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Perception of Mothers among Cerebral Palsy Children with Disabilities in Tamil Nadu, India

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ABSTRACT

The purpose of the study is to check the perception of mothers of cerebral palsy children with disabilities in Tamil Nadu. Data, from India, on perceptions about Cerebral palsy disability are scant. This study explored mother's knowledge, social well-being and awareness of treatment rendered. During the development of the questionnaire, review of the literature has been primarily made; during developing the questionnaire personal and social values were considered. The questionnaire was emerged with 9 themes, Knowledge of disability condition, Parental stress, Community support, Child ability, Mothers Confidence, Improvement, Health status, Benefits & Belief. Data were collected from mothers of both male and female children with cerebral palsy aged between 1 to 18 years. 220 mothers, averaged 33.44 + 6.14 years, of children with CP were randomly selected for this study. Data was collected from mothers attending rehabilitation centers from different institution and special schools in Tamil Nadu. Mothers can hold both a fatalistic view of disability and a belief in the course of disability. The raw data was tabulated and analyzed by using SPSS 17 version software. Cronbach's Alpha was calculated, the results showed that its Cronbach's Alpha was extremely good (r=0.96). Our results suggest that there is significance difference with in the mother's perception towards types of disability in Parental stress, child's ability, mother's confidence, improvement, health status, benefits and belief. Mothers should be motivated to maximize rehabilitation services in order to improve their children's functional capacity. The appreciation of this phenomenon could move towards a model for the delivery of rehabilitation that integrates and harmonizes such beliefs.

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INTRODUCTION

The World Health Organization (WHO) describes disability as a general term, including impairments, activity limitations and participation restrictions. Impairment is an issue in the function of the body; impairment of activity is an obstacle that a person faces in carrying out a task; and restriction of involvement is a challenge that an individual experiences while participating in life situations. Disability is therefore not just a health issue. It is a complex phenomenon, representing the relationship between the characteristics of a person's body and the characteristics of a culture in which he or she lives (Kamath, 2015). The WHO reports that 85 per cent of them are in developing countries. It is estimated that 10% of the world's populace has some form of disability, including some 200 million children in 2008. Statistics indicate that in India, 3.8% of the populace has some form of disability. Thus, the problem of disability should be looked into seriously in India (Ansari, 2016) .Cerebral palsy (CP) is the most frequent cause of neurological disability in children (Elanchezhian and Kumari, 2019). CP is the most frequent reason of childhood disability and is seen from 1000 births in 2–2.5 (Chinnavan and Swarnakumari, 2019). Mothers of cerebral palsy disabled, deaf, and blind children ranked mental retardation as the most severe disability, but mothers of mentally retarded children listed CP first, brain injury second, and mental retardation third.

Most parents of children with CP lack basic knowledge of the disease, its cause, prognosis, treatment modality, and outcome. There is also a limited number of studies carrying out any intervention and evaluating the response of that intervention to parental knowledge of CP (Arora *et al.*, 2014).

Parental stress and adaptation depend on the type of impairment, family management resources, and formal and informal community support. The stress of parenting depends on the severity, type of disability, behavior and development. Higher parental stress was associated with behavioral and developmental disability (Bakhshi *et al.*, 2017). Lower socio-economic status of the family is associated with more stress due to fewer resources. Proximate spousal and immediate family support was established to facilitate family adaptation and reduce stress. Religious coping has been reported to reduce parental stress by two types of social support systems in terms of group support. Formal social support includes services provided by health workers such as school programs, parent education teachers, and physical therapist and family support agencies. Informal social support includes family members, family members, neighbors, friends and community groups (Gupta *et al.*, 2012).

Researchers also found that disability is viewed differently in every culture. Cultural beliefs play an important role in deciding how the family perceives disability, and the kind of prevention, treatment and rehabilitation initiatives it takes. Families of certain cultural backgrounds have double clinical and conventional beliefs about the existence, cause and treatment of disability (Gupta and Nidhisinghal, 2004; Madi *et al.*, 2019) . Environmental risk factors including lack of services and negative attitudes can also adversely affect the prognosis of the disabled child.

The state of Tamil Nadu has a better healthcare system, which is reflected in its improved performance in key health indicators compared to other states. The burden of disability must be quantified, as this knowledge is necessary for the government to devise strategies, allocate adequate resources and introduce appropriate intervention programs for people with disabilities (Banurekhavelayutham *et al.*, 2017).

Parents of children with cerebral palsy need to know and treat the disorder. This would help in the study of treatment in order to attain efficient abilities and improve quality of life. No two mothers and no two children are exactly the same thing. The aim of this current study was to examine the perception of mothers with disabled cerebral palsy children about knowledge, social well-being and awareness of treatment in Tamil Nadu. In this study, Tamil Nadu serves as a unique example of a society with a strong family-based and religious organization that has also recently experienced rapid developments and changes in the medical field.

Inclusion Criteria

The study included mothers who were primary caregivers of patients diagnosed with spastic, dyskinetic, ataxic, flaccid and mixed cerebral palsy according to the GMFCS criteria. Patients could be of both sexes with age groups between 1 and 18 years of age.

Exclusion criteria

Caregivers of patients diagnosed with motor impairments other than CP, children over 18 years of age with cerebral palsy and children who have lost their mothers.

Methodology

The study was approved by Ethical committee in Holy cross college; Tiruchirapalli. Additionally study was registered in Thai Clinical Trial Registry (TCTR 20200326002). Subjects for the study were included if they were a mother of a disabled CP child attending rehabilitation centers and willing to participate in the completion of the disability questionnaire. A member of the rehabilitation center who was not involved in patient care recruited mothers who met the inclusion criteria. Potential participants were informed of the study objective, that their participation was entirely voluntary, that all information would remain confidential and that they would be free to withdraw without any consequences at any time. Parents were also assured that choosing not to participate would in no way affect the treatment of their child.

Table 1: Comparison of perception of mother's with disability

	Types of Disability	Mean+ SD	P value
Knowledge of the condition	Physical	16.09+3.874	0.206(NS)
	Speech	16.91+3.778	
	Visual	16.50+5.043	
	Mentally	18.70+4.111	
Parental Stress / Family support	Physical	50.72+10.483	0.000***
	Speech	60.91+9.484	
	Visual	55.63+6.022	
	Mentally	59.60+11.266	
Community Support	Physical	29.42+7.429	0.435(NS)
	Speech	31.66+9.276	
	Visual	31.63+5.236	
	Mentally	30.30+10.646	
Child's ability	Physical	35.91+7.600	0.000***
	Speech	42.61+7.062	
	Visual	40.13+3.357	
	Mentally	44.20+8.509	
Mother's Confidence	Physical	18.37+4.106	0.000***
	Speech	23.75+1.978	
	Visual	22.00+2.726	
	Mentally	23.00+3.742	
Improvement	Physical	17.37+3.954	0.000***
	Speech	21.23+3.516	
	Visual	20.75+3.412	
	Mentally	22.80+3.011	
Health status	Physical	19.58+5.668	0.000***
	Speech	25.70+4.402	
	Visual	23.63+6.906	
	Mentally	25.90+6.385	
Benefits	Physical	15.62+3.817	0.000***
	Speech	18.27+3.605	
	Visual	18.38+3.889	
	Mentally	20.10+2.726	
Belief	Physical	24.06+8.271	0.001**
	Speech	28.91+7.417	
	Visual	26.63+5.630	
	Mentally	24.10+9.146	

NS – Not significant, *p < 0.05, ** p< 0.01, *** p< 0.001 was considered statistically significant

If the mother was interested in participating, a schedule would be organized by the staff member. If she remained interested after this first information session, a questionnaire was submitted at a scheduled convenient time. During the first session with the staff member, the potential risk of discomfort in the disclosure of personal information on the experience of mothers with children with disabilities was discussed. The next session was followed by informed consent to the collection of data.

220 volunteers, mothers with CP children were taken up for the study. A Self-administered questionnaire were utilised to collect primary data. The questionnaire consisted of 72 structured psychometric response scale questions. Physiotherapist conducted data on all 9 key informant areas in the questionnaire any doubt about the question were explained on request from mother. All data collection was conducted in Tamil or English version of questionnaire, and once the data collection was completed, the physiotherapist immediately checked for all questions were answered.

Data Analysis an interpretation

All statistical analysis was performed using Statistical Package for Social Science (version 17) for Microsoft windows. The data were not normally distributed. And therefore parametric / Non Parametric tests were performed. One way analysis of variance with a post hoc Tukey HSD test was used for continuous data / Krushkall'swllis test. Independent sample student t test / Mann Whitney test were used to compare continuous variables between two groups. A chi-squared test was used for comparison between two attributes. A Pearson correlation coefficient/ Kendall tau analysis was used to examine the association of two related variables. A two sided p value < 0.05 was considered statistically significant.

Test reliability –retest reliability: The aim here is to test scale stability versus time. The initial test was therefore applied to 22 mothers and then, after a week, the test was reapplied to the same mothers. The test-retest data was collected this way. Test – The reliability coefficient of the retest has been calculated as 0.96. The two test-retest tests found no significant difference.

Mothers participated in the study with their mean age and standard deviation 33.44+ 6.14. Mothers of male children were 119 and female children 101 with the mean and standard deviation 8.85+4.98. Among 220 subject's children with 56 subjects with Hemiplegic, 26 with diplegic, 53 with quadriplegic, 8 with monoplegic, 17 with ataxic, 43 subjects with flaccid and 17 subjects with mixed type of CP. The children had associated problem, were the mothers expressed that disability that impaired the children were due physical disability were 158, with speech problem were 44, with visual disabled were 8, with mentally disabled were 10. India being a multilingual, the mothers who participated in the study were Tamil speaking mothers -128, Telegu - 63, Urudu - 28 and Malayalam -1. Mothers of diferen religion participated in the study in which they comprised Hindu -148, Muslim - 42 and Christian - 30.

RESULTS AND DISCUSSION

The main result of this study is that mothers' perception is dependent on age of the mother, type disability and age of the child (Tables 1 and 2). There is a significant association in Knowledge, child ability, mother's confidence, improvement, benefits and beliefs (Table 3). This is supported by the others authors in their study. Michel D Landry et al., The study reported that the family, community, spirituality/culture and rehabilitation outcomes could have a positive impact on perception, a more positive perception of the mother towards the child, and a greater likelihood of contextualizing goals well beyond impairment, and maximizing social integration for their children with disabilities (Landry *et al.*, 2015).

There is a scarcity of educational activities aimed at improving parental awareness; therefore, it leads to reduced treatment and interferes with the rehabilitation process. More information is needed, and families need to be informed about the diagnosis, treatment and prognosis, so that parents can make better choices about their children and reduce the stress caused by confusion and uncertainty. Greater understanding would form a association of trust between families and health professionals, resulting in better care and thus an better result. Parents' knowledge of child development in normal children has shown that parents who have better understanding of the stage of child improvement can take better care of their children, and this has a positive impact on the child's improvement. The same would also apply to parents of children with disabilities (Arora *et al.*, 2014).

The age and gender of a child with disabilities may have influenced the perception of the mother. For example, it indicated that parents' stress levels are declining as the child grows older. Most mothers were aware of the medical condition underlying their child's disability, but at the same time believed that God had chosen them to take on the responsibility of raising a child with disabilities.

Table 2: Comparison of mother's perception towards sex of the subject

	Sex	Mean+ SD	P value
Knowledge of the condition			
	Male	16.04+4.032	0.196(NS)
	Female	16.79+3.782	
Parental Stress / Family support			
	Male	54.78+10.033	0.044*
	Female	51.63+11.892	
Community Support			
	Male	30.35+7.163	0.130(NS)
	Female	29.56+8.765	
Child's ability			
	Male	37.44+7.760	0.669(NS)
	Female	38.18+8.275	
Mother's Confidence			
	Male	19.96+4.231	0.467(NS)
	Female	19.58+4.499	
Improvement			
	Male	18.62+4.152	0.696(NS)
	Female	18.39+4.320	
Health status			
	Male	21.54+5.755	0.418(NS)
	Female	20.88+6.500	
Benefits			
	Male	16.59+3.859	0.468(NS)
	Female	16.30+4.093	
Belief			
	Male	26.03+7.824	0.032*
	Female	24.06+8.648	

NS – Not significant, *p < 0.05, ** p< 0.01, *** p< 0.001 was considered statistically significant

Table 3: Association of Mothers age, Age of patient, Sex of patient, Religion, Types of CP, Associated problem and Mother tongue with Items

Item	Mother age	Age of patients	Sex of patient	Religion	Types of CP	Associated problem	Mother tongue
1	0.024*	0.039*	0.195(NS)	0.884(NS)	0.119(NS)	0.616(NS)	0.649(NS)
2	0.156(NS)	0.328(NS)	0.040*	0.823(NS)	0.002**	0.000***	0.001**
3	0.060(NS)	0.063(NS)	0.05*	0.256(NS)	0.188(NS)	0.089(NS)	0.037*
4	0.002**	0.000***	0.500(NS)	0.019**	0.032*	0.000***	0.003**
5	0.015**	0.033*	0.901(NS)	0.761(NS)	0.025*	0.000***	0.000***
6	0.047*	0.039*	0.256(NS)	0.227(NS)	0.018**	0.000***	0.000***
7	0.090(NS)	0.107(NS)	0.05*	0.859(NS)	0.079(NS)	0.000***	0.000***
8	0.018**	0.034*	0.896(NS)	0.064(NS)	0.005**	0.000***	0.000***
9	0.020*	0.259(NS)	0.384(NS)	0.020*	0.009**	0.003**	0.000***

NS – Not significant, *p < 0.05, ** p< 0.01, *** p< 0.001 was considered statistically significant

Mothers believed that this path had been chosen for them and that they had been given this gift by God because of their personal resources, knowledge and strength, the resources necessary to be responsible for a child with a disability (Raman *et al.*, 2010).

Maintaining disability typically requires a supportive environment and social participation to reduce negative ideas related to anxiety, insecurity, and depression, as well as education, counseling, and vocational training to develop the capabilities of individuals.

CONCLUSIONS

There is a need for increase in awareness on disability among mothers with CP. This research work provides a comprehensive description of Tamil Nadu mothers towards perception of the term CP through a self-administered questionnaire. It shows how mothers hold multiple and apparently conflicting beliefs and explores how their children's disabilities have affected both their mothers and their families' daily lives. We survey how mothers have developed their coping strategies and, in some instances, resisted and even challenged dominant culture. Our research should lead to a theoretical basis for health professionals and social care professionals to take into account the expertise of mothers and their living interactions with children with CP. It also underlines the importance of establishing support or self-promoting groups in Tamil Nadu for mothers of CP children, empowering them to become more involved and more aware of their children's rights, and enhancing their ability to cope with the challenging and demanding role of raising children with CP.

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Conflict of Interest

No declarations of interest are stated by the authors.

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