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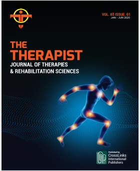

Original Article

Knowledge and Care Among Mothers Having Children with Cerebral Palsy

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ABSTRACT

Cerebral palsy (CP) is a chronic, non-progressive, and incurable disorder that affects mobility and posture. **Objective:** To assess the Knowledge and Care among mothers having Children with Cerebral Palsy at Nishter hospital Multan. **Methods:** A cross sectional study designed was used. A sample of n=85 participants was recruited from Nishtar Hospital Multan Pakistan, through purposive sampling. The knowledge and care questionnaire were used for measurement of knowledge and care among mothers having children with cerebral palsy (CP). Filled questionnaires were entered and analyzed through SPSS version 21. **Results:** Findings revealed that 71.8% participants had poor knowledge regarding CP, 21.2% had fair knowledge and only 7% of participants had good knowledge regarding CP. Similarly it was revealed that 50.6% participants had poor care, 41.2% had satisfactory care and only 8.2% were having good care for cerebral palsy children. **Conclusions:** Majority of the mothers of children with cerebral palsy in this study are unaware of the condition and show no concern for it. Support groups may be developed further to increase care giving' awareness of and concern with CP, which may aid them in finding the most suitable and timely interventions for their charges.

INTRODUCTION

In the developing fetus or immature baby brain, cerebral palsy (CP) is a chronic, non-progressive, and incurable disorder that affects mobility and posture and results in restricted behavior. Children with cerebral palsy experience a wide range of issues, including malnutrition, digestive issues, spastic paralysis, perceptive impairment, poor eyesight, and impaired speech. Additionally, they face several challenges while doing self-care activities like eating, dressing themselves, moving about, and taking a bath, which can result in a requirement for long-term care that is far greater than that of a typical kid [1]. There are 2 to 3.5 cases of cerebral palsy for every 1,000 live births. With a frequency ranging from 90 instances per 1,000 newborn survival weighing less than 1 kg to 1.5 cases per 1,000 for those born weighing 2.5 kg or more, its incidence is inversely related to gestational age and birth weight [2].

Recent research from low- and middle-income countries (LMICs) has found that the burden and severity of CP, as well as the related impairments, are higher in LMICs [3]. Within the first five years of life, children with CP accomplish 90% of their gross motor potential, and even sooner for those with severe CP [4]. Early intervention is thus critical for children with CP to achieve optimal motor and functional results. Cerebral Palsy numbers in Pakistan are equally concerning. According to a research done in Karachi, Pakistan, 658 instances were gathered from 14 health organizations between 2010 and 2016, with 383 (58.2%) men outnumbering 275 (41.7%) girls. At the end of 2016, the pattern of CP occurrence exhibited an increase in men [5]. Intellectual, cognitive, and sensory deficits, speech disturbances, seizures, dental, and dietary difficulties are all common in children with CP. To attain child independence and community involvement, care of children with CP requires a multidisciplinary and integrated approach [6]. For parents or caregivers, learning that their kid has a permanent condition such as cerebral palsy (CP) can be devastating. It's frequently accompanied with emotions of pessimism, worry, and the dread of the unknown. Furthermore, CP is the most prevalent childhood impairment globally, and it is a lifelong disorder with a complicated and diverse presentation [7]. It is believed that care givers who are more aware about CP would be better able to adjust and cope with the responsibilities of caregiving. According to studies, informed caregivers are more likely to have high self-efficacy, good psychosocial indices, and provide greater care and comfort [8]. Maintaining balance in the home requires help from family, friends, the community, or paid caregivers [9]. Although there is no cure for CP, treatment, education, and technology can improve the functional skills of children with the condition [10]. Early detection of CP, the implementation of suitable intervention programs, and the utilization of a multidisciplinary team approach have all been shown to help children with CP and are also closely associated to later performance in school and in life. Physiotherapy, speech therapy, occupational therapy, orthotic devices, behavioral treatment, surgery, and alternative therapies such as massage therapy are all now utilized to treat CP [11]. In the present era, mental disability is a major public health problem in the society. The disabled like CP children constitute a small part of the population of any society. Their upbringing, welfare and rehabilitation are obligatory for individuals closely related or committed to them [12]. The households, which have disabled persons like CP child, need to be helped by health care providers where the role of nurses becomes vital. Nurses can play their role in rehabilitation and health care training of parents [13]. Unfortunately Nurses involvement in rehabilitation care of CP children is not very visible. This study can be a beginning to the role involvement of nurses in guiding and training mothers of CP children to boost their knowledge and enhance their care [14]. Knowledge of care providers of children with Cerebral Palsy about home care in Vellore City was evaluated using an interventional research design. 40 mothers with Cerebral Palsy children were chosen using convenience sampling. The data for the study was collected using a standardized questionnaire. According to findings, the pre interventional mean knowledge score was 13.10± 3 SD, which was considered to be poor knowledge [15]. Another study looked at the mothers' awareness of their children with cerebral palsy. The study's findings revealed that the majority of the moms evaluated had inadequate understanding regarding cerebral palsy, where 44% of the study participants had unsatisfactory knowledge and 56% had satisfactory knowledge [16].

METHODS

A descriptive cross sectional study was conducted to see the knowledge and care among mothers having children with cerebral palsy. A cross sectional descriptive study was conducted to carry on this study. This study was conducted at the paeds neurology department of the Nishtar hospital Multan Punjab. The study participants were mothers of all patients coming to neurological OPDs having children with cerebral palsy. A nonprobability purposive sample of n=85 participants was recruited based on the following criteria. Slovin's formula used for taking sample size. Total mothers of CP children = 110

If N=Population, n=Sample size, E= Margin of error

$n=N/1+(N)(E)^2$

$n=110/1+(110)(0.05)^2$

$n=110/1+(110)(0.0025)$

$n=110/1+0.25$

$n=110/1.275=85$

A round figure of n=85 was recruited. Only mothers who are primary caregivers, with age 20 to 50 years, mothers of those children who are diagnosed with Cerebral Palsy, mothers of those children who are with moderate and severe degree of severity with cerebral palsy and mothers of CP child with age 12 or below were included. The exclusion criteria was mothers as formal care givers (Nurses, Doctors), working mothers, and mothers of those children who are having cerebral palsy but do not required assistance in routine activities. The rules and regulations set by the ethical committee of university of Lahore were followed while conducting the research and the rights of the research participants were respected. Permission was taken from head of the department of Pediatric Neurology clinic and OPDs Nishtar Hospital Multan. Written informed consent was taken from all the participants. All information and data collection was kept confidential. Participants were kept anonymous throughout the study. A close ended questionnaire for assessing mothers' knowledge regarding CP was adopted from a previous study of Jacob Deepa, which consisted of 23 multiple choice questions regarding Cerebral Palsy. Each correct response was having Score of 1 while incorrect response was marked as 0 [17]· To assess the care score among mothers of cerebral palsy children, a care questionnaire was used which was adopted from a previous study of Miriam Hwang 2011. This tool consisted of total 18 statements where 12 statements were assessed on likert scale of very easy=1 to impossible=5, whereas 6 statements were assessed on never=0 to always=4 scale. Content Validity index testing was done to check the

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content validity for this developed knowledge based questionnaire and Care questionnaire. The CVI for knowledge questionnaire is (0.90), and the CVI for Care questionnaire is (0.91). The Reliability of the questionnaires are checked through Cronbach's Alpha after conducting the pilot study. The Cronbach's Alpha value for knowledge questionnaire is .773 while the Cronbach's Alpha value for care questionnaire is 0.808. All participants were given close ended questionnaires along with further detailed sheet of information. A written consent was implied to every participant along with the questionnaire. Introduction to every participant was done. Participants were questioned individually at the outpatient department of the given hospital where the assessment of the participants was done using data collection tool. After data collection it was entered and analyzed in SPSS version 21.0. Quantitative variables were presented in the form of mean ± standard deviation. Qualitative variables were presented in the form of frequency and percentages. Frequency distribution tables were used to present the emotional distress and self-efficacy levels among the study participants.3

RESULTS

Table 1 shows that 4.7% research participants were between the ages of 20-30 years age group, 76.5% were 30-40 years of age and remaining 18.8% were 40-50 years of age. It was also found that 92.9% participants were Muslims and 7.1% were Christians. Furthermore, it is also shown that that in according to educational status 23.5% of the study participants were illiterate, 27.1% were primary, 32.9% higher secondary and 16.5% were graduated and above. Moreover, the findings also indicated that 38.8% of the participants had Unconsangious marriage and 61.2% have got Consangious marriage. Regarding type of family, it was revealed that 11.8% had nuclear family, 77.6% were having joint family and 10.6% had single parent family. Majority 62.4% had cared for CP children 0-5 years , 37.6% have cared for 5-10 years and no participant was there who have been caring or cared for more than 10 years.

Demographic	n (%)
Age	
20-30 Years	4 (4.7%)
30-40 Years	65 (76.5%)
40-50 Years	16 (18.8%)
Religion	
Muslim	79 (92.9%)
Christian	06 (7.1%)
Education Status	
Illiterate	20 (23.5%)
Primary	23 (27.1%)
Higher Secondary	28 (32.9%)
Graduation& above	14 (16.5%)
Type of marriage	
Unconsangious marriage	33 (38.8%)
Consangious marriage	52 (61.2%)
Type of Family	
Nuclear family	10 (11.8%)
Joint Family	66 (77.6%)
Single Parent Family	09 (10.6%)
Years of Caring	
0-5 years	53 (62.4%)
5-10 years	32 (37.6%)
More than 10 years	00 (0.00%)

Table 1: Demographic characteristics of the participants (n=85)

The table 2 revealed the score of the participants care among mothers regarding caring CP children. They were asked about performing oral-facial hygiene (eg, brushing teeth, washing face etc) in which 37 (43.5%) stated it difficult and 48 (56.5%) responded that it is impossible. Mothers were asked if putting on shirts is difficult for them, where 3 (3.5%) responded with not easy, 50 (58.8%) responded with difficult and 32 (37.6%) stated that is impossible. When the participants were asked if taking off shirts of cp child is difficult, 8 (9.4%) of them said it is not easy, 44 (51.8%) stated that it is difficult and 33 (38.8%) said it is impossible. They were also asked about putting on pants in which 8 (9.4%) stated it is not easy, 31 (36.5%) stated it difficult and 46 (54.1%) responded that it is impossible. Mothers were asked if if taking off pants is difficult for them, where 15(17.6%) responded with not easy, 57 (67.1%) responded with difficult and 13 (15.3%) stated that is impossible. When the participants were asked if Cleaning buttocks or perineum with toileting is difficult, 31 (36.5%) stated that it is difficult and 54 (63.5%) said it is impossible. Mothers were asked if cleaning buttocks or perineum with toileting of CP children is difficult for them, where 1 (1.2%) responded with not easy, 18 (21.2%) responded with difficult and 66 (77.6%) stated that is impossible. When the participants were asked if washing upper body of CP child is difficult, 3 (3.5%) of them said it is not easy, 20 (23.5%) stated that it is difficult and 62 (72.9%) said it is impossible. They were also asked about Washing lower body in which 1 (1.2%) stated it is not easy, 18 (22.4%) stated it difficult and 66 (76.5%) responded that it is impossible.

Statement	Very Easy 1	Little easy 2	Not easy 3	Difficult 4	Impossible 5
	F(%)	F(%)	F(%)	F(%)	F(%)
Performing oral-facial hygiene (eg, brushing teeth, washing face etc).				37 (43.5)	48 (56.5)
Putting on shirts			3 (3.5)	50 (58.8)	32 (37.6)
Taking off shirts			8 (9.4)	44 (51.8)	33 (38.8)
Putting on pants			8 (9.4)	31 (36.5)	46 (54.1)
Taking off pants			15(17.6)	57 (67.1)	13 (15.3)
Changing incontinence pads or briefs (underwear)				31 (36.5)	54 (63.5)
Cleaning buttocks or perineum with toileting			1 (1.2)	18 (21.2	66 (77.6)
Washing upper body			3 (3.5)	20 (23.5)	62 (72.9)
Washing lower body			1 (1.2)	18 (22.4)	66 (76.5)
How easy do you think it is for your child to remain sitting in a wheelchair?			1 (1.2)	55(64.7.)	29 (34.1)
Ease of transferring your child into/out of wheelchair or other surfaces		4 (4.7)	34 (40)	46 (54.1)	1(1.2)
Ease of applying orthotics (braces)		1(1.2)	47 (55.3)\	33 (38.8)	4 (4.7)
Activities in Past Month	**Never 0**	**Rarely 1**	**Sometimes 2**	**Frequently 3**	**Always 4**
How often do you think your child has had pain or discomfort during diaper or clothing changes?			3 (3.5)	42 (49.4)	40 (47.1)
How often do you think your child has had pain or discomfort during position changes?			18 (21.2)	41 (48.2)	26 (30.6)
How often do you think your child has had pain or discomfort while sitting in a wheel chair?		2 (2.4)	25 (29.4)	43 (50.6)	15 (17.7)
How often do you think pain or discomfort has prevented your child from participating in family activities?			25 (29.4)	30 (35.3)	30 (35.3)
How often do you think pain or discomfort has prevented your child from participating in school programs or community activities?			29 (34.1)	32 (37.6)	24 (28.2)
How often has your child had difficulty sleeping through the night?		31 (36.5)	34 (40)	16 (18.8)	4 (4.7)

Table 2: Descriptive results of Mothers' Care (n=85)

Table 3 indicate the knowledge among the study participants. Findings revealed that 71.8% of the participants had poor knowledge regarding CP, 21.2% were having fair knowledge and only 7% of the study participants had good knowledge regarding cerebral palsy and caring children with cerebral palsy. This finding indicated that a good majority of the participants who were having children with cerebral palsy were having poor knowledge of cerebral palsy.

Status	N (%)
Poor Knowledge	61 (71.8%)
Fair Knowledge	18 (21.2%)
Good Knowledge	06 (7%)

Table 3: Knowledge Level among Mothers Having Children with Cerebral palsy

Table 4 indicates the care among mothers having children with cerebral palsy. Findings revealed that 50.6% of the participants were having poor care regarding caring there CP children, 41.2% were having satisfactory care for their CP children and only 8.2% were having good care for their cerebral palsy children. This finding indicates that a majority of the participants caring for their CP children were having poor care practices.

Status	N (%)
Poor Care	43 (50.6%)
Satisfactory Care	35 (41.2%)
Good Care	07 (8.2%0

Table 4: Care Level among Mothers Having Children with Cerebral palsy

DISUSSION

The results of the present study as demonstrates 65(76.5%) were aged (30 – 40) years old; that their level of education was 23.5% illiterate, 27.1% primary and very few 16.5% were graduated and above. A similar study was found conducted by Moenardi *et al*. 2020 where 41.94% were age 20 to 29 years and 45.16% were age 30-39 years. Similarly education status was also consistent with the current study where 100% of the study participants were higher education or below. In contrast, a previous study found that the majority of the study sample 71(48.0%) aged (18 – 27) years old; that their level of education was read and write estimating as 67 (45.3%) [1]. This current study found that 10.6% participants were single parents which are inconsistent with a past study where the single parents were found 3.23% [18]. Findings of this current study revealed that 71.8% of the participants had poor knowledge regarding CP and only 7% of the study participants had good knowledge regarding cerebral palsy and caring children with cerebral palsy. This finding indicated that a good majority of the participants who were having children with cerebral palsy were having poor knowledge of cerebral palsy. In consistent to the current study, a past study found that the participants had poor knowledge were (38.9%), especially regarding awareness of the diagnosis of CP [19]. A different study findings were found in a study at Saudi

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Arabia where substantial lack of knowledge about the etiology and the prognosis of CP. According to that score, 50% of the studied caregivers had good level of knowledge about CP [2]. Findings of this current study revealed that 50.6% of the participants were having poor care regarding caring there CP children, 41.2% were having satisfactory care for their CP children and only 8.2% were having good care for their cerebral palsy children. This finding indicated that a majority of the participants caring for their CP children were having poor care practices. Opposite to the current study, a past study found that some participants knew little about the function and offerings of social workers. This suggests that social workers may not be properly marketing their services. Furthermore, the fathers of the children's lack of support were a major issue that necessitated social work assistance. Despite the difficulties and terrible situations they have faced, mothers maintain a positive outlook on providing care. The findings culminated in the presentation of recommendations for future study, practice, legislation, education, and support for social workers [20].

CONCLUSIONS

The majority of the mothers of children with cerebral palsy in this study are unaware of the condition and show no concern for it. Support groups may be developed further to increase care giving' awareness of and concern with CP, which may aid them in finding the most suitable and timely interventions for their charges.

Authors Contribution

Conceptualization: SP
Methodology: AA, SP
Formal analysis: SP
Writing-review and editing: SP, AA, HS

All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

The authors declare no conflict of interest

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REFERENCES

[1] Baiee ZA, AL-Doori NM, Hassan AA. Mother's Knowledge Towards their Children with Cerebral Palsy in Babylon Province. Indian Journal of Public Health. 2019 Oct; 10(10): 3898-903.

[2] Alruwaished A, Ali B, Alhowaimil L, Alhowaimil A, Alhowaimil AA, Alessa A. Knowledge and attitude of caregivers of cerebral palsy children in Riyadh city. International Journal of Medicine in Developing Countries. 2020; 4(1): 12-7. doi: 10.24911/IJMDC.51-1547833051

[3] Korzeniewski SJ, Slaughter J, Lenski M, Haak P, Paneth N. The complex aetiology of cerebral palsy. Nature Reviews Neurology. 2018 Sep; 14(9): 528-43. doi: 10.1038/s41582-018-0043-6

[4] Karim T, Muhit M, Jahan I, Galea C, Morgan C, Smithers-Sheedy H, Badawi N, Khandaker G. Outcome of community-based early intervention and rehabilitation for children with cerebral palsy in rural Bangladesh: a quasi-experimental study. Brain Sciences. 2021 Sep; 11(9). doi: 10.3390/brainsci11091189

[5] Rafique A and Naz H. A survey-based report on the occurrence of cerebral palsy in Urban areas of Karachi. JPMA. 2020 Mar; 2020. doi: 10.5455/JPMA.28135

[6] Shaunak M and Kelly VB. Cerebral palsy in under 25 s: assessment and management (NICE Guideline NG62). Archives of Disease in Childhood-Education and Practice. 2018 Aug; 103(4): 189-93. doi: 10.1136/archdischild-2017-312970

[7] Dambi JM, Mandizvidza C, Chiwaridzo M, Nhunzvi C, Tadyanemhandu C. Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers. Malawi medical journal. 2016; 28(4): 167-73. doi: 10.4314/mmj.v28i4.4

[8] Polack S, Adams M, O'banion D, Baltussen M, Asante S, Kerac M, *et al*. Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life. Developmental Medicine & Child Neurology. 2018 Sep; 60(9): 914-21. doi: 10.1111/dmcn.13797

[9] Das S, Aggarwal A, Roy S, Kumar P. Quality of life in Indian children with cerebral palsy using cerebral palsy-quality of life questionnaire. Journal of Pediatric Neurosciences. 2017 Jul; 12(3): 251. doi: 10.4103/jpn.JPN_127_16

[10] Moura R, Andrade PM, Fontes PL, Ferreira FO, Salvador LD, Carvalho MR, *et al*. Mini-mental state exam for children (MMC) in children with hemiplegic cerebral palsy. Dementia & Neuropsychologia. 2017 Jul; 11: 287-96. doi: 10.1590/1980-57642016dn11-030011

[11] Earde PT, Praipruk A, Rodpradit P, Seanjumla P. Facilitators and barriers to performing activities and participation in children with cerebral palsy: Caregivers' perspective. Pediatric Physical Therapy. 2018 Jan; 30(1): 27-32. doi: 10.1097/PEP.0000000000000459

[12] Alsharkawy AT, Draz SF, Hassan GS, Alhofi MA. Effect of Educational Empowerment on Student Nurses' Knowledge, Practice, and Attitude toward Genomic Counselling. Evidence-Based Nursing Research. 2021 Jul; 3(1). doi: 10.47104/ebnrojs3.v3i1.208

[13] Boztepe H, Çınar S, Ay A, Kerimoğlu Yıldız G, Kılıç C. Predictors of caregiver burden in mothers of children with leukemia and cerebral palsy. Journal of psychosocial oncology. 2019 Jan; 37(1): 69-78. doi: 10.1080/07347332.2018.1489441

[14] Branjerdporn N, Crawford E, Ziviani J, Boyd RN, Benfer K, *et al*. Mothers' perspectives on the influences shaping their early experiences with infants at risk of cerebral palsy in India. Research in Developmental Disabilities. 2021 Jun; 113. doi: 10.1016/j.ridd.2021.103957

[15] Priyadharishini J, Sadan V, Sebastian T. Community-Based intervention package on knowledge, attitude and selected skills of home care among primary care givers of children with cerebral palsy. Indian Journal of Continuing Nursing Education. 2017 Jul; 18(2): 46-50. doi: 10.5958/2395-180X.2016.00029.3

[16] Hashem SF, Abd El Aziz MA. The Effect of an Educational Intervention for Improving Mothersâ€™ Care for their Children with Cerebral Palsy. International Journal of Nursing Didactics. 2018 Apr 30; 8(04): 10-20. doi: 10.15520/ijnd.v8i04.2126

[17] JACOB D. A Quasi Experimental Study to Evaluate the Effectiveness of the Structured Teaching Programme on the Familial Concerns among the Mothers of the Mentally Challenged Children in the Selected Special Schools in Bangalore, Karnataka. Doctoral dissertation. 2012.

[18] Moenardi MC, Sungkar E, Hawani D. Cerebral Palsy Parents' Knowledge, Attitude, and Behavior at Dr. Hasan Sadikin General Hospital Bandung 2014. Althea Medical Journal. 2020 Jun; 7(2): 84-8. doi: 10.15850/amj.v7n2.1790

[19] Salih EM, Alghamdi SA, Alghamdi RA, Alghamdi MS, Alzahrani TA. Level of Awareness and Attitude Toward Cerebral Palsy Among Parents in Al-Baha City, Saudi Arabia. Cureus. 2022 Nov;14(11):e31791. doi: 10.7759/cureus.31791

[20] Phumudzo R, Shirindi ML, Makofane MD. Mothers caring for children living with cerebral palsy: Suggestions for psycho-social support. Social Work. 2021; 57(3): 359-75 doi: 10.15270/57-3-952