

Factors affecting the health-related quality of life of children with cerebral palsy in Indonesia: a cross-sectional study

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Received: May 17, 2023

Revised: July 4, 2023

Accepted: September 19, 2023

Purpose: Children with cerebral palsy (CP) and their parents experience various problems that can affect their quality of life. This study examined factors affecting the quality of life of children with CP. **Methods:** A cross-sectional study was conducted in Yogyakarta, Indonesia, from January to August 2019. The participants were consecutively recruited children with CP aged 2 to 18 years and their parents. Ninety-eight children with CP and their parents, specifically their mothers, were recruited. Children's health-related quality of life (HRQoL) was measured using the Pediatrics Quality of Life Cerebral Palsy. Parental HRQoL and stress were measured using the WHOQOL-BREF and Parenting Stress Index (PSI). **Results:** Functional level V was the most common category for both Gross Motor Function Classification System (GMFCS) and Bimanual Fine Motor Function (BFMF) (35% and 28%, respectively). Children's mean HRQoL was medium (49.81±20.35). The mean total PSI score was high (94.93±17.02), and 64% of parents experienced severe stress. Bivariate analysis showed that GMFCS, BFMF, number of comorbidities, presence of pain, and parental stress were significantly correlated with the total score for children's HRQoL ($p<.05$). Multiple linear regression analysis ($p<.05$) demonstrated that more severe GMFCS and parental stress were associated with lower mean HRQoL scores in children. **Conclusion:** Factors including the level of GMFCS and parental stress affected the HRQoL of children with CP. Parental stress management should be included in the comprehensive management of these children.

Keywords: Cerebral palsy; Child; Quality of life; Stress, psychological

INTRODUCTION

Cerebral palsy (CP) is the leading cause of childhood disability, presenting a significant burden in low- and middle-income countries (LMICs) [1]. It is the most prevalent motor disability in children, often accompanied by issues related to sensation, perception, cognition, communication, and behavior, as well as epilepsy and secondary musculoskeletal problems [2]. Recent epidemiological data estimate

the global prevalence of CP to be between 1 and approximately 4 per 1,000 live births, or children of the same age. However, it has been difficult to estimate the prevalence of CP in Indonesia due to a lack of comprehensive epidemiological data on CP [3]. Yogyakarta, a region in Indonesia, has reported an increasing number of CP cases in children each year [1]. According to an internal report from the Wahana Keluarga Cerebral Palsy (WKCP), the prevalence of children with CP has been rising annually, with a total of 121 and 392

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registered members in the WKCP in 2017 and 2022, respectively.

Children with CP often face limitations in physical activity, verbal and non-verbal communication, and social interactions. According to the Centers for Disease Control and Prevention, over half of children with CP (58.2%) are able to walk independently, while the majority suffer from spastic CP (77.4%). Additionally, 11.3% of these children walk using a hand-held mobility device, and 30.6% experience mobility disruption or lack the ability to walk. Approximately 60% of these children experience developmental disorders with more than one condition by the age of eight [4]. Children with CP from LMICs are at a high risk of poor health-related quality of life (HRQoL), especially physical well-being, which is associated with impaired motor function [5]. Pain, psychological problems, and parenting stress have been identified as predictors of lower HRQoL among adolescents with CP across most domains [6].

Children with CP often experience disabilities that can hinder their developmental progress towards achieving independence. These conditions can also negatively impact their parents in various ways, including physical and mental health, financial stability, and social interaction [6]. In LMICs, particularly in Indonesia, both children and parents are required to navigate a range of long-term medical and non-medical treatments for CP. This not only incurs significant financial costs and time commitments, but also disrupts parents' daily routines and can lead to psychological distress [7]. The effects of physical activity limitations on the quality of life for both children and their parents are not yet fully understood. Gaining insight into the most challenging aspects of this situation is vital, as it allows nurses to provide interventions that are tailored to the specific needs of both parents and children, taking into account Indonesian cultural norms. However, many studies investigating the HRQoL of Indonesian children with CP have been limited by small sample sizes [3,8]. This survey based study was designed to explore the factors affecting the quality of life of children with CP.

METHODS

Ethical statements: This study was approved by the Institutional Review Board (IRB) of Medicine, Public health, and Nursing, Universitas Gadjah Mada, Indonesia (No. KE/FK/0023/EC/2019). Informed consent was obtained from all participants.

1. Study Design

This research descriptive and cross-sectional study investigated the factors affecting the quality of life of children with CP in Yogyakarta, Indonesia. The reporting of this study was based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines [9].

2. Study Participants

The study participants were children diagnosed with CP, along with their parents, who were members of the WKCP, a family association for cerebral palsy, and received treatment at an academic hospital in Yogyakarta, Indonesia. The exclusion criteria for the study were as follows: children who were hospitalized at the time of data collection, parents who did not reside in the same household as the child, and parents who did not fully complete the questionnaire. Out of the total participants, 106 mothers agreed to participate, but eight of them did not fill out the questionnaire in its entirety. Consequently, the final analysis included 98 children with CP and their respective mothers. A sample size calculation based on the Lemeshow formula, using a 95% confidence level, 50% as the assumed population proportion, and 10% for absolute error, resulted in a minimum sample size of 96.

3. Measurements

The study variables analyzed were the demographic characteristics of the participants and their parents, type of CP, HRQoL in children with CP and their parents, motor function related to CP, and parenting stress. The measurement tools used for primary data collection were the Indonesian versions of developed questionnaires.

1) Demographic characteristics

The demographic characteristics of children with CP and their parents were collected using several question items. These items pertained to the child's age, sex, and weight, and were derived from the primary data. Additionally, questions related to the characteristics of both parents were included, covering aspects such as age, education level, employment status, family income, health insurance, and any history of disability. The parents of the participants were responsible for completing these question items.

2) Type of cerebral palsy

A pediatrician directly assessed the type of CP (spastic, ataxic, dyskinetic, or mixed) in children with CP based on their movement and body parts affected.

3) Comorbidities

Comorbidities were evaluated by a professional physician through a physical examination, interview with parents, and specific tests related to hearing and vision problems, as well as hip dislocation. These comorbidities were categorized into several types, including pain, hearing issues, visual impairments, emotional disturbances, epilepsy, dysphagia, constipation, hip dislocation, and urination disturbances. Using the Galeazzi test maneuver, the pediatrician screened for potential hip dislocation.

4) Pain assessment

Children with CP often experience difficulties in expressing their emotions, including pain, both verbally and non-verbally. The Face, Legs, Activity, Cry, and Consolability (FLACC) scale is a tool used to measure pain, especially in children with disabilities such as CP. This user-friendly tool is valid for children with cognitive impairments, as it thoroughly assesses changes in behavior related to pain including facial expressions, leg movements, activity levels, crying, and consolability. Parents, due to their role as caregivers and their understanding of their children's conditions, completed the pain perception section using the Indonesian validated version of the FLACC questionnaire. Pain was categorized as no pain (score 0), mild pain (scores 1-3), moderate pain (scores 4-6), and severe pain (scores 7-10) [10].

5) Motor function assessment

The pediatrician evaluated the motor function of children with CP to determine the severity of their condition based on their daily needs, using the Gross Motor Function Classification System – Expanded and Revised (GMFCS-E&R) and the Bimanual Fine Motor Function (BFMF) version 2.0. The GMFCS-E&R, which is available in 22 languages, has been validated in numerous countries. The GMFCS is a system used to classify gross motor abilities. The levels of GMFCS are defined as follows: level I indicates the child is ambulant without limitations; level II signifies the child is ambulant but with limitations; level III indicates the need for a hand-held mobility device; level IV means the child is self-mobile but with limitations; and level V signifies the need for a manual

wheelchair [11,12].

BFMF is a classification system that assesses an individual's fine motor abilities and limitations at a specific point in time. The BFMF system is divided into five levels. Level I indicates that both hands can manipulate objects without any restrictions. Level II signifies that both hands can manipulate objects, but with some limitations. Level III denotes that one hand can manipulate with limitations, while the other hand is only capable of grasping or less. Level IV indicates that both hands are only able to grasp. Lastly, Level V means that both hands can only hold objects [11].

6) Pediatric HRQoL

The HRQoL of children with CP was assessed, taking into account daily activities, school activities, movement and balance, pain, fatigue, eating habits, language, and communication. This was done using the Indonesian version of the HRQoL questionnaire (PedsQL Cerebral Palsy Module Version 3.0 Questionnaire). The original questionnaire has previously undergone validity, reliability, and sensitivity testing, yielding medium to large Pearson's product-moment correlation coefficient effects and an Cronbach's α value of .79 [13]. Furthermore, all question items were translated into Indonesian and validated according to the guidelines set by the Mapi Trust Organization [2]. Each question uses a Likert scale, ranging from 0 (never) to 4 (almost always). These scores are then transformed onto a scale of 0 to 100, with each question scored in reverse: 0=100, 1=75, 2=50, 3=25, 4=0. Next, the score for each dimension is calculated, although the score cannot be computed if more than half of the items in the scale are missing. The mean score is then calculated as the sum of the items' scores divided by the number of items answered. A mean score closer to 100 indicates better QoL. There is no total score.

7) Parental HRQoL

This study utilized the Indonesian version of the WHO-QOL-BREF, to measure parents' quality of life. The WHO-QOL-BREF is a validated instrument comprising 26 questions that assess four broad domains: physical health, psychological health, social relations, and the environment. In addition to these, two separate items were included to gauge an individual's overall perception of their quality of life (rated as very poor, poor, neither poor nor good, good, or very good) and their overall perception of their health (rated as very dissatisfied, dissatisfied, neither dissatisfied nor satis-

fied, satisfied, or very satisfied). This questionnaire has been translated into Indonesian and validated for use. Respondents were instructed to select a number from 1 to 5 for each question. The mean scores were then multiplied by 4 to align the domain scores with those used in the WHOQOL-100 and subsequently converted to a 0–100 scale. The domain scores are scaled positively, with higher scores indicating a higher HRQoL.

8) Parenting stress index

This study examined parental stress levels using the Parenting Stress Index (PSI), which consists of 36 questions. The Indonesian version of the PSI showed a satisfactory level of reliability (Cronbach's $\alpha = .823$) [14]. Each question has a Likert-scale response, from 1 (strong disagreement) to 5 (strong agreement). The scores on the PSI are interpreted as the total scores, which are obtained by adding the scores for parental distress (PD) (score for items 1–12), parent-child dysfunction interaction (PCDI) (scores for items 13–24), and difficult child (DC) (scores for items 25–36). The total score was adjusted for the percentile raw scores for classification of participants based on their level of stress. Parental stress levels are categorized as typical stress (normal) (1st to 10th percentile), high stress (mild to moderate stress level) (15th to 80th percentile), and clinically significant stress (severe stress) (85th to 100th percentile).

4. Data Collection

Data collection involving children with CP and their parents took place in Yogyakarta, Indonesia, from January to August 2019, at an academic hospital in Yogyakarta. This study systematically recruited children with CP from both the WKCP and an academic hospital in Yogyakarta, Indonesia. All members of the WKCP and children with CP who were patients at an academic hospital in Yogyakarta were invited to receive a detailed explanation of the study. A pediatrician conducted physical examinations and health assessments for the children with CP. Concurrently, their parents were asked to participate in a survey, which involved filling out questionnaires. This was done after obtaining written consent from the parents.

The data collection process utilized case report form questionnaires by parent's report, which encompassed demographic and medical characteristics. These questionnaires included the Indonesian version of an HRQoL questionnaire

(PedsQL Cerebral Palsy Module Version 3.0 Questionnaire), the Indonesian version of an instrument for evaluating parents' HRQoL (WHOQOL-BREF), and the PSI. A pediatrician was responsible for assessing the children's level of GMFCS-E&R and BFMF version 2.0.

5. Data Analysis

The data collected in this study were analyzed using SPSS 22.0 (IBM Corp.). Descriptive statistics were used for the demographic and clinical characteristics of children with CP. Analysis of variance was used to confirm the relationships between the independent variables and the mean HRQoL score of the children, which was treated as the dependent variable. The independent variables included the PSI as a measure of parental stress, the GMFCS level, the BFMF level, the mother's level of education, parental HRQoL, the number of comorbidities, and the presence of pain. We used multiple linear regression to analyze the relationship between the predicted confounding variables and the mean QoL score of the children. A p -value of less than .05 was deemed statistically significant.

RESULTS

1. The Demographic and Clinical Characteristics of Participants

The demographic and clinical characteristics of the children with CP are shown in Table 1. Of the 210 WKCP members, 106 children with CP participated in the study. There were no significant differences in demographic characteristics between the participants and non-participants. Eight parents did not complete the questionnaire. The study analyzed a total of 98 children with CP (mean age 6.27 ± 3.37 years) and their parents. The mean ages of the parents were 35.33 ± 6.63 years and 38.43 ± 7.31 years for fathers and mothers, respectively.

The majority of these children were boys (63%), and most had the spastic type of CP (88%). The percentages of children with a history of low birth weight and very low birth weight were 28% and 14%, respectively. Most of the children were classified as having a severe level of GMFCS and BFMF. The majority of the children had two or more comorbidities, with pain (54%) being the most common, followed by epilepsy (45%).

The characteristics of the parents are outlined in Table 2.

Table 1. Characteristics of Children with Cerebral Palsy According to Socio-demographics, Degree of Motor Function, and Comorbidities (N=98)

Characteristics	n or M±SD	%
Age (year)	6.27±3.37	
Sex		
Boy	62	63
Girl	36	37
Birth weight (g)		
≥2,500	57	58
1,500 to <2,500	27	28
<1,500	14	14
Type of cerebral palsy		
Spastic	86	88
Ataxic	0	0
Dyskinetic	5	5
Mixed	7	7
GMFCS level		
Level I	18	18
Level II	8	8
Level III	25	26
Level IV	13	13
Level V	34	35
BFMF level		
Level I	18	18
Level II	27	28
Level III	12	12
Level IV	14	14
Level V	27	28
Comorbidities ^{a)}		
Pain	53	54
Hearing problems	10	10
Visual problems	11	11
Emotional disturbance	16	16
Epilepsy	44	45
Dysphagia	25	26
Constipation	16	16
Hip dislocation	12	12
Urination disturbance	3	3
Number of comorbidities		
0	10	10
1–2	52	53
>3	36	37

^{a)}Multiple responses; BFMF, Bimanual Fine Motor Function; GMFCS, Gross Motor Function Classification System; M, mean; SD, standard deviation.

Most parents had a low educational background, with 62% of mothers and 67% of fathers falling into this category. The average income was below the regional minimum wage in the province of Yogyakarta. A significant majority of these families, 90%, had health insurance. The mean PSI total score was 94.93 (standard deviation [SD]=17.02). According to the PSI total score, severe stress was experienced by 64% of par-

Table 2. Socio-demographic and Clinical Characteristics of Parents (N=98)

Characteristics	M±SD	n (%)
Age (year)		
Mother	35.33±6.63	
Father	38.43±7.31	
Mother's education		
Low		61 (62)
High		37 (38)
Father's education		
Low		66 (67)
High		32 (33)
Parent's work		
Mother		30 (31)
Father		94 (95)
Family income		
<Regional minimum salary		31 (32)
≥Regional minimum salary		67 (68)
Health insurance		
Yes		88 (90)
No		10 (10)
Other family members with disabilities		
Yes		6 (6)
No		92 (94)
Parenting Stress Index (PSI)	94.93±17.02	
PSI total score level		
Normal		21 (22)
Mild-moderate		14 (14)
Severe		63 (64)
Parent-child dysfunctional interaction		
Normal		4 (4)
Mild-moderate		2 (2)
Severe		92 (94)
Difficult child		
Normal		67 (67)
Mild-moderate		16 (17)
Severe		15 (16)
Parental distress		
Normal		61 (62)
Mild-moderate		9 (9)
Severe		28 (29)

M, mean; SD, standard deviation.

ents. A high percentage of parents (94%) experienced severe stress in the PCDI domain. Meanwhile, 29% faced severe stress in the PD domain, and 16% in the DC domain.

2. Health-related Quality of Life of Children with Cerebral Palsy and Their Parents

The HRQoL of children with CP is presented in [Table 3](#). The domains of school activity and daily activity received the lowest scores. The HRQoL of parents is also presented in [Ta-](#)

Table 3. Health-related Quality of Life of Children with Cerebral Palsy and Their Parents (N=98)

Domains	Quality of life	
	Mean	SD
Children's health-related quality of life (n=98)		
Mean total score	49.81	20.35
Daily activity	34.37	26.91
School activity	33.52	30.13
Movement and balance	51.25	28.81
Pain	70.32	29.75
Exhausted	62.25	27.50
Eating activity	49.12	30.77
Language and communication	50.04	34.29
Parental health-related quality of life (n=98)		
Mean total score ^{a)}	55.76	8.19
Physical health	50.67	8.15
Psychologist health	53.47	14.28
Social interaction	60.69	12.43
Environment	58.64	11.69

^{a)}Parental health-related quality of life is divided into good (mean score≥55.76) and poor (mean score<55.76) based on total mean score; SD, standard deviation.

ble 3, with a total mean score of 55.76 (SD=8.19). Approximately 47% of parents reported having a good HRQoL. The domain of physical health received the lowest mean score, 50.67 (SD=8.15), while the social interaction domain received the highest, 60.69 (SD=12.43). When asked to rate their overall perception of HRQoL, parents responded as follows: 2% rated it as poor, 47% as neither poor nor good, 47% as good, and 4% as very good. When asked about their overall perception of their health, parents responded as follows: 7% were not satisfied, 49% were neither dissatisfied nor satisfied, 42% were satisfied, and 2% were very satisfied.

3. Differences in Quality of Life of Children with Cerebral Palsy according to Demographic and Clinical Characteristics of Children and Their Parents

One-way analysis of variance showed significant differences in the mean total score of children's HRQoL according to the level of GMFCS, level of BFMF, number of comorbidities, and parental stress ($p < .05$) (Table 4).

4. Factors Affecting the Health-related Quality of Life of the Children with Cerebral Palsy

Multivariate analysis using linear regression identified the significant factors affecting children's HRQoL. Apart from the PSI value, GMFCS levels were a significant variable that

Table 4. Differences in Quality of Life of Children with Cerebral Palsy according to Demographic and Clinical Characteristics of Children and Their Parents (N=98)

	Health-related quality of life in children with cerebral palsy M±SD	F	p
Level of GMFCS			
Level I (n=18)	63.89±15.52	11.02	<.001
Level II (n=8)	52.38±10.26		
Level III (n=25)	50.47±14.97		
Level IV (n=13)	49.50±19.27		
Level V (n=34)	34.45±16.25		
Level of BFMF			
Level I (n=18)	60.75±14.28	8.41	<.001
Level II (n=27)	54.83±17.58		
Level III (n=12)	44.56±13.74		
Level IV (n=14)	41.47±16.76		
Level V (n=27)	35.42±17.62		
Mother's education			
Low (n=61)	46.17±19.94	0.69	.408
High (n=37)	49.44±16.96		
Parental quality of life			
Good (n=46)	48.56±19.71	0.06	.805
Poor (n=37)	46.20±18.04		
Number of comorbidities			
0 (n=10)	50.63±18.67	3.95	.022
1-2 (n=52)	51.50±19.50		
>2 (n=35)	40.59±16.29		
The presence of pain			
No pain (n=45)	51.09±18.04	3.25	.074
Mild pain (n=41)	48.67±14.84		
Moderate pain (n=8)	40.33±25.36		
Severe pain (n=4)	33.23±17.05		
PSI			
Total score of PSI			
Normal (n=21)	58.50±18.73	5.24	.007
Mild-moderate stress (n=2)	47.19±14.97		
Severe stress (n=63)	43.75±18.46		
PCDI			
Normal (n=4)	71.29±10.66	3.90	.024
Mild-moderate stress (n=2)	57.17±20.03		
Severe stress (n=92)	46.15±18.49		
Difficult child			
Normal (n=52)	46.91±19.60	0.11	.895
Mild-moderate stress (n=18)	49.30±17.76		
Severe stress (n=28)	47.09±18.70		
Parent distress			
Normal (n=61)	49.70±19.19	1.35	.265
Mild-moderate stress (n=9)	46.45±13.76		
Severe stress (n=28)	42.69±18.86		

BFMF, Bimanual Fine Motor Function; GMFCS, Gross Motor Function Classification System; M, mean; PCDI, parent-child dysfunction interaction; PSI, Parenting Stress Index; SD, standard deviation.

affected HRQoL in children. An increase in the parental stress level reduced the mean score of HRQoL children by -5.52 points ($p = .004$), while an increased severity level in the GMFCS also reduced the mean score of HRQoL in children by -4.65 points ($p = .004$) (Table 5).

DISCUSSION

Children with CP often transition into adulthood with various limitations and associated diseases, such as intellectual disabilities, developmental disorders, vision problems, and epilepsy, which is a major comorbidity in children with CP [15]. This study showed that pain was the most common comorbidity in children with CP, followed by epilepsy, dysphagia, and constipation. Pain is a primary predictor of quality of life among children with CP and tends to increase with age. Therefore, understanding and managing pain signals is crucial for maintaining their quality of life. A study reported that approximately 65% of 104 non-verbal children with CP in Malaysia experienced pain, which was more frequent in older children with CP and those with spastic quadriplegia [16]. Another 5-year longitudinal study conducted in Europe concluded that pain was a strong predictor of adult HRQoL [17]. This study found that a higher severity of pain corresponded to a lower HRQoL score in children with CP ($p = .045$). Therefore, it is necessary to assess the presence of pain using the FLACC pain scale in the overall evaluation of children with CP to manage their symptoms appropriately. Pelvic dislocation should be evaluated using the Galeazzi test as a physical examination for early diagnosis, rather than a radiological examination, due to its usefulness in assessing the growth and development of the hip in children older than 4 to 6 months [18]. This study found that 12% of children with CP were suspected of having pelvic dislocation.

The prevalence of pelvic dislocation in children with CP was reported to be approximately 10% to 15%. Immediate treatment of pelvic and hip displacements is recommended to prevent an increased prevalence of morbidity and a decrease in quality of life [19]. These findings also highlight several comorbidities related to the HRQoL score in children. This is consistent with other studies that reported a strong relationship between the number of comorbidities and the HRQoL of children with CP.

This study reveals that the average HRQoL score for children with CP was 49.81 ± 20.35 , indicating a moderate quality of life. The lowest score was observed in school activities (mean 33.52 ± 30.13), while the highest score was in pain (mean 70.31 ± 29.75). This may be attributed to the fact that the children with CP in this study predominantly had severe physical disabilities, classified as level V on the GMFCS. The severity level on the GMFCS corresponded to a decrease in the average HRQoL score by 4.72 points ($p = .003$), due to deteriorating motor abilities and movement restrictions, leading to disruptions in school activities. It is crucial, therefore, that caregivers of CP patients increase their attention and understanding of the patients' conditions and needs to ensure the maintenance of their quality of life [20].

The domain of pain does not appear to be a significant issue for children with CP, despite pain being recognized as the most common comorbidity. This may be due to our assessment of the HRQoL of these children being based on parental reports rather than self-reports. This approach was necessitated by the constraints of our study population, which primarily consisted of children with CP who have severe GMFCS and BFMF levels and limited verbal language abilities. A longitudinal study reported on the HRQoL of preschool children with CP, focusing on motor function after a 6-month observation period [20]. Children with CP who have severe physical disabilities (GMFCS level V) were found to have improved motor and cognitive functions, but they also exhibited severe emotional function problems compared to those with milder disabilities. Another study highlighted the variation in the condition of children with CP across different countries, particularly in terms of the distribution of GMFCS levels and the superior HRQoL of children with CP [11,12]. A systematic review reported that children with CP aged 2 to 18 years from LMICs had a significantly lower HRQoL than their counterparts from high-income countries [5].

Previous research in Indonesia has not widely reported the

Table 5. Factor Affecting of the Health-related Quality of Life in Children with Cerebral Palsy ($N=98$)

Variables ^{a)}	B	SE	β	p
Constant	87.28	5.99		<.001
Level of GMFCS	-4.65	1.56	-.37	.004
Level of BFMF	-2.30	1.55	-.18	.140
PSI total score	-5.52	1.87	-.24	.004
Number of comorbidities	-2.95	2.47	-.10	.235

^{a)}Dependent variable: The quality of life in children with cerebral palsy (PEDSQL score); Analysis with linear regression ($R^2=0.393$); BFMF, Bi-manual Fine Motor Function; GMFCS, Gross Motor Function Classification System; PSI, Parenting Stress Index; SE, standard error.

HRQoL of parents. This study found that the mean parental HRQoL score was 55.76 (SD=8.19), a score lower than those reported in most European and East Asian countries, with the exception of Saudi Arabia [21]. The lowest mean was found in physical health (50.67 ± 8.15), while social relations scored the highest (60.69 ± 12.43). No significant correlation was found between the HRQoL of parents and that of their children ($p = .486$). Interestingly, we noted high average HRQoL scores in the social relationship domain among parents. This could be attributed to the Indonesian cultural practice of cooperation and mutual assistance, which may influence parents' perceptions in the social relation domain [22]. As the severity of motor function increased, the health burden also increased, necessitating intensive care from parents. This resulted in parents experiencing increased physical fatigue, contributing to the lowest score in the physical health domain. Several studies have explored HRQoL and related factors in parents of children with CP, including the HRQoL of the children and their functional status. These studies found no correlation between maternal HRQoL and child functional level, asserting that there is no correlation with parents' HRQoL. However, lower parenting stress levels and adequate social support play a significant role in higher HRQoL among parents [21]. Chalipat et al. [22] examined the HRQoL of caregivers of children with CP using the WHO-QOL-BREF questionnaire. They reported that caregivers' HRQoL had a low mean in all aspects, with the lowest in the social domain (9.33 ± 1.49), followed by the psychological domain (18.23 ± 1.50). Approximately 70% of parents described their HRQoL as moderate, and around 66.7% expressed satisfaction with their health condition [22].

The mean total PSI score was 94.93 (SD = 17.02), indicating that the majority of parents fell into the severe stress category. According to PSI domains, 94% of parents experienced severe stress in the PCDI domain. The mean HRQoL for children decreased by 5.46 points as parental stress severity increased, both in the total PSI score and in the PSI domains (PD, PCDI, and DC) ($p < .05$). Parenting stress can impact many aspects, particularly in terms of caring for their children, meeting their children's needs, and the effectiveness of their communication, which directly contributes to a decrease in children's quality of life by up to 5% [23,24]. A severe degree of dysfunction in parent-child interactions reflects feelings of disappointment, rejection, and a lack of bonding between the parent and child. Support from groups and professional experts is necessary to help reduce parental

stress and enhance the parent-child bond. Parent distress refers to the stress parents experience when caring for their children, leading to withdrawal from relationships, social life, and potentially causing depression. The term "difficult child" describes the characteristics of the child's behavior and its impact on the parents [23]. A study showed that the PCDI and DC domains are the main contributors to the total PSI score in parents of children with CP. Parents are more likely to experience severe stress when the child has communication loss (odds ratio [OR]=1.9; 95% confidence interval [95% CI]=1.2-3.0), severe pain (OR=1.7; 95% CI=1.1-2.4), or intellectual disabilities (OR=1.8; 95% CI=1.2-2.9) [25]. A European study comparing parents of children with CP to parents of typically developing children found that 26% of parents of children with CP experience a very severe degree of stress, five times more severe than the control group [25]. Mothers of children with CP experience more severe stress as the child's motor function deteriorates compared to mothers of typically developing children [26]. This study demonstrated a correlation between the degree of parental stress and the HRQoL of children with CP. Improved parent-child interaction can be achieved by encouraging parents to participate in support groups and seek professional intervention to reduce parental stress [27,28]. Parents who receive adequate professional support will gain a better understanding of their child's progress and acquire the knowledge and skills needed to effectively manage their child's behavior [28]. Providing early explanations related to the condition of the disease and information on parents' expectations regarding the child's functional abilities can help reduce parental stress [27,28].

This study also has limitations. We relied on proxy reports to evaluate the children's HRQoL, as most children struggle with communication and find interviews challenging. Another study has indicated that self-reported HRQoL tends to score higher than proxy reports, and that elevated stress levels in parenting can negatively impact parents' perception of their child's HRQoL [29]. This study did not collect cognitive and adaptive function tests, nor did it involve specific examinations of hearing and vision dysfunction by professional physicians. Despite these limitations, this study is the first to analyze the stress levels in parents in relation to the HRQoL of children with CP in Indonesia. As such, it can serve as a reference for future long-term intervention strategies for children with CP.

CONCLUSION

Parenting stress was found to be associated with HRQoL in children with CP. These findings suggest that healthcare professionals, such as clinicians and nurses, should offer attention, support, and counseling to parents to improve the quality of life for both the children and their parents. Identifying the most impactful and significant type of healthcare worker intervention is crucial for enhancing parenting stress and HRQoL in children with CP. The comprehensive management of children with CP should incorporate strategies for improving parental stress.

ARTICLE INFORMATION

Authors' contribution

Conceptualization: all authors; Data collection and formal analysis: all authors; Writing-review and editing: all authors; Final approval of published version: all authors.

Conflict of interest

No existing or potential conflict of interest relevant to this article was reported.

Funding

None.

Data availability

Please contact the corresponding author for data availability.

Acknowledgements

The authors would like to thank the WKCP for the contribution and the participating patients for their time and effort in this study.

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