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Emotional & Behavioural Problems among Siblings of Children with Chronic Neuromuscular Illnesses

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Method: It is a cross-sectional study conducted in a tertiary care hospital from over a period of 34 months. Siblings of children with chronic neuromuscular illnesses were serially recruited while attending pediatric OPD and IPD. Parents were interviewed and requested to fill the Strength and Difficulty Questionnaire (SDQ) to assess and analyze emotional and behavioral problems among siblings.

Results: Study included 171 siblings of children with chronic neuromuscular illnesses. Of 171 siblings, 124 (72.51%) had normal scores, 25 siblings (14.62%) were in borderline range and remaining 22 (12.87%) had abnormal values. The mean ± SD of SDQ score was 12.41 ± 3.6 with median score of 11. There was no significant difference between total SDQ scores of male vs female siblings (p value= 0.229) or between birth order of the sibling or GMFCS class of the affected child to emotional and behavioural problems. Subgroup analysis was not possible because of small sample size.

Keywords: *cerebral palsy; emotional disturbances; neuromuscular diseases; sibling relations.*

GJMR-A Classification: *NLMC Code: WE 550*



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Emotional & Behavioural Problems among Siblings of Children with Chronic Neuromuscular Illnesses

Psycho-Social Difficulties in Siblings of Neurodisabled

Nidhi Garg [α] & Krishna Moorthi Adhikari [σ]

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Conclusion: This study emphasizes that identifying and treating even small proportion of siblings with behavioral problems can have a long-term impact on development and well-being of the child, family, community and nation as a whole.

Keywords: cerebral palsy; emotional disturbances; neuromuscular diseases; sibling relations.

I. Introduction

The prevalence of children living with chronic neuromuscular illnesses has risen as a result of improvement in health care facilities and change in social philosophy about their health care requirements and home-based supportive care [1]. These achievements are commendable but are accompanied by increased care giving burden being born by all members of a household with a child with disability.

Such affected children require family and community support at multiple levels for survival as well as day to day functioning. They have multiple associated comorbidities like intellectual disabilities, seizures, feeding difficulties, hearing and visual impairments and behavioural problems that impose extra financial, social and emotional burden on the family [2]. Families tend to divert all their resources in rearing such disabled child, thus exposing the well sibling to the risk of various emotional and behavioural problems as a result of parental deprivation and interplay of various other factors. The mechanism by which a particular family or a parent copes well compared to others is largely unknown. Several theories are documented which states that stress arises when the demands imposed by a patient's condition collide with a caregiver's subjective ability to respond, or when these demands obstruct the pursuit of other objectives [3].

Research exploring the impact of disability on typically developing siblings has been mixed. Vermaes et al [4] published a meta-analysis studying the psychological functioning of siblings in families with children with chronic conditions and concluded that siblings of children with disability are at increased risk of developing negative self-attributes and internalizing problems. In another study conducted to investigate behavioural adjustment among siblings of 96 children and adolescents with spinal muscular atrophy, non-affected siblings had a two to threefold higher rate of behavioural problems than the normative population [5]. There are some studies that have quoted positive effect (e.g, sibling bonding) on siblings residing in a household with a child with disability [6]. Certain studies mention interplay of four general characteristics that guides sibling adjustment to the chronic illness, namely family, parent, illness and sibling characteristics [7].

Emotional and behavioural problems among siblings of children with chronic neuromuscular illnesses have been the topic of research for many decades. A study by Williams et al mentions feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, worry about the ill child, school problems, poor peer relations, withdrawal or shyness, somatic complaints,

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low self-esteem, and behaviour problems (internalizing and externalizing) among siblings with a sick child at home [7]. The Ontario Child Health Study (OCHS) found a 2-fold risk in emotional disorders, including depression, anxiety, and obsessive-compulsive disorder, and a 1.6-fold increase in poor peer relationships among siblings [8]. There are feelings of embarrassment that arise which further hamper adjusting with peers and getting involved in social activities [9].

The purpose of this study is to empirically estimate the magnitude of emotional and behavioural impairment in siblings of children with neuromuscular disability. The siblings residing in households with a child with disability are more likely to experience significant functional impairment. Functional impairment is a key indicator for the need of mental health services, and as such early assessment using easy to use tools like Strength and Difficulty Questionnaire (SDQ), CBCL etc. and interventions to check increasing severity and further adverse consequences need to be addressed.

II. Materials and Methods

A cross-sectional study was conducted in a tertiary care hospital of Maharashtra over a period of 34 months. Neurologically normal siblings (4-17 years old) of children with chronic neuromuscular illnesses (GMFCS II or more) attending paediatric out-patient department (OPD) or in-patient department (IPD) were included in the study. Siblings themselves with chronic diseases/disabilities requiring constant supervision or prolong medications or recurrent hospitalizations or dependency on others for day to day functioning were excluded. *(Figure 1)*

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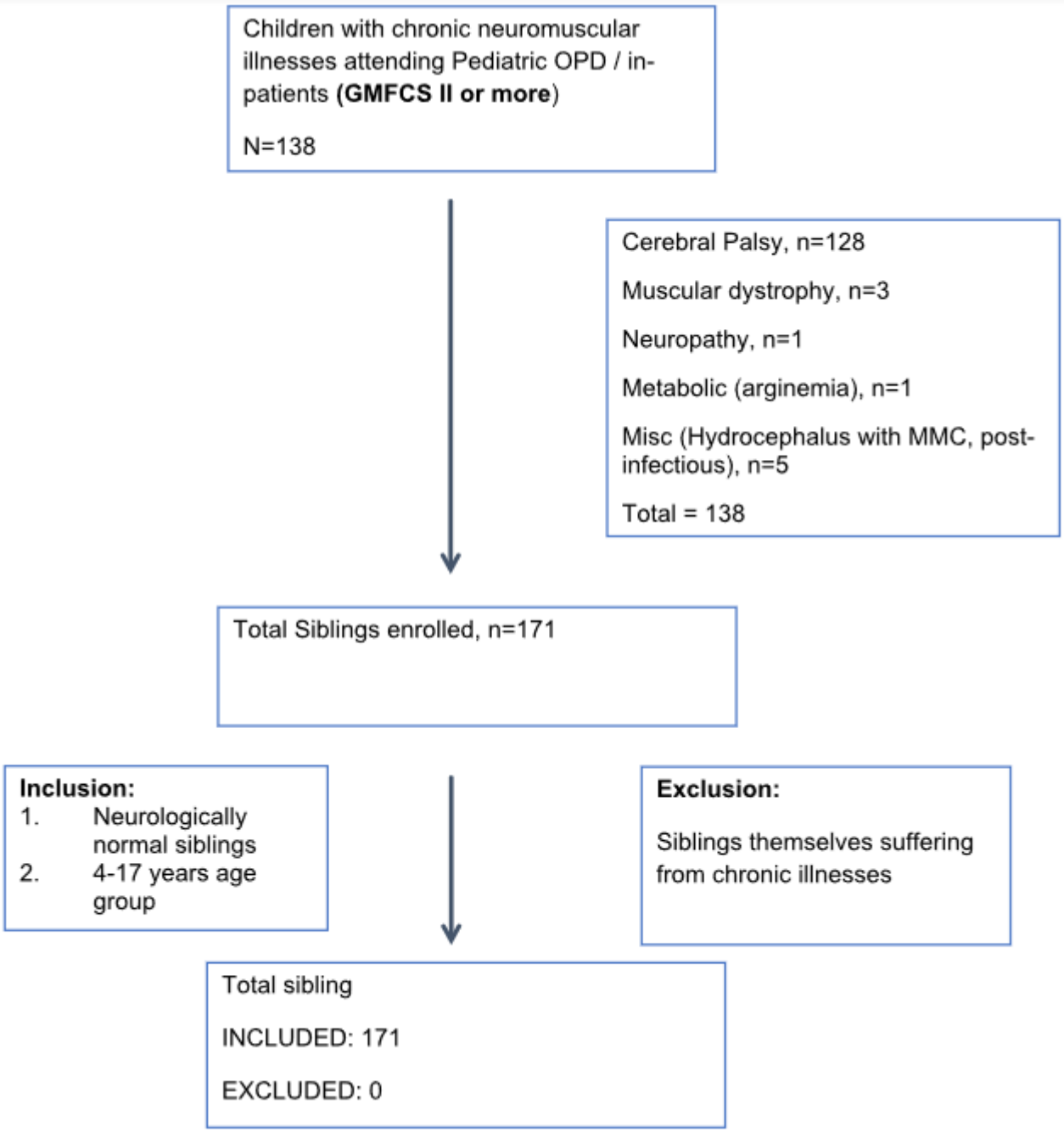


Figure 1: Flow chart showing study design

Based on few earlier studies and assuming 20% abnormal SDQ score among siblings, with 95% confidence and 5% error, the minimum sample size calculated was 171.

Data was collected by interviewing parents using pre-designed proforma to obtain the demographic data and clinical subtype, associated comorbidities and severity of functional impairment of the affected child with chronic neuromuscular illness. Also baseline demographic data was obtained for the parents and siblings using the same proforma. *(Table 1)*

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Table 1: Baseline characteristics of siblings

Baseline Characteristics	Total (n=171)	
	No	%
1. Age		
a) 48-71 months	60	35.09
b) 72-119 months	62	36.28
c) 120-204	49	28.65
2. Sex		
a) Male	64	37.43
b) Female	107	62.57
3. Sibling Order		
a) I	81	47.37
b) II	74	43.27
c) III	13	7.6
d) IV	2	1.17
e) V	1	0.58
4. Goes to school		
a) Yes	170	99.42
b) No	1	0.58
5. Scholastic Performance		
a) Poor	3	1.75
b) Average	15	8.77
c) Good	153	89.47
6. Associated illnesses		
a) Yes	4	2.34
b) No	167	97.66
7. Extra-curricular activities		
a) Yes	87	50.88
b) No	84	49.12

Widely used and validated parent completed Strength and Difficulty Questionnaire (SDQ) was used for assessment of behavioral problems among siblings. Total SDQ scores and subscale scores namely emotional problems, hyperactivity issues, conduct problems, peer problems and pro-social behavior were analyzed. The cut off for normal SDQ scores was 0-13, borderline was 14-16 and abnormal was 17-40. A master sheet was tabulated in the excel format. Demographic data was tabulated and proportions and percentages were calculated. Mann-Whitney rank sum test was applied for comparison of variables with non-normally distribution data. ANOVA was used for comparison of variables with normal distribution by using Medcalc Version 9.0.1.0.

III. Results

Of 171 siblings studied, 107 cases (62.57%) were females and 64 cases (37.43%) were males. The female to male sex ratio in the entire study group was1.67:1.

In total, 171 siblings were assessed for emotional and behavioural problems based on SDQ questionnaire filled by parents. The scores ranged from 0-40. On evaluation 124 (72.51%) had normal scores, 25 siblings (14.62%) were in borderline range and remaining 22 (12.87%) had abnormal values. The mean ± SD of SDQ scores among siblings was 12.41 ± 3.6and median score was 11. *(Figure 2)*

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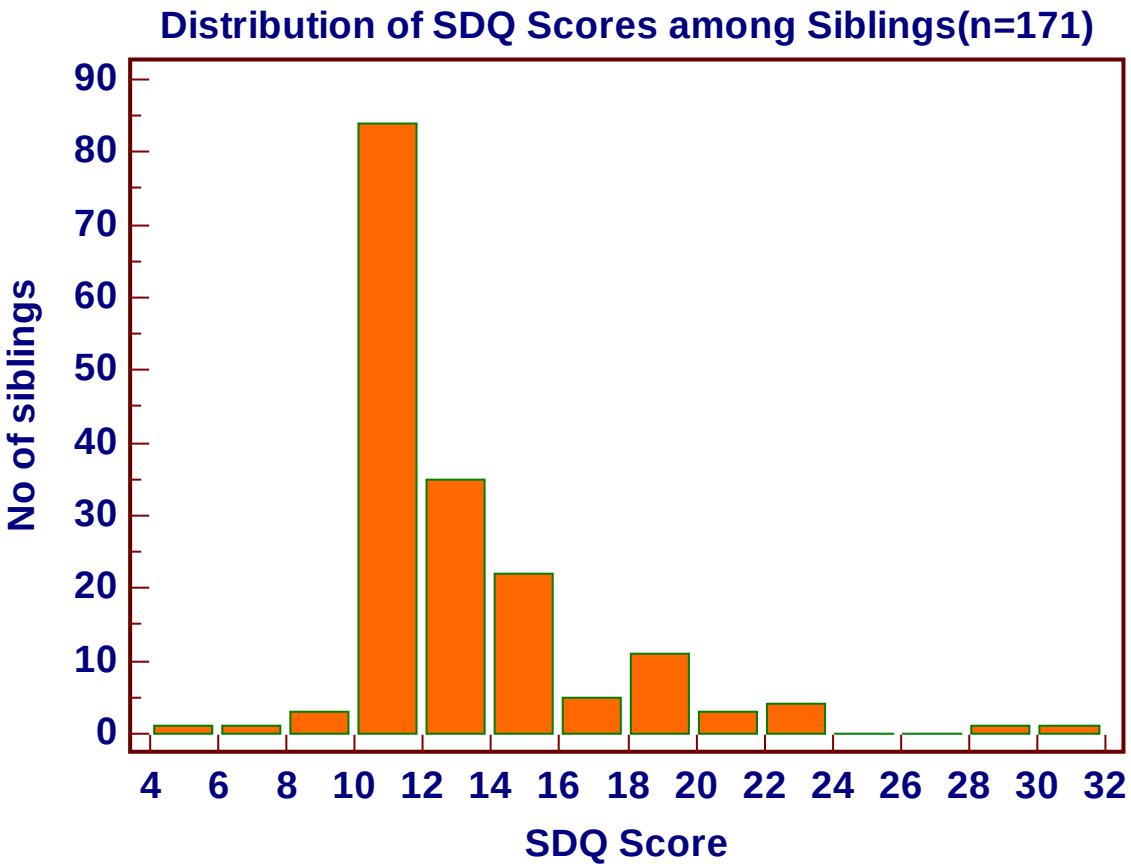


Figure 2: Distribution of Total SDQ scores among siblings

Of the total 107 female siblings 77 (71.96%) had normal, 17 (15.89%) had borderline and 13 (12.15%) females had abnormal score. Among 64 male siblings 47(73.44%) have normal, 8(12.5%) with borderline and 9 (14.06%) were with abnormal scores.

Mann Whiney rank sum test was applied to compare mean SDQ scores between male and female siblings. No significant difference was found between the two groups (p value= 0.229).

The association of sibling order with behavioural and emotional problems was analysed. Out of the total 171 siblings studied, 81(47.37%) were first order, 74(43.27%) were second order, 13(7.60%) were third order and remaining 3 were fourth and fifth order siblings. However, siblings with birth order III and beyond could not be compared because of their relatively small number available for analysis. Among 81 first order siblings 55 (67.9%) had normal, 12 (14.81%) had borderline and 14 (17.29%) siblings had abnormal score. Out of 74 second order siblings 54(72.98%) had normal, 12(16.22%) with borderline and 8 (10.8%) were with abnormal scores. SDQ scores between the first and second order siblings were compared and no significant difference was found between the two groups (p value =0.244).

Out of the total 171 siblings, 49 (28.65%) had the affected child with GMFCS III in the family, 39 (22.8%) as GMFCS IV and 77 (45.02%) were siblings of children with GMFCS V. Siblings of children with GMFCS II were not involved in this group comparison because of the relatively small number (6 cases). ANOVA was applied for comparison of mean SDQ scores among siblings of CP children with GMFCS III, IV and V. There was no significant difference in the mean SDQ scores (p=0.234) amongst siblings of cases who were grouped into three subgroups based on GMFCS class of the affected child, viz, Class III, IV and V.

Tabulation of scores under various subscales of SDQ questionnaire was carried out *(Table 2)*. It was found that majority of children had sub-scores in various domains in normal range and only few had borderline or abnormal scores. Hence separate sub-score analysis was not possible due to small number of children involved in borderline-abnormal zone.

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Table 2: Table showing SDQ sub-scores of siblings

SDQ scores	Total		Female		Male	
	No	%	No	%	No	%
1. Hyperactivity Score						
Normal (0-5)	168	98.25	107	100	61	95.31
Borderline (6)	1	0.58	0	0	1	1.56
Abnormal (7-10)	2	1.17	0	0	2	3.13
2. Emotional Problems Score						
Normal (0-3)	161	94.15	101	94.4	60	93.75
Borderline (4)	6	3.51	3	2.8	3	4.69
Abnormal (5-10)	4	2.34	3	2.8	1	1.56
3. Conduct Problems Score						
Normal (0-2)	158	92.4	101	94.4	57	89.06
Borderline (3)	6	3.51	3	2.8	3	4.69
Abnormal (4-10)	7	4.09	3	2.8	4	6.25
4. Peer Problems Score						
Normal (0-2)	159	92.98	99	92.52	60	93.75
Borderline (3)	7	4.09	3	2.8	4	6.25
Abnormal (4-10)	5	2.93	5	4.68	0	0
5. Pro-social Behaviour score						
Normal (6-10)	167	97.66	104	97.2	63	98.44
Borderline (5)	0	0	0	0	0	0
Abnormal (0-4)	4	2.34	3	2.8	1	1.56

IV. Discussion

Children born with significant chronic neuromuscular problems and disabilities are living longer and achieving more due to advances in medicine and allied health services [1]. Special health care services and therapies for children with chronic neuromuscular problems can be exhaustive and expensive. Parents exhaust their financial, physical, and emotional resources to provide for their children with special health care needs [3]. In addition to the significant expenses incurred on these therapies, substantial time is spent learning to navigate the service delivery, coordinating care and augmenting therapy with practice at home [10]. The typically developing offspring fare relatively well compared with the disabled child, and parents instinctively give more time and energy to the child most in need.

There are very few Indian studies relating to this sensitive issue. In the present study an attempt was made to assess the prevalence of emotional and behavioural problems among siblings of children with chronic neuromuscular illnesses and also the factors contributing to such problems.

In our study, of the total 171 well siblings living with children with chronic neuromuscular illnesses majority (72.51%) had normal scores. Of the remaining siblings studied, 14.62% had borderline score 12.57% had abnormal total SDQ score. In similar studies, Giallo et al had reported 15-52% siblings with emotional and behavioural difficulties in at risk/abnormal range as measured on parents' completed SDQ scores [11]. In another study by Goudie et al 16-24% siblings of children with disability were reported to have some degree of functional impairment [11]. A review by Williams et al covered at least 40 studies published between 1970 and 1995 and revealed that approximately 60% of the studies reported manifestations of increased risk for negative outcomes in siblings, 30% found no increased risk while remaining 10% reported both negative and positive effects [7]. Our study revealed 12.57% children with abnormal SDQ scores which indicate lower prevalence in comparison to quoted studies. Most of the children of cerebral palsy were under regular follow up with multimodality management with ready access to all modalities of supportive therapy ensured through neurology OPD services, which had significantly reduced the stress on

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the parents. This could be the plausible reason for the smaller number of children with abnormal SDQ scores.

Almost 15% of the siblings had borderline SDQs. This observation is significant as regular ambulatory clinical services with frequent assessment and counselling of parents has the potential to prevent this subgroup from transiting into abnormal score category.

Siblings were assessed separately for their behaviour on various subscales namely- emotional problems, hyperactivity, conduct issues, peer problems and pro-social behaviour. Majority of them, around 80% had subscores within the normal range. Giallo et al also found that majority of the siblings have subscores on various emotional and behavioural problems within the normal range [11]. This is an encouraging observation that siblings have emotional and behavioural functioning within the normal range on all subscales of SDQ despite the family crisis.

SDQ scores of female and male siblings were analysed separately. On comparing, no significant difference was found between the two groups (p value=0.229). In a study by S.A. Fleary et al they found significant gender difference in behavioural problems in certain domains with males having more problems in acting out and females having more issues with alienation. This difference could be attributed to different coping styles of males (externalizing) and females (internalizing) behaviour in general [12]. Hannah et al in their study in 1999 found that brothers of affected children had problem in school functioning while sisters expressed their adjustment issues through internalization [13]. However sub-scores analysis between male and female siblings was not possible in our study due to small sample size.

Sibling order could also have an impact on emotional and behavioural adjustment in children. In our study, SDQ scores of first and second order were analysed and compared to find this association. Siblings with birth order three and above could not be compared as the numbers involved was very small for analysis. On comparison no significant difference was found between the two groups (p value=.0.244). Breslau et al in their study found that neither relative birth order nor sex had a statistically significant main effect on overall level of psychological functioning in siblings but together they have significant "crossed" interaction on psychological functioning. Younger male siblings of disabled child showed greater psychological impairment, whereas among females, those younger than the disabled were better off than those older [14]. Tew et al did not find any effect of birth order on the psychological impairment of normal siblings [15].

Another probable factor that could affect the level of psychological impairment in well sibling is the level of functional impairment of the disabled child. This is because severe functional impairment poses significant and time-intensive demands on the parents. We analysed the SDQ scores of siblings based on GMFCS classification of the disabled child in the family. Majority of siblings (73.3%) scored in the normal range. On comparing the three groups no significant association was found between level of severity or functional impairment of the affected child to the degree of psychological or emotional problems in siblings (p value= 0.234). Lavigne et al in their meta-analysis found that though inter-disease variation to psychological adjustment might occur but overall, there is no significant difference on these adjustment in various sensory/neurological disorders [16].

Besides these there are certain parental and family related variables also that can affect the emotional and behavioural adjustments in siblings: absence of parental depression, good marital adjustment, high levels of community support and family resources, and effective parent-sibling communication about illness. Another important variable is maternal education and her understanding and adaptability to the circumstances [7]. Sometimes parents have to quit job, take unplanned leaves or sick leaves to take care of the affected child [7]. Though these variables were not separately analysed in our study but it was found that out of the total 129 non-working mothers interviewed, 12 (9.3%) told that they had to quit job to fulfil their responsibility as a caregiver.

As far as the limitations of the index study goes, the authors feel that similar studies, if carried out on a larger population at multiple centres involving patients of different races and ethnic origin, may give an even better insight and understanding of the psychosocial commotion caused in the siblings of the disabled children. This may help in early diagnosis of psychosocial impairment and behavioural deviation in siblings and early intervention thereafter.

V. Conclusion

To conclude, the prevalence of chronic neuromuscular illnesses among pediatric population is substantial, even with improvement in health care facilities and change in social philosophy about their health care requirements and home-based supportive care. Apart from limited mobility affected children have multiple co-morbidities which poses additional burden upon parents and other family members particularly siblings in coping with the extra responsibilities. Though majority of siblings were found to have no emotional and behavioural problems in the study but the small percentage definitely had these problems to warrant caregiver and medical attention. Using a simple, easily available and easy to administer screening tools like SDQ can help pick up these children so that necessary

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interventions are applied in a timely and efficient manner. Having well-organised family-oriented neurology OPD with counselling facilities can have a long-term impact on the well-being of the siblings and the entire family who is constantly coping with a disabled child.

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Clinical Trial Registration (if any): Not applicable

Abbreviations:

ANOVA	Analysis of Variance
CBCL	Child Behaviour Check List
CP	Cerebral Palsy
e.g.	For example
GMFCS	Gross Motor Function Classification System
IPD	In Patient Department
OCHS	Ontario Child Health Study
OPD	Out Patient Department
SD	Standard Deviation
SDQ	Strength and Difficulty Questionnaire

Table of Content Summary: Identifying and treating even small proportion of siblings with behavioural problems can have a long-term impact on development and well-being of the child

What's known on this Subject: A neurologically impaired child in a family imposes immense financial, emotional and social burden. Nurturing a healthy sibling in such environment is a challenge having both positive and negative impacts on his psychological and emotional development.

What this Study Adds: A neurologically disabled child in a family can have adverse emotional-psychological effect on small percentage of normally developing siblings. Using a simple, easy to administer screening tool like SDQ can help pick up those affected and early intervention applied.

Contributor's Statement Page

Dr. Nidhi Garg and Dr Krishna Moorthi Adhikari both were fully involved in the conception, planning, intervention, data collection and interpretation, literature review, manuscript preparation and review of the write-up.

Both approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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