Test-Retest Reliability and Internal Consistency of Cerebral Palsy Quality of Life Questionnaire (Thai version)

ความเชื่อถือได้ในการประเมินซ้ำและความสอดคล้องภายในเนื้อหาของแบบสอบถามคุณภาพชีวิตของเด็กซีพี (ภาษาไทย)

Kwanchanok Suwanna[1],Saipin Prasertsukdee[1]*, Piyatida Khajornchaikul[2]
ขวัญชนก สุวรรณา[1], สายพิณ ประเสริฐสุขดี[1]*, ปิยะธิดา ขจรชัยกุล[2]
[1]Faculty of Physical Therapy, Mahidol University
[2]Faculty of Public Health, Mahidol University
[1]คณะกายภาพบำบัด มหาวิทยาลัยมหิดล
[2]คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล

Abstract

Cerebral palsy (CP) is a common physical disability in children. In developed countries, the incidence has been estimated as 2–2.5 per thousand live births. Measuring quality of life (QOL) is a part of assessing the health condition of children with CP. The Cerebral Palsy Quality of Life for Children (CP QOL-Child) is a condition-specific QOL measure for children with CP which that the CP QOL-Child did not have formal translation into Thai language, and deserves reliability study. The aims of this study were to cross-culturally translate and examine reliability and internal consistency of CP QOL-Child questionnaire (Thai version).The authors conducted cross translation of the CP-QOL-child questionnaires based on the original authors' translation guidelines. The primary caregiver proxy form of the CP QOL-Child was developed for primary caregivers of children with CP aged 4–12 years (66 items). The child self-report form was for children with CP aged 9–12 years (52 items).For study of test–retest reliability and internal consistency of the CP-QOL child (Thai version), 30 primary caregivers and 30 children with CP were asked to complete the questionnaire andre-answer in two weeks later. Intraclass correlation coefficient (ICC) was used to examine test–retest reliability at the domain level. Internal consistency was estimated using Cronbach's alpha. Excellent test-retest reliability and internal consistency were obtained. All intraclass correlation coefficients were above 0.7.Cronbach's alpha coefficients were between 0.76 and 0.91.

Keywords: cerebral palsy, questionnaire, reliability, quality of life, CP-QOL-Child

บทคัดย่อ

ซีพีเป็นกลุ่มอาการที่มีความผิดปกติของการควบคุมการเคลื่อนไหวและการทรงท่าในประเทศที่พัฒนาแล้ว อุบัติการณ์ของภาวะนี้เท่ากับ 2-2.5ต่อทารกแรกเกิดหนึ่งพันคน การประเมินคุณภาพชีวิตเป็นส่วนหนึ่งของการวัดระดับสุขภาพของเด็ก แบบสอบถามคุณภาพชีวิตของเด็กซีพีถูกพัฒนาขึ้นเพื่อวัดระดับคุณภาพชีวิตของเด็กซีพีโดยเฉพาะและแบบสอบถามนี้ยังไม่ได้รับการแปลเป็นภาษาไทยอย่างเป็นทางการและสมควรศึกษาความเชื่อถือได้ของแบบสอบถาม วัตถุประสงค์ของการศึกษานี้เพื่อแปลแบบสอบถามคุณภาพชีวิตของเด็กซีพีเป็นภาษาไทย และตรวจสอบค่าความเชื่อถือได้ในการประเมินซ้ำและความสอดคล้องภายในเนื้อหาของแบบสอบถามคุณภาพชีวิตของเด็กซีพีฉบับภาษาไทย ผู้เขียนได้แปลแบบสอบถามนี้ตามคำแนะนำในการแปลของผู้พัฒนาแบบสอบถาม

---

* Corresponding author: Faculty of Physical Therapy, Mahidol University, 999 Phutthamonthon Sai 4 Road Salaya, Phutthamonthon, Nakhon Pathom THAILAND 73170 Email saipin.pra@mahidol.ac.th

แบบสอบถามสำหรับผู้ดูแลหลักเป็นแบบสอบถามสำหรับผู้ที่ดูแลหลักของเด็กซีพีอายุ 4-12 ปี (66 หัวข้อ) แบบสอบถามสำหรับรายงานด้วยตนเองเป็นแบบสอบถามสำหรับเด็กซีพีอายุ 9-12 ปี(52 หัวข้อ) เพื่อศึกษาความเชื่อถือได้ในการประเมินซ้ำและความสอดคล้องภายในเนื้อหาของแบบสอบถามคุณภาพชีวิตของเด็กซีพีฉบับภาษาไทย ผู้ดูแลหลักจำนวน -30 คน และเด็กซีพีจำนวน 30 คนตอบแบบสอบถาม จากนั้นตอบแบบสอบถามซ้ำอีกภายใน 2 สัปดาห์ต่อมา สถิติที่ใช้ในการคำนวณคือ Intraclass correlation coefficient (ICC) เพื่อประเมินค่าความเชื่อถือได้ในการประเมินซ้ำและ Cronbach's alpha เพื่อประเมินความสอดคล้องภายในเนื้อหาของแบบสอบถามผลการศึกษาพบว่าความเชื่อถือได้ในการประเมินซ้ำและความสอดคล้องภายในเนื้อหาของแบบสอบถามคุณภาพชีวิตของเด็กซีพีฉบับภาษาไทยอยู่ในระดับดีเยี่ยม โดยมีค่า ICC มากกว่า 0.7และมีค่า Cronbach's alpha ระหว่าง 0.76 - 0.91

Introduction

Cerebral palsy (CP) is a group of non-progressive disorder of movement and posture caused by a defect of the brain in the prenatal, perinatal, and postnatal period [1-6] CP is a major physical disability affecting the functional development in children. In developed countries, the prevalence is 2-2.5/1000 live births. About 25% of these children severely involved and have difficulties with many aspects of their lives including daily activities, communication, mobility, and health[7]. They are the largest group treated in pediatric rehabilitation. Many potential causes of poor quality of life (QOL) in children with CP have been reported[8-10]. Good QOL is a key outcome for the individual children and that is social need for all children[11]. In children with CP, QOL is not only concepts of illness, functional status, mental health, and comfort, but also parental impact, family functioning and environmental factors[12].The QOL questionnaires are important outcome variables in clinical trials for children with CP. There are many questionnaires for studying QOL in children with CP. Several researchers have reported decreased QOL in children with CP[13-16], however, few studies used specific outcome measurement. Condition specific QOL questionnaires are designed to applicable to one group, and are useful to detect small changes in a condition[17]. Based on the reviewed literature, two studies of QOL in children with CP in Thailand did not use specific outcome measurement[18-19]. They used functional independent questionnaire, which was developed and applied from Functional Independent Measure for Children. It is non specific outcome measurement for children with CP. Currently, one study used a CP specific outcome--the Pediatric Quality of Life Inventory 3.0 cerebral palsy module (Thai version)[20] However, this questionnaire seems to be asked about disability but not focus on mental health, comfort, parental impact, family functioning and environmental factors.Cerebral palsy quality of life questionnaire (CP-QOL) was designed to integrate CP-specific approach[17]. That questionnaire was developed for a new QOL instrument for children with CP and completed the concept of QOL. The CP QOL-Child did not have formal translation or formal cross-cultural translation into Thai language, and deserves reliability study. It would be beneficial in translating the CP QOL-Child into Thai. Clinicians, researchers, health professionals and educators could use it to measure and assess changes in children's QOL. The aims of this study were to cross-culturally translate and to examine reliability of CP QOL-Child.

Method

Thirty children with CP and thirty primary caregivers of children with CP were recruited from pediatric rehabilitation center, hospitals, physical therapy clinics and special schools in Bangkok and perimeter. Children with CP aged between 9 to 12 years. They were able to read Thai or able to understand 5 questions from the questionnaire and able to give the same answer in those questions when they were repeated. Parents or primary caregivers of children with CP age between 4 to12 years, who were most responsible for day-to-day caring of the child and have currently lived with the child for at least 6 months. Ethics approval was given by Mahidol University; informed consent was obtained prior to data collection.

Measures

The primary caregiver proxy form of the CP QOL-Child was developed for primary caregivers of children with CP aged 4–12 years (66 items). The child self-report form is for children with CP aged 9–12 years (52 items). The questionnaire measures seven domains of QOL for a child with CP: (1) friends and family; (2) participation; (3) communication; (4) health; (5) social equipment; (6) pain and bother and ; (7) access to services and family health. The last domain is only included on the primary caregiver proxy form. Almost all items are rated on a nine-point scale ranging from 1 to 9. One item from the domain of pain and bother (i.e., Do you worry about who will take care of you in the future?) is rated on a five-point scale. In addition, the neuromotor classification of CP[3] was used to identify type of CP, and the Gross Motor Function Classification System (GMFCS)[21]was used to classify severity of motor disability.

Procedure

Part I: Formal translation of CP-QOL-Child Questionnaire

A process of formal translation of CP QOL-Child was conducted as follows: (1) the permission to translate the English version into Thai was approved by original author; (2) forward translation was done by two Thai native speakers who had acceptable knowledge of both Thai and English languages and had experiences in test development and in the research field concerning QOL in children; (3) reconciliation of translated items was conducted by the two forward translators in order to get the most clear translated items concerning Thai users; (4) backward translation was done by a native English speaker who was able to well understand both Thai and English. The translator has never worked with CP QOL-Child before and was blinded to the original version of CP QOL-Child. She translated the reconciled Thai items into the English version; (5) The forward and backward translations were reviewed by two members of the research group; (6) the process of cognitive interview were conducted in 8 children with CP and 8 mothers/caregivers based on the inclusive criteria. Some items were revised based on the feedback from the primary caregivers and children with CP regarding the meaning and clarity of the questions. Furthermore, the respite care items were deleted with an approval from the original developer because there was no this service for children with disabilities in Thailand. All participants in the pilot study did not know about the respite care and misunderstood that the respite care was a care by a baby-sister.

Part II: Reliability Study

For examining test-retest reliability and internal consistency of CP-QOL-Child questionnaire, the researcher did as follows: For primary caregivers, the researcher asked for the primary caregivers to fill the CP QOL - Child questionnaire (Thai version) – parent proxy. For children with CP, the researcher asked for the children to fill the CP QOL - Child questionnaire (Thai version) – self-report. If the children could not read or fill the questionnaires by themselves, the researcher assisted as needed. If the parents or caregivers and his/her children answered the questionnaire, they were asked for detaining any discussion until the study completed. The same parents and children with CP were got the questionnaire again for at least 2 weeks apart. The data were used for test-retest reliability and internal consistency. The data from the questionnaire was converted into percentage scores based on process of the original manual[17]. The percentage scores for two sessions were used to examine test-retest reliability and internal consistency.

Data analysis

Intraclass correlation coefficient (ICC 3,1) was used to examine test–retest reliability at the domain level. A value of 0.60 or greater of ICC was considered acceptable for reliability[22]. Internal consistency was estimated using Cronbach's alpha. A Cronbach's α of multiple scales is 0.71 or higher was considered sufficient interval consistency[22].

Results

Table 1 displayed the demographic characteristics of the participants. The total of 30 children consisting of 17 girls (57.7%) and 13 boys (43.3%) completed the CP QOL-Child (Thai version).The mean age of children who participated the study was 10.5 ± 1.1 years old. Most children with CP had GMFCS at level 1-3 and spastic diplegia. The mean age of 30 primary caregivers was 45.1 ± 9.9 years old. Most of the respondents were mother (66.7%).Fifteen primary caregivers (50%) had graduated at the levels of the primary and secondary school. Whereas, fourteen primary caregivers (46.7%) had graduated at the level of university.

Table 1 Demographic characteristics of the participants

	Frequency (%)
Children (n=30)	
Age – mean (range) (years)	10.5 (9-12)
Gender	
Male	13 (43.3)
Female	17 (56.7)
GMFCS levels	
GMFCS I	8 (26.7)
GMFCS II	8 (26.7)
GMFCS III	7(23.3)
GMFCS IV	5 (16.7)
GMFCS V	2 (6.7)
Neuromotor Classification	
Hemiplegia	7 (23.3)
Spastic diplegia	14 (46.7)
Spastic quadriplegia	4 (13.3)
Athetoid	3 (10)
Other	2 (6.7)
Primary caregiver (n=30)	
Age – mean (range) (years)	45.1(25-63)
Gender	
Male	5 (16.7)
Female	25 (83.3)
Relationship to the child	
Mother	20 (66.7)
Father	5 (16.7)
Grandmother	3 (10.0)
Babysitter	2(6.7)
Level of education	
Primary and secondary school	15(50)
University(bachelor level)	14 (46.7)
Higher than bachelor level	1 (3.3)

Table 2 Test–retest reliability of CP QOL-Child questionnaire (Thai version) for parent proxy and child self-report in all domains

Domain	ICC (Parent proxy) (n=30)	ICC (Child self-report) (n=30)
Friends and family	0.92	0.78
Participation	0.94	0.83
Communication	0.91	0.86
Health	0.96	0.81
Social equipment	0.91	0.84
Pain and bother	0.93	0.86
Access to services and family health	0.94	b

[b] indicates domains that were not included in child self-report

Table 3 Internal consistency of CP QOL-Child questionnaire (Thai version) for parent proxy and child self-report in all domains

Domain	Cronbach's alpha (Primary caregiver proxy) (n=30)	Cronbach's alpha (Child report proxy) (n=30)
Friends and family	0.82	0.85
Participation	0.87	0.91
Communication	0.83	0.76
Health	0.90	0.91
Social equipment	0.82	0.81
Pain and bother	0.84	0.78
Access to services and family health	0.83	b

[b] indicates domains that were not included in child self-report version

Test–retest reliability

Table 2 showed the results on test–retest reliabilities of CP QOL-child questionnaire (Thai version) for parent proxy and child self-report in all domains. All intraclass correlation coefficients were above 0.7 (0.78-0.96). For the primary caregiver proxy, the highest reliable domain was health domain (ICC = 0.96), whereas, the lowest reliable domain were communication domain and social equipment domain (ICC = 0.91). For child report proxy, the highest reliable domain were communication domain and pain and bother domain (ICC = 0.86), whereas, the lowest reliable domain was friends and family domain (ICC = 0.78).

Internal consistency

Table 3 showed the results on internal consistency of CP QOL-child questionnaire (Thai version) for primary caregiver proxy and child report proxy in all domains. Cronbach's alpha coefficients were between 0.76 and 0.91.In primary caregiver proxy, all Cronbach's alpha coefficients were above 0.7. For the primary caregiver proxy, the highest internal consistent domain was health domain (Cronbach's alpha = 0.90), whereas, the lowest internal consistent domain were friend and family domain and social equipment domain (Cronbach's alpha = 0.82).

For child report proxy, all Cronbach's alpha coefficients were above 0.7. The highest internal

Consistent domain were participation domain and health domain (Cronbach's alpha = 0.91), whereas, the lowest internal consistent domain was communication domain (Cronbach's alpha = 0.76).

Discussion

Numbers of children and primary caregivers who completed the questionnaire (i.e., 30 participants per group) were reached our expectation based on the sample size calculation. Distributions of the children by age were relatively equaled (i.e., 7-8 children per age group). In addition, severity of CP based on the GMFCS and types of CP were covered all severity level and types of CP. Relatively equal distribution of severity and types of CP were not reached. Most children with CP have GMFCS at level 1-3. Most children in the study are also spastic diplegia. The study found many children with spastic quadriplegia, athetoid, and mixed types could not answer or understand the questionnaire. However, a major limitation of the study would be the geographic distribution. Most children with CP and the primary caregivers in this study were the residents in the central part of Thailand (i.e., Bangkokand perimeter). Different residential locations implying different local language and culture might affect the outcome. It was also unclear whether children with CP and caregivers of children with CP in remote areas who used local languages would cope with the formal Thai use in this tool.

Numbers of primary caregivers who completed the questionnaire (i.e., 30 participants per group) were reached our expectation based on the sample size calculation. Most participants related to the children with CP as mother (66.7%)

indicating majority of the primary caregiver of children with CP. The results were similar to Hui-Yi Wang and colleagues' study[23]. Distribution of education of primary caregiver in university level relatively equaled to it in primary and secondary school level.

Most of the primary caregivers who participated in the study expressed that they were confident in recording how their children felt. A majority of the participating children reported that they completed the questionnaire with no or very little help. These findings were important in terms of demonstrating that the words and expressions used in the Thai CP QOL-Child were not difficult for the target populations to read and respond.

The study showed that the test-retest reliabilities of the CP-QOL-Child in both proxies were acceptable. All intraclass correlation coefficients were above 0.7. In particular, in primary caregiver proxy, all ICCs were above 0.9 indicating excellent reliabilities. Even though the test-retest reliabilities in the child report proxy were reported less than the primary caregiver proxy, the reliabilities of all domains in the child report proxy were excellent. Age and intellectual capacities were possible impact. The test–retest reliabilities of the CP QOL-Child (Thai version) in this study were supported by the previous studies[23-24]. The test-retest reliabilities of the CP-QOL-Child questionnaire for primary caregiver proxy by original authors (English version) were 0.76 to 0.89. The previous study regarding the test-retest reliabilities of the CP QOL-Child for primary caregiver proxy in Chinese version were from 0.86 to 0.97[23]. Similarly, the previous studies regarding the test-retest reliabilities of the CP QOL-Child for child report proxy (Chinese version) were 0.74 to 0.92. However, test-retest of the CP-QOL-Child questionnaire for child report proxy by original authors (English version) were not reported[24].

The results of the study indicated sufficient internal consistency of the CP QOL-Child (Thai version). Cronbach's alpha coefficients were between 0.76 and 0.91. A Cronbach's α of multiple scales was higher 0.7 that indicating sufficient internal consistency. The internal consistency of the CP QOL-Child (Thai version) in this study were supported by the previous studies[23-24]. The internal consistency of the CP-QOL-Child questionnaire for primary caregiver proxy by original authors (English version) were 0.74 to 0.92 and for child report proxy were from 0.80 to 0.90[24]. The previous study regarding the internal consistency of the CP QOL-Child for the Chinese version were from 0.82 to 0.90 for primary caregiver proxy and from 0.76 to 0.91 for child report proxy[23].

According to the limitation of this study, further studies of reliabilities in different geographic locations with obviously different local language and culture are suggested to confirm the applicability of the CP QOL-child in all areas of Thailand. The validity of the CP QOL-Child should be studied in the future. Currently, our research team has been conducting the validity and feasibility.

In conclusion, this study provided a preliminary examination of the psychometric properties of the Thai CP QOL-Child. The reliability and of the instrument appears to be acceptable. We believed that the CP QOL-Child questionnaire (Thai version) would be useful in clinical practice and studies that attempted to evaluate the QOL of children with cerebral palsy aged from 4 to 12 years.

Acknowledgements

We would like to thank parents and children with cerebral palsy for contributing their time in the study. We also would like to thank Ladprao Foundation for Handicapped Children Center, Yanhee Hospital in Bangkok, and Srisungwal School in Nonthaburi.

References

1. Michael VJ, Alexander H. Cerebral palsy. Neuromol Med. 2006; 8: 435-50.
2. Russman B, Ashwal S. Evaluation of children with cerebral palsy. Semin Pediatr Neurol. 2004; 11:47-57.
3. Carr LJ, Reddy SK, Stevens S, Blair E, Love S. Definition and classification of cerebral palsy. Dev Med Child Neurol. 2005; 47: 508-10.
4. Martha WJ, Elaine M, Jean S. Cerebral palsy: Introduction and diagnosis (part I). J Pediar Health Care. 2007; 21:146-52.
5. Michael OS. Cerebral palsy. Semin Perinatol. 2008; 32: 35-41.
6. Thomas MO. Diagnosis, treatment and prevention of cerebral palsy. ClinObstetr& Gyne. 2008; 51:51-60.
7. Else O, Marji ER, Hendrink JS. The epidemiology of cerebral palsy: Incidence, impairments and risk factor. DisabilRehabil. 2006; 28:183-91.
8. Anita M. Outcome assessments in children with cerebral palsy, Part II: discriminatory ability of outcome tools. Dev Med Child Neurol. 2007;49:181-6.
9. Yvonne W, Steven M, David JS, Robert MS. Prognosis for ambulation in cerebral palsy: A population-based study. Pediatrics. 2008; 114:164-71.
10. Heather ODae. Self-reported quality of life of 8-12-year-old children with cerebral palsy. Lancet. 2007; 369: 2171-8.
11. World Health Organization. International classification of functional, disability and health. Geneva: World Health Organization, 2001.
12. World Health Organization. International classification of functioning, disability and health version for children and youth. Genrva: Wold Health Organization, 2007.
13. Jilda VA. Health-relate quality of life in childhood cerebral palsy. Arch Phys Med Rehabil. 2005; 86: 940-5.
14. Liu WY, Hou YJ, Wong AM, Lin PS, Lin YH, Chen CL. Relationships between gross motor functions and health-related quality of life of Taiwanese children with cerebral palsy. Am J Phys Med Rehabil. 2009; 88: 473-83.
15. White-Koning M, Grandjean H, Colver A, Arnaud C. Parent and professional reports of the quality of life of children with cerebral palsy and associated

intellectual impairment. Dev Med Child Neurol. 2008; 50: 618-24.

16. Dickinson H, Parkinson K, McManus V, et al. Assessment of data quality in a multi-centre cross-sectional study of participation and quality of life of children with cerebral palsy. BMC Public Health. 2006; 6: 273.

17. Davis E, Waters E, Mackinnon A, Reddihough D, Boyd R, Graham HK. Quality of life of children with CP: condition-specific instrument and proxy reports. Dev Med Child Neurol. 2008; 50:167.

18. Sriseub P. Quality of life of cerebral palsy children (thesis): Chiangmai University; 2000.

19. Somporn Ae. Impact of family who have cerebral palsy children (thesis): Khonkan University; 2007.

20. Tantilipikorn P, Watter P, Prasertsukdee S. Feasibility, reliability, and validity of the Thai version of Pediatric Quality of Life inventory 3.0 cerebral palsy module. Qual Life Res. 2013; 22: 415-21.

21. Liabsirinon S, Tantilipikorn P, MahasupN. Interrater reliability of Thai version of Gross Motor Function Classification System (GMFCS) in Thai children with cerebral palsy. Thai J Phys Ther. 2551; 30: 26-36.

22. Portney LG & Watkins MP. Foundations of clinical research: Application to practice. 3rd ed Upper Saddle River: Pearson Prentice Hall, 2009.

23. Wang HY, Cheng CC, Hung JW, Ju YH, Lin JH &Lo SK. Validating the cerebral palsy quality of life for children (CP QOL-Child) questionnaire for use in Chinese populations. Neuropsychol Rehabil. 2011; 20: 883-98.

24. Morris C, Kurinczuk JJ, Fitzpatrick R. Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. Child Care Health Dev. 2005; 31: 397-407.