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ILLNESS PERCEPTION AND TREATMENT EXPECTATION IN PATIENTS WITH FUNCTIONAL NEUROLOGICAL SYMPTOM DISORDER AT LAHORE, PAKISTAN

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ABSTRACT

OBJECTIVE

To explore the perceived illness and treatment expectations of patients with Functional Neurological Symptom Disorder.

DESIGN OF STUDY

Qualitative Research Design

PLACE AND DURATION OF STUDY

The study was executed at the Departments of Psychiatry of six government and four private teaching hospitals in Lahore, Pakistan over a period of 12 months, from January 2023 to December 2023.

METHOD

A total of 100 adult participants were recruited as per criteria. Demographic Information Questionnaire and Short Explanatory Model Interview (SEMI) were employed, and the qualitative data generated from SEMI was converted to numerical codes and discrete categories by the method of stepwise reduction. The descriptive frequencies were then presented in the tabular format.

RESULTS

A total of 2/3rd of the participants were female, educated, students and housewives. The duration of the illness of half of the participants' was 16 months, with mixed symptoms presentation (35%), pseudo seizures (33%), and motor symptoms (18%). The main reasons for onset of illness were cited as marital (25%), familial and social factors (19%) and a large proportion of participants believed that magic had impacted them. Perceived as "extreme intense," by 47%, the severity of the symptoms was linked to significant discomfort and anxiety about their worsening. Lack of interest in daily activities (48%) and Relationship issues (32%) were reported as the two biggest challenges brought on by illness. The patients (70%) expect proper treatment and prescription of medicines, which was followed by responses that they will learn the diagnosis and will receive advice from doctors regarding their illness (26%).

CONCLUSION

The patient's perception towards their illness was serious and concerned and their expectations were receiving proper treatment, medications and learning about the disorder and receiving doctor's advice.

KEYWORDS

Adult; Fear; Female; Marriage; Motivation; Perception; Prescriptions; Pseudo-Seizures; Social Factors.

INTRODUCTION

Functional Neurological Symptom Disorder (FNSD) is characterised as genuine experience of psychogenic non-epileptic seizures or functional movement disorders. These symptoms are inconsistent and incongruent with neurologic disease or pathophysiology that is confirmed via neurological examination or lab findings.[1] FNSD is identified as one of the common occurring disorders for an outpatient neurology consultation.[2] These medically unexplained neurologic symptoms are basically the conversion of emotional problems into physical symptoms at the unconscious level.[3] Its presentation is peculiar with gender, age, and geographical area, i.e., in women, early adulthood, and low socio-economic countries, respectively. The common stressors identified in a study were domestic conflict, death in family, financial issues, illness in family, abuse, and drug intake.[4] Likewise, in another Pakistani sample, marriage-related problems, family relationships, romantic relationships, and religiosity were the most common stress factors reported.[5]

The core symptoms of FNSD might be the same across cultures, but it has been observed that it has significant cultural variations in clinical presentation. Culture plays a vital role in shaping psychosocial distress and thereby impacts patient's experiences of their illness. Studies carried out in Pakistan revealed commonly occurring symptoms such as non-epileptic seizures,[6] unresponsiveness and muteness,[4] mixed presentation[5] and motor symptoms.[7] In Pakistan, due to lack of adequate knowledge about FNSD, the family members often brush aside the patient's problems.[8] They merely see it as an attention-seeking behaviour or perhaps attribute it to supernatural forces or black magic, which may lead them to adopt methods such as going to spiritual healers to deal with the issues.[8-9] Indigenous studies reflect that such patients attribute its onset to social world and perceive and report symptoms to be very intense.[10] In another study in India, it was found that patients with FNSD often lack understanding of their illness, leading to distrust and low treatment expectations.[11]

It is also imperative to understand the patient's perception of the impact of the illness on their daily functioning.[12] The main problems due to the illness are generally reported to be breathing difficulties, mood issues, and affected body parts.[10] However, this is not always the case, as La Belle indifference is also a prominent feature of FNSD, where despite serious symptoms, patients experience a paradoxical absence of

psychological distress.[13] Although the frequency of La Belle indifference was found to be insignificant, such as only 21%,[13] it needs further exploration in cultural context.

Furthermore, patient's help-seeking behaviour and treatment expectations are also shaped by cultural experiences, as a study in India revealed that language barriers and gender differences between patients and physicians hinder effective communication during psychiatric visits.[14] The patients desire that they be tranquilly understood and, in return, clearly communicated about their illness, diagnosis, and prognosis.[15] They expect proper examinations, scans, and investigations and are often willing to seek psychiatric medications or psychotherapy. However, few patients avoid medications due to their side effects.[15] Literature also suggests that properly communicating diagnosis to the patients and psycho-educating them about the aetiology, symptomatology, course, and prognosis is key to better health outcomes and eventual recovery.[16]

As FNSD is projected to be the leading cause of disease burden, specifically in underdeveloped and low socioeconomic societies,[17] therefore it is of utmost importance to explore the patient's perception towards their illness and expectations from the treatment. The patient's conceptualisation of their illness, differences in causal attribution, nature of the available health care system, and burden of disease complicated access to care.[18] Often the patients are reluctant to explain a nonphysical explanation of their symptoms, and the physicians themselves are unable to diagnose FNSD in initial settings, which eventually results in patients losing their confidence and hope in psychiatric treatment, and eventually it results in patient dropout.[14] Therefore, the present study has been designed to delve into how patients with FNSD view their condition and what they hope to achieve from treatment. Understanding patient's frames of reference and endorsing effective communication between the health care provider and the patients will improve adherence and outcomes in Pakistan.

METHOD

Participants

Qualitative research design and non-probability purposive sampling strategy were employed to recruit the participants diagnosed with Functional Neurological Symptom Disorder (FNSD). The sample size was estimated on the basis of literature.[12] Only adult participants who met the following criteria were included:

i. Diagnosed with FNSD as the primary diagnosis (secondary diagnosis could be depression or anxiety).
ii. Diagnosed by psychiatrists and clinical psychologists according to the International Classification of Diseases (ICD-11) and Diagnostic and Statistical Manual for Mental Disorders (DSM-5 TR), respectively.
iii. Patients with FNSD as a secondary diagnosis or with a primary diagnosis of FNSD but a secondary diagnosis other than depression or anxiety were excluded from the study.

Measures

Data was collected after obtaining informed consent from all the participants. Demographic Information Questionnaire and Short Explanatory Model Interview (SEMI) were employed to assess patients and their caregivers' beliefs, attitudes, and behaviours pertaining to conversion disorder. SEMI was modified according to the purpose of the study and with the consent of the original author[12] and the authors who translated the questionnaire.

Procedure

This study was conducted from January 2023 to December 2023 after approval from the Ethical Review Committee of Punjab University (D. NO.3755 ACAD, dated: 21-04-2022). Permission from the heads of the six government and four private hospitals and clinics of Lahore, Pakistan (Sir Ganga Ram Hospital, Sheikh Zayed Hospital, Jinnah Hospital, Mayo Hospital, Fatima Memorial Hospital, GK Institute of Neurosciences, Omar Hospital, Al Razi Hospital, Mid City Hospital and Rehman Clinic) as well as from the authors of the questionnaire who developed and translated it, were sought. Participants were approached, and those who met criteria were explained the rationale and purpose of the study. Participation was completely voluntary, and it was ensured that they would be allowed to withdraw from the study at any time due to any genuine reason. A written consent form was taken from the participants, and they were ensured that their identity and responses would not be disclosed and the information they would provide would only be used for research and academic purposes. Furthermore, all ethical considerations were adhered to during the study.

A total of 130 participants met criteria and gave consent. Preliminary demographic information was collected, which was followed by a Short Explanatory Model Interview (SEMI) in a one-to-one setting. The researcher, who was also a clinical psychologist, took field notes. A total time consumed per interview was 60–90 minutes. After discarding 30 forms that were either incomplete or had uniform responses throughout, data from a total of 100 participants was finalized. The data obtained from the SEMI was transformed into numerical codes using a stepwise reduction method. These codes were then categorised, and the frequency of each category was calculated and presented in tabular format.

RESULTS

Table 1
Demographic Characteristics (N = 100)

Variables	*f* (%)
Gender	
Male	23
Female	77
Education	
Uneducated	06
Primary-Middle	17
Matric-Intermediate	59
Masters and above	27
Occupation	
Students	30
House wives	31
Self-employed/business owners	29
Govt./ private job	09
Unemployed	04
Marital status	
Unmarried	54
Married	39
Separated/ Divorcee	07
Duration of Illness	
1 week – 1 month	33
1-3 months	20
3-6 months	32
6 months – 1 year	15
Symptoms	
Pseudo-seizures	33
Motor Symptoms	18
Sensory Symptoms	07
somatic symptoms	07
Mixed presentation	35

Note: M= Mean, SD= Standard Deviation, f=frequency, %=percentage

Table 2
Patients' Perceived Health and Illness Behavior (n=100)

Variables	*f*
Reason for Onset	
Familial/ social	19
Marital	25
Financial	10
Academic/ occupational	14
Personal/physical Illness	18
Psychological	14
Beliefs on that 'Magic can affect others'	
No	39
Yes	51
Do not know/Not confirmed	10
Perceived intensity of symptoms	
To Some Extent	02
Medium	03
To Great Extent	55
Extreme Intense	40
Perceived fear of illness	
Worsening of symptoms	47
Death	19
Major disability	09
Serious discomfort	17
No fear, other people referred	02
More than one fear	06

A quarter of the patients cited marriage-related factors as the primary reason for the onset of their problems. These included strained relationships with spouses or in-laws, divorce, and miscarriage. The second most common factors were familial and social issues (19%), such as an uncongenial home environment, external environmental issues, the death of a close family member, and lack of attention. Personal/physical illness (18%) was also mentioned as a contributing factor, including accidents, blood deficiency, weakness, hormonal issues, menstrual cycle disturbances, and misuse of medicines. Psychological factors (14%) included tension/stress, overthinking, lack of attention, and adjustment issues. Academic and occupational problems (14%), such as poor grades, job stress, and workplace bullying were also significant contributors. Financial issues, included business losses and property disputes (10%).

Over half of the patients reported a belief in the impact of magic on them, perceiving the intensity of their symptoms to a great extent. Numerous patients (47%) expressed fears about their illness, believing that symptoms could worsen and lead to serious discomfort. They feared that their condition might escalate into a serious illness, potentially causing complete paralysis or unconsciousness in front of others. A few patients (28%) also reported fears of death and acquiring a major disability.

FIGURE 1
Graphical representation of percentage of patient's perception towards activities and functioning affected due to illness

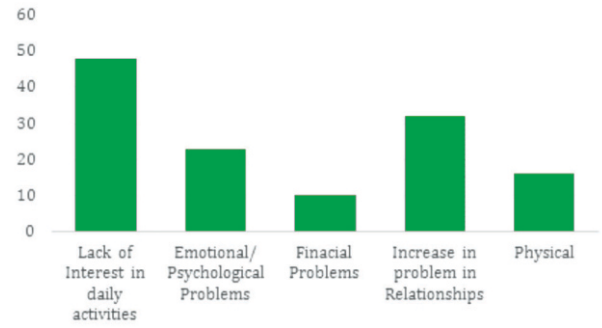

Table 3
Patient's Expectation of benefits from Seeking Medical help from Doctors (n=100)

Variables	*f*
Tablets/Injections will be prescribed/Proper treatment	70
learning the diagnosis and receiving explanation & advice	26
No as such advantage/family forcefully brought here	04

f= frequency

DISCUSSION

Functional Neurological Symptom Disorder (FNSD) presents a complex challenge within psychiatry due to the diverse cultural expressions of symptoms, impacting how these manifestations are interpreted and consequently influencing help-seeking behaviors. A meticulous clinical approach is essential for optimal health outcomes. Clinicians must be mindful of the varied presentations of FNSD, patients' perceptions of their illness, and their treatment expectations. Thus, the current study aims to understand patients' illness perceptions and treatment expectations to better optimise clinical practice.

In this study, the sociodemographic factors revealed that over half of the participants with FNSD were female, educated up to matric level, had illness durations of 52% participants from one to six months, and exhibited mixed symptoms (35%), including pseudo-seizures (33%), and motor issues (18%). Indigenous studies also depict that FNSD is more common in females and with low educational status.[19] Studies conducted in Sweden and Turkey also presented similar findings, i.e., FNSD is associated with low educational level.[20] Likewise, studies Conducted in Pakistan depict that mixed symptoms, unresponsiveness, and jerky movements are a common presentation.[19-21] The duration of illness between onset and diagnosis was reported to be one week (62%) to one month (19%).[7] In another study, it was reported to be less than two years.

Findings of this study further divulge that the 25% patients mentioned 'marriage-related factors' as the reason for the onset of the problem. An indigenous study also confirms that marriage is a significant source of stress for women.[13] The marital system in Pakistan is rooted in an extended joint family system; thereby, it is associated with quarrels and unexpressed emotions.[2] Likewise, stress and conflicts are also found to be associated with FNSD.[22] In a study executed in Sri Lanka, it was found that the patients with FNSD perceive internal, social, and natural factors as the cause of their illness.[23] Patients in this study also expressed belief in magic and viewed their illness as severe, fearing symptom progression into serious illness, disability, or death. Previous studies affirm these findings, as FNSD is still ascribed to supernatural forces/evil eye/black magic, etc.[6] A study conducted in South India also revealed that 42% of patients with FNSD believe in black magic, and 98% of patients thought that their illness was serious.[24] Another study executed in London among Whites, Africans, Zimbabweans, and Asians revealed that a high proportion of Africans and Zimbabweans believe in black magic as compared to Whites and Asians. Asians comparatively perceive FNSD as more serious and are afraid that it may lead to disability.[12]

The study also reveals that 48% participants experience diminished interest in daily activities, worsening relationship problems (32%), emotional (23%), and physical (16%) and financial issues (10%). These findings are consistent with the previous literature, which depicts that patients with FNSD perceive emotional problems and used to feel that their problems influenced their family, work, and social life.[24]

Lastly, it was found that 70% patients expect proper treatment and medications to be prescribed, which was supported by previous studies that a huge percentage of Asians expect tablets or injections to be advised. They are more interested in learning the diagnosis and receiving explanations and advice.[24] In another study also, it was affirmed that the patients reported that they desire adequate support and effective communication from their physicians.[25] Few patients reported that they expect that their treatment will be proved ineffective as they perceive that the doctors have misdiagnosed their illness or lack understanding of the diagnosis, they are suffering from.[11]

This study offers a holistic understanding of patients' emotional, psychological, and social experiences, shedding light on their treatment expectations and providing insights for culturally tailored psychological interventions that can improve patient satisfaction and outcomes. It also serves as a valuable resource for training healthcare professionals, highlighting the importance of empathy and patient-centred Care in medical education. However, the study is limited to hospital settings, excluding patients seeking alternative treatments. The qualitative nature of the research could lead to interpretive inconsistencies, potentially affecting generalisability and validity. Future research should explore cultural formulations, patient experiences and use triangulation methods to deepen our understanding of FNSD patients' beliefs and attitudes.

CONCLUSION

Patients with FNSD commonly present with mixed symptoms, including pseudo-seizures and motor issues. The primary perceived cause is often related to marital problems. The illness is seen as severe, causing significant anxiety about its progression and leading to reduced interest in daily activities and strained relationships. Approximately two-thirds of patients expect effective treatment and medication from hospital visits, while one-third are interested in understanding their diagnosis and receiving advice from doctors.

CONFLICTS OF INTEREST

None to declare

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DISCLOSURE

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1	Sara Latif	PhD Scholar, Centre for Clinical Psychology, University of the Punjab, Lahore, Pakistan	Corresponding author; Conception of Idea, Data Collection, Data Analyses, Manuscript preparation and Preparation of the documents for Article Publication.
2	Dr. Aisha Sitwat	Assistant Professor, Centre for Clinical Psychology, University of the Punjab, Lahore, Pakistan	Supervised the study, Data Analyses, Reviewed and finalized the Manuscript.