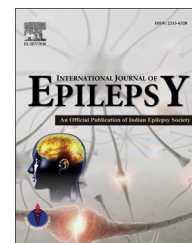


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Original Article

Psychosocial care needs of the parents having children with epilepsy



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ABSTRACT

Aim: The present study aimed to assess the psychosocial care needs of parents having children with epilepsy.

Methods: Descriptive research design was adapted and it was conducted in neurology OPD at NIMHANS, Bangalore. Fifty subjects that are parents having children with epilepsy were selected after considering the inclusion and exclusion criteria through simple random sampling method. The study subjects were interviewed for socio demographic characteristics and psychosocial care needs using Socio Demographic Data Sheet and Parent Report Psychosocial Care Needs Scale (Austin et al 1998) respectively. ANOVA and t test, Frequency and mean percentage were used to identify the psychosocial care needs of the parents.

Results: Majority of the parents received lesser information about seizure than they wanted and expressed strong need for information about epilepsy diagnostic procedures, treatment and management at home and school and they were not expressed much concern and fear towards causes and complications of the children's seizure. There were no significant associations seen between parent psychosocial care needs and their socio demographic characteristic but family history of epilepsy and number of drugs used by the children was associated significantly.

Conclusion: The findings showed that majority of the study subjects received lesser information than they needed about epilepsy and not had much concern about the causes and the complications of epilepsy, but at the same time most of the parents expressed that they need information about the management of children's seizure.

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1. Background of the study

Epilepsy is a universal neurological disorder in childhood. It affects 50 million people in the world. One in 26 people

develops epilepsy all through the lifetime. It is the most broadly seen neurological disease in children and affects both the child and the family because of its psychological and social consequences. When a child is diagnosed with a severe health problem, they and their families are at increased risk of

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experiencing psychological distress and disorder. The objectives of the treatment twofold: firstly, they have to examine the relationships amongst child illness, parental and child distress, quality of life and medical regimen adherence; and secondly, to understand the degree of parent interest in receiving psychological support and health care professionals' perceptions of family psychosocial needs towards epilepsy. Occurrence rates of epilepsy are 5–10 per 1000. Over 90 per cent of people with epilepsy in developing countries are not on any regular, treatment (WHO).^{1,2}

Epilepsy can have far reaching psychological and social ramifications and for some individuals these can be more overwhelming than the seizures. Attentiveness of the psychosocial problems which may arise is essential for professionals working with people with epilepsy and their families. Such difficulties can have a profound impact on a person's mental health and also upon seizure control. Greater acknowledgment of the wider impact of epilepsy is also needed to enable the development and targeting of suitable services and support.^{3,4}

1.1. Statement of the problem

A descriptive study to assess the psychosocial care needs of parents having children with epilepsy at NIMHANS.

1.2. Aim of the study

To assess the psychosocial care needs of parents having children with epilepsy.

1.3. Objectives of the study

1. To identify the socio demographic characteristics of the study subjects that is parents of children with epilepsy.
2. To assess the psychosocial care needs of the study subjects.
3. To associate socio demographic characteristics with psychosocial care needs of the study subjects.

2. Materials & methods

2.1. Population

The requirement of defining population for a research project arises from the need to specify the group to which the study can be performed. In this study population means all the parents having children with epilepsy.

2.2. Sample size

All those subjects selected for the study as per the inclusion criteria forms the sample of the study, the researcher identified the respondents (parents) who met the inclusion criteria and included them as the sample for the study. For the present study, 50 subjects were selected.

2.3. Setting

The National Institute of Mental Health and Neuroscience (NIMHANS), located in Bangalore, is a premier institute for

mental health sciences as well as neurosciences. It is recognized by the Government of India (2012) as an 'Institute of National Importance' in south East Asia. Neurology is a medical specialty dealing with disorders of the nervous system including epilepsy. Multidisciplinary team approach is being used to sort out the neurological and mental health issues of all the age group of patients. Neurology OPD runs on all week days from 9.00 am to 4.00 pm. There are 150–200 patients treated in a day, out of that 25–30 patients were found with epilepsy. Apart from clinical services, education, research and manpower training are also being conducted in neuropsychiatric units at NIMHANS.

2.4. Sampling techniques

Simple random sampling technique was used for the selection of the subjects. Those parents who met the sample selection criteria were selected by using the lottery method.

2.5. Inclusion criteria

1. Parents having children (up to the age of 14 years) with epilepsy, staying along with children for the last one year and accompanying the children to receive epilepsy treatment services at NIMHANS.
2. Parents having children with generalized seizures.

2.6. Exclusion criteria

1. Parents having a history of epilepsy.
2. Parents having more than one child with epilepsy.

2.7. Instrument used for data collection

Socio demographic data sheet and Parent Report Psychosocial Care Scale developed by Joan Austin et al (1998)⁵ were used for the assessment of the psychosocial care needs. The scale was reviewed for content validity by four clinical nurse specialists with expatriation in pediatric epilepsy. They found that the tool covered all the major contents. The alpha reliability was (0.84) found after the test retest method, by administering to the 10 parents.

2.8. Pilot study

The pilot study was undertaken before starting the main study. A pilot study was conducted in the month of July 2012 at neurology OPD – NIMHANS among ten (20 per cent of the sample included in the study) parents of children having epilepsy. There was no problem encountered by the researcher during pilot study.

3. Procedure for data collection

The data collection was carried out in the month of August 2012. On every Tuesday, Thursday and Saturday at follow-up Neurology OPD – NIMHANS. The selected subjects were met

by the researcher in neurology OPD – NIMHANS. The nature and purpose of the study was explained by the researcher and doubts were clarified. Informed written consent was obtained from them. One to one interview method was used to collect the data. The subjects were made to sit comfortably in the separate room. They were given necessary instructions and assured about confidentiality of their responses. First the socio demographic details were obtained and then the responses for the items on parent report of psychosocial care were elicited. This order was systematically followed for all the subjects.

4. Analyses of data & interpretation

Analyses of the data were done in accordance with the objectives using descriptive and inferential statistics, using SPSS 21.0 and windows 7 version. To describe socio demographic characteristics frequency and percentage were calculated. To identify the psychosocial care needs of the study subjects the item wise analysis of the three dimensions were done and mean scores were found. ANOVA and t test was used to

Table 1 – Socio demographic data of the study subjects (parents): n = 50.

Characteristics	Category	Number	Percentage
Parental status	Father	23	46
	Mother	27	54
Age	<20 years	2	4
	21–30 years	19	38
	31–40 years	20	40
	41–50 years	9	18
Religion	Hindu	42	84
	Christian	3	6
	Muslim	5	10
Education	Illiterate	10	20
	<10th	18	36
	10th	8	16
	PUC	5	10
	UG	6	12
	PG	2	04
	Others	1	02
Occupation	Private	11	22
	Govt	1	2
	Own Business	4	8
	Daily wage	14	28
	Unemployed	4	8
	Farmer	9	18
	House wife	7	14
Income per month	<Rs. 5000	35	70
	5001–10,000	9	18
	10,001–20,000	3	6
	20,001–30,000	1	2
	30,001–40,000	–	–
	>40,000	2	4
Types of family	Nuclear family	36	72
	Joint family	14	28
Place of domicile	Rural	26	52
	Urban	23	46
Presence of chronic illness	Semi urban	1	2
	Yes	10	20
	No	40	80

Table 2 – Socio demographic data of the (children): n = 48.

Characteristics	Category	Number	Percentage
1 Gender	Male	30	62
	Female	18	38
2 Age of the child	Less than 2 years	7	14
	3–9 years	21	44
	10–14 years	20	42
	15–19 years	10	21
3 Status of attending to the school	Yes	35	73
	No	13	27
4 Age of onset	Less than 2 years	22	46
	3–9 years	18	37
	10–14 years	8	17
	15–19 years	10	21
5 Duration of seizure	1–5 years	34	71
	5–10 years	9	19
	10–14 years	5	10
	15–19 years	10	21
6 Number of attacks per month	Less than 2 days	24	50
	3–6	13	27
	7–10	3	6
	Greater than 10	8	17
7 Last seizure attack	Within 7 days	14	30
	8–15 days	4	8
	16–30 days	4	8
	1 month before	26	54
8 Family history	Positive	10	21
	Negative	38	79
9 Number of drugs	One	25	52
	Two	12	25
	Three	8	17
	More than three	3	6
10 Seizure status	Controlled	32	67
	Uncontrolled	16	33

associate socio demographic data with information need of the parents regarding the epilepsy and managements. Mann–Whitney U test and Kruskal–Wallis test were used to associate socio demographic data with the information received from health care professionals and parents concern and fear towards the causes and complications.

5. Results

To identify the socio demographic characteristics of the study subjects that is parents of children with epilepsy. Table 1 revealed majority of the parents were between the age of 31 and 40 years (40%), were mothers (54%), Hindus (84%), studied less than 10th standard (36%) and worked as daily wages (28 per cent), had monthly income lesser than Rs. 5000 (70%) and rural (52%) nuclear family (72%) and had no chronic illness (80%). Table 2 revealed that most of the children were boys (62%) aged between 3 and 9 years (44%) were going to the school (73%), had seizure onset at the age of less than 2 years (46%), with duration of 1–5 years (71%) experienced less than 2

Table 3 – Distribution based on the dimension wise mean score: n = 50.

Variables	Mean ± SD
Information received	12.50 ± 2.94
Information need	30.60 ± 7.44
Concern and fear	8.32 ± 2.82

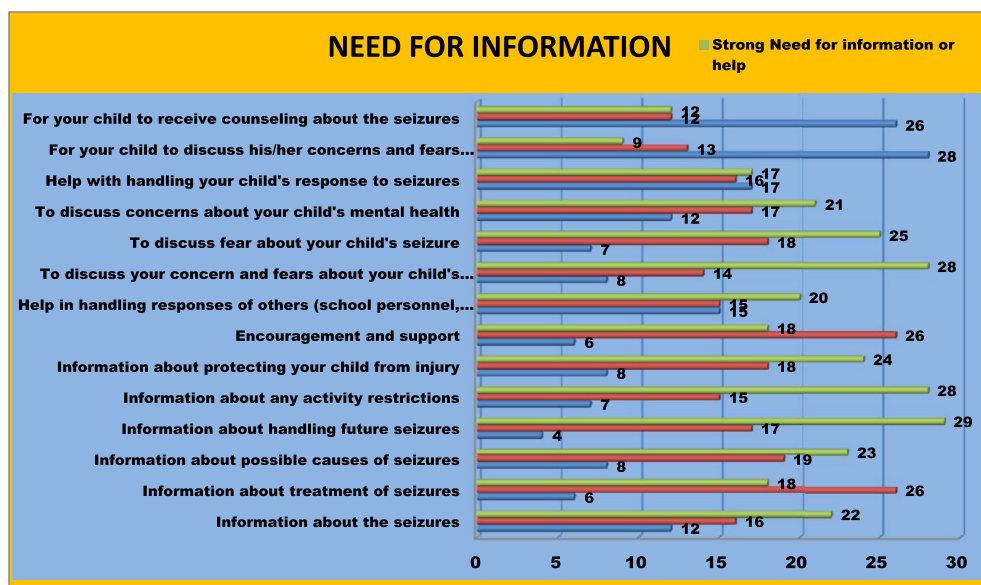


Fig. 1 – Distribution of the responses given by the study subjects in dimension two (Information need).

seizure attacks per month (50%), had their last seizure attack one month before (54%), had no family history of epilepsy (79%) taking only one anti-epileptic drug (52%) and their (67%) seizures were controlled with the medication. Table 3 and Fig. 1, revealed that majority of the parents ($\Sigma = 21$) strongly felt that they needed further information or help and the mean score was 30.60 ± 7.44 . Table 4 and Fig. 2, revealed that majority of the parents ($\Sigma = 23$) expressed that they were not at all having concern and fear towards cause of the children's seizure and the mean score was 8.32 ± 2.82 . To associate the socio demographic characteristics of the parents with their psychosocial care needs, there were no significant association between parent psychosocial care needs and parental status, age, sex, religion, type of family, education, occupation, income and the place of domicile, chronic illness. To associate the socio demographic characteristics of the children with their parents' psychosocial care needs, Tables 5 and 6 revealed that no significant association between parent psychosocial care needs and children's gender, age, status of attending to the school and seizure details like, age of onset, total duration, number of attacks per month, last attacks and status of seizure control. The family history of epilepsy had significant association with Information need dimensions (D2) ($P = 0.025^*$) and Concern and fears dimension (D3) ($P = 0.024^*$). The same way numbers of drugs used by

the children had the significant association with Concern and fears dimension (D3) ($P = 0.027^*$).

6. Discussions

The study revealed that majority of the parents received less information about seizure than they wanted. Similarly Uthramani (2006) revealed in her study that majority of the children and parents received less information about epilepsy from the doctors and nurses than they wanted, expressed the need for further more information and showed more concern and fears about child's epilepsy.⁶ Majority of the parents strongly felt that they needed further information or help. Similar findings were reported by Buelow (2007) that parents needed more time for epilepsy education and interacting with one another and that the intervention was to form partnerships with health care and school professionals.⁷ Another study of Frank-Briggs and Alikor (2011) found out that there was a need to disseminate more information to the parents about its causes, clinical manifestation, and approach to manage a convulsing child, and its outcome.⁸ Majority of the parents expressed that they were not at all having concern and fear towards cause of the children's seizure. It could be due to adequate diagnostic assessment and consultation

Table 4 – Distribution of the responses given by the study subjects in dimension three: $n = 50$. D3-Concern and fear.

S. no	Items	1 Not at all	2 Some what	3 Moderately	4 Very much
1	Is epilepsy caused by a brain tumor?	32 (64.00)	7 (14.00)	6 (12.00)	5 (10.00)
2	Is epilepsy will cause a loss of intelligence?	19 (38.00)	11 (22.00)	8 (16.00)	12 (24.00)
3	Is epilepsy will cause brain damage?	20 (40.00)	7 (14.00)	10 (20.00)	13 (26.00)
4	Is epilepsy will cause death?	19 (38.00)	7 (14.00)	6 (12.00)	8 (16.00)
Average responses given by total subjects		23 (45.00)	11 (21.00)	8 (15.00)	10 (19.00)

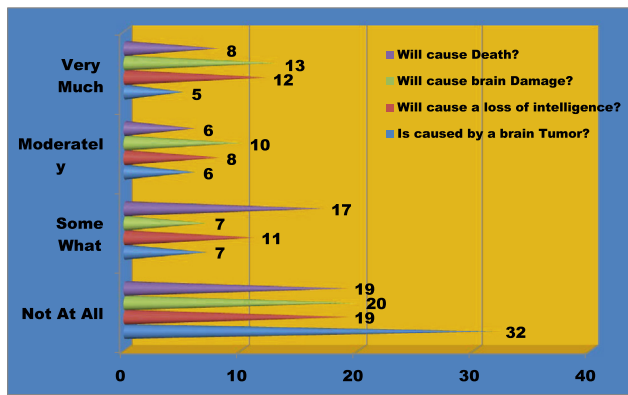


Fig. 2 – Distribution of the responses given by the study subjects in dimension three (Concern and fears).

about child's seizure and ignorance due to less education, poor socioeconomic status and chronicity of the illness. Whereas Cheryl et al (2009) found that worries and concerns and needs for information and support persisted for 24 months in parents.⁹ Similarly Besag et al (2005) also found that seizures often causing major concern in parents and many of them thought that their child was dying.¹⁰ There were no significant association between parent psychosocial care needs and parental status, age, sex, religion, type of family, education, occupation, income and the place of domicile, chronic illness. Similar findings were seen in the study of Pal, Chaudhury, Das, and Sengupta (2002) where in parental education, and income did not have a significant association with parent psychosocial care needs.¹¹ Also there were no significant association between parent psychosocial care needs and children's gender, age, status of attending to the school and seizure details like, age of onset, total duration, number of attacks per month, last attacks and status of seizure control.

But family history of epilepsy had significant association with Information need dimensions and Concern and fears dimension. It could be justified that members in the family

wants to find out the genetic role in causation of epilepsy in the future generation. The same way numbers of drugs used by the children had the significant association with Concern and fears dimension. It could be due to number of drugs as they cause side effects.

7. Implications to nursing

The findings of the study can be used by nurses to design and develop psycho educational interventional strategies based on patients and parents preferences and to meet the specific needs of epilepsy to enhance their ability to cope with demands of lifelong debilitating chronic illness. The study result can help the nurse to understand psychosocial needs as determinants of quality of life in epilepsy children and their parents.

7.1. Nursing education

The study results can be utilized to plan training program for student nurses, school health nurses and community health nurses about the management of epileptic children and issues related with the parents and family members. The nurses can be trained to provide educational services to parents regarding childhood epilepsy.

7.2. Nursing administration

By bearing in mind, the enormity of problems the parents of children with epilepsy have, nurse administrator may conduct short term in-service education Programmes for various levels of nursing personnel working with children and parents of children with epilepsy.

7.3. Nursing research

By pursuing research, nurses could contribute towards enriching knowledge about psychosocial problems of children with epilepsy and their parents.

Table 5 – Association of the family history of seizure with parent psychosocial care needs: n = 48.

S. no	Variables	Positive n = 10 Mean ± SD	Negative n = 38 Mean ± SD	t Value	u Value	P-value
1	Information received (D1)	13.40 ± 3.34	12.21 ± 2.88	–	149.50	0.300
2	Information need (D2)	34.80 ± 4.57	29.03 ± 7.50	2.312	–	0.025*
3	Concern and fear (D3)	10.10 ± 2.69	7.79 ± 2.68	–	102.00	0.024*

*Level of significant at 0.05.

Table 6 – Association of the number of drugs used for seizure with parent psychosocial care needs: n = 48.

S. no	Variables	One n = 25 Mean ± SD	Two n = 12 mean ± SD	Three and more than three n = 11 Mean ± SD	F value	x ² (K–W) value	P-value
1	Information received (D1)	11.80 ± 2.96	14.00 ± 3.25	12.27 ± 2.28	–	4.578	0.102
2	Information need (D2)	29.96 ± 6.59	29.17 ± 7.94	32.00 ± 8.65	0.451	–	0.640
3	Concern and fear (D3)	7.88 ± 2.88	10.08 ± 2.47	7.18 ± 2.27	–	7.256	0.027*

*Level of significant at 0.05.

8. Conclusion

The findings showed that majority of the study subjects received lesser information than they needed about epilepsy and not had much concern about the causes and the complications of epilepsy, but at the same time most of the parents expressed that they need information about the management of children's seizure. The information booklet prepared by the researcher contains required information that would improve the ability of the subjects to manage their children's future seizure and its complications.

Conflicts of interest

All authors have none to declare.

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