ORIGINAL ARTICLE:

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

It is a Qualitative Research Design

PLACE AND DURATION

The study was executed at Department of Psychiatry of six government and four private teaching hospitals of Lahore, Pakistan over a period of 12 months, from Jan 2023 to Dec 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

Majority of the participants were female, educated, students and housewives, with 1 – 6 months duration of the illness, mixed symptoms presentation, pseudo seizures and motor symptoms. The main reasons of onset of illness was mentioned as marriage related factors and familial and social factors and majority participants believe that magic can affect others. The intensity of the symptoms were perceived as 'extreme intense' associated with the fear about the worsening of symptoms and serious discomfort. The main difficulties due to illness was reported to be lack of interest in daily activities, and increase in problem in relationships. The patients 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.

CONCLUSION

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

KEYWORDS

Illness perception, treatment expectation, FNSD

INTRODUCTION

Functional Neurological Symptom Disorder (FNSD) is characterized as genuine experience of psychogenic non-epileptic seizures or functional movement disorders. These symptoms are inconsistent and incongruent with neurologic disease/ pathophysiology that is confirmed via neurological examination or lab findings.[1] FNSD is identified as one of the common occurring disorder for an outpatient neurology consultation.[2] These medically unexplained neurologic symptoms are basically the conversion of emotional problems in to physical symptoms at unconscious level.[3] Its presentation is peculiar with gender, age and geographical area i.e. in women, early adulthood and in low socio-economic countries respectively[4]. The common stressors identified in a study were domestic conflict, death in family, financial issues, illness in family, abuse and drugs intake[5]. Likewise in another Pakistani sample, marriage related problems, family relationships, romantic relationships and religiosity were the most common stress factors reported[6].

The core symptoms of FNSD might be 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[4], unresponsiveness and muteness[5], mixed presentation[6] 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 behavior or perhaps attribute it to supernatural forces/ 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 patient's perception of the impact of the illness on their daily functioning[12]. The main problems due to the illness is 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], however it needs further exploration in cultural context.

Furthermore, patient's help-seeking behavior 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 must be tranquilly understood and in return clearly communicated about their illness, diagnosis and prognosis[15]. They expect proper examinations, scans and investigations and often are willing to sought psychiatric medications or psychotherapy. However, few patients avoid medications due to it side effects[15]. Literature also suggests that properly communicating diagnosis to the patients and psycho educating them about the etiology, 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 conceptualization of their illness, differences in causal attribution, nature of available health care system, and burden of disease complicated access to care[18]. Often the patients are

reluctant to explain nonphysical explanation of their symptoms and the physician themselves are unable to diagnose FNSD in initial settings which eventually result in patients losing their confidence and hope in psychiatric treatment and eventually it results in patient drop out[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 frame of reference and endorsing effective communication between the health care provider and the patients will improve adherence and outcomes in Pakistan.

SUBJECT AND METHODS

Participants

Qualitative research design and non-probability purposive sampling strategy was 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 form all the participants. Demographic Information Questionnaire and Short Explanatory Model Interview (SEMI) were employed to

assess patients and their caregivers' beliefs, attitudes and behavior 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[27].

Procedure

This study was conducted from Jan 2023 to Dec 2023 after approval from Ethical Review Committee of Punjab University. Permission from Head of the six government and four private hospitals and clinics 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 will be allowed to withdraw from study at any time due to any genuine reason. 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 will provide will only be used for research and academic purposes. Furthermore, all ethical considerations were adhered 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 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 categorized, 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 man	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 1 depicts that 2/3rd of the participants were female, educated up to matric, were students or housewives, and few were self-employed. The duration of illness of majority patients were one to six months with mixed symptoms, pseudo seizures and motor symptoms.

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
Don't Know/ Not confirm	10
Perceived intensity of symptoms	
To Some Extent	02
Medium	03
To Great Extent	55
Extreme Intense	40
Perceived fear about illness	
Getting symptoms worse	47
Death	19
Major disability	09
Serious discomfort	17
No fear, other people referred	02
More than one fear	06

The majority of 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, such as an uncongenial home environment, external environmental issues, the death of a close family member, and lack of attention. Financial issues, including business losses and property disputes, were the third most reported factors. Academic and occupational problems, such as poor grades, job stress, and workplace bullying, were also significant contributors. Personal/physical illness was also mentioned as a contributing factor, including accidents, blood deficiency, weakness, hormonal issues, menstrual cycle disturbances, and misuse of medicines. Psychological factors included tension/stress, overthinking, lack of attention, and adjustment issues.

The majority of patients reported a belief in the impact of magic on others, perceiving the intensity of their symptoms to a great extent. Additionally, many patients 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 also reported fears of death and acquiring a major disability.

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

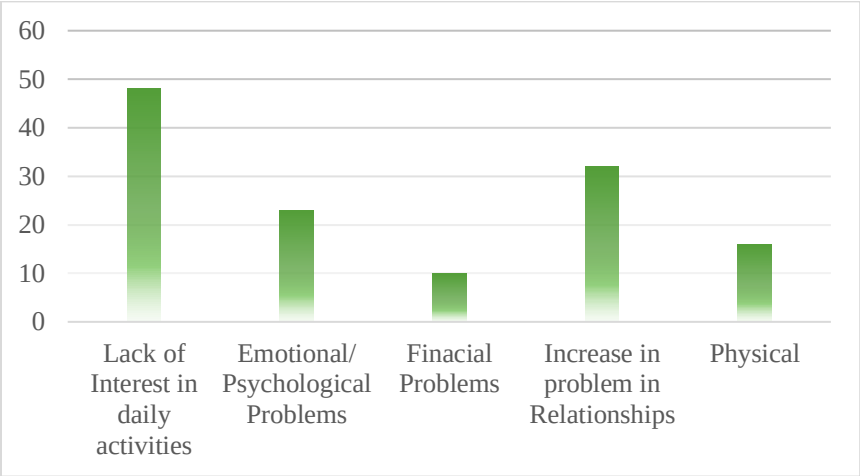

Figure shows that majority of participants reported that their main challenges due to illness were disinterest in daily activities (such as studies or household chores), strained relationships, mood swings (anger, crying spells), muscle pain, and financial difficulties.

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

Table shows majority of the patients reported that they expect proper treatment which was followed by responses that they will learn the diagnosis and will receive advice from doctors regarding their illness.

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 deeply understand patients' illness perceptions and treatment expectations to better optimize clinical practice.

In this study, the socio demographics factors revealed that over half of the participants with FNSD were female, educated up to matric level, had illness durations of one to six months, and exhibited mixed symptoms, including pseudo-seizures and motor issues. Indigenous studies also depicts that FNSD is more common in females and with low educational status[19]. Studies conducted in Sweden and Turkey also came up with similar findings i.e. FNSD is associated with low educational level[20]. Likewise, studies conducted in Pakistan depicts that mixed symptoms, unresponsiveness and jerky movements are a common presentation[19-21]. Furthermore, 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[10].

Findings of this study further divulges that majority patients mentioned ‘marriage related factors’ as the reason for onset of the problem. An indigenous study also confirms that marriage is a significant source of stress for women[13]. As marital system in Pakistan is rooted in 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% patients with FNSD believe in black magic and 98% 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 were afraid that it may leads to disability[12].

The study also reveals that most participants experience diminished interest in daily activities, worsening relationship problems, emotional and psychological issues. 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 majority of the 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 prescribed. They are more interested in learning the diagnosis and of receiving explanation 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-centered 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

generalizability 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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