

ORIGINAL ARTICLE

Quality of Life among Parents of Cerebral Palsy Children

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ABSTRACT

Introduction: Parents have a heavy burden and responsibility to their children. Cerebral palsy children are dependent on their parents due to their limitations. Having cerebral palsy children impacts parent's QoL. Research related to this is still lacking in Indonesia. Therefore, this study aims to describe the QoL and its domain among parents of cerebral palsy children. **Methods:** The study was quantitative descriptive. The respondents were 36 parents of cerebral palsy children from two special needs schools taken by convenience sampling. The QoL was measured using the Indonesian version of Family QoL (FQoL). Data were analyzed using univariate and bivariate analysis using chi-square. **Results:** The results presented that 91.7% of respondents had a high QoL, and 8.3% had a low QoL. All domains were in the high category: parenting 94.4%; family interaction 91.7%; emotional well-being 88.9%; physical well-being; and disability-related support at 86.1%. The results of the bivariate analysis showed that parental age had a significant relationship with parental QoL ($p=0.042$), while parents gender ($p=0.747$), parents education ($p=0.295$), job status ($p=0.250$), marital status ($p=0.764$), family income ($p=0.500$), child's age ($p=0.580$), child's gender ($p=0.585$), and the degree of cerebral palsy ($p=0.411$) do not have a significant correlation with the parents' QoL. **Conclusion:** Parents of cerebral palsy mainly had a high QoL. The highest domain was parenting, while the lowest was disability-related support. Parental age has a correlation with parental QoL. Thus, nurses need to continue to support parents of cerebral palsy children's for adapting through the socialization of a disability-friendly environment.

Keywords: Cerebral Palsy, Children, Parents, QoL**Corresponding Author:**

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INTRODUCTION

Cerebral palsy is one type of motor disability that is quite severe in children and greatly impacts families (1). The prevalence of cerebral palsy children worldwide is 1-15 out of 1,000 childbirths. Based on the Indonesian Basic Health Survey, the prevalence of cerebral palsy children in Indonesia at the age of 24-59 months was reported to be 0.09% (2).

Most cerebral palsy children experience posture disorder due to non-progressive brain development disorders that imply limited child activity (3). In addition, children with cerebral palsy will also experience damage to vision, hearing, speech, and intelligence that lasts a lifetime (4). Thus, it has a significant impact on children's development. Children are very dependent on their families. The progress of a child's development to achieve a level of independence and QoL ultimately depends on the commitment and dedication of the family (5).

These conditions can harm parents, in terms of physical health problems, disturbed sleep, lack of social relationships, financial burden, parenting burden, and limited support from the community (6). Moreover, parents also experience disruption concerning work and financial stability in the family (7). Parents also report that they are worried about the future of their cerebral palsy children.

Having disabilities can impact the stigma from others, yet it impacts the QoL (8-10). Therefore, caring for cerebral palsy children may impact all dimensions of parents' QoL as the primary caregiver. Low QoL will adversely affect the care provided by parents to their children (7). Various studies are continuing to examine which dimensions of QoL are most affected. There are at least four dimensions of QoL of parents who have children with cerebral palsy: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support.

Another study stated that parents of cerebral palsy children experience severe parenting stress due to difficulties in childcare. These difficulties include child dependence, behavioral problems, emotional control, and child anxiety (11). While another study concluded

that physical and material problems were the worst dimensions experienced by parents (6).

A study in Italy concluded that the physical and psychological domains were low (12). Studies on parents' QoL with cerebral palsy's children have previously been conducted in Indonesia. The study stated that mothers with cerebral palsy children have a moderate QoL. The study also says that the QoL of mothers with children with cerebral palsy is related to the background of family conditions (economic, education, employment status, and age) (13). Other research also concluded a significant positive relationship between rugged personality and the QoL of mothers with cerebral palsy children (14). Another study in Cambodia found that parents' three main domains (health, material well-being, and emotional well-being) were unsatisfactory, and health problem was the worst (15). Information about which dimensions are most problematic is essential so nurses can provide specific interventions according to the parent's needs in the diverse context of Indonesian culture.

Studies on the QoL of parents with cerebral palsy children in Indonesia were still limited. Previous studies have focused on studying the QoL of the mothers but not focusing on the dimensions of QoL. (13). This study conducted research of QoL of cerebral palsy children's parents (both mothers and fathers), also identified the dimensions of QoL (parenting, family interaction, emotional well-being, and physical-material well-being), and the correlation between parent's characteristics and their QoL level.

MATERIALS AND METHODS

Study design

This study was a quantitative descriptive study with a cross-sectional approach. Data collection was carried out from June to August 2019.

Participants and setting

The population in this study were parents of children with cerebral palsy who attended two special schools [Educational School for Children with Disabilities Bandung or YPAC (Yayasan Pembinaan Anak Cacat [Children with Disability Development Foundation]) for Bandung Municipality area and Cileunyi State Special School (SLB Negeri Cileunyi) for Bandung District area. The selection of these two special schools is because only these two special schools accommodate children with cerebral palsy in each of area. The population was 45 parents of cerebral palsy children. The sampling technique used convenience sampling with the total of 36 respondents (80% of response rate) consisting of 18 parents from YPAC Special Need School and 18 parents from Cileunyi State Special School.

Ethical considerations

The ethical clearance was obtained from the Universitas Padjadjaran Ethical Committee on June 10, 2019, 727/UN6.KEP/EC/2019. Also, we had obtained research permission from YPAC Special Need School with letter number 148/SLB-DYPACBDG/VI/2019 and Cileunyi State Special Need School with letter number 421.9/023/C.1/VII/2019. Respondents' involvement was voluntary, and they could withdraw from the study without any consequences.

Data collection

Parents' QoL was measured using the Indonesian version of Family QoL (FQoL) instruments. Family Quality of Life (FQoL) instrument is developed by the Beach Center on Disability at the University of Kansas, USA. The FQoL instrument used in this study was back-translated by the Institute for Language & Professional Education – Lembaga Indonesia Amerika (LIA or the American Indonesian Institute). Family Quality of Life (FQoL) questionnaire consists of 25 question items divided into five domains, with a minimum score of 25 and a maximum score of 125. The domain of variables consists of family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. The Indonesian version of the FQoL instrument had an r-value ranged from 0.394 to 0.914, and greater than the r table (0.329). It indicates that the instrument is valid. In addition, the reliability test had a Cronbach alpha value of 0.973 (greater than 0.6).

Data Analysis

The FQoL scale uses satisfaction as the primary response format. The items rated on satisfaction are rated on a 5-point scale, where 1=very dissatisfied, 3=neither satisfied nor dissatisfied, and 5=very satisfied, with an overall score minimum is 25 and maximum is 125. The higher the score represents the better the QoL (19). FQoL categorization can be done based on the mean or median score (16). This study categorized QoL and each domain using the median and divided it into two categories (high and low categories). For FQoL, they were included in the high category if the median score was ≥ 75 ; and low if the median score was < 75 . Furthermore, each domain was divided into two categories: high and low with the cut off points for each domain: family interaction 18; emotional well-being 12; physical well-being 15; and disability-related support 12. After the respondent's score is higher or equal to the cut value, it is categorized as high and vice versa. Furthermore, we did chi-square test to identify the correlation between the QoL with the characteristics of parents (age, gender, education, occupation, income, and marital status of parents) and children (age, gender and level of cerebral palsy of children).

RESULTS

Almost half of parents were in late adulthood, dominated by female, married, graduated from high school and not

working. Most of them had an estimated monthly family income of more than Rp. 3,339,580. The children in this study were predominantly early teens (12-16 years), almost half of them were boys, and the severity of cerebral palsy was moderate (Table I).

QoL

It is found that almost all parents have a high QoL (91.17%), and a small proportion of respondents (8.3%) have a low QoL. The disability-related support has the lowest percentage (86.1%) of the five domains in QoL, while the highest rate is in the domain of parenting which is 94.4% (Table II).

Table I. Characteristics of Respondents (n=36)

Characteristics	Frequency (f)	Percentage (%)
Parents Age		
Early Adulthood (26-35 years old)	4	11.1
Late Adulthood (36-45 years old)	14	38.9
Early Elderly (46-55 years old)	13	36.1
Late Elderly (56-65 years old)	5	13.9
Parents Gender		
Male	12	33.3
Female	24	66.7
Last Education		
Not going to school	0	0
Elementary School	3	8.3
Junior High School	3	8.3
Senior High School	20	55.6
College	10	27.8
Job Status		
Working	15	41.7
Not Working	21	58.3
Marital Status		
Married	33	91.7
Divorced	3	8.3
Income		
<Rp. 3.339.580	15	41.7
>Rp. 3.339.580	21	58.3
Child's Age		
School Age (5-11 years old)	8	22.2
Early Adolescent (12-16 years old)	16	44.4
Late Adolescent (17-25 years old)	12	33.3
Child's Gender		
Male	20	55.6
Female	16	44.4
Degree of Cerebral Palsy		
Mild	12	33.3
Moderate	19	52.8
Severe	5	13.9

The Correlation between Respondent Characteristics and QoL

All nine respondent characteristics do not have a significant correlation with the family's quality of life, except for the age of the parents which is significantly related to the quality of life of family (p=0.042; $\alpha=0.05$) (Table III).

DISCUSSION

This study indicates that most parents had high scores of QoL. This finding was contrary to the previous studies in Indonesia, where most of the parents' QoL tends to be low (13). In general, the parenting domain was the domain

Table II: Frequency Distribution by Parent's Quality of Life and It's Domains (n=36)

Variable:	Frequency (f)	Percentage (%)
Quality of Life		
Low	3	8.3
High	33	91.7
Sub Variable:		
Family Interaction		
Low	3	8.3
High	33	91.7
Parenting		
Low	2	5.6
High	34	94.4
Emotional Well-being		
Low	4	11.1
High	32	88.9
Physical Well-being		
Low	4	11.1
High	32	88.9
Disability Related Support		
Low	5	13.9
High	31	86.1

with the highest score. Nevertheless, some items have the lowest scores on the question "My family members help my cerebral palsy child do their schoolwork and activities". This situation could happen because family members cannot fully help children do schoolwork and activities. Therefore, this aspect needs to be further improved. The third domain is emotional well-being that describes the support given by the closest people to relieve stress. In this study, the emotional well-being domain had a low score. The question item that had the lowest score was: "My family gets help from outside to take care of the special needs of all family members." This question has the lowest score of all the questions items in the FQoL instrument. It can be interpreted that the surrounding community does not provide much help for the necessities needed by the family. Support from the community, such as the closest neighbors and local communities, is essential for parents. This support helps parents to survive and understand what they need in parenting (17).

Thus, the domain of disability-related support describes support for family members who have conditions with special needs. This support comes from outside or within the family, including support for socializing with peers, achieving goals at school, educational and health access, and services for the child. This study shows that the disability-related support domain has the lowest score compared to the four domains. This study indicates that children with special needs have not received support to make friends with their peers. Parents in this study revealed that their children often received bullying from their peers. This condition limits the child's ability to socialize. Families also do not have access to adequate health care, whereas parents need much information about the special care of their children. Chambers stated that health care providers must always pay attention by communicating effectively and exchanging information with families of disabled children (18).

Table III: The Correlation between Characteristics of respondents and Parent's Quality of Life (n=36)

Characteristics of Respondents	Quality of Life				Total	%	p-value
	Low		High				
	f	%	f	%			
Parents Age							
Early Adulthood (26-35 years old)	0	0	4	11.1	4	11.1	0.042*
Late Adulthood (36-45 years old)	0	0	14	38.9	14	38.9	
Early Elderly (46-55 years old)	1	2.8	12	33.3	13	36.1	
Late Elderly (56-65 years old)	2	5.6	3	8.3	3	13.9	
Parents Gender							
Male	1	2.8	11	33.3	12	36.1	0.747
Female	2	5.6	22	61.1	24	66.7	
Last Education							
Not going to school	0	0	0	0	0	0	0.295
Elementary School	1	2.8	2	5.6	3	8.4	
Junior High School	0	0	3	8.3	3	8.5	
Senior High School	2	5.6	18	50.0	20	55.6	
College	0	0	10	27.8	10	27.8	
Job Status							
Working	0	0	15	41.7	15	41.7	0.250
Not Working	3	8.3	18	50.0	21	58.3	
Marital Status							
Married	3	8.3	30	83.3	33	91.6	0.764
Divorced	0	0	3	8.3	3	8.3	
Income							
< Rp. 3.339.580	2	5.6	13	36.1	15	41.7	0.500
≥ Rp. 3.339.580	1	2.8	20	55.6	21	58.4	
Child's Age							
School Age (5-11 years old)	0	0	8	22.2	8	22.2	0.580
Early Adolescent (12-16 years old)	2	5.6	14	38.9	16	44.5	
Late Adolescent (17-25 years old)	1	2.8	11	30.6	12	33.4	
Child's Gender							
Male	2	5.6	18	50.0	20	55.6	0.585
Female	1	2.8	15	41.7	16	44.5	
Degree of Cerebral Palsy							
Mild	2	5.6	10	27.8	12	33.4	0.411
Moderate	1	2.8	18	50.0	19	52.8	
Severe	0	0	5	13.9	5	13.9	

f: frequency; %: percentage

The finding indicates that most parents had high scores in the physical/material domain. Its domains describe physical health and material well-being such as medical care, dental care, having a personal vehicle to carry out, managing expenses, and feeling safe in the neighborhood. Contrary, the parents' behavior in supporting dental care is still low, even though dental care for children with cerebral palsy is critical. Bensi stated that neuromuscular dysfunction related to children with cerebral palsy may affect oral health due to changes of orofacial structure, development of parafunctional habits, nutritional problems, and difficulties in observing oral hygiene (19). Also, many other health problems can be affected by oral health in children with cerebral palsy, as well as dental caries, anterior open bite, sleep disorder breathing (including

sleep apnea), and others (19).

This study concludes that parental age is related to quality of life. The group of respondents who had the highest QoL score in the high category was in the group of late adulthood parents. The older a person is, the more mature the way they see things (13). Moreover, with increasing age, parents are increasingly adapting to their children's conditions (13). These situations allow for better emotional aspects in parents.

The limitation of this study included that the sample in this study was obtained based on data from special need schools. Because the number of cerebral palsy children attending school is limited, the number of samples in this study is also limited. Further study is needed to identify

the quality of life of families using a larger sample, both from school and community-based, including parents and siblings. Furthermore, it is necessary to examine how the influence of demographic factors on the QoL of parents who have children with cerebral palsy.

CONCLUSION

The QoL of parents who have cerebral palsy children was mainly in the high category. Furthermore, based on the QoL domain, the domains with the highest to the lowest score are parenting, family interaction, emotional well-being, physical/material well-being, and disability-related support. However, a small proportion of parents have low QoL scores. Therefore, they need special attention from nurses, families, and local communities to provide support and care for families who have children with cerebral palsy particularly in the disability-related support domain. Pediatric and community nurses need to raise awareness of the local community to provide support and care for families with cerebral palsy. Families also need to be well connected with health care providers.

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