



A STUDY TO ASSESS THE STRESS AND COPING OF MOTHERS HAVING CEREBRAL PALSY CHILDREN IN SELECTED SPECIAL SCHOOLS AT KANYAKUMARI DISTRICT

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ABSTRACT

Introduction: This study was conducted with the purpose of associating the stress and coping of mother with cerebral palsy children. **Materials and method:** An explorative approach was used for this study. The study was conducted in a five selected school for cerebral palsy. A convenience sampling technique was utilized to select 75 mothers of cerebral palsy children, the investigator used semi structured interview schedule. It consisted of stress scale which has four areas, 20 questions. The content validity and reliability of the tool were tested. It was found valid and reliable. A pilot study was conducted to check the feasibility of the tool, on 7 mothers, who were not included in the final study. The final study was conducted on 75 mothers of cerebral palsy children from selected school for cerebral palsy. **Results:** On analyzing the data on stress and coping of mothers, it is reveal that of the mothers studied, 8% of the mothers had mild stress, and 13% of the mothers had severe stress and 79% of the mothers had moderate stress. The coping of mothers, shows, 14% had poor coping, 69% of mothers had moderate coping and 17% of mothers had effective coping. **Discussion:** The study concluded that mothers of cerebral palsy children experienced moderate level of stress and moderate level coping.

Key words: Stress, Coping, Cerebral Palsy, Special Schools Etc.

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INTRODUCTION

Cerebral palsy is a non progressive motor and posture dysfunction that occurs secondary to anoxic, damage in the motor centers of the brain during the prenatal, prenatal, or postnatal (up to 2-years) periods. It is the most common chronic disorder of childhood, occurring in an estimated 27 in 1,000 children [1, 2].

Among the Chronic conditions that arise in childhood cerebral palsy is the most common cause of disability, with prevalence of 2 to 3 cases per 1,000 live births. It is a serious disorder that has a great impact on the life of the person affected, on the family dynamics, on society, and on public policies, as it represents a chronic and complex condition that generates high costs. Most function impaired is the main characteristic. However, patients may present sensory, intellectual and

communication deficits and complex limitations in self care functions. Students over the past several decades have provided the following statistics, commonly quoted in the United States [3, 4].

About have cerebral palsy, About 500,000 Children under age of 18 currently have CP. About 2 to 3 children out of every 1,000 have cerebral palsy (United States) have yielded rated as low as 23 per 1,000 children to as high as 36 per 1,000 children). About 10,000 babies born each year will develop cerebral palsy. Around 8,000 to 10,000 babies and infants are diagnosed per year with Cerebral palsy. Around 1,200 to 1,500 preschool ages children are diagnose per year with CP [5].

The worldwide incidence of CP is approximately 2 to 2.5 cases per 1,000 live births. According to WHO estimation 10% of the global population have some form



of disability due to different causes. In India, it is 3.8% of the population. Nearly 15 – 20% of the total physically handicapped children suffer from Cerebral palsy [6, 8].

BACKGROUND OF THE STUDY

Family is the Cradle in which is nursed and brought up. It is the nursery of the future of the child. The family provides an excellent supportive environment for the emotionally vulnerable. The relationship of parents with the child is also very much responsible for the development of the personality of man, which is formed in his childhood. Having a disabled child in the family will constitute a prolonged serious stressor for some parents. It will require extraordinary psychological adjustment for these parents and in some instances require a major reorganization of the family system. Cerebral palsy is the most common permanent physical disability of childhood. World disability day celebrated on December 3rd is an International observance promoted by the United Nations since 1992. This day aims to promote understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities.

Green is the color for CP awareness, so you should wear green on more than St. Patrick's day. March is National Cerebral palsy awareness month. World cerebral palsy day is October 6 [7, 9].

SIGNIFICANCE OF THE STUDY

Sympathetic understanding results in good human relationships. Emotional bond gives empathetic touch to the patient. Nurse, especially the psychiatric nurse, is well capable of establishing a rapport with the patient. The family having developmentally disabled child undergoes severe distress due to social stigma, in-law cursing, quilt feeling, economic crises etc. They need sympathetic understanding of their problem and acceptance of their attitudes in order to free themselves from the feeling of guilt. Despite strain and pressure, very rarely does a family fully accept the responsibility for caring disabled child. They state "God given burden" that is here along. They find line between burden and responsibility is reflected in the ambivalent feeling of wanting to be free and the sense of being needed. These factors need to be explored to support them in future to adapt with the problem. This, in turn, will help to plan interventional studies in future. Indian literature is limited in the area of cerebral palsy. Besides, the researcher has not come across any studies or data related to cerebral palsy done in Kanyakumari District. This made the researcher to take up the study [3].

OBJECTIVES OF THE STUDY

1. To assess the stress and coping of mothers having cerebral palsy children in selected special schools in Kanyakumari District.

2. To determine the association between the stress and coping of mothers having cerebral palsy children in selected schools in Kanyakumari district.
3. To determine the association between the stress of the mothers and selected demographic variables in selected special schools in Kanyakumari District.
4. To determine the association between the coping of the mothers and selected demographic variables in selected special schools in Kanyakumari District.

HYPOTHESIS

1. There will be a significant association between stress and coping of mothers having cerebral palsy children in selected schools in Kanyakumari district.
2. There will be a significant association between stress of the mothers and selected demographic variables in selected special schools in Kanyakumari District.
3. There will be a significant association between coping of the mothers and selected demographic variables in selected special schools at Kanyakumari District

CONCEPTUAL FRAMEWORK

The investigator adopted the Neumann's system model for this study. The study was conducted to assess stress and coping of mothers of cerebral palsy children. The findings of the study will help the professional nurse to provide information related to cerebral palsy and can introduce to the family members the available resources. In the community, she can bring health awareness to meet the needs of the cerebral palsy children and the challenges of their parents

MATERIALS AND METHODS

Research approach

An descriptive approach was adopted for this study.

Setting of the study

The study was conducted in 5 special schools for cerebral palsy children in Kanyakumari District. They provide Physiotherapy exercises, training about self-care activities, guiding the parents carryout in the home also, and conducting parent meeting regularly.

Population

Mothers of cerebral palsy children below 10-years admitted them in the above schools.

Sample

The sample comprised of 75 mothers those who are sending their children with cerebral palsy under 10-years.

Sampling technique

The sample was selected by convenient sampling method.



Criteria for sample selection

Inclusion Criteria

- Mothers having children under 10 – years diagnosed with cerebral palsy.
- Both Male and female school children were included.

Exclusion Criteria

- Mothers who were taken for pilot study.
- Mothers who can not speak Tamil or English.

Instrument for data collection

The tool is a semi-structured interview schedule consisting of three section

Section A

It consists of selected demographics data, which includes the name, age and sex of the child, education, occupation, type of marriage and religion of mothers, type of family, income and residence of the family.

Section B : Modified stress assessment scale for mothers.

It consists of 20 questions to elicit stress of mothers with regard to the stress of daily care, family emotional, social and financial stress of the mother.

Section C : Coping assessment scale for mothers.

It contain 20 questions related to various coping strategies of the mothers. The tool was initially written in English and then translated in to Tamil.

Content validity of the tool

Content validity was established by submitting the tool to five expert in the field of Nursing, medicine, Psychology and Psychiatry for their opinion and suggestion. Based on their comments reining of the tool was done.

Reliability of the tool

The reliability of the tool was established by test-retest method. The tool was administered to 7 samples. The test was administered first time and readministered after 5 days. In both cases, response was similar and the test was measuring the same attribute. Thus the tool was found to be reliable one ($r=0.91$).

RESULTS

Section – A

Table 1: Frequency, distribution and percentage of child data.

Characteristic	Frequency	Percentage
Age		
Below 1 year	-	-
2 to 5 year	13	17
6 to 10 year	62	83
Sex		
Male	54	72
Female	21	28

The data in the table shows that majority 83% of the children belong to the age of 6 – 10 years. Table 1 reveals that majority of the children were males (72%).

Pilot study

The refined tool was used for pilot study at Bethsan School to test the reliability, feasibility and practicability. Formal approval was obtained from the head of the institution and the pilot study was conducted one week before the real study. The instrument was found to be feasible and practicable. The data analysis of pilot study was done to ensure achievement of objectives of the study.

Data collection procedure

A written permission was obtained from the concerned authorities of each school, where explained the nature and purpose of the study and assured that the study will not interfere with the routine schedule of the school. The period of data collection was 4 weeks; in the above prescribed period the investigator visited the school. The purpose and nature of the study was explained to each subject and obtained their consent. The investigator visited the school and collected the children addresses from the school and met them in their residence. The data was collected, after providing adequate privacy, and everyone was assured about the confidentiality fo the interview. The duration of interview was about 30 minutes, during the interview unnecessary explanation was not given. After completion of interview, doubts, where clarified and additional information was provided. Finally, mothers were thanked for their participation in the study.

Plan for data analysis

The data obtained was analyzed by using both descriptive (percentage, frequency) and inferential statistics (chi-square) the plan for data analysis was Frequency and percentage distribution of sample by the demographic variables. Chi-square test to determine the association between the stress and demographic variable. Chi-square test to determine the association between the coping and demographic variables such as family income, occupation of mother, sex of the child and the stress and coping of mothers.



Table 2: Frequency distribution and percentage of the family data N = 75

Characteristic	Frequency	Percentage
Type of Family		
Nuclear	42	56
Joint	27	36
Exended	6	8
Income		
Below Rs.1000	18	24
1001 – 2500	26	35
2501 – 5000	20	26
Above 5001	11	15
Residence		
Rural	46	61
Urban	29	39

The data presented in the table shows that a large majority 42 (56%) of the respondents are from the nuclear family. The large majority 46 (61%) of the sample is from rural area and 29 (39%) is from urban area. More than half 44 (60%) of the sample is from income below 2500.

Table 3: Frequency distribution and percentage of mother data. = 75

Characteristic	Frequency	Percentage
Age		
Below 25 year	8	11
26 – 30 year	36	48
31 – 35 year	28	37
36 – 40 year	3	4
Education		
Illiterate	14	19
Primary	29	39
Secondary	15	20
Collegiate	17	22
Occupation		
Working	22	29
Not working	53	71
Religion		
Hindu	33	44
Christian	41	55
Muslim	1	1
Type of Marriage		
Consanguineous	12	16
Non – Consanguineous	63	84

The data in the table shows that majority 44 (59%) of the mothers belong to the age group below 30 years. Only 31 (41%) belong to the age group 31 to 40 years. Regarding education, 29 (39%) of the sample had primary education. A large majority (71%) of mother are not working. More than half 41 (55%) of the sample are Christian and 33(44%) are Hindus. A large majority 63 (84%) of respondents marriage was non-consanguineous.

Section – B

Table 4: Stress of Mothers having Cerebral palsy children

Stress	Frequency	Percentage
Mild (below 20)	6	8
Moderate (21 – 40)	59	79
Severe (41 – 60)	10	13

Data on the table shows that majority 59(79%) of mothers experienced moderate stress.



Table 5: Coping of Mother having cerebral Palsy children

Coping	Frequency	Percentage
Poor (below 20)	10	14
Moderate (21 – 40)	52	69
Effective (41 – 60)	13	17

The data shows that majority 52(69%) of mothers had moderate coping.

Section – C

Table 6: Association between the level of stress coping of mothers having cerebral palsy children = 75

	Poor n=10	Moderate n=52	Effective n=13	Table value & level of significance
Mild n = 6	1	2	3	12.04
Moderate n = 59	8	41	10	P< 0.05. significant
Severe n = 10	1	9	0	4df.

The table shows, the association between the stress and coping of mothers. The obtained X² value 12.04. This indicates that there is a significant association between the stress and coping of mothers. So the null hypothesis was rejected.

Section – D

Table 7: Association between stress and selected demographic variables. N = 75

Variable	Mild stress n = 6	Moderate stress n = 6	Severe stress n = 6	X ² value& level of significance
Income				*
>2400 (44)	4	34	6	7.6214. P< 0.05. significant
<2500 (31)	2	25	4	
Occupation				2.0871. P> 0.05. Not significant
Working (22)	2	19	1	
Non-working (53)	4	40	8	
Sex of the Child				*
Male (54)	6	44	4	7.6066. P< 0.05. significant
Female (21)	0	15	6	

The table shows, the association between the stress of mothers and the selected demographic variables. The X² value 7.6066, shows it is significant. It indicates that the stress of mothers of cerebral palsy children is associated with the sex of the child. Hence the null hypothesis is rejected and research hypothesis is accepted. The obtained X² values 7.6314 show it is significant. It indicates that the stress of mothers of cerebral palsy children is associated with the income of the family. Hence the null hypothesis is rejected and research hypothesis is accepted. The obtained X² values show that there is no significant association between the stress of mothers and occupation of mothers.

Table 8: Association between the coping of mother's and selected demographic variables.

Variable	Poor coping n = 10	Moderate coping n = 52	Effective coping n = 13	X ² value& level of significance
Income				5.8586. P> 0.05. Not significant
>2400 (44)	4	34	6	5.8586. P> 0.05. Not significant
<2500 (31)	6	16	9	
Occupation				*
Working (22)	2	15	5	6.8727. P< 0.05. significant
Non-working (53)	8	37	8	
Sex of the Child				2.3317. P> 0.05. Not significant
Male (54)	9	35	10	2.3317. P> 0.05. Not significant
Female (21)	1	17	3	

The table shows, the association between coping of mothers and selected demographic variables. The X² value 6.8727, Shows it is significant. It indicates that the coping of mothers of cerebral palsy children is associate with the occupation of the mother. Hence null hypothesis is rejected and research hypothesis is accepted. The obtained X² values show that there is no significant association between the coping of mothers and the selected demographic variables such as Family income and sex of the child.



DISCUSSION

This finding shows the obtained X^2 value is 12.04 which indicates that there is significant association between stress and coping of mothers having cerebral palsy children. So the null hypothesis rejected. Data obtained shows that majority (83%) of the children belong to the age of 6 – 10. Majority of the children were males (72%). Minority of the sample mothers were below 30 years having priority education and majority of them are house wives. 63 out of the 75 children were born out of non consanguineous marriage relationship. In the association between the stress of the mothers and income X^2 value 7.6214. It shows that there is significant association present in the association between stress of mothers and occupation X^2 value is 2.0871. So there is no significant association between stress of mothers and occupation. There is significant association between stress of mothers and sex of the child X^2 value is 7.6066. In the association between the coping of mothers and income X^2 value is 5.8586. It shows there is no significant association present. In the association between coping of mothers and occupation X^2 value is 6.8727. So there is significant association present. There is no significant

association between coping of mother and sex of the child X^2 value 2.3317.

CONCLUSION

The study concluded there is a need of extensive research in this area. Regarding counseling and intervention programmes. For the family members to cope up with the chronic stress. Different type of research can be done regarding the stress and coping of mothers having cerebral palsy childrens a nurse educator nursing students should be taught about the holistic care of children with cerebral palsy including their family members. Due to the social stigma associated with the disease, the care of the family members also should be given more important. It will enable the family members to take active part in the care, findings of the study can be used for updating the knowledge of nursing personal. The overall experience of conducting the study was new experience for the investigator in the field of research. The constant encouragement and the direction of the guides, co-operation of the respondents to participate the study contribute to the fruitful and successful completion of the study.. The published work is a part of The Tamilnadu Dr. MGR Medical University Chennai.

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