



ORIGINAL ARTICLE

Unveiling the impact of neurodevelopmental disabilities on intra family dynamics: A phenomenological exploration.

Fareeha Latif¹, Saqib Bajwa², Rabbia Ashraf³, Sarwat Malik⁴, Farasat Ali Dogar⁵, Ali Anjum⁶

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ABSTRACT... **Objective:** To explore perceived intrafamily challenges and experiences of having a child with neurodevelopmental disabilities and provide a multifacet impact of having NDD on three familial subsystems: Parental, Spousal and Sibling subsystem. **Study Design:** Descriptive Exploratory Phenomenological Design was utilized. **Setting:** The Children's Hospital & Institute of Child Health, Lahore. **Period:** September 2022 to January 2023. **Methods:** Qualitative research method was used in current study. Sample X three families having a child diagnosed with NDD were included. Purposive sampling was used, with the inclusion of all members of the families. Families having only one child with NDD were included in the study. **Results:** Thematic analysis found two superordinate themes i.e. family role and societal factors, with five major themes i.e. father, mother and sister factors, coping strategies and family support. **Conclusion:** Families having autism spectrum disorder children had relatively more stress than families of having children with other developmental disabilities. Mothers were reported to face more emotional reactions than fathers. Spirituality and spouse support was considered the most effective coping by mothers. Siblings faced mixed feelings in the presence of a child having NDD. Society needs awareness, acceptance, and sensitivity towards these families. More rehabilitation and treatment services need to be developed in Pakistan.

Key words: Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, Developmental Disabilities.

INTRODUCTION

According to DSM V-TR¹ neurodevelopmental disorders (NDD) are a group of conditions with early onset in life of affected individuals, characterized by developmental deficits and behavioral impairments in several areas of functioning of daily life (personal, social, academic, and occupational domains). In Pakistan, 2.49% of the population has a disability and 6.5% of the disabled population has mild intellectual disabilities, 1.91% of severe intellectual disabilities², about 350,000 children are suffering from ASD.²

Awareness about neurodevelopmental disability has risen during the last two decades. However, parents are usually reluctant to accept the diagnosis of this pervasive disorder. They experience different psychological reactions like denial, agony, rejection, uncertainty,

shame, and blame at the time of diagnosis and afterwards.^{3,4,5} According to research⁶ the families of children with disabilities are badly affected and have more instability and dysfunction than "normal" families. Indeed, parenting a child with a neurodevelopmental disability is a real-life challenge. Parents face challenges regarding financial issues, discrimination from society, challenging and problematic behaviors of the child and social isolation. Parents of children with developmental disabilities often say they are more stressed than parents of children who are growing normally.⁷ This type of stress may result in feelings of isolation, frustration, depression, hostility, anxiety, marital discontentment⁸, and the abandonment of the hope of having a child who develops normally and is healthy. Moreover, parents have to deal with a lot of problems, like having to pay more to treat their child's illness, dealing with the child's bad behavior, disability-

1. Ph.D Scholar, Principal Clinical Psychologist Developmental & Behavioral Pediatrics, University of Child Health & Children Hospital (UCH &CH), Lahore.

2. FCPS, Associate Professor Psychiatry, Punjab Institutes of Mental Health (PIMH), Lahore.

3. MS (Clinical Psychologist), Clinical Psychologist Developmental & Behavioral Pediatrics, University of Child Health & Children Hospital (UCH &CH), Lahore.

4. Ph.D, Assistant Professor, DUHS.

5. FCPS, Associate Professor Psychiatry, Punjab Institutes of Mental Health (PIMH), Lahore.

6. FCPS, Assistant Professor Psychiatry, Punjab Institutes of Mental Health (PIMH), Lahore.

Correspondence Address:

Rabbia Ashraf
Department of Developmental & Behavioral Pediatrics, University of Child Health & Children Hospital (UCH &CH), Lahore.
rabbiaashraf14@gmail.com

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related stigma, more physical health symptoms⁹, negative consequences, and poor mental well-being.¹⁰

Autism spectrum disorders and intellectual disabilities are two types of developmental disabilities that are strongly linked to mental health problems in mothers.¹¹ Research¹² indicates that parental distress and family functioning have a multifaceted influence on children, encompassing cognitive, behavioral, and social development. Furthermore, Siblings also keep resentment when parents give more time to a child with a disability. Some siblings reported that they are positively affected by the presence of an ASD sibling in the family.¹³ As Caregivers play a central role in the rehabilitation and education of NDD children, so their own well-being and health is important.

Previous studies have investigated the impact of NDD on the parents of these children, whereas the impact of NDD on each family still needs to be explored extensively.

The current study is designed to explore the psychosocial impact of children with NDD on all family member. Furthermore, the current study aims to explore the differences in the perception, thoughts and problems of the family members, each having a child suffering from a different type of NDD (Autism, Down's Syndrome and Cerebral Palsy).

METHODS

A descriptive phenomenological design using face-to-face in-depth interview was conducted from September 2022 to January 2023 at The Children's Hospital & Institute of Child Health, Lahore.

Children were screened using standardized tests and clinical examination in the hospital setting to diagnose the children. A Clinical Psychologist administered Childhood Autism Rating Scale (CARS) to diagnose autism spectrum disorder.¹³ In contrast, Cerebral Palsy and Down's syndrome were diagnosed by a neurodevelopmental pediatrician during the clinical examination. The formal assessment was done by a Clinical

Psychologist using SIT (Slosson Intelligence Test) and CARS (Childhood Autism Rating Scale) for children with autism spectrum disorder. In contrast, the children with cerebral palsy and Down's syndrome were formally assessed using SIT and CABS (Children Adaptive Behavior Scale).

Purposive sampling technique was used for recruitment of the sample group of families of children with NDD. All three children selected for the study had a moderate intellectual disability and adaptive and daily living skills. Their age range was between 15-17 years and the sample consisted of 3 families: family 1 had a child aged 15 years with ASD, family 2 had a child aged 15 years with Down's syndrome and family 3, having a child aged 17 years with cerebral palsy, were approached for interviews.

Families with at least one child with diagnosed NDD who could communicate in simple words were included in the study. Families with more than one child with NDD and families with a physical disability were excluded. The undiagnosed cases that had never been on regular follow-up were not included in the study.

The purpose of the study was explained to the participants, and permission was sought before visiting the family homes at convenient times for interviews. A semi-structured interview guide was used with open-ended questions, and families were met at their given time when all family members were present, including the child (Table-I). Permission was taken to record the interviews and confidentiality of the family /child were maintained. Semi-structured interviews were individually conducted with all members of these families. Each family member was interviewed individually about the problems they faced by them at home and in society, until theoretical saturation was achieved.

Thematic analysis is an iterative and nonlinear method of qualitative analysis, requiring the researcher to move back and forth through the analysis phases as necessary.¹⁴ The researcher got familiarized with the transcripts by reading and

re-reading the transcription multiple times. The initial codes, themes and potential themes were generated, and then the themes and potential themes were reviewed. The superordinate themes were generated and associated with major and sub-themes. For the three families, ASD, CP and Down syndrome, three superordinate themes were identified: family role, family factors and society/religious factors. Sub-themes were further explained with the help of verbatim discussion. Integrity of the qualitative data.

The study employed credibility, transferability, dependability, and confirmability to attain various aspects of rigor designated by Lincoln and Guba.¹⁵ To obtain credibility, information was approved by peer debriefing and reviews of the data, codes, subcategories, and categories. Moreover, the selection of a suitable data collection method, member checking of transcripts through study participants, and the development of themes to rightness by a 2-3 vast number of experienced qualitative researchers ensured the study's credibility. Dependability is achieved by engaging more than one researcher in data analysis. The audit trail was made to establish the confirmability of the study findings. Written informed consent

was taken from all participants before conducting the in-depth interviews. Participants' privacy, anonymity, and voluntary participation were guaranteed in the research process.

Written informed consent was taken from all the participants before the data collection after informing them about all the aims and objectives of the study. The study protocols were approved by The University of Lahore reference no: ERC-21/03.

RESULTS

Family 1 Autism Spectrum Disorder

Coding of the data in ASD family resulted in two subordinate categories, divided into six major themes, each comprising several sub themes. In ASD family, the dynamics differ from those of typical families. Filled with care and support, they face distinct challenges compared to typical families. Despite financial stability, occasional jealousy and a persistent longing for a "normal" brother punctuate their experiences. Initially father reported that he felt embarrassed to discuss the child, and wished his child to be normal as the other child.

Research Question: What are the psychosocial Impacts of children with developmental disabilities on their Families. Questions were asked from parents, siblings, and special child.

Parents

What is the family's response towards child with neurodevelopmental disability?

What is society's response towards this child with neurodevelopmental disability?

Probe: Do other kids play with this child?

Do you participate in social gatherings with a neurodevelopmental disabled child?

What do other siblings think about this NDD child?

Are you able to give equal time and attention to all children?

Do you find any change in your life in the presence of a child with a developmental neurodevelopmental disability?

Probe: how you will define your present life

Do you find any change in your relationships with your spouse in the presence of a developmentally disabled child?

How do you see your child in future?

Probe: are you happy with the way he is going?

Siblings:

What do you feel about this child?

How are your relations with this child with a developmental neurodevelopmental disability?

Special child:

Are you happy?

Whom do you like the most, mama or papa?

Do you like your siblings?

Do they love you?

Probe: Do they play with you?

Table-I. Shows the interview guide related to the impact of the developmental neurodevelopmental disability of a child on the family.

	Superordinate Themes	Major Themes	Sub-Themes	
Family 1 (Autistic spectrum disorder)	Family role	Father factors	Comparison with normal children.	
		Mother factors	Distress, Depression Spouse care, little awareness of illness, Sibling jealousy	
		Sister factors	Wishes for a normal Sibling	
		Coping strategies	Spirituality, unavoidable challenge	
		Societal factors	family support	Support from friends
				Unacceptance
Family 2(Down’s syndrome)	Superordinate Themes	Major themes	Sub-themes	
	Family role			
		Father reaction	Allah gift, hope	
		Mother reactions	unacceptance, wishful thinking, embarrassment	
		Sisters’ reviews	Wishful	
		Coping strategies of mother	Social support, religiosity	
	Societal factors	Societal reactions	Rejection, Isolation, avoidance, source to connect with God	
Family 3(Cerebral palsy)	Superordinate themes	Major- themes	Sub-themes	
	Family factor	Mother Factors	Regrets but hopeful, guilt, depressed	
		Sisters factor	Feeling of being ignored, blaming toward family	
		Family neglect	Sisters and family matters were neglected by mother	
		Financial issue	Transportation issue	
		Coping strategies	Avoidance, asociality	
	Societal factors	Social reaction	Disregard child need,	
			Unacceptance	

Table-II. Shows the Superordinate theme, Major themes and Sub-themes of the three families. (Family 1 ASD, Family 2 Down syndrome, Family 3 Cerebral palsy)

As he reported.

“When the child was first diagnosed with ASD we accepted it quickly, as we knew that every problem had a solution. And we tried to make him go to main stream school”

“I usually avoid the conversation, when my colleagues discuss their children, as I feel that my child is different from theirs and unconsciously keep on comparing their child activities with mine and I feel a bit distress.”

He also reported that,

“Initially when he used to take part in group activities, children used to avoid playing with him at that time we do feel embarrassed, but this spark struggle in me.”

However, the mother reported:

“My child diagnosis felt like a blast in my head”
Mother reported further:

“I have zero information about the treatment. I didn’t expect it to last life-long. I am still depressed, I get scared of small things, and my heart start pounding”

Regarding spousal relations mother reported:

“We had a congenital relationship, when I feel down my husband support me, if his support wasn't there then we might had a worst relationship”

Regarding sibling relationship the mother reported that sister wish if she could share her feelings with mother

“I wish my brother would have been normal so that I could share my feeling with her”

Mother reported that sister feels jealous when mother gives more time to person with disability
“I get jealous when my mother give my brother more attention, I feel bad about this”

Major theme is coping strategies sub themes are spatiality and challenge

Father took child problem as challenge:

“Life give you many unavoidable challenges. Maybe God has put this challenge for us”

Whereas mother reported

“When a person is on stress or depression then you only seek God help. I have become very spiritual, and credit goes to my child diagnosis. Now I pray 5 times a day”

Subordinate theme is social support with sub themes of support from friends and family and un acceptance from society.

Mother reported good attitude of family members but odd behavior of society, she reported that she is blessed to have supportive relatives:

“its my good luck that I was married into my relatives, so my in laws and family cares a lot about him and never made us feel different”
She reported further

“But something I think it's fun for people, I don't like this. Society don't represent this problem nicely”

Family 2 Down Syndrome person with disability

Major subordinated themes were father, sister and mother reactions, coping strategies and societal reaction.

Father reported,

“He is source of engagement in our family. Allah give special child to special people”

Father takes his child diagnosis positive:

“I praise Allah that he gives us a beautiful child. We take him with us everywhere. I never felt ashamed of him and never hide him from the society”

Whereas mother reported his diagnosis as a trial from God.

“When doctor first diagnosed him, it hurts a lot, I often thought if he would have been normal we could have taken his sister to academy. I am human, so it hurts to see him like that. Adult son is a source of support to parent.”

She reported further,

“He was very hyper before, I ran after hi for 13 years, but now he is much better. We gave him home task, he washes dishes, but still he behave oddly in front of guest which embarrassed us, so I avoid bring him in front of guest”

Sister said as he did not annoy her like normal brothers of her friends

“Normal brother tease their sisters, so I said to my mother that I would have love if my brother would have been normal”

The major theme of coping strategies include social support from family

Parents reported that family attitude towards person with disability was good.

“one of my brother and sister in law take care of him, brings things that he likes”

Father said that,

“these children are God gifted and a trial from Allah. I thank God for giving me a lovely son who can do his own work. I know he is a bit mentally weak but with time he will get better and learn something, Inshallah”

Societal reactions subthemes are Rejection and

isolation

According to mother

“Neighbor used to kicked him out if he went to their home, pregnant women used to hide her face from him, as they don’t want her child to be like him”

Sister reported

“Children don’t play with him, then our father used to play with him, now he plays on his own”

Father reported

“People talk several things about him which are distressing but we are confident as we don’t hide him from everyone”

However, the family reported that society reaction toward the child is inconsistent. In general they don’t want their child to be like him but then they also think him as a way to seek God forgiveness.

“At one time they don’t let their child play with him, as they don’t want their child to be lie him. On the other hand, they ask him to pray for them.”

Family of person with disability having Cerebral Palsy

Family of CP comprised of three family members, i.e. a single mother and two sisters. Child suffered from paraplegia. The subordinated themes emerged were family and societal factors and were divided into six major themes. Mother and sister factors, family neglect, coping strategies, financial issues, and social reaction.

According to mother she was not told by doctor about the child conditions which waste a lot of golden time in which the child could have improved.

“I get to know about his condition very late, doctor didn’t tell me about this, they just said that the child was premature and will get better with time, I regret this so much, would I have know early I would have start his treatment at golden time”

She was distressed about his diagnosis at first but now this feeling is better

“I used to feel that I am stuck under a heavy load,

but this feeling has improved a bit”

Mother admitted that she has guilty feeling that she neglected his family and other siblings due to the child responsibility.

“I gave my all time to her, I ignore my both daughters and that’s why I think that they are good in academics”

The youngest daughter got more problematic and adopted neurotic traits

“My youngest become irritable and she even start thumb sucking.”

But she find the family was supportive

Societal reaction was very variable, although they treat him with care and love but they used to disregard his special needs

“My family member consider him normal and thinks he do not have any problem and she is deliberately not coming toward education. I think my family didn’t accept her as she talk fine”

The mother was in distress when due to this societal reaction but she cope well through spirituality

“No was willing to listen that she was special, I was alone with her and that’s why I was depressed but now I have accept this fact. When I see other child with severe disorder, I thank God that she is much better”

However the mother is proud about her effort as she can see the changing in her

“She is very independent now and od most of her work on her own, she never behave odd is social gathering and I feel proud about this. Everyone adore her”

But it was hard for her to move in different places

“Its hard to arrange special transport for her transportation and with the therapeutic fees as well, sometime we get burdened by the transportation fee” because of this the child do not like to move around much and she stayed home.

According to the sister mother was overprotective towards the child and she spoiled her to be

moody, stubborn and emotionally weak. She gets angry and frustrated and get upset easily but she was not guided by the family about these things.

“My sister is emotionally weak, mother didn’t make her emotionally strong; family didn’t bother to guide her or aware about managing her emotion. Normal children are guided about these kind of things”

Moreover, the sister confirmed that she was neglected by the mother and blamed her mother for her bad grades

“I was not given proper time, a mother should know about his own child but I was left on the hand of the aunt, how can she know my feeling and my demands? I was not given proper time and that’s why my grades are bad”

DISCUSSION

The current qualitative study explored the impact of having a child with NDD in the family. The previous research studies supported that families having developmental disabilities face various psychosocial problems. The major concerns of family members were explained about family roles, family factors and societal factors. The current study supported the previous findings that parents of children with NDD experience high levels of stress, hopelessness, and regrets in comparison to the families of typically developing children. Whereas, comparative studies reported that, parents of ASD children were significantly more distressed than the parents of children who have Down’s Syndrome.¹⁶

Parent of NDD child face experience many unique challenges. This brings them stress and feeling of helplessness. Families face multifaceted problems, handling child behaviors, tolerating societal stigma, maintaining balance among children, generating resources for rehabilitation and coping with future apprehensions. The families of children with NDD use different coping strategies to manage stress, such as avoiding it as a challenge, keeping one’s problems to oneself or seeking social and religious support. These findings are similar to the results of the

previous studies that found families of children with NDD using different coping strategies more than the families of normal children.¹⁷

Parents of children with NDD usually adopt religious strategies to cope with stress. As the Muslims believe that good deeds will be rewarded on judgment day, so the coping strategy most commonly used by Pakistani Muslim families is to accept disability as the notion of “God’s will” In previous studies conducted in Pakistan, mothers mostly gave a theological reference by referring to the child as a result of punishment or gift from God. These findings align with the present study’s findings; parents considered children with NDD as Allah’s gift or” Allah’s test”. The parents reported trying to fulfil their duties towards these children to make Allah happy on the Day of Judgment.¹⁸

Family dynamics and patient characteristics also significantly affect families living with children suffering from NDD. Spousal support is considered positive and alleviates stress as two wives reported positive feelings from their partners as they admired their efforts. Previous studies have also indicated that spousal support was positively related to less depressive symptoms and more satisfaction towards life and inversely related to anxiety social support can be both formal and informal.¹⁹

Friends and family give social support which help managing the family stress. Similar results have been found in the current study, as the mother of the CP child was a widow and managed her job and house independently. She reported feeling satisfied as she lived in a joint family and had continuous support from her family. The siblings of the children suffering from NDD reported mixed feelings of sympathy and jealousy towards a disabled sibling.²⁰ However, the CP child, the sister thought the parents could not give her quality time. Mothers usually have a main role in the care and therapy of such children. While struggling to fulfil their requirements, mothers unintentionally ignore their normal children. Children are aware that parents struggle to keep all children equal, but unfortunately, they cannot do it. In aligned with current findings, reported

that families silently wished to have a normally developing child, as the sister of an autistic child wished to have a normal brother, and the mother also wished the same so that she could have someone to share her responsibilities.²¹

The patient's characteristics are significant in understanding the perspective of developmentally disordered children. All three children knew that they were different from the others. Although the ASD and DS children had limited facial expressions, the parents reported that their body gestures showed that they understood this difference.²² CP's child was responsive to questions and expressed that she was reluctant to go to gatherings as people were not good to her. The autistic child also was aware of his NDD and used to pray "May God made us better", showing his wish to lead a normal life like his siblings. An important consideration is that people did not allow such children to play with normal children.²³ The typically developing individuals have been reported to be less prepared to mingle with ASD and were found not to be much interested in more interaction with children having ASD after discussing with them previously, however, in the current study, it was reported that the neighbor of the child who has Down's syndrome often asked the DS child to pray for her as she believed that his prayers were answered quickly due to his condition by the Almighty. The parents reported that society lacked empathy towards families having children with NDD. In the current study, the parents reported that societal stigmatization was a significant reason for their distress. The mother of the child with Down's syndrome reported that pregnant women covered their faces with a veil when they saw her child with NDD.²⁴

The other major theme found in the current study was social and religious factors. In the previous studies, parents usually reported changes in their value system, style of life and meaning to life. Spirituality was considered a strong healing factor by mothers of DD children as it gave them strength and a feeling of commitment towards their and also provided resilience against psychological reactions.

These findings highlighted the emphasis of increase interaction between children suffering from NDD and typically developing children to bring a healthy change in attitudes towards developmentally disabled children. The agony and distress of families having children with NDD can be reduced, at least to some extent, by educating society about NDD.

CONCLUSION

The current study explored that; the parents of ASD children are in distress due to the child's disorder. However, fathers had a more positive attitude towards their child disability than mothers. Mothers reported feeling depression and other adverse psychological reactions. Siblings reported having a good relationship with the children having NDD. However, at the same time, they also reported feeling emptiness in their lives as they could not share their feelings with their NDD sibling.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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




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AUTHORSHIP AND CONTRIBUTION DECLARATION

No.	Author(s) Full Name	Contribution to the paper	Author(s) Signature
1	Fareeha Latif	Concept or design of the article, Drafted the article or revised it critically for important intellectual content.	
2	Saqib Bajwa	Supervision and Reviewed manuscript, Approved the final version to be published.	
3	Rabbia Ashraf	Acquisition, analysis, or interpretation of data for the article.	
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