

Visit to the Disability Integrating Health Post and Its Effect on the Quality of Life of Children with Cerebral Palsy: A Multivariate Evidence from Sukoharjo, Central Java

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ABSTRACT

Background: An assessment of the quality of life of children with cerebral palsy is important to be carried out, as part of the indicators of achieving health service delivery goals. To facilitate access to health services for children with disabilities, the government of Sukoharjo District established an integrated health post (posyandu) for children with disabilities called inclusion centers. This study aimed to determine the quality of life of children with cerebral palsy who receive services at the inclusion center.

Subjects and Method: This was a cross-sectional study conducted in 12 inclusion centers in Sukoharjo, Central Java. A sample of 100 children with cerebral palsy (CP) aged 4-18 years old was selected by fixed disease sampling. The dependent variable was the quality of life of CP children. The independent variables were the level of gross motor function capability, parental coping, quality service, and frequency of posyandu visits. Gross motor function capability was measured by Gross Motor Function Classification System (GMFCS). Quality of life was measured by the Cerebral Palsy Quality of Life (CP-QOL) version of the parent proxy. Data collection used question-

naire and analyzed by a multiple linear regression run on Stata 13.

Results: Better quality of life of children with cerebral palsy was influenced by lower GMFCS levels ($b = -128.72$; 95% CI = -220.34 to -37.10 ; $p = 0.006$), good parental coping ($b = 18.87$; 95% CI = 10.85 to 26.89 ; $p < 0.001$), good service quality ($b = 20.79$; 95% CI = 9.99 to 31.59 ; $p < 0.001$), and more frequent visits to posyandu ($b = 214.86$; 95% CI = 56.66 to 373.15 ; $p = 0.008$).

Conclusion: Quality of life of children with cerebral palsy is influenced by lower GMFCS levels, good parental coping, good service quality, and more frequent visits to posyandu.

Keywords: quality of life, disability, cerebral palsy, integrating health post (posyandu)

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BACKGROUND

Access to health services for rehabilitation for persons with disabilities is often limited especially in low and middle income countries (Bright et al., 2018). A study in Latvia showed difficulties in accessing services for dis-

abilities, lack of coordination, delay in handling, unavailability of therapists, and lack of financial capacity to obtain services. Most respondents (70%) said that their children received good services (17.9%), were quite good (62.5%), were not good (14.3%), and did

not receive rehabilitation services at all (5.3%). More than half of the respondents (62.5%) stated that rehabilitation services were not available in their communities (Greitane et al., 2012).

Whereas affordable and high-quality services should be available for all who need it (WHO, 2017). This is the main rationale for Universal Health Coverage (UHC), which is defined as, "ensuring all people have access to the promotive, preventive, curative, rehabilitative, and palliative services they need, with sufficient quality to be effective, while ensuring that the use of this service does not cause users financial difficulties", (WHO, 2018).

Unfulfilled needs for rehabilitation services have an impact on limited activities, limited participation, and can lead to poor health and quality of life (World Report on Disability, 2011). To facilitate access to services for children with disabilities, the government of Sukoharjo District has formed an inclusion center that functions as a posyandu. The services provided are physiotherapy, occupational therapy, speech therapy, and counseling from psychologists. Children who use the services are children with cerebral palsy, Down syndrome, intellectual disability, hearing and speech impaired, autism, attention deficit hyper-activity disorder (ADHD), speech delay and developmental delay.

Assessment of the quality of life of children with cerebral palsy includes social biopsychology (Chen et al., 2014). These aspects include; body structure and function, one of which is the level of ability of gross motor functions, and factors related to parents, such as parental coping abilities. Besides these factors, Zheng et al. (2013) stated the quality of services provided affects the quality of life of people with disabilities service.

SUBJECTS AND METHOD

1. Study Design

This was an analytic observational study with a cross sectional design. The study was conducted in 12 inclusion centers in Sukoharjo, Central Java, in October 2019.

2. Population and Sample

The population in this study were children with a diagnosis of cerebral palsy aged 4-18 years old who visited the disability service center at Sukoharjo inclusion center. A sample of 100 children with cerebral palsy was selected by fixed disease sampling.

3. Study Variables

The dependent variable was the quality of life. The independent variables were the level of gross motor function ability, parental coping, perceived service quality, and frequency of visits to posyandu.

4. Operational Definition of Variables

The level of ability of gross motor function measured through the ability to move and coordinate the body which involves the work of large muscles such as standing, walking, running, and jumping which can be done by the children. The data were measured by Gross Motor Function Classification System (GMFCS). The measurement scale was continuous.

Parent's coping was seen by assessing parents' efforts both cognitively and behaviorally in dealing with stressful conditions. The data were measured by the Coping Health Inventory for Parents (CHIP). The measurement scale was continuous.

Perceived service quality was assessed through the provision of services that the patient seems to exceed expectations and to achieve the highest clinical outcome possible with the available resources. The data were measured by the Quality of Care and Support (QOCS) questionnaire for people with disability. The measurement scale was continuous.

The frequency of visits was measured by looking at the frequency of visits to the inclusion studio services every week. The data were collected by questionnaire. The measurement scale was continuous.

5. Data Analysis

Univariate analysis generally described each of the variables studied included quality of life, level of GMFCS, parent coping, quality of service, frequency of visits. Bivariate analysis explained the effect of each one independent variable (GMFCS level, parental coping, perceived service quality, and frequency of visits) on one dependent variable (quality of life). Multivariate analysis explained the effect of more than one independent variable (GMFCS level, parent's coping, service quality, frequency of visits) on the quality of life of cerebral palsy children.

6. Research Ethic

This study was conducted based on study ethics, namely informed consent anonymity, confidentiality, and ethical clearance. Ethics permission in this study was obtained from the Health Research Ethics Commission of Dr. Moewardi Hospital, Surakarta, Indonesia, No. 1.074/X/HREC/2019.

RESULTS

1. Univariate analysis

Univariate analysis is shown in tables 1 and 2. Table 2 shows the results of the categorical data analysis which explained that most of

the children were male with 65 children (65%), most were <11 years old, who were 60 children (60%). The occupation of caregivers was housewife, with the largest percentage (64%), with a mean age of 37.81 years. The percentage of GMFCS levels from level 1 to 5 were 12%, 19%, 22%, 23%, and 24%. Most parents have good coping, which was 63 people (63%). Perceived service quality was good by the majority of samples (55%). A total of 84 respondents (84%) had a good frequency of visits and most cerebral palsy children had a good quality of life, who were 57 children (57%).

2. The result of multivariate analysis

Multivariate analysis was using multiple linear regression run on Stata 13. Table 3 was a multiple linear regression analysis of variables that affect the quality of life of CP children. This table showed the influence of GMFCS levels, parent coping, service quality, and frequency of visits to the quality of life of cerebral palsy children.

Low levels of GMFCS (b= -128.72; 95% CI= -220.34 to -37.10; p= 0.006), good parental coping (b= 18.87; 95% CI= 10.85 to 26.89; p= 0.001), good quality of service (b= 20.79; 95% CI= 9.99 to 31.59; p= 0.001), and frequency of visits to posyandu ≥3x/month (b= 214.86; 95% CI= 56.66 to 373.15; p= 0.008) increased the quality of life of children with cerebral palsy.

Table 1. Sample characteristics of continuous data

| Variables | n | Mean | SD | Min. | Max. |
|---------------------------|-----|---------|--------|------|------|
| Age of children (year) | 100 | 8.16 | 3.86 | 4 | 18 |
| Age of caregiver (year) | 100 | 37.81 | 6.82 | 25 | 62 |
| Parents coping | 100 | 95.49 | 16.12 | 45 | 126 |
| Perceived service quality | 100 | 63.86 | 10.74 | 43 | 81 |
| Frequency of visits | 100 | 3.59 | 0.87 | 1 | 4 |
| Quality of life | 100 | 4535.25 | 801.36 | 2287 | 6400 |

Table 2. Sample characteristics of categorical data

| | Variables | Frequency | % |
|------------------------------------|----------------------------|------------------|----------|
| Gender | Male | 65 | 65 |
| | Female | 35 | 35 |
| Age | Median <11 years old | 60 | 60 |
| | Median> 11 years old | 40 | 40 |
| Parents employment | Housewife | 64 | 64 |
| | Civil Servant | 1 | 1 |
| | Employees | 8 | 8 |
| | Entrepreneur | 27 | 27 |
| GMFCS | Level 1 | 12 | 12 |
| | Level 2 | 19 | 19 |
| | Level 3 | 22 | 22 |
| | Level 4 | 23 | 23 |
| | Level 5 | 24 | 24 |
| Parents coping | Poor (score <95) | 37 | 37 |
| | Good (score ≥95) | 63 | 63 |
| Quality of service | Poor (score <63) | 45 | 45 |
| | Good (score ≥63) | 55 | 55 |
| Frequency of visits | Lack of visit (<3 x/month) | 16 | 16 |
| | Good visit (≥3 x/month) | 84 | 84 |
| CP children quality of life | Poor (score <4,535) | 43 | 43 |
| | Good (score ≥4,535) | 57 | 57 |

Table 3. Multiple linear regression analysis of factors affecting the quality of life of children with cerebral palsy

| Independent Variables | b | 95% CI | | p |
|---------------------------|---------|-------------|-------------|--------|
| | | Lower Limit | Upper Limit | |
| GMFCS | -128.72 | -220.34 | -37.10 | 0.006 |
| Parent's coping | 18.87 | 10.85 | 26.89 | <0.001 |
| Perceived service quality | 20.79 | 9.99 | 31.59 | <0.001 |
| Frequency of visits | 214.86 | 56.66 | 373.15 | 0.008 |

Number of observation= 100

R - Squared (R²)= 54.2%

p<0.001

GMFCS: Gross Motor Function Classification System

DISCUSSION

1. The effect of the level of gross motor function classification system (GMFCS) on the quality of life of children with CP

Body structure and function have a great influence on the quality of life of CP children (Chen et al., 2014). Boling et al. (2013) stated that the level of GMFCS is directly related to physical health, bodily functions, and the level of children's participation. Previous study found that the level of gross motor function (GMFCS) affected the quality of life of CP children (Boling, et al., 2013; Ibrahim et

al., 2016; Surender et al., 2016 and Ramadhani et al., 2018). At a lower GMFCS level, it allowed children to do activities better. This was in accordance with Palisano et al. (2011) who stated that children with higher physical abilities, have limited activity and lower participation than children with lower physical abilities. The better the gross motor function ability, the better the level of participation.

This was also stated by Tseng et al. (2011) that the level of gross motor skills affected children's daily functions. Physical activity and participation include mobility, self-care and interpersonal interaction, which

significantly influence the quality of life of CP children (Park et al., 2016). Maher et al., (2015) revealed that the ability of physical activity is better, significantly related to the quality of life and happiness of children with CP.

2. The effect of parental coping on the quality of life of children with CP

Parent's coping has been proven to affect the quality of life of CP children. Chen et al. (2014), explained that family functions, such as parenting abilities and coping abilities have an influence on children's behavior problems. Knowledge of parental coping strategies was also important and useful for the development of therapeutic interventions aimed at facilitating the adaptation of families with children with disabilities (Krstic et al., 2012). A good parent's coping allowed good parenting for cerebral palsy children. Good parenting has been shown to significantly influence the quality of life of children with cerebral palsy (Pangestu et al., 2017).

Inclusion centers can be a supporting source for parents of CP children. This disability posyandu is a place to meet and socialize for parents to be able to share experiences in the care of CP children. In addition, there is also a psychologist who visits once a month, to help provide motivation and help with consultation. Therefore, this can become a source of support and increase the ability of parenting and coping strategy capabilities that are important for caring for CP children. Thus it would have an impact on improving the quality of life of CP children (District Health Office of Sukoharjo, 2019).

3. The effect of service quality on the quality of life of CP children

Good quality health services can significantly improve the quality of life of people with disabilities (Zheng et al., 2014). Greitane et al. (2012), found that the quality of life of CP children was influenced by medical interventions that were able to facilitate improved

gross motor function. And with regular and efficient physiotherapy can improve the physical health of CP children. In this study, there were 55 parents of CP children (55%), who had the perception that the quality of services provided at the inclusion studio was good. This can be caused by several things, among others; access to services that are closer and easier to reach, easy to get services, (no need for a referral letter or insurance card), do not require long queues, and do not need to spend any costs at all (Health Office of Sukoharjo Regency, 2019).

4. The effect of frequency of visits on the quality of life of CP children

A visit to get health services, especially regular and efficient physiotherapy, has proven to be able to improve the physical health of CP children (Greitane et al., 2012). The results of this study indicated that children with a higher frequency of visits (34x/month) have a better quality of life than fewer visits (1-2x/month).

AUTHORS CONTRIBUTION

Retno Dwi Rohaniyati collected and analyzed data, and wrote the draft. Harsono Salimo formulated the conceptual framework. Eti Poncorini Pamungkasari wrote the study methods and discussion.

CONFLICT OF INTEREST

There was no conflict of interest in this study.

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