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ORIGINAL RESEARCH

ASSESSMENT QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY, AGES 2–18 YEARS

Penilaian Kualitas Hidup Anak Usia 2-18 Tahun dengan Palsi Serebral

Alfira Nailatul Izzah[1], Irwanto Irwanto[2], Andriati Andriati[3], Prastiya Indra Gunawan[4]
[1]Faculty of Medicine, Universitas Airlangga, Surabaya, alviraizzah17@gmail.com
[2]Department of Child Health, Faculty of Medicine, Universitas Airlangga, Surabaya, irwanto@fk.unair.ac.id
[3]Department of Physical Medicine and Rehabilitation, Faculty of Medicine, Universitas Airlangga, Surabaya, andriatiwahyudi@gmail.com
[4]Department of Child Health, Faculty of Medicine, Universitas Airlangga, Surabaya, prastiya_ig@yahoo.co.id
Correspondence Author: Irwanto Irwanto, irwanto@fk.unair.ac.id, Department of Child Health, Universitas Airlangga, Mayjen Prof. Dr. Moestopo 47 Street, Pacar Kembang, Surabaya City, East Java, 60132, Indonesia.

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ABSTRACT

Background: Cerebral palsy is non-progressive disorder that can cause limited movement and lead to postural deformity in children, which can affects all the psychosocial aspects and, thus, impacts children's' quality of life as well. Assessment of quality of life is important to evaluate suitable intervention measures for children with cerebral palsy. **Purpose:** This study aims to investigate the domains and determine the quality of life in children with cerebral palsy between ages 2 and 18. **Methods:** This was a descriptive study that employed a cross-sectional design approach. Primary data was obtained through a questionnaire. This study used the pediatric quality of life inventory (PedsQL)^{TM} 3.0 cerebral palsy module. The study was conducted from November 2019 to February 2020. The data was collected at the Department of Medical Rehabilitation at the Dr. Soetomo Hospital, Peduli CP Foundation, and the Happy CP Community. This study involved 52 subjects, aged 2–18 years. **Results:** Almost all of the subjects (76.90%) had an impaired or poor quality of life. From the seven existing domains, only one domain received a good score: the domain of movement and balance. **Conclusion:** Based on the PedsQL^{TM} 3.0 cerebral palsy module, parents reported that the quality of life in children (ages 2–18 years) having cerebral palsy was still low. Only the movement and balance domain got a good score.

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ABSTRAK

Latar Belakang: *Palsi Serebral merupakan gangguan nonprogresif*

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yang mengakibatkan keterbatasan gerak dan postur pada anak-anak, yang mempengaruhi seluruh aspek psikososial anak sehingga berpengaruh juga terhadap kualitas hidup mereka. Penilaiam kualitas hidup penting untuk dievaluasi agar dapat mengetahui intervensi yang tepat untuk anak dengan palsi serebral. ***Tujuan:*** *Penelitian ini bertujuan untuk mengetahui kualitas hidup anak usia 2-18 tahun dengan palsi serebral dan menilai domain yang ada.* ***Metode:*** *Penelitian ini merupakan penelitian deskriptif yang menggunakan desain cross sectional. Pengumpulan data primer didapatkan melalui kuesioner. Penelitian ini menggunakan instrument Pediatric Quality of Life Inventory (PedsQL)^{TM} 3.0 modul palsi serebral. Pengambilan data dilakukan pada bulan November 2019 sampai Februari 2020 di Poli Rehab Medik RSUD Dr.Soetomo, Yayasan Peduli Cerebral Palsy, dan Komunitas Happy CP. Penelitian ini melibatkan 52 subjek berusia 2-18 tahun.* ***Hasil:*** *Hampir seluruh (76.90%) dari subjek memiliki kualitas hidup terganggu atau rendah. Dari tujuh domain yang ada, hanya satu domain yang memiliki kualitas hidup baik yaitu domain gerak dan keseimbangan.* ***Kesimpulan:*** *Berdasarkan PedsQL^{TM} 3.0 modul palsi serebral, laporan orang tua pada kualitas hidup pada anak usia 2-18 tahun dengan palsi serebral masih rendah. Hanya domain gerak dan keseimbangan saja yang mempunyai nilai rata-rata paling baik.*

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INTRODUCTION

One of the most common forms of motor disabilities is Cerebral Palsy (CP) (Stavsky et al., 2017). Quoted from the Global Help Organization, cerebral palsy is a movement and posture disorder that appears during infancy or early childhood (Berker et al., 2010). CP can be caused by non-progressive brain damage before, during, or several days after birth. CP is a group of disorders that can diminish a person's ability to move and maintain balance. Sometimes, this ability is completely absent. CP is more prevalent in men than in women (Centers for Disease Control and Prevention, 2020). CP is the most common motor disorder observed in childhood, with an estimated prevalence of two to three cases per 1,000 children. Population-based studies from around the world have provided an estimate of CP prevalence, which ranges from 1.50 to more than 4 per 1,000 live births or children of a defined age range (Stavsky et al., 2017). CP can impact children's quality of life (QOL). Assessment of QOL is important and should be made to examine the problem areas in chronically ill children so as to provide supportive treatment and intervention in serious cases (Vles et al., 2015).

Health-Related Quality of Life (HRQOL) can severely affect two-thirds of the children with CP. It can also affect these children's families. The dimensions of HRQOL, physical independence, mobility, and social integration, are more affected than clinical burden, economic burden, and the school dimensions. Patients with CP reported the most impaired HRQOL among all disease categories. Studies using various tools have indicated that children with CP experience a low QOL (Dobhal, Juneja, Jain, Sairam, & Thiagarajan, 2014). CP causes movement disorders in children. This situation can also interfere with the development process of the brain, which can, in turn, affect their intellectual thought patterns. There are many effects of CP. Recurring complications severely affect the QOL in children. To date, the definition of QOL itself has not changed: a subjective perception of satisfaction or happiness in life is the definition of QOL of a person (Karimi & Brazier, 2016). Three main domains can be assessed in QOL: physical, psychological, and social. The QOL can be assessed in various ways, whereby emphasis is placed on several supporting factors that impact the QOL rather than the QOL itself. Supporting factors include health conditions, including therapy, parenting style, socioeconomic status, and the environment in which the child is raised (Sekartini & Maharani, 2015).

In terms of QOL, 9% of the children who had CP were rated as good; 24% were slightly affected; 37% were moderately affected; and 30% were severely affected. Physical independence, mobility, and social integration dimensions were more severely affected by the clinical burden, economic burden, and educational factors (Dobhal, Juneja, Jain, Sairam, & Thiagarajan, 2014). In contrast, a study conducted by Shrestha, Paudel, & Thapa (2017) in Nepal suggested that QOL is quite good in children with CP, in terms of children's psychosocial conditions; however, the physical attributes were still poor or low in QOL. The QOL of children with CP in Indonesia varies. Even factors such as healthcare and the method of therapy in Indonesia can affect the QOL in children with CP. Children with CP show different clinical appearances: some have a high intellectual level, while some have low ones. The risk factors and complications that children with CP have can also vary. The purpose of this study was to investigate the domain and determine the QOL in children with CP.

METHODS

A cross-sectional study of QOL in children with CP was conducted at the Department of Physical Medicine and Rehabilitation in the Dr. Soetomo General Hospital, Yayasan Peduli CP, and the Community Happy CP. All children diagnosed with CP were included in this study from November 2019 to February 2020. The inclusion criteria was children between 2 and 18 years of age with CP. A signed consent form from parents was included so that their children could participate in this research. Primary data was collected using a questionnaire with the PedsQL 3.0 cerebral palsy module tool. The questions were translated into the Indonesian language and validated as per the guidelines established by the Mapi Trust Organization. The population for this study was 52 children.

The dependent variable was the QOL in children with CP; the independent variables were the demographic data: age (toddlers, 2–4 years; young children, 5–7 years; children, 8–12 years; and teens, 13–18 years), gender, parents, and children's education level (pre-school included early childhood education programs (PAUD) and kindergarten; primary education included elementary school; middle school was junior high school; and higher level was equivalent to senior high school and college level), parents' education level (low was elementary school; middle level was junior high school; and higher level was senior high school or college), parents' occupation (entrepreneurs, private employees, government employees, housewives among other occupations), and parents' income levels or Regional Minimum Wage (RMW) =Rp 3,900.00,00, classified as <RMW, >RMW, or =RMW. This research has passed the ethical test by the Health Research Ethics Committee in Dr. Soetomo General Hospital, Surabaya, with the ethical certificate number, worthy of ethics, 1658/KEPK/XI /2019.

RESULTS

Data Characteristics of the Subjects

There were 52 subjects with complete data that fit the inclusion criteria yet did not fulfil the exclusion criteria. Based on Table 1 (indicated below), most of the subjects were male (67.30% or 35 children). Meanwhile, almost half of the subjects were female (32.70% or 17 children). Almost half (46.20%) of the subjects (24 children) were in the largest age group, between the ages of 2 and 4 years. A small proportion (23.20%) of the subjects were between the ages of 5 and 7 years—12 children. A small proportion (21.10%) of the subjects were between the ages of 8 and 12 years—11 children, and a small proportion again (9.50%) of the subjects were between the ages of 13 and 18 years—five children. The oldest child was 16 years old. None of the subjects were over 16 years of age. Age had a mean and standard deviation of 6.31±4.08 (mean ± SD).

Table 1 indicates the data on subjects' education. Most of the subjects in this study (69.20% or 36 children) from various age groups did not attend school, especially in the age group of 2–4 years. The education level of the subjects varied: from preschool to senior high school equivalent levels. A small proportion (13.50%) of the children with CP were at the pre-school education level; their ages varied from 3 to 10 years. A small proportion of the subjects were at the kindergarten and elementary levels of education. There was only one subject who was at the junior high school level, and one subject who was at the senior high school level. This indicated that the subjects in this study were very enthusiastic about going to school and studying, even though they faced limitations. Clearly, education has no age limit.

Data Characteristics of Subjects' Parents

This study involved parents filling out a questionnaire. An examination of parents' education and occupation revealed that most of the fathers and almost all mothers, who were the subjects in this study, had sound education or were educated up to the higher levels (high school and university). This indicated that the parents of children with CP had sufficient knowledge about their children's conditions. In terms of the parents' occupation, most of the fathers (57.70%) worked as private employees. Almost all the mothers (78%) were housewives. The nature of parental occupation indicated that mothers could spend more time with their children. The fathers worked to earn the income that would help with their family's survival. Almost half (46.20%) of the subjects' parents had an income equivalent to the RMW or about Rp 3,900,000,00. There were 23 subjects whose income was more than the RMW, and only a few parents had an income below the RMW. By examining the parents' economic status, we could notice that the parents had a sufficient income in order to meet the needs of their children economically. The economic level indicated here is the income of the parents, which is a combination of the income of the father and the mother (in case the mothers worked) (see Table 2).

Table 1.
Demographic Data Distribution of Children with Cerebral Palsy

Characteristics	n	%
Gender		
Male	35	67.30
Female	17	32.70
Age (years)		
2-4	24	46.20
5-7	12	23.20
8-12	11	21.10
13-18	5	9.50
Education		
Did not attend school	36	69.20
Pre-school	7	13.50
Kindergarten	3	5.80
Elementary school	3	5.80
Junior high school	2	3.80
Senior high school	1	1.90
Total	52	100.00

Quality of Life with PedsQL™ 3.0 Cerebral Palsy module

Table 2.

A total of 52 parents answered the PedsQL™ 3.0 questionnaire. The parents' report comprised ages 2-18 years, meanwhile, the children's report was only for ages 5–18 years. Different kinds of answers were received. Only a small portion of the subjects (13.30%, or 7 children) could answer this questionnaire because these children had different intellectual abilities. In Table 3, which reveals the QOL of these subjects, almost all (76.90%) of the research subjects obtained poor scores in the QOL aspect. The questions concerning QOL were distributed to 40 children. The questions were designed based on seven existing domains. A small proportion (23.10% or 12 children) had a good QOL value. These results were based on the primary data retrieved from parents' reports. Meanwhile, the results of the children's report had n-miss (missing data), 21 in total. This was because some children could not answer the questions presented in the questionnaire. They lacked the intellectual ability to answer the questions (see Table 4). A children's report was not available for ages 2–4 years, so the number 24 (missing data) was only based on parents' report. Based on the data collected, there were only seven research subjects (out of 52) who were able to fill out the children's report. After calculating the average value from all domains, the results of their QOL obtained was good.

There were seven domains in the PedsQL™ 3.0 cerebral palsy module questionnaire. Each domain had different questions and different results (see Table 5). Based on the PedsQL guideline, there was no total score indicated; only the average or mean score for each domain was calculated. QOL was interpreted as follows: mean score ≥70 meant good, and a mean score ≤70 indicated low or disturbed (Varni et al., 2006). There were domains that were only for ages above four years: the domain of school activities, and the domain of speaking communication. In Table 5, the domain of daily activities, it can be noticed that the mean score was quite small, which indicated that the number of CP children was still low or it meant that these children were unable to carry out their daily activities (e.g., bathing alone). The domain of motion and balance produced the highest mean score, indicating that many children with CP could move and maintain their balance (indicated by the high score from the parents' answers).

Demographic Data Distribution of Subjects' Parents

Characteristics	n	%
Income Level (minimum wage)		
>RMW	23	44.20
=RMW	24	46.20
<RMW	5	9.60
Father's Characteristics		
Profession		
Entrepreneur	15	28.80
Private employees	30	57.70
Government employees	4	7.70
Other	3	5.80
Education		
Low (elementary school)	3	5.80
Intermediate (junior high school)	17	32.70
Above (senior high school or college)	32	61.50
Mother's Characteristics		
Profession		
Government employees	1	1.90
Private employees	6	11.50
Housewives	41	78.80
Other	4	7.70
Education		
Low (elementary school)	1	1.90
Intermediate (junior high school)	10	19.20
Above (senior high school or college)	41	78.80
Total	52	100.00

Table 3.
Quality of Life Children with CP Based on Parents' Report

Quality of Life	n	%
Good	12	23.10
Low or disturbed	40	76.90
Total	52	100.00

Table 4.
Quality of Life Children with CP Based on Child's Report (N=28)

	Quality of Life	n	%
Valid	Good	7	25.00
	Low or disturbed	0	0.00
Missing Data		21	75.00
Total		28	100.00

Table 5.
Mean and Standard Deviation of Each Domain (from PedsQL™ 3.0 Cerebral Palsy Module)

Domain	Mean ± SD
Daily Activities	16.66 ± 30.10
School Activities	32.62 ± 38.44
Movement and Balance	70.00 ± 20.02
Pain and Hurt	67.24 ± 19.21
Fatigue	67.12 ± 20.90
Eating Activities	44.95 ± 31.35
Speech and Communication	58.71 ± 33.86

DISCUSSION

Demographic Data Distribution of Children (with Cerebral Palsy) and Their Parents

There were 52 subjects, of which 35 were male (63.70%) and 17 were female (32.70%). Most of the children with CP were males (as was the case with previous studies). There was a greater number of male CP patients than females.

Literature written by the National Institute of Child Health and Human Development mentions that the onset of CP is marked by its appearance in the early months of life; however, most children are not diagnosed until two years of age. Therefore, most of the children with CP are between 2 and 4 years of age, and this age group distribution was the most prevalent in this study. The results of the education level indicated that out of the 52 subjects, 36 children (69.20%) did not have any education. (These children did not attend school) (Jonsson, Eek, Sunnerhagen, &

Himmelmann, 2019; Toyokawa, Maeda, & Kobayashi, 2017).

Based on the results obtained from the education level of children with CP, it can be noticed that education is very important for children with special needs, especially for children with CP. Most of the children attend special schools or schools with special needs, but some also attend public schools. Usually, school activities in both special schools and public schools also include therapy. For instance, physiotherapy can reduce the spasticity in legs, can decrease dependency, and also improve gross motor functions. However, therapy still does not change the Quality of Life (QOL) (Özkan & Zincir, 2017).

The most common parents' education level observed was middle to high school (or equivalent) and college. With regard to parents' occupation, all fathers in this study worked and held various professions. Most fathers worked as entrepreneurs and private employees. Almost all the mothers did not work and were housewives. It can be concluded that parents shared the roles in their families. The fathers worked to provide for their families, while the mothers focused on educating their children who had CP. The results of the income of parents revealed that almost half (46.20%) of the parents of children with CP had an income equivalent to the RMW, which was IDR 3,900,000.00. Also, almost half (44.20%) of the parents of the subjects had an income higher than the RMW, however, there were still some parents, five subjects, who had incomes below the RMW. It was noticed that the economic status of most of the subjects' parents was equivalent to the minimum wage. These findings differed from other studies, which suggested that parents of children with CP came from low-income families (Lowes, Clark, & Noritz, 2016; Tseng, Lee, Chou, Sheu, & Lee, 2018).

Quality of Life in Children with Cerebral Palsy

Based on parental reports and by considering subjects of various ages, it was noticed that 76.90% of the population had an impaired or poor QOL. The average value calculated, based on the answers provided to the questionnaire under one of the domains that ascertains the QOL value, was less than 70, which meant that the QOL was low or disturbed. The total number of subjects who obtained this average value was 40. In a previous study, it was revealed that mothers received a slightly higher average score than fathers, and this trend was also observed in this study (Parisi et al., 2016), however, this did not impact the percentage or the number of children who had problems with their QOL. Previous research studies conducted on the QOL in children with CP (using a questionnaire or measuring instrument instead of PedsQL) revealed that children with CP encountered disturbances in their QOL. These disturbances were associated with other factors, such as drug usage for a certain period of time, sleep quality factors among others (Anggreany, Saing, Deliana, & Dimyati, 2015; Dobhal, Juneja, Jain, Sairam, & Thiagarajan, 2014; Kołtuniuk, Rozensztrauch, Budzińska, & Rosińczuk, 2019; Parisi et al., 2016; Puspitarini, 2017; Surender et al., 2016; Vles et al., 2015).

Meanwhile, with regard to the results of the children's report, only seven children could provide answers. The rest were those between 2 and 4 years of age and those over 5 years of age. These children did not have the ability to answer. The result was that the QOL was good for these seven children because they felt that they had the enthusiasm to answer and tried to answer all of the questions. These findings differed from those obtained in previous research studies, which suggested that the ability to self-report in adolescents was weak. This led to a low QOL value in the domains of psychological wellbeing and pain (Colver et al., 2015). Another study carried by Jiang, Walstab, Reid, Davis, & Reddihough (2016) revealed similar results: The ability to self-report is associated with a high QOL value, especially in the domain of social relationships and environmental contexts. However, this same self-reporting ability led to low scores in the domains of physical health, psychology, and role function.

A value mean of ± SD of 16.66±30.10 was obtained in the domain of daily activities, which made the domain of daily activities the one with the lowest mean value compared to the other domains. In this study, the domain of daily activities still had a poor QOL, even though, from previous studies, physical activity was indicated as the key to a good QOL and happiness in young people with CP (Maher, Toohey, & Ferguson, 2016). In the domain of school activities, only children above five years of age were included. However, a small mean value was still noticed (see Table 4). Half of the children who were educated had a good quality of life. These findings are in line with the results of the study titled "Impact of School Participation on Quality of Life of Brazilian Children with Cerebral Palsy." The article suggested that children who enrolled in school had a good QOL compared to those who did not enroll (Braccialli, Silva, Braccialli, Sankako, & de Cássia Tibério Araújo, 2016).

The next domain, movement and balance, was the only domain that had the highest mean value (as noticed from the mean and standard deviation values). Physical conditions (including movement and balance) affect the HRQOL of individuals with CP. Nevertheless, in adolescents with CP, psychological and emotional aspects are more important HRQOL indicators. These indicators also affect these children's physical activity (Mohammed, Ali, & Mustafa, 2016). Pain and hurt greatly affect the QOL. A study by Findlay, Switzer, Narayanan, Chen, & Fehlings (2016) described that the presence of pain and increasing age have a negative impact on HRQOL.

The pain and hurt domain did not have a value of 0, which meant that the questions in this domain could still be answered. The fatigue domain had a low mean result, but it was the same result obtained in the domains of pain and movement and balance (which had a minimum value not equal to 0). Fatigue is related to the QOL. If fatigue increases, the QOL will decrease in adolescents or adults who have bilateral CP (Lundh, Nasic, & Riad, 2018). The last two domains, the domain of eating activities and speech and communication (only noticed in ages over five years), also indicated a low mean value. Therefore, all domains had an impact on the QOL; however, the domains of pain, fatigue, movement and balance were the most influential in impacting the QOL in children with CP.

Research Limitations

There was no data present motor systems, thus, we employed the gross motor function classification system to score children with CP. Additionally, the author did not record medical data in this research (e.g., the type of CP and the risk factors associated with CP).

CONCLUSION

The QOL in children with CP, between 2 and 18 years of age, was low. The parents' report and the children's report indicated a different value, with the children's report showing a value higher than the parents' report. Among the seven domains, the movement and balance domain was the only domain that had a good mean score.

CONFLICT OF INTEREST

The authors declare that no conflict of interest in this study.

AUTHOR CONTRIBUTION

ANI, II, and AA: conseptualization and methodology. ANI: gathering data, analysis data and writing original draft. II, AA, and PIG: verified article, revision of the article and supervised. II, AA, and PIG: reviewing. ANI: writing and editing final manuscript. All authors read and approve the final manuscript.

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