

Reliability and Validity of the Cerebral Palsy Quality of Life Questionnaire in the South Korean Population

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Objective: This study examined the reliability and validity of the Korean version of the Cerebral Palsy Quality of Life (CP QOL) questionnaire.

Background: Quality of life (QoL) for the children with cerebral palsy (CP) is also essential aspect of the functioning. However, few QoL assessment tools specific to CP are available in South Korea.

Method: The English version of the Cerebral Palsy Quality of Life (CP-QOL) parent proxy form and the CP-child self-report form was translated into Korean. This study was to verify the reliability and validity of the two Korean versions of the CP-QOL documents. A total of 153 primary caregivers and 61 CP children answered the Korean questionnaires in two sessions two weeks apart. The reliability and validity were analyzed using the intra-class correlation coefficient (ICC), Cronbach's α , and ANOVA.

Results: Cronbach's α ranged from 0.80 to 0.92 for the Korean version of the CP-QOL (K-CP-QOL) parent proxy form and from 0.84 to 0.96 for the child self-report form. All ICCs were above 0.75 except for emotional well-being and pain for the parent proxy form. For the K-CP-QOL child self-report form, all ICCs were 0.75 except for pain. There were significant differences in the feeling about function, emotional well-being, pain, and participation by the CP functional severity.

Conclusion: The K-CP-QOL parent proxy and child self-report forms appear to be valid to use for Korean CP children and their parents.

Application: Korean version of the CP-QoL could be used for both of clinical and research purposes.

Keywords: Cerebral palsy; Children; Reliability; Assessment; Quality of life

1. Introduction

Cerebral Palsy (CP) is one of the most common childhood disorders, affecting about 2.5 out of every 1,000 new born babies. CP is caused by a non-progressive brain lesion during a baby's early developmental period (Oskoui et al., 2013). Preterm delivery (59.5%) and low birth weight (60.3%) were also the main causes of CP children in Korea (Yim et al., 2017). This non-progressive brain lesion can generate a permanent abnormal posture and movement disorder, including problems with sensation, perception, cognition, and communication (Rosenbaum et al., 2007a). Understanding the levels of the disability is critical for guiding intervention policies.

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(Global Burden of Disease Pediatrics et al., 2016). Because of those conditions, the quality of life of CP children is much affected by their limited ability to participate in normal activities (Rosenbaum et al., 2007b). For those reasons, it is important to assess the quality of life of CP children as well as their motor functions when their clinical outcomes are evaluated (Bjornson and McLaughlin, 2001; Viehweger et al., 2008). The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Illum and Gradel, 2017; 1993).

There are two measurement tools to evaluate the quality of life for children: a generic measure and a condition-specific measure (Baars et al., 2005; Mueller-Godeffroy et al., 2016). The generic measurement tool is used to evaluate the quality of life of children whether or not they have a disease. It is, however, not an efficient tool to evaluate the intervention effect on children with specific conditions because the generic tool does not have the ability to evaluate a specific condition or a certain disability. The condition-specific tool, in contrast, is good for evaluating the difference before and after an intervention. It is also effective for evaluating small status changes of a patient over time (Bjornson and McLaughlin, 2001; Sakzewski et al., 2012).

A CP-specific measurement tool covers many aspects, including physical health, body pain and discomfort, daily living tasks, participation in regular physical and social activities, emotional well-being and self-esteem, interaction with the community, communication, family health, supportive physical environment, access to services, financial stability, and social well-being (Waters et al., 2005). The generic tool could not analyze those areas in detail and it reveals only the factors affecting the quality of life for the CP children (Waters et al., 2005).

The Pediatric Quality of Life Inventory (PedsQL) CP Module and the DISABKIDS CP Module were designed as condition-specific tools to measure the quality of life for CP children (Varni et al., 2006). However, they also began to show limitations in measuring quality of life in detail because they could not measure the feeling of the life with CP and they focus much on the caregivers. In the meantime, the Cerebral Palsy-Quality of Life (CP-QOL) questionnaire, a condition-specific quality of life assessment tool, was developed by a team of clinicians, scientists, parents/foster parents of CP children as well as children with mild to severe CP who communicated well. The CP-QOL provides two different forms: the primary caregiver proxy form and the child self-report form. The two forms have shown high validity and reliability (Waters et al., 2005).

Outcome measure research on CP children is also increasing in Korea. However, it is not easy to find a reliable quality of life assessment tool for the Korean CP children except one study on the path analysis of strength, spasticity, gross motor function and health-related QOL (Park, 2018). The original English version of the CP-QOL questionnaire has been translated and validated into several languages, including Turkish, Chinese, Brazilian, Portuguese, and Hindi (Wang et al., 2010; Braccialli et al., 2016; Das et al., 2017; Atasavun Uysal et al., 2016).

In this study, we translated and validated the original English version of the CP-QOL parent proxy form and the child self-report form into Korean. Specifically, the purposes of this study were to investigate the reliability of the Korean versions of the CP-QOL (K-CP-QOL) forms and to examine the construct validity by the CP severity and gender. It would be also a good example study for researchers studying the quality of life of the Korean seniors regarding their physical health, body pain and discomfort, daily living tasks and so on using a questionnaire to measure physical and social activities, emotional well-being and self-esteem.

2. Methods

2.1 Participants

We gathered data from five different rehabilitation centers in South Korea. Informed consent forms were obtained from the parents.

There were two inclusion criteria: 1) CP children aged 9~12 who could understand and answer questionnaire questions or could otherwise self-report, and 2) parents with 4~12 year-old CP children who could complete the questionnaire. The exclusion criterion was CP children who might have been infected by the Botulinum Toxin, including an injection or any surgical surgery in 6 months before the study. A total of 61 children with cerebral palsy participated in the study (boys=39, girls=22, and average age=9.6±1.6 years) for the child's self-report. CP types were spastic (n=54), dyskinesia (n=3), and ataxia (n=4). A total of 153 parents participated in the study who had a CP child (boys=98, girls=55, and average age=7.1±2.4 years) for the parent proxy. Mainly the mothers (n=149, 97.4%, average age=38.6±2.0 years) completed the questionnaires. CP types of the children were spastic (n=54), dyskinesia (n=3), and ataxia (n=4).

2.2 Cerebral Palsy-Quality of Life (CP-QOL) questionnaire

The CP-QOL questionnaires consisted of Cerebral Palsy-Quality of Life parent proxy (CP-QOL parent proxy) and Cerebral Palsy-Quality of Life child self-report (CP-QOL child self-report). The CP-QOL parent proxy had 66 questions for parents with CP children aged 4~12. CP-QOL child self-report had 52 questions for CP children aged 9~12 and it was for a direct report from the CP child. The CP-QOL parent proxy had questions to evaluate 7 domains: social well-being and acceptance, participation and physical health, functioning, emotional well-being, access to services, pain and impact of disability, and family health. The CP-QOL child self-report had the same domains except for access to services and pain and impact of disability. From 1 to 9 points was given to all questions except the 47th question (domain for pain and impact of disability); from 1 to 5 points was given to this question. These original scores were transformed to scaled score 0~100 points during the post process according to the manual; Questionnaire has both of positive and negative questions and therefore it needs the post process.

Higher scores indicate a better quality of life (Waters et al., 2007). Parents completed the CP-QOL parent proxy form and the CP-child completed the CP-QOL child self-report form. CP children were allowed to be assisted by a researcher or parents if they needed assistance with reading the questions or answering the questions. The CP-QOL questionnaire was completed either by face to face interviews or through the mail (Waters et al., 2007).

2.3 Functioning evaluation

For the essential features of the children, irrespective of having a motor disability, functional mobility and functional communication ability of the CP children were examined with the Gross Motor Function Classification System (GMFCS) and the communication function classification system (CFCS).

The GMFCS-E & R is a classification method to differentiate the independence ability of CP children for their mobility from level I (walks without limitations) to the level V (transported in a manual wheelchair) (Palisano et al., 1997), which is a classification method used worldwide for CP children based on self-initiated movements such as sitting, transfers, and mobility (Begnoche et al., 2016). In this study, we used K-GMFCS-E & R written in Korean (Ko et al., 2011). In summary, according to the K-GMFCS, 13 (21%) children were level I, 26 (43%) level II, 10 (16%) level III, 8 (13%) level IV, and 4 (7%) level V for the child self-report. In addition, 23 (15%) children were level I, 39 (25%) level II, 25 (16%) level III, 42 (27%) level IV, and 24 (16%) level V for the parent proxy report.

The CFCS was developed in 2011 to evaluate the communication ability of CP children (Hidecker et al., 2011). The CFCS has five levels according to the ability of communication: from effective sender and receiver with unfamiliar and familiar partners (level 1) to seldom effective sender and receiver with familiar partners (level 5).

2.4 Questionnaire on demographic variables

Parents completed a questionnaire providing information about their employment, educational level, marital status, number of siblings, address, their child's school grade, and which school they attended.

2.5 Translation and adaptation

We translated the English versions of the CP-QOL parent proxy form and the CP-QOL child self-report form into Korean. A forward translation, item reconciliation, backward translation, review of forward and backward translation, and pre-test cognitive interview were made sequentially with the permission of the original authors.

2.6 Statistical analysis for validation and reliability

To determine the reliability and validity of the CP-QOL parent proxy form and the CP-QOL child self-report form translated into Korean, parents and CP children answered the questionnaire twice with a two-week interval. Two research assistants helped them complete the questionnaires. A descriptive statistical analysis including average and standard deviations was made for continuous parameters. Frequency was analyzed for nominal parameters. Internal consistency was tested using Cronbach's α test. Test-retest reliability was determined using intra-class correlation coefficient (ICC) analysis. The ICC is generally considered excellent when the $ICC \geq 0.75$; satisfactory when the $0.4 \leq ICC < 0.75$ and weak when the $ICC < 0.4$ (Hulley et al., 2013). The construct validity was evaluated using a t -test and a post hoc test in ANOVA for gender difference and GMFCS levels. Data were analyzed using SPSS version 18.0. A significance level of $p < 0.05$ was used.

3. Results

The general characteristics of the participants are listed in Table 1. The mean scores and standard deviations (SD) for each domain at baseline and follow-up (two weeks later from baseline) are presented in Table 2. From the K-CP-QOL parent proxy form, the highest domain score was 68.6, which was found in the domain of emotional well-being. From the K-CP-QOL child self-report form, the highest domain score 70.4, which was in the emotional well-being range. The lowest score was found in the domain of

Table 1. Characteristics of the participants

	CP-QOL parent proxy (N=153)	CP-QOL child self-report (N=61)
Children's age (years)	7.1 \pm 2.4	9.6 \pm 0.6
Sex		
Boys	98 (64.1)	39 (63.9)
Girls	55 (35.9)	22 (36.1)
GMFCS		
I	23 (15.0)	13 (21.3)
II	39 (25.5)	26 (42.6)
III	25 (16.3)	10 (16.4)
IV	42 (27.5)	8 (13.1)
V	24 (15.7)	4 (6.6)

Table 1. Characteristics of the participants (Continued)

	CP-QOL parent proxy (N=153)	CP-QOL child self-report (N=61)
CFCS		
I	70 (45.8)	48 (78.7)
II	29 (19.0)	12 (19.7)
III	29 (19.0)	1 (1.6)
IV	12 (7.8)	-
V	13 (8.4)	-
CP types		
Spastic	125 (81.7)	54 (88.5)
Dyskinesia	13 (8.5)	3 (4.9)
Hypotonia	8 (5.2)	4 (6.6)
Ataxia	4 (2.6)	-
Mixed	3 (2.0)	-
Visual impairment		
Yes	26 (17.0)	2 (3.3)
No	127 (83.0)	59 (96.7)
School grade		
Preschooler	92 (60.1)	3 (4.9)
Elementary 1	18 (11.8)	8 (13.1)
Elementary 2	13 (8.5)	6 (9.8)
Elementary 3	11 (7.2)	10 (16.4)
Elementary 4	9 (5.9)	12 (19.7)
Elementary 5	5 (3.3)	12 (19.7)
Elementary 6	5 (3.3)	10 (16.4)
Type of schooling		
Kindergarten	90 (58.8)	3 (4.9)
Special education school	21 (13.7)	16 (26.2)
Mainstream school	24 (15.7)	35 (57.4)
Special class in mainstream school	13 (8.5)	7 (11.5)
Home schooling	5 (3.3)	-
Mother's age (years)	38.6 ± 4.0	
Father's age (years)	38.7 ± 1.2	
Address		
Rural	47 (30.7)	
City	106 (69.3)	

Table 1. Characteristics of the participants (Continued)

	CP-QOL parent proxy (N=153)	CP-QOL child self-report (N=61)
Mother's education levels		
High school	63 (41.2)	
Junior college	28 (18.3)	
Higher than university	62 (40.5)	
Father's education levels		
High school	51 (33.3)	
Junior college	21 (13.7)	
Higher than university	81 (52.9)	
Marital status		
Married	149 (97.4)	
Divorced	4 (2.6)	
Father's job		
Yes	146 (95.4)	
No	7 (4.6)	
Mother's job		
Yes	17 (11.1)	
No	136 (88.9)	
Siblings		
None	25 (16.3)	
More than one	128 (83.7)	
Respondent		
Mother	149 (97.4)	
Father	4 (2.6)	

Values are presented as mean (SD) for the children's age, mother's age, and father's age

The other values are presented as n (%)

CP-QOL, cerebral palsy-quality of life; GMFCS, gross motor function classification system; CFCS, communication function classification system

Table 2. Descriptive statistics of CP-QOL at baseline and follow-up

	Baseline		Follow-up	
	Mean (SD)	Min-Max	Mean (SD)	Min-Max
CP-QOL parent proxy				
Social well-being and acceptance	66.2 (9.9)	38.8~91.6	64.8 (9.9)	38.9~92.7
Feelings about functioning	57.9 (13.1)	13.5~86.5	55.5 (14.3)	10.4~97.9
Participation and physical health	57.6 (13.1)	14.8~87.5	55.5 (13.8)	18.1~89.8

Table 2. Descriptive statistics of CP-QOL at baseline and follow-up (Continued)

	Baseline		Follow-up	
	Mean (SD)	Min-Max	Mean (SD)	Min-Max
CP-QOL parent proxy				
Emotional well-being	68.6 (11.5)	35.4~97.9	63.4 (12.9)	27.1~100
Access to services	56.2 (14.4)	13.5~89.6	55.7 (15.9)	13.5~93.5
Pain and feeling about disability	52.3 (13.4)	12.5~88.6	51.8 (14.5)	0~88.6
Family health	55.3 (15.8)	18.8~93.8	54.9 (16.6)	21.9~93.8
CP-QOL child self-report				
Social well-being and acceptance	64.0 (14.1)	28.1~100.0	66.4 (14.1)	33.3~100.0
Feelings about functioning	63.6 (12.2)	33.3~91.7	66.1 (13.5)	31.3~94.8
Participation and physical health	65.0 (14.8)	26.1~95.5	66.5 (14.2)	27.3~97.7
Emotional well-being	68.8 (17.3)	31.3~100.0	70.4 (15.7)	37.5~100.0
Pain and feeling about disability	51.1(13.6)	22.8~77.7	50.3 (14.0)	19.7~90.6

Values are presented as mean (SD)
 CP-QOL, cerebral palsy-quality of life

Table 3. Internal consistency and test-retest reliability for the CP-QOL

CP-QOL	Internal consistency		Test-retest reliability			
	Parent proxy	Child self-report	Parent proxy		Child self-report	
	Cronbach's α	Cronbach's α	ICC	95% CI	ICC	95% CI
SWB	0.87	0.96	0.76	0.69~0.82	0.93	0.88~0.96
FUN	0.90	0.94	0.82	0.76~0.87	0.88	0.81~0.93
PART	0.90	0.91	0.82	0.76~0.87	0.83	0.73~0.89
EWB	0.85	0.90	0.73	0.65~0.80	0.83	0.72~0.89
ACCESS	0.90	-	0.82	0.76~0.87	-	-
PAIN	0.80	0.84	0.67	0.57~0.75	0.72	0.57~0.82
FAMILY	0.92	-	0.85	0.81~0.89	-	-

CP-QOL, cerebral palsy-quality of life; SWB, social well-being and acceptance; FUN, feelings about functioning; PART, participation and physical health; EWB, emotional well-being; ACCESS, access to services; PAIN, pain and feeling about disability; FAMILY, family health

pain and feeling about disability for both the parent proxy (52.3) and child self-report forms (51.1). The results from the baseline and follow-up showed almost the same results.

To examine reliability for the K-CP-QOL, internal consistency and test-retest reliability were obtained. Cronbach's α ranged from 0.80 to 0.92 for the parent proxy form and from 0.84 to 0.96 for the child self-report form (Table 3), which indicates good to excellent internal consistency. All ICCs were above 0.75 except for the emotional well-being (ICC=0.73) and pain and feeling about

disability (ICC=0.67) for the K-CP-QOL parent proxy form. For the child self-report, all ICCs were 0.75 except for the pain and feeling about disability (ICC=0.72).

To investigate the construct validity for the K-CP-QOL, the mean and SD by the GMFCS levels and sex were obtained. For the parent proxy version, statistically significant differences were found between the child's functional level and in areas such as feelings about functioning ($p=0.034$), emotional well-being ($p=0.015$), and pain and feeling about disability ($p=0.037$) (Table 4). For child-report version, a significant difference was found between participation and physical health ($p=0.039$). There was no statistically significant gender difference between girls and boys in either questionnaire (Table 4).

Table 4. Mean and SD by the GMFCS levels and sex of child for CP-QOL

CP-QOL	Level of GMFCS						Sex		
	I (n=23) Mean (SD)	II (n=39) Mean (SD)	III (n=25) Mean (SD)	IV (n=42) Mean (SD)	V (n=24) Mean (SD)	p	Boy Mean (SD)	Girl Mean (SD)	p
Parent proxy									
SWB	62.0 (11.6)	67.6 (8.3)	66.2 (9.0)	66.5 (10.0)	66.9 (10.6)	0.276	65.9 (8.64)	66.5 (11.7)	0.71
FUN*	51.6 (16.5)	58.1 (12.2)	56.7 (9.7)	58.2 (14.5)	63.7 (8.5)	0.034	57.6 (12.7)	58.1 (13.8)	0.81
PART	52.3 (14.6)	57.3 (11.0)	56.8 (9.7)	58.5 (14.6)	62.4 (13.4)	0.114	57.7 (12.2)	57.5 (14.4)	0.95
EWB*	61.7 (13.2)	70.6 (8.9)	67.7 (10.3)	68.7 (12.5)	72.3 (10.9)	0.015	68.2 (11.2)	69.2 (12.1)	0.60
ACCESS	53.2 (16.3)	57.2 (13.4)	56.3 (14.1)	55.8 (15.3)	57.6 (13.5)	0.845	56.1 (13.3)	56.3 (16.3)	0.95
PAIN*	48.6 (12.9)	54.7 (9.9)	54.3 (14.6)	48.2 (12.7)	56.7 (16.4)	0.037	52.6 (13.9)	51.6 (12.3)	0.65
FAMILY	48.5 (12.6)	59.6 (15.0)	51.5 (19.9)	57.2 (13.9)	55.4 (16.0)	0.052	54.3 (14.6)	57.1 (17.5)	0.31
Child self-report									
SEB	65.2 (16.5)	62.4 (10.6)	66.9 (16.4)	66.4 (15.5)	58.5 (21.7)	0.811	63.2 (14.3)	65.5 (14.0)	0.54
FUN	66.9 (15.4)	62.9 (10.1)	66.3 (10.6)	64.1 (12.2)	49.7 (11.3)	0.148	63.7 (10.7)	63.3 (14.7)	0.91
PART*	73.5 (16.2)	64.0 (13.0)	66.8 (14.2)	59.8 (11.6)	49.7 (17.5)	0.039	64.8 (14.4)	65.3 (15.8)	0.89
EWB	74.6 (15.7)	66.9 (17.9)	75 (12.9)	65.6 (19.6)	53.1 (17.1)	0.157	67.6 (17.4)	70.9 (17.4)	0.48
PAIN	53.3 (12.2)	47.4 (13.6)	54.0 (10.6)	55.2 (15.3)	51.9 (22.4)	0.505	53.1 (13.9)	47.5 (12.7)	0.12

CP-QOL, cerebral palsy-quality of life; SWB, social well-being and acceptance; FUN, feelings about functioning; PART, participation and physical health; EWB, emotional well-being; ACCESS, access to services; PAIN, pain and feeling about disability; FAMILY, family health

* $p < 0.05$

For Parent proxy, significant differences between the GMFCS level I and V for the FUN, EWB, and PAIN

For Child self-report, significant differences between the GMFCS level I and V for the PART

4. Discussion

It is necessary and important to effectively measure the quality of life of children with CP to make a better strategies for better outcomes (Global Burden of Disease Pediatrics et al., 2016). Psychometric properties of the CP-QOL have been primarily suggested and measured by a standardized method that was translated into many languages, including Polish, Chinese, Brazilian, and Turkish from the English version (Wang et al., 2010; Braccialli et al., 2016; Atasavun Uysal et al., 2016; Waters et al., 2007; Dmitruk et al., 2014).

Physical function and psychometric properties are highly related and should be measured precisely to provide appropriate information on them (Chae et al., 2018). This study was designed to verify and evaluate whether the psychometric properties of both the CP-QOL parent proxy and CP-QOL child-report forms translated into Korean were acceptable. Sometimes cultural difference confuses people and makes it difficult for them to understand a sentence if they do not have enough background knowledge or if they are from multiple cultural environments (Braccialli et al., 2016). No additional cultural adaptation, however, was necessary during this study. No parents or children reported such problems.

Internal consistency (= Cronbach's α) from the previous studies was 0.74~0.92 for the CP-QOL parent proxy form, 0.80~0.90 for the CP-QOL child self-report (English version, (Waters et al., 2007), 0.78~0.91 for the parent proxy form, 0.84~0.89 for the child self-report (Chinese version, (Wang et al., 2010)), and 0.63~0.93 for the parent proxy form, 0.61~0.92 for the child self-report (Atasavun Uysal et al., 2016). Internal consistency analysis of the K-CP-QOL was 0.80~0.92 for the CP-QOL parent proxy form, 0.84~0.96 for the CP-QOL child self-report which showed similar internal consistency or slightly stronger internal consistency compared to other language versions. In our best understanding, the judgement of parents on their children's function are more sensitive than the judgement of children because the parents, especially mothers, are much emotionally changeable to their child's functions. It might be the reason why ICC values of parent-proxy were lower than those of child self-report.

For the test-retest reliability, ICCs were reported for the parent-proxy form in English, Chinese, Brazilian-Portuguese, and Turkish. The ICCs ranged from 0.76 to 0.89 for the English version (N=205), from 0.86 to 0.97 for the Chinese version (N=145), from 0.62 to 0.81 for the Brazilian-Portuguese (N=30), and from 0.82 to 0.97 for the Turkish version (N=149). This study (N=153) showed 0.67 to 0.85, which were similar or slightly greater ICC values than the Chinese version. Compared to countries such as Brazil, Portugal, and Turkey, the ICC values of this study were not higher.

ICCs of CP-QOL child-report forms have been reported for Chinese, Brazilian, and Turkish version. The ICCs ranged from 0.74 to 0.92 for the Chinese version (N=44), 0.41~0.89 for the Brazilian (N=65), and 0.91~0.97 for the Turkish version (N=58). In the Korean version, the ICCs were 0.72~0.93 (N=61). The reliability of the Korean version had a level similar to those of other countries' language versions.

Quality of life is an important aspect for CP children. In general, the quality of life of CP children is related to gender and the physical functional level as well as the parental psychological status (Bult et al., 2011; Davis et al., 2012). It has been suggested that the parent's psychological state should also be measured when the parent proxy is used to evaluate the status of CP children because they are somehow related (Davis et al., 2012). In this study, the structural validity was evaluated by the methods proposed by the Polish and Turkish versions of the CP-QOL. Some significant differences were found between groups classified by the GMFCS levels. However, we did not find any significant differences between genders.

This study methods using a questionnaire to analyze the quality of life of the CP children and their parents could be also applied to the senior people because their disabled functions and discomfort are the exactly the same to the disabled people (Cho et al., 2018). It would be also applied to the geriatric patients with cancer (Won et al., 2018), stroke (Yang et al., 2017), or diabetes (Kim and Kim, 2017) to measure their quality of life.

A limitation of this study is that we did not measure the parent's psychological status. It should be considered in future studies. In addition, the total number of CP children (N=61) that participated in this study for the CP-QOL child-report form was relatively small. Even though it was neither the smallest number of CP children nor the greatest compared to previous studies, in the English version (N=53) Chinese version (N=44), or Brazilian-Portuguese (N=65), the sampling number was still not great enough. It was not easy to recruit children between 9 and 12 years-old. Furthermore, it would be valuable to examine changes in the quality of life for the CP children using K-CP-QOL questionnaires from the longitudinal intervention.

5. Conclusion

We conducted a study to determine the psychometric properties of the Korean version of the CP-QOL questionnaires. The results showed high consistency and reliability for the Korean version for measuring the quality of life of CP children. Thus, it is a suitable and reliable assessment tool to evaluate Korean CP children's quality of life.

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(부록) 삶의 질 평가서

아동 보고용 설문지(9-12 세용)

작성일 20 . . .

가족, 친구, 건강 그리고 학교생활에 대해 묻고자 합니다.

질문의 내용은 위의 사항들에 대해 어떻게 느끼고 있는지에 대해 묻는 것입니다.

질문에 대해 자신의 느낌을 가장 잘 나타내주는 숫자에 동그라미 하십시오.

이 질문서는 무엇을 할 수 있느냐를 측정하는 것이 아니라 어떻게 느끼고 있는지를 알아보는 것입니다.

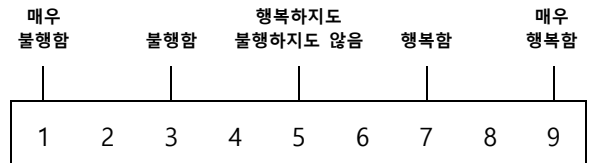
다음은 "예"입니다.

친구들과 놀이를 하는 '나'의 모습이 어떻게 느껴지나요?

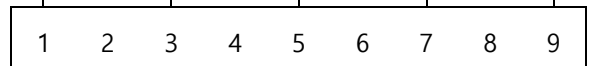


친구 및 가족(Friend and family)

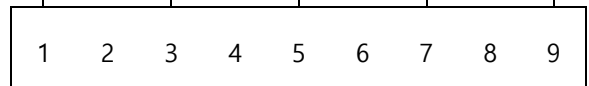
1. 주위 사람들을 생각하면 어떤가요? _____



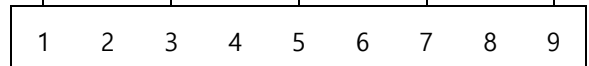
2. '나'를 돌봐주는 사람을 생각하면 어떤가요? _____



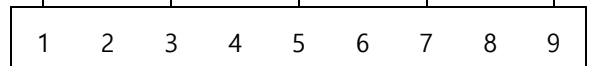
3. 형제자매를 생각하면 어떤가요?(없다면 아래 박스에 체크)
 나는 형제자매가 없다 _____



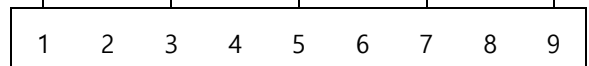
4. 학교 친구들을 생각하면 어떤가요? _____



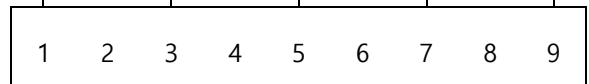
5. 학교 밖에서 사귀 친구들을 생각하면 어떤가요? _____



6. 어른들을 생각하면 어떤 기분이 드나요? _____



7. 선생님이나 자신을 돌보아 주는 사람을 생각하면 어떤가요? _____



	매우 불행함		불행함		행복하지도 불행하지도 않음		행복함		매우 행복함
8. 혼자서 놀이하는 수준을 생각하면 어떤가요?	1	2	3	4	5	6	7	8	9
9. 친구들과 함께 노는 수준을 생각하면 어떤가요?	1	2	3	4	5	6	7	8	9
10. 가족들과 함께 여행을 갈 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
11. '나'를 바라보는 가족의 눈길에 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
12. '나'를 바라보는 학교 친구들의 눈길에 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
13. '나'를 바라보는 학교 밖 친구들의 눈길에 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
14. '나'를 바라보는 어른들의 눈길에 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
15. 일반적으로 '나'를 바라보는 사람들의 눈길에 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
16. 원하던 일을 할 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9

참여(Participation)

	매우 불행함		불행함		행복하지도 불행하지도 않음		행복함		매우 행복함
17. 학교활동에 참여하는 수준을 생각하면 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
18. 여가활동에 참여하는 수준을 생각하면 어떤가요?	1	2	3	4	5	6	7	8	9

19. 스포츠활동에 참여하는 수준을 생각하면 어떤가요?
 (스포츠 활동에 참여할 수 있는지 묻는 것이 아니고,
 실제로 스포츠 활동에 참여하는 수준이 어느
 정도인지를 묻는 것입니다)

1	2	3	4	5	6	7	8	9
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20. 학교 밖에서 사회활동에 참여하는 수준을
 생각하면 어떤가요?

1	2	3	4	5	6	7	8	9
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21. 동네에서 활동하는 수준을 생각하면 어떤가요?

1	2	3	4	5	6	7	8	9
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의사소통(Communication)

매우 불행함 불행함 행복하지도 불행하지도 않음 행복함 매우 행복함

22. 친한 사람들과 의사를 소통하는 방법에
 대해 어떻게 느끼나요?
 (의사소통 수단은 어떤 것이든 상관없습니다)

1	2	3	4	5	6	7	8	9
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23. 친하지 않은 사람들과 의사를 소통하는
 방법에 대해 어떻게 느끼나요?
 (의사소통 수단은 어떤 것이든 상관없습니다)

1	2	3	4	5	6	7	8	9
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24. 타인이 나에게 의사를 표현하는 방법에 대해
 어떻게 느끼나요?

1	2	3	4	5	6	7	8	9
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건강(Health)

매우 불행함 불행함 행복하지도 불행하지도 않음 행복함 매우 행복함

25. 자신의 건강상태를 생각하면 어떤가요?

1	2	3	4	5	6	7	8	9
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26. 자신이 움직이는 방법을 생각하면 어떤가요?

1	2	3	4	5	6	7	8	9
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27. 평소에 자고 난 후 느낌이 어떤가요?

1	2	3	4	5	6	7	8	9
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28. 자기 외모를 생각하면 기분이 어떤가요?

1	2	3	4	5	6	7	8	9
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29. 친구들과 비교했을 때 자신의 학교성적을 생각하면 어떤가요?	1	2	3	4	5	6	7	8	9
30. 친구들과 비교했을 때 자신의 신체활동능력을 생각하면 어떤가요?	1	2	3	4	5	6	7	8	9
31. 보통, 일상생활을 생각하면 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
32. 자신을 생각하면 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
33. 미래를 생각하면 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
34. 앞으로 '나'에게 주어질 기회들을 생각하면 기분이 어떤가요?	1	2	3	4	5	6	7	8	9

다음 세 가지 질문은 신체를 사용할 수 있는 지 여부를 묻는 것이 아니라 신체를 사용하는 능력에 대해 묻는 것입니다.

	매우 불행함	불행함	행복하지도 불행하지도 않음	행복함	매우 행복함				
35. 팔을 쓸 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
36. 다리를 쓸 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9
37. 손을 쓸 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9

다음 세 가지 질문은 일상생활을 완벽히 하는 능력에 대한 느낌을 묻는 질문으로, 일상생활을 수행할 수 있는지의 여부를 묻는 것이 아닙니다.

	매우 불행함	불행함	행복하지도 불행하지도 않음	행복함	매우 행복함				
38. 혼자 옷 입는 능력을 생각할 때 기분이 어떤가요?	1	2	3	4	5	6	7	8	9

39. 혼자 음식을 먹거나 음료를 마시는 능력을
생각할 때 기분이 어떤가요?
-
40. 혼자 화장실을 사용하는 능력을 생각할 때
기분이 어떤가요?
-

1	2	3	4	5	6	7	8	9
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1	2	3	4	5	6	7	8	9
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특수장비(Special equipment)

41. 집에서 보조도구(예; 특수 의자, 서는 도구,
휠체어, 워커)를 사용할 때 기분이 어떤가요?
또는 나는 집에서 보조도구가 필요 없다
-
42. 학교에서 보조도구(예; 특수 의자, 서는 도구,
휠체어, 워커)를 사용할 때 기분이 어떤가요?
또는 나는 학교에서 보조도구가 필요 없다
-
43. 동네에서 턱을 올라가거나, 에스컬레이터, 휠체어를
타기 위해 보조도구를 사용할 때 기분이 어떤가요?
또는 나는 동네에서 보조도구가 필요 없다
-

매우 불행함	불행함	행복하지도 불행하지도 않음	행복함	매우 행복함
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1	2	3	4	5	6	7	8	9
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1	2	3	4	5	6	7	8	9
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1	2	3	4	5	6	7	8	9
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통증 및 불편함(Pain and bother)

다음의 질문들은 '나'를 괴롭히는 것에 관한 것입니다.

44. 병원에 다니는 게 싫은가요?
-
45. 몸이 아파서 학교를 결석할 때 싫은가요?
-
46. 자신이 남의 손에 다루어지는 게 싫은가요?
-
47. 나중에 누가 '나'를 돌보아 줄 지 걱정되나요?
-

전혀 아님								매우 그려함
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1	2	3	4	5	6	7	8	9
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1	2	3	4	5	6	7	8	9
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1	2	3	4	5
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전혀 아님	거의 안 함	가끔	빈번히	매우 그려함
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마지막으로 '나'에 관한 질문이 몇 문항 계속됩니다.

48. 뇌성마비라는 게 신경 쓰이나요?

전혀 아님										매우 그려함
	1	2	3	4	5	6	7	8	9	

49. 통증이 있나요?

전혀 없음										매우 심함
	1	2	3	4	5	6	7	8	9	

50. 통증의 정도는 어떤가요?

아무렇지 않음										매우 심함
	1	2	3	4	5	6	7	8	9	

51. 불편한 게 있나요?

전혀 아님										매우 불편함
	1	2	3	4	5	6	7	8	9	

52. 행복한가요?

매우 불행함			불행함			불행하지도 행복하지도 않음			행복함		매우 행복함
	1	2	3	4	5	6	7	8	9		

53. 이 설문지를 작성할 때 부모님(선생님)의 도움을 받았나요?

아님			네, 아주 조금			네, 상당히			네, 많이
	1	2	3	4					

Quality of life questionnaire for children (CP QOL-CHILD) 작성일 20 . . .

부모 보고형(4-12 세)

자녀가 가족, 친구, 건강 및 학교 생활에 대해 어떻게 느끼고 있는지에 대해 부모님의 생각을 묻고자 합니다. 질문은 "자녀가 ...에 대해 어떻게 느낀다고 생각하십니까?"의 형식입니다.

귀하께서 자녀의 생각을 잘 알고 계셔야 합니다. 물론 아이의 생각을 표현하기가 어려울 수도 있습니다. 최선을 다해 답변해주시기를 부탁드립니다.

자녀의 느낌을 나타내주는 번호에 동그라미 표시를 해주시면 됩니다. 1(매우 불행함)에서 9(매우 행복함)까지의 '숫자'에 동그라미 해주십시오.

이 질문서는 자녀가 어떻게 느끼는지에 대해 묻는 것으로, 무엇을 할 수 있는가를 묻지는 않습니다.

다음은 '예'입니다.

자녀가 친구들과 함께 놀이를 하는 능력에 대해 어떻게 느낄까요?



친구 및 가족(Friends and family)

1. 일반적으로, 자녀가 사람들과의 관계에 대해 어떻게 느낄까요?

2. 자녀가 부모님과의 관계에 대해 어떻게 느낄까요?

3. 자녀가 형제자매와의 관계에 대해 어떻게 느낄까요?
또는 아이에게 다른 형제자매가 없다
4. 자녀가 유치원(어린이집)이나 학교에서 아이들과의 관계에 대해 어떻게 느낄까요?
또는 아이가 유치원(어린이집)이나 학교에 다니지 않는다
5. 자녀가 유치원(어린이집)이나 학교 밖에서 아이들과의 관계에 대해 어떻게 느낄까요?

6. <u>자녀가 어른들과의 관계에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
7. <u>자녀가 선생님 그리고/또는 돌보아주는 사람과의 관계에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
8. <u>자녀가 혼자서 놀이할 수 있는 능력에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
9. <u>자녀가 친구들과 함께 놀이를 하는 능력에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
10. <u>자녀가 가족과 함께 여행하는 것에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
11. <u>자녀가 가족들의 시선을 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
12. <u>자녀가 유치원(어린이집)이나 학교에서 아이들의 시선을 어떻게 느낄까요? 또는 <input type="checkbox"/> 아이가 유치원(어린이집)이나 학교에 다니지 않는다</u>	1	2	3	4	5	6	7	8	9
13. <u>자녀가 유치원(어린이집) 외에 밖에서 만나는 아이들의 시선을 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
14. <u>자녀가 어른들의 시선을 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
15. <u>일반적으로 자녀가 사람들이 자신을 바라보는 시선을 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
16. <u>자녀가 원하던 일을 할 때 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9

참여(Participation)

	매우 불행함	불행함	불행하지도 행복하지도 않음	행복함	매우 행복함				
17. 자녀가 유치원(어린이집)이나 학교에서의 참여 수준에 대해 어떻게 느낄까요? 또는 <input type="checkbox"/> 아이가 유치원(어린이집)이나 학교에 다니지 않는다	1	2	3	4	5	6	7	8	9
18. 자녀가 여가활동에 참여하는 수준에 대해 어떻게 느낄까요?	1	2	3	4	5	6	7	8	9
19. 자녀가 스포츠활동(예를 들어, 자전거타기 등)에 참여하고 있습니까? 그렇다면 만족도는 어떨까요? (스포츠 활동에 참여하고 있지 않다면 바로 20 번 문항으로 넘어가 주십시오).	1	2	3	4	5	6	7	8	9
20. 자녀가 유치원(어린이집)이나 학교 밖에서의 사회활동에 참여하는 수준에 대해 어떻게 느낄까요?	1	2	3	4	5	6	7	8	9
21. 자녀가 동네에서 활동하는 수준에 대해 어떻게 느낄까요?	1	2	3	4	5	6	7	8	9

의사소통(Communication)

	매우 불행함	불행함	불행하지도 행복하지도 않음	행복함	매우 행복함				
22. 자녀가 친숙한 사람들과의 의사소통 방식에 대해 어떻게 느낄까요? (의사소통 수단은 어떤 것이든 상관없습니다)	1	2	3	4	5	6	7	8	9
23. 자녀가 친숙하지 않은 사람들과의 의사소통 방식에 대해 어떻게 느낄까요? (의사소통 수단은 어떤 것이든 상관없습니다)	1	2	3	4	5	6	7	8	9
24. 자녀가 사람들이 자신과 의사 소통하는 방식에 대해 어떻게 느낄까요?	1	2	3	4	5	6	7	8	9

건강(Health)

	매우 불행함		불행함		불행하지도 행복하지도 않음		행복함		매우 행복함
25. <u>자녀가 건강에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
26. <u>자녀가 움직이는 방법에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
27. <u>자녀의 수면 만족도는 어떨까요?</u>	1	2	3	4	5	6	7	8	9
28. <u>자녀가 외모에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
29. <u>자녀가 또래들과 학업경쟁에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
30. <u>자녀가 또래들과 신체활동에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
31. <u>자녀가 대체적으로 일상생활에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
32. <u>자녀가 '스스로'를 생각할 때 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
33. <u>자녀가 미래에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
34. <u>자녀가 살면서 주어질 기회에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9

다음 세 가지 질문은 자녀가 신체를 사용할 수 있는 지 여부를 묻는 것이 아니라 신체를 사용하는 능력에 대해 묻는 것입니다.

	매우 불행함		불행함		불행하지도 행복하지도 않음		행복함		매우 행복함
35. <u>자녀가 팔을 쓰는 능력에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9
36. <u>자녀가 다리를 쓰는 능력에 대해 어떻게 느낄까요?</u>	1	2	3	4	5	6	7	8	9

37. 자녀가 손을 쓰는 능력에 대해 어떻게 느낄까요?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

다음 세 가지 질문은 자녀가 일상생활을 완벽히 수행하는 것에 대한 느낌을 묻는 질문으로, 일상생활을 수행할 수 있는지의 여부를 묻는 것이 아닙니다.

38. 자녀가 스스로 옷 입을 능력에 대해 어떻게 느낄까요?

매우 불행함	불행함	불행하지도 행복하지도 않음	행복함	매우 행복함				
1	2	3	4	5	6	7	8	9

39. 자녀가 혼자서 먹고 마시는 능력에 대해 어떻게 느낄까요?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

40. 자녀가 혼자서 용변 처리하는 능력에 대해 어떻게 느낄까요?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

특수장비(Special equipment)

41. 자녀가 집에서 보조도구(예를 들면 특수의자, 서는 도구, 휠체어, 워커)를 사용할 때 어떤 느낌일까요?
또는 집에서 보조도구가 필요 없다

매우 불행함	불행함	불행하지도 행복하지도 않음	행복함	매우 행복함				
1	2	3	4	5	6	7	8	9

42. 자녀가 학교에서 보조도구(예를 들면 특수의자, 서는 도구, 휠체어, 워커)를 사용할 때 어떤 느낌일까요?
또는 학교에서 보조도구가 필요 없다

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

43. 자녀가 동네에서 턱을 올라가거나, 에스컬레이터, 휠체어를 타기 위해 보조도구를 사용할 때 어떤 느낌일까요?
또는 동네에서 이동할 때 보조도구가 필요 없다

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

통증 및 불편함(Pain and bother)

다음의 질문들은 자녀를 괴롭히는 것들에 관해 묻는 것입니다.

44. 자녀가 병원에 다니는 것을 싫어하나요?

전혀 아님	매우 그려함							
1	2	3	4	5	6	7	8	9

45. 자녀가 몸이 아파 학교를 결석할 때 싫어하나요?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

46. 자녀가 남에 의해 다루어지는 것을 싫어하나요?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

47. 자녀가 나중에 누가 자신을 돌보아줄지 걱정하나요?

전혀 아님		거의 안 함		가끔		빈번히		항상	
1	2	3	4	5	6	7	8	9	10

마지막으로 자녀에 관한 문제가 몇 문항 더 계속됩니다.

48. 자녀가 뇌성마비라는 것을 걱정할까요?

전혀 아님								매우 그러함	
1	2	3	4	5	6	7	8	9	10

49. 자녀가 통증이 있는 것 같나요?

전혀 없음								매우 심함	
1	2	3	4	5	6	7	8	9	10

50. 자녀가 얼마나 통증을 느낄까요?

아무렇지 않음								매우 심함	
1	2	3	4	5	6	7	8	9	10

51. 자녀가 불편함을 느낄까요?

전혀 아님								매우 불편함	
1	2	3	4	5	6	7	8	9	10

52. 자녀가 행복할까요?

매우 불행함		불행함		불행하지도 행복하지도 않음		행복함		매우 행복함	
1	2	3	4	5	6	7	8	9	10

다음의 질문들은 부모님과 서비스 이용에 관한 느낌을 묻는 것입니다(Access to services).

	매우 불행함		불행함		불행하지도 행복하지도 않음		행복함		매우 행복함
53. <u>치료에 대한 접근성에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
54. <u>자녀에게 필요한 물리치료, 언어치료, 작업치료 같은 치료를 받는 기회에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
55. <u>자녀에게 필요한 특별한 의학적 또는 수술치료를 받을 수 있는 기회에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
56. <u>의사에게 조언을 얻는 것에 대해서는 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
57. <u>일시 위탁의 이용에 대해 어떻게 느끼십니까? 또는 <input type="checkbox"/> 일시 위탁을 이용한 적이 없다 (일시 위탁에 대한 다음의 2 문제를 건너뛰십시오)</u>	1	2	3	4	5	6	7	8	9
58. <u>일시 위탁의 기회에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
59. <u>일시 위탁 이용을 할 수 있는 접근성에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
60. <u>지역사회 서비스 및 기관(예를 들면, 유치원, 육아, 방과후프로그램, 휴일프로그램, 걸스카우트 및 보이스카우트 등)에 대한 아이의 접근성에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9
61. <u>유치원(어린이집)이나 학교에서 과외학습을 받을 수 있는 기회에 대해 어떻게 느끼십니까?</u>	1	2	3	4	5	6	7	8	9

이제 부모님에 관한 질문입니다.

부모님 건강(Parent health)

62. 건강에 대해 어떻게 느끼십니까?

매우 불행함			불행함		불행하지도 행복하지도 않음		행복함		매우 행복함
1	2	3	4	5	6	7	8	9	

63. 직업상황에 대해 어떻게 느끼십니까?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

64. 가정의 재정상태에 대해 어떻게 느끼십니까?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

65. 행복하십니까?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

자녀의 느낌을 대신 응답하신 것에 대해
얼마나 자신 있으십니까?

전혀 자신 없음									매우 자신 있음
1	2	3	4	5	6	7	8	9	