https://doi.org/10.15218/ejnm.2022.07 Erbil j. nurs. midwifery, Vol. 5, No. (2), Nov 2022
Original Article

Caregiver's Knowledge regarding Homecare Management of Spastic Cerebral Palsy Children Under 12 Years Old in Rapareen Province

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ABSTRACT

Background and objectives: Spasticity, sometimes called hypertonia, makes movement difficult or even impossible. Spastic children with Cerebral Palsy face many health problems that need significant attention at home. This study aimed to assess caregivers' knowledge about home care management of spastic CP children in the Rapareen Region.

Methods: A quantitative, descriptive cross-sectional study was carried out in the Rapareen Region of Sulaimani city. The period started from October 1st, 2020, to October 1st, 2021. Purposive (non-probability) sampling techniques of 115 caregivers, who attend rehabilitation centers in Ranya, Chwarqwrne, and Qaladeze in Rapareen province, were respectively recruited to the study. The investigators prepared a questionnaire format after reviewing related literature. Direct interview (face to face) and a home visit was conducted to collect the data. Descriptive statistics SPSS version 25 was used, and statistics of frequencies, percentages, and inferential statistical analysis of Chi-square test and regression were used.

Results: The vast majority (98.3%) of the primary caregivers were mothers of spastic CP children. Almost all (94.8) of the caregivers were married. The majority (88.7%) of caregivers were housewives. Less than half (48.7%) of the sample were between 31 to 40 years. More than three quarter (67%) of the sample were male children and more than half (65.2%) were School-age children with Spastic Cerebral Palsy. There was a statistically highly significant association between formal years of education and residency area of caregiver with the caregiver's knowledge at a p-value of 0.020 and 0.003 respectively. Factors significantly associated with caregivers' knowledge of homecare of spastic CP children include the level of education of caregiver, age of caregiver, and height of spastic Cerebral Palsy children.

Conclusion: The findings of the present study showed that level of education, age of caregiver, and residency areas are associated with caregiver's knowledge regarding homecare of spastic Cerebral Palsy children. Mothers are required educational programs to boost knowledge regarding homecare management of spastic CP children.

Keywords: Spastic CP children; Caregiver; Internship and residency; Homecare services.

Received: 29/11/2021 *Accepted: 22/02/2022* *Published: 30/11/2022*

INTRODUCTION

Cerebral Palsy (CP) is an umbrella term that "describes a collection of movement and posture problems that cause activity restrictions and are related to nonprogressive disruptions in the developing fetus or infant's brain" [1-2,8,11,17]. Motor disorders may be accompanied by cognition, communication, perception, and epilepsy disorders [1-2]. Cerebral palsy is one of the chronic diseases that has become a significant health concern worldwide [3]. However, the physical characteristics of CP include neuromotor disorders and the presence of pain [4]. CP manifests itself relatively early in childhood, despite being classified as a nonprogressive condition [4]. The brain damage induced by CP has no cure, and it is neither continuous nor progressive [6]. Clinical signs and symptoms vary depending on which part of the central nervous system (CNS) is damaged and range from average intelligence and well-functioning moderate monoplegia to severe spastic quadriplegia and mental retardation [5]. It affects about 2 out of every 1000 live births, making it the most prevalent motor disability in children [7]. Injury to the developing brain has a variety of causes and consequences [5]. Agenesis, schizencephaly, hemimegaloencephaly, pachygyria, polymicrogyria, lissencephaly, and other migration and embryogenetic abnormalities are caused by regional anatomical deformities with motor deficiencies [9]. Congenital, genetic, inflammatory, anoxic, traumatic, toxic, and metabolic variables all have the potential to develop CP [8]. One of the predictors of a better prognosis is the early detection of neurological impairment and its progression to a clinical manifestation of CP [9]. The affected limbs [hemiparesis, diplegia, and quadriplegia]; the motor impairment of the global motor functions (GMFCS I to V); and the anatomical distribution, unilateral (monoprotic, hemiparetic) and bilateral (diparetic, triparetic, quadriparetic) can all be used to classify patients [10]. The difficulties in managing CP range from one sufferer to the next. The issues may be severe soon after birth in some people, while they are not apparent until early infancy in others [6]. Incontinence, constipation, tooth decay, skin sores, and chest infection are all symptoms of intellectual impairment, epilepsy, failure to thrive, vision and hearing problems, impaired touch and pain sensation, hip dislocation, and spine curvature (scoliosis) there are the signs and symptoms CP [11]. Medical treatment for seizures, spasticity, reflux, constipation and depression should be thoroughly researched, especially in terms of side effects and any combinations [5]. Following a diagnosis, a detailed management regimen should be implemented. Different components of the condition are managed by parents, doctors, speech therapists, occupational therapists, and other medical practitioners or specialists [6]. Nursing management of children with CP is an option and depends on ambulatory status. Thus, the family of a child with CP becomes crucial and will be very much necessary to guide the child's development in a favorable environment and to care for and maintain their health status [10]. The primary medical care at home should include proactive care coordination, including monitoring, interpreting, and arranging with specialists and specialty teams, as well as communicating with therapeutic, educational, family support, and other community resources [12]. According to an official census in Rapareen Province General Health Directorate of Rapareen, 160 Spastic CP cases have been registered and are receiving medical care and physiotherapy care in rehabilitation centers (GHDR, 2020). When assessing therapy choices for children with CP, their caregivers prioritize motor development. Physiotherapy interventions are administered over the lifespan to improve motor capacities, increase function, and avoid subsequent impairments while considering the preferences and values of the patient and family. Children with CP and their caregivers want to know everything they can about their child's health, including their prognosis and rehabilitation needs. On the other hand, caregivers frequently believe that health professionals undervalue their demand for information [28-29]. Caregivers' understanding of how to manage homecare for children with impairments is sometimes overlooked. Because of the potential for scorn and taunting from others, it is rarely carried outside the home. The greatest option to provide daily care and management for children with persistent disabilities is through home care [3]. This study aimed to determine the level of caregiver's knowledge regarding homecare management of spastic CP Children in the Rapareen province.

METHODS

A quantitative, descriptive cross-sectional study was conducted. The study was carried out in the Rapareen province in Sulaimania city. A non-probability convenient sample of 115 caregivers was selected from three different rehabilitation centers with a total of 160 cases: Kewarash primary health center in Ranya city (90 Spastic CP cases), Qaladze center (60 Spastic CP cases), Chwarqurna rehabilitation center (10 Spastic CP cases). Data were collected from January 25th to April 25th, 2021, to identify caregivers' knowledge of homecare management of Spastic CP children in the Rapareen region. According to Rapareen General Health Directorate's annual census, 160 Spastic CP children are registered in the three centers. Yamane formula has been used to estimate the sample size (n=N/(1+N(e)2), n=160/1+160 (0.05)2 and n=115. The study has recruited 115 spastic CP children with their caregivers willing to participate in the study. Caregivers who did not suffer from chronic diseases (diabetes, hypertension, asthma, etc.), took care of spastic CP children under 12 years old, spoke fluently Kurdish language, and did not complain of mental and psychological problems were included. Caregivers of children with other types of CP were excluded from the study. The researchers constructed a questionnaire consisting of two parts: part one assessed the socio-demographical characteristics of caregivers and CP children, such as the age of the caregiver, marital status, occupation, level of education, type of family, economic status, and type of delivery, and part two the second consisted of 20 questions related to caregiver's knowledge regarding spastic CP. A three-point scale was used (0 for bad knowledge, 1 for fair knowledge, and 2 for good knowledge) and overall knowledge was categorized into three groups: bad knowledge (0-6), fair knowledge (7-13), and good knowledge (14-20). Data were gathered through face-to-face interviews during the home visits and the investigator filled out the questionnaire tool. Nineteen experts in related fields validated the questionnaire, and the pilot study of 10 caregivers indicated that the tool was eligible for data collection, the person correlation (r) was 0.87. Before starting data collection, the researcher explained the research process and the aim to participants and asked each of the agreement participants to fill in a consent form. Prior to the data collection, formal permission was obtained from the University of Sulaimani/ College of Nursing and Rapareen Health General Administration in Ranya City/ Sulaimani/Kurdistan/ Iraq. The researchers explained the purpose of the study. All participants have the right to withdraw at any time. The researchers have promised to keep the data information for confidentiality and anonymity. The data were analyzed using SPSS software for statistical analysis Version 25, to calculate descriptive statistical analysis (frequency and percentage). Inferential statistical analysis (chi-square and regression) was used to determine the association between variables, the P-value ≤ 0.05 is considered statistically significant.

RESULTS

The result shows that the majority (98.3%) of the main primary caregivers were mothers. Most caregivers were primary school graduates (33%). Less than half (48.7%) of caregivers were aged 31 to 40 years old and were of middle socioeconomic status. The majority of caregivers were housewives (88.7%), more than one-third (38.3%) lived in urban and suburban areas, and less than three-quarters (72.2%) were in a traditional nuclear family Table 1. The higher percentage (65.2%) of spastic CP children were school-age children. Sixty-seven percent were males, 63.5% were between one to six months of age at the time of diagnosis, 53% did not have birth asphyxia, and 80% were on a normal diet. About 60.9% were born by normal delivery, and 91.3% were delivered in public hospitals. Most of the sample (80%) did not have a child previously affected with CP, and less than half (40%) of the children were the middle child in the family. About 75.7% have one or more complications associated with CP, and less than half (44.3%) were in the level V of independence Table 2. A highly significant association between formal years of education and residency area of caregiver with the caregiver's knowledge at a p-value of 0.020 and 0.003, respectively was observed. Level of education, age of caregiver, and height of the spastic CP children were significantly associated with caregiver's knowledge at p-values of 0.002. 0.050 and 0.012, respectively Table 3.

Table 1: Distribution of sample according to caregivers' socio-demographic characteristics

Items		**F.**	**(%)**
The main primary caregiver	Mother	113	(98.3)
	Grandmother	1	(0.9)
	Aunt	1	(0.9)
Level of education	Illiterate	33	(28.7)
	Primary school	38	(33)
	Secondary school	28	(24.3)
	Institute Diploma	10	(8.7)
	University and above	6	(5.2)
Age of caregiver/years	20-30	25	(21.7)
	31-40	56	(48.7)
	41-50	31	(27)
	51 and above.	3	(2.6)
Marital status	Married	109	(94.8)
	Unmarried	6	(5.2)
Occupation	Housewife	102	(88.7)
	Governmental employee	8	(7)
	Non-government employee	5	(4.3)
Place of residence	Rural	27	(23.5)
	Urban	44	(38.3)
	Suburban	44	(38.3)
Socio-economic status	High	11	(9.6)
	Middle	56	(48.7)
	Low	48	(41.7)
Types of family	Traditional nuclear family	83	(72.2)
	Nuclear family	13	(11.3)
	Blended family	2	(1.7)
	Extended family	13	(11.3)
	Single parent family	4	(3.5)
Total		115	(100)

F. frequency ** % percentages

Table 2: Distribution of sample according to spastic CP child socio-demographic characteristics.

Items		F.*	(%)**
Developmental stage	Toddler	7	(6.1)
	Preschool-age	33	(28.7)
	School-age	75	(65.2)
Gender	Male	77	(67)
	Female	38	(33)
Age at diagnosis/months	1 to 6	73	(63.5)
	7 to 12	29	(25.2)
	13 to 18	4	(3.5)
	19 to 24	1	(0.9)
	25 or more	8	(7)
Birth asphyxia	Yes	54	(47)
	No	61	(53)
Type of feeding	Breastfeeding		
	Bottle feeding	9	(7.8)
	Mixed	14	(12.2)
	Normal diet	92	(80)
Mode of delivery	Normal delivery	70	(60.9)
	Cesarean Section	45	(39.1)
Place of delivery	Home	10	(8.7)
	Hospital	105	(91.3)
Another affected child with CP	Yes	23	(20)
	No	92	(80)
Child's order in the family	Firstborn	38	(33)
	Middle born	46	(40)
	Young child	31	(27)
Complications associated pregnancy	Yes	87	(75.7)
	No	28	(24.3)
Level of independence	Level I	14	(12.2)
	Level II	6	(5.2)
	Level III	19	(16.5)
	Level IV	25	(21.7)
	Level V	51	(44.3)
Total		115	(100)

*F. frequency ** % percentages

Table 3: Association between caregiver's knowledge and socio-demographic characteristics.

Knowledge Socio-demographical characteristics		Fair K.*** F. (%)	Good K. F.(%)	X^2 (Sig.)
Primary caregiver	Mother	81 (71.5)	32 (28.5)	2.895(0.2350)
	Father	0 (0.0)	0 (0.0)	
	Grandmother	0(0.0)	1 (100.0)	
	Aunt	1(100.0)	0 (0.0)	
Level of education	Illiterate	18 (54.5)	15 (45.5)	11.652(0.020)
	Read and wright	0 (0.0)	0 (0.0)	
	Primary school	25 (65.8)	13 (34.2)	
	Secondary school	25 (89.3)	3 (10.7)	
	Diploma institute	9 (90.0)	1 (10.0)	
	University and above	5 (83.3)	1 (16.7)	
Age/ years old	20-30	21 (84.0)	4 (16.0)	5.645(0.227)
	31-40	41 (73.2)	15 (26.8)	
	41-50	17 (56.7)	13 (43.3)	
	51 and above.	3 (66.7)	1 (33.3)	
Occupation	Housewife	70 (68.6)	32 (31.4)	3.395(0.183)
	Public employee	7 (87.5)	1 (12.5)	
	Private employee	5 (100.0)	0 (0.0)	
Marital status	Unmarried	5 (83.3)	1 (16.7)	448(0.503)
	Married	77 (70.6)	32 (29.4)	
Residency areas	Rural	13 (48.1)	14 (51.9)	11.968(0.003)
	Urban	38 (86.4)	6 (13.6)	
	Suburban	31 (70.5)	13 (29.5)	
Socio-economic status	Low	7 (63.6)	4 (36.4)	4.378(0.112)
	Middle	45 (80.4)	11 (19.6)	
	Low	30 (62.5)	18 (37.5)	
Type of family	Traditional nuclear family	62 (74.7)	21 (25.3)	3.841(0.428)
	Nuclear family	7 (53.8)	6(46.2)	
	Blended family	2 (100.0)	0 (0.0)	
	Extended family	8 (61.5)	5 (38.5)	
	Single parent family	3 (75.0)	1 (25)	

***K. Knowledge

That level of education, age of caregiver, and height of the spastic CP were factors associated with the caregiver's knowledge and shows a highly significant p-value of 0.002. 0.050 and 0.012 respectively Table 4.

Table 4: Factors associated with caregiver's knowledge regarding homecare of spastic CP.

Factors	Score	df	Sig.*	Exp [B]
Formal years of education	9.313	1	0.002	0.680
Age of caregiver	3.715	1	0.050	1.986
Height of SCP child	6.312	1	0.012	0.209

P-value < 0.05 significant * Significant

DISCUSSION

The demographic characteristics of caregivers of children with CP. The results of the present study reflected that the majority (98.3%) of primary caregivers of Spastic CP children were mothers. This result agreed with previous studies which mentioned that the caregivers of CP children were mothers and states that they are more effective in initiating and reciprocating the child's needs [13-17]. Regarding the caregiver's marital status, the majority (94.8%) of caregivers in the present study were married. The current results showed that most of the caregivers were primary school graduates and illiterates. A similar study was conducted by Hasan in Erbil city of the Iraqi Kurdistan region which reported that 43% of the sample were illiterate, [3]. Other studies report caregivers were literate and a high percentage of them had reached high school education (33.3% and 37.0%, respectively) [13]. Around half of the sample were aged 31 to 40 years old with a mean age of mothers of 32.5 years old [3]. In another study, the majority of the parents were mothers aged 21 to 82 years old [12]. Most (88.7%) of the caregivers were housewives. The result is in agreement with a study done in King Saud Medical City, Riyadh, Saudi Arabia which states that almost 90% of the sample were unemployed and took care of their children [13]. Regarding the residential areas of the participants, the current study found that more than one-third (38.3%) of the caregivers live in urban and suburban areas. This finding is in contrast with other studies that reported that more than half of caregivers were living in urban areas [3], and more than two-thirds of the caregivers were living in rural areas [16]. These results indicate that the residential areas of the caregivers sometimes create problems for the CP child because the parents are facing a lack of service facilities for their child's treatment such as hospitals, clinics, pharmacies, and private and public sector physiotherapy departments. Therefore, in this case, the CP child and his/her family might face great health difficulties. Regarding socioeconomic status, less than half (48.7%) of the caregivers were of middle socioeconomic status. One study found that a moderate level of income was most frequently reported (79.3%) [13] and another study in Egypt found that most CP children and their families were low-income. A study in China reported a monthly family income of less than US $500 [15]. Most of the caregivers (72.2%) are living in a traditional nuclear family, similar to another study which found that the family size of their study sample mainly consisted of three to five people [21].

Assessment of socio-demographic characteristics of spastic CP childrenThe results show that about two-thirds (65.2%) of spastic CP children were school-age. This result is supported by other studies reporting SP children aged 2-10 years [22], and aged 2-6 years [20]. The result is in disagreement with a study in Erbil city stating that more than half (53%) of CP children were in the toddler developmental stage [3]. The CP children of the present study are mainly between the toddler ages to school ages. Results of the current study show that two-thirds of Spastic CP children were males. This result is in agreement with other studies reporting a higher sample proportion of boys [20], [22], [16], [19]. Regarding the diagnostic age of spastic CP children, the study reveals that less than two-thirds were between one to six months of age at the time of diagnosis. Another study reported that most of the children were less than one year at the time of their diagnosis [19]. CP condition is usually detected at the early ages of six months to one year. In the present study, more than half (53%) of the CP children did not have birth asphyxia, which is supported by a study done in Osun State, Nigeria which showed that the h asphyxia was 57.2% [23]. This is an indication of the fact that it is not always the case for children to experience birth asphyxia at the time of delivery. Birth asphyxia was in 42 (36%) of cases [11], the contrast pattern occurred in the study by birth asphyxia (17.3%) of the child with CP condition [12], [29], Only 6% or 7% of asphyxia at birth [12]. Concerning the type of feeding, the study found that the majority (80%) of the CP children were on a normal diet. This result is in agreement with a study reporting that the majority of CP children were on oral feeding while only 18% of them were on tube feeding [16]. The current study also reveals that most spastic CP children were born by normal delivery. One study reported more than half of SP children were born by cesarean section delivery, three-quarter by vaginal deliveries, and less than one-fifth or few by caesarian sections [11]. A study conducted in Baghdad's Children's Welfare teaching hospital found that, out of 100 CP participants, 70 were normal vaginal delivery, in which one only had assisted delivery (forceps), and 29 were cesarean section (13% of them were elective procedures and 16% were emergency ones) [24]. Almost all the CP children were delivered in the public hospitals in the present study, and only a few (8.7%) were delivered at home. This is in contrast to a study conducted in Nigeria where the majority of the CP children were delivered at home (310, 37.17%), and only 24 children (2.88%) were delivered at the University of Port Harcourt teaching hospital [25]. Another study reported that most patients were born at a hospital or in a private clinic, and very few were born at home [11]. This could mean that the place of the CP childbirth varied across settings and could be interpreted in a way that the place of delivery is less associated with the cause of CP in children. In the present study, most of the caregiver families (80%) haven't had any child previously affected by CP. The recurrence of CP in the same family is uncommon [26] indicating that the CP condition in children is not hereditary. Less than half (40%) of the CP children were the middle child in the family, 33% of them were firstborn, and 27% were the last-born child in the family. Studies report that 48% of children with CP were the first children in the family [19], and about one-fourth of them were the first born [16]. This could be interpreted in the way that CP condition in children can happen in any childbirth ordinal. three-quartier of respondents have one or more complications related to spastic CP Studies have reported that the majority of the sample report epilepsy as the onset symptom (78.0%), and mental retardation was the least mentioned (6.0%) [19]. In the current study, the complications associated with spastic CP child reported include mental retardation, convulsion, epilepsy, strabismus, blindness, deafness, and heart problems. Less than half (44.3%) of the CP children participating in the current study were in level V (five) of independence. A similar pattern of 17 caregivers of CP children in Iran found that of the participating children, 29.4% were in level III of Growth Motor Function Classification System Expanded and Revised, (GMFCS E&R), 29.4% were in level V, 17.6% were in level IV, 17.6% in level I, and 6% were in the level II [22]. This is the indication that children with CP can perform independently in almost all the five levels except Spastic CP who will be staying in IV and V levels. Association between caregiver's knowledge and socio-demographic characteristics. A highly significant association between formal years of education and residency area of caregiver with the caregiver’s knowledge at p-value of 0.020 and 0.003 respectively. Also, independent factors that had a positive impact on observed knowledge scores were the caregiver's urban residence and higher family income. Meanwhile, caregivers’ higher education had a negative impact, which means that the improvement of observed knowledge was higher among those caregivers with lower levels of education [16]. However, there is a significant association between the educational status of family caregivers with total knowledge scores ($r = .521$, $p = .000$) [21]. The other socio demographic variables of the other caregivers had no significance on their knowledge score [16].Factors associated with caregiver’s knowledge regarding homecare of spastic CP The level of education of the caregivers of spastic CP is significantly associated with caregivers’ knowledge ($p=0.002$). In contrast, one study reported a significant difference between the level of education of caregivers and total family caregivers’ knowledge regarding hemiplegic CP ($x^2 = 127.8$, $p= 0 .000$) [21]. The age of the caregiver was significantly associated with the caregiver’s knowledge ($p=0.050$). One study showed a significant association between the age of the mother and knowledge about homecare ($p = 0.024$) and revealed that caregivers aged 24 to 30 were less knowledgeable about homecare [3]. The height of the spastic CP was significantly associated with the caregiver’s knowledge ($p= 0.012$). A study in Brazil found a statistically significant height difference, according to the reference curves specific for CP and those commonly used in pediatrics, with a Kappa index obtained by comparing the caregiver’s awareness [30]. There was no significant association between any of the selected socio-demographic caregiver variables and the level of knowledge of the caregivers. [27]. Another study reported significant differences were found, in caregivers’ knowledge of height ($p = 0.001$) [31].

CONCLUSION

The results of the present study indicated a highly significant association between formal years of education and residency area of caregiver with the caregiver’s knowledge regarding home care management of spastic CP children. The level of education of the caregiver, age of the caregiver, and height of the spastic CP were factors significantly associated with the caregiver’s knowledge regarding home care management of spastic CP children.

CONFLICT OF INTEREST

The authors (s) report no conflict of interest.

FUNDING

The authors (s) report no funding support .

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