysis (CFA) for validity assessment was conducted using Amos version 21 software. CFA was conducted on the sample using maximum likelihood (ML) estimation with bootstrapping technique due to violation of multivariate normality assumption. Several fit indices were considered to determine the goodness-of-fit of the measurement model.

## 3. RESULTS

### 3.1. Sociodemographic Characteristics

A total of 383 caregivers were involved in this study; their demographic characteristics are listed in Table 1. Almost all participants were Malays (97.9%), and the majority of them were female (77.0%) and attended formal education until secondary school (70.2%). Many of the participants were the biological parents of the children (93.0%). The participants had a mean age of 46 years old (SD 9.40), and their median total monthly household income was MYR800. The mean age of their children with learning disabilities was 12 years old (SD 4.29). Majority of the children were children with intellectual disability (36.8%) and Down syndrome (35.8%).

### 3.2. CFA and Reliability

PedsQL<sup>TM</sup> FIM measurement model was proposed as a second-order Family Impact factor. Figure 1 shows that main construct of Family Impact was exerted by other eight subconstructs. Initially, first order CFA was conducted on the original eight-factor model

TABLE 1: Demographic characteristics of caregivers and children

Characteristics	Mean (SD)	Frequency (%)
Age (years)	45.57 (9.40)	
Relationship to the children		
Father/Mother		356 (93.0)
Grandfather/Grandmother		5 (1.3)
Siblings		11 (2.9)
Others		11 (2.9)
Gender		
Male		88 (23.0)
Female		295 (77.0)
Marital status		
Married		344 (89.8)
Single		7 (1.8)
Divorced		13 (3.4)
Widowed		19 (5.0)
Occupation		
Unemployed/Housewives		212 (55.4)
Private employee		18 (4.7)
Government employee		41 (10.7)
Self-employed		112 (29.2)
Educational level		
No formal education		17 (4.4)
Primary school		67 (17.5)
Secondary school		269 (70.2)
University/college		30 (7.8)
Monthly household income (MYR)	800.00 (1000.00) <sup>a</sup>	
Age of children with learning disabilities	11.71 (4.29)	
Characteristics	Mean (SD)	Frequency (%)
Types of diagnosis of children		
Down Syndrome		137 (35.8)
ADHD		17 (4.4)
ASD		35 (9.1)
Global developmental delay		30 (7.8)
Intellectual disability		141 (36.8)
Specific learning disability		23 (6.0)

<sup>a</sup>Median (IQR)

with 36 items in Model 1. This model did not result in a good fit with the data sample ( $\chi^2(566)=1205.627, p<0.001; RMSEA=0.054; CFI=0.895; \chi^2/df=2.130$ ). Three items from

TABLE 2: The reliability and CFA of the Malay version PedsQL<sup>TM</sup> Family Impact Module

Constructs	Cronbach's alpha	CR (Minimum 0.6)	AVE (Minimum 0.5)
Family Impact	0.937	0.906	0.550
Physical Functioning	0.816	0.818	0.428
Emotional Functioning	0.830	0.835	0.505
Social Functioning	0.751	0.751	0.601
Cognitive Functioning	0.863	0.868	0.571
Communication	0.782	0.791	0.558
Worry	0.776	0.776	0.634
Daily Activities	0.779	0.790	0.558
Family Relationships	0.858	0.859	0.554

subconstruct Worry were removed due to factor loading below 0.6. Second-order Family Impact model after removing the three items (Model 2) showed an acceptable model fit ( $\chi^2(487)=1023.144$ ,  $p<0.001$ ; RMSEA=0.054; CFI=0.908;  $\chi^2/df=2.101$ ). However, the average variance extracted (AVE) of two subconstructs, Physical Functioning and Social Functioning did not achieve the minimum values of 0.5. The model was re-specified and modification was done by deleting two items from Social Functioning subconstruct. The fit indices for the final measurement model (Model 3) resulted in better fit ( $\chi^2(426) = 878.842$ ,  $p<0.001$ ; RMSEA = 0.053; CFI = 0.918;  $\chi^2/df = 2.063$ ) (Figure 2).

Table 2 shows the results of convergent validity and reliability of the final model. AVE for main construct and all subconstructs achieved minimum value except Physical Functioning (AVE < 0.5). All domains demonstrated good construct reliability with composite reliability (CR) was ranging from 0.75 to 0.91 and Cronbach's alpha was ranging from 0.75 to 0.94.

#### 4. DISCUSSION

A number of HRQOL instruments have been applied to disability research. Instruments used in the measurements of individual and population HRQOL are generic, or, may be specific for a particular disease or condition. PedsQL<sup>TM</sup> FIM was developed specifically to assess the impact of paediatric chronic conditions on the HRQOL of parents and family functioning [18]. This study was conducted among caregivers of children with learning disabilities in community settings to validate the Malay version of the

PedsQL<sup>TM</sup> FIM. In the current study, CFA was utilized to determine the construct validity and reliability of the FIM. CFA has become one of the commonly used statistical procedures to confirm that the indicator measures what they are intended to measure [2]. CFA also provides evidence of the convergent and discriminant validity of the theoretical constructs (Byrne 2010).

The premeditated eight-factor model with 36 items demonstrated inadequate model fit indicated by several fitness indexes. In the current paper, we present Chi-Square Goodness-Of-Fit ( $\chi^2$ ), Comparative Fit Index (CFI), Root Mean-Square Error of Approximation (RMSEA), and Chi-square normalized degree of freedom [2, 3]. The CFI value of hypothesized model did not reach acceptable value of 0.9 [9]. The repeated process of modification in CFA analysis was performed based on the factor loadings, standardized residuals and modification indices given by theoretical consideration. This study conducted the CFA procedure in the form of second order construct because the eight subconstruct are being necessary to measure parental HRQoL and family functioning, thus reflects the main construct which is named as Family Impact construct.

The final model of one main construct with eight subconstructs and 31 items was accepted because it demonstrated acceptable factor loadings, no multicollinearity between domains and best fit. The factor loading initiation model evaluation was followed by convergent validity and construct reliability evaluation. The AVE is a summary measure of convergence among the items [3]. The present study showed that the main construct of Family Impact and all subconstructs except Physical Functioning have adequate convergent validity and construct reliability. The constructs achieved the acceptable AVE value of more 0.5 and CR value of more 0.6 [5].

Furthermore, this study also showed that the Malay version of FIM had good internal consistency, with Cronbach's alpha values ranging from 0.751 to 0.937 across 8 domains and main construct. It is suggested that a Cronbach's alpha of 0.7 indicates good internal consistency [5]. Varni et al. (2004) found that all scales of the original version exceeded the minimum reliability standard of 0.7. The present finding also similar to the finding of prior local study that found Cronbach's alpha values for all 8 subscales were above 0.7 [1].

## 5. CONCLUSION

The Malay version of PedsQL<sup>TM</sup> Family Impact Module with eight subscales and 31 items had adequate construct validity and reliability. This suggests that it could be used

to assess the impact of pediatric disability on parent HRQoL and family functioning in Malay-speaking Malaysian families. Construct validity and reliability tested by CFA should be further assessed on parents of children with other chronic medical conditions in other areas in future research. 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.

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## References

- [1] Azriani, A.R., Norsarwany, M., Kamarul Imran, M., Wan Pauzi, W.I., Azizah, O., Aniza, A.A., Sakinah, H., Mohd Ismail, I., Nor Hashimah, A., and Hans, V.R. 2011. "A preliminary study on the reliability of the Malay version of PedsQL<sup>TM</sup> Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia." *Malaysian Journal of Medical Sciences* 18(4): 62-67.
- [2] Brown, T.A. 2006. *Confirmatory Factor Analysis for Applied Research*. New York: The Guilford Press.
- [3] Byrne, B.M. 2010. *Structural Equation Modeling Amos: Basic Concepts, Applications, and Programming*. 2nd ed. New York: Taylor and Francis Group.
- [4] Davis, E. Shelly, A., Waters, E., Boyd, R., Cook, K., and Davern, M. 2009. "The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers." *Child: care, health and development* 36(1): 63-73.
- [5] Hair, J.F., Black, W.C., Babin, B.J., and Anderson, R.E. 2010. *Multivariate Data Analysis*. 7th Edition. Upper Saddle River, NJ: Pearson Prentice-Hall.
- [6] Hatzmann, J., Maurice-Stam, H., Heymans, H.S.A., and Grootenhuis, M.A. 2009. "A predictive model of health-related quality of life of parents of chronically ill children: the importance of caredependency of their child and their support system." *Health and Quality of Life Outcomes* 7: 72
- [7] Hu, X., Wang, M., and Fei, X. 2012. "Family quality of life of Chinese families of children with intellectual disabilities." *Journal of Intellectual Disability Research* 56(1), 30-44.

- [8] Isa, S. N. I., Abd Aziz, A., Ab Rahman, A., Ibrahim, M. I., Wan Ibrahim, W. P., Mohamad, N., Othman, A., Abd Rahman, N., Harith, S., and Van Rostenberghe, H. 2013. "The impact of disabled children on parent health-related quality of life and family functioning in Kelantan and its associated factors." *Journal of Developmental & Behavioural Pediatrics* 34 (4): 262-268.
- [9] Kline, R.B. 2011. *Principles and Practice of Structural Equation Modeling*. 3rd Edition. New York: Guilford Publications.
- [10] McConkey, R., Truesdale-Kennedy, M., Chang, M.Y., Jarrah, S., and Shukri, R. 2008. "The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study." *International Journal of Nursing Studies* 45: 65-74.
- [11] Mugno, D., Ruta, L., D'Arrigo, V.G., and Mazzone, L. 2007. "Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder." *Health and Quality of Life Outcomes* 5: 22.
- [12] Norizan, A., and Shamsuddin, K. 2010. "Predictors of parenting stress among Malaysian mothers of children with Down syndrome." *Journal of Intellectual Disability Research* 54 (11): 992-1003.
- [13] Ong, L. C., Chandran, V., and Peng, R. 1999. "Stress experienced by mothers of Malaysian children with mental retardation." *Journal of Paediatrics and Child Health* 35: 358-362.
- [14] Ong, L.C., Norshireen, N.A.R., and Chandran, V. 2011. "Maternal mental health in families of children with spina bifida." *World Journal of Pediatrics* 7 (1): 54-59.
- [15] Panepinto, J.A., Hoffmann, R.G., and Pajewski, N.M. 2009. "A psychometric evaluation of the PedsQL<sup>TM</sup> Family Impact Module in parents of children with sickle cell disease." *Health and Quality of Life Outcomes* 7: 32.
- [16] Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., Swinton, M., Zhu, B., and Wood, E. 2005. "The health and well-being of caregivers of children with cerebral palsy." *Pediatrics* 115 (6).
- [17] Shobana, M., and Saravanan, C. 2014. "Comparative study on attitudes and psychological problems of mothers towards their children with developmental disability." *East Asian Arch Psychiatry* 24: 16-22.
- [18] Varni, J.W., Sherman, S.A., Burwinkle, T.M., Dickinson, P.E., and Dixon, P. 2004. "The PedsQL<sup>TM</sup> Family Impact Module: Preliminary reliability and validity." *Health and Quality of Life Outcomes* 2: 55-60.