

Quality of Life of Mothers Having Children with Cerebral Palsy

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Abstract

Background: Mothers who have children with Cerebral Palsy (CP) experience numerous difficulties that affect their physical and psychological health, social relationships, and financial situation. These countless challenges have negative impact on mothers' Quality of Life (QOL) and the entire family dynamics. The study **aimed** to identify quality of life of mothers having children with cerebral palsy. **Settings:** The study was conducted in the Outpatient Psychiatric and Neurological Clinic at the Specialized University Hospital for children at Smouha, and the Rehabilitation and Physiotherapy Department at EL-Raml Hospital for Children (Wingat) in Alexandria. **Subjects:** A convenient sample of 100 mothers who have children with any type of CP comprised the study subjects. **Tools:** Two tools named Pediatric Quality of Life Inventory: Family Impact Module and Gross Motor Function Classification System were used for data collection. **Results:** Fifty-seven percent of mothers who have children with CP had "low" QOL level, while 30% of them had "moderate" level and only 13% had "high" level. The overall parent functioning and family functioning were "low" among 66% and 37% of mothers respectively. **Conclusion:** It was concluded from this study that QOL was low among more than half of mothers who have children with CP, while nearly one-third of them had moderate level.

Keywords: Children, Cerebral Palsy, Mothers, Quality of Life.

Introduction

Cerebral palsy (CP) is a non-progressive neurological disorder that refers to group of disabilities such as movement abnormalities, speech difficulties, learning obstacles, cognitive and sensory impairments, epilepsy as well as behavioral challenges (Upadhyay et al., 2020). Because of the functional limitations experienced by children with CP, they become dependent on their mothers that far exceeds the usual

needs of typically developing children (Sadowska et al., 2020). According to Centers for Disease Control and Prevention (CDC, 2022a), prevalence of CP ranges from 1 to 4 per 1,000 live births worldwide. In Egypt, the prevalence of CP among children in Al-Karga District of New Valley Governorate was 2.04 per 1000 live births (El-Tallawy et al., 2014). While, a study in Al-Quseir City of Red Sea Governorate

reported that the prevalence of CP among children was around 3.06 per 1000 live births (Khalil et al., 2018).

Cerebral Palsy can be classified based on the form of neuromuscular deficit into four main types including spastic, dyskinetic, Ataxic and mixed CP (Bhattacharjee, 2020). Children with spastic CP have persistent primitive reflexes, exaggerated stretch reflexes and eventual development of contractures. Dyskinetic CP is marked by abnormal movements in the arms, hands, and legs, making it difficult to sit and walk. While, ataxic CP is the least common type in which children have problems with balance and coordination. Children with mixed CP may develop a combination of both dyskinetic and spastic types (Sadowska et al., 2020; Gulati and Sondhi, 2018).

Caring for children with CP permeates all aspects of mothers' life, causing a deterioration of physical and mental health, as well as, their Quality of Life (QOL) (Glinac et al., 2017). World Health Organization (WHO, 2012) defined QOL as "an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". Mothers of children with CP often experience series of emotional, physical, social and financial obstacles. They are often physically exhausted due to continuous assistance in activities of daily living of their children (Farajzadeh et al., 2020). Furthermore, they are at a higher risk to experience psychological problems as worry about

children's future, anxiety and depression (Smith, 2022).

Considering social challenges, mothers' time is diminished for their recreational activities or social life (Majumdar & Jain, 2020). Chronic illness with unpredictable characteristics like CP puts the family at risk for poor communication, cohesiveness and integration. All of these reflect on the QOL of mothers having children with CP.

Taking a family-centered approach to care is important not only to address the needs of CP children but also the demands of their families (Mahmoud et al., 2016). So, the basic goals of pediatric nursing care for children with CP include facilitation of normal motor development, prevention of secondary complications and improvement of functional acquisition and community integration besides acknowledging and addressing mothers' concerns and supporting them in the long process of rehabilitation (Bryant, 2015; Mahmoud et al., 2016). Although increasing attention has been given to the QOL of children with CP, much less attention has been given to the QOL of their mothers. So, this study brought light to the impact of having children with CP on mothers' own life, and how much the presence of such illness will affect their functioning.

AIM OF THE STUDY

The aim of the present study was to identify quality of life of mothers having children with cerebral palsy.

RESEARCH QUESTION

What is the level of quality of life of mothers having children with cerebral palsy?

Materials and Methods

Study design:

A descriptive research design was utilized in this study.

Setting:

The study was conducted at the Outpatient Psychiatric and Neurological Clinic in the Specialized University Hospital for children in Smouha as well as the Rehabilitation and Physiotherapy Department in EL-Raml Hospital for Children (Wingat) in Alexandria.

Subjects

Epi info program V 10.0 was used to estimate the sample size using the following parameters: expected frequency of errors 50%, margin of error 5%, and Confidence coefficient 95%. Minimum sample size was 100. So, a convenient sample of 100 mothers having children with any type of CP and free from other chronic illness such as diabetes mellitus comprised the study subjects. Children' age ranged from 3 to 6 years.

Tools

Three tools were used for data collection. **Tool I** was **Characteristics and Medical Data of Mothers and their Children with Cerebral Palsy Interview**. It included two parts: **Part 1**; Socio-demographic characteristics and medical data of mothers such as age, educational level, occupation and presence of chronic illness. **Part 2**; Characteristics and medical

data of children such as age, sex, type of CP and current treatment.

Tool II included **Gross Motor Function Classification System (GMFCS)**. It was adopted from Palisano et al. (2007) to reveal the gross motor abilities of CP children as they were classified into five levels of impairment

- **Level I:** The child can walk without limitations
- **Level II:** The child can walk with limitations
- **Level III:** The child can walk using a hand-held mobility device
- **Level IV:** Limited self-mobility as the child can sit on a chair but need adaptive seating for trunk control
- **Level V:** All areas of motor function are limited.

Tool III was **Pediatric Quality of Life Inventory™: Family Impact Module (PedsQL™ 2.0)** which was developed by Varni et al. (2004). It contains eight subscales with 36 items and divided into 6 subscales measuring parents' functioning, as well as 2 subscales measuring family functioning. Each item was rated on five-points Likert scale as follow; never a problem (0), almost never a problem (1), sometimes a problem (2), often a problem (3) and almost always a problem (4). the total percent score of mothers' QOL levels was classified as follows:

- Low QOL: 0 - less than 50%
- Moderate QOL: 50% - less than 75%
- High QOL: 75% - 100%

METHOD

- Approval from the Research Ethics Committee of the Faculty of Nursing at Alexandria University was obtained. Official letter from the Dean of the Faculty of Nursing

was sent to the directors of the previously mentioned settings. Permission was gained to conduct the study

- Tools were tested for their content validity by five experts in the Pediatric Nursing field and it was 92% for tool I and 96% for tool II.
- Reliability of tools was ascertained by measuring their internal consistency. They demonstrated high reliability where Cronbach's alpha Coefficient ($r = 0.78$ for tool I and $r = 0.92$ for tool II)
- The pilot study was carried out on 10 mothers to test the feasibility of tools. No modifications were done. Those mothers were excluded from study subjects.
- Every mother was interviewed individually to obtain the necessary data using tools I and II. Each interview session lasted for approximately 10-15 minutes. The data were collected for 12 months starting from the beginning of September 2020 to October 2021.

Ethical Considerations

- Written informed consent was obtained from mothers after explaining the aim of the study. Their voluntary participation and the right to withdraw from the study at any time were emphasized. Confidentiality of data was ascertained; mothers' privacy and anonymity were maintained.

Statistical analysis

Data were fed to the computer and analyzed using IBM SPSS software package version 20.0. (Armonk, NY: IBM Corp). Cronbach's Alpha test was used to assess reliability of tools. The Kolmogorov-Smirnov test was used to verify the normality of distribution. Qualitative data were described using number and percent.

Quantitative data were described using range (minimum and maximum), mean and standard deviation. Significance of the obtained results was judged at the 5% level.

Results

Table (I) clarifies socio-demographic characteristics and medical data of mothers. Nearly two-thirds of mothers were in the age group from 30 to less than 40 years (60.0%). Thirty-nine percentage of mothers finished secondary education whereas 27.0% were illiterate. Majority of mothers were housewives (93.0 %). More than half of families were living in urban areas (59%) and 53% were extended. Income of more than half of families was not enough for living (59.0%). Regarding medical data, 29.0% of mothers had health problems.

Table (II) portrays characteristics and medical data of children with cerebral palsy. The age of 63.0% of children was from 5 to 6 years. Sixty-seven percentage of children were males. One-third of children have been diagnosed as spastic hemiplegia and quadriplegia (33% for each).

Gross motor function classification system of children with cerebral palsy is presented in **Figure (1)**. Only 17% of the children were walking without limitations (level I). While, nearly one-third of children were walking with limitations (level II) or having limitations in all motor functions (level V) (33% for each).

Percentage distribution of mothers' quality of life levels is illustrated in **Table (III)**. Regarding parents' functioning, 80% of mothers had "low" QOL related to worry and 71% and 67% of them had "low" QOL related to physical and emotional

functioning respectively. Concerning family functioning, 57% of mothers had "low" QOL level in daily activities. On the other hand, 56% of mothers had "high" QOL related to family relationships.

Figures (2) reveals mothers' quality of life related to parent and family functioning. Overall QOL of parent functioning was "low" among two-thirds of mothers (66%). Moreover, the overall family functioning was "low" among more than one-third of mothers (37%).

Figures (3) clarifies mothers' overall quality of life levels. It is clear from the figure that the overall QOL was "low" among more than half of mothers (57%). However, 30% of mothers had "moderate" level and only 13% of mothers had "high" QOL.

The relationship between mothers' quality of life and their socio-demographic characteristics is presented in **Table (IV)**. All mothers who were 50 years or more had "low" QOL (100%). Also, 63.4% of those whose age were from 30 to less than 40 years had "low" QOL. Around two-thirds of mothers who finished secondary education had "low" QOL level (61.5%) and the difference was statistically significant ($P=0.032$). Two-thirds of mothers who had 5 or 6 children had "low" QOL (66.7%) with statistical significant difference ($P=0.016$). It is also clear from the table that 63.4% of mothers who were living in rural areas had "low" QOL. On the other hand, 32.2% of mothers who were living in urban areas had "moderate" level. Similar percentages of mothers who live in both nuclear and extended families had "low" QOL (57.4% and 56.6% respectively). The QOL level

was "low" among more than two-thirds of mothers who live in families with insufficient income (67.8%) with statistical significant difference ($P=0.010$).

Table (V) illustrates the relationship between mothers' quality of life and their children's characteristics. It is clear from the table that 68.3% of mothers who had children with age from 5 to less than 6 years had "low" QOL with statistically significant difference ($P=0.011$). On the other hand, the difference between mothers' QOL and their children's gender is not statistically significant. More than two-thirds of mothers having first and third born children with CP had "low" level of QOL (68.7% and 62.8% respectively). Regarding GMFCS, more than two-thirds of mothers whose children were classified as level V had "low" QOL level (69.7%), while a very small percentage of them had "high" level (3.0%).

Discussion

Cerebral palsy is the most common cause of developmental delay among children. Mothers of children with CP are often burdened with the care of their children and other family members leading to severe distress (Olawale et al., 2013; Vadivelan et al., 2020). Taking care of disabled children who require special and long-term support has significant influence on physical and emotional health status of mothers as well as their QOL (Dehghan et al., 2016). In such context, the present findings illustrated that more than half of mothers having children with CP had "low" QOL, while nearly one-third of them had "moderate" level (**Table III**). These findings may be related to behavioral and

cognitive characteristics of those children due to the disability and the chronicity of their disease which affect all facets of mothers' life physically, socially, psychologically, and financially. These current results are congruent with Jamali et al. (2020) who stated that caring for a child with CP has negative impact on all aspect of mothers' life thus influencing their QOL.

Mothers of children with CP tend to bear a huge burden of physical work and emotional instabilities during the process of caregiving (Vadivelan et al., 2020). The present study results revealed that two-thirds of mothers had "low" QOL related to parent functioning (**Table III**). This finding may be attributed to impaired emotional and physical functioning by more than two-thirds of mothers (**Table III**). Mothers' worry regarding their children medical treatment, side-effects of medications and reaction of others to their children's illness were influencing their QOL related to emotional functioning (**Table III**). Besides, mothers were physically exhausted related to the functional limitations and overdependence of their children with CP as the current results showed that nearly two-thirds of children were either walking with restrictions or having limitations in all motor functions (**Table II**). The findings of the present study are supported by Ramanandi et al. (2019) who stated that mothers having children with CP experience higher levels of stress and low self-efficacy which affect their emotional functioning. Smith (2022) also found that mothers of CP children often experience shoulder and back pain as well as generalized body aches that

have negative impact on their physical functioning.

Having disabled children with CP create high level of anxiety and social isolation that disrupts family dynamics and deteriorates its functions (Misyagci & Büyükönenç, 2020). The present findings showed that more than one-third of mothers had "low" QOL related to family functioning (**Table III**). This finding may be justified by impaired daily activities of the family as reported by more than half of mothers in the current study (**Table III**). Mothers of children with problematic health conditions as CP devote much of their time to children's nutrition, treatment, rehabilitation, and exercise therapy. Therefore, they encounter difficulty in organizing a well-defined schedule for their daily activities. In addition, barriers related to higher costs of services and equipment and home modifications that pose more financial burden and affect negatively on family functioning. Similarly, Borzoo et al. (2014) stated that families of disabled children experience additional levels of psychological stress, depression and financial difficulties which affect their functioning.

There are several factors that affect mothers' QOL such as their educational level, family income, children's age and their number. Concerning educational level, the results of the present study showed that more than half of mothers who finished either secondary or university education had "low" QOL (**Table IV**). These results may be justified by the higher knowledge of those mothers about the irreversibility,

severity, chronicity, long-term nature and prognosis of CP which significantly alter their psychological wellbeing and in turn their QOL. In the same line, Lipscombe et al. (2016) suggested that QOL of mothers having children with CP is negatively correlated with their educational level.

Regarding family income, the current findings presented that the QOL was “**low**” among more than two-thirds of mothers who live in families with insufficient income (**Table IV**). This result may be due to the large financial burden imposed by having children with CP as it places significant economic stress on mothers related to health care costs, work disruption and travel expenses. Consequently, financial stress experienced by mothers contributes to depleted QOL. This finding is congruent with Vadivelan et al. (2020) who stated that mothers having children with CP are burdened with the family’s financial situation that puts substantial stress on mothers and impairs their QOL.

Regarding the age of children with CP, the current results revealed that more than two-thirds of mothers whose children’s age was from 5 to 6 years had “**low**” QOL compared to mothers having younger children (**Table V**). This result may be attributed to children’s weight gain combined with their functional limitations that might increase the hardship of handling and contribute to exhaustion leading to negative impact on mothers’ physical functioning. Likewise, most mothers are usually overwhelmed by their children education and future specifically during this

specific age which contribute to impairment in their psychological functioning. Hence, deterioration in both physical and psychological functioning of mothers definitely affect their health, wellbeing and QOL. In such context, Dehghan et al. (2016) stated that growing up of children with CP is one of the factors that affect QOL of mothers due to functional limitation and possible long-term dependency.

The current findings reveal that two-thirds of mothers who had 5 or 6 children had “**low**” QOL compared to mothers who have one or two children (**Table IV**). This study result may be related to extra pressure exerted on mothers either physically or psychologically which greatly affect their QOL as those mothers require more time, energy and cost to meet the demands of parenting. This finding is congruent with Zhang et al. (2020) and Qian et al. (2020) who found that multi-child mothers have higher parenting pressure than one-child counterparts which affect their health and wellbeing.

Finally, the current study had been able to shed some light on the impact of having children with CP on mothers’ QOL.

CONCLUSION

According to the findings of the present study, it can be concluded that having children with CP impose negative impact on mothers’ QOL. The QOL was low among more than half of mothers, while nearly one-third had moderate level.

RECOMMENDATIONS

Characteristics of mothers		No (n= 100)	%
Mother's age (Years)	▪ 20-	25	25.0
	▪ 30 –	60	60.0
	▪ 40 –	11	11.0
	▪ 50 or more	4	4.0
Min. – Max. Mean ± SD.		20.0 – 52.0 33.69 ± 7.083	
Educational level	▪ Illiterate	27	27.0
	▪ Read and write.	2	2.0
	▪ Finished primary education.	9	9.0
	▪ Finished preparatory education.	11	11.0
	▪ Finished secondary education	39	39.0
	▪ Finished university education	12	12.0
Occupation	▪ Housewives	93	93.0
	▪ Employed	7	7.0
Numbers of children	▪ 1-	33	33.0
	▪ 3-	61	61.0
	▪ 5-6	6	6.0
Place of residence	▪ Urban	59	59.0
	▪ Rural	41	41.0
Type of family	▪ Nuclear	47	47.0
	▪ Extended	53	53.0
Family income	▪ Enough	41	41.0
	▪ Not enough	59	59.0
Social support	▪ Yes	25	25.0
	▪ No	75	75.0
Presence of health problem	▪ Yes	29	29.0
	▪ No	71	71.0

Based on the previous findings and conclusion, the following recommendations are suggested:

- Establishing face to face or online support group of parents with the same experience to enhance coping strategies, increase self-efficiency and improve QOL.

- Establishing a hot-line telephone number to answer parents’ questions about CP.
- Governmental and non-governmental organizations efforts should be integrated to provide support for families of children having CP with financial aids, social support and increasing awareness about available community services.

Table (I): Socio-Demographic Characteristics and Medical Data of Mothers

*Multiple responses were given.

Table (II): Characteristics and Medical Data of Children with Cerebral Palsy

* Multiple responses were given

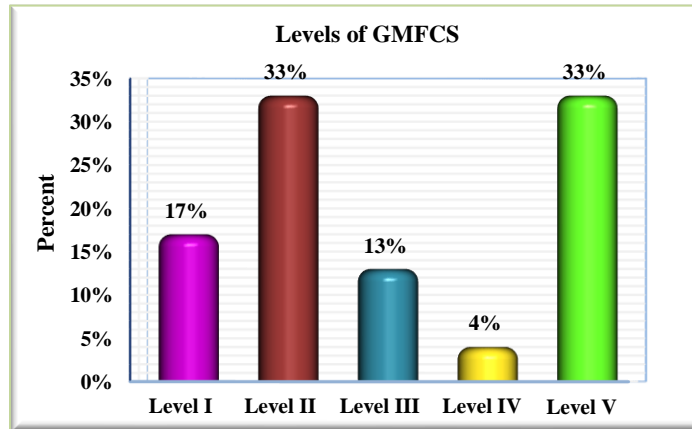


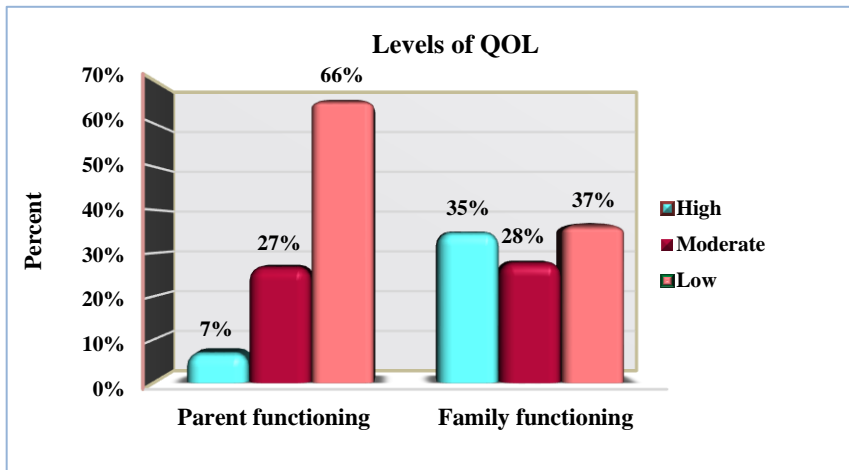
Figure (1): Gross Motor Function Classification System of Children with Cerebral Palsy

Table (III): Percentage Distribution of Mothers' Quality of Life Levels

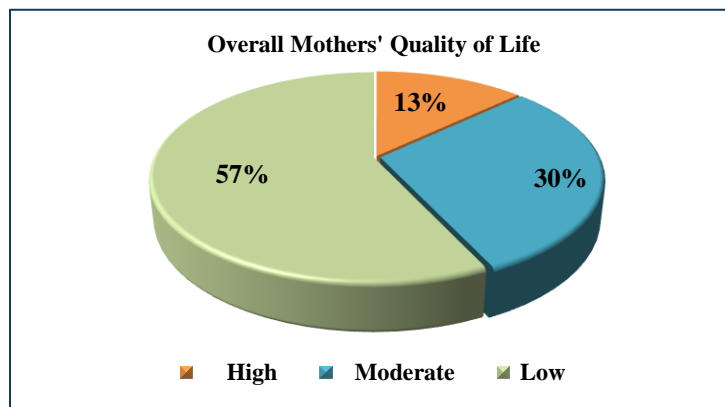
Mothers' Quality of Life	Levels of QOL			
	High	Moderate	Low	Total
	%	%	%	%
A. Parent functioning				
▪ Communication	51.0	25.0	24.0	100
▪ Social Functioning	50.0	18.0	32.0	100
▪ Cognitive Functioning	46.0	12.0	42.0	100
▪ Emotional Functioning	20.0	13.0	67.0	100
▪ Physical Functioning	14.0	15.0	71.0	100
▪ Worry	6.0	14.0	80.0	100
B. Family functioning				

Children's characteristics		No (n=100)	%
Child's age (years)	▪ 3-	21	21.0
	▪ 4-	16	16.0
	▪ 5-6.	63	63.0
Max- Min Mean ± SD.		3-6 4.96 ± 1.14	
Gender	▪ Male	67	67.0
	▪ Female	33	33.0
Birth order	▪ First	30	30.0
	▪ Second	27	27.0
	▪ Third	35	35.0
	▪ Fourth	8	8.0
Types of cerebral palsy	▪ Spastic hemiplegia	33	33.0
	▪ Spastic quadriplegia	33	33.0
	▪ Dyskinetic	12	12.0
	▪ Spastic diplegia	10	10.0
	▪ Spastic double hemiplegia	7	7.0
	▪ Ataxic	5	5.0
Regular follow up	▪ Yes	69	69.0
	▪ No	31	31.0

▪ Daily Activities	34.0	9.0	57.0	100
▪ Family Relationships	56.0	12.0	32.0	100



Figures (2): Mothers' Quality of Life related to Parent and Family Functioning



Figures (3): Levels of Mothers' Overall Quality of Life

Table (IV): Relationship between Mothers' Quality of Life and their Socio-Demographic Characteristics

Socio-Demographic Characteristics	Levels of Quality of Life (n=100)						χ^2	P
	Low		Moderate		High			
	No.	%	No.	%	No.	%		
a. Mother's characteristics								
Mother's age (Years)								
▪ 20-	11	44.0	11	44.0	3	12.0	7.843	$MC_p=0.197$
▪ 30 –	38	63.4	14	23.3	8	13.3		
▪ 40 –	4	36.4	5	45.5	2	18.1		
▪ 50 or more	4	100.0	0	0.0	0	0.0		
Educational level							17.601*	$MC_p=0.032^*$
▪ Illiterate /Read and write	16	55.2	13	44.8	0	0.0		
▪ Finished basic education	10	50.0	8	40.0	2	10.0		
▪ Finished Secondary education	24	61.5	6	15.4	9	23.1		
▪ Finished university education	7	58.3	3	25.0	2	16.7		
Mother's occupation								

<ul style="list-style-type: none"> ▪ Employed ▪ Housewife 	4	57.1	1	14.3	2	28.6	2.087	^{MC} p=0.325
	53	57.0	29	31.2	11	11.8		
Numbers of children							11.330*	^{MC} p=0.016*
<ul style="list-style-type: none"> ▪ 1- ▪ 3- ▪ 5-6 	17	51.6	8	24.2	8	24.2		
	36	59.0	22	36.1	3	4.9		
	4	66.7	0	0.0	2	33.3		
Social support							2.530	^{MC} p=0.282
<ul style="list-style-type: none"> ▪ Yes ▪ No 	15	60.0	9	36.0	1	4.0		
	42	56.0	21	28.0	12	16.0		
b. Families' characteristics								
Place of residence							1.297	^{MC} p=0.523
<ul style="list-style-type: none"> ▪ Urban ▪ Rural 	31	52.5	19	32.2	9	15.3		
	26	63.4	11	26.8	4	9.8		
Type of family							0.410	^{MC} p=0.815
<ul style="list-style-type: none"> ▪ Nuclear ▪ Extended 	27	57.4	13	27.7	7	14.9		
	30	56.6	17	32.1	6	11.3		
Family income							9.163	^{MC} p=0.010*
<ul style="list-style-type: none"> ▪ Enough ▪ Not enough 	17	41.5	19	46.3	5	12.2		
	40	67.8	11	18.6	8	13.6		

χ^2 : Chi square test

MC: Monte Carlo

FE: Fisher Exact

*: Statistically significant at $p \leq 0.05$

Table (V): Relation between Mothers' Quality of Life and their children's characteristics

Children's Characteristics	Levels of Quality of Life (n=100)						χ^2	P
	Low		Moderate		High			
	No.	%	No.	%	No.	%		
Child's age (years)							12.620	^{MC} p=0.011*
<ul style="list-style-type: none"> • 3- • 4- • 5-6 	9	42.8	6	28.6	6	28.6		
	5	31.2	9	56.3	2	12.5		
	43	68.3	15	23.8	5	7.9		
Gender							3.151	^{MC} p=0.207
<ul style="list-style-type: none"> • Male • Female 	39	58.2	22	32.8	6	9.0		
	18	54.6	8	24.2	7	21.2		
Child's order in the family							9.844	^{MC} p=1.109
<ul style="list-style-type: none"> • First • Second • Third • Fourth 	20	68.7	4	13.7	6	20.6		
	11	40.7	13	48.2	3	11.1		
	22	62.8	10	28.6	3	8.6		
	4	50.0	3	37.5	1	12.5		
Growth Motor Function Classification System							9.212	^{MC} p=0.276
<ul style="list-style-type: none"> • Level I • Level II • Level III • Level IV • Level V 	8	47.1	7	41.2	2	11.7		
	17	51.5	8	24.2	8	24.3		
	7	53.8	4	30.8	2	15.4		
	2	50	2	50	0	0.0		
	23	69.7	9	27.3	1	3.0		

χ^2 : Chi square test

MC: Monte Carlo

FE: Fisher Exact

*: Statistically significant at $p \leq 0.05$

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