

# Study of Parental Perceptions on Health & Social Needs of Children with Neuro-Developmental Disability and It's Impact on the Family

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## ABSTRACT

**Introduction:** The term Neuro Developmental Disorder (NDD) is used for conditions caused by a dysfunction in any part of the brain or nervous system, resulting in physical and/or psychological symptoms as a child develops. Family of children with NDD face many problems. It is very important to find them and create awareness so that gaps in essential services and supports can be decreased.

**Aim:** To explore parental perceptions on health & social needs of children with NDD, to understand the impact of disability on the families having children with disability, and to find out the parental perceptions on availability of services for children with NDD and its utilization by families.

**Materials and Methods:** The parents of 30 children with NDD were interviewed using a questionnaire and data elicited in these interviews were analysed. The questionnaire had preliminary information about parents and child with NDDs, socio-demographic profile of the family and the parental perceptions on health and social needs of their child having NDDs.

**Results:** There were total 30 patients 17 were males and 13 were females. Most of the patients suffered from Cerebral Palsy (13 cases) and were diagnosed by General Practitioner (22 cases) while Developmental Neurologist/paediatrician had diagnosed remaining cases of NDD (8 cases). Most common disability for which parents were worried was inability to walk (17 cases).

Common difficulties countered in daily care by parents were feeding and bathing (10 cases). Only 2 children were given assistance with tuition & psychologist (cases of ADHD). Most of the parents knew about special schools but didn't know which place such facilities were available and none of the children were attending special schools. Twenty two parents said they have no plans for the future studies but wish that at least child learns to read & write. With help of spiritual power (doing prayers and pooja) 25 parents got courage to face the difficulties and discrimination. Two parents required antidepressants. Six Mothers had to quit their jobs so as to concentrate and give more time to their children.

Experience with services provided was satisfactory in 17 cases, while 13 parents reported problem of arranging money, adjusting time for long travelling and regular follow-up.

**Conclusion:** The findings can be utilized in developing supportive activities for families with disabled children. It addresses the need for new prospective of stigma reduction in our society. The study has found that the care givers of child with NDDs suffer from significant physical and mental stress, and their health should be taken into consideration. The study has found need of "care givers` support group". The professionals can help parents in establishing positive thinking towards care giving. There is need of provision of comprehensive and latest rehabilitation/ support resources & information.

**Keywords:** Child, Family life, Knowledge, Mental stress, Neurodisability, Parents

## INTRODUCTION

The term Neuro Developmental Disorder (NDD) is an umbrella term for any condition that is caused by a dysfunction in part of the brain or nervous system, resulting in physical and/or psychological symptoms as a child develops. A huge range of conditions fall under this heading. Some of the most common are Autistic Spectrum Disorders (ASDs), Attention Deficit Hyperactivity Disorder (ADHD), traumatic brain injury, brain tumour, communication disorders and cerebral palsy, as well as a vast range of genetic conditions such as Fragile X syndrome and Down syndrome.

The World Health Organization estimates that about 10% of the world's population has some form of disability. Statistics from different sources indicate that in India, 3.8% of the population has some form of disability [1]. Thus, the problem of disability should be looked into seriously in India.

Despite the well documented needs of children with disabilities and their families, gaps in essential services and supports remain. These needs are even more extreme in low-income families [2]. Parents

consistently report an urgent, unmet need for respite care, care giving support, household assistance and accessible child care. Approximately 50% of children with a disability require some form of assistive technology (i.e., lifts, hand or arm brace, hearing aids or wheelchairs) and just over half of these children do not have all the specialized aids they need. One in four school-aged children with a disability has an unmet need for special education services or educational aids, and at least 16% have unmet needs for health care services. In 2001, nearly two in five school-aged children with disabilities were unable to participate in social or recreational activities in their community [2]. Focus on creating positive outcomes for all children, which, from a determinant of health perspective means health gains are only possible if a child and family's basic needs for well-living are met first.

A report recently issued by United Nations International Children's Emergency Fund (UNICEF), finds that while all children are at risk of being victims of violence, disabled children have significantly increased risk because of stigma, negative traditional beliefs and ignorance. Lack of social support, limited opportunities for

education, employment or participation in the community further isolates disabled children and their families, leading to increased levels of stress and hardship [3]. This study summarizes the needs of children and youth with disabilities and their families, including specific factors contributing to available program and policy successes or failure.

## MATERIALS AND METHODS

This cross-sectional observation study was carried out at Sant Dnyaneshwar Medical Education and Research Centre Pune from Pune and nearby villages (aale phata, ambegaon, kothrud, akurdi and kamshet) and was approved by the institutional ethics committee. Written consent was taken from all the parents participating in the study. There were no selection criteria all patients coming to Neurodevelopmental OPD were enrolled after consent irrespective of field of origin. Parents who did not give consent and parents of Children with disabilities other than NDDs were excluded from the study. We had enrolled consecutive children with NDD regularly coming for follow-up at the neurodevelopmental OPD during study period of June 2012 to Dec 2012. Such cases were 30 during this time period so our sample size was 30.

Participants were assessed using a questionnaire with the following information as follows (Appendix I):

**Section A:** Preliminary information about parents and child with NDDs

**Section B:** Socio-demographic profile of the family.

**Section C:** Parental perceptions on health and social needs of their child having NDDs.

Parents were explained about the study and given the questionnaires to fill (assistance was provided in case of language problem, inability to write or inability to read/understand questions). Incomplete data was completed on follow-up visit in few cases.

## Data analysis

Answers given by all 30 parents were compiled and parental perceptions were tabulated; proportions and percentages were calculated among the groups [4-13].

## RESULTS

Thirty parents of children with Neurodevelopmental disabilities participated in the study over a period of 6 months. Parents of children with NDDs were recruited from follow-up cases coming to Neurodevelopmental OPD. Parents were explained and given the questionnaires to fill and data collected was analysed and results were prepared. There were total 30 patients, out of which 17 were males and 13 were females. Amongst all 30 patients 9 were below one year of age, 19 were between 1 to 5 year and 2 were above 5 years of age. The youngest child with NDD was eight-month-old and the oldest child was seven-year-old [Table/Fig-1]. Maximum number of patients suffered from Cerebral Palsy and minimum with Autism in our study. There were 2 cases of multiple disabilities one was case of Tuberous sclerosis with Hydrocephalus with spastic Cerebral Palsy and second was case of Developmental Delay with CTEV [Table/Fig-2] [5]. According to modified Kuppuswamy's socioeconomic scale, the population was divided as in [Table/Fig-3]. The results of the interview are tabulated in [Table/Fig-4].

## DISCUSSION

This study was regarding parental perceptions on health & social needs of children with NDD and its impact on the family. The WHO World Report on Disability recommended that increased research is required on the type & quality of rehabilitation services available as well as unmet needs and barriers faced, incorporating user and health care provider view [4]. With this study parental experiences and perceptions have been explored.

In our study 56.67% patients were male, maximum number of patients (63.3%) were in the age group between 1 to 5 years of age & Cerebral Palsy (43.33%) was the most common NDD followed by Global Developmental Delay (23.33%).

In study done by Joneja M et al., who studied profile of children from child development clinic in north India they found 66% of patients were male, their mean age of referral being  $54.06 \pm 44.4$  months & 68.64% patients had GDD 26.2% cases had CP [7].

In our study maximum parents came to know about NDD in their child between 12 months to 18 months. In study done by Joneja M et al., who studied on time of referral of children with Neurodisability and they found 62.8% of children were referred before three years of age and remaining presented at or after 3 years of age [8].

In maximum number of patients (22 cases) diagnosis was suspected by General Practitioners and parents were told to consult higher centres for further management of child. Remaining 8 cases were diagnosed by Developmental neurologists & Pediatricians while following in High risk newborn OPD.

In a study done by Shimpi A et al., about awareness of role of physiotherapy in patients with disability and handicap in the 'E' Ward of BMC (Brinhanmumbai Municipal Corporation). There was a significant awareness of Physiotherapy and its various functions (150 out of 196) with a the high number of written informed references (172 out of 196) amongst the referring doctors. However, this study included adults also [9].

Presence of child with NDD affects all the family members. We found that the mother's health and life was most affected. Most of the mothers had to complete all household work and also to assist child with activities of daily living. She was over worked. Six mothers had to quit their job. Active participation of father and other siblings was less in the child care, as fathers were working and could spend less time with child.

In study done by Yeung et al., they observed that in the population of families with typically developing children fathers remain less involved than mothers and that relative difference remains same across the development [10].

Age (years)	Number of patients (Percentage)
<1	9 (30%)
1 to 5	19 (63.33%)
>5	2 (6.67%)
Total	30 (100%)

[Table/Fig-1]: Distribution of patients with NDDs with respect to age (years).

Type of NDDs	Number of patients(Percentage)
Cerebral Palsy	13 (43.33%)
Global Developmental delay	7 (23.33%)
Hearing impairment	2 (6.67%)
ADHD	2 (6.67%)
Autism	1 (3.33%)
Multiple disabilities	2 (6.67%)
Total	30 (100%)

[Table/Fig-2]: Distribution of patients with respect to type of NDDs [5].

Socioeconomic class	Number of patients (Percentage)
Lower	11 (36.67%)
Upper lower	8 (27.78%)
Lower middle	9 (30%)
Upper middle	2 (6.67%)
Upper	0 (0.0)
Total	30 (100%)

[Table/Fig-3]: Distribution of patients with respect to socio economic class.

Sr. No	Questions	Answers/Perceptions	
		In most of the cases	Others
1	Age of diagnosis of NDD	12-18 Months (21 cases)	Before 1 year (9cases)
2	Person diagnosing NDD	General Practitioner (22 cases)	Developmental Neurologist/ paediatrician (8cases)
3	Most common disability parents are worried for	Inability to walk	a) Inability to attend schools with other children. b) Inability to play with other children. c) Inability to express their needs due to either speech problem or other disability.
4	Patients requiring assistance for daily care (bathing, feeding, combing hair, dressing etc.,)	Yes (18 cases)	Able to manage with minimal assistance (i.e., they were able to feed themselves with spilling when food was served, could assist in dressing, could go to toilet without help)
5	Common difficulties countered in daily care	Feeding and bathing (10 cases)	Dressing and undressing was difficult in few cases due to spasticity.
6	Special needs a. Care at home	i) Preparing and giving food ii) Doing exercises taught by physiotherapist.	
	b. Medical	i) Administering medications to the child (anti-convulsants, multivitamins and calcium) ii) Regular follow-up for physiotherapy	
	c. Education	Yes, all parents said education is important but none of the needy children were going to special school. (due to unavailability of such services in nearby area, unaffordability or due to recurrent illness of the child in few cases). Only 2 children were given assistance with tuition & Psychologist. (cases of ADHD)	
7	a. Knowledge	Yes (20 cases). But half of them were aware that such schools are there but didn't know which place such facilities are available.	Didn't have any idea about such facilities available anywhere. (10 cases)
	b. Attending special schools	None	
8	Educational plans	No, 22 parents said they have no plans for the future studies but wish that at least child learns to read & write.	Some parents (8 cases) wanted their children to study at least 10 <sup>th</sup> standard with help of some tuitions, So that child becomes self dependent.
9	Is Integration in society possible??	Yes. (23cases)	No. (7cases) (due to stigma & discrimination)
10	Behaviour of neighbours & relatives	Supportive & encouraging (20 cases)	Discrimination (4cases) (Few neighbours did not allow their child to mix and play with child with NDD considering it will affect the health of their child)
11	Attending social gatherings and family functions	Was possible in half cases. (15 cases)	i) 7 parents avoided attending social gatherings or left child alone at home with fear of social stigma and discrimination. ii) 8 parents avoided attending family functions as care of child becomes more difficult at such places.
12	Did parents face discrimination in the society?	Yes. (Most of the parents had faced with discrimination at sometime or other in the society though neighbour & close relatives were supportive in many cases)	
13	How did they overcome the discrimination?	With help of spiritual power (doing prayers and pooja) many parents (25 cases) got courage to face the difficulties and to overcome discrimination.	Counselling sessions were useful in few cases. (5cases) Two parents required antidepressants.
14	Impact on the family a. Mother	i. Over worked with child care, as have to do maximum household work too. ii. Increase physical and mental stress.	
	b. Father	i. Increase burden and stress as expenditure for child care and treatment increased due to NDD. ii. Two fathers needed antidepressants. iii. In five cases counseling sessions were found useful.	
	c. Sibling	i. Parents concentrated more for affected child so in few families other siblings were neglected (9 cases). * ii. Due to increase parental stress and expenditure for treatment of affected child other siblings had less freedom and financial support for education and other things (5 cases).	
15	Special changes in the family lifestyle to meet the various needs of child with NDD	a. Mother had to quit her job so as to concentrate and give more time to child. (6 cases) b. Fathers had increase burden of work as expenses increased (12 cases) c. Many parents got strength & courage with pooja and prayers (25 cases) d. Family outings and visits to other relatives decreased. (10 cases) e. Use of wheelchair for travelling with child. (3cases) f. Taking child to garden on weekends so child feels better. (5cases)	
16	Source of information regarding neurodevelopmental clinics, special school and NGOs working for children with NDD	a. Media (Television) 14 cases b. Internet(for educated parents) 4cases	General practitioners/ paediatricians 12 cases
17	Availability of services in nearby area (physiotherapy, special schools, educators & psychologist)	No (22 cases)	Yes (8 cases) (Had physiotherapy facility in nearby areas - 5 cases were attending)
18	Frequency of follow-up	Two weekly (20 cases)	Every week (7cases) Every month (3cases)
19	Services found Most useful	Physiotherapy (11 cases) And counselling sessions (5 cases)	Play therapy. (4 cases)
20	Experience with services provided	Satisfactory (17 cases)	Problem of arranging money, adjusting time for long travelling and regular follow-up (13 cases)
21	Rating of facilities in the centre at SDMER for children with NDD (out of 5)	a. Availability- Mean score= 4, N=30 b. Affordability- Mean score= 4, N=30 c. Acceptability- Mean score= 5, N=30	
22	Parental suggestions to improve present status of facilities for children with NDD	a. There should be special health care centers for children with NDD in government hospitals (13 cases). b. There should be provision of facility for special education of such children in government schools (4 cases). c. Families of children with NDD should get financial assistance from government. (9 cases). d. Like other health camps, government should organize health and awareness camps for children with NDD in remote areas and villages to remove stigma and discrimination from society (5 cases). e. The cost of health care facilities for such children should be subsidized in private hospitals for poor patients (9 cases).	

**[Table/Fig-4]:** Information on Parental perceptions collected during interview is described above.

\* Total 16 families had more than one child. Nine parents felt that they had ignored the health and social need of the normal child at some time or other. Five fathers said that due to increased expenditure on treatment & care of affected child they could not give that much financial support for the other child's education, but none of them discontinued schooling or education of child for such reasons. We could talk to 5 of unaffected children of all 16 cases, 3 children felt that they were neglected as parents were busy caring for the other child & they felt bad about it.

There was even impairment of quality of life of older siblings in one third cases. This was in accordance with study conducted by Rana P et al., who found quality of life of unaffected siblings of neurologically affected siblings of children with chronic neurological disorder was significantly impaired [11].

In the studies conducted by Faculty of Health Sciences, Institute for Applied Health Sciences, McMaster University, Hamilton, it was found that parents' well-being is significantly impaired compared with that of matched adults. However, this study only dealt with parents of children with Cerebral Palsy [12].

Most of the parents had faced social stigma and discrimination at sometime or other. Coping with discrimination and stigma was one issue where in maximum number of cases it was spiritual power and beliefs which helped parents to overcome the stress. Two parents were on antidepressants and needed psychiatry consultation.

In the study done by Khana A et al., regarding social, psychological and financial burden on care givers of children with chronic illness, 37% parents reported mild depressive symptoms, 38% reported moderate depressive symptoms. Also, mild anxiety symptoms were reported in 50% cases while 17% had severe anxiety symptoms. Disruption of routine life as well as significant higher social and financial burden was seen in care givers of Cerebral Palsy patients. These findings are consistent with our study [13].

In the study done by Baker BL et al., it was found that relative to comparison group of parents of typically developing preschool-age children, parents of children with IDD were more detached, more negative and less positive [14].

In our experience with services provided was satisfactory in 17 cases, while 13 parents reported problem of arranging money, adjusting time for long travelling and regular follow-up.

When compared with the study by Juneja M et al., on parental experience from referral centre in developing country 29.8% had difficulty in bringing the child to CDC due to travelling long distances, they faced hardship in carrying the child and lose their day's earning apart from spending time and money for their child's therapy [4].

## LIMITATION

The duration since the diagnosis of NDD might affect the parental perceptions but it was not considered for the enrollment of the subjects in our study.

## CONCLUSION

NDD in child has significant influence on the family in terms of emotional, financial, educational and social issues. It also affects the care of other siblings in the family. General Practitioners (GPs) are first point of contact in maximum number of cases. Therefore, training GPs with counselling and referral as per need of child will help in better management of child. Diagnosis gets delayed in most of the cases. Awareness within the society and training of health care professionals in the management of such children will decrease burden of disease and help in improving their outcome by means of early and timely interventions. More awareness should be created in the society to remove the stigma and discrimination from society. Effective counselling and emphasizing on the involvement of other family members in Child care so burden on mother decreases and care of child improves.

There should be financial support provided to families with disabled child, so parents can concentrate on care of child. Though services are available, but they are not utilized as they should be. Hence, making services more accessible and affordable will improve the utility of services and will be helpful in improving outcome of children with NDDs.

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## APPENDIX I

Questionnaire used for the interview

### Parental perceptions

1. When (at what age of the child) & how did you come to know that (name of the child) has NDD?
2. Who diagnosed (name of the child) as having NDD? (Type of health facility & health personnel)
3. What deficiencies do you observe in (name of the child)?
4. What are the various activities in which (name of the child) require your help?
5. What difficulties do you face in the daily care of (name of the child)?
6. What are the special needs of (name of the child)?  
Care at home  
Medical care  
Education  
Any other
7. Does (name of the child) attend any special school?  
If yes, has he/she benefitted from it? How, please specify.
8. How much and what type of education or training do you plan for your child in future?
9. Do you think children with NDD like (name of the child) can be integrated into mainstream society? If yes, how? If no, why?
10. How do the neighbours & relatives behave with (name of the child)?
11. Do you involve (name of the child) in social activities like marriage, family get-together's etc.? If yes, how? If no, why?
12. Have you ever faced any discrimination/stigma (in the community, social gatherings, workplace etc..) due to the presence of (name of the child) in your family? If yes, please specify
13. How do you cope with this discrimination/stigma?
14. What impact has the presence of (name of the child) had on you & your family?  
Interference with family routine  
Relationship among members  
Emotional  
Financial  
Educational  
Any other
15. What are the special changes/adjustments that your family has had to make to meet the various needs of (name of the child)? e.g., In daily life routine, social, economic etc..)
16. How did you come to know of these facilities/services/support systems? (Source of information)
17. What facilities for NDD children are available in your area? (Special schools, special health care facility, day care facility etc..)

18. At present, are you availing any of the above mentioned facilities for (name of the child)? If no, why?
19. If yes, please specify what facilities/services? Do you think that these services have benefitted (name of the child)? If yes, how?
20. What has your experience in availing these services? Are you satisfied with the quality of these services? Please specify.
21. How will you rate the present available with respect to availability, affordability, acceptability & the actual impact they have on the lives of NDD children & their families?
22. What are your suggestions to improve the present status of facilities for NDD children & their families?

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Date of Submission: **Jul 03, 2016**

Date of Peer Review: **Aug 18, 2016**

Date of Acceptance: **Sep 19, 2016**

Date of Publishing: **Dec 01, 2016**

**FINANCIAL OR OTHER COMPETING INTERESTS:** None.