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A Qualitative Study to Explore Various Meanings of Mental Distress and Help-Seeking in the Yamuna Valley, North India

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Abstract

Context: In rural India, mental healthcare remains limited due to scant state services and incongruency between provider- and patient-framing distress. Help-seeking by people with mental health problems is related to how meanings of distress are understood differently by individuals, based on their interaction with various actors in the community and the available cultural explanation within their local ecologies. **Methodology:** This study examines the mutually constituted relationship between meanings of mental distress and help-seeking among people residing in the Upper Yamuna Valley, Uttarakhand, North India. This qualitative study builds on six in-depth interviews with people with severe mental health issues and one person with epilepsy, referred as people with psychosocial disability (PPSD) in the study. The data analysis was iterative and followed thematic approach. **Results:** The study found that personal belief based on one's experience, such as negative self-judgment and wider cultural explanations, such as supernatural beliefs, as well as gender roles, impacted the way people address their mental health problems, in turn shaping their help-seeking behavior. Participants lost hope for a cure after years of trying to find an effective solution. Moreover, lack of access to care and remoteness of the mountainous area made help-seeking and recovery feel impossible. **Conclusions:** This study underscores the need for researchers and policy professionals to explore the local context and culture to improve care and treatment quality. The study also explains that personal explanation of psychosocial problems and help seeking are not unidirectional. It is a complex phenomenon layered with the local contexts which should be addressed in clinical practice, as well as future research. Finally, clinicians' training should address the local cultural language of distress to identify the problem and suggest an effective solution.

Keywords: *Help-seeking, India, mental distress, rural, traditional healer*

Introduction

One in seven people in India is affected by mental health issues.[1] Despite continuous efforts to improve mental health through national policies,[2,3] people with mental health issues struggle to access care, especially in rural and remote areas. We used the term "people with psychosocial disabilities (PPSD)" to include people both formally diagnosed with mental health issues and those who have not received a formal diagnosis. The term is also preferred in other studies where people have experience negative social factors such as exclusions, stigma, and shame because of their diagnosed or undiagnosed mental health issues.[4]

Social determinants of mental health,[5] low service availability, limited awareness by community members, and scarcity of trained mental health professionals[6] are major factors that exacerbate lack of access to care. In addition, mental health professionals and the government mental health services in India remain unresponsive to local and cultural contexts which shape the help-seeking behavior of people with mental health problems and their caregivers.[7-9]

Mental health concepts held by the majority of the Indian population are often constructed from notions and explanations inherently tied to their sociocultural identity (for example, gender or caste), and local ecology[10,11] and their cultural context. The term "idiom of distress" (used first by Nichter in 1981[12]) expresses how distress is conveyed within a given culture and ranges from interpersonal to political and spiritual factors. Common "idioms of

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distress" in the Indian subcontinent include "thinking too much,"[13] "tension,"[14,15] and feelings related to the "body and mind,"[16,17] and these influence help-seeking.[18] Yet, in India, a narrow biomedical understanding of mental health dominates most clinical encounters.[8] Thus, culturally relevant "idioms of distress" are underdiagnosed or made to fit into existing western psychiatric diagnostic categories.[7,8,56]

This "cultural chasm" between state mental health providers and PPSD exists in both rural and urban areas[12,19] and limits help-seeking and access to care.[20,21] For example, a comprehensive mental health intervention in Madhya Pradesh for people with depression and alcohol use concluded that increasing human resources and clinic space did not improve mental health and proposed that contextually appropriate community-based care was critical for improving mental health outcomes.[20]

Understanding the way sociocultural identity and cultural contexts shape distress and help-seeking is key to improving mental health provision in India – especially in rural and remote regions.[22,23] This study seeks examine the relationship between meanings of mental distress and help-seeking among people residing in the Upper Yamuna Valley. It explores how individuals describe and understand mental distress and are cared for within this remote rural setting.

Methodology

Setting

The study was set in the rural hilly terrain of Uttarkashi district, in the Upper Yamuna Valley, in Uttarakhand state. The area had been identified as a place with sparse population and very limited access to care and a rich culture. The study location was first identified as an important location for integrated rural mental health program run by Burans - a community mental health organization, and the research question was set based on the experience and observations made by MR and KM during the initial months of project implementation. In the Yamuna Valley, people work primarily in agricultural production. The population is principally Hindu, with a significant Dalit community and a small minority of migrant laborers predominantly from Nepal. Table 1 profiles the study's area characteristics underlining its high rurality and low literacy. There are two community health centers in Naugaon block, and the nearest government hospitals are in Dehradun and Uttarkashi (both 150 km distant). There is only one mental hospital in Uttarakhand, located in Selaqui (120 km away). The setting of the mental health system in Uttarkashi district has been described in greater details in another paper by the same group of authors.[24] Traditional healers known as "*Mali*" (oracle) are perceived as having direct relations with Gods and often the first consulted for mental health problems in the region.

Study participants

Seven in-depth interviews of PPSD were conducted. All the participants had severe mental disorders (SMDs) except AB, who had epilepsy. Table 2 provides further details on participants. The respondents were purposively sampled to represent a spread of experiences and sociodemographic identities. At the time of the study, all the participants were active stakeholders of Burans and fulfilled the criterion of having severe mental illness as per the mental health assessment conducted by trained community workers using tools such as SRQ20[25] and PHQ9[26] in the beginning of their engagement. The participants were informed about the purpose of the study using plain language statement form and all those who consented were included. There was no case of nonparticipation.

Data collection process

Data collection was conducted from August to December 2019 by MR, KM, and two social work interns living in Naugaon at this time. Interviews lasting 30–90 min were conducted in Hindi and Garhwali (local language spoken in Uttarakhand, North Indian state of India) and recorded. Participants were contacted face to face by community health workers from the host project, at their home. Five out of seven interviews were conducted alone with the PPSD; however, in two interviews (EF and IJ), caregivers were also present. MR and two field assistants transcribed the recordings and then translated them into English. The field notes were made by MR after each interview which also included informal conversation with caregivers and community members. The interview schedule was prepared by MR with consultation of KM

Table 1: Sociodemographic profile of the study block with the district, state, and national comparison data

Indicator	National - India	Uttarakhand	Uttarkashi	Naugaon block
Total population	1200 million	10.1 million	3.3 lakhs	60 thousand
Percentage population rural	72.2	69.5	92.6	100
Percentage population SC	16.6	18.76	24.41	29.14
Percentage population ST	8.6	2.89	1.06	0.97
Sex ratio (female to 1000 males)	940	963	1031	969
Literacy (percentage literate female)	65.5	70.1	62.3	40.0
Literacy (percentage literate male)	82.1	87.4	88.8	59.0

SC=Schedule caste, ST=Schedule tribe

Table 2: Profile of people with psychosocial disability participating in the study

Pseudonym	Sex, age	Caste[§]	Marital status, type of mental health problem	Household composition
SD	Female, 53	SC	Widow, SMD	Lives with her son, daughter-in-law, and granddaughter. Has no one in the maternal family
PD	Female, 55	SC	Married, SMD	Lives with her partner and has one son and six married daughters. Son went to the city for work
AB	Male, 26	OBC	Unmarried, epilepsy	Lives with his parents and younger brother. Mother is the primary caregiver
CD	Male, 37	OBC	Unmarried, SMD	Lives with parents. Mother is the primary caregiver
EF	Male, 34	SC	Separated, SMD	He lives with his parents and two brothers. Mother is the primary caregiver
GH	Male, 51	SC	Divorced, SMD	He lives with his 70-year-old mother and 11-year-old nephew
IJ	Male, 32	SC	Married, SMD	Lives with father, wife, and elder brother

[§]As per the Indian constitution for the purpose of affirmative action the population has been divided into 4 groups - General, OBC, SC, and ST. OBCs, SCs, and STs are the disadvantaged categories. OBCs=Other backward classes, SC=Schedule caste, ST=Schedule tribe, SMD=Severe mental disorder

after reviewing the literature and conducting preliminary field visits. The interview schedule was first piloted with four participants, and changes were made accordingly. The detailed questionnaire and tables containing lists of culturally specific terms and idioms used by community members to describe their psychosocial problems can be found in Appendix 1. Verbatim quotes are identified with the convention: sex, age, caste, marital status, and type of mental health problem, e.g., SMD to protect their anonymity.

Data analysis

Data analysis followed the thematic analysis approach described by Braun and Clarke (2006)[27] paying attention to the journey of help-seeking, illness and meanings of distress, and how they are constructed and re-constructed. First KM and MR coded the same three interviews using inductive gerund-based codes that were entered into Open code software[28] and compared and contrasted their codes to develop a coding framework. MR then re-coded remaining interviews. During the coding process, high level of repetition was observed in the last two interviews and no new themes emerged. At the end, a total of 240 codes and 21 categories emerged. Table 3 illustrates the process of coding. Categories were then discussed with the whole author team, and with discussion and analysis through the development of Figure 1, three themes were identified: meaning of distress, help-seeking, and role of sociocultural identity emerged with eight subthemes. During the analysis process, MR tracked different explanations which made PPSD and their caregivers choose their journey of seeking mental health care. A common and complex pattern was observed which is illustrated in Figure 2 of the Discussion section. Triangulation across different villages and participants and analysis by authors with different geographic, academic, and ethnic backgrounds increased the study's credibility.

Researcher stance

MR (female) was born and spent her childhood in urban Uttarakhand. SJ (male) is an Indian, trained and worked in India for the past 35 years. CB (male) has researched in India for several years. KM (female) is a New Zealander who has lived more than 20 years in India and speaks fluent Hindi.

Ethics

All participants were informed about the purpose of the study and gave written consent. Emmanuel Hospital Association Institutional Ethics Committee, New Delhi, in August 2019 approved the study proposal, Protocol No. 208.

Findings

In the study, it was found that different sociocultural explanations and social identities are used to understand mental distress which impacts help-seeking behavior. Figure 1 illustrates this relationship where external forces such as social relationships and cultural beliefs both impact the way distress is understood. For example, some believed mental distress to be a curse while others believe it to be a bad luck. Similarly, an example of the influence of the sociocultural environment is seen in the widespread trust in traditional healers or the way that gender relations are understood determining the pathway to care. Below are the three themes and their inter-relationships are described in detail.

Meaning of distress

"Thinking too much" makes mental distress worse

PPSD described how excessive thinking amplified their mental distress and that they could not understand where distress came from or where to seek help. They described feeling scared, angry, and worried and felt that "thinking too much" may have caused the problem in the first place, as described below:

Table 3: Example of coding and thematic development process

Original text	Codes	Interim theme	Final theme
For mental health issues, we go to our *Devta* (God). We seek God's blessings before and after everything, that is imbibed in our culture. We do it with the help of *mali*. They bless families and treat any illness	Faith in nonmedical healing methods *Devi-devta* bring recovery Role of *mali*-Central to family operations	Religious practices and their impact on people's help-seeking behavior	Dominant magico-religious explanatory framework

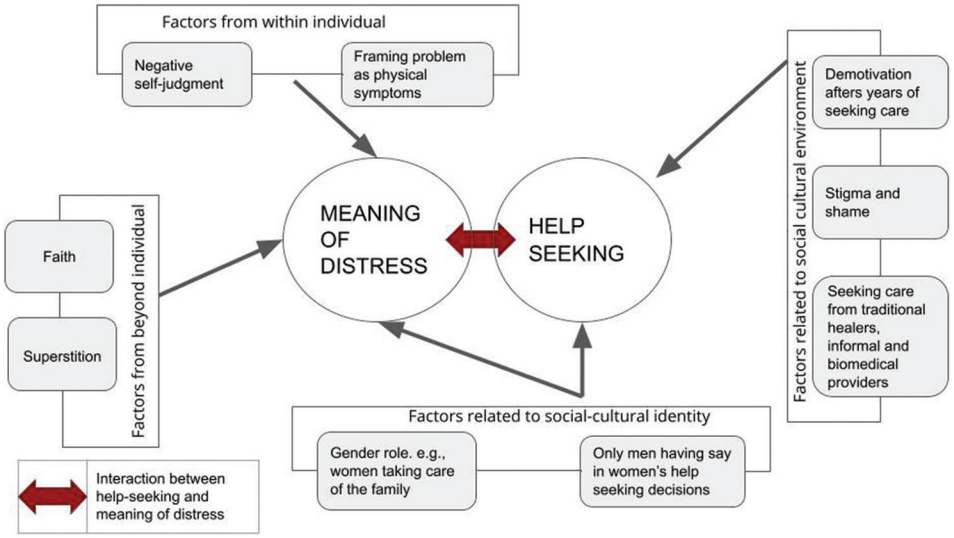

Figure 1: Schematic description of the interaction between the meaning of distress and help-seeking

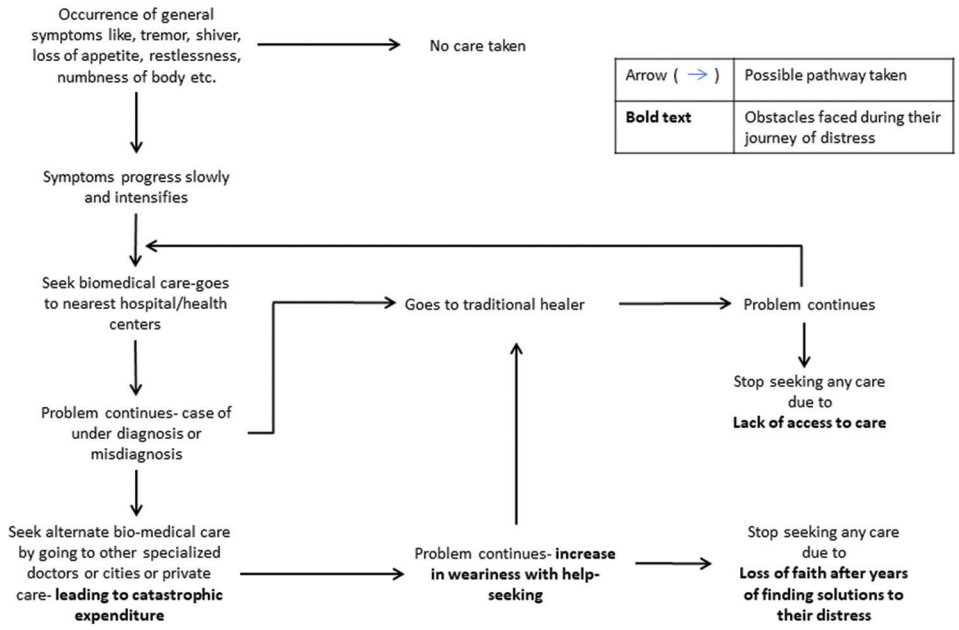

Figure 2: A representative journey of the distress of a person with psychosocial disabilities

"I feel unfortunate, and I am unable to sleep, also waking up screaming sometimes () If I hear of some mishap, I easily get worried () People ask me not to worry too much, and the reason behind my problem is that I think too much and easily get stressed." (M, 32 years, SC, Married, SMD).

Bodily expressions of distress

Somatic symptoms marking mental distress were common and included headaches, pain, tiredness, trouble sleeping, and appetite loss. Treatment is focused on treating these physical symptoms. As a result, the mental and psychosocial problems

Table 4: Glossary-common ways of expressing distress

Idioms	Description	Category
I am unable to relax. *"koi aram nahi hain…bahut pareshan rehti hu"*	The respondent felt incapable of doing everyday chores or handling everyday matters. It can also mean that the person is not satisfied with their current treatment process	Bodily expression of distress
I am unable to sleep… and constantly keep thinking something or other thing "*Main so nahi pati, kuch na kuch socthi rehti hu…dimag main koi na ki khayal ata rehta hain*"	The respondent has a regular occurrence of negative thoughts and feels distressed or anxious while resting or alone	
I feel week and tired for no reason. "*Bahut kamjori aur thakan mehsus hota hain*"	Excessive fatigue after any small chore or physical exertion. The respondent experienced tiredness as distressing	
I feel restlessness. "*Jhan-jhanahat hota hain*"	The respondent cannot breathe easily; feels a trembling or shaking sensation in the entire body	
My body tremors. "*Kapan hota hain poore sharer main*"	The respondent feels shaking and shivering; this may be re-occurring at various intervals	
The whole body pains all the time. "*Sarrer main dard hi rehta hain*"	There is a feeling of bodily weakness or exhaustion accompanied by physical pain or aches. It can last for days or longer, something which cannot be explained by a physical problem	
My body is giving up. "*Sarrer main jaan nahi hain*"	Feeling mentally or physically tired and unable to restore energy after minor tasks. It can last for days or longer	
I think too much. "*Sochti rehti hu*"	Emphasis is on unpleasant thoughts, difficulty concentrating or focusing on one task, and experience decrease in productivity level	Distress related to mind and body relationship
My mind has gone numb "*Dimag sun ho gaya hain*"	Often expressed by people when they feel angry, get in rage or feel bewildered	
I want to stop these bad thoughts in my mind. "*Mere dimag ke bure khyal se mukti chahie*"	It expresses a suicidal feeling, perhaps due to feeling overburdened to family members	
I don't have any physical problem now but I still feel restless and have constant pain "*mijhe ab koi beemari nhi hain par mujhe abhi bhi ajeeb sa lagta hain…jese pet main kuch hora ho*"	Symptoms are related initially to some physical disorder but later exaggerated by psychological factors like financial issues, fear of not getting better, or no satisfaction from treatment	
Not feeling happy about anything good. "*Achi cheezon ka sun ke bhi khushi nahi hoti*"	After years of finding an effective solution to their problem and spending lots of money during the process, there is a feeling of weariness. Also, there is the loss of any hope to get better	Psychological distress
I have episodes of sadness every 3-8 months. "*Har 3-8 mahine main mujhe bhut bekar mehsus hota hain*"	A feeling that one is useless or good for nothing	
I just want to be alone. "*mujhe akele rehna hain bus*"	Feeling irritated around people and uncomfortable conversing socially	
I get angry very easily. "*Choti Choti baat par gussa ata hain*"	Feeling angry and irritated without any reason	
I have tension, also have headache. "*Tension hoti hain. Sir dard hota hain bhut*"	Here the tension (often used English word) describes headaches or aches without any physical problem. It could also denote the psychological distress of worrying about family and their well-being, family finances, marriage, etc.	

are missed and/or dismissed as unimportant, as outlined below:

> "I feel restless and have constant pain in my ankles and hand. Eight-nine years ago, suddenly, my body started tremor - "*kap kap*" and shiver () that is when I went to see the doctor. The doctor said that my nerves are not circulating blood, and the food pipe was blocking. I got better, but the blackness on my body was still there, and then I started feeling anxious () doctor told me not to worry and that nobody dies of this." (F, 55 years, SC, Married, SMD).

Often, PPSD used words or sounds such as "*jhan-jhan*" or "*kap-kap*" to denote a tremor or a feeling of uneasiness which they found hard to explain. PPSD and their families were also responsive in seeking care when there were unbearable and explainable physical symptoms. However, as the problem persisted, they continued to

Table 5: Terms commonly used in Yamuna valley by community members to refer to person with psychosocial disability people with psychosocial disabilities

Common terms used for PPSDs	Description
Mad - "*Jhalla*" Mental - "*Pagal*" Cracked - "*Teda/lata*" Someone with no sesnse/senseless person - "*Kuch samajh nhi hoti*" Crazy/half minded - "*Sanaki*" Bad/useless person - "*Bekar Admi*" Carefree - "*Awara*" Someone who is different from mind - "*Dimag se alag*"	Terms interchangeably used to describe someone who does not carry themselves properly in public or who is unconcerned by their social presentation. Someone who is not well-groomed does not understand what others say or does not know the difference between right or wrong. The person is considered to have little sense of social relationships
Someone possessed by evil spirit - "*Chudail lag jata hain*"	Someone possessed by an evil spirit leads to a culturally accepted ceremony or rituals performed by traditional healers
Someone with bad luck - "*Naseeb hi kharab hota hain*"	Someone considered having bad luck. It can be understood as punishment by God

PPSD=People with psychosocial disabilities

go from one provider to another in search of cure, as described below:

> "Initially, I did not understand anything. My hands and legs were paralyzed, and I used to feel trembling sensation (making sound of *Jhan-jhan jhan-jhanataa*) whenever I walk. My stomach and even my entire body aches, I feel difficulty in breathing, and there is a lot of sneezing as well () Doctor told me that I have stones in my kidney and gave medicines () when the problem continued we went to other doctors and also *pandit* - priest and *mali* - oracle." (F, 53 years, SC, Widow, SMD).

"It is written in the stars" – These troubles ordained by the Divine

There is a widespread understanding among community members that mental distress is often caused by malevolent force (e.g., an evil spirit) or bad luck. This notion stems from a pervasive cultural belief in local deities popularly known as "*kul devta.*"

"*Chaya padi hain*" - The evil eye is to blame

A prevalent explanation among PPSD and other community members was that any kind of unknown or unidentified form of mental distress is caused by some evil spirit(s). Thus, only God can help them. The *Mali* is considered to have direct relations with God, and their advice is often trusted by community members as described below:

> "The *Mali* told me that an evil spirit - *chudail* possesses me and that I should sacrifice a goat () everyone in the village believes in *kul-devta* and trusts the advice of the *mali*." (F, 53 years, SC, Widow, SMD).

"*Naseeb ka khel*" - Good luck versus bad luck

PPSD and caregivers believed in a fatalistic notion that their problems were more a matter of bad luck or God's wishes. This explanation is sometimes so strong that subjects continue to pray even in the absence of positive results, accepting their mental health conditions as destiny. For example, some described continuing practicing religious rituals, hoping that it would work:

> "We have sacrificed a goat and prayed before () we will continue doing it, if we are lucky it may work with time (*kya pata naseeb raha to sab acha ho jayega*)" (M, 34 years, SC, Separated, SMD).

Participants suggested a shared help-seeking path that was followed by community members and a risk of social sanction for people who do not "believe in their own culture:"

> "I did it [went to *Mali*] like anyone else in our society. More than belief, I think it is superstition, and there is no medicine for superstition. When a *pandit* (Hindu priest) or a *mali* says to do this or do that, you do it. You do not want to be seen as someone who does not believe in their own culture. People will blame you if you do not do or follow these traditions." (F, 53 years, SC, Widow, SMD).

Help-seeking

Knocking on every door - Going to both traditional healers and biomedical providers

PPSDs and caregivers described their engagement with different healing systems in pragmatic ways. They went to and fro from one care provider to another based on the effectiveness of the treatment. For example, a frequent help-seeking pattern was trying one doctor and treatment regimen, and if this did not solve the problem, they would consult with other community members or people with similar experiences. Typically, the more disabling and long-lasting the symptoms, the more willing people were to spend large sums of money by either going far away in search of better medical facilities or by doing various devotional activities. Participants' description of "even going to Rajasthan" or "even sacrificed a goat" denoted their extensive efforts to find help.

"In the beginning, the doctor told her she has stone - *pathri* and gave her medicines, which she took for some time. But, when the problem was not solved, she went to other places, even sacrificed a goat and did prayer." (F, 55 years, SC, Married, SMD).

In addition, PPSD also described that when their symptoms and distress were more severe, it made them willing to give any healing system a try.

"We have tried everything possible, gone to doctor, *pandit* - priest and *mali* - oracle () we did whatever they asked, went to anyone who can help as we were desperate to find a solution anywhere." (M, 32 years, SC, Married, SMD).

Increased stigma and shame for people with psychosocial disability and their families

There was a sense of shame and stigma in PPSD's and caregivers' experiences of mental distress, leading to the nondisclosure of those affected from the public eye and not reaching out for help. In particular, participants described that if it became known that their son or daughter had mental health problems, it would limit their children's marriage prospects. One of the participants mentioned that his extensive attempts at getting married were all in vain:

"There have been many attempts made to get him married [referring to his son, who has epilepsy], but nothing has worked yet. He wants to get married, just recently, there was a girl who he wanted to marry, but now she does not respond to his calls, and he is upset about it." (Mother of a 26-year-old unmarried son with epilepsy).

Worn out and worn down by years of failed attempt to seek care

PPSD and caregivers described feeling worn out from their long journey of seeking a cure and unmotivated after catastrophic spending on treatment frequently without positive outcomes:

"The illness is there for the past 13 years. We must have spent around five lakhs (USD6700) in treatment, but nothing has helped. It is a waste of money, and traveling is an added cost. We had to sell our land for the treatment." (M, 51 years, SC, Divorced, SMD).

Caregivers also described a loss of hope over the possibility of any favorable treatment and their family member's recovery. Sometimes, due to both the emotional and financial cost of help-seeking, they had given up on even the most trusted source of healing, i.e., going to an oracle and doing religious rituals:

"We went to *mali* and *pandit*, prayed and sacrificed a goat to God, but we stopped when nothing worked. Now, we do not as it is ineffective and costs a lot of money." (M, 34 years, SC, Separated, SMD).

Social-cultural identity, meaning of distress, and help-seeking

Gender impacted both meaning of distress and help-seeking, e.g., women framed their psychological problem as physical symptoms using words or sounds such as "*jhan-jhan*" or "*kap-kap*" (to denote a tremor or a feeling of uneasiness) to ensure that family members are responsive in seeking care for the affected subject.

Women were expected to be responsible for all domestic chores as well as family member's health

Participants underlined that women's responsibility is to do the cooking, cleaning, and other household chores. They are also the one held responsible for family health. Fulfilling their domestic responsibilities was a key marker of a "good and respected" household and suggested recovery for those with mental distress.

"[Mother in law referring to her daughter in law] Women do not step out of the house unnecessarily () women of good and respected household stay at home, take care of the family, cook and clean, host guest () that is how they keep the family healthy." (Mother of a 32-year-old married son with SMD).

Moreover, thus, women felt burdened and even blamed for their child's ill health:

"There is no support for either household chores or earning money () I am the sole earner/caretaker of the family, my husband only sometimes sits in the small ration shop we have () he is always too high to do anything [referring to his addiction] () people blame me, saying that I must have given drugs to my son (*tune his pilaya hoga bhang*), but why would I do that to my son." (Mother of a 26-year-old unmarried son with epilepsy).

Gendered relations limit women's help-seeking

PPSD and family members described that the male head of the household is responsible for deciding where and when to seek help. Other male friends and relatives (such as uncles and brothers), as well as the village oracle (also men), were vital in influencing help-seeking. Women described minimal opportunity to make decisions around help-seeking and had to be accompanied by a man to seek care:

"I went to many places, but later one of our uncle who lives in Dehradun told us about a doctor, and eventually, we went there () my husband and that uncle took me to the hospital" (F, 55 years, SC, Married, SMD).

Discussion

Pluralistic pathway to care: A fluid and complex phenomenon

Help-seeking is not a linear care pathway; instead, it is a fluid, iterative, and complex one where factors such as

access to biomedical care, community belief, and financial burden determine the next step.[29] Our study found that PPSDs, with caregivers' support, undertook multiple actions to seek care but ultimately felt worn out and lost hope due to catastrophic expenditure (catastrophic expenditure as defined by the WHO https://www.who.int/health_financing/documents/pb_e_05_2-cata_sys.pdf) [Figure 2].

The two-way relationship between meanings of distress and help-seeking described in this study demonstrates the fluid and complex dynamics that determine how, where, and when someone seeks care. Help-seeking in this study emerged as inextricably linked with multiple local meanings of distress and as pragmatic response to local context. For example, supernatural expression of distress does not necessarily lead to visiting a traditional healer. Similarly, holding a more medical explanation does not imply seeking professional care. At the same time, stigma and shame related to mental health often determine both the expression and help-seeking behavior of PPSD.[30] Mental distress thus operates within the complex web created between biomedical frameworks and alternative nonbiomedical expressions of distress and help-seeking.[7,31,32] Being attentive to alternative explanatory framework and addressing core social mental health determinants can ensure PPSD receive adequate care and support.[32,33] In addition, seeking care from the informal and private sector impoverished families as its expensive,[34] and profiteering is widespread among all types of providers,[35] leading to loss of hope and abandonment of help-seeking. The stigmatizing nature of mental illness is such that it makes PPSDs vulnerable to unscrupulous practices by private providers.[36]

Remoteness and under-resources health systems limiting access to care

The remoteness of our study location and long distance from major healthcare services resulted in significant travel and time costs, which increase the perceived help-seeking burden. Yet, there are no quick fixes, and single-session interventions sought by a rural help-seeker who may travel long distances to the city for care do not exist. Our study highlights that people's illness experience and care trajectory often shaped by local patriarchal forces are tightly linked to pragmatic factors such as proximity, cost and familiarity, and other factors such as symptoms severity, advice from relatives, and season of the year. Mental healthcare must be ongoing, including psychosocial components, and a stepped care format that cascades community workers to primary care providers to specialist care.[37]

Gender influences help-seeking decision

This study highlighted the importance of gender as a core social identity of PPSD, which critically influences their mental distress as well as caregiving and help-seeking experiences (e.g., women described that somatic symptoms led to increased priority for help-seeking). Women are expected to be primary caregivers but are only peripherally involved in decisions about care-seeking. This phenomenon aligns with the findings of several recent studies, highlighting the central contribution of gender relations and gendered forms of marginalization to women's experiences of mental distress and the asymmetric burden of caregiving borne by them.[38,39] In addition, women are more prone to depressive disorders and other common mental disorders then men,[40] due to high stress of nurturing and caring for old family members and children, lack of family support, and low individual agency.[14,41,42] In Yamuna Valley, women had additional responsibility of getting heavy woods from mountains, going to field, feeding cattle, doing labor work apart from cooking, and caring for family which usually overburdens them and increases their distress level.

Methodological consideration

Researchers' involvement (MR and KM) with the concurrent community project may have influenced respondents to provide socially desirable responses; however, it also meant PPSD received psychosocial support and ongoing access to care. Researchers (MR and KM) familiarity with the study area and the authors co-developing the thematic overview using inductive and emergent analysis increased dependability and conformability. A significant limitation of the study is that it did not collect sufficient in-depth data to analyze the intersectional contribution of caste, age, educational level, and social class-forms of disadvantage to mental ill-health experiences – and an important set of questions for future research.

Implications

This study adds to a small number of studies in India that focus on the mental health experiences of people who do not seek help from formal biomedical care services. This study allows for a focus on endogenous resources and culturally determined rationale deployed by women and men, which can guide and support efforts to both prevent mental ill-health and also build upon community mental health competence.[38,43]

First and foremost, this study suggests that India's public health system continues to fail rural and remote populations. This valley's remote and under resourced health system results in many people with mental distress having limited or no access to care. The weariness and hopelessness described by PPSD underline the many dysfunctions in the public health system, which has few doctors, even fewer in mental health services. The issue is compounded by private system which is avarice and provide irrational care.[36] A key implication from this study is rural India's need for a public health system that is accessible, relevant to the community, and accountable and which provides universal health coverage.[24,44,45]

Second, this study re-affirms that not only effective community mental health services be accessible both physically (opening hours and distance of travel), and financially, they must also be culturally relevant to the community which requires cultural competencies among all providers.[46] Accordingly, there is an urgent need to ensure that primary health and mental health providers are informed and responsive to the social determinants and cultural contexts that shape their patients' mental distress. Some practical solutions can be implemented by mental health professionals to achieve this, including novel ways of engaging with medical record keeping and clinical interviewing. Indeed, engaging with the richness of patients' experiences and stories is crucial to understanding how social determinants impact their health as well as to developing culturally competent care.[47] Yet, these aspects are typically omitted from medical records.[47,48] Engaging with patients' culture during the clinical interview can also be done using a cultural formulation approach. For example, the Bloomsbury Cultural Formulation Interview[49] is a technique that helps clinicians engage with patients' vocabulary and experience of illness on their own terms. Relatedly, the manual "clinical appeal of culture formulations in rural mental health"[50] lists possible ways for clinicians to engage with local ecologies of rural Indian people.[11] Such techniques offer potential to improve trust, engagement, and shape more effective care-seeking pathways.

Third, this study, along with other studies, underlines the centrality of culture in mental distress – yet, Western knowledge and biomedical psychiatry continue to dominate the practice and training of Indian psychiatrists and that of many other mental health professionals.[8,10,51] Beyond ensuring clinicians are culturally safe and competent, it is important that health professionals can identify and acknowledge the ways that social identity and disadvantage determines health and impacts ways people seek help. By focusing on social determinant of health in training, clinicians will be better equipped to engage with social challenges in their region and intervene accordingly. This will also decrease the rate of misdiagnosis and help clinicians create a safe space for patients to talk about sensitive issues which are important in their journey of recovery.[52]

Fourth, this study illustrates that health services must be designed and governed with representation and active participation by service users. A recent example of co-production of a mental health resource with people with lived experience has been completed by authors of this study.[53] Including the perspectives of people with lived experience in the design and implementation of policies, services and interventions is the only way to ensure that the latter are relevant, accessible and responsive to the need of people with mental health problems in the hugely diverse context of India.[54,55]

Conclusions

The study demonstrates that the relationship between help-seeking and illness explanations is fluid, pragmatic, shaped by local forms of rationality and is iterative rather than linear.[48,51] The personal experience of suffering and help-seeking are mutually constituted. By defining, eliciting, and understanding local meanings and idioms of distress, mental health clinicians and services could become more responsive and relevant for community concerns. Training of mental health professionals on cultural social identity can help clinicians to understand the cause of mental distress and develop an effective treatment process. It is also vital to recognize that traditional healing and biomedical care can run in parallel while also complementing each other. People who suffer from mental distress need to be understood as active agents in determining help they seek and the treatment they follow.

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Conflicts of interest

There are no conflicts of interest.

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Appendix

Appendix 1

The appendix contains Tables 4 and 5 with a list of culturally specific terms and idioms used by respondents to describe their problems. This list can assist clinicians and can serve as a training reference material to understand the mental health symptoms and develop relevant biomedical categories. The list is not exhaustive and has a further scope for expansion.

Interview Guideline:

Date:	Data Collector's name:	Signed consent: (Y/N)
Participant's name:	Care giver name:	Village name:
	Contact:	
Contact:		

Section A: Demographic Details

1. Age:	2. Gender:
3. Marital status:	4. Caste:
5. Religion:	6. Highest education level:
7. Number of members in the household:	8. Other member in the family with any kind of disability:
9. Type of housing:	10. Source of income:
11. Part of any support group:	12. In the last month, did your family run out for food or essentials (Y/N):
13. Did your family take a loan for health or household costs in last 12 months?	

Tick for Entitlements:

Aadhar	Ayushman Card
Bank Account	Ration Card
BPL card	Pan Card
Disability Certificate	Domicile Certificate
Disability Pension	Caste Certificate
Voter ID	

Section B: Open-Ended Questions

1. Since when do you have mental health problem?
2. How did the problem begin? Probe further and ask about symptoms and explanations of words used by responded.
3. What did you do about it? Probe on their steps toward getting treatment-
   a. Have you consulted anyone about it? If Yes, whom? If not why? Who recommended you?
   b. How did you decide which place to visit? Why did you decide that?
   c. Did you follow the advice of the person who you consulted? And why? Why not?
   d. What did the person told you?
   e. How was your experience? Can you tell me in details? Probe on procedure. How satisfied you were?
   f. If you did not get help there, how far you are willing to go?
   g. What factor made you go back to the person? Why and why not?
4. What do you think are factors in the place you live that support people to have mental health and well-being? Give examples. Probe, do you know someone who is mentally healthy. Why do you think they are mentally healthy and what are the things in your community that support them for being mentally healthy.
5. Who do you think are the people who are most resourceful and supportive to others in the place where you live?
6. What do you consider are the best things about living in Naugaon/Purola – Can you give one specific example of an event illustrating this/these positive features?
7. What do you think are the biggest health needs for people around you for health broadly?

8. Do you know anyone else with mental illness or seizure problems – Do you know where they went to get care? What are likely factors people consider in help seeking?
9. Have you heard about any suicide cases nearby? What happened?
10. Why do you think they did it? What other options you think are there for someone who is feeling helpless.
11. Do you know about any incidence of violence or something bad happened in your locality due to somebody's caste status?

Section C: Understanding Role of Social Determinants

12. Do you think your situation would have been different if-Further ask, how it would be different?

Caste	Is everyone in your village OBC or SC or Brahmin? What are the caste practices or rituals people follow in village?
Gender	
Age	
Economic well-being	
Location	
Education level	
Ethnic identity	

If there are any three things you would have changed about yourself, if gotten a chance what would it be?