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ORIGINAL ARTICLE

Unseen struggles: The psychosocial toll of raising a child with functional neurological disorder

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ABSTRACT

Background: Functional neurological disorder (FND) is characterized by neurological symptoms that are inconsistent with structural or known pathophysiological causes.

Objective: To explore the psychosocial experiences of parents raising a child with a functional neurological disorder, focusing on emotional distress, social challenges, and financial burdens.

Methods: A phenomenological approach to exploratory qualitative research was employed, using a nonprobability purposive sampling strategy to collect data. The parents of children (n=12) having FND were recruited from a private hospital in Lahore, Pakistan. A demographic sheet and semi-structured interview guide were used to collect data. Braun & Clarke's (2009) 6-step approach to thematic analysis was used to analyze the data in NVivo.

Results: There were six fathers and six mothers of children with FND, varying between 25 and 45 years of age, with a mean age of 35±2 years, from Lahore. The themes that emerged from the thematic analysis were psychological stressors and socioeconomic and caregiving burdens. The subthemes were emotional stressors, anxiousness and depression, lack of social support, financial burdens, difficulties in time management, and social isolation and stigma.

Conclusion: Having special children can affect parental interpersonal connections and psychological well-being. Healthcare leaders and authorities need to consider the special needs of affected parents.

Key Words: Functional Neurological Disorder, Psychology, Parental, Stress, Caregiving Burden, Qualitative Research, Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

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INTRODUCTION

Functional Neurological Disorder (FND), previously known as conversion disorder, is a condition characterized by neurological symptoms that are inconsistent with the structural or known pathophysiological causes.[1] The symptoms often include motor dysfunction (e.g., weakness, tremors, abnormal movements), sensory deficits (e.g., numbness, blindness, deafness), and episodes that resemble epileptic seizures (psychogenic non-epileptic seizures).[2] The disorder falls under the umbrella of somatic symptom disorders and is thought to arise from maladaptive neural processing rather than identifiable structural or neurophysiological abnormalities.[3]

FND presents a diagnostic challenge due to its complex and heterogeneous nature. The diagnosis is primarily clinical and relies on positive neurological symptoms rather than being an exclusionary diagnosis.[4]

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), the following criteria are used for the FND:

a. One or more symptoms of altered voluntary motor and sensory function.

b. Clinical findings provide evidence of incompatibility between the symptoms and recognized neurological or medical conditions.

c. The symptom or deficit is not better explained by another medical or mental disorder.

d. The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation.

Children with FND pose unique diagnostic and therapeutic challenges due to the interplay of biological, psychological, and social factors. Given the high rates of psychiatric comorbidities, including anxiety, depression, and somatization disorders, management often requires a multidisciplinary approach, integrating neurology, psychiatry, psychology, and physiotherapy.[6] However, despite growing awareness, caregivers of children with FND frequently encounter significant difficulties, including stigma, uncertainty regarding the diagnosis, and challenges in accessing appropriate care.[7]

While substantial research has explored the clinical presentation and management of FND, less attention has been given to the experiences of parents navigating the complexities of the disorder. Parental experiences are crucial, as they influence treatment adherence, coping mechanisms, and the child's overall prognosis.[7,8]

Existing literature has predominantly focused on the neurobiological and psychological aspects of FND in children, with limited attention to the broader psychosocial impact on their families.[9,10] Research on parental stress, coping strategies, and their role in the child's illness trajectory remains scarce. While studies have documented caregiver burden in other pediatric chronic illnesses, the unique challenges posed by FND, including its stigma, diagnostic ambiguity, and healthcare system barriers, remain underexplored, especially from a Pakistani perspective.[11,12] This study addresses this critical gap by providing qualitative insights into parents' lived experiences, highlighting their struggles, resilience, and unmet needs. The present study was conducted to explore the psychosocial experiences of those parents who were raising a child with FND, focusing on emotional distress, social challenges, and financial burdens.

METHODS

It was a qualitative study, and a phenomenological approach was employed with the constructivist underpinnings. Ethical approval was obtained from the Ethics Review Board of Azra Naheed Medical College, Lahore, Pakistan. The researchers were Pediatricians with experience in managing children with FND from Chaudhry Muhammad Akram Teaching & Research Hospital, Lahore; the University College of Medicine and Dentistry, Lahore; and Sharif Medical City Hospital, Lahore; and an experienced clinical psychologist from Riphah International University, Lahore, Pakistan.

To minimize bias, bracketing techniques were employed to prevent the researcher's personal experiences from influencing data interpretation. Before conducting the interviews, the researchers obtained informed consent from participants by providing detailed information about the purpose and nature of the interviews.

A purposive non-probability sampling technique was used to recruit 12 parents (6 fathers, 6 mothers) of children diagnosed with FND for at least 6 months, who were fluent in Urdu or English, actively involved in caregiving, and willing to participate in an in-depth interview. Patients were numbered from 1 to 6 to ensure anonymity.

The following research questions were answered through the study:

1. What are the psychological experiences of parents of a child with Functional Neurological Disorder?
2. What are the social experiences of parents of an affected child?

Semi-structured interviews guided by an interview guide were audio-recorded in English and Urdu at the Pediatrics outpatient clinics of Azra Naheed Medical College, Lahore, with participants' permission, and the same researcher took field notes as well. Each interview lasted approximately 30-40 minutes; in addition to the participants and interviewers, no one else was present. Both the parents of patients 1-6 were interviewed together for the convenience of interviewers and participants. Data collection continued until saturation was reached. The researchers transcribed the interviews. A summary of the transcripts was sent to the participants. The coding and theme identification were done using Braun & Clarke's six-step thematic analysis,[13] supplemented by NVivo software for categorization.

Ethical Approval

The study was conducted from March to August 2024, following approval from the Ethical Review Board of

Azra Naheed Medical College, Lahore, Pakistan (ref no: ANMC/IRB/2024/005) dated 02 February 2025.

1. Can you tell me about the challenges or stressors you are facing because of the functional neurological disorder of your child?
2. In what ways have you and your family’s quality of life altered since you’ve had a child who is affected by this disease, as compared to before?
3. For you or your child, what sort of feeling do you get when your child is admitted?
4. Would you inform me of the challenges you encountered in your day-to-day activities when your child was in the ward?
5. What did you experience in society related to your child with this deficit?
6. How did this condition impact your relations with family and friends?
7. Please describe what problems you are facing while managing your daily life.
8. Please explain your experience of stigma or other Psychological issues coming from society related to your child’s condition.
9. How did your child's condition psychologically affect you?
10. Do your family and friends support you? If yes, how?

Figure 1: Interview Guide

RESULTS

The study included twelve parents (6 fathers and 6 mothers) of 6 children diagnosed with FND. Demographic details are summarized in Table 1.

The main themes identified were psychological stressors and socioeconomic and caregiving burdens (Table 2). In the theme “psychological stressors,” the subthemes identified were emotional stressors, social isolation, and stigma.

Following the diagnosis of this condition, parents expressed a range of emotional reactions, including disbelief, shock, sadness, and worry, as mentioned by one of the participants, stating that:

"The state of uncertainty permeates every day. I'm always concerned about when and how bad the next episode will be." (mother, P1).

Although the fathers shared a close relationship with their children, they often felt frustrated. For instance, a father said:

“It's tiring to ride the emotional rollercoaster. Some days I am completely devoid of hope, while other days I am clinging to any tiny hint of progress." (father, P2)

Many parents expressed feelings of hopelessness and fear, not knowing how to contribute to their child's welfare or deal with the difficulties in a constructive way. A mother expressed her feelings as:

“It's similar to being terrified all the time. I'm afraid about what my child may encounter every day." (mother, P2).

The close involvement with child-rearing and the stress of watching their child endure discomfort can damage the psychological and emotional health of parents, even sometimes causing depression. One father testified as follows:

"Most of the time, I have the feeling I'm almost out of gas. It eventually wears you out to be constantly anxious and stressed. Sometimes it's difficult to keep going." (father, P2).

Another important subtheme that emerged was social isolation and stigma, which represented the effects of caregiving obligations and the particular difficulties involved in raising a child with FNSD on parents' friendships and connections with others:

"Social isolation follows us around all the time. We frequently feel like we're traveling this path alone as parents since it's hard to relate to other mothers who aren't experiencing our experiences." (father, P4)

The parents felt that the diagnosis of FNSD had become a social stigma for their family as they had reduced interaction with extended family, friends, and neighbors. For example, a mother said:

“Socially, we feel completely isolated. No one truly understands what we go through.” (mother, P6)

Responses from participants demonstrated how disruptive these feelings are:

"Having treated provokes a cascade of anxiety about 'what ifs.' It seems like you're constantly terrified about whatever the following day could bring." (mother, P5)

The second main theme identified was socioeconomic and caregiving burdens. Financial burden was one of the subthemes under this theme. The parents explained that after exhausting their resources, and their medical bills kept increasing, they had to resort to financial help, and some of them were in debt as well. As said by the mother of Patient 5:

"My child's needs forced me to give up my work, which had a huge impact on our family income. The financial strain is ongoing." (mother, P5).

It was reaffirmed by another mother saying:

"The enormous amount of medical costs keeps coming in. I occasionally worry about how we're going to make our finances meet." (mother, P1)

Time management challenge was another subtheme found due to frequent doctors'/psychologists' visits. Appointments for therapy and constant monitoring are frequently necessary for the disorder, which leaves barely any time for other obligations or self-care. One of the parents gave the following statement:

"My child's requirements take up my entire day. Finding time for my favorite activities is difficult, including job, housework, and even a little relaxation." (father, P3)

Shared anomalies appeared to be an overarching problem within the broad spectrum of the everyday problems with which caregivers of children with FND contend. They all shared how their children's health interfered significantly with their daily reliability and stability:

"Our child's illness has severely disrupted our routine. Even the apparently simple things that people used to take for granted now require careful planning and organization." (mother, P2).

The final subtheme under the major theme of socioeconomic and caregiving was the healthcare system barriers. The parents had difficulty accessing specialized treatment and therapy services, as very few are available in the public sector hospitals of Lahore, which is the largest city in the Punjab province of Pakistan. Moreover, the trained pediatricians and child psychologists are even more scarce, as a father said:

"*When we were looking for a suitable doctor for our child, we had to consult at least three or four hospitals in Lahore. I thought that what would be happening to a parent coming from other small cities or towns of Punjab"* (father, P2)

Table 1: Demographic characteristics of caregivers

Variable	n (%)
Gender	
Fathers	6 (50)
Mothers	6 (50)
Education	
Graduation	5 (41.7)
Masters	6 (50.0)
PhD	1 (8.30)
Residence	
Urban (Lahore)	12 (100)
	mean ± SD
Age (years)	35.00 ± 02.00
Monthly income (PKR)	275,000±83,500

Table 2: Themes, subthemes, and codes

Main Themes	Sub-Themes	Codes
Psychological Stressors	**Emotional Stressors**	-Restlessness - Persistent sadness -Heightened emotional reactivity -Physical fatigue -Overthinking -Emotional concerns about a child -Ongoing worry about the child -Anxiety about the child's future
	Social Isolation and Stigma	-Feeling overwhelmed by caregiving responsibilities -Irritability and frustration -Loss of hope -Experiences of social rejection -Perception of stigma and disgrace -Sense of isolation
Socioeconomic and Caregiving Burdens	**Financial Burden**	-Escalating medical expenses -Disruptions in parental employment
	Time Management Challenges	-Lack of time for self-care -Difficulty balancing care with work -Disruption of routines
	Healthcare System Barriers	-Limited availability of experts -Restricted access to specialized care -Scarcity of services in public hospitals

DISCUSSION

This study explored the psychosocial experiences of parents raising children with FND through qualitative thematic analysis. Twelve parents of six children with FND participated, and two major themes emerged: psychosocial stressors and socioeconomic and caregiving burdens. The study aimed to provide comprehensive insights into the challenges parents face in raising children with this disorder. The results resonate with the existing literature while offering context-specific insights from a lower-middle-income country such as Pakistan.

The first theme identified was the psychological stressors for the parents. Our study showed that complex stressors, including persistent worry about their child's health, sadness, restlessness, and fatigue, significantly affect the dynamics of care and parents' well-being. These findings are mirrored by other authors, who emphasized the psychosocial distress and social isolation after receiving an FND diagnosis.[14,15]

Most of the parents described that lack of social support is one of the critical reasons leading to their poor emotional and psychological health. Pakistan and other low-middle-income countries face this problem due to limited financial resources for children with chronic illnesses, which is in contrast to the high-income countries, as argued in one of the studies.[16] In contrast, some studies from high-income countries often report better coping mechanisms, partly due to more structured psychosocial support and early intervention services.[17]

Our participants described feelings of hopelessness and a sense of being emotionally "drained' by continuous caregiving demands. Similarly, a study also noted that unrelenting caregiving stress contributes to high levels of parental burnout.[15] In a report from a Western study where parents sometimes identify positive growth or resilience from caregiving, none of our participants mentioned such experiences.[18] This divergence may be attributed to contextual differences: in Pakistan, caregiving is compounded by financial stress, lack of flexible work arrangements, and limited access to respite care.

Parents shared their experiences about their struggle with high treatment costs and found it challenging to manage their children's health in addition to their other responsibilities. Similarly, researchers highlighted the financial burdens and time-management challenges of caregiving, reinforcing participants' financial strain.[14] Yet, some researchers suggest that community and peer-support programs can alleviate financial strain, which may include the role of non-governmental organizations and a social fund created by the community of parents of children affected by FND.[9]

Most of the parents having children with this disorder identified symptoms of depression and anxiety, because of which they had to seek professional psychological treatment themselves, further adding to the financial burden faced by them.

The second subtheme, under the psychosocial stressors theme, was social isolation and stigmatization by the extended family, friends, and even healthcare professionals. This aligns with findings by other authors, who found that parents often face skepticism and judgment from both family and healthcare providers.[19] Conversely, less stigma and greater empathy towards affected families have also been reported.[20] These differences from our study may be because participants had access to structured multidisciplinary clinics, while in our study, families navigated multiple hospitals independently.

The second major theme reported was socioeconomic and caregiving burdens. The financial burden, disruption of parental routines, disruption of parental employment, and lack of time for self-care compounded the caregivers' socioeconomic well-being. These findings align with previous reports describing the financial and time-management challenges faced by parents of children with chronic neurological conditions.[19] This points to a lack of a well-integrated, multidisciplinary care model in low- and middle-income countries such as Pakistan.

CONCLUSION

Raising a child with a functional neurological disorder is an unseen struggle that disrupts family dynamics, strains resilience, and places heavy emotional, social, and financial burdens on parents. This study highlights the psychosocial toll of caregiving. It underscores the need for innovative, family-centered support systems, including technology-driven and community-based interventions, to reduce caregiver burden and improve well-being.

Limitations and future recommendations

The study is based on a small, purposively sampled group of 12 parents recruited from two hospitals in Lahore, which limits the transferability to other populations, and it captures their experiences only at a single point in time through self-reported, joint interviews. As a result, the findings may be affected by selection and response biases and may not fully reflect the diversity of caregiver experiences.

REFERENCES

1. Hallett M, Aybek S, Dworetzky BA, McWhirter L, Staab JP, Stone J. Functional neurological disorder: new subtypes and shared mechanisms. Lancet Neurol. 2022; 21(6): 537- 550. doi: 10.1016/s1474-4422(21)00422-1.
2. Bennett K, Diamond C, Hoeritzauer I, Gardiner P, McWhirter L, Carson A, et al. A practical review of functional neurological disorder (FND) for the general physician. Clin Med (Lond). 2021; 21(1): 28-36. doi: 10.7861/clinmed. 2020-0987.
3. Espay AJ, Aybek S, Carson A, Edwards MJ, Goldstein LH, Hallett M, et al. Current concepts in diagnosis and treatment of functional neurological disorders. JAMA Neurol. 2018; 75(9): 1132-1141. doi: 10.1001/jamaneurol.2018.1264.
4. Edwards MJ, Bhatia KP. Functional movement disorders group. functional (psychogenic) movement disorders: merging mind and brain. Lancet Neurol. 2012; 11(3): 250-260. doi: 10.1016/s1474-4422(11)70310-6.

5. Harm, M., Hope, M. and Household, A. American psychiatric association, 2013, diagnostic and statistical manual of mental disorders, 5th ed. Washington, DC: American Psychiatric; 2013.
6. Ernstmeyer K, Christman E. Nursing skills – 2nd ed. Eau Claire, Wisconsin: WisTech Open; 2023.
7. Jambekar AS, Padhyegurjar MS, Padhyegurjar SB, Joshi SP, Shahri P. Impact of having a child with special needs on the psychosocial well-being of the parents: a cross-sectional study. J Ment Health Hum Be. 2018; 23(2): 115-119. doi: 10.4103/jmhhb.jmhhb_24_18.
8. Stone J and Carson A. Functional neurologic disorders. Continuum (Minneap Minn). 2015; 21(3): 818-37. doi: 10.1212/01.CON.0000466669.02477.45.
9. Roelofs K, Spinhoven P. Trauma and medically unexplained symptoms: towards an integration of cognitive and neurobiological perspectives. Clin Psychol Rev. 2007; 27(7):798-820. doi: 10.1016/j.cpr.2007.07.004.
10. Kozlowska K, Scher S. Recent advances in understanding the neurobiology of pediatric functional neurological disorder. Expert Review of Neurotherapeutics. 2024; 24(5): 497-516. doi: 10.1080/14737175.2024.2333390.
11. Finkelstein SA, Diamond C, Carson A, Stone J. Incidence and prevalence of functional neurological disorder: a systematic review. Journal of Neurology, Neurosurgery & Psychiatry. 2025; 96(4):383-95. doi: 10.1136/jnnp-2024-334767.
12. Ahmed SK, Mohammed RA, Nashwan AJ, Ibrahim RH, Abdalla AQ, Ameen BM, et al. Using thematic analysis in qualitative research. J Med Surg Public Health. 2025; 6: 100198. doi: 10.1016/j.glmedi.2025.100198.
13. Naeem M, Ozuem W, Howell K, Ranfagni S. A step-by-step process of thematic analysis to develop a conceptual model in qualitative research. Int J Qual Methods. 2023; 22: 16094069231205789. doi: 10.1177/1609406923120578.
14. Bokharey IZ, Fahim U, Tahir K. Family conflicts are bitter splits that hurt: a qualitative inquiry toward understanding the impact of family issues in functional neurological symptom disorder. Front Psychol. 2021; 12: 652917. doi: 10.3389/fpsyg.2021.652917.
15. Fobian AD, Elliott L. A review of functional neurological symptom disorder etiology and the integrated etiological summary model. J Psychiatry Neurosci. 2019; 44(1): 8-18. doi: 10.1503/jpn.170190.
16. Carle-Toulemonde G, Goutte J, Do-Quang-Cantagrel N, Mouchabac S, Joly C, Garcin B**.** Overall comorbidities in functional neurological disorder: a narrative review. Encephale. 2023. doi: 10.1016/j.encep.2023.06.004.
17. Hong A, Zhou S, Yang C, Liu X, Su S, Wang Z. Impact of childhood trauma on the abnormal functional connectivity of brain regions in the fear network model of panic disorder. J Affect Disord. 2023; 329: 500-510. doi: 10.1016/j.jad.2023.02.128.
18. Staunton C, Rudrappa R, Rathnaiah M. The prevalence of attention-deficit hyperactivity disorder in functional neurological disorder: an integrative literature review. BJPsych Open. 2024; 10 (S1): S83-S84. doi:10.1192/bjo.2024.252.
19. Yong K, Chin RF, Shetty J, Hogg K, Burgess K, Lindsay M, et al. Functional neurological disorder in children and young people: incidence, clinical features, and prognosis. Dev Med Child Neurol. 2023; 65(9): 1238-1246. doi: 10.1111/dmcn.15538.
20. Baglioni V, Esposito D, Bernardi K, Novelli M, Zaccaria V, Galosi S, et al. Misdiagnosis of functional neurological symptom disorders in pediatrics: narrative review and relevant case report. Clin Child Psychol Psychiatry. 2024; 29(3): 1026-1040. doi: 10. 1177/13591045241240805.

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MD: design of the work, data collection, drafting the work, final approval of the version to be published
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SA: Data collection and analysis, manuscript drafting, final approval of the version to be published
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All Authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

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