Impact of spastic cerebral palsy upon the quality of life of children under the age of 12 years in Erbil City: parents' reports

اثر الشلل الدماغ التشنجي على نوعية الحياة للاطفال تحت سن ١٢ سنة في مدينة أربيل : تقارير من الوالدين

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المستخلص:

الهدف : تهدف الدراسة الى تقييم تأثير شلل الدماغ التشنجي على نوعية الحياة لاطفال المصابين بشلل الدماغي دون ١٢ سنة في مدينة أربيل.

المنهجية: اجريت دراسة وصفية للفترة من اول من كانون الثاني لغاية ٣١ من شهر مايس لعام ٢٠١٤. أختيرت عينة غير احتمالية "غرضية" من ١٠٠ ام من اللواتي لديهن طفل مصاب بشلل الدماغي ويراجعن مركز هيلينا للتاهيل الطبي شهريا او اسبوعيا. جمعت البيانات من خلال استخدام استمارة استبيانية متكونة من جزئين، الجزء الاول شمل صفحة البيانات الديوغرافية، لكلا من الام والطفل المصاب بشلل الدماغ ، أما الجزء الثاني تم استخدام استبانة الشلل الدماغي للاطفال (PedsQL ™ 3.0). (تقرير الآباء) لجمع البيانات ، جمعت البيانات عن طريق المقابلة الشخصية،. تم تحليل البيانات باستعمال الحقيبة الاحصائية للعلوم الاجتماعية، الاصدار ١٨. و أجراء التحليل الاستنتاجي (معامل الثبات، معامل التوافق و مربع كاي) لايجاد العلاقة .

النتائج: كشفت النتائج أن حوالي نصف الامهات كانت اعمارهن بين (٢٨–٣٧) سنة، وهن ذوات الوضع الاجتماعي والاقتصادي المنخفض ، والغالبية يعيشون في المناطق الحضرية . و النسبة العالية من هؤلاء الاطفال يتراوح اعمارهم بين ٢–٤ سنوات من العمر، والغالبية كانوا من الذكور و النوع التشنجي لشلل الدماغ. وجد أن هناك ارتباط ذو دلالة احصائية بين أنواع الشلل الدماغي والأنشطة اليومية، والألم و الأذى ،التكلم و التواصل ، الأكل و الأنشطة ، بقيمة ٠,٠٣٢ ، ٠,٠٠ ، ٠،٠١١ ، ٠,٠١٤٠ على التوالي .

التوصيات :أوصت الدراسة بتطبيق برنامج صحي تعليمي للأمهات لتحسين نوعية حياة اطفالهن المصابين .

Abstract:

Objectives: This study aims to assess the quality of life of cerebral palsy children less than 12 years old reported by parents in Erbil city/Iraq.

Methodology: A descriptive study was conducted during 2014, to describe the quality of life of cerebral palsy children. One hundred mothers have cerebral palsy children were participated in this study. The study took place at Helena Center for handicapped children in Erbil City**.** Questionnaire was used to collect data, which consists of two main parts. The first part is divided into two sections; section one was described the mothers' demographic characteristics, while the second section was for identifying the demographical characteristics of cerebral palsy children. The inventory trademark" (PedsQL^{TM}) 3.0 (parents' reports) was used in second part of the questionnaire. Statistical Package for Social Science (SPSS) version 18 was used to analyze date. Chi-squared test was applied to find out the association and significance.

Results: Most of the mothers were from low socioeconomic status, living in urban areas and aged between 28-37 years old. Majority of cerebral palsy children were male, aged between 2 - 4 and diagnosed with spastic type. The significant associations were found between types of cerebral palsy and daily activities, pain and hurt, speech and communication and eating and activities respectively at p-value 0.032, 0.000, 0.011, and 0.014**.**

Recommendations: The study recommended special health educational programs for mothers to improve the quality of life of their cerebral palsy children.

Key words: Spastic Cerebral Palsy, Quality of life, Children under the age of 12 year.

Introduction:

In recent years, there has been an increasing interest in measuring quality of life (QoL) of children with cerebral palsy (CP) [1]. Quality of life (QoL) is a person's subjective well-being and physical health, material well-being, interpersonal relationships within and outside the family and fulfillments, and active reactions [2], is defined as a 'disorder of movement and non-progressive posture due to defect or lesion of the immature brain, which affects the movements and daily activities, occurring in approximately 2 to 2.5 per 1000 live births [3] , others emphasized that affects 1.2 to 2.5 per 1000 new births, and added that the rates vary from country to country and also within countries [4]. Statistics indicated that approximately 80% to 90% of individuals with CP are complaining of spastic type [5]. The clinical manifestations of CP are mainly classified into four major types: spastic, dyskenitic, ataxia and mixed. Furthermore, the topographic distributed into diplegia, quadriplegia, hemilegia, triplegia and monoplegia [6]. Bilateral and unilateral spastic is the most common types of CP [7], but Surveillance of cerebral palsy in Europe has divided CP into spastic unilateral, bilateral, dyskinetic, and ataxic and mixed [8]. Others stated that CP ranges in severity to mild spasticity and affects the legs about 4-limbs involved (quadriplegia), and others added that CP is associated with cognitive The victims suffer with many complications such as spasticity, joint with CP, and had health problems like (2.2%) attention deficit (11.1%) orthopaedic problems, (13.2%) behavior problems, and (2.2%) cognitive problems [10]. The complications associated with spastic CP can affect physical ability and QoL of individuals suffering from this motor disorder [4]. The parent-reported quality of life for children with CP is associated strongly with impairment [7]. Children with brain damage may show lethargy or lack of alertness, irritability or fussiness, a high-pitched cry, trembling of the arms and legs, poor feeding abilities, problems of sucking and swallowing, low muscle tone, difficulty in feeding, poor head control and poor communication [11, 12].

Helena Centre for Handicapped Children in Erbil City has registered 1700 CP children under the age of 17 years [13]. Children with CP are markedly poorer HRQoL compared with healthy children. To the best of our knowledge, the present study is the first study which evaluates the QoL of CP children in Erbil, and aimed to identify the impact of spastic CP upon QoL of children under the age of 12 years in Erbil City, reported by the parents, and to identify the association between types of CP and QoL domains.

Methodology:

A descriptive study was conducted between 1st of Jan. to May 31st 2014. One hundred mothers who have CP children and attended Helena centre to receive physiotherapy and other medical services were asked to participate in this study, this centre was selected for data collection; and it is the only governmental centre of all over Erbil city which provides medical and physiotherapy services for handicapped children in Erbil city. The questionnaire was consisted of two main parts: Part one consists of two sections. The first section was to identify the demographic characteristics of mothers, such as age, level of education, residential areas, and socioeconomic status (SES.) while, the second section was to describe the demographical characteristics of CP children such as age, sex and types of CP. In the second part of the questionnaire, the inventory trademark" (PedsQL™) 3.0 cerebral palsy version (parent proxy-report scales) was used and translated into Kurdish language by official translator. It was used to assess the QoL of CP (reported by parents) which has three likert scales (1) for never, (2) for sometimes, and (3) for always. The questionnaire was contained of 23 items, categorized into six domains: daily activities (9 items) , movement and balance (5 items), pain and hurt (4 items), eating activities (5 items), and speech and communication (4 items). However, school achievement domain was deleted because CP deprives all affected children of school services in Erbil city. Ethical approval was obtained from Erbil General Directorate of Health and both of the scientific and ethical

consideration committees of the Nursing College at Hawler Medical University. The questionnaire was completed through using face-to-face interviews with the mothers. The aims and benefits of the study were explained to the mothers. Verbal agreement was obtained from all the participants. The data was collected with the help of three Kurdish-speaking researchers. The reliability of the questionnaire was determined through a pilot study and it was prepared by testing the final questionnaire on 10 mothers, the result was (r = 0.89). Validity of questionnaire was obtained through a panel of (12) experts in different specialty. Descriptive statistical analysis procedures (frequency, percentage, mean score, and standard deviation), and interferential statistical analysis procedures (reliability, contingency coefficient, and chi square tests) were used for data analysis under application of the Statistical Package of Social Science (SPSS) version 18. The P value of ≤ 0.05 was considered statistically significant.

reflux, gastritis, chronic pulmonary aspiration, constipation, and speech difficulty [3]. Cerebral palsy (CP) can have a tremendous impact on the child's capacity to carry out activities of daily living (ADL); contractures, hip dislocation, spinal disorders, dysphagia, gastroesophageal hence, the impact on the QoL of the child and also his family and their careers has impaired health related QoL [5]. The severity of disability had a negative impact on health related quality of life (HRQoL) of children impairments, seizures, visual impairment, hearing loss, and complete functional dependency [3, 9].

Results:

Table1. Frequencies and percentages of demographic characteristics of mothers with CP children

	Items	*N0. (**F)
1.	**Age of mothers**	
	18-27	**36 (36)**
	28-37	**47 (47)**
	38-47	**11 (11)**
	48-57	**6 (6)**
	$\bar{x}$ and SD ***	**34.13 ± 4.70**
2.	**Level of education**	
	Illiterate	**46 (46)**
	Primary school	**28 (28)**
	Preparatory school	**19 (19)**
	Secondary school	**2 (2)**
	High graduate (diploma and Bachelor)	**5 (5)**
3.	**Socioeconomic status**	
	Low	**52 (52)**
	Middle	**26 (26)**
	High	**22 (22)**
4.	**Residency areas**	
	Urban	**58 (58)**
	Rural	**42 (42)**
	Total	**100 (100)**

***N0. Number** **F. frequency** ***$\bar{x}$ and SD. Mean and Standard deviation**

The finding of this table revealed that the high percentages (47%) of mothers were aged between 28-37 years old, and their mean and standard deviation of ages were (34.13 ± 7.70). Furthermore, less than half (46%) of the participants were illiterate, and approximately half percent of mothers were living in low SES and urban areas respectively (52%), (58%).

Table 2. Frequencies and percentages of demographic characteristics of CP children

	Items	*N0. (**F)
1.	**Age of CP children**	
	2-4	**54 (54)**
	5-7	**38 (38)**
	8 and above	**8 (8)**
	***$\bar{x}$ and SD**	**4.165 ± 1.54**
2.	**Sex of CP children**	
	Male	**58 (58)**
	Female	**42 (52)**
3.	**Types of CP**	
	Spastic	**75 (75)**
	Athetoid	**10 (10)**
	Ataxia	**10 (10)**
	Mixed	**5 (5)**
	Total	**100 (100)**

***N0. Number** **F. frequency** ***$\bar{x}$ and SD. Mean and Standard deviation**

Table 2. Shows that more than half (54%) of CP children were aged between 2-4 (including toddler and preschool age), mean and standard deviation were (4.165 ± 1.54). More than half (58%) of CP children were male, and most of the participated children (75%) were diagnosed with spastic CP.

Table 3. Association between daily activities and types of CP

Daily activities / Types of CP	Never * N0. ** (F)	Sometimes N0. (F)	Always N0. (F)	***n. (100)	**** χ^2	***** P-value
Spastics	3 (3)	14 (14)	58 (58)	75 (75)	19.674	.032
Athetoid	1 (1)	1 (1)	8 (8)	10 (10)		
Ataxia	3(3)	5(5)	2(2)	10 (10)		
Mixed	0 (.0)	0 (.0)	5 (5)	5 (5)		

N0*. Number F. Frequency n.*** Sample size ****χ^2 Chi squared test *****p. Probability**

Table number 3 shows that more than half 58% of mothers had spastic CP children and reported that their children were complained from difficulties in daily activities. However, only 3% of mothers mentioned that their children were not struggling with daily activities. A significant association was found between CP children and daily activities at p-value .032.

Table 4. Association between pain and hurt and types of CP

Pain and hurt / Types of CP	Never * N0. ** (F)	Sometimes N0. (F)	Always N0. (F)	***n. (100)	**** χ^2	***** P-value
Spastics	0 (0)	35 (35)	40 (40)	75 (75)	24.733	.000
Athetoid	2 (2)	2 (2)	6 (6)	10 (10)		
Ataxia	3 (3)	5 (5)	2 (2)	10 (10)		
Mixed	0 (.0)	2 (2)	3 (3)	5 (5)		

N0*. Number F. Frequency n.*** Sample size ****χ^2 Chi squared test *****p. Probability**

Table 4; shows a significant association between types of CP and pain and hurt at P value 0.000. Out of 75 mothers who had spastic cerebral children only 40 % of them stated their children are suffering from pain and hurt during their daily living and 35% of mothers declared sometimes.

Table 5. Association between speech and communication and types of CP

Speech an communicatio / Types of CP	Never * N0. ** (F)	Sometimes N0. (F)	Always N0. (F)	***n. (100)	**** χ^2	***** P-value
Spastics	2 (2)	20 (20)	53 (53)	75 (75)	16.560	.011
Athetoid	0 (.0)	2 (2)	8 (8)	10 (10)		
Ataxia	2 (2)	6 (6)	2 (2)	10 (10)		
Mixed	0 (.0)	3 (3)	2 (2)	5 (5)		

N0*. Number F. Frequency n.*** Sample size ****χ^2 Chi squared test *****p. Probability**

Above table shows us that there was a significant association between types of CP and speech and communication at P value 0.011. Most of the mothers 53% who had spastic CP children reported their children were complained from difficulties in communication skills. However, only 2 % of them stated their children were able to communicate with their family.

Table 6. Association between eating and activities and types of CP

Eating and activities / Types of CP	Never * N0. ** (F)	Sometimes N0. (F)	Always N0. (F)	***n. (100)	**** χ^2	***** P-value
Spastics	0 (.0)	24 (24)	51 (51)	75 (75)	15.984	.014
Athetoid	0 (.0)	3 (3)	7 (7)	10 (10)		
Ataxia	1 (1)	7 (7)	2 (2)	10 (10)		
Mixed	0 (.0)	3 (3)	2 (2)	5 (5)		

N0*. Number F. Frequency n.*** Sample size ****χ^2 Chi squared test *****p. Probability**

This table shows a significant association between types of CP and eating and activities at P-value .014. Approximately half percent (51%) out of 75 mothers mentioned their CP children were always complained from eating habits and activities, such as chewing, swallowing and biting.

Discussion:

1. Discussion of demographic characteristics of mothers.

The results of the study recognized that most of the mothers were aged between 28-37 years, its mean and standard deviation was 34.13 ± 4.70. According to Mu'ala's study the mothers who have CP children in Erbil city were aged between 25-31 years old [14]. This result in agreement with study that found the maternal age was (37.2 ± 6.7) years old. [15], but disagreed with a study which found that the mean ages of chronic disability children's caregiver in Australian were 40:2± 6.53 years of age [16] .

Illiteracy is still one of the biggest problems in Iraqi society. The study found that 46% of mothers who have CP children in Erbil city were illiterate. However, the numbers of illiterates were declined as compared to a study, which found that 60% of CP caregivers in Erbil city were illiterate, this result indicated that the level of illiterate reduced among mother having CP children. Having security and economic stability are two major factors behind decreasing the level of illiteracy among Kurdish society [14, 15] .

The result of the study found that mothers were complained of low family income due to the needs of their CP children. This result supported by other research which found that majority of families who having CP children were complained of low SES [12 , 14] . Majority of the mothers 58% were living in urban areas. This result is agreed with a study which found that 64.9% of CP caregivers in European countries were form urban areas [17].The current study was agreed with a study which found that 64.9% of CP caregivers in European countries were form urban areas [7].

2. Discussion of demographic characteristics of CP children.

Majority of CP children who participated in the study were at preschool stage 4.165 ± 1.54, this result was agreed by researchers who found that 50% of CP children in Helena center in Erbil city were in preschool stage [14]. The present study found out that the high percentages of CP children in this study were male, current result was agreed with the other studies who emphasized that the incidences of CP were more among male than female [14 , 15] .

The highest percentages of CP children in Erbil city were complaining from spastic CP. This result supported by researchers who emphasized that spastic types represent 70-80%, athetoid or dyskinitic were 4-8%, ataxic is (5-10%) and mixed was 1-2% [11, 14 , 16] . Spasticity is one of the most common types of CP , which causes stiffness or tightness of muscles and sending error messages from the damaged part of the brain to other parts of the body [8].

3. Discussion the quality of life domains and its association with types of CP.

The significant association was found between types of CP and daily activities. Mothers reported that their CP children never crawled, and walked. Spastic children remain dependent on their parents due to muscle stiffness and inability to perform their daily living activities. The best management choice for CP is physiotherapy and occupational therapy, which is lead to somehow sufficient of independence from parents. [11],

The present study found out that there was a significant association between types of CP and daily activities, and reported that there CP children never walk; crawl, and setting well, and children with spasticity remain dependent on their parents because they have daily living and self-care deficit, this result agreed by a study who found out the majority (77.8%) of CP children had complained of deficit limitations in daily activities that took a lot of energy [11], and also supported by a study which reported that the caregivers of CP children reported that their CP children had poor daily activities, and found out a significant association between CP and daily activities (.001) [17] . Other study noticed that the highest scores of children with unilateral spastic had more effects on their daily activities than other types of CP [18]. The nature of the condition had similar effectiveness of their daily activities. This means that CP children had deficit in their daily activities.

Lack of physiotherapy and poor mother's knowledge about home physiotherapy in our country is the best reason which clearly reflects on their QoL. Spastic type refers to stiffness of muscles which obviously respond with pain and hurt, which are showed as another problem which associated with CP children in Erbil city, they spend a lot of energy and high efforts for reaching a toy or

dealing with a specific play. The present study found out the association between pain, hurt, and types of CP. The results agreed with another study which found out the significant association between body pain and CP types of p-value 0.04 [19]. However, the present study did not test the children's level of pain due to lack of special equipment such as pain scale in Helena center, but it clearly reflects that our CP children complained of high pain. Lack of mothers'knowledge about home physiotherapy is one of the main reasons, which clearly affects their children's QoL In Erbil city. In this study it is realized that spastic CP children need more energy and efforts to play games due to stiffness of their muscles [20]. Children's level of pain was not evaluated due to lack of mothers' knowledge and pain assessment scale in Helena center. However, it is clearly noticed that Iraqi's CP children are complaining of severe pain as compared to CP children in developed countries. Other study reported that 5.7% of CP children felt pain very often, 18.9% fairly often, 37.7% once or twice, and only 18.9% did not feel pain and discomfort [12]. Pain was associated with poor quality of life in the physical and psychological well-being and self-perception domains [7].

Literature states that difficulty in communication and speech among CP children reduces the relationship between CP children and their parents [12, 10]. This study found significant association between types of CP and communication and speech at p = .000, this result was agreed with a study who emphasized that CP children had more impaired verbal communication skills. Research found that difficulty in speech and communication is one of the most common problems among spastic type of CP [20, 14]. This result reflects that our CP children in city of Erbil have a poor QoL.

A difficulty in swallowing among CP children is one of the other problems that cause delay millstone and growth retardation. The present study revealed that 51 (47.3%) of mothers reported that their CP children have eating disorder and difficulty in chewing and swallowing. The study discovered that there was a significant association between types of CP and eating habits. Study shows that children with brain damage have problems with sucking and swallowing, low muscle tone, difficulty in feeding, poor head control and poor communication [11, 12]. The current result also is agreed with study which found 61% of parents identified at least one priority related to mobility, eating, and swallowing difficulties [18]. It has been reported that systemic causes of swallowing dysfunction or pharynx, and upper oesophagus, this mean that may affect the QoL [12]. However it may not be possible to obtain reliable information from children with severe intellectual impairments or significant communic-ation problems, and the use of proxies (usually mothers) for the assessment of QoL in such children is necessary [7].

Recommendations:

The current study emphasized that CP children in Helena center were complaining of bad QoL. Most of the children were diagnosed with spastic CP, which in turn affected their QoL. Health education program regarding home care management was recomm-endded for mothers who have CP children.

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