Quality of Life and Its effect on Mothers who Providing Care for Their Children with Cerebral Palsy

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Abstract

Background: Cerebral palsy is the most common cause of physical disability among children which lead to a potentially negative impact on the quality of life for their mothers **Aim:** This study aimed to assess quality of life and Its effect on mothers who Providing Care for Their children with cerebral palsy in El-Qaliobyea. **Design:** A descriptive analytical design was utilized to conduct this study. **Setting:** The study was conducted at in AL-Kanateir AL-Khairya Hospital and Rehabilitation Center affiliated to El-Hady El-Basher Hospital in El-Qaliobyea governorate. **Sample:** Convenient sample was used in this study which consisted of 104 children with cerebral palsy and their mothers, **Tools:** Two tools were used for data collection, the first tool: An interviewing questionnaire to assess sociodemographic data for mothers and their children, mothers' knowledge, practices, QOl for mothers, health needs of the children with CP. The second tool: Children Health Status Assessment Sheet. **Results:** The result found that 71% of mothers had satisfactory knowledge about the preventive measures of cerebral palsy and its complications and 59.6% for them had adequate practices. Regarding to the total quality of life of mothers, 76.9% of them had poor , QOl level. The health needs of children with CP were moderately achieved for only 67,3 % of them. **Conclusion:** A highly statistical significant relations between total mothers' knowledge and practices which lead to illustration of poor level of quality of life for mothers with highly significant statistical differences between quality of life for mothers and their demographic characteristics such as educational level, social status, and job. **Recommendation:** Further intervention studies should be conducted to improve mothers'level of knowledge and practices for proper dealing with their children with CP as it plays an important role on their quality of life

Introduction:

Cerebral palsy (CP) is the term applied to a group of children with motor impairment and related service requirements. Since this group is heterogeneous with respect to clinical signs, etiology and pathology, It suggested that it is more appropriate to refer to the cerebral palsies, in the plural **(Blair and Cans, 2018).**

The etiology of (CP) is of heterogeneous, with multifactorial and only partially understood. When looking at the etiological risk factors, traditionally within the context of CP, as they are considered by timing of exposure, i.e. prenatal, perinatal or postnatal. But with greater use of imaging, and better

understanding of brain development, it becomes apparent that the causal pathways to the development of CP are more complex. While CP may result from exposure to a single etiological factor such as perinatal stroke, it may also follow serial exposure to multiple factors, interacting to produce irreversible brain injury. Perinatal asphyxia in the preterm neonate, for example, may be followed by circulatory failure and neonatal infection. Intrauterine infection, is an important although relatively rare etiological factor of CP **(Huitfeldt, 2016).**

The symptoms of CP vary with each child and may range from mild to severe. Many children with CP have normal intelligence. The disease is suspected during infancy if there are feeding problems, seizures not associated with high fever, and developmental delays. Developmental milestones are not achieved at the expected age levels. Persistence of primitive reflexes (e.g., the Moro and tonic neck reflexes) may be seen. Diagnostic tests may include metabolic and genetic testing and MRI. Early recognition is important for appropriate referrals **(Leifer, 2018).**

Living with a chronic condition not only affects the child but its effect can extend to other members of the child's family especially the caregiver, who often is the child's mother. The Quality of Life (QoL) of a caregiver as it relates to health, psychological well-being, social networks and support, The family dynamics can be negatively impacted when a significant amount of time is being committed to the care of a child with a chronic condition **(Jahan et al., 2019).**

The impact of a lifelong condition such as cerebral palsy is widespread, and the impact on lives of their mothers is

extremely important. Stress and QoL have been an ongoing concern for care providers. Coping with the news related to a health concern and a subsequent diagnosis of cerebral palsy has been related to parental grieving and stress. There is evidence of high levels of depression among this population of care providers. There has also been report of social isolation, impact on family dynamics, physical strain, sleep disturbance, and decreased ability to maintain employment **(van Hulst et al., 2018)**.

Role of the Nurse: The CHN uses every opportunity for teaching and encourage the mothers to be involved in the child's actual care within the scope of their comfort level. The community health nurse roles in home health care (HHC) are the roles of clinician that provide direct care to the clients and families, as an educator, researcher, administrator and consultant, all are seen among home health care nurses. **(Stanhope & Faan, 2019)**.

Significance of the study:

According to the reports of **WHO (2018),** CP is one of the most common causes of physical disability among childhood, with a reported prevalence of approximately 1.5–3 per 1,000 children. **El-Tallawy et al. (2015)** reported in their study that 1.5–3 per 1,000 children in AL-Quseir City and 52 of 25,540 children in Al-Kharga District, Egypt, had CP, giving a prevalence of 2.04 per 1,000 live births.

A study done by **Altonoby, (2017)** at Egypt conducted to establish data base for cerebral palsy (CP) in Tanta city and its surrounding cities as Kafr Alzayat, Basioon and Elsanta, Al-Gharbia

Governorate which including Children with CP who are receiving physical therapy services of both genders, from birth to 18 years old in Ministry of Health, Insurance hospitals, units of family medicine in villages and all private centers of physical therapy in Tanta and its surrounding cities. There total number were 224 cases. He found that percentage of CP based on System Gross Motor Function Classification (GMFCS) as ; 12.9% for level I, 13.8% for level II, 29% for level III, 20.9% for level IV, and 23.2% for level V. Percentage according to Manual Ability Classification System (MACS) were level I- 23.4 %, level II 9.3%, level III 20.3%, level IV 45.3%, and level V 1.5% also Viking speech scale were Level I 20.3%, level II 22.97%, Level III 35.14%,and level IV 21.62%.

Aim of the Study:

The aim of this study is to assess quality of life and its effect on mothers who Providing Care for Their children with cerepral palsy through:

➢ Assessing mother's knowledge and practices toward care of children with cerebral palsy.

➢ Assessing the health needs of children with cerebral palsy.

➢ Assessing growth and development of children with cerebral palsy.

➢ Assessing aspects of quality of life for mother's who care children with cerebral palsy.

Research Questions:

1. What are quality of life aspects for mothers and its effect on children with CP?

2. What are the health needs of children with cerebral palsy?

3. Is there relation between mother's knowledge and practice about care of children with cerebral palsy?

4. Is there a relation between demographic characteristics and QOL for mothers who care for children with CP?

Subject and Methods:

Research Design:

A descriptive analytical study was utilized the study in order to assess mother's quality of life for children with cerebral Palsy through.

I- Technical Design:

Setting:

This study conducted in two setting; the outpatient clinic of AL-Kanateir AL-Khairya Hospital and Rehabilitation Center affiliated to El-Hady El-Basher Hospital in El-Qaliobyea governorate because it is located in an urban area providing services for sub-urban areas and covers a large area of cities and population so it was considered an appropriate field including representable study subjects which needed in this study. Kanateir AL-Khairya is the important city in Egypt. It is located in Qalyubia Governorate and characterized by high population density and low socioeconomic status. Those selected health setting are characterized

by high flow rate where cover large numbers of families and provided preventive and curative health services for mothers and their children with cerebral palsy.

Sampling:

convenient sample was used in this study which consisted of 104 children with cerebral palsy and their mothers, this sample selected through consequence's 6 months from outpatient clinic in the previous mentioned setting which characterized by the frequency rate of CP cases in these clinics, as through the last years is estimated by 200 - 250 cases per year from 2018 to 2019 with the following criteria.

Inclusion criteria:

All children their age from 5 years to 12 years. Diagnosed with Cerebral palsy.

Technical design:

Tools of data collection:

The data were collected using the following two tools:

Both were developed by the investigator, based on reviewing the related literatures, magazines and experts opinions, written in Arabic and English language to assess mother's quality of life for children with cerebral palsy.

First tool: An interviewing questionnaire:

This included the following three parts.

Part (I): This part included: (A) Questions to assess the socio-

demographic characteristics of the study sample the mothers for children with CP. This part included 9 closed and open ended questions (Question 1: question 9): such as mother's age, social status, educational level, job, income per month, residence, consanguinity, its type of Consanguinity, and if other child in the family had a disease. **(B)** Demographic data for children with CP which consisted of 4 questions (Q10: Q13) such as gender, age, child rank, and educational level

Part (II): It was used to assess mothers' knowledge about cerebral palsy which consisted of 16 questions closed ended with 110 items distributed as 5 questions regarding meaning of CP, 21 questions related to risk factors during pregnancy, during labour, and postpartum period, 10 questions about types of CP disease and movement problems, 25 questions about health problems due to CP and complications, 16 questions related to CP methods of diagnosis, the main goals of CP treatment and its methods, 19 questions about the preventive measures of CP, 14 questions related to health services for children with PC and medical health team**.**

❖ **Scoring system of knowledge:**

The score ranged from zero to one, For non-selected (unsatisfactory knowledge) ="(0)" and for selected items (satisfactory knowledge) take "(1)". The total score for all items related to knowledge was 110 point are summed up and categorized into two levels as followings: Unsatisfactory knowledge = <50% or from 1:55 marks. Satisfactory knowledge = > 50 % or from 56:110 marks.

Part (III): This part for mothers to assess their practices toward care of CP

among children which consisted of 71 open and closed ended questions divided into six parts as follow.

(1) Mothers' practices toward health care of feeding for their children: this part included 22 closed ended questions **such as:** the various ways to prepare food, feeding the child, appropriate time to feed, Oral hygiene after eating, healthy behaviors of children with cerebral palsy during feeding, and fluid intake.

(2) Mothers' practices about proper position for their children with CP which consisted of 8 closed ended questions such as: toward proper position, positions of a child who can sit alone without assistance, and position of a child who cannot sit alone (needs assistance).

(3) Mothers' practices towards proper exercise for children with CP. This part included 9 closed ended questions such **as** excises to relax stiff muscles, exercises for balance and body control, exercises to encourage gesture and rotation movements.

(4) Mothers' practices towards care in case of difficulty swallowing among children with CP. This part included 18 closed ended questions such a**s** oral function control, food cutting process, the complete chewing and swallowing food process, the process of washing the mouth after the completion of the eating process, and care of the child independently eat.

(5) Mothers' practices towards care in case of difficulty speaking children with CP. This part included 5 closed ended questions such as avoiding difficulty.

(6) Mothers' practices towards care in case of epilepsy children with CP. This part included 10 closed ended questions such as avoiding epileptic seizures, and during epileptic seizures.

❖ **Scoring system of practices:**

A scoring system for each of practical items as reported by mothers correctly was scored "1", and each item not reported or incorrectly scored "zero". All items of practices were summed up and changed into percentage. The total score for all items related to mother practices was 72 points and categorized into two levels as followings <60 (0:43 grads) is considered inadequate and >60 (44: 72 grads) is considered adequate practices.

Part (IV): This part to assess QOL of the studied mothers which consisted 31 closed ended questions for physical, psychological, social, spiritual and emotional health aspects adapted from WHO SF─36 QUESTIONNAIRE. https://clinmedjournals.org/articles/jmdt/jmdt-2-023-figure-1. and modified by investigator.

This part included 31 closed-ended questions by using three categories of Likert scale as always, sometimes, and never. The items included were quality of life physical aspects (6 items), quality of life according to psychological aspects (10 items), quality of life according to social domain (8 items), and quality of life according to spiritual domain (7 items).

❖ **Scoring system for quality-of-life aspects:**

Each of the quality-of-life items scored "3" marks for "always" response, "2" mark for "Sometimes" response and

"1" for "Never" response for all items accept item 5 and 6 which is versus to 1 for "always" response, 2 mark, for "Sometimes" response and 3 marks for "Never" response and the total score of quality of life aspects' were categorized as no effects, moderate effects and highly effects.

The total quality of life level scores was calculated by summing all these marks and converting them into percentages as the following: The total quality of life was considered poor quality of life if the percent score was <30% (1: 1:31grads), average if the percent score was 30%: 60% (32:62 grads), and good if the percent score was > 60% (63:93grades).

Part (V): This part designed to assess the health needs among children with CP which consisted of 43 closed ended questions divided into 7 sections with 43 points such as nutrition, rest / sleep, activity / movement, personal hygiene, medical follow-up, social and material needs, and Safety environment**.**

❖ **Scoring system of health needs:**

The total score of the questionnaire responses was three score levels were made accordingly. It consists of 43 statements, were rated with likert rating scale rarely, scored (1), sometimes, scored (2) and always, scored (3). The total degree of rating scale ranged from 1 –87 (100%). The degree of child health needs achievement was categorized into 3 levels. Poor achieved= Less than <50% (1: 43). Moderate achieved = 50: 75% (44: 64). Good achieved = more than 75% (65:87).

The second tool: Children Health Status Assessment list:

Part VI: This part of assessment tool used to assess health status of the studied children with CP which consisted of 11 questions such as child weight and height to calculate BMI, child's age when the disease was diagnosed, the medical diagnosis, follow up in a school or institution for intellectual development, types of CP, Current complain, the effect of intellectual disability on the child, the neurological problems associated with cerebral palsy, the bone problems that the child was exposed to in addition to illness and medications administration.

❖ **Scoring System of health status assessment sheet:**

The **metric formula** to calculate BMI is weight ÷ (height x height) x 10,000. After BMI is calculated for children from 5:12 years, it is expressed as a percentile which can be obtained from either a graph or a percentile calculator (see links http://www.cdc.gov/growthcharts/ clinical_charts.htm). These percentiles express a child's BMI relative to children, because weight and height change during growth and development, as does their relation to body fatness, a child's BMI must be interpreted relative to other children of the same sex and age. According to WHO growth charts for children ages 0–24 months adopted by **(CDC, 2010).**

Weight Status Category	Percentile Range
Underweight	Less than the 5th percentile
Normal or Healthy Weight	5th percentile to less than the 85th percentile
Overweight	85th to less than the 95th percentile
Obese	Equal to or greater than the 95th percentile

Part VII: Developmental level (Functional Motor Ability assessment

list). This part to assess the developmental characteristics among children with CP which consisted of 6 sections with 5 level such as Gross Motor function classification system (GMFCS) Levels, manual ability classification system (MACS) Levels, communication function classification system (CFCS) Levels, eating and drinking classification system (EDACS) levels dysphasia management staging Scale (DMSS) Levels.

Validity and Reliability:

Content and face validity were performed by 3 professors of the community health nursing department and two professors from the Pediatric specialty of Faculty of Medicine, all experts were affiliated to Ain Shams University, Egypt who reviewed the tools for content accuracy. The developed tools were tested for reliability on a sample of 50 subjects. The reliability test of translated version was established by using the Cronbach alpha and Pearson correlation which showed good internal consistency construct validity Cronbach alpha = (0.887).

II- Operational Design:

Preparatory Phase: A review of literature was done regarding current and past available literature, covering the various aspects of the problem, using text books, articles, magazines and internet sites through research gate. This was necessary for the investigator to get aquatinted with, and oriented about aspects of the research problems, as well as to assist in development of data collection tools.

Ethical consideration:

All ethical considerations were considered for ensuring the mothers' privacy and confidentiality of the collected data during the study. Firstly the study protocol take agreement of Ethical Committee affiliated to Faculty of Nursing Ain Shams University. Secondly the purpose and nature of the study were explained for the participants and oral consent was taken to gain their participation after explain the purpose of the study and being informed that each study subject is free to withdrawal at any time through the study. Finally all selected study sample agreed to participate in the study and they were assured that the study would posed no risks or hazards on their social, psychological or physical health.

Pilot Study:

A pilot study was conducted at the beginning of the study for 10 cases (10% of the total sample) to investigate the feasibility of data collection tools, their content, clarity and simplicity. It took about one month from beginning of June 2019 to the end January 2020. Subjects included in the pilot study were included in the actual study sample.

Field work:

The actual process of data collection was carried out in six months consequently the period from the beginning of June 2019 until the end of January 2020, four days /weekly nearly about 4 hours daily (Saturdays, Tuesdays, Wednesdays and Thursday) in order to collect the total sample of 104 children. The investigator introduced her to the two previous mentioned setting directors and the nurse supervisors and the other health team workers that will help her in data

collection to save the time and to also gain the trust of mothers. The investigator explained the aim of the study to all of them and then distributed the questionnaire after clear explanation the way to fill it out. The interviewing tools took about maximum 30 minutes for every mother to fill it and the physical examination tool took about 15 minutes for each child. The check list took about 15 minutes.

III-Administrative Design:

Formal letter from the Dean of the Faculty of Nursing, Ain Shams

Results:

Table (1): presents that, 71.1% of children's mothers were between the age group 25: < 35 years with mean age = 31.62 and Std. Deviation= 5.759, Regarding to the educational level there were 13.5% of mothers were illiterate while 40.4% of them were secondary education and 75.0% of them were jobless which reflects that, there were 46.1% of family hadn't enough income that ranged from 1500:2000 LE. As well as, 75.0% of that family lived in rural area which reflect that there were 40.4% of them with parental Consanguinity and 57.2% out of them were first degree of Consanguinity and there were 19.2% of total families have another child who suffered from the disease.

Figure (1): illustrates that there were 71% of mothers had satisfactory knowledge about the preventive measures of cerebral palsy and its complications and 29% of them had unsatisfactory knowledge.

Figure (2): illustrated that, 40.4 % of mothers' total practices toward the preventive measures of cerebral palsy and

University directed to the directors of Kanateir AL-Kharia Hospital and Rehabilitation Center affiliated to El-Hady El-Basher Hospital

IV-Statistical design:

Data was analyzed using the Statistical Package for Social Science (SPSS) version 19. Qualitative data was presented as number and percent. Relations between different qualitative variables were tested using Chi-square test (X^2). Probability (p-value) < 0.05 was considered significant and < 0.001 was considered highly significant.

its complications were inadequate practices while 59.6% of them had adequate practices.

Figure (3): illustrated that, the quality of life of mothers was at poor level among 76.9% of those mothers, who have children with cerebral palsy disease while 21.2% of them moderate level and 1.9% of them have no effect which means good level.

Table (2): prove that, only there are highly significant statistical differences between quality of life for mothers and their demographic characteristics regarding mother's educational level with **(x2 = 28.628 and P=< 0.001)** while, insignificant relation with family income (**x2 = 6.288 P= > 0.05**). Also there are significant statistical differences between quality of life and social status, mother's job, and another child has a disease in the family with **(x^2 = 15.083, 6.642, and 12.550 respectively and P=< 0.005)**.

Table (3): evinces that, there is a significant statistical relation between total mother's total level of knowledge about health care of children with

cerebral palsy and their Quality of life level with X^2 = 6.116 and **P value** <0.05.

Table (4): proves that there is a significant statistical relation between total mother's practices toward health care of children with cerebral palsy and their Quality of life level with X^2 = 5.748 and **P value** <0.05.

Table (1): Distribution of sociodemographic characteristics of mothers who have children with Cerebral Palsy (n=104).

| Items	No	%
Mother's age		
<25 years	6	5.8
25: < 35 years	74	71.1
35: < 45 years	18	17.3
≥ 45years	6	5.8
Mean = 31.62 Std. Deviation= 5.759 Minimum= 22 Maximum = 48		
Social status		
Married	96	92.3
Divorced	0	0.0
Widow	8	7.7
Mother's educational level		
Illiterate	14	13.5
Primary	12	11.5
Preparatory education	16	15.4
Secondary education	42	40.4
Undergraduate	20	19.2
Post graduate	0	0.0
Mother's job		
Have a job	26	25.0
Jobless	78	75.0
The family income / month		
< 1500 LE /month	32	30.8
1500:2000 LE /month	48	46.1
> 2000 LE/ month	24	23.1
Residence		
Rural	78	75.0
Urban	26	25.0
Parental Consanguinity		
yes	42	40.4
No	62	59.6
Type of Consanguinity (n= 42)		
First	24	57.2
Second	10	23.8
Third	8	19.0
Other family child has a disease		
Yes	20	19.2
No	84	80.8
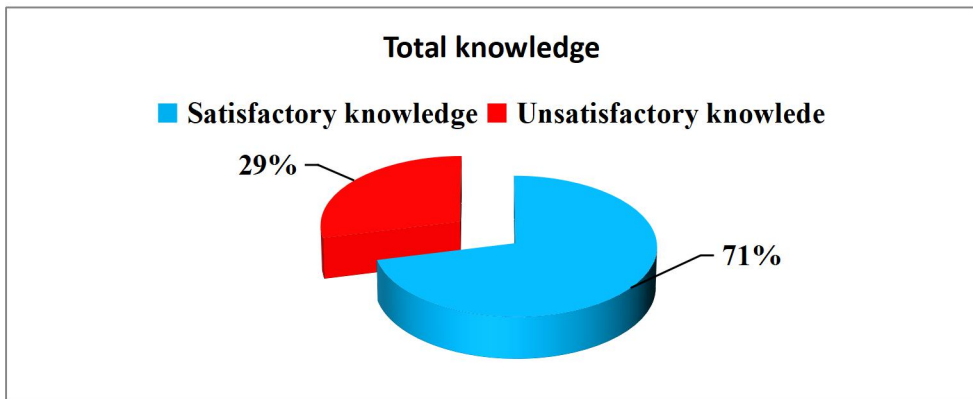
Figure (1): -Distribution of the studied children's mothers according to their total knowledge about the preventive measures of cerebral palsy and its complications (n=104).
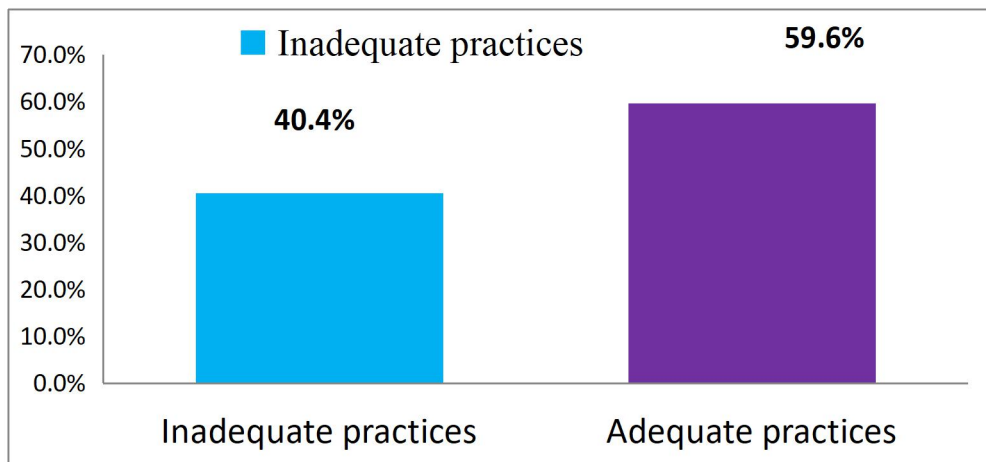

Figure (2): Distribution of the studied children's mothers was according to their total practices toward the preventive measures of cerebral palsy and its complications (n=104).
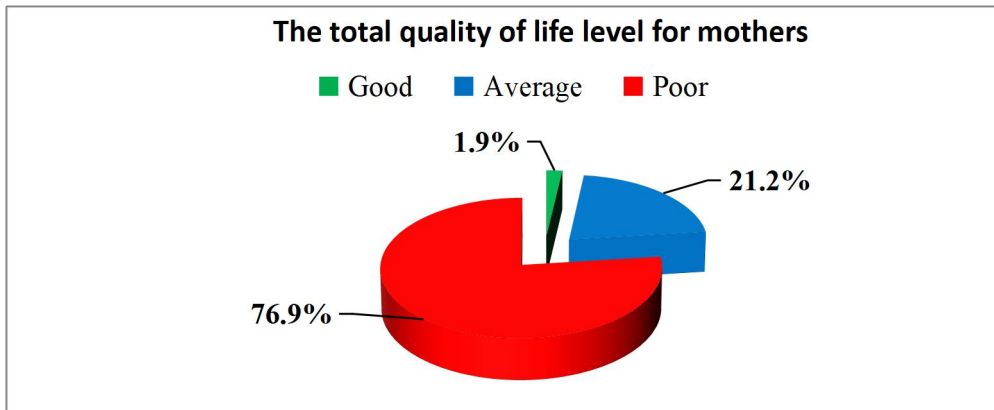
Figure (3): Distribution of the total aspects' quality of life level among mothers who have children with cerebral palsy (n=104).
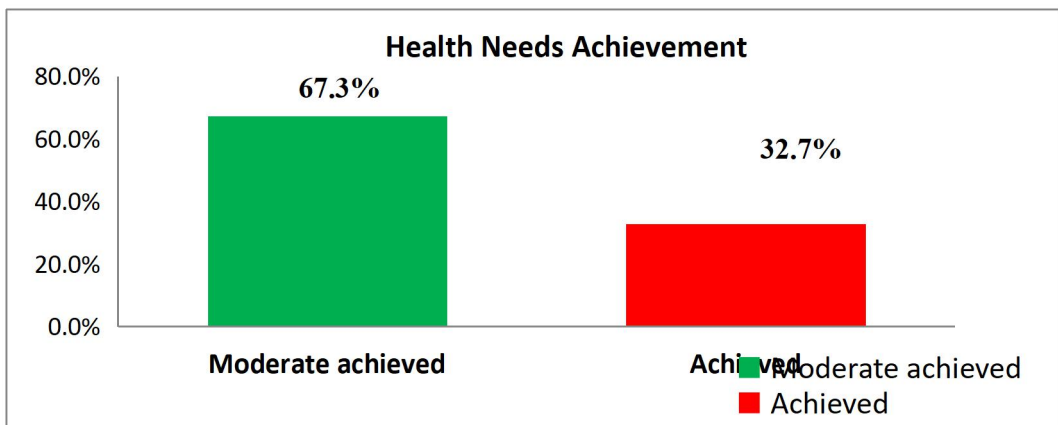

Figure (4): Distribution of the total health needs of children with cerebral palsy (n=104).

Table (2): The relation between demographic characteristics and QOL for mothers who have children with CP (n=104).

Items	Good Quality Level		Average Quality Level		Poor Quality Level		Chi-Square X² P value
	No	**%**	**No**	**%**	**No**	**%**	
Mother's age							**.**
<25 years	0	0.0	0	0.0	6	5.8	10.059
25: < 35 years	2	1.9	14	13.5	58	55.8	P=
35: < 45 years	0	0	8	7.7	10	9.6	0.122
≥ 45years	0	.0	0	.0	6	5.8	*NS
Social status							**15.083**
Married	2	1.9	16	15.4	78	75.0	**P=**
Divorced	0	0.0	0	0.0	0	0.0	**0.001**
Widow	0	0.0	6	5.8	2	1.9	**** S**
Mother's educational level							
Illiterate	0	.0	0	.0	14	13.5	
Primary	0	.0	0	.0	12	11.5	**28.628**
Preparatory education	0	.0	4	3.8	12	11.5	**P= 0.000**
Secondary education	2	1.9	18	17.3	22	21.2	***HS**
Undergraduate	0	0.0	0	0.0	20	19.2	
Postgraduate	0	0.0	0	0.0	14	13.5	
Mother's job							**6.642**
Have a job	0	0.0	10	9.6	16	15.4	**P= 0.036**
Jobless	2	1.9	12	11.5	64	61.5	****S**
The family income							6.288
< 1500 LE	0	.0	10	9.6	22	21.2	P= 0.179
1500:2000 LE	2	1.9	6	5.8	40	38.5	*NS
>2000 LE	0	0.0	6	5.8	18	17.3	
Residence							1.479
Rural	2	1.9	18	17.3	58	55.8	P=0.477
Urban	0	.0	4	3.8	22	21.2	*NS
Parental Consanguinity							3.634
Yes	0	0.0	6	5.8	36	34.6	P=0.163
No	2	1.9	16	15.4	44	42.3	*NS
Type of Consanguinity(n= 42)							5.499a P= 0.482 *NS
First	0	0.0	4	3.8	20	19.2	
Second	0	0.0	0	0.0	10	9.6	
Third	0	0.0	2	1.9	6	5.8	
Other family child has a disease							**12.550 P= 0.002**
Yes	0	.0	10	9.6	10	9.6	****S**
No	2	1.9	12	11.5	70	67.3	

Table (3): The relation between mother's total knowledge about health care of children with cerebral palsy and their Quality of life level (n=104).

Mothers' QOL	Mothers' knowledge						Chi-Square X²	P value
	Unsatisfactory		Satisfactory		Total			
	No	%	No	%	No	%		
Good Level	2	1.9	0	0.0	2	1.9	6.116	0.047 **S
Average Level	8	7.7	14	13.5	22	21.2		
Poor Level	20	19.2	60	57.7	80	76.9		
Total	30	28.8	74	71.2	104	100.0		

Table (4): The relation between mother's total level of practices toward health care of children with cerebral palsy and their Quality of life level (n=104).

Mothers' QOL	Mothers' practices						Chi-Square X²	P value
	Inadequate		Adequate		Total			
	No	%	No	%	No	%		
Good Level	2	1.9%	0	.0%	2	1.9	5.748	0.041 **S
Average Level	12	11.5%	10	9.6%	22	21.2		
Poor Level	28	26.9%	52	50.0%	80	76.9		
Total	42	40.4	62	59.6	104	100.0		

Discussion:

Regarding to the educational level of mothers of children with CP, there were two fifth of them were secondary educational level while there were three quarters of them were jobless which reflects that, the family income was not enough, ranged from 1500 to 2000 LE for slightly less than half of them**.**

This results are disagree with **Kashoo and Ahmad, (2019)** in this study title "Rehabilitation Program for Children with Cerebral Palsy and Caregivers. It's their sample size was 90 patients" who mentioned that in their research in titled "Rehabilitation for children with Cerebral palsy and caregiver" more than half of them were illiterate or could read and write, So the family income was ranged between 200 and 300 pounds per month for more than half of the families,

furthermore almost one quarter of the mothers of children in the study conducted by **Mohammed (2015)** with the title " knowledge, attitude and practice of mothers of children with cerebral palsy. Their sample size was 204 patients". (22.1%), Of them were illiterate which is a high percentage, in comparing to the results reported by **Feldman et al. (2012)** in this study titled " Public perceptions of cerebral palsy. Where their sample size was 100 patients " only 5% of them were with lowest educational level this reflects that illiteracy is a big problem in developing countries.

In addition to, three quarters of those families are living in rural area which reflect that there were more than two fifth of them with consanguineal and more than half out of them were first degree of consanguinity**.**

This result in agreement with **Michael et al., (2017),** in this study title " The genetic basis of cerebral palsy. Were their sample size was 124 patients " who stated in their study that many of these childrenwho having a genetic basis to their condition were suspected that to develop recent findings have implicated copy number variants and mutations in single genes in children with CP. The current studies are limited by relatively to the small patient numbers, the underlying genetic heterogeneity identified, and the paucity of validation studies that have been performed. However, several genes mapping to intersecting pathways controlling neurodevelopment and neuronal connectivity have been identified.

In our study group of parental consanguinity families were one fifth out of those families have another child suffering from cerebral palsy**.** Which contradicted the found results of previous research in Sudan by **Mohammed (2015) & Ibrahim, et al., (2011)** under the title "Cerebral palsy in Khartoum Cheshire Home 1982-1997: in which they Analyze 1200 cases " as a small percentage 2.9% had a positive family history of cerebral palsy.

From the researcher's point of view, this is due to the customs and traditions that characterize the people at the Egyptian villages, which impose the marriage of relatives, where there is no healthy culture and lack of awareness about genetic disorders.

Regarding the children's educational level, the result showed that, one quarter of children with CP were preschool age and more than half of them out of school**.** This current results was in agreement with the study of **Malcolm et al., (2017) in study title** " Educational

outcomes for children with cerebral palsy: a linked data cohort study. Were their sample size was 3944 patients" they said that the studied sample of children with CP were exempt from reading assessment for 46% of them because of intellectual or functional disability, 7% were absent or withdrawn from examination and analyze 47% participated in examination. Also it compatible with that found by **Mohammed (2015),** whose conducted at Khartoum University in a study titled "knowledge, attitude and practice of mothers of children with cerebral palsy" he found that Schooling was deficient among 77% of children at school age due to transportation problems and the remainder were in ordinary schools.

Our study result illustrated that there were more than two third of mothers had satisfactory knowledge about the preventive measures of cerebral palsy and its complications**.** This result was compatible with **Baiee et al., (2019),** in the study title " Mother's Knowledge Towards their Children with Cerebral Palsy in Babylon Province**.** Their sample size was 148 patients**"** who indicated that the overall assessment of mother's knowledge towered cerebral palsy was fair for 33.7% and good for 34.4% of study sample.

In contrast with **Gracy (2014)** in a study title" a study on the knowledge attitude and practice of caregivers of children with cerebral palsy. The sample size was 204 patients " he conduct his study in India which revealed that, 5% of the caregivers had good knowledge, with a mean score of 70.33, 57.5% of the caregivers had average knowledge, with a mean score of 56.96, 37.5% of the caregivers and had poor knowledge with a mean score of 46.42.

Our study result demonstrated that, there were three fifth of mothers' total practices toward the preventive measures of cerebral palsy and its complications were adequately**.** This result matches of with study of **Mohammed (2015),** in which he found that the practices of the physiotherapy methods by the mothers was high in 77%, mothers who conducted the exercises of physiotherapy at home, besides what the child have in the physiotherapy clinics.

In contrast with **Gracy (2014),** who founded that, the Percentage distribution of caregivers according to the level of practice. He reveals that 20% of the caregivers had good level of practices. 13.5% of the caregivers had average level and 66.5% of caregivers had poor level of practices.

This study indicated that, the total quality of life for mothers who have children with cerebral palsy disease was poor for more than three quarters of those mothers and little of them have no effect which means good level**.** Contrary to the results of our study, in a study done by **Okurowska et al., (2011)** under the title " Quality of life of parents of children with cerebral palsy. Their sample size was 30 patients " " They described that, half of the studied sample of parents of children with cerebral palsy their quality of life and health is good.

From the researcher point of view this refers to the level of dependency of their children with CP, feeling of incomplete mothers' obligations, fatigue, lack of rest, which often leads to more exhausted mother, conflict and crisis among family members. The disability of a child as, in terms of quality of life, affects all family and especially mother more than the child, because the restrictions in the child's independence cause greater burden on the mothers.

Regarding to the total health needs of children with CP were moderately achieved for 67,3 % of them and achieved by 32.7% of them**.** Unfortunately, the study results show that, despite the fact that in recent years the support that provided to families with children with CP by local governmental and non-governmental health services has grown, as it is provided in the legislation, the range services offered one insufficient, and coordination of these services is still inefficient.

 Our study results proved that, there are highly significant statistical differences between quality of life for mothers and their demographic characteristics such as mother's educational level with ($x2 = 28.628$ and $P=< 0.001$) while, insignificant relation was found between family income with ($x2 = 6.288$ $P < 0.05$). Also, there are significant statistical differences between quality of life and other demographic characteristics like social status, mother's job, and another child has a disease in the family with ($x^2 = 15.083$, 6.642, and 12.550 respectively with $P=< 0.005$).

These results are in contrast with **Yilmaz, et al., (2013),** in his study title **"** Quality of Life in Mothers of Children with Cerebral Palsy. Their sample size was 140 patients **"**As they conducted their research study to investigate health-related quality of life in mothers of children with cerebral palsy and to determine factors of Health-related quality of life (HRQoL). On two groups of participants comprised 137 mothers of children with CP, and control group comprised 140 mothers with healthy children. All mothers in both groups were

housewives and no statistically significant difference was found between participants in the two groups as to educational level, and level of income (*P* > 0.05).

In a similar study, reported by **Lipscombe et al., (2016),** titled " Quality of life in parents of children with cerebral palsy: Is it influenced by the child's behaviour?. Their sample size was 60 patients "They suggested that, HRQoL of mothers with CP children is negatively correlated with the educational level of the mothers and also a study by **Bumin et al., (2018),** "Anxiety, depression and quality of life in mothers of disabled children. Their sample size was 140 patients" in which they emphasized that HRQoL of disabled children was associated with depression and anxiety levels of their mothers, and a negative association was also present between HRQoL and mothers' educational status.

The results of this study indicated an important factor, which was that, the mothers who have child with CP and had a job had a significant relation to QOL more than those who were unemployed, that lead to stability of the social life of mothers to a large extent, but it may be limiting the factor for childcare. While, there were insignificant relation between family income because, caring of a child with CP can affect the family's financial situation due to the cost of treatment, as the presence of a child with CP can result a large financial burden on the families.

Our study result evinces that, there was a significant statistical relation between mother's total level of knowledge and practices about health care of children with cerebral palsy and their Quality of life level with **P value** <0.05.

The entire research proved that, mothers' knowledge and their practices of care for children with CP have an effect on their own quality of life aspects in consistent with **Gracy, (2014),** who stated that, mothers as main caregivers for their children, need to raise their awareness about CP. Because they having a proper knowledge, and proper skills to look after these children which will affect their health status and level of child dependency. Many time, lack of knowledge may lead to faulty practices and the Quality of life of mothers will be affected negatively on their care provided to her children.

Conclusion:

The study result indicated that, more than half of study children with CP were male with mean age 7.86 ± 2.565 years. While, more than half of them out of school. Regarding mothers' knowledge and practices about health care of CP were satisfactory for more than two third of them with highly statistically significant relations between total mothers' knowledge and practices. Which lead to illustration of poor level of quality of life for mothers with highly significant statistical differences between quality of life for mothers and their demographic characteristics such as mother's educational level, social status, and mother's job. As well as a significant statistical relation with mothers' knowledge and practices. Also, the result demonstrated that, the health needs for children with CP were achieved moderately for more than two third, while insignificant statistic difference with mothers' knowledge and practices.

Recommendations:

Based on the findings of the present study the following recommendations were formulated:

- Give emphasis on the importance of health education program especially for mothers to raise their awareness about CP disease and its risk factors.

- Counseling session for mothers to secure and help them to cope effectively with their children with disabilities which influence the improvement of their own quality of life.

- Community Health services of rehabilitation should be advocated for mothers about health care of their children at home and medical follow up.

- Further studies should be conducted to improve the mothers' knowledge and practices for proper dealing with their children with CP as it plays an important role on their quality of life which and lead to achieve their children's health needs.

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