



# Correlation Between the Dependency and Quality of Life of Children with Cerebral Palsy

Dr. Agnes Monica Victor

Lecturer, Psychiatric and Mental Health Nursing, College of Nursing, King Saud Bin Abdulaziz University for Health Sciences, King Abdullah International Medical Research Center, Riyadh, Saudi Arabia.

\*Corresponding Author: Dr. Agnes Monica Victor, RN, PhD; [yoguddi@gmail.com](mailto:yoguddi@gmail.com)

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## Abstract

**Introduction:** Cerebral palsy is one of the neuro developmental disorders with many problems such as physical, functional, psychological, social and financial, as they are dependent upon caregivers on every activity. When these parents learn that their child has cerebral palsy, it distresses them. Even though caring for a child without a disability requires significant resources, these demands are frequently higher. Additionally, psychosocial issues in children with cerebral palsy increases the care burden. The objectives of the study were to correlate the level of dependency and quality of life of children with cerebral palsy before and after intervention. **Methods:** The study was conducted in Pediatric Rehabilitation Department, 'King Abdullah Specialist Children's Hospital, National Guard Health Affairs, Riyadh. The study subjects were the children with cerebral palsy aged 4-12 years along with their caregivers. The researcher had chosen the descriptive study design. 30 children with cerebral palsy were selected using purposive sampling technique. **Results & Discussion:** Showed that there was a highly significant association at  $p < 0.001$  level between the overall quality of life and the level of dependency in the study group. **Conclusion:** There was an association between level of dependency and the overall quality of life among children with Cerebral palsy.

**Keywords:** Cerebral Palsy, dependency, Quality of life, rehabilitation, and Caregivers.

## Introduction

Worldwide, neurologic illnesses are a leading source of morbidity and mortality [1]. The severe burden on the person, the family, and society is exacerbated by the chronicity, progression, recurrence, and high mortality of certain neurologic illnesses that cause physical, mental, and cognitive incapacity, as well as by the scarcity of available therapies. Realizing the patterns in the occurrence of significant neurologic illnesses is crucial for assessing initial preventive initiatives and calculating the required medical attention and social resources for impacted kids and their families [2].

There is little data currently available, primarily for hospital-based populations, about the pattern and prevalence of major neurologic illnesses in children in the Kingdom of Saudi Arabia [3-4]. The higher prevalence of genetic and inherited neurologic illnesses may be attributed to the high rates of consanguinity that account for 56% to 70% of marriages in the Saudi population [5-6].

According to Ansari SA and Akhdar F (1998), the prevalence of child disability in Saudi Arabia was 4.28 per 1000 people for minor impairment and 3.76 per 1000 people for serious impairment. In addition to affecting motor skills like walking, balance, and stability limits, cerebral palsy (CP) can also have an impact on cognitive abilities including attention span and rhythm creation. Deficits in both motor and non-motor functions make regular tasks more challenging.

The aim of the present study was to correlate the level of dependency and quality of life of children with cerebral palsy. An intervention is a service that aims to improve the condition of

cerebral palsy and the day-to-day experience of the person living with it. Most cerebral palsy symptoms, as well as coexisting conditions, can be managed or improved with a combination of treatment methods such as medication, therapy, assistive devices, and mobility aids. More severe cases of cerebral palsy can be treated with surgery, potentially offering a longer life expectancy.

The degree of a child's disability has been shown to increase the caring load and have an impact on caregivers' quality of life [8-9]. This led to the application of the Gross Motor Function Classification System (GMFCS). It is widely used to evaluate lower limb motor function in children with cerebral palsy, with a focus on sitting, walking, and wheeled mobility. The GMFCS has been extensively validated in relation to ambulation and activity restrictions, and is frequently utilized in clinical evaluations, research, and population-based investigations [10-14]. Based on functional abilities and limits, a five-level age-categorized system was established to assess the degree of motor participation in children with cerebral palsy. Youngsters classified as Level I are self-sufficient walkers who do not require assistance from mobility equipment in any situation.

The ideal approach to assist a person with cerebral palsy aid with personal hygiene (tooth brushing, bathing, and using the restroom) just to always be there for the person; those with severe CP could need help around-the-clock. Promote sociability by taking the person to a park, assisting them in engaging in various activities, and providing them with entertainment options.

It can be difficult for people with cerebral palsy to establish and sustain relationships. People with cerebral palsy may have

difficulty forming connections for a variety of reasons. This covers issues including social anxiety, developmental disabilities, and self-esteem.

Therapy is an essential component of a well-rounded, coordinated treatment strategy that helps maximize mobility while controlling physical impairment. The methods of interventions for the children with cerebral palsy like physical therapy, occupational therapy, speech and language therapy, and adaptive equipment are common modalities of treatment. The purpose of this initiative is to empower the cerebral palsy children to become more active, more aware of their rights, and stronger in their ability to cope with the demanding work of raising children with CP. The researcher's clinical working experience on children with CP and their caregiver's struggles became the source of motivation for the researcher to conduct the current study.

## Methods and Materials

### Aim of the Study

The aim of the current study was to correlate the level of dependency and quality of life of children with cerebral palsy before and after intervention in the Rehabilitation center, King Abdullah Specialty children hospital, Riyadh.

### Specific Objectives

1. To correlate the level of dependency of children with cerebral palsy before and after intervention
2. To correlate the quality of life of children with cerebral palsy before and after intervention

### Study area/Setting

The study was conducted in Pediatric Rehabilitation center, 'King Abdullah Specialist Children's Hospital (KASCH), Ministry of National Guard Health Affairs (MNGHA), Riyadh, Saudi Arabia. It was founded in 2005 and is based in the capital of Saudi Arabia, Riyadh. It has two other branches in Al-Ahsa and Jeddah. The university has fourteen colleges spread throughout three university cities: Riyadh, Jeddah, and Al-Ahsa.

### Study subjects

The study subjects were the children with cerebral palsy aged 4-12 years along with their caregivers.

### Inclusion criteria

CP children along with their caregivers aged between 4-12 years, both inpatients and outpatients attending KASCH Rehabilitation unit and Who were willing to participate in the study

### Research design

The researcher had chosen the observational/descriptive study design.

### Sample Size and Sampling Technique

A sample of 30 children with cerebral palsy were included in the study to ensure representativeness of the total study population. A purposive sampling technique was utilized in the current study.

### Data Collection methods, instruments used, measurements

Data was collected using three parts.

The instruments used for the study were

- i. Demographic and health status data Questionnaire for the children with CP and their caregivers,
- ii. Level of dependency (GMFCS) Questionnaire with five levels of degree and
- iii. Quality of life questionnaire (CPQOL) which consists of different aspects of QOL on family and friends, participation, communication, Health, Special equipment, Pain and bother, Access to service, and overall quality of health.

After obtaining all necessary ethical approvals from CON-R research unit and KAIMRC ethical committee, the principle investigator sent an invitation email to King Abdullah Pediatric rehabilitation department. Data was collected after explaining the purpose and nature of the study to the participants along with their caregivers and secured consents who visited during their appointments. Voluntarily participation, confidentiality, and anonymity were ensured.

### Data Management and Analysis Plan

The Statistical Software (JMP, Pro 17) was utilized to analyze the quantitative data. Once the completed surveys was received from the participants, data was immediately imported and cleaned into JMP. Descriptive statistics was conducted to describe the sample characteristics and to evaluate whether the results were normally distributed or not. Appropriate inferential statistical tests were used to determine the strength and direction of relationships among study variables. Significance level was chosen as ( $p < 0.05$ ).

### Ethical Considerations

Approval from the research unit at college of nursing, Riyadh at King Saud bin Abdulaziz for Health Sciences was obtained. Ethical approval of the Institutional Review Board Committee (IRB) at King Abdullah International Medical Research Center (KAIMRC) will also be granted. All participants was inculcated about informed consent in this study and was assured that they have the right to withdraw from the study at any time without any penalty. Data was collected after explanation of the purpose and nature of the study. There was neither any known harm resulting from participation in the study nor any gained entitlement. The questionnaire was totally anonymous and there was no identifying data that might reveal the identity of the participants. All collected data was kept confidential and was used only for the purpose of the current research study.

## Results & Discussion

Thirty children diagnosed with cerebral palsy participated in the study (table 1). Participants age ranged from 4-12 years and the majority were male children found in both study and control group.

**Table 1: Frequency and Percentage Distribution of Demographic Variables among Cerebral palsy children for Study and Control group**

Demographic variables for Children	Study group (n=30)		Control group (n=30)		Chi-square test and p value
	No.	%	No.	%	
1. Gender of the child					$\chi^2 = 0.635$ d.f = 1 p= 0.426(N.S)
a. Male	20	54.1	17	45.9	
b. Female	10	43.5	13	56.5	
2. Age (year) of the child					$\chi^2 = 2.121$ d.f = 2 p=0.346 (N.S)
a. 4 – 6	16	59.3	11	40.7	
b. 7 – 9	5	35.7	9	64.3	
c. 10 – 12	9	47.4	10	52.6	
3. Type of cerebral Palsy					$\chi^2 = 4.385$ d.f = 3
a. Bilateral spastic	4	36.4	7	63.6	

b. Spastic hemiplegic	5	33.3	10	66.7	p=0.232 (N.S)
c. Dyskinetic	6	60.0	4	40.0	
d. Ataxic/Diplegic	15	62.5	9	37.5	
4. Associate Impairment of the child					$\chi^2 = 2.500$ d.f= 4 p=0.645 (N.S)
a. Epilepsy	0	0.0	2	100.0	
b. Eating and feeding impairment	9	47.4	10	52.6	
c. Communication impairment	8	53.3	7	46.7	
d. Cognitive impairment	11	52.4	10	47.6	
e. Visual/Hearing impairment.	2	66.7	1	33.3	
5. School attendance to the child					$\chi^2 = 1.071$ d.f= 1 p=0.301 (N.S)
a. Yes	12	42.9	16	57.1	
b. No	18	56.3	14	43.8	
6. Relationship to the child					$\chi^2 = 3.138$ d.f= 2 p=0.208 (N.S)
a. Father	8	38.1	13	61.9	
b. Mother	22	57.9	16	42.1	
c. Brother	0	0.0	1	100.0	

Note: N.S – Not Significant

**Table 2: Frequency and Percentage Distribution of Demographic Variables of Caregivers among Cerebral palsy children for Study and Control group**

Demographic variables of Caregiver	Study group (n=30)		Control group (n=30)		Chi-square test and p value
	No.	%	No.	%	
1. Education Level of caregiver					$\chi^2 = 0.067$ d.f= 1 p= 0.795 (N.S)
a. Non-university studies/non-literate	16	48.5	17	51.5	
b. University studies	14	51.9	13	48.1	
2. Marital status of caregiver					$\chi^2 = 4.043$ d.f= 1 p=0.044 *
a. Single	1	14.3	6	85.7	
b. Married	29	54.7	24	45.3	
3. Employment status of caregiver					$\chi^2 = 0.606$ d.f= 1 p=0.488 (N.S)
a. Working	12	44.4	15	55.6	
b. Non-working	18	54.5	15	45.5	
4. Other people involved care of child					$\chi^2 = 0.480$ d.f= 1 p=0.488 (N.S)
a. Yes	26	52.0	24	48.0	
b. No	4	40.0	6	60.0	
5. Number of children in the family					$\chi^2 = 1.667$ d.f= 1 p=0.197 (N.S)
a. 1 - 4	22	45.8	26	54.2	
b. 5 - 10	8	66.7	4	33.3	
6. Care giving duration					Not applicable
a. 3 months	0	0.0	0	0.0	
b. 6 months	0	0.0	0	0.0	
c. 9 months	0	0.0	0	0.0	
d. 12 months and more	30	100.0	30	100.0	
7. Income of the family (per month)					$\chi^2 = 1.686$ d.f= 2 p=0.431 (N.S)
a. < 5000 sr	2	33.3	4	66.7	
b. 5001 - 10000 sr	1	100.0	0	0.0	
c. >= 10,001 sr	27	50.9	26	49.1	
8. Family history of cerebral palsy					$\chi^2 = 2.308$ d.f= 1 p=0.129 (N.S)
a. Yes	4	75.0	2	25.0	
b. No	24	46.2	28	53.8	

Note: \* - p<0.05 Level of significant, N.S – Not Significant

**Table 3: GMFCS level of Cerebral palsy children for Study and Control group**

GMFCS Level	Study Group (n=30)		Control Group (n=30)	
	No.	%	No.	%
1. Walks without limitations	4	13.3	1	3.3
2. Walks with limitations	4	13.3	6	20.0
3. Walks using a hand held mobility device	11	36.7	11	36.7
4. Self-mobility with limitations, may use powered mobility	3	10.0	11	36.7
5. Transported in a manual wheelchair	8	26.7	1	3.3
<b>Chi-square test p value</b>	$\chi^2 = 12.216$ , d.f= 4, p=0.016 (Significant at p<0.05)			

**Table 4: Comparison between Study and Control group for Quality of Life in different aspects**

Different aspects of QOL	Study group (n=30)		Control group (n=30)		t-test p value
	Mean	SD	Mean	SD	
Family and Friends	58.21	29.12	38.17	23.19	t = 2.949 p = 0.005 **

Participation	61.19	28.83	41.48	22.71	t = 2.941 p = 0.005 **
Communication	57.53	30.74	42.72	24.77	t = 2.055 p = 0.044 *
Health	59.35	28.14	41.04	23.42	t = 2.739 p = 0.008 **
Special Equipment	54.57	32.16	41.97	28.04	t = 1.617 p = 0.111 (N.S)
Pain and bother	64.44	25.27	40.74	25.58	t = 3.611 p = 0.001 ***
Final question about child	64.07	24.46	43.70	26.73	t = 3.080 p = 0.003 **
Access to service	59.59	27.08	41.11	26.77	t = 2.658 p = 0.010 **
Your health	63.11	24.26	43.11	25.75	t = 3.097 p = 0.003 **
Overall quality of life	59.87	26.87	40.81	23.01	t = 2.952 p = 0.005 **

Note: \* - P<0.05, \*\* - P<0.01, \*\*\* - P<0.001 Level of Significant

In all the aspects of QOL except special equipment, there was statistically significant difference in mean between study group and control group (p<0.05). The mean score in the different aspects (family and friends, participation, communication, health, pain and

bother, final question about child, access to service, your health and overall quality of life) was found to be statistically significantly higher in study group as compared to control group.

Table 5: Level of Quality of Life in different aspects for Study and Control group

Different aspects of QOL	Study group (n=30)		Control group (n=30)		Chi-square test and p value
	No.	%	No.	%	
<b>Family and Family</b>					
Unhappy	8	26.7	17	56.7	$\chi^2 = 18.191$ d.f = 3 p=0.000 ***
Neither happy nor unhappy	9	30.0	5	16.7	
Happy	1	3.3	7	23.3	
Very happy	12	40.0	1	3.3	
<b>Participation</b>					
Unhappy	6	20.0	13	43.3	$\chi^2 = 11.265$ d.f = 3 p=0.010 **
Neither happy nor unhappy	7	23.3	8	26.7	
Happy	6	20.0	8	26.7	
Very happy	11	36.7	1	3.3	
<b>Communication</b>					
Unhappy	10	33.3	14	46.7	$\chi^2 = 9.030$ d.f = 3 p=0.029 *
Neither happy nor unhappy	4	13.3	6	20.0	
Happy	6	20.0	9	30.0	
Very happy	10	33.3	1	3.3	
<b>Health</b>					
Unhappy	8	26.7	11	36.7	$\chi^2 = 7.993$ d.f = 3 p=0.046 *
Neither happy nor unhappy	7	23.3	11	36.7	
Happy	4	13.3	6	20.0	
Very happy	11	36.7	2	6.7	
<b>Special Equipment</b>					
Unhappy	14	46.7	15	50.0	$\chi^2 = 9.988$ d.f = 3 p=0.019 *
Neither happy nor unhappy	1	3.3	4	13.3	
Happy	4	13.3	9	30.0	
Very happy	11	36.7	2	6.7	
<b>Pain and bother</b>					
Unhappy	2	6.7	14	46.7	$\chi^2 = 19.123$ d.f = 3 p=0.000 ***
Neither happy nor unhappy	10	33.3	7	23.3	
Happy	6	20.0	8	26.7	
Very happy	12	40.0	1	3.3	
<b>Final question about child</b>					
Unhappy	3	10.0	13	43.3	$\chi^2 = 15.143$ d.f = 3 p=0.002 **
Neither happy nor unhappy	10	33.3	6	20.0	
Happy	7	23.3	10	33.3	
Very happy	10	33.3	1	3.3	
<b>Access to service</b>					
Unhappy	6	20.0	12	40.0	$\chi^2 = 8.218$ d.f = 3 p=0.042 *
Neither happy nor unhappy	8	26.7	8	26.7	
Happy	4	13.3	7	23.3	

Very happy	12	40.0	3	10.0	
<b>Your health</b>					
Unhappy	4	13.3	12	40.0	$\chi^2 = 8.730$ d.f = 3 p=0.033 *
Neither happy nor unhappy	11	36.7	10	33.3	
Happy	4	13.3	5	16.7	
Very happy	11	36.7	3	10.0	
<b>Overall Quality of Life</b>					
Unhappy	6	20.0	13	43.3	$\chi^2 = 4.077$ d.f = 2 p=0.130 (N.S)
Neither happy nor unhappy	12	40.0	10	33.3	
Happy	12	40.0	7	23.3	
Very happy					

Note: \* – P<0.05, \*\* - P<0.01, \*\*\* - P<0.001 Level of Significant

In all the aspects of QOL except special equipment, there was statistically significant difference in proportion between study group and control group (p<0.05). Regarding overall quality of life, 20% were unhappy, 40% were neither happy nor unhappy and 40% were happy in the study group whereas 43.3% were unhappy, 33.3% were

neither happy nor unhappy and 23.3% were happy in the control group which was not significant (p=0.130), whereas all the different aspects of quality of life showed significance between study group and control group (p=0.001).

**Table 6: Correlation between Quality of Life and Level of Dependency (GMFCS) among Cerebral palsy children for Study group (n=30)**

Level of Dependency (GMFCS)	Overall Quality of Life			
	Number	Mean	SD	ANOVA (F) p - value
I. Walks without limitations	4	33.09	3.93	F = 7.937 p = 0.000 (Significant at p<0.001)
II. Walks with limitations	4	65.05	28.39	
III. Walks using a handheld mobility device	11	44.32	16.57	
IV. Self-mobility with limitations, may use powered mobility	3	86.68	4.99	
V. Transported in a manual wheelchair	8	82.01	23.79	

There was a highly significant association at p<0.001 level between the overall quality of life and the level of dependency (GMFCS) in the study group.

**Table 7: Correlation between Quality of Life and Level of Dependency (GMFCS) among Cerebral palsy children for Control group (n=30)**

Level of Dependency (GMFCS)	Overall Quality of Life			
	Number	Mean	SD	ANOVA (F) p - value
I. Walks without limitations	1	30.51	0.0	F = 0.472 p = 0.756 (Not Significant)
II. Walks with limitations	6	34.22	9.96	
III. Walks using a handheld mobility device	11	45.50	22.20	
IV. Self-mobility with limitations, may use powered mobility	11	42.55	29.76	
V. Transported in a manual wheelchair	1	19.90	0.0	

There was no statistically significant association between the overall quality of life and the level of dependency (GMFCS) (p>0.05) in the control group.

## Conclusion

To conclude, there are number of studies successfully done on CP on its various dimensions, including intervention programs, but no study has been endeavored to correlate the dependency level with overall quality of life of children with Cerebral Palsy. In addition, it was concluded that dependency level GMFCS has a significant impact on overall quality of life of children with cerebral palsy. However, these researches are much needed to plan for effectiveness of nursing interventions on all functional classification systems for children with Cerebral Palsy.

## Declensions

## Conflict of Interest

The authors declare that they have no conflict of interests with any organization regarding the materials discussed in this manuscript.

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