

PARENTAL PERCEPTIONS ON HEALTH & SOCIAL NEEDS OF CHILDREN WITH NEURO-DEVELOPMENTAL DISABILITIES

Ashikabanu Mujibur Rahman ¹ and Lal Devayani Vasudevan Nair ²

¹ Paediatric Postgraduate, Saveetha Medical College and Hospital,
Thandalam, Kanchipuram, India.

² Professor, Child Development Centre, Saveetha Medical College And Hospital,
Thandalam, Kanchipuram, India.

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Abstract

INTRODUCTION: The Special needs of children result in a considerable load- physical, monetary, and mental to the parents. The health and social needs of children have been studied in the past, but how a parent perceives such needs has not been pondered much. With the considerable increase in children with Neurodevelopmental disabilities (NDD), there is a need for such information; hence this study.

AIMS AND OBJECTIVES: The study aims to analyse the parental perception of health and social needs, awareness of the availability of social support initiatives and their utilization by families, and the impact of disability on families.

MATERIALS AND METHODOLOGY: This multicentre study was conducted at 3 units of Vistara CDC and Saveetha CDC, Saveetha Medical College. Considering the paucity of data, it was decided to do a qualitative study with a semi-structured questionnaire as the main tool. The interview was transcribed and thematic content analysis was done.

RESULT: There was considerable pressure on the parents along with social and familial problems. The special needs care was neither sufficient nor qualitatively good in most places. Lack of awareness of support and the importance of early assessment were glaring. The skills affected in each child, difficulties in rearing a special needs child, and response of other family members and society were studied. The impact of having such a child on the family and also it has on relationships within the family been found to be profound. Families were not supportive of care. **CONCLUSION:** Challenges faced by parents in spite of support offered at governmental level is high and support systems are inadequate to attend to the needs. Drastic changes are needed at the policy level and implementation level at institutions as well as families. There should be greater support for families caring for young children with NDDs, improving the process of service delivery and services itself. Regulation of NGOs and therapy centers to offer quality services, reducing the financial burden on families, and integrated therapies under the supervision of qualified personnel are some of the recommendations that came out of this study.

Keywords: Special Needs, Neurodevelopment Disorders, Child Development, Social Problem, Family Problem.

INTRODUCTION

'Neuro-Developmental Disabilities' (NDD) brings together under one label a group of related, clinically distinct, chronic disorders that share a documented disturbance either quantitative or qualitative or both in developmental progress in one or more recognized developmental domains compared with established norms (1). These domains traditionally include motor (gross motor or fine), speech/language, cognition, personal/social, and activities of daily living. The following conditions are included under the rubric of Neuro-Developmental Disability: Cerebral Palsy (CP), Learning Disability (LD), Hearing Impairment, Epilepsy, Intellectual Disability or Mental Retardation (ID/MR), attention deficit hyperactivity disorder (ADHD), Autism or Autistic Spectrum Disorder, Visual Impairment, Speech / Language and Neuromuscular disorder (2). Despite the well-documented needs of children with disabilities and their families, gaps in essential services and supports remain. These needs will be even more acute in low-income families.

Providing for the physical, social, emotional, and developmental needs of a child with a disability can be overwhelming for families, particularly in the absence of adequate resources and social support. The caregiving demands of these parents have been shown to directly and negatively impact both their psychological well-being and physical health (Arasu s 2021).

Caregivers (principally mothers) have reported spending between 50-60 hours per week, above and beyond household responsibilities and paid work, on personal care, advocacy, coordination of services, and transportation for their child with a disability. (Gardiner E,2016) In addition, parents often work to create peer relationships for their children, lobby for needed services and support, and work to ensure their child's acceptance and participation in the community. Such demands often result in exhaustion and create undue hardships for caregivers, particularly mothers.

In India where education of the nondisabled is a challenge to achieve, the education scenario for the disabled children reflects a rather grim picture. The situation of special schools in India is quite appalling.

MATERIALS AND METHODS

The study aimed to explore the parental perception of social and health needs of NDD children and its impact on the family.

Design of Study:

This multi-centric qualitative exploratory study was conducted in the Department of Paediatrics, Saveetha Medical College, and 3 different units of Vistara child development centres in Chennai, Tamil Nadu from May 2022- May 2023.

Objectives: The main research areas and objectives were: a) to explore the parental perception of social and health needs of Neuro-Developmentally Disabled children. b). to explore parental perception of the availability of services for children with Neuro-Developmentally Disabled children. c). to find out the utilization of services by the families to decrease the morbidity due to Neuro-Developmental Disability. d). to understand the impact of disability on families having children with Neuro-Developmental disability.

Recruitment:

Sensitization of parents with special needs was made with IEC materials. Parental perspectives were taken and were allowed to voluntarily decide on participation before getting Informed consent from them. The sources of study population were the three different locations- Saveetha Medical College, and 3 branches of Vistara CDC. Only 166 participants participated in the study after giving consent. The inclusion criteria were children having NDD with at least a family member or parent/s involved in the care of that child; willingness to give consent and participate, and ability to express in English, Hindi, or Tamil language.

Sampling method: Parents of children with NDD were selected by non-probability, convenience sampling method. By this qualitative study, in-depth information about the varying health and social needs of children with special needs as perceived by parents was analysed.

Tools:

Parents of children with NDD were interviewed using semi-structured questionnaires, mini-focus group discussions, and investigators' journals. The questionnaire was developed by the principal investigator in consultation with a qualitative expert consultant. It had information about 4 aspects of respondents- condition of Neuro-Developmental Disability, information about the parents regarding parental perception of social & health needs, availability of services for children with disability and their utilization by families.

The Procedure of Data Collection:

The interviews were held privately and separately in English and the local language, to get their independent unbiased perspective and to avoid influence from other family members. Data collected each day were analysed. The voice recordings were done and for others go for it data in written and signature was obtained. The participants were allowed to describe their feelings in their language without any leading questions, though some clarifications were given when requested for clarification of the meaning of some questions.

Mini Focus Group discussions with parents were conducted when children were undergoing group therapy sessions in the centres. We had 3 distinct groups- autism & communication problem group, Cerebral palsy & multiple disability group, and learning disability & ADHD group. Parents were encouraged to share their experiences and asked to suggest or reflect on similar situations for themselves. The mean duration of the focus groups was 75 minutes (range: 60-90minutes). The mean number of participants in the focus groups was 16

The principal investigator kept a research journal throughout the data collection and analysis process which helped the principal investigator to recall what participants said in the interviews during the analysis process and identify any distractions or comments the principal investigator felt were important findings.

Data Analysis: The text was analysed using thematic content analysis (TCA) as described by Polit & Beck. The research questions guided the data analysis. The qualitative data were tabulated and converted into the master chart to show how common a certain phenomenon appeared to be. Multiple copies of the interview transcript relevant and stipulated according to the semi-structured interview were made in Microsoft Word format. Relevant portions of words, phrases, and sentences/s in the transcripts were labelled (coding done). A few of these codes that looked common were grouped (Categorized). The connections of the categories, if any, were analysed to distinguish each broad category(theme) and sub-category(subtheme).

RESULTS

The analyses of the data yielded two major themes as the notable challenges faced by parents- a) those related to the Child's NDD and b) those impacting family. Under the broad theme of 'About NDD', the major subthemes were meeting care needs, medical needs, educational needs, and socioeconomic needs. Under the next major theme- 'impact on family' were the subthemes- interference in family routine, interference in relationships, emotional needs, financial needs, Adaptation needs, and perception of special needs facilities.

Qualitative data analysis was conducted and results are reported according to each of the twenty-three questions posed in the interview and based on the final coding and categorization. The socio-demographic data on the subjects are given below. (Table 1).

Table 1: Sociodemographic Characteristics (Personal Characteristics)

Variables	Response	Parents	Relatives
Sex	Female	100	
	Male	64	2
Age(years)	18-34	81F,49M	
	>34	19F,15M	2
Education	Up to 5 th / informally educated	10F, 8M	1
	6-10 th	20F,15M	
	10-12	34F,15M	
	Degree & above	37F, 25M	1
	Professional	2M	
	Other	-	
Religion	Hindu	77	
	Muslim	42	
	Christian	46	
	Jain	1	
Occupation	Unemployed	0	
	Day labourer or unskilled	16	
	Skilled worker	36	
	self-employed (doctor, tailor etc)	54	
	Business	20	
	Service private/government	40	
	Refuse to answer	0	
Family	Nuclear / Joint	57 / 9	
NDD in family		5	

Of the one sixty-six participants, two were grandparents. Fifty-four participants were self-employed, 15 were businessmen, and forty were in the service sector like the teachers, salesmen, etc. Sixteen were skilled and six were unskilled workers. Most of the respondents (n=130; 78%) were 18-34 years old. 35(21%) were educated till 6-10th and 62(39%) had degrees and above, 49 (28%) were of 10-12th standard & 18(9%) were up to 5th or informally educated & rest 2(1.5%) were professional.

Analysis of the themes: 2 major themes (categories) evolved- 'About the NDD' and 'Impact on the family'. The major NDDs detected and personal characteristics were tabulated percentage-wise below. (Table2 &3)

Table 2: NDD among Children- as Perceived by Parents

Type of Neuro-Developmental Disability NDD	Number of Children (n=166)	Percentage
Cerebral palsy/motor delays	35	21
Intellectual disability	18	10.8
Autistic spectrum Disorders	35	21
Attention deficit hyperactivity disorder	32	19
Learning disability	23	13.6
Hearing impairment	8	3
Vision impairment	-	-
Neuromuscular disorder	-	-
Epilepsy	10	6
Multiple disability	5	3

Table 3: Personal Characteristic of Children with Neurodevelopmental Disability

Variables	Parameter	No. children with NDD
Sex	F	64
	M	102
Age	0-6 m	0
	7-12 m	2
	13-36 m	50
	37 m- 5 yrs.	92
	6-10 yrs.	12
	11-15 yrs.	7
	16-20 yrs.	3
Age at diagnosis of NDD	0-6 m	12
	7-12 m	46
	13-36 m	64
	37 m- 5 yrs.	32
	6-10 yrs.	8
	11-15 yrs.	3
NDD in sibling	0-6 m	-
	7-12 m	2
	13-36 m	75
	37 m- 5 yrs.	56
	6-10 yrs.	34
	11-15 yrs.	1
Birth order of child	16-20 yrs.	0
	1	75
	2	56
	3	34
	4 th	1
	5 th or more	0

Eighty-one percent of children were below the age of five years i.e. below school age. The onset of Neuro-Developmental Disability as reported by participants was before 3 years.

Parental Perceptions:

A) About NDD:

Table 4

CATEGORY		n		%	
1. TRAINING AND MEETING NEEDS					
A. CARE AT HOME(n=40)					
CP/motor impairment/multiple disabilities (feeding methods and modification of utensils)		36		90%	
Immobilization of joints/ positioning limbs		17		42%	
Try various training methods for swallowing		21		51.5%	
Felt it good for their children to be thin to handle and not feed properly		27		67.6%	
Expenditure for nappies as high/ unnecessary		8		21.2%	
Found taxing to have NDD child at home		25		62%	
B. EDUCATIONAL NEEDS					
		<5 years N=142	%ge	>5 yrs. N=24	%ge
School	Special	24	16.6	14	58.3
	Normal	39	27.3	10	41.6
Education- expensive		49	34.8	19	79
Issues in education even in normal school		120	84.8	22	91.6
Pre academic deficiencies	Pre verbal	119	84.1	5	20.8
	Pre-reading	100	70.5	12	50
	Pre-writing	90	63.6	16	66.6
	Pre-maths	129	90.9	17	70.8
C. MEDICAL NEEDS					
Continue therapies for long		101		61	
Want to stop medicines		21/33		63.6% of those taking medicines	
Loss session because of financial issues		44		26.5	
Thought of experience in quality of therapy services		57		35.3	

Felt therapies offered by unqualified people	7	4.2
Tried with unproven interventions	15	9
D. SOCIOECONOMIC NEEDS		
Disability benefits from the government	6	3.6%

Deficiencies & Difficulties: The main deficiencies the parent noticed were poor hand functions, locomotor problems, hyperactivity & inattention, speech and socialization problems, feeding problems, activities of daily living problems, and unusual behaviors. It was found that most had ADL limitations. Many (n=25;62%) felt that their life was difficult due to the presence of a child with NDD at home. They felt it was ruined by one or more of the following reasons - the need to give more time to NDD children resulting in inadequate attention to other children at home, interference in educational support of other children as significant financial resources and time redirected for special needs, significant financial constraint due to logistic reasons like travel, expenses incurred on house rent as they are displaced due to lack of therapy support at home towns, nonavailability of family support since displaced from the familial environment to meet special needs, deficiency of quality time for recreation with other family members. Some mothers found it difficult to meet the demands of other children in the family. Parents, especially those with Autism or ADHD children at home, were the most affected in this group, as they found it so difficult to manage/ help siblings with their homework and other activities. Most felt that studies of other children at home were disrupted. Another difficulty was the "weird behavior" of NDD children in public places especially in noisy environments or crowded places. Except for cerebral palsy and learning disability groups, most of the parents experienced this problem, more so while taking too crowded places like grocery shops. Many (n=34/166; 21%) were hiding the problem of their children and were initially unwilling to accept the presence of NDD resulting in delayed initiations of interventions (n=43/166; 26%) affecting prognosis detrimentally. (Table 3)

Impact of Deficiencies in Social Activities and Behavior:

Deficiencies in social activities and behavior fell under 2 subthemes - Avoidance and Self restrictions.

Avoidance by others- Few (n=6) found that they were set aside in some social gatherings like marriage for fear of jeopardizing the new relationship.

Self-restriction on social activities- Many (n=46/67) especially those with Autism, and ADHD self-restricted from attending the functions as they had no one to take care of the child nor could they take the "out of synch child" to the function. However, those with CP children(n=35) genuinely felt it difficult to attend social functions because of both physical and mental stress.

Avoiding other children from playing with NDDs- Many had experienced (n=32/166) distant relatives and others preventing their kids from playing with NDD children on at least one occasion in their life so far. Though the majority of the participants did not share this view, many felt that others were a little inconvenienced by the presence of their child along with their children as they feared- "it may not be safe- may injure" etc. The most surprising finding was that even among parents with children having NDD, 9 of the respondents, had reservations about combined therapy sessions in centers, especially parents of mild autistic children, as they feared that they may mimic the activities and behaviors of other "mentally retarded children".

Stigma or discrimination: Most of the parents experienced that (n=38/166; 23%) they felt social stigma at times while the rest did not experience any stigma. Some of the neighbors were found to be accommodating in stressful situations and induced a positive attitude. Social support seems to be better off with self-employed (n=12/54) and skilled worker (n=8/36) groups giving favorable responses regarding a non-stigmatizing response in social settings.

Special Schools & Integration Plans:

38 (23%) parents knew about special schools but most felt that services were not as expected. 26 (16%) parents felt that children coming to special schools were so “down” that they felt their child also would become mentally down. 35 delayed putting their children to school as they feared that once in a special school, they would always be in a special school. Almost all did not like mixing up children with all NDD together as they felt their child also may develop some mannerisms and behavior of an “extremely retarded child”.

Most felt that special schools are cost-effective when compared to individual therapy centers. However, they felt that integration into mainstream schools was a distant possibility, especially those going to special schools (n=11/). However, 34/39 (87%) of parents of those who have not attended special schools and are young (< 5 years) and attending only therapy sessions in centers were satisfied that their child may get integrated into normal school.

Most parents of ADHD and Autism groups had a significant problem in managing crowded areas. Many parents had unrealistic expectations about the future of their children.

Concern for the future: All Parents were concerned about the future development of their children in terms of education and security. Most of them felt the need to somehow train them to lead a self-sustained life. Parents (n=16) of these children especially CP children (n=35) were more concerned about motor development than mental development.

Socioeconomic needs: The support of the families from different stakeholders and services were assessed. Most of the participants (108/166) said they were not receiving any support from the government. But the good thing was that many were getting support from family, friends, relatives & neighborhood. Only less than 10 %(n=16) were availing of disability benefits from the government. None of the places they visited had advised them regarding the disability benefits.

Table 5: Impact on family

2. MAJOR IMPACT ON FAMILY		n	%
A. INTERFERENCE WITH FAMILY ROUTINE			
● Stay at home; not affected their routine		58	35
● Joint family(n=9) ('somebody at home will take care'); does not affect their routine.		7	-
● Stay away from home to raise money (especially males)		10	6
B. RELATIONSHIP AMONG FAMILY MEMBERS			
Interference in married life	Affect their marital & sexual life	51	30.7
	Separated in same room	12	7.2
Fear of separation and desertion	Abdication of responsibility more in higher education/ businessman	15	9
	Fear of separation from pair	8	5

	Already separated	3	0.45
C. EMOTIONAL NEEDS			
Unconcerned Males		21	12.6
Confrontation and fights due to high emotions		35	21
Little and family support		26	15.6
Job related & displaced homes		30	18.7
Relocating homes for rehabilitation of child		15	9
D. EDUCATIONAL NEEDS			
School	Normal school/preschool	39	23.5
	Special school	24	14.5
	Not school going (<5 yrs.)	103	63.0
E. FINANCIAL NEEDS- (those who felt the need to seek)			
Type of work	Engineer/professional	29	43.4
	Daily workers	5	3.5
E. CHANGES/ADJUSTMENTS NEEDS			
Staying back at home		32	19
Moved to metro		12	7.2
Resigned their jobs		7	4
3. PERCEPTION OF SPECIAL NEEDS FACILITY			
Aware of facilities available near them		149	90%
Parents were utilizing the available facility		33	20%
Lack of awareness of qualified personnel		58	35%
Suspicious Parents-on the qualifications & skill level of therapists; but are unwilling to expose fearing repercussions on their child's services.		33	20%
Need for more integration among the different therapists as they found many contradictions in explanations given to them on the same topic of interest.		83	50%

Parental Suggestion for Improvement of Facilities:

Health Care Services:

Most of the respondents (n=69) felt that medical care was available but costly or not timely. Hence when needed at stressful times (e.g.: when a seizure) they find it difficult to reach healthcare facilities in time often needing prolonged hospitalization. The cost of investigation and hospital stay is another factor that is affecting them as otherwise it could be used productively for the future of the child –in training or creating assets. Though 46 parents admitted to the need for private therapy services at home or the center level, only 26 parents admitted to the idea of getting services from DEICs as they fear being labeled as disabled. 10 felt that enrolment in government setup will attract labeling as disabled which they do not approve. However, all were in for their child's services being covered under insurance, which is not the scenario currently.

Special Needs Services:

Standardization of services: Many parents(n=45) felt the need to have standardization of therapy services offered by centers as many had unguided personnel.

Limitations of NGOs: There should be coordination in the distribution of services provided by government, non-governmental organizations, and international organizations working in the field, special schools, private institutions, and persons on a humanitarian basis.

Need for Quality guidance for special needs clinics:

- a) 45 parents felt the need to integrate the different therapies under one domain and be supervised in hospital settings by trained medical specialists to guide in interventions.
- b) 75% reported that uncontrolled proliferation of centers run by small groups of therapists should be discouraged or should be mandatorily monitored by trained medical professionals.
- c) 10% felt the use of technology in special needs services should be encouraged
- d) Child development problems should be seen as more as a medical problem (brain development / physical problem) and not as a charity or social problem.
- e) To minimize the expenditure, therapists should be trained in all developmental aspects. 12% believe that a single therapist should be trained in all basic aspects of child development and interventions to manage children in their early years. A child's development has to be seen holistically and not individually deficit-wise. Many (n=24) parents say that they do not need sympathy, but only empathy and some consideration.

Awareness - for Families:

- a) Families should be made aware of existing facilities and be encouraged to use them. In the present study as only a very few (<20%) parents were utilizing the available facility (reason- poor knowledge and awareness of special services and nonspecific referral).
- b) Community participation in NDD programs was found to be abysmal (<5%).

Awareness & responsibilities – for doctors:

- A) 100% of parents opined that Primary care/ pediatricians should be given the responsibility of monitoring the child's progress and hence should be trained.
- B) All parents concurred on the fact that Parental training regarding how to manage at home rather than the theoretical basis of diseases.
- C) 40% (n=66) said that Pediatricians and health care providers should stress on timely and proper guidance by giving time from their busy practices, to contribute to decreasing morbidity because of Neuro-Developmental disability.

DISCUSSION

The results showed that parents had main concerns in basic needs like care at home, medical care, and education; and for that, many families need socio-economic support. Other less common challenges faced by families were concern for the future and stigma. The major special needs which the parents felt were –poor hand functions, poor sitting tolerance(hyperactivity), locomotor problems, feeding problems, socialization and language issues, lack of ADL skills, and behavioral issues. In similar studies, the special needs burden is found to be greater than for chronic diseases. And it depends on the type of disability, more for the physical disability. (3-4) Many felt their life was made more difficult by the presence of NDD children and most readily submitted to it.

There is a great need for support from the community & society with the majority from the middle-income group of which 30% studied 10-12th standard and were skilled laborers and 37.5% were self-employed. This is in tune with the Neurodevelopmental disabilities study by INCLIN which states that NDDs in children, especially between 2-9 years, should be considered a significant problem especially among the low and middle-income groups as almost one in eight children of the age 2–9 years have at least one of the nine NDDs (5)

Women outnumbered men as caregivers in the present study. This is in agreement with Sharma et al, (6) who found that the participation of men was less than women in providing care to their differently abled children. In India traditionally it is the women who take responsibility for household activities and look after children which is also observed in this study.

This did not change even in the case of special needs kids, only about fourteen percent of participants in this study claimed that they had perceived the presence of Neurodevelopmental disability in their family positively. This perception has repercussions on the management of the child unlike in the study of Gardiner 2018 (7). A recent study has shown that very often parents have a negative attitude towards their children with disabilities (8).

The present study is no different in which 57/66(83%) respondents felt the same. The cause of the NDD in their children was not clearly understood by most respondents. This indicates a lack of proper information about NDD among the parents and hence the need to inform and educate. Most women were significantly affected to the extent that they couldn't have leisure time or quality time to spend with their husbands and other children.

Many authors have highlighted the need to support families having children with NDD (9). This is essential because the problems faced by these parents are financial, educational social, psychological, family issues, and skill deficits in taking care of special needs.

Soft skills enhancement for the staff involved in taking care of special needs urgent attention. Studies have found that interpersonal relationships are central to the quality of care for patients (10). Lack of communication in the desired/aimed goals and the expected outcome was not properly communicated with parents. Similarly, there was a significant lack of communication among the therapists taking care of children also resulting in duplication of services, lack of coherence and continuity in services, etc. Often technical aspects of treatment become secondary when compared to the need of good interpersonal skills. This holds in certain areas like ADL skills training, educating basic concepts, etc. as also pointed by Neeley barns (11), who noted that quality of care is based on the interpersonal relationships of nurses/staff with their clients in activity of daily living.

Society's response was not felt as favorable for special education needs of children with NDD as 35% of our participants felt that the service offered were not up to the mark. The government's effort to put up schools for children with Neuro-Developmental Disability is ineffective so far in the larger context of the needs. The services offered by the government under "**Sarva Siksha Abhiyan**" where special educators were introduced at the village level in a laudable step in the right direction but too little with less talent. 11/54 (20%) children who were already going to special schools and 35 % of their parents were feeling let down. Even in those going to normal school, the

learning environment was de-motivating for the differently abled child. This finding is important as 30% of the >5-year-old children were not having even preacademic skills (pre-reading, pre writing etc.) These children need well-programmed integrated sessions to benefit them. This will require teachers who are well-trained and equipped to teach children with NDD. The education of children with Neuro-Developmental Disability should include areas of life skills from early life as discussed in the ICF-CY format (12)

Economic difficulties experienced by the parents in the provision of care of the child were significant in the present study. However, therapy expenses still take a toll on the finances of families. This is in line with various studies as reported in a literature review by Shahat et al.(13)where it was found that in developing countries all efforts should be towards avoiding preventable childhood disabilities and supporting disabled children and their households to make them more independent and increase their productivity. Many participants expressed concerns about the future as they feared that later they may not be able to take care of the responsibility of their children. This is similar to other studies conducted in different settings by Cheng et al (14) But a significant number of parents had unrealistic expectations also about the future of their kids.

Family perspective in the care of children with Neuro-Developmental disability in developing countries is under-researched. Families do not receive supervision and professional guidance. In the present study, the parents and the community were found to have little knowledge about NDD. In general, in communities and families' misconceptions about people with NDDs were widely prevalent. This makes it difficult for families having children with NDD to give care at a proper time resulting in the loss of precious time for early diagnosis & intervention increasing the long-term morbidity. In addition, many were preventing their children from playing with children with NDD; thereby significantly affecting the chances of improvement in these kids due to peer interaction.

There are some limitations in the present study- The caregiver groups were not matched in terms of socioeconomic indicators, e.g., maternal education; which may impact our conclusions, as higher levels of education are associated with higher levels of health care awareness. The next limitation is the small sample size across groups; however, some previous studies have justified the small sample size (15)

CONCLUSION

From the present qualitative study, it can be inferred that the families with Neuro-Developmentally disabled children require more attention in clinical, social financial research and in the policy making. Clinician should inform parents about the need of range of services and where they can avail it along with constant follow-up visits. They should get to local support and advocacy groups, national organizations focusing on specific conditions.

What is required is an integrated set of services that optimize the use of limited resources and coordinate to address the unique needs of each child and family. Creative adaptation of current services, to provide high quality, coordinated and comprehensive care to this vulnerable population of children and their families may better meet their considerable needs than the introduction of additional and costly

specialist services. Adequate support from the society, and government in particular, should be made available in such scenario.

Family perspective in the care of children with Neuro-Developmental disability in India and developing countries is under researched and needs further study. The main point for policy implication is that care of NDD should be seen in a medical way by combining many approaches that need to be coordinated effectively (integrated approach) by health personal with more involvement of medical practitioners in the said domains.

Policy Implications

The results of the study can be used in devising strategies to secure the participation of parents & families in the care of children with Neuro-Developmental disability at health facilities and community levels. Care of NDD requires combining many approaches that need to be coordinated effectively (integrated approach) by health personnel. Hence, the health care facilities should devise modalities or modify existing modalities of care to promote the quality of care, especially at the family level. Also, effective legislation to regulate the centers delivering such care should be taken with the medical aspect in mind rather than relying only on the social aspect alone.

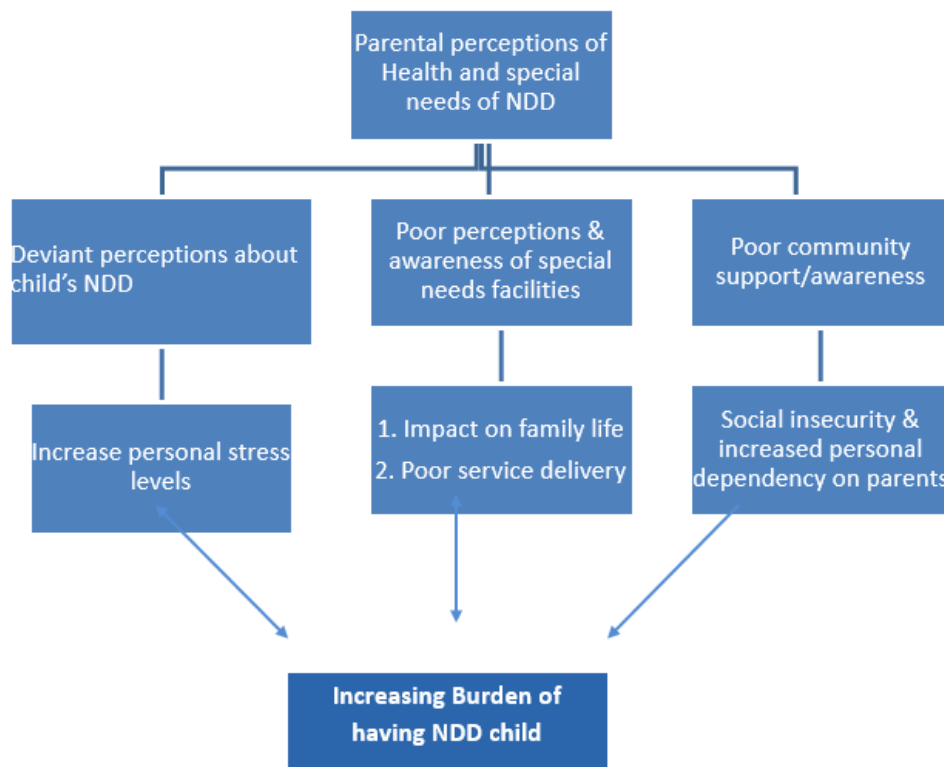


Figure: 1 The Lessons Learned

Moreover, from the medical community perspective provider need to consider how clinical evaluation and treatment may be stigmatizing, especially in pediatric primary care setting. A shift from seeing this problem from a social level to a more medico-educational level is needed as most of these NDD results in skill deficits (due to physical-executive or mental) leading to a behavioral or educational deficiency. Parental groups should be empowered to assist parents of new children diagnosed with NDD. Community/home-based NDD services should be made available, with the participation of the community.

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