

# Translation with Cross-cultural Adaptation of Cerebral Palsy Quality of Life Questionnaire for Children into Nepali and its Psychometric Properties

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## ABSTRACT

### Background

Cerebral Palsy Quality of Life questionnaire for children primary caregiver version is the widely used condition specific outcome measure which assesses the wellbeing of the child. It has been translated to many languages and shows excellent psychometric properties. Availability in Nepali would facilitate the use in clinical practice and research in Nepali population.

### Objective

The objective of this study was translation with cross-culturally adaption of Cerebral Palsy Quality of Life questionnaire for children primary caregiver version into Nepali and assess its psychometric properties.

### Method

Cross-cultural adaptation was performed using forward and backward translation protocol. Pretesting was done on six participants to confirm that the original concept was preserved. The Nepali version of questionnaire was administered twice for data collection. The feasibility, sensitivity, internal consistency and test-retest reliability was determined.

### Result

Culturally adapted Nepali version showed good feasibility only the domain "Access to service" had a highest missing score related to use of the special equipment, attending kindergarten and applying for respite care. Floor and ceiling effect were < 15% in all the domains except in few items of "Pain and impact of disability" and "Social well being and acceptance". Test retest reliability (0.82 – 0.91) and internal consistency (0.68 – 0.84) was good. There were weak association of domains with the gross motor functional classification system level.

### Conclusion

Cross-culturally adapted Nepali Cerebral Palsy Quality of Life questionnaire for children primary caregiver was developed. It demonstrates good psychometric properties confirming to assess quality of life of children with Cerebral palsy in Nepal.

## KEY WORDS

*Cerebral palsy, Cross-cultural adaptation, Primary care giver, Quality of life questionnaire, Reliability*

## INTRODUCTION

Cerebral Palsy (CP) is the leading cause of chronic disability in children.<sup>1</sup> It is a group of permanent disorders of development of movement and posture, accompanied by disturbance of sensation, perception, cognition, communication and secondary musculoskeletal problems attributed to non-progressive disturbance that occurred in the developing brain.<sup>2</sup> Globally, the prevalence of CP has been estimated 2 per 1000 live births.<sup>3</sup> However, evidence indicates a substantial high burden of CP in low and middle-income countries.<sup>4-7</sup> CP increases activity limitation and participation restriction due to the impairments leading to reduced quality of life (QOL).<sup>8-11</sup> The Cerebral Palsy Quality of Life questionnaire for children CPQOL-Child is a condition specific QOL questionnaire designed to assess the well-being rather than ill being for children. The CPQOL-Child is the only measure which wholly fulfills the definition criteria of QOL.<sup>12</sup>

This tool has been widely used as an outcome measure in participants, because a) it is based on International classification of function b) developed by international expertise c) recognizes the importance of obtaining the view of primary caregivers and d) it has been cross-culturally adapted and has excellent psychometric properties in many languages.<sup>13-20</sup>

Despite the importance of assessing condition specific QOL in children with CP in Nepal. There is not any evidence to our knowledge that CPQOL-Child has been cross-culturally adapted into Nepali language.

Therefore, the aim of this study was translation, cross-culturally adaptation of the CPQOL-Child primary caregiver questionnaire into Nepali version and to determine the psychometric properties of Nepali version.

## METHODS

The translation with cross cultural adaptation and its psychometric properties were undertaken at Dhulikhel hospital and during the camp organized by Department of Physiotherapy, Dhulikhel hospital from March 01 – July 30, 2019. The conduct and reporting of this research were based on cerebral palsy quality of life questionnaire translation guideline.<sup>21</sup> Approval from institutional review committee (IRC), Kathmandu University School of Medical Sciences (KUSMS) was obtained to conduct the study. Informed written consent was obtained from all the participants prior to data collection.

### Participants

To be eligible to participate in the study, participants were required to be: a) Primary caregivers of Nepalese children diagnosed with CP aged 4 - 12 years b) a citizen of Nepal c) able to understand and speak Nepali fluently d) caregiver who have completed primary school education and d) willing to participate. Exclusion criteria included: a) Children

diagnosed with other neurodegenerative condition b) medically and surgically unstable children with CP.

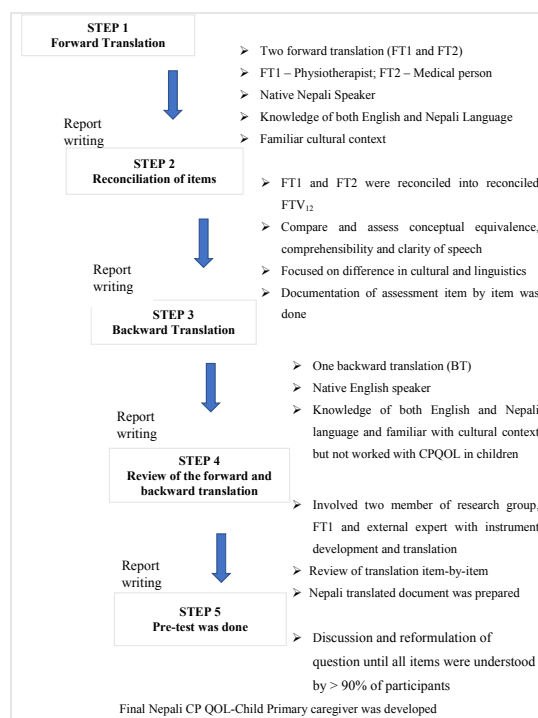
The study was conducted in two Stage: Section I – the translation and cross-cultural adaptation of CPQOL-Child primary caregiver version into Nepali version, including the pre-testing of the translated Nepali version; and Section II – determining the psychometric properties of Nepali CPQOL-Child primary caregiver questionnaire.

### Measure

The CPQOL - Child Primary caregiver questionnaire measures seven areas of child's life: 'social wellbeing and acceptance' (12 items), 'Feeling about Functioning' (12 items), 'Participation and physical health' (11 items), 'Emotional wellbeing' (6 items), 'Access to services' (12 items), 'Pain and impact of disability' (8 items) and 'Family health'(4 items). Participants are asked to rate their feelings on nine-point Likert scale from 1, 'very unhappy' to 9, 'very happy' by thinking about how they feel, rather than about what they can do. One item from the domain of pain and impact of disability is rated on five-point scale. Each question commences with the phrasing 'how do think your child feels about...?'

### Section I: Translation and cross-cultural adaptation of CPQOL-Child into Nepali language

We obtained written consent from the original developer of CPQOL-Child to translate and cross-culturally adapt the tool into Nepali. The translation and cross-cultural adaptation process were conducted using "Translation guideline by CPQOL-Child".<sup>17</sup> The steps are briefly described in figure 1.



**Figure 1.** Steps of Translation and Cross-cultural adaptation of the questionnaire

\*CPQOL-Child: Cerebral Palsy Quality of Life questionnaire for Children

**Steps I: Forward translation**

Two native Nepali speakers, FT1 and FT2 (Forward Translators) familiar with the culture of both English-speaking countries and Nepal having experience in the research field concerning quality of life carried out independent translation from original English version to Nepali, resulting in 2 versions: FTV1 and FTV2.

**Steps II: Reconciliation of items**

The forward translators (FT1 and FT2) and researchers organized a reconciliation meeting. The forward translations were compared and assessed in term of their conceptual equivalence, comprehensibility and clarity of speech relative to the English version. The assessments were documented item by item focusing differences in cultural and linguistics. The reconciled forward translation FTV12 was produced. A detailed report of the process has been prepared.

**Steps III: Back translation**

A native English speaker BT1 (Back Translator) who was unaware of the purpose of the translation and was blinded to original English version of CPQOL-Child primary caregiver questionnaire back translated the FTV12 into the Nepali version resulting in BTV. The purpose of the back translation was to make sure that the translated version is reflecting the same items as the original version which expresses the face validity of the tool.

**Steps IV: Review of the forward and backward translation**

The back translated version was reviewed by two authors of this research, FT1 and external expert in translation of tool. An important change was made in the domain of "social well-being and acceptance" during the expert committee meeting. The translation of "preschool" did not convey the original meaning in the Nepali context. The expert committee proposed of two alternatives that were "kindergarten" and "primary school". Discussion were undertaken to resolve discrepancies in the translations that did not reflect the original English version. This was to ascertain the attained translation was comprehensible and in accordance with the cultural context of Nepal and the original CPQOL-Child English version. A final Nepali version (FNV) was approved after significant modification on the measures.

**Steps V: Pre-testing (cognitive interview)**

The FNV of Nepali CPQOL-Child primary caregiver questionnaire was then pre-tested on six caregivers of children diagnosed with CP with different level of function capacity. During the pre-testing, test was administered using face-to-face interview to complete the Nepali version. The participants were asked what they thought the question was asking, to repeat the question in their own words, what came to their mind when they heard a particular phrase or term and to explain how they choose their

answer using a Likert scale. Participants were also given the choice between "kindergarten" and "primary school", they preferred culturally adapted phase of "kindergarten". Therefore, the Nepali translation of "preschool" was discarded and translation of "kindergarten" was retained. Questions were discussed and reformulated until all items were understood by > 90% of participants. The response on all the items were further discussed in the expert committee meeting and the final Nepali version of CPQOL-Child Primary caregiver questionnaire was finalised.

**Section II: Psychometric testing procedure of Nepali CPQOL - Child primary caregiver**

Data were collected at two points of time from the primary caregivers; an initial assessment was performed and re-administration of the same questionnaire was done after two weeks. Primary caregiver was considered as those who knew the most about the child. To minimize loss of re-administration of the questionnaire and facilitate follow up among the community participants, researchers visited individuals at a time convenient to them. Researcher individually readout the instruction on the first page of the questionnaire and assured all the caregiver understood the questionnaire.

The data were manually entered into Statistical Package for Social Sciences (SPSS) 24 version and checked for accuracy of data entry. Sociodemographic variables including age, sex, education level and occupation were reported using descriptive statistics. The voluntary movement of children with CP, with specialized focus on walking and sitting was assessed using Gross Motor Functional Classification System (GMFCS) which is a five-level classification system.<sup>22,23</sup> CPQOL-Child scores were converted to values between 0 and 100, the domain score (average) were used for all subsequent analysis. The higher score indicated happier status or better quality of life expect for the domain 'Pain and impact of disability' were score is in reversed order.

Feasibility was assessed as the proportion of missing values and was analyzed by case-wise deletion. Instrument sensitivity was assessed using floor and ceiling effects, defined as the proportion of participants reporting the lowest and highest scores for each instrument dimension. Floor or ceiling effects > 15% were considered as high indicating that the instrument is not sensitive in the target population.<sup>24</sup>

Internal consistency was estimated using Cronbach's alpha. Test-retest reliability was evaluated by using Intraclass correlation coefficient (ICC). ICC values closer to 1.0 indicates higher test-retest reliability.<sup>25</sup> A p value of < 0.05 was considered significant.

The association of domain scores with other relevant information including child age, primary caregivers age and GMFCS was examined by calculating the Spearman's correlation coefficients.

## RESULTS

The total of 56 primary caregivers visited Dhulikhel hospital and during the camp organized by Department of Physiotherapy, Dhulikhel Hospital. Out of which 32 completed the Nepali CPQOL-Child questionnaire based on the inclusion criteria. Children were aged 4 to 12 years with mean age 8.53 years and was distribution across different level of GMFCS. Majority of participants were primary caregiver of male child diagnosed with CP. Primary caregivers mean age was 33.4 years and majority had completed a primary school level of education. The detail clinical and demographic information of the participants are presented in Table 1.

**Table 1. Demographic characteristics of the participants**

	Variables	Mean / N (%)
Children with CP	Age in years	8.53(2.9)
	Range in years	4 – 12
	Male	20(62.5)
	Female	12(37.5)
	GMFCS Level I	4(12.5)
	GMFCS Level II	7(21.9)
	GMFCS Level III	7(21.9)
	GMFCS Level IV	1 (34.4)
	GMFCS Level V	1(3.1)
	Primary Caregiver of children with CP	Age in years
Male		2(6.3)
Female		30(93.8)
Educational status		
Primary School		10(31.3)
Secondary School		8(25)
Higher secondary		8(25)
University		5(15.6)
Master		1(3.1)
Occupation		
Housewife	23(71.88)	
Government officers	1(3.13)	
Business	8(25)	

\*CP: Cerebral Palsy, GMFCS: Gross Motor Functional Classification System, SD: Standard Deviation

The mean score and standard deviation (SD) for each domain of CPQOL-Child primary caregiver questionnaire are present in Table 2. The highest domain mean score was 78.8 which was found in the domain of “social well-being and acceptance” and the lowest score of 23.16 was found in the domain of “family health”. All the participants (100%) completed the follow up assessment. The initial assessment and the reassessment for all the participants were performed at an average interval of 14.5 days while the duration ranged from 14 days to 16 days.

### Feasibility

There was no missing data in two domains “emotional

**Table 2. Descriptive statistics of Nepali CPQOL-Child primary caregiver domain scores**

Domain of CPQOL-Child Primary Caregiver (N=32)	Items	Mean ± SD	Missing Value n (%)
Social wellbeing and acceptance	12	78.83±(12.19)	9(28)
Feeling about Functioning	12	68.19±(11.28)	5(15)
Participation and physical health	11	63.89±(10.46)	5(15)
Emotional wellbeing	6	33.84±(5.32)	0(0)
Access to services	12	66.00±(6.32)	27(84)
Pain and impact of disability	8	37.15±(9.06)	5(15)
Family health	4	23.16±(5.44)	0(0)

\*CP QOL-Child: Cerebral Palsy Quality of Life questionnaire for Children

wellbeing” and “family health”. Different domain had a different missing value with the highest missing value in the domain “Access to service” as presented in Table 2. However, in domain ‘access to services’ few items had a missing value > 50%. The missing values related to the items were about used of special equipment, going to kindergarten or school and respite care. The CPQOL-Child is designed for children across all levels of impairment and it is problematic to include items that are not appropriate for almost 50% of sample. Given that such a large proportion of primary caregivers did not complete items, they were deleted.<sup>15</sup>

On the CPQOL-Child Primary Caregiver questionnaire, the last item asked about, “How confident are you that you can report how your child feels?” using a 1-9 point Likert scale ranging from “not at all confident” to “very confident”. A total of 68.75% reported “Very confident”, 31.25% reported confident and no one reported “not at all confident”.

### Sensitivity

Floor and ceiling effects have been considered significant at < 15%. There was no domain specific floor and ceiling effect conforming good content validity. Considering the individual items in the domain “social well-being and acceptance” and “participation and physical health” showed ceiling effect up to 34%. Floor effect was seen in the individual items of domain “Pain and impact of disability” and the value was till 28%.

### Internal consistency

The Nepali version CPQOL-Child Primary Caregiver showed good internal consistency of the Cronbach’s alpha ranged from 0.58 to 0.84, which is presented in Table 3.

### Test-retest reliability

The test-retest reliability was reassessed at two weeks interval, Intraclass correlation coefficient (ICC) ranged from 0.82 - 0.91, which indicated good to excellent reliability.

**Table 3. Results of Internal consistency, Test re-test reliability and Standard error of measurement of the Nepali CPQOL-Child Primary caregiver version**

Domain of CPQOL-Child Primary Caregiver (n=32)	Cronbach's alpha	ICC	SEM
Social wellbeing and acceptance	0.84	0.91	2.54
Feeling about Functioning	0.76	0.88	6.14
Participation and physical health	0.68	0.89	5.36
Emotional wellbeing	0.73	0.84	3.86
Access to services	0.75	0.90	2.82
Pain and impact of disability	0.58	0.82	5.89
Family health	0.71	0.90	2.37

\*ICC: Intraclass correlation coefficient, CI: Confidence Interval, SEM: Standard Error of Measurement

The standard error of measurement (SEM) was 2.37 - 6.14 as presented in Table 3

Correlation of the domain scores with the primary caregiver age, child age and GMFCS severity of motor disability showed a weak correlation.

## DISCUSSION

This study has translated CPQOL-Child, Primary caregiver questionnaire to Nepali version with a cross cultural adaptation and it demonstrated overall good psychometric properties for its application in Nepalese population.

### Translation and cross-cultural adaptation

The cross-cultural adaptation was done fully based on "Translation guideline by CPQOL-Child". The guideline included multistage forward and back translation with pre-testing step. During the pre-testing step participants were interviewed and asked to grade on Likert scale about their understanding level of all the questions. The expert committee then produced a Nepali CPQOL-Child primary caregiver version through their critical decision ensuring that the original concept of the tool was retained. Detailed written report has been prepared on each step including differences found and the ways they were solved by bringing consensus.

A majority of the primary caregiver stated that they were very confident on reporting how their child felt which is the strong point of the present study that the CPQOL-Child Nepali version is understandable and easy to respond for caregiver of Nepali child.

### Psychometric Properties of Nepali CPQOL-Child Primary caregiver version

As per the original article from Australia, the CPQOL-Child is designed for children across all levels of impairment and it is problematic to include items that are not appropriate for almost 50% of sample.<sup>15</sup> Given that such a large proportion of primary caregivers did not complete items,

they were deleted.<sup>15</sup> Similarly in our study, items in the domain of 'access to service' had a missing score of > 50% and the specific items were deleted. Our sample had limited availability and use of special equipment, attending kindergarten and they had never tried to access respite care.

Considering the domain, the Nepali version reported no ceiling or floor effects which indicated good content validity. There is no floor or ceiling effect established of the original or other translated version of CPQOL-Child.<sup>12,15</sup> Ceiling effect was noted in the item of the domain "social well-being and acceptance" and "participation and physical health" and the Floor effect was seen in the items of domain "Pain and impact of disability". This could be due to the questionnaire measurement system higher score indicated greater wellbeing whereas the domain "pain and impact of disability" is in reverse order high score indicated increase in pain level.

For the internal consistency, Cronbach's alpha in the Australian CPQOL-Child was 0.74 - 0.92, Chinese version was 0.78 - 0.91 and Persian version was 0.61 - 0.87 for primary caregiver version.<sup>15-17</sup> Cronbach's alpha of the Nepali version was 0.58 - 0.84 which indicates good internal consistency of the Nepali version of the CPQOL-Child primary caregiver version. The domain "Pain and impact of disability" has the lowest Cronbach's alpha value which is consistent to the study conducted in Australian, Chinese and Persian version with a larger sample size.

For the test-retest reliability, ICCs ranged from 0.76 to 0.89 in the Australian, 0.47 to 0.84 for the Persian, 0.88 to 0.97 in Turkish and 0.86 to 0.97 Chinese version.<sup>15-17,20</sup> Our study showed ICCs ranged from 0.82 - 0.91 for the primary caregiver version. Compared to other version, the Nepali version shows similar ICCs which indicates items of the Nepali version of CPQOL-Child primary caregiver have minimal difference in the answer between two-week interval and it has an acceptable ability to reflect differences in the well-being status.

Association of domain score of CPQOL-Child primary caregiver version with primary caregiver age, child age and GMFCS were analysed. We took this approach, as there is no tool specific to QOL in CP that has been translated into Nepali language to our knowledge. We hypothesized higher QOL would be associated with less severe motor disability in children with CP. Our study showed weak correlation with primary caregiver age, child age and GMFCS. Similar to our study, studies conducted in Turkish, Chinese and Persian version showed no correlation of domain score with primary caregivers age and children age. The studies conducted in different countries showed the CPQOL-Child primary caregiver version were mild to moderate correlated with GMFCS levels in the domains, social well-being, functioning, participation and emotional well-being.<sup>16,17,20</sup>

The result of the current study is supported by good methodology, demonstrated by no loss of follow up. However, the major limitation is that the number of samples was less. The children were required to be 4-12 year and diagnosed case of CP and primary caregiver who have completed primary school education could fill the questionnaire, our sample site had limited number of children diagnosed with CP and most of the caregiver were uneducated. Another limitation was lack of heterogeneity of the sample between different geographical regions and prevalence of children with level IV of GMFCS level were predominate. A larger subset of sample size with heterogeneity in the sample would have strengthened this study. Therefore, Administration of CPQOL-Child primary caregiver amongst child with CP in other geographical regions of Nepal with larger sample size is recommended for further testing.

The responsiveness of the instrument is needed to be examined in further studies employing a prospective design. Additionally, we did not validate the CPQOL-

Child primary caregivers' version against other QOL measure because Nepal does not have a valid Child QOL questionnaire. Keeping these in mind the Nepali CPQOL-Child primary caregivers' version might be the valuable tool to measure the QOL in children with CP. Establishing other psychometric properties is an ongoing process and further research is required.

## CONCLUSION

The Nepali version of Cerebral palsy quality of life questionnaire is developed. Retaining its equivalence with the original version we found the questionnaire to be reliable in Nepalese cultural background and context. We believe that this Nepali CPQOL-Child primary caregiver version will be useful in clinical practice and research to assess the QOL of children with CP in Nepalese population.

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