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Reliability of the Thai Version of the Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen)

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ABSTRACT

This study aimed to assess the reliability of the Thai version of the Cerebral Palsy Quality of Life Questionnaire for adolescent (CP QOL-Teen) as a measure of Health-Related Quality of Life (HRQOL). The translation was performed according to the author's translation guideline. Forty-five adolescents with CP aged 13-18 years were completed the CP QOL-Teen (self-report) twice in 2 weeks apart. The Intraclass correlation coefficient (ICC) and Cronbach's alpha were used to assess test-retest reliability and internal consistency, respectively. The results were found that the test-retest reliability of the CP QOL-Teen (self-report) was moderate to excellent (ICC = 0.62-0.84) and the internal consistency of the questionnaire was good to excellent (Cronbach's alpha = 0.77-0.91). This study supported the Thai version of CP QOL-Teen (self-report) has acceptable reliabilities in measuring HRQOL in adolescents with CP in Thailand.

Keywords: CP QOL-Teen, Cerebral palsy, Quality of life

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Introduction

Cerebral palsy (CP) is common physical disability in childhood, occurring in 2-2.5 per 1,000 live births (Oskoui *et al.*, 2013). The definition of CP is the disorder of movement and posture involved with communication problems, intellectual deficit, epilepsy, and secondary musculoskeletal problems, which caused by a lesion in the immature brain (Rosenbaum *et al.*, 2007). CP is a lifelong disorder; thus, approaches to intervention that is not recognized only physical function but also includes quality of life and social participation (Colver *et al.*, 2014; Hoon *et al.*, 2015).

Quality of life (QOL) was defined by WHO as "the individual's perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns" (World Health Organization [WHO], 1993). Enhancing QOL is crucial but, in practical, is not primarily concerned by health professionals. Most physical therapists intervened the motor impairments, less focused in activities and social participation (Tantilipikorn *et al.*, 2012; Colver *et al.*, 2014). For increasing awareness and having measure outcome in rehabilitation, it should have an instrument to assess health-related quality of life (HRQOL), which HRQOL was meant the impact of health conditions on a patient's whole life (Bjornson *et al.*, 2001; Sommer *et al.*, 2015). In addition, HRQOL is subjective and should be self-reported whenever possible.

Recently, there are one generic and two condition-specific HRQOL instruments were translated into Thai as follows: the Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL 4.0)(Sritipsukho *et al.*, 2013), the Pediatric Quality of Life Inventory 3.0 Cerebral Palsy Module (PedsQL 3.0 CP)(Tantilipikorn *et al.*, 2013), and the Cerebral Palsy Quality of Life Questionnaire for children (CP QOL-child)(Suwanna *et al.*, 2014). Nevertheless, the PedsQL 4.0 and PedsQL 3.0 CP seemed to measure functioning rather than their perception in life (Carlon *et al.*, 2010; Waters *et al.*, 2009). Although, the CP QOL- child is designed to measure how people feel in all domains of life (Bjornson and McLaughlin, 2001; Carlon, 2010), but it can assess HRQOL in children with CP aged 9-12 years, which is not covered age ranges in adolescent (13-18 years). Moreover, the developers of the CP QOL questionnaires demonstrated that there are different domains emerging during adolescent period including: maintaining independently living and transitioning, acceptance of disability and getting on well at school. (Davis *et al.*, 2009). Thus, it has necessary to translate the Cerebral Palsy Quality of Life Questionnaire for adolescent (CP QOL-Teen) into Thai and determine the reliability.

Objectives of the study

To assess test-retest reliability and internal consistency of the Thai version of CP-QOL Teen (self-report)

Methodology

Participation

Forty five adolescents with CP were recruited by purposive sampling from the Pediatric clinic of Faculty of Physical Therapy, Mahidol University; Srisangwan School, Nonthaburi; and Home for Children with Disabilities (Nonthapoom), Nonthaburi. To attain power 80% at 0.05 level of significance for reliability, a sample of 45 was needed (Walter et al., 1998). Ethical Approval was gained by the Institutional Review Board (IRB), Mahidol University. The informed consent was obtained by each participant before answering the questionnaires.

Translation

The researchers asked for formal permission to translate the CP QOL-Teen into Thai. After that, the cross-cultural translation was translated following the CP QOL translation guideline (Davis E, 2013). The forward translation was carried by two Thai-native speakers. They are fluent in Thai and English and have experiences in test development, questionnaire translation, and have been working in studies related quality of life in children with CP. After forward translation, the reconciliation of items was done by the two forward translators to verify the translated questionnaire. The backward translation was then done by one English-native speaker who is fluent in English and Thai. The reviews of the forward and backward translation were finalized by one forward translator and one member of the research group with good knowledge of both English and Thai. Finally, the cognitive interview was conducted in 7 adolescents with CP in order to know whether all items can be understood and acceptable. Some items of the Thai version of CP QOL-Teen were revised after the cognitive to ensure better comprehension in the questionnaire.

Measure

The CP QOL-Teen (self-report) included 72 items in five domains as follows: (1) General wellbeing and participation (21 items); (2) Communication and physical health (17 items); (3) School wellbeing (8 items); (4) Social wellbeing (7 items); (5) Feelings about functioning (5 items). However, there are only 58 items using for calculating the reliability because 14 items according to the author's guideline had missing values more than 30% which were removed in the testing of psychometric properties(Davis E, 2013). The questionnaire is designed to ask what an adolescent feels in varieties aspects related quality of life. Each question begins with "how do you feel about…?" A 9-point response scale was used in most items, where "1" was meant very unhappy to "9" was meant very happy. The scales of some items concerning your condition and pain were reversed, where "1" was meant not concerned at all, not pain at all, and not upset at all, while "9" was meant very concerned, a lot of pain, and very upset, respectively. The time to complete the questionnaires was approximately 30-60 minutes.

Procedure

The eligible participants were recruited following the inclusion criteria as follows: (1) the adolescents with CP aged 13-18 years, (2) they can communicate using either speech or non-speech method, (3) they have to choose the same answer from the randomly chosen questions of the CP QOL-Teen in 3 out of 5 items when repeating the questions after 15 minutes apart.

For examining test-retest reliability of the CP QOL-Teen questionnaire (self- report), the adolescents were asked to fill the questionnaires two times. If they could not read or fill the questionnaire by themselves, the researcher assisted as needed. The same adolescents with CP were got the questionnaire again for at least 2 weeks apart. For examining internal consistency, the data in the first session were used for data analysis. The response scales in each item were converted into percentage scores based on process of the original manual. The percentage scores for two sessions were used to examine test-retest reliability and internal consistency.

Statistical Analyses

The descriptive statistics to characterize the participants were performed. Intraclass correlation coefficient (ICC 3, k) with type consistency was used to examine test–retest reliability at the domain level. According to ICC (3, k), the former number "3" meant two way- fixed effect model of ICC. In this study, the same questionnaires were rated by the same adolescents within 2 times. The latter letter "k" meant averages rating of items in each domain were used. The ICC was considered acceptable when ICC is equal or greater than 0.60. Cronbach's alpha coefficient was used to determine internal consistency. Cronbach's alpha was considered sufficient when it is equal or more than 0.70.

Results

Demographic information

The demographic data of the participants are shown in Table 1. The participants were 45 adolescents including 28 boys (62.2%), mean age was 15.09, SD 1.38 years (range 13-18 years). The educational levels of the participants were as follows: grade 4 (4.4%), grade 5 (17.8%), grade 6 (8.9%), grade 7 (11.1%), grade 8 (24.4%), and grade 9 (33.3%). Most of the adolescents with CP were spastic diplegic type and in junior high school (grade 7-9). The distribution of the participant across GMFCS as follows: 4 adolescents (8.9%) are in level 1, ten of them (22.2%) are in level 2, ten are in level 3 (22.2%), nineteen (42.2%) are in level 4, and Two (4.4%) are in level 5.

Table 1 demographic characteristics of the adolescents with CP

	N (%)
Adolescents with CP (n=45)	
Ages (years) mean ± SD	15.09 ± 1.38
Gender	
Male	28 (62.2 %)
female	17 (37.8 %)
GMFCS	
I	4 (8.9%)
II	10 (22.2%)
III	10 (22.2%)
IV	19 (42.2%)
V	2 (4.4%)
Type of CP	
Hemiplegia	1 (2.2%)
Diplegia	31 (68.9%)
Triplegia	6 (13.3%)
Quadriplegia	5 (11.1%)
Athetoid	2 (4.4%)

Reliability – internal consistency, test-retest reliability

The Cronbach's alpha coefficients, indexed for internal consistency and the ICC indexed for test-retest reliability are presented in Table 2. The Cronbach's alpha scales ranged from 0.77-0.91, whereas the ICC scales ranged from 0.62-0.84. All domains exceeded the minimum acceptable values for internal consistency (Cronbach's alpha □ 0.60) and test-retest reliability (ICC □ 0.70).

Table 2: Internal consistency and test-retest reliability for the Thai version of the CP QOL-Teen (self-reported)

CP QOL-Teen domains (Numbers of items)	Internal consistency (Cronbach's alpha)	Test-retest reliability (ICC 3, k)
General wellbeing and participation (21 items)	0.917	0.621
Communication and physical health (17 items)	0.874	0.629
School wellbeing (8 items)	0.873	0.718
Social wellbeing (7 items)	0.788	0.651
Feelings about functioning (5 items)	0.774	0.843

Discussion and Conclusions

This study purposed to evaluate the reliability of the Thai version of the CP QOL-Teen (self-report). The results demonstrated good to excellent for test-retest reliability and acceptable to excellent for internal consistency (Portney *et al.*, 2009), which are similar results to those found in the original version (Cronbach's alpha ranged from 0.78-0.95; ICC ranged from 0.57-0.88) (Davis *et al.*, 2013). Thus, the CP QOL-Teen (Thai version) can be considered to be internally consistent and homogeneous instrument. The highest value of test-retest reliability was shown in the domains of feeling about function domain (ICC = 0.843). A possible reason is the questions are asked about the feeling when using their hands, legs and their ability to do daily lives which were the common questions regarding the stable conditions, hardly to change in 14 days.

This study had limitations regarding the predominance of the adolescents with diplegia CP and GMFCS level 2-4 and the distribution of samples from all regions in Thailand. There are few of the adolescents with CP in GMFCS level 5 because the adolescents with more severe CP usually have associated problems such as intellectual deficit. They could not self-report and were excluded from the study. The samples also had a few of the participants in GMFCS level 1; it is possible that the adolescents with CP in level 1 of GMFCS usually study in mainstream schools. In addition, the majority of the adolescent with CP were only recruited from the special schools for children with disability in Central region. It had unequally distributed of samples for measuring reliability to others regions, where imply different local languages and cultures. Therefore, it might be required the participants from a variety of settings in many regions of Thailand. Future study will be conducted to examine the validity in larger samples.

In conclusion, this study confirms that the CP QOL-Teen (Thai version) had adequate reliability and can be used for measuring QOL in adolescent with CP aged 13-18 years in Thailand.

Acknowledgements

I would like to deeply thank all adolescents with CP and their families for their kind participation. Most of all, I sincerely thank Assistant Professor Dr. Saipin Prasertsukdee, my advisor for her precious advices and supports throughout the process of my thesis. This study got a research grant by Faculty of Physical Therapy, Mahidol University.

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