Egyptian Journal of Physical Therapy (EJPT)

Egy. J. Phys. Ther. 2024; 18:42-47

Original article

https://ejpt.journals.ekb.eg

Quality of Life in Educated and Non-Educated Cerebral Palsy Children

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Published online:
June 2024

Abstract:

Purpose: The main objectives of this study are to clarify whether cerebral palsy has an impact on children's quality of life (QOL). In addition, highlighting the difference in quality of life between educated and non-educated cerebral palsy children.

Methods: Care givers of five hundred of cerebral palsy children, aged between 4 to 12 years, from different governmental hospitals and private centers were screened by spreading the Cerebral Palsy Quality of Life Questionnaire for Children (CPQOL - Child). After completing the initial data collection, data was analyzed through Statistical package of social science (SPSS) version 20.

Results: The study results showed that the score of quality of life for children was higher in preparatory education which it ranged from 41.42-78.17 with mean value 61.13 ± 12.81 and median 60.38 followed by primary education 20.19-79.10 with mean value 56.97 ± 13.06 and median 59.89, while the lowest score was in does not study cases 12.12-73.81 with mean value 39.95 ± 14.55 and median 39.21.

Conclusion: Cerebral Palsy has a negative effect on the children's quality of life compared to normal healthy children and that education has a real positive impact on the children's quality of life since providing education to cerebral palsy children would improve their intellectual abilities and therefore improves their overall quality of life.

Key words:
Cerebral Palsy, Quality of life, Education, Questionnaire, CPQOL -Child.

1.Introduction

With incidence rates in the range of 2 to 2.5 per 1000 live births, cerebral palsy (CP) is the most common cause of childhood disability. Damage to the developing brain causes the non-progressive medical illness known as cerebral palsy, which, depending on where it occurs, can cause problems with movement, spasticity, cognition, communication, and behaviors (1).

Spastic, dyskinetic, and ataxic cerebral palsy are the three kinds that are distinguished based on the predominating motor disability. Spastic cerebral palsy is further broken down based on the number of afflicted limbs. For instance, hemiplegia only affects one side of the body, diplegia just hits the legs, and quadriplegia affects all four limbs. While ataxic diseases are linked to issues with coordination, muscular tone, and balance,

Pleas cite this article as follows: Amal Y. Wahba, Ola M. Elgohary, Haitham A. Elessawy, Nouran I. Mohamed. Quality of life in educated and non-educated cerebral palsy children. EJPT. 2024; 18:42-47.

dyskinetic cerebral palsy (athetoid and dystonic) is related with varying or stiff muscle tone (1).

Additionally, studies have indicated that children with disabilities are more likely to experience mental health issues, such as conduct or mood disorders. Thus, while contemplating a comprehensive approach to care and wellbeing, the study of quality of life is thought vital (2).

Although there has been a lot of research on children with CP's quality of life (QOL), the results have been inequitable. While some studies suggest that children's QOL is on par with that of their peers who are normally developing (TD), others claim that QOL is lower than would be predicted (3).

Some of the disparities in research findings could be attributed to challenges evaluating QOL/Health Related Quality of Life (HRQOL) in populations with cerebral palsy (such as communication issues, the wide variety of impairments children may suffer, and a lack of validated measures) (4).

Some of the disparities in research findings could be attributed to challenges evaluating QOL/Health Related Quality of Life (HRQOL) in populations with cerebral palsy (such as communication issues, the wide variety of impairments children may suffer, and a lack of validated measures) (5).

In the absence of emotional distortion, cognitive impairment, and learning problems, children with CP can self-report their reliability quality. However, it could be challenging to get trustworthy information from those who have communication issues and mild to major intellectual disability. Therefore, to obtain accurate information about Quality of Life, parents, particularly mothers, need to be questioned (6).

The International Classification of Functioning, Disability and Health (ICF) Framework is the foundation of the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-child), a global tool designed specifically for CP. It was created in partnership with parents and kids with cerebral palsy by an international multidisciplinary group of clinical and child health researchers (7).

2.Patients and Methods:

2.1. Study participants and recruitment criteria:

Care givers of a total number of 500 cerebral palsy children, their age range between 4-12 years who receives service from pediatric units were engaged in the study. In this study convenient sampling technique was used. Randomization method was used through a set of tamper-evident envelopes were provided to each participating site among Cerebral Palsy children to determine the quality of life in Cerebral Palsy children, considering the inclusion – exclusion criteria of the patients, who came to pediatric units.

2.2. Study Design:

A cross-sectional survey design was used for describing and quantifying variables present in CP-QOL questionnaire over a study population as shown in (**Table 1**) at point of time. The study was conducted between May 2022 till January 2023.

2.3. Methods: Cerebral Palsy Quality of Life Questionnaire for Children (CPQOL -Child) which measures Quality of Life (QOL) across seven domains was used, it has 88 questions, some of which are about the parents themselves, covering topics like family and friends, school, involvement, communication, health, special equipment, pain and inconvenience, access to services, and a few questions about their own lives. The questions are divided into seven categories: overall acceptance and well-being, physical and communicative health, school and social well-being, services access, family health, and feelings about functioning. Parents were notified that inquiries about their adolescent's life, including his or her family, friends, health, and school, are made. The first sentence of every query is "How do you imagine your child FEELS about." The parent was given a 9-point visual analog scale with 1 denoting extreme unhappiness and 9 denoting extreme happiness in order to elicit a response. They were instructed to circle the one that best fit them (8).

Data was collected from patients present in pediatric units (outpatient and inpatient) through CP-QOL questionnaire which was turned to a google form and it was spread by sending the form to the children's caregiver(s), so they fill the form and submit the responses back.

Illiterate parents and those without smartphones who were unable to fill the google form, a consent form was obtained from them, and data was collected from the participants by face-to-face conversation then their responses was filled in the google form by the researcher and submitted.

Statistical Analysis:

After completing the initial data collection, every questionnaire was checked again to find out any mistakes or unclear information. Data was analyzed through Statistical package of social science (SPSS) version 20 through descriptive statistics, Mann Whitney test and Kruskal Wallis test.

4. Results:

Age ranged from 4-12 years with mean value 6.67 ± 2.43 and median 6.0 (4.50 – 8.0). Regarding education, cases who doesn’t study were

higher with 274(54.8%) followed by study cases 226(45.2%) and primary cases 163(32.6%). Urban cases were higher with 382(76.2%) while rural cases were 118(23.6%).

Regarding father job, employee cases were higher with 186(37.2%) followed by free business cases 117(23.4%) and professional 106(21.2%), while working mothers were higher with 401(80.2%) as shown in (**Table 2**) and illustrated in **Fig. (1) and (2).**

Table (1) Distribution of the studied sample regarding the governorate.

Governorate	Number of children
Alexandria Governorate	248
Al-Beheira Governorate	202
Kafr Al sheikh governorate	50

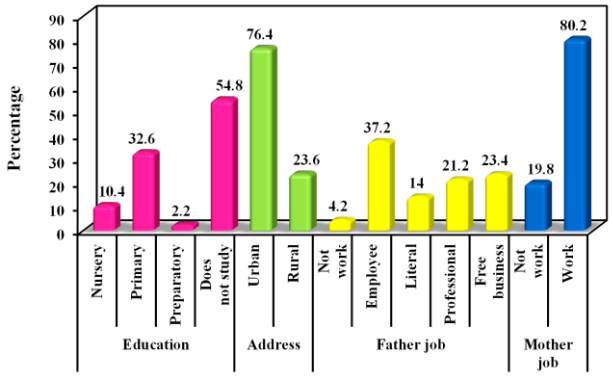

Fig. (1): Distribution of the studied cases according to demographic data (n = 500).

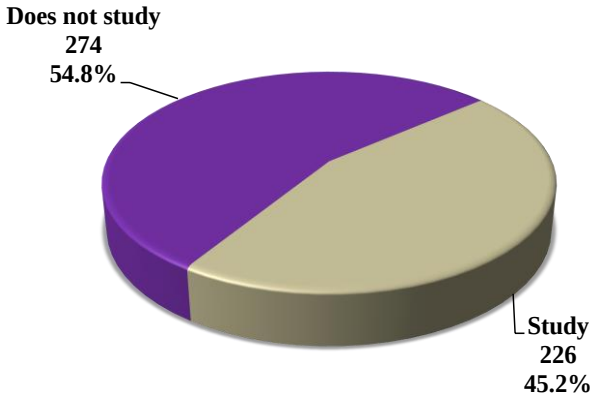

Fig. (2): Distribution of the studied cases according to Education (n = 500)

Table (2): Distribution of the studied cases according to demographic data (n = 500).

Demographic data	No.	%
Age (years)		
Min. – Max.	4.0 – 12.0	
Mean ± SD.	6.67 ± 2.43	
Median (IQR)	6.0 (4.50 – 8.0)	
Education		
Nursery	52	10.4
Primary	163	32.6
Preparatory	11	2.2
Does not study	274	54.8
Study	226	45.2
Does not study	274	54.8
Address		
Urban	382	76.4
Rural	118	23.6
Father job		
Not work	21	4.2
Employee	186	37.2
Literal	70	14.0
Professional	106	21.2
Free business	117	23.4
Mother job		
Not **work**	99	19.8
Work	**401**	**80.2**
SD: Standard deviation. **IQR: Inter quartile range.**		

The quality of life for children according to total score ranged from 126-500 with mean value 308.6 ± 87.10 and median 318.0, while percent score ranged from 12.12-80.78 with mean value 47.45 ± 16.0 and median 49.71 as shown in **(Table 3).**

Table (3): Descriptive analysis of the studied cases according to score of quality-of-life questionnaire for children (n = 500)

Quality of life for children	Total Score	Percent Score
Min. – Max.	126.0 – 500.0	12.12 – 80.78
Mean ± SD.	308.6 ± 87.10	47.45 ± 16.0
Median (IQR)	318.0	49.71

SD: Standard deviation.
IQR: Inter quartile range.

This study results showed that the score of quality of life is low in children with Cerebral palsy. Higher scores in QOL were obtained in educated children when compared to non-educated children. It was found that the score of QOL for children in preparatory education was higher than other levels of education when comparing the children QOL according to different levels of education (nursery, primary, preparatory)

The study results showed that the score of quality of life for children was higher in preparatory education which it ranged from 41.42-78.17 with mean value 61.13 ± 12.81 and median 60.38 followed by primary education which it ranged from 20.19-79.10 with mean value 56.97 ± 13.06 and median 59.89, while the lowest score was in does not study cases which it ranged from 12.12-73.81 with mean value 39.95 ± 14.55 and median 39.21.

There was statistically significant difference between educated and non-educated groups regarding score of quality of life (P < 0.001) as shown in (**Table 4**) and illustrated in **Fig. (3,4).**

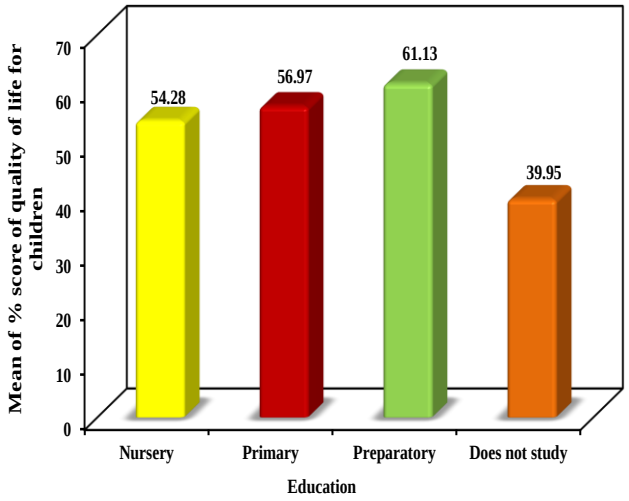

Fig. (3): Descriptive analysis of the studied cases according to score of quality-of-life questionnaire for children (n = 500)

Table (4): Descriptive analysis of the studied cases according to score of quality-of-life questionnaire for children (n = 500).

	% Score of quality of life for children			Test of sig.	P
	Min – Max.	Mean ± SD.	Median		
Education					
Nursery	26.59 – 80.7	54.28 ±10.80	54.93	H= 137.90*	<0.001*
Primary	20.19 – 79.1	56.97 ± 13.06	59.89		
Preparatory	41.42 – 78.1	61.13 ± 12.81	60.38		
Does not study	12.12 – 73.8	39.95 ± 14.55	39.21		
Study	20.19 – 80.78	56.55 ± 12.60	58.52	U= 12249.50*	<0.001*
Does not study	12.12 – 73.8	39.95 ± 14.55	39.21		

SD: Standard deviation
H: H for Kruskal Wallis test U: Mann Whitney test
***: Statistically significant at p ≤ 0.05**

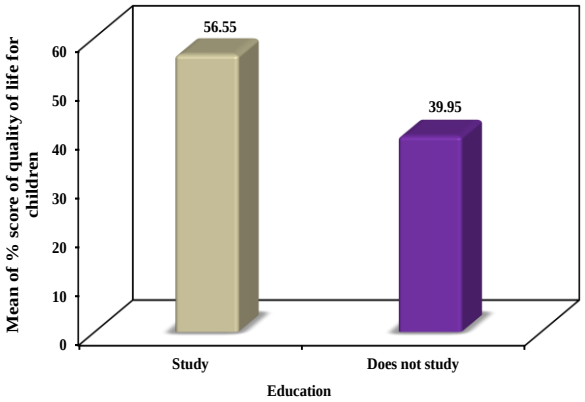

Fig. (4): Descriptive analysis of the studied cases according to score of quality-of-life questionnaire for children (n = 500)

5. Discussion:

The study results showed that the score of QOL is low in children with Cerebral palsy compared to the normal children. Higher scores in QOL were obtained in educated children when compared to non-educated children. It was found that the score of QOL for children in preparatory education was higher than other levels of education when comparing the children QOL according to different levels of education (nursery, primary, preparatory).

The study results also showed that the score of QOL for children was the highest in preparatory education which is ranged from 41.42-78.17 with mean value 61.13 ± 12.81 and median 60.38 followed by primary education which it ranged from

20.19-79.10 with mean value 56.97 ± 13.06 and median 59.89, while the lowest score was in does not study cases which it ranged from 12.12-73.81 with mean value 39.95 ± 14.55 and median 39.21. There was statistically significant difference between educated and non-educated groups regarding score of quality of life ($P < 0.001$).

According to a study by Mohammed et al. (2016), both children as well as their caregivers had low overall QOL scores, with variations noted across domains. The QOL of both children and carers was found to be influenced by sociodemographic features of both children and caregivers and also by the child's health state. However, these are not the only two factors attributed to the low QOL noticed by CP patients and their families. Other factors include the physical impairment of CP and the comorbidities that are linked to it (9).

In agreement with the current study, Saka et al; (2017) also stated that children with CP have better quality of life when their parents are more educated, and their higher educational status helped to improve their QOL (10).

QOL study using CP-QOL questionnaire in CP in Indian kids Researchers found that cerebral palsy is a persistent handicap that impacts both parents' and children's QOL. It is influenced by the quality of care provided and how educated the parents are about the illness. A QOL assessment of these children is required. In order to evaluate our children's QOL, we used this questionnaire. The overall QOL of the study was 38.29 ± 5.2. Additionally, this study showed that sex had no effect on the kids' quality of life. This outcome was consistent with findings from two other studies that looked at factors related to psychosocial QOL in children with cerebral palsy and research on children with CP in Malaysia (11).

Despite having shown that an Indian study found that males QOL was more negatively impacted than female was. The disparity in findings between these studies could be explained by parents' differing perspectives on disability. Additionally, they discovered a substantial correlation between parents' education levels and children's educational levels (12).

The result of this study shows that education has a positive role in improving the QOL in children with CP, however, many studies have been found that talk about the impact of CP on QOL in children although there were a lack of studies examining the impact of education on the QOL of children with CP.

Ethical approval:

Ethical approval was obtained from the unit of research ethics approval committee, Pharos University in Alexandria. (No.: PUA 0320235283107).

Funding:

Authors received no financial support for conducting this study.

Declaration of interest:

The authors declare no conflict of interest as this research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conclusion:

According to previous discussions of these results and reviews of academic research associated with the current study, it is possible to state that cerebral Palsy has a negative effect on the children's quality of life compared to normal healthy children and that education has a real positive impact on the children's quality of life since providing education to CP children would improve their intellectual abilities and therefore it improve their overall QOL and this agrees with the hypothesis stated in the beginning of this survey.

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