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Perspectives of patients, caregivers, and healthcare professionals in Indian context: A qualitative study on Medically Unexplained Physical Symptoms (MUPS)

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Abstract:

BACKGROUND: Approximately one-fourth of individuals who seek treatment in outpatient medical settings have Medically Unexplained Physical Symptoms (MUPS), a prevalent medical ailment. Patients with MUPS have a considerable functional impairment, and a lower quality of life, and may also have co-occurring psychiatric conditions.

MATERIALS AND METHODS: Eleven Focus Group Discussions (FGDs) (four virtual and seven face-to-face) were conducted with patients, caregivers, and healthcare professionals in 2021 in a tertiary care hospital in New Delhi. Thematic analysis was carried out using QSR Nvivo software.

RESULTS: A total of 36 participants were recruited in the study, including patients with MUPS (n = 12), caregivers (n = 10), and healthcare professionals (n = 14) dealing with the patients of MUPS. Three themes were identified: burden of MUPS, symptom profile of patients with MUPS, and psychological profile of patients with MUPS. These were further categorized into eight sub-themes: prevalence, symptoms, course of illness, improvement with treatment, duration of symptoms, attribution of symptoms, psychological impact, and coping strategies.

CONCLUSION: The study helped us to gain insight into the characteristics and experiences of patients, caregivers, and healthcare professionals dealing with MUPS in an Indian setup. Greater awareness of MUPS and training of care providers about the occurrence, management, and referral of MUPS can be beneficial.

Keywords:

Allied healthcare workers, FGDs, Indian setup, MUPS, qualitative analysis

Introduction

Medically Unexplained Physical Symptoms (MUPS) is a common medical condition constituting about one-fourth of patients' attendance in medical outpatient settings.^[1-3] Patients suffering from MUPS have significant functional impairment, have a poor quality of life, and may have psychiatric

co-morbidities.^[4] Along with this, healthcare professionals dealing with patients of MUPS recognize them as frustrating and difficult to treat.^[5] This adds to the burden on the entire healthcare system and restricts the provision of robust care.

Studies in the West have tried to gauge the understanding and experiences of these patients, family members, and healthcare

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professionals.^[6-8] Patients are often stressed and anxious about their physical health.^[8,9] Whereas caregivers disregard the problems of the patients and at times look upon them as *malingers*. Such perceptions of individuals are often influenced by socio-cultural factors. Therefore, this necessitates the need to study the perspective of all stakeholders (patients, caregivers, and healthcare professionals) in different settings to develop a better insight into the problem. Previous studies have looked at the opinions of patients and healthcare professionals separately, and none of them has made an inclusive comparison of accounts of different stakeholders which can be useful to understand the focus and approaches towards MUPS. This exploratory study is the initial effort to understand the life experiences, symptoms, and impact on the lives of patients with MUPS from among different stakeholders involved in the care of such patients (the patients themselves, their family members, and health care providers. Every psychological problem including MUPS is bound to be affected by the sociocultural milieu of a country, thus making it necessary to investigate it in a large country with 125 million population.

Materials and Methods

Study design and settings

This qualitative study was conducted in the department of medicine at a tertiary care center in North India. It consisted of focus group discussions and thematic analysis. The index study followed COREQ (COnsolidated criteria for REporting Qualitative research) guidelines.^[10]

Study participants and sampling

Participants were selected through convenience and snowball sampling methods between September to December 2021. The principle of maximum diversity was conserved by recruiting participants from various socio-economic, occupational, and educational groups. Participants belonged to one of the following three groups:

Group 1: *Patients with MUPS*: MUPS patients between 18 and 60 years of age, who could communicate in Hindi and/or English, and whose diagnosis of MUPS was confirmed by the consultant were included in this group.

Group 2: *Caregivers of patients with MUPS*: Parents/caregivers of patients with MUPS, aged 18-60 years, staying with the patient for a minimum of two years, and willing to give written informed consent. Caregivers were excluded if another family member also had a psychiatric, neurological, or chronic medical illness.

Group 3: *Healthcare professionals*: This group included physicians, psychiatrists, and clinical psychologists

specialized in managing MUPS cases and having at least three years of work experience.

Outcome measures

Focus Group Discussion (FGD) guide: FGD guide was prepared for the study to gather information on the symptom profile, quality of life, and coping mechanisms of patients with MUPS. It had open-ended questions to discuss with patients, caregivers, and healthcare professionals. We developed FGD moderator guides that were prepared for each group of patients, caregivers, and healthcare workers [Table 1a and 1b].

Procedure

The methodology has been shown in Figure 1.

Table 1a: Semi-structured guide for the FGDs (patients and attendants)

What are the symptoms that you experience?
 How long have you had these symptoms?
 What has been the course of your illness?
 What impact do these symptoms have on your quality of life?
 How much distress do these symptoms cause you in your day-to-day life?
 What do you attribute these symptoms to?
 How much improvement in your symptoms have you felt with the treatment being offered to you?
 How are you dealing with your symptoms?

Table 1b: Semi-structured guide for the FGDs (healthcare professionals)

Case 1: A 55-year-old lady presents to the OPD with complaints of pain at multiple sites for 2 years for which she had been to multiple doctors over the last 2 years. She had undergone many tests but doctors were unable to give her a diagnosis. She spoke extensively about distress caused by her symptoms.
 Case 2: A 30-year-old lady presents to the OPD with complaints of 'ghabraha' and dizziness. She also complains of excessive 'gas' formation because of which she always felt bloated. She also has complaints of on-and-off headaches.
 Have you experienced [or seen a person who has experienced MUPS] a condition like the one described in the case? How is it described/named in the local idiom?
 What are some of the most commonly reported symptoms by these patients?
 What is the local people's understanding of the nature, causation, and manifestations of such an illness? (What impact do these symptoms have on the patient's life and how much distress is caused to them as a result of these symptoms?)
 How commonly do you encounter patients with medically unexplained physical symptoms in clinical practice?
 How do people afflicted by this condition manage it?
 How important do you think is it to create a diagnostic scale based on local data?
 What do you think should be the response format of the proposed scale?
 What rating format should be used so that patients can rate the severity of their symptoms?
 Symptoms occurring during what period should be included in the scale?

The FGDs have been conducted online as well as offline mode. Patients and attendants visiting the outpatient services of the Department of Medicine were contacted for the FGDs. If they fulfilled the inclusion and exclusion criteria and agreed to participate, they were allotted a specific day and time for the offline discussion and were reminded about the session one day prior. For healthcare workers, a formal mail was sent and those who agreed to join the discussion were provided with a link for an online meeting.

The offline discussions were held in the Medicine OPD of the tertiary care hospital whereas the online discussions were carried out over a video conferencing platform, Google Meet. The participants were explained the purpose of the discussion before enrollment. Each FGD was moderated by one of the investigators, and the FGDs lasted for about 45 minutes to 1 hour. Most of the discussions were carried out in the Hindi language. These discussions were guided using semi-structured guiding questions to facilitate the discussion (included in Table 1a and 1b). The open-ended questions ensured discussion on various issues related to MUPS. The participants were probed to elaborate upon their views. Saturation was determined when similar responses were recorded among the participants. Each session was audio and video recorded with the participants' permission. All FGDs were then translated from Hindi/bilingual to English by following the standard translation-procedures to ensure the actual meaning for further analysis.

Data analysis

QSR Nvivo was used to process the data. A co-author transcribed the discussion verbatim. Two of the authors coded the transcriptions and generated themes and subthemes. Further, the investigator triangulation method was adopted to ensure the trustworthiness of data, enhance the objectivity of the coding, and reduce biased decisions

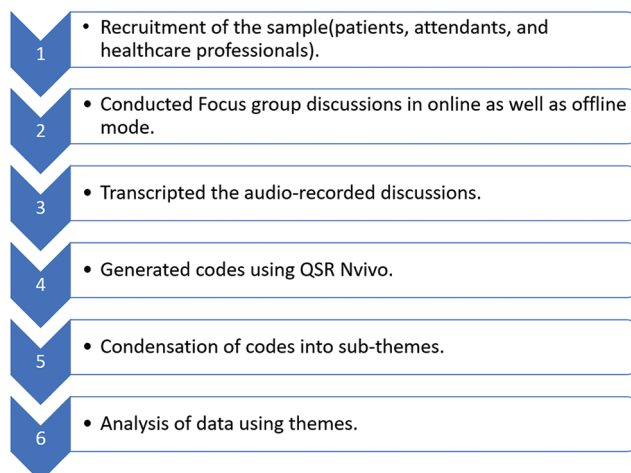


Figure 1: Methodology for conducting FGDs and Thematic analysis

in category development. Three other independent experts reviewed codes and categories. To reduce biased decisions and differences in the coding scheme (differences considered if disagreements >50%) and to generate alternate opinions, frequent debriefing sessions were held amongst researchers to reach a consensus.

Ethical consideration

The ethical approval was obtained from the institute's ethics committee (IECPG- 293/22.07.2020). Informed consent was also obtained from all participants before enrollment.

Results

Participant characteristics

A total of 36 participants were included across eleven FGDs including patients (N = 12), caregivers (N = 10), and healthcare professionals (N = 14). The age of the participants ranged from 20 to 61 years. More than half of the total participants were females and the majority of them belonged to the urban residence. The socio-demographic profile of the participants is presented in Table 2. Eight sub-themes were generated, which are presented in Table 3.

Burden of MUPS

Healthcare professionals reported that up to 25–30% of the patients attending the hospital are diagnosed with MUPS. Most of these patients are middle-aged females and those belonging to lower-socio economic strata.

Symptom profile of patients with MUPS

The participants in the study described their experience with MUPS. They reported some of the symptoms which

Table 2: Socio-demographic characteristics of the participants (n=36)

Demographics	Frequency (Percentage)
Age	20-61 years
Gender	
Male	16 (44.44%)
Female	20 (55.56%)
Group	
Patients	12 (33.33%)
Attendants	10 (27.77%)
Healthcare professionals	14 (38.90%)
Residence	
Urban	24 (66.66%)
Rural	12 (33.34%)
Educational qualification	
Illiterate	02 (5.55%)
10 th Pass	05 (13.88)
12 th Pass	10 (27.77%)
Graduated/MBBS	09 (25.00%)
Post-graduated/MD	08 (22.22%)
DM/PhD	02 (5.55%)

Table 3: Sub-themes generated from Focus Group Discussions

	Patient	Caregiver	Healthcare provider
Prevalence	NA	NA	H11: "What I have seen is that, I feel that 25 to 30% of a normal medicine OPD would comprise such patients." H4: "It is usually found in middle aged ladies." H2: "Generally it is seen in the patients belonging to lower socio-economic status." H3: "Lack of sleep is another main issue. According to them, the pain doesn't let them sleep." H10: "So I think that the basic complaint that most of our patients have is that they have some sort of heartburn, burning sensation from the inside, feeling of tightness in the chest all the time."
Symptoms	P3: "I sometimes have pain in my back, sometimes in my shoulder, and sometimes in my hands or feet." P7: "Sometimes I feel dizzy for a minute or so and feel as if my head is spinning which resolves on its own." P8: "I'm having chest pain then I might be having a heart attack." P11: "I have a sudden dry cough after which I find it difficult to breathe."	A4: "Gas and burping"	
Course of illness	P2: "My symptoms have had a fluctuating course. Sometimes they increase and sometimes they decrease."	A3: "Her problems have been pretty much the same and while she is taking medicines, she is better but as soon as the effect of the medicine wears off, her pain starts again."	NA
Improvement with treatment	NA	A6: "She is normal when she is taking medications but after stopping medications her symptoms start again."	NA
Duration of symptoms	NA	A9: "She has had these symptoms for the last 5 years."	H11: "Regarding the OPD patients that we have seen, I think maximum patients have a history of approximately 3-6 months with some patient's symptoms dating back to even 2 years."
Attribution of symptoms	P9: "I think my symptoms are because of hypothyroidism."	A7: "I feel most of her symptoms are the result of stress and tension. Tension is mostly related to household matters as my husband also has cancer."	H11: "More often than not these patients are the ones who are sitting at home or are housewives and probably there could be some, I am not sure, some involvement of primary or secondary gain."
Psychological impact	P3: "I face a lot of distress because of my symptoms. Sometimes I feel like I won't survive."	A6: "She is stressed because she has been taking treatment for quite some time now but there has been only slight improvement and she is not completely fine." A7: "She is unable to sleep."	H6: "these symptoms are very troublesome to the patients. Their day-to-day activities are suffering. Their quality of sleep, as well as routine activities, are affected and they are physically distressed but they are mentally more distressed."
Coping strategies	P10: "Physical work gives me both a sense of physical and mental well-being". P5: "I try not to think too much about these things."	A10: "She doesn't like anything and does not want to go anywhere." A4: "She has also tried <i>ayurveda</i> for her symptoms".	NA

could be further classified into seven categories (*pain, respiratory, cardiovascular, gastrointestinal, biological function, somatic and non-specific somatic sensory*). Most of the patients and their caregivers reported that these symptoms are prolonged and have been present for several years. The symptoms have been found to improve partially after taking medications but as soon as the medication is stopped, the symptoms are back with the same intensity. The course of illness is found to be somewhat fluctuating between moderate to severe in most cases. The excerpts have been provided in Table 3.

Psychological profile of patients with MUPS

The participants reported that the undiagnosable nature of these symptoms causes a significant level of psychological distress among the patients as well as their caregivers. Psychological distress is further categorized into four domains namely, *physiological, behavioral, emotional, and social*. As most of the domains of individuals' lives are affected, it harms the quality of life. To deal with the distress caused due to these symptoms, patients resort to several coping strategies. These coping strategies are further categorized into three

major domains Behavioural, *psychological and alternative medical treatments*. The healthcare workers also addressed the issue of hesitancy in seeking help from a mental health professional. Patients believe that their illness has an organic cause, which makes them reluctant in seeking psychological intervention. The excerpts have been provided in Table 3.

Discussion

This qualitative study has given us a divergent perspective and enriched our understanding of the lived experience of patients, caregivers, and healthcare professionals regarding MUPS in an Indian setup. The study has yielded certain noteworthy findings.

Firstly, MUPS is an important disease in an Indian setup. Significant prevalence and morbidity have been attributed to the remarkable burden of the disease in the healthcare system. The healthcare professionals reported that one-fourth of the patients presenting to the hospital are diagnosed with MUPS, which is well supported by previous studies.^[1,11] These patients present with a variety of symptoms such as pain, bloating, loss of consciousness, and “bizarre complaints that are often difficult to characterize. These symptoms persist for a long time in many and may become severe with time and difficult to treat. It can cause an inability to perform day-to-day tasks and can result in psychological distress.^[3]

Secondly, the approach of healthcare professionals toward MUPS patients requires refinement. The general approach is to counsel the patients that there is no underlying cause and therefore they should not continue to worry about the issue. This approach usually has the effect of unsettling the patient even further as they continue to be plagued by the symptoms without any hope of remedy and now feel like their complaint has been neglected, instead of being addressed by the doctor. The absence of diagnosis causes distress and dissatisfaction among the patients and the caregivers, which the doctor’s advice fails to consider or assuage.^[12] The treating physician needs to acknowledge the psychological impact caused to these patients rather than invalidating the patient’s lived experience of pain or sickness. Healthcare professionals, if trained well to deal with MUPS patients, can impart a great level of confidence to these patients. In the absence of this, the patient comes back from the consultation even more disturbed and anxious than they were going into it. Additionally, they may be newly uncertain about whether help can be provided to them at all.

Another important point that we found during discussions is that patients with MUPS are often hesitant

in seeking help from mental health professionals. These patients have a firm belief that there is an underlying physical cause to their symptoms, which is not being diagnosed by medical professionals. It is not commonly known that mental and emotional turbulence can present itself as physical symptoms. Therefore, it is far easier to believe the assumption that the doctor is unable to locate the problem because of either incompetence or apathy. This hesitancy in approaching a mental health professional is exacerbated due to the stigma associated with mental health in India.^[13-15] Since patients with MUPS do not exhibit symptoms of mental instability in their perception, it is difficult to convince them that the answers to their physical sickness lie with mental health professionals.

During the interviews, it was seen that different aspects of MUPS were of concern to the different stakeholders. While the healthcare providers were more cognizant of the burden and prevalence of MUPS in the clinical setting, the patients and attendees did not highlight such facts. Symptom profile and psychological impact of the symptoms were highlighted by the patients, caregivers, and healthcare providers. The attribution of symptoms was different across patients, caregivers, and healthcare providers, with a disease being an attribution of symptoms by the patients, and caregivers thinking about stress and worry as the cause, while healthcare providers invoked constructs like primary or secondary gain. The healthcare providers and caregivers did emphasize the chronicity of the problems, and fluctuation of the symptoms being highlighted by the patients and the caregivers.

Therefore, creating awareness at the community level about the existence and prevalence of MUPS and an appropriate approach for management is important. The current way of dealing with this problem fosters increased anxiety among patients and caregivers and distrust for healthcare providers. Patients often do not feel heard or reassured when the doctor tries to soothe them, and the doctor’s credibility suffers as a result. With more awareness and training, healthcare professionals can adopt more emotionally intelligent and medically appropriate ways of dealing with a distressed patient presenting with MUPS, and if needed, direct them to a mental healthcare professional who can effectively address the complaint. Correspondingly, when there is more information about MUPS in the public domain, the patient also may become more receptive to a multidisciplinary course of treatment involving psycho-therapy, which resolves their complaint as well as reduces the burden on the healthcare system as a whole provided the patients desists from visiting different doctors and trying to find the elusive physical cause to their illness. Policymakers need to make a

dedicated plan to address MUPS, as it continues to be under-reported and largely untreated despite being responsible for a large number of persisting cases in the healthcare system.

Limitations and recommendation

There are several strengths associated with this study. This includes understanding the perception of all the stakeholders (patients, caregivers, and healthcare professionals) regarding MUPS in an Indian context. However, it has the limitation of any qualitative study. The same material can be inferred in different manners by different individuals. The directions of qualitative interviews of the patients, attendees, and caregivers were different. We did not seek to triangulate the data.

Conclusion

The study helped us to gain insight into the characteristics and experiences of patients, caregivers, and healthcare professionals dealing with MUPS in an Indian setup. Patients with MUPS are often found to have psychological distress, causing impairment in their day-to-day functioning. Therefore, acknowledging the psychological impact the physicians in primary care will help in developing confidence among the patients and will make them receptive to a multidisciplinary course of treatment involving psychotherapy which resolves their complaints as well as reduces the burden on the healthcare system as a whole.

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Conflicts of interest

There are no conflicts of interest.

References

1. Baitha U, Deb KS, Ranjan P, Mukherjee A, Baudhh NK, Kaloia GS, *et al.* Estimated prevalence of medically unexplained physical symptoms in the medicine outpatient department of a

2. tertiary care hospital in India. *Gen Hosp Psychiatry* 2019;61:47-52.
3. Kashyap A, Chopra S, Ranjan P, Sarkar S, Poorna A, Baitha U. Yoga therapy for medically unexplained physical symptoms. *Adv Mind Body Med* 2020;34:17-21.
4. Rao GR, Ranjan P, Chadda RK, Kaloia GS, Dwivedi SN, Baitha U, *et al.* A descriptive study of disability in patients presenting with medically unexplained physical symptoms in a medical OPD setting. *J Family Med Prim Care* 2019;8:1755-9.
5. Dirkzwager AJ, Verhaak PF. Patients with persistent medically unexplained symptoms in general practice: Characteristics and quality of care. *BMC Fam Pract* 2007;8:33.
6. Brownell AK, Atkins C, Whiteley A, Woollard RF, Kornelsen J. Clinical practitioners' views on the management of patients with medically unexplained physical symptoms (MUPS): A qualitative study. *BMJ Open* 2016;6:e012379.
7. Claassen-van Dessel N, Velzeboer F, van der Wouden J, den Boer C, Dekker J, Van Der Horst HE. Patients' perspectives on improvement of medically unexplained physical symptoms: A qualitative analysis. *Ment Health Fam Med* 2015;11:42-8.
8. Aamland A, Fosse A, Ree E, Abildsnes E, Malterud K. Helpful strategies for GPs seeing patients with medically unexplained physical symptoms: A focus group study. *Br J Gen Pract* 2017;67:e572-9.
9. Knapen J, Vancampfort D, Moriën Y, Marchal Y. Exercise therapy improves both mental and physical health in patients with major depression. *Disabil Rehabil* 2015;37:1490-5.
10. Mohebibi B, Tafaghodi B, Sadeghi R, Tol A, Yekanenejad MS. Factors predicting nutritional knowledge, illness perceptions, and dietary adherence among hypertensive middle-aged women: Application of transtheoretical model. *J Educ Health Promot* 2021;10:212.
11. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-57.
12. van Dessel N, den Boeft M, van der Wouden JC, Kleinstäuber M, Leone SS, Terluin B, Numans ME, van der Horst HE, van Marwijk H. Non-pharmacological interventions for somatoform disorders and medically unexplained physical symptoms (MUPS) in adults. *Cochrane Database Syst Rev.* 2014 Nov 1;(11):CD011142. doi: 10.1002/14651858.CD011142.pub2. PMID: 25362239.
13. Sabouri M, Shakibazadeh E, Mohebibi B, Tol A, Yaseri M, Babae S. Effectiveness of an educational intervention using theory of planned behavior on health care empowerment among married reproductive-age women: A randomized controlled trial. *J Educ Health Promot* 2020;9:293.
14. Grover S, Avasthi A, Singh A, Dan A, Neogi R, Kaur D, *et al.* Stigma experienced by caregivers of patients with severe mental disorders: A nationwide multicentric study. *Int J Soc Psychiatry* 2017;63:407-17.
15. Sarkar S, Punnoose VP. Stigma toward psychiatric disorders: What can we do about it? *Indian J Soc Psychiatry* 2016;32:81-2.
16. Karimi N, Saadat-Gharin S, Tol A, Sadeghi R, Yaseri M, Mohebibi B. A problem-based learning health literacy intervention program on improving health-promoting behaviors among girl students. *J Educ Health Promot* 2019;8:251.