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Exploring the digital support needs of caregivers of people with serious mental illness

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ABSTRACT

In low-and middle-income countries like India, people with severe mental illness (PSMI) rely on their families as a primary source of care, given the lack of support from healthcare systems. The demanding nature of caregiving places significant physical and mental demands on caregivers, who are the primary source of support to PSMI. We explore how caregivers in under-resourced settings can be better supported through everyday digital technologies. We conducted interviews with caregivers (from urban and rural India), as well as workshops with professionals from Indian NGOs that work directly with PSMIs. We found that technology has the potential to (1) provide carer-centred support that empowers carers who experience stigma and issues with existing support networks; (2) provide support for carers to overcome barriers and progress in the recovery of the PSMI. We conclude with design considerations, proposing how an online peer community can leverage carers' expertise to actualise support provision.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; *Computer supported cooperative work.*

KEYWORDS

caregivers, mental health, empowerment, peer support, online communities, mhealth, HCI4D, India

1 INTRODUCTION

Mental health is a growing area of interest within Human-Computer Interaction (HCI) [83–86]. Severe mental illnesses (SMIs), such as schizophrenia and other psychosis (SOP),and bipolar disorder (BPD), are defined as diagnosable mental, behavioural, or emotional diseases that cause considerable functional impairment in one or more daily activities [64]. SMIs usually strike people in their late adolescence, or early twenties [30] and exist throughout one's lifetime [69]. They not only transcend most physical ailments in terms of expense and impairment [116], but also accelerate the incidence of several physical illnesses such as cardiovascular disease, infectious diseases, non-insulin-dependent diabetes, respiratory diseases, some forms of cancers and HIV infection [96]. SMIs are a pressing health issue and affect over 60 million people globally [103], and India accounts for a substantial percentage of the global PSMI population. It is estimated that 18% of all SMI patients worldwide reside

in India, accounting for over 14 million cases in the country [76, 77], with SOP affecting 0.4% [69], and BPD 0.6% of the population [102].

While SMIs have far-reaching repercussions for diagnosed individuals (for example, 25-year loss in lifespan documented by Viron and Stern [132]), they also substantially impact families and caregivers[1] [69]. Given that healthcare services are inadequate and inequitably spread in India, with rural areas faring worse than urban areas [31], over 90% of PSMI rely on their families as caregivers [125]. This results in family members being laboriously involved in most facets of the care and frequently maintaining control over treatment decisions, filling many of the functions performed by health or social care personnel in high-income countries [73]. Studies have reported that caregivers encounter work overload, sleeplessness, financial hardship, diminished leisure, exhaustion, and social isolation, which decreases their quality of life and their physical and psychological well-being [66, 91].

Information and Communication Technologies (ICT) are one of the solutions to this challenging situation allowing informal caregivers to acquire the knowledge and skills they need to deliver care while managing their wellbeing [59]. Literature indicates an upward trend in the delivery of technology-based interventions over the previous decade, with the focus shifting to internet-and mobile-based interventions as technology becomes more pervasive and affordable [59]. In the past, mHealth (*'medical and public health practice supported by mobile devices'* [78]) has been used to empower caregivers by mitigating the physical and psychological impacts of caregiving [59, 116]. A considerable relief to caregivers has been seen to be provided by peer-based systems, which is premised on the belief that peers who have overcome adversity may offer valuable support and hope to others experiencing similar problems [19, 21, 45, 47, 82, 105, 118] and alleviate distress [62, 95]. Glynn et al. [29] reported that an online psychoeducation program for multiple families of PSMI reduced relapse rates by up to 50%, consistent with other research conducted over the past two decades [63, 88, 90]. The union of families has also been evidenced to reduce stress among relatives [40], and online interventions, in particular, have been shown to improve outcomes in anxiety disorders [3, 22, 109, 138], and depression [119]. Peer-to-peer networks have been shown to offer significant relief to caregivers in high-income countries [2, 18, 38, 50]; however, less attention has been dedicated to facilitating such support in India.

To address this gap, this research aims to explore how digital tools can support caregivers and mitigate caregiving burdens, which can foster PSMI's recovery. Our research involved investigations with two cohorts: (i) ten semi-structured interviews with caregivers of PSMI from urban and rural Indian settings; and (ii) two workshops with professionals from three non-government organisations (NGOs) in India. Interviews were used to comprehend the needs of caregivers of PSMI and the potential of digital technologies in addressing these requirements in diverse settings. The workshops highlighted the issues encountered by practitioners in their current support services for caregivers, which aided in determining the core design elements of the possible digital design space. Our contributions to HCI research are three-fold. Firstly, we extend

the current understanding of mental health in the Global South with added insights into challenges faced by caregivers. Second, we identify how technology can play a role in bridging service gaps in mental health care provision in the Global South. Third, we provide considerations around the design of digital tools to offer personalised support to individual caregivers and sustain their existing peer networks.

2 RELATED WORK

2.1 Mental Health and the Burden on Caregivers in India

South Asia is home to some of the world's most densely populated areas, with nearly 23% of the global population and one-fifth of psychiatrically ill patients [42, 130]. Ganguli [26] found that India has a fourfold higher risk of psychiatric problems than the median rate in the Asian region. The prevalence of schizophrenia has shown consistency over the last two decades in India, with around 0.4% of the population [26, 34, 69, 101]. In contrast, the studies indicate a rise in bipolar disorder from 0.3% [69] to 0.6% [101]. This could be a result of inadequate medical provision in the country [108]. The WHO states that India has 0.3 psychiatrists, 0.12 nurses, 0.07 psychologists, 0.07 social workers, and 0.8 nurses per 100,000 people [75], compared to an ideal 3 psychiatrists and psychologists per 100,000 people [27], resulting in a treatment gap of 75.5% and 70.4 per cent for SOP and BPD, respectively [69]. In fact, mental health funding is only 1.3% of the total health budget (about USD 83,915,758) [81], which is far less than western countries such as Australia, New Zealand or France, where mental health budgets range from 7.6 per cent to 12.9 per cent and go up to USD 3,978,795,361 [74]. Since medical provision struggles to deliver effective mental health treatments in India, caregivers are obliged to function as healthcare providers throughout the continuum of care, ultimately catering to all the needs of PSMI [5, 106], which are usually covered by the government in developed nations [114]. This negatively affects caregivers' health in the long run [131].

The impact of caregiving has been widely noted in prior medical and psychiatry literature [66, 113] with a focus on caregiver burden that denotes that patients frequently require 24-hour care from their family members. From catering to the patient's primary, emotional, and financial needs to deciding whether or not to seek treatment, the role of the Indian family is all-pervasive [113]. Unfortunately, caregivers experience a decreased quality of life [55] and are constantly stressed [81]. Additionally, limited financial and healthcare resources exacerbate the burden, a substantial barrier for lower-income households [10, 87]. Given the lack of awareness, [124] and support [66], families often discontinue patients' treatment as they fail to manage the pressure alone. Since family engagement in patients' care is fundamental, Singh et al. [115] assert that Indian caregivers should be educated about SMIs and how to manage them, which can alleviate their burden and improve overall outcomes for PSMI.

Furthermore, an intervention in India needs to combat stigma. Stigma is a mark of shame or disapproval of an individual by society and impacts not just PSMI but also their caregivers because of their significant role in the lives of PSMI [16]. Unfortunately,

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[1]In this paper, the terms family members, friends, relatives, and caregivers are used interchangeably to refer to informal caregivers for PSMI.

caregivers are often abandoned by family and friends or left unsupported in isolation [16]. In an attempt to maintain social inclusion and prevent discrimination, caregivers often conceal the disease of PSMI [31, 115], resulting in an 80% treatment gap. The treatment neglection [61] could also be because of the association of mental illness with other facets of social, cultural, religious, and spiritual life in India [92]. The onset of the disease is linked to the possession of spirits, the "evil eye," black magic, or taboos, and entrusting the cure to traditional healers, elders, or other influential people in the community [31]. One HCI study [86] also noted that stigma could be ingrained in the call providers in India, experienced by people who interact with mental health helpline numbers. Numerous researchers have stressed that it is essential to recognise and moderate the effect of stigma on caregivers and investigate which factors may protect caregivers from experiencing high stigma to manage mental health challenges effectively [23, 54, 99, 100].

2.2 Mental health and SMIs in HCI

The fields of HCI & CSCW have also drawn considerable attention to the influence that family members can have on an individual's mental health. These studies [33, 65, 89, 121] acknowledged the caregiver's role in the patient's life, indicating that caregivers have substantial responsibilities, including monitoring care recipients, managing interactions with the healthcare system, and helping with activities of daily living like eating, bathing, and using the internet. In the research on family caregivers of people experiencing depression, [136] discovered that while caregivers frequently felt stressed out by their duties, they also struggled with when and how to share their distress. Parallel to this, Murnane et al. [68] discuss an intricate network of caregivers and stakeholders, emphasising that the nature and stability of these interactions frequently affect an individual's mental health.

Therefore, studies have contributed to research on ICT prototype design, and deployment [70, 136] and analysed how to leverage existing technologies [127] to support caregiving. However, most of these researchers have focused on aiding patients, such as Consolvo et al. [14] investigated how technologies can simplify the coordination of essential care endeavours and suggest possible solutions for caregivers to benefit patients. Miller et. al [65] demonstrated how technologies might provide caregivers greater flexibility in their representative roles to communicate patient concerns transparently. Similarly, Slovak et al. [117] examined the potential of technology to empower parents and children, allowing children with mental illness to learn through actionable support in the context of family life. Health-tracking technologies were investigated in another study [136] to assist family carers in handling a depressive family member more effectively and to enhance patient-caregiver communication.

Nevertheless, the trajectory of HCI research has shifted through time, and academics have come to understand the need to treat caregivers as separate entities. Prominently, Chen [12] has addressed that caregivers' personal health and wellness is an indispensable concern and that the HCI/CSCW field's neglect of caregiver burden in system design may exacerbate this already severe issue, given that new chronic care management systems usually facilitate caregivers to do more, which may escalate their burden. Thus, she argued that ICT could offer caregivers the social support they need,

notably if that support is lacking in their immediate environment. As shown by the ComputerLink study [25] that showed patients could create online support groups to help and encourage one another, ICT can be applied to support caretakers digitally. Other HCI studies also recognised online mental health communities to alleviate caregivers' stress by forming alliances and developing robust support networks with people who understand their situation [127]. The importance of technology in long-term caregiving was detailed in a systematic review by Schultz et al. [112] in 2002, specifically with caregivers of dementia patients. They noted that technology could benefit the caregiver in myriad ways, including effectively communicating information, promoting social interaction, and managing and promoting their own health [112].

2.3 Context of the study

Although HCI researchers in the west have realised the significance of caregivers for some time, this is not the case in India. One HCI study [120] explored technology-enabled initiatives for enhancing mental health care by understanding challenges across different parts of the healthcare continuum, addressing patients, caregivers, doctors, and social workers. Particularly for SMI, there were merely two other studies in India that focused on digital solutions [97, 131], and of those, only one considered caregivers, however, only to coordinate patient activities with the doctor [131]. None of the studies particularly examined the impact caregivers bear or how to alleviate their stress to enhance the quality of life for both caregivers and PSMI, which is this study's premise.

Moreover, most interventions are delivered through customised applications. Their adoption can be a barrier due to unfamiliarity with operations and misconceived notions of apps which is particularly true for the elderly, who frequently lose interest in using them [60]. This is especially concerning, given that 41% of caregivers are parents [49]. Also, it is plausible these services are not accessible to all, given that two-thirds of Indians live in poverty and earn less than USD 2 a day [9]. These challenges call for design solutions through unplatfomed design [56], such as social networking [71] or telephone-based platforms [57], which has the advantage of universal adoption over specialised apps given that 73.34% of the country's population is connected via phone, with wireless mobile phones accounting for 96.6% [116].

3 METHODS

3.1 Study Design

This study explores leveraging digital technology to enable caregivers to assist one another in a collaborative environment. Our participants are categorised into two cohorts: (1) caregivers providing care for at least one PSMI; and (2) professionals from three NGOs working in mental healthcare. Data was collected through interviews with caregivers and workshops with professionals. The interviews aimed at understanding the fundamental issues of caregivers, while the workshops explored challenges in service delivery and potential design features to mitigate these challenges.

This study focused on the following research questions:

(1) What are the specific challenges experienced by caregivers?
(2) What are the forms of connection and support they perceive as useful that can be provided by other caregivers?

(3) How can this connection be facilitated digitally via communication tools such as social media or mobile phone services?

(4) What kind of training or experience is necessary to lead or facilitate such a group?

3.2 Recruitment and Participants

After obtaining ethics, we contacted the collaborating NGOs to identify potential participants for the interviews. All research participants were referred to the study by a key contact from the three collaborating NGOs. Before and during the sessions (interview and workshop), all participants were sent/given details of the study to which they gave written consent. The consent form was emailed directly to urban caregivers and professionals. Due to low technological literacy in the rural population, information was forwarded to the village moderator to be communicated to the eligible participants and later, at the interviews, they were also provided hard copies of information and consent forms. This staged approach to the identification and official recruitment was undertaken to establish a layer of separation between the organisations and the research, lowering the possibility that individuals might feel pressured to participate because of their affiliation with the organisations. In order to maintain anonymity, individual participants are referred to as U_CG1-6 for urban interview participants, R_CG7-10 for interviews with rural participants (Table 1), and W1_P1-4 for first workshop attendees and W2_P5-7 for second workshop attendees (Table 2). Five of the authors (including the first author) are Indian researchers. The first author volunteered with one of the NGOs engaged in this research for 3 months and as part of this work, attended several NGO capacity programs with PSMI caregivers. These experiences gave them a deeper understanding and first-hand experience in welfare services.

Six caregivers were recruited and interviewed from the urban region, while four were from rural areas. An attempt to include the rural population was made as it constitutes three-quarters of India's population and is frequently under-represented [28]. Table 1 presents the demographics of the ten participating caregivers and PSMI's age and illness details. People in the metropolitan areas were technically skilled, educated, and of middle-to-upper-class backgrounds. In contrast, rural participants had lower technological literacy and qualifications and belonged to the working-class population.

The two workshops included professionals from three reputable NGOs situated in India (Workshop 1: n=4, Workshop 2: n=3). They were certified psychologists and social workers with a wealth of expertise working with PSMI and their caregivers. The inclusion of the two NGOs helped recognise diverse working practices for families in mental health.

3.3 Data Collection

All sessions with urban participants and the professionals were conducted through Zoom owing to participants' preferences, resulting from Covid-19 social distancing practices. Although rural participants lacked a high level of technological literacy, they were engaged equitably through face-to-face interviews in their houses, where they felt more comfortable and had a village moderator. Workshops and interviews with urban participants were held in English, whereas interviews with participants from rural areas were conducted in Hindi. All interview and workshop data were audio-recorded by the researcher and transcribed/translated to English by professional agencies.

3.3.1 Interviews. Ten semi-structured interviews (approx. 60 minutes) were conducted with caregivers. Through the interviews, we sought participants' perspectives on their needs and challenges, their options for accessing support, and the potential for technology and digital services to support them. Interviews followed a semi-structured approach so that participants could lead the conversation toward topics they were most comfortable with, allowing for personal disclosures without feeling obligated to talk about stressful circumstances. Interviews provided a contextualised understanding of caregivers' needs and requirements, support accessible from various experts, and present experience with technology and digital tools before exploring prospective design solutions.

Figure 1: Interview with caregiver in Rural India

*3.3.2 Workshops.* Two 100-minute workshops were conducted.

In the first workshop, professionals (n=4) gave views on their current service delivery. There were three activities: (i) a focus group discussion to understand diverse support and communication strategies employed by professionals to assist caregivers and issues they encountered in service delivery; (ii) generating design ideas for a peer support group through brainstorming; and (iii) a mix of open and closed questions informed the potential functions of a digital tool and its critical enablers following the "How Might We" technique, which was influenced by the caregivers' interviews earlier to produce various ideas and draw links between them. These phases provided insights into the existing roles that could be transferred in designing digital technology to address caregivers' well-defined challenges and new possibilities for remote support by leveraging technology.

The second workshop was structured around two design activities: (i) personas and (ii) keep & grow tools combined to gather professionals' views on responding to the themes we developed from the interviews and early ideation ideas from the first workshop. The persona method generated diverse user profiles showing distinct caregivers' needs and challenges (Figures 2, 3). This helped the professionals to empathize with these archetypal caregivers. They also helped us identify the main features to include in the design of the support group. Keep & grow (Figure 4) identified the essence of an idea and worked out what needs to be developed

Table 1: Profiles for caregiver of PSMI(Ages and illness durations are in terms of years)

ID	Caregiver age	Employment	Relation to PSMI	PSMI age	Illness length	Treatment length	Setting
U_CG1	43	Psychologist	Daughter-in-law	65	40-45	5	Urban
U_CG2	29	Artist	Son	55	4	3	Urban
U_CG3	58	Businessman	Father	32	15	14-15	Urban
U_CG4	70	Businesswoman	Mother	40	25	24	Urban
U_CG5	35	Engineer	Niece	57	24	2	Urban
U_CG6	70	Social worker	Mother	40	15	10	Rural
R_CG7	36	Confectionery store	Wife	39	7	4	Rural
R_CG8	30	Tailor	Wife	35	9	6-7	Rural
R_CG9	60	Unemployed	Mother	38	22	15	Rural
R_CG10	33	Social worker	Sister-in-law	52	25	20	Rural

before their implementation [36]. The strategy allowed us to reduce the number of tests of the eventual prototypes that must be presented to the caregivers, as we can test these ideas against the profiles generated.
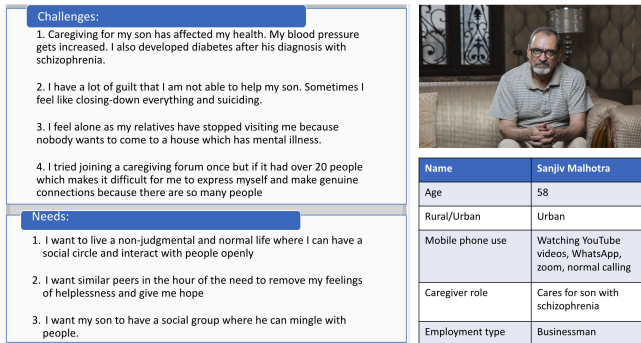

Figure 2: Persona 1 describing urban participants

3.4 Analysis

The analysis for the interview data was executed using reflexive thematic analysis (TA) as recommended by Braun & Clarke [7]. Reflexive TA is a post-positivist data analysis method that considers the researcher's subjectivity as they construct and refine codes [7]. This involved the first author becoming familiar with the data and then developing a set of preliminary codes that corresponded to the general needs of caregivers for PSMI and their current technology

Table 2: Profiles of professionals

ID	Employment
W1_P1	Psychologist
W1_P2	Social worker
W1_P3	Social worker
W1_P4	Psychologist
W2_P5	Psychologist
W2_P6	Social worker
W3_P7	Social worker
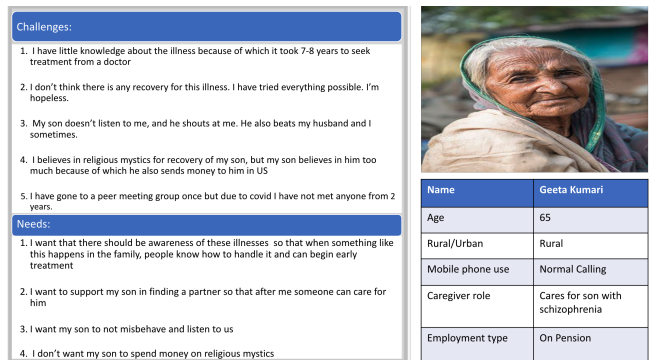
Figure 3: Persona 2 describing rural participants

Figure 4: Keep & Grow Activity with Participants

usage. Using the inductive approach to establish a solid connection to the raw data, the first author manually coded all the interview transcripts line-by-line to stem open and low-level codes, producing 350 initial codes and categories. These codes were organised into sub-themes and overarching themes, which were further refined through several rounds of discussions with other research team members, during which the first author visually presented the themes, sub-themes and their associated codes alongside excerpts from transcripts. Through this approach, the research team arrived at the final set of themes and their descriptions after assuring that

each theme adequately represented the underlying sub-themes and codes, which resulted in five overarching themes.

In contrast to the inductive approach for the interview analysis, deductive TA [7] was used for the workshop data based on the themes derived from the interview analysis, leading to the further development of interview data themes. A thematic map was developed to visualise concepts to represent associations between interview outcomes and workshop data, which helped the formation of functions and enablers of an effective digital tool. This concept was informed by Buzan et al. [8], who promoted data interactions to stimulate innovative thinking and higher degrees of solutions. The analysis was framed around the design synthesis technique [6]: aiming to refine and prioritise design spaces that establish a connection between the challenges experienced by caregivers and any potential solutions put forth by experts that integrate technology and user needs. Similar to the analysis of interview transcripts, these were initially done by the first author and subsequently carried out by the research team, with the first author facilitating a series of analysis workshops.

4 FINDINGS

The results revealed challenges related to the caregiving of PSMI, barriers to recovery, social support networks, current communication and technology practices, and support expectations. We outline the key characteristics to incorporate in a digital tool to aid caregivers of PSMI.

4.1 Interview findings

4.1.1 Extreme burden on caregivers. The caregivers articulated the extreme burden they experienced in caring for PSMI due to the significant challenges they faced in meeting their needs which have had a major impact on their own physical and mental health. The lack of effective healthcare support systems for PSMI at a societal level meant the caregivers encountered tremendous difficulties in meeting the physiological and social needs of both the PSMI and their own. The carers had to serve as a 'medic' to ensure treatment efficacy. Urban and rural caregivers reported comparable responsibilities. As R_CG7 expressed, *"After giving him [PSMI] breakfast in morning, I need to give him medicines. I must keep an eye if he is taking medicines, because he doesn't take medicines on his own."* Since these responsibilities were a substantial proportion of a caregiver's daily tasks, it often left them with little to no time for other activities. It also hampered their productivity at work, with some rearranging their schedules to work irregular hours. One participant said, *"In the hospital, I accompanied my aunt. I made the necessary arrangements and began doing my office work at night while taking complete care of her in the morning. Two to three hours of sleep is also not guaranteed"* [U_CG5]. This caused a severe impact on caregivers' physical and mental health, and several participants characterised managing PSMI as 'very difficult,' and damaging to their health. For example, U_CG3 stated, *"The day he got ill, I became diabetic one month later. I never used to have any medicine before that [...] in situations like this, you feel like committing suicide and closing down everything."* Added to this struggle, unrecognisable efforts and abusive behaviour due to the condition by PSMI are commonly faced by caregivers, as described by R_CG7: *"He (PSMI) smacked*

his father's head, causing him to bleed. He also broke my finger. He wouldn't allow us to go out, and if we did, he would yell and abuse us terribly. He wouldn't even let us eat in peace."

The severe burden on caregivers' mental health is mainly stemmed from a tremendous sense of obligation that they are responsible for the PSMI's recovery and feeling disheartened by their inability to do so. The absence of robust healthcare systems and social support combined with the stigma associated with mental illness led to caregivers experiencing emotional distress. Cares commonly reported 'guilt,' stemming from a sense of 'helplessness,' as one participant expressed: *"It's very difficult to see your child suffering. How can you sleep or eat or feel good if you have so much guilt??"* [U_CG4]. The duties of caregivers were not simply associated with providing treatment and caring for PSMI but also guarding them against mistreatment. Abuse directed against PSMI was widely reported, for instance, U_CG1 explained how her father-in-law [PSMI], who had been ill for 40 years, faced *"physical violence"* in the family, and "*finally the physical abuse has stopped in the last four or five years"* after delivering continuous psychoeducation to the family. Caregivers also protected them from abuse by other groups, as U_CG5 reports, *"Some of the neighbours want to beat her. [...] I requested a few of my neighbours and issued a warning to a few of them."*

4.1.2 Barriers to recovery for PSMI. A number of key barriers to recovery emerged from the analysis, including caregivers feeling that they lacked essential knowledge about the condition experienced by the PSMI. The information and support they received from medical professionals were insufficient and, at times, ineffective. Information about mental illness is not widespread in this context, and popular media does not portray it frequently or accurately. As a result, the onset of mental health problems was difficult to understand, and some carers expressed remorse about how little they knew about the condition prior to the diagnosis. For example, R_CG9 described: *"We thought he would become alright if we beat him. Then we had beaten him a lot."* Most caregivers were perplexed by the symptoms during the first few months. They primarily regretted their inability to manage PSMI's challenging behaviour, which was often misinterpreted as deliberate misbehaviour, and not something that would require medical attention. Participants underscored the need for awareness and understanding of the illness in order to facilitate early intervention and treatment for recovery: *"If families understand that the symptoms are not something they [PSMI] are habitual of, they will recover soon"* [R_CG10]. One participant connected their unawareness of SMI to the government's lower priority for spreading knowledge about these illnesses in comparison to other diseases: *"There are TV commercials for HIV, AIDS, and cancer. There is no awareness of the mental illness, no posters or advertisements in markets, hospitals, or movie theatres"* [U_CG6].

Additionally, most participants reported facing particularly challenging decisions about the medical support they sought out as, in addition to their own lack of understanding about mental health problems, they had to contend with medical professionals' whose sympathy and abilities varied dramatically, and they needed to make decisions about who to bring their loved ones to for treatment. This was closely related to the disregard for caregivers' role

in PSMI recovery since the focus in care planning and appointments is solely on PSMI. As U_CG4 mentioned, *"The doctor doesn't have time to talk to me or doesn't want to even though I offer to pay him a separate consultation."* The term *"psychiatrist shopping"* [U_CG1] was coined to describe caregivers' tendency to switch doctors repeatedly due to inconsistent treatment and substandard outcomes, which was also provoked by their mistrust in the healthcare system, especially among first-time caregivers. As CG3 mentioned, *"I met my first doctor, but things didn't improve, so I immediately went to another doctor where his signs and symptoms got aggravated, physical symptoms started coming, then I realised this got wrong. I went back to my first doctor, he shouted at me that how could you change the doctor so soon"* [U_CG3]. There is also a desire for an open communication channel with caregivers for continuous support, particularly at critical phases when prompt replies are required: *"We all want to help the patient, whether the family, counsellor or doctor, but somehow we are disconnected. Something has to happen for this whole system to flow for it to help the patient"* [U_CG4].

4.1.3 Expansive and elevated stigma. The PSMI's conduct, especially in public, commonly caused family members anger or shame in the face of pervasive, serious societal stigma, leading to family members holding extremely hostile attitudes towards the PSMI. For example, U_CG5 stated: *"My father hit her [PSMI] and said don't spoil our image in public."* The primary caregivers can be blamed for initiating the process of seeking treatment for PSMI, which was largely associated with how disclosure might affect the PSMI's ability to fulfil external criteria in socially valued areas of life, particularly marital prospects. As U_CG6 articulated: *"The family refused to seek treatment for their daughter with schizophrenia for fear that no one would marry her if people got to know."* Many participants, predominantly in urban regions, admitted that living with SMI is a lonely journey since PSMI are believed to exhibit disruptive and violent behaviours and are deemed dangerous by society. As U_CG4 described, *"When you have a mental illness patient, nobody is willing to come and help you. Because they think this person [PSMI] is mad. They don't even want to come to your home."* This has a direct impact on their quality of life. Besides, inappropriate and unhealthy family circumstances objected to caregivers in defending the interests of PSMI, which interfered with caring and reduced individual self-esteem of PSMI: *"When I took my aunt [PSMI] to the parlour, and provided dresses, my father and elder aunt laughed. She just got afraid that these people would laugh at her. So, these are the small pleasures, but this will be like a load to them at one stage"* [U_CG5]. Caregivers also asserted the attribution of critical comments or *"being looked down upon"* by the people who have *"never really known caring for mental health condition"* U_CG1 continued that *"somebody who has lived with PSMI would understand the families."*

In sharp contrast with participants in urban areas, people in rural areas reported more accepting and supportive social environments. They discussed the advantages of broader family involvement, including working together to solve caretaking problems. R_CG7 stated, *"I have no shame,"* in response to active disclosure to trustworthy individuals, adding, *"Who will assist us if we keep it hidden from our relatives? All of our relatives come to see us and enquire about our well-being. Instead of hiding it, I believe it is wiser to tell others about it."* Some carers even felt it could be beneficial to tell others to

gather information about various therapies: *"My neighbour worked in the NGO and took him there to seek care"* [R_CG9]. A participant from the urban population confirmed the less stigmatised feelings in rural areas: *"It's unfortunate to see how educated people in society disrespect mental health hospitals and patients, whereas unprivileged people don't"* [U_CG6]. Although people in rural areas are more vocal about the illness, they are diagnosed fairly late as they express scepticism about the nature and aetiology of SMI and often attribute it to religious practices. The most commonly reported explanation was 'evil spiriting,' for which they pursued remedies from faith healers, which not only delayed the appropriate treatment facility but also caused unnecessary financial expenditures, a grave concern, particularly in lower-income groups. As R_CG9 mentioned, *"He [PSMI] sent a money order for INR 2500 to a Guruji (religious mystic) in America three months ago. We have all the hopes from Guruji."*

4.1.4 Experience with peer support groups. Participants used diverse peer support platforms, including online outlets and face-to-face interactions, which were usually distinct for urban and rural participants, but not always. The caregivers found a 'sense of hope' or confidence in their abilities to overcome challenges. U_CG4 described it by saying *"I realised about others' [caregivers'] challenges by attending the meeting. So definitely, it was a great feeling that others had won. And you can also win it."* Online peer support mirrored the democratic process of giving and receiving opinions, including conversations about SMI-related subjects, as well as personal anecdotes and mutual interests, reflecting the formation of social relationships: *"The group engages in a variety of activities, including entertainment and illness discussions. We chat about our hobbies to find some joy in life"* [R_CG8]. Caregivers stressed the importance of having groups to receive emotional support, *"otherwise people don't have time to listen to your problems [R_CG7],"* which proved useful when the caregiver's own family was not very helpful: *"I started recognising who all can help us from outside my family"* [U_CG5].

However, caregivers also identified barriers, online and offline, to effective support, including negative online interactions, lack of individualised support, and difficulties in attending face-to-face settings due to caring duties. For example, one participant suggested that peer groups should demonstrate strategies to address issues, but most of the time, caregivers just vented without offering solutions as U_CG1 reported, *"caregiving forums don't continue for too long, because they become like a complaint box".* Larger groups could overwhelm or mislead caregivers with excessive patient information or promote an imbalance in sharing experiences: *"If it [peer support group] is too large, then you probably won't get enough time to talk"* [U_CG4]. The group occasionally failed to meet the caregivers' needs as it served more generalised purposes rather than personalised: *"I attended one of the virtual symposia with other caregivers, then I realised I already know those things"* [U_CG3]. The problems in the group were also distinguished based on their mode of delivery. Several participants described that it was logistically difficult to establish face-to-face peer relationships, which hindered their work and even disrupted their capacity to provide care: *"I don't go anywhere. Who will feed him [PSMI] if I go out?"* [R_CG9]. Participants also found it challenging to trust the internet, and

some anticipated risk of damaging their reputation by engaging with people online based on participants' attitudes and previous experiences with online exploitation.

Accessibility of digital health tools and devices (i.e. smartphones and internet) was also a significant barrier to online engagement as the tools were relatively new to many caregivers. Several participants expressed dissatisfaction and apprehension associated with the time and effort required to learn and use new applications. For example, U_CG3 stated, *"Health app I use is a normal one on iPhone. But the rest of them I have not downloaded because that increases your anxiety"*. The rural population did not use smartphone technology extensively, and sometimes, their communication channels were limited to phone calls (n=2). This was caused by the difficulty accessing smartphones and the internet that emerged from a lack of digital literacy, making them prefer phone-based conversation or technology for support. For example, U_CG8 mentioned, *"I'm a little hesitant to talk on [social] media. But I can speak on the phone."*

4.1.5 Expectations of online support. The findings show that caregivers value the support that is timely, authentic and empathetic while needing information to fulfil their needs to learn more about the diagnosis, formulate effective management strategies, and ultimately construct their own support networks for the people they care for as well as themselves. Participants' comments reflected the significance of identifying peers with similar experiences at the time of need to alleviate feelings of helplessness. Listening and empathy skills were indicated as extremely important in offering sympathetic understanding: *"We need a kind of person who can empathise our feelings. We're just waiting for a word of support, not money or anything, just a time of one hour or two hours for them"* [U_CG5]. In many cases, caregivers reported feeling alienated and stigmatised while giving care and longed for a support group *"to remove that isolation"* [U_CG3]. Caregivers noted a requirement for the peer to be sensitive to various feelings and experiences to seek validation and elicit supportive responses, which appears conceivable when people go through the same illness: *"Somebody who's lived with a person with untreated schizophrenia would realise that the family is tired, they would appreciate it"* [U_CG1]. A lack of authentic empathy and true understanding of what they experience with the condition was also brought up by another participant. As U_CG5 reported, *"We can't get that kind of comfort with every person. If we share all these things with friends, they'll say things like this happens in life, and it will be fine. They will not take it seriously."*

Most caregivers, mainly those whose dependents had recently been diagnosed with SMI, expressed a willingness to learn more about the condition: *"I am learning from my experience. It's like me having my first baby. So, there should be experts who know about this, who can help us"* [U_CG4]. When describing the expertise or background required for useful information, all respondents acknowledged that 'just life experiences' were essential. Although some caregivers had unpleasant experiences disclosing personal information in the past, they unanimously asserted their comfort in doing so if the recipients would be other trustworthy caregivers to exchange knowledge, emphasising the significance of spreading awareness. For instance, R_CG7 stated, *"I want what happened to me to never happen to anyone else. We were traumatised when it happened in our house."*

Another reason for participating in peer interactions emerged around more practical strategies to assist each other. Nearly all the caregivers received and provided some level of tangible support informally. As R_CG10 stated, *"I try to take other families with me to the hospital as they don't have much information in the village."* Efforts like these were encouraged to be organised to advocate for common goals. One participant voiced a need for peer groups to contribute to legislation, programs, and procedures: *"I believe there should be employment opportunities for women whose husbands have a severe mental illness"* [R_CG8]. Furthermore, caregivers emphasised the importance of setting the stage for peers to leverage one another's strengths. As U_CG1 expressed, *"If I'm not there, I can ask another caregiver to come and take care of my child. I can't trust my relative, but I can trust another caregiver because I know they are going through what I'm, and they know how to deal with it".*

4.2 Workshop findings

4.2.1 Creating value for caregivers.

Offering solutions through lived experiences. In contemplating the key values an online community should create, the professionals agreed that it must assist caregivers in incorporating 'real-life experiences' from people who have gone through the same problems. One participant shared that they try to do this in the current service delivery by distributing magazines in which they included voices of several caregivers, as W1_P1 stated, *"during the COVID phase we started with this magazine, only for the caregivers ...] who started to then discover lots of labels, discovered the support that is available [...] we have a lot of quotes that are shared, we have a lot of short snippets of videos that the families have shared in."* However, participants expressed a need for more representation of the solutions that provided an impetus for change. As W2_P7 stated, *"The level of consistency of the family is largely due to getting motivated when they see the difference, that they see in their neighbour's life, that's how they will absolutely get the commitment in joining zoom group"*. As this discussion snippet from the second workshop highlights, participants mentioned that this is key to generating hope amongst caregivers.

Cultivating a sense of belonging. Participants expressed that caregivers are burdened with difficult emotions, such as feeling stigmatised and isolated, which can be alleviated by connecting with other caregivers facing similar situations. WP1 stressed the importance of satisfying the *"belonging needs"* of caregivers that enable them to feel less isolated and alone. It was also reflected in their current practice as W1_P1 described, *"We've had Annual Day Celebrations where the family members and PSMI have participated equally in different forms, provided them platforms for advocacy to express their concerns and challenges"*. Workshop participants stressed that it was critical that the caregivers were made to feel that they belong to a wider community where they can celebrate social events or form meaningful groups to voice their shared concerns and advocate for their loved ones. Additionally, connecting with others might introduce ideas that would not be discovered otherwise, fostering continued relationships. E.g., W1_P1 stated, *"By becoming peers with other caregivers, they [caregivers] will learn that*

there are others sailing in the same boat and they can offer solutions to others and put those suggestions into practice on their circumstances".

Building empathy. The professionals emphasised the need to establish empathic and safe spaces for caregivers to connect with peers who would not judge them but instead would offer empathic connection due to shared experiences. One participant reported, *"They [caregivers] come to us and say that they want to connect with people who would not stigmatize them, who would not locate them, who know what is schizophrenia, who knows what it is like to be caring for somebody who has illness in the family"* [W1_P3]. Professionals emphasised that creating a safe environment requires each group member to be diligently involved in providing care for the PSMI *"to provide a layer of security and authenticity in their practices to other peers"* [W2_P5]. This appears to be in accordance with the assertion made by W1_P1, who posited that peer support must include a *"genuine acknowledgement of caregivers' concerns"* in order for those grievances to be *"acted upon by professionals or other peers"*. Additionally, they expanded on the need to *"include open communication"* [W1_P2], promoting a safe space where peers can engage in two-way personalised and responsive communications to meet each other's needs.

Accommodating diversity. The professionals proposed that caregivers should be connected based on various characteristics (e.g. their background and needs). Profiles that include information about their preferences could serve as the basis for creating diverse groups in contrast to current 'one-size-fits-all' approaches, which frequently led to group inappropriateness. To gain more clarity about diversity, participants undertook a poll about the group's morphology and determined that age (n=3), gender (n=2), similar experiences (n=2), skills or education (n=2), capacities, location, cultural background, gender, and service need as the most critical properties to consider when configuring the group. Other suggestions included discovering mutual interests and recognising different needs, which would serve as a motivator for the continued engagement of peers. As W1_P3 expressed: *"They want to know of different activities for them. For example, we have these groups which would be more attractive to young people in the family for them to come forward and talk about it. So, you can use these different strategies and techniques to get them interested."*

4.2.2 Enabling ongoing engagement.

Recognising accessibility requirements. The foremost enabling factor was that a digital tool should cater to people of all technical literacy and cultural backgrounds. This hinged on enablers such as the availability of the necessary equipment, including the internet and mobile devices. A professional underlined that caregivers find online meetings more convenient: *"I have seen once you teach them [caregivers] how to connect, they are willing to attend online meetings over physical meetings"* [W1_P3]. This was associated with the accessibility of the internet and smartphones, which was especially applicable to the urban population. As [W1_P1] stated, *"The only blessing that we have in urban areas is most of the people have the affordability of the internet, smartphone or a laptop. If not directly them, they have some youngsters in the house who can help*

them connect." On the other hand, professionals advised that the digital tool should feature an offline mode so that peers could review information even if they did not have access to the internet, which was crucial in rural areas. As [W1_P1] mentioned, *"It's very difficult to use online peer support in the village because not too many people in the village have internet and smartphone"*. The participants emphasised the need for interactive voice response systems (IVRS) or regular calling to facilitate simple connectivity for individuals with lower literacy or the unavailability of smartphones. One workshop participant reported that the calling function could be extremely helpful when other modes of communication are unavailable. This stemmed from their experience in assisting families in managing the condition of PSMI during Covid-19: *"During Covid-19, patients and families could not visit us, so we were dealing with them on call only to tell them about medicines or changes in symptoms of PSMI and how to manage them. "* [W1_P4]. It was stressed that digital solutions, with their easy accessibility, could be a boon in times of crisis or urgent needs. As W2_P6 stated, *"Only through phone we can start connecting with people for immediate virtual help. We can't visit them directly."*

Training and resources for effective facilitation. Workshop participants expressed interest in getting involved in peer-to-peer groups on both social media and via phone and raised insights for the effective facilitation of the group. Professionals indicated that in their existing practices, a few individuals dominated the group discussion, which was a barrier to engaging more members in support groups. In this situation, a group facilitator should oversee that each group member has the chance to express themselves when they want to and ensure a variety of views. As W1_P1 mentioned, *"There are times when families can be dictating what needs to be done. So, we are observing and realising how the families are being dealt with so that we sort of handle the situation."* In continuation, W1_P2 deemed that it was necessary to establish *"proper documentation of group's roles and responsibilities"* in order to manage it well. Participants suggested that the facilitator should be able to provide information if someone requires immediate assistance. As such, experts declared that broad knowledge about mental health concerns and understanding its sensitivities were the utmost necessary skills in facilitators. W1_P1 mentioned, *"There are times where there is information related to mental illness and somebody needs help. So, they should be able to directly reach out to the group or pass out our information so they can reach out to us."*

These ideas were further developed to comprehend how facilitators could be made competent to aid caregivers in need. The participants raised the use of 'psychological first aid' so that the facilitator can be trained in various psychological modules at both the individual and group levels to cater to different circumstances or refer people to helpful resources whenever appropriate. As W2_P7 mentioned, *"We train our peers in self-care and psychological first aid. So, we have built in this model in which these training run. So psychological first aid is like your physical first aid, anybody can be trained in that."* In rural communities, people commonly have ties with the local institutions such as temples, primary healthcare centres, or *"Asha"* workers, who are appointed by the government to counsel women on maternity STDs and care for the child, it is preferable to engage them as group facilitators. Since the rural

community tends not to follow any formal procedures and instead relies on simple communication practices, these local bodies could offer better support regarding the availability of more regulated medical support when needed. Additionally, professionals regularly approached subject matter experts to facilitate groups and assist caregivers in understanding and normalising the problems they encounter when caring for SMI patients. For instance, families can mitigate their problems by consulting with counsellors about concerns like *"Can their loved ones marry or not? Would they be independent? Will their children also have this illness?"* [W1 P2]. Additionally, a forum or question-and-answer session could be integrated into the support group to provide greater flexibility to caregivers in addressing their questions.

Empowering Caregivers to take ownership. Finally, it was suggested that a support group should empower caregivers by providing support and solutions that are highly contextualised and personalised. This was reflected in a participant's response to Persona 2 (Figure 3): *"We must visit her [caregiver] in a group of people, one must be a psychologist, and one must be who is ready to work in the field. We have to sit and discuss all the problems so that we can offer solutions based on the exact problem of her son [PSMI], and if needed, we can take him to the hospital."* [W2_P7]. The participants believed that it is essential to increasingly instil competencies in caregivers necessary for their own needs and challenges that arise from caring for PSMI. W1_P3 claimed that they attempt to do so in their current practice: *"Our support group is not just about supporting the family member to help the person who is ill, but also for the families to deal with their own issues related to the loss, their own stigma, their own behavioural patterns and this approach I felt have dealt us to get families to feel more empowered"*. Another participant asserted that caregivers must be able to engage with one another, even in the absence of mobilisers, in order to gain autonomy. According to W1_P2, they focus on equipping caregivers with skills and knowledge required to operate the groups: *"We started a family leadership training in which families can take charge and lead other families. We are in the starting phase of leading the families on how to conduct the support group"*. The participants also discussed the positives of fostering caregivers' independence so that they can unite and advocate for their rights collectively. E.g., W1_P2 stated, *"we combined our existing family members who were facing difficulty taking medicines from the hospital and made them write a letter to the government authority so that it creates a bigger impact"*. It was also confirmed that if the peer group is created and can forge genuine connections, it will eventually shift the need for professional facilitation to peer-led moderation. As W2_P7 stated, *"We have a group of three men. I connected all three of them. They like talking to each other. Now I don't even facilitate the groups, and if one of them is not well, the other two would call me and say he's not doing well. So, they have become peers to each other. They're in different cities. They haven't even met, but they're so close."*

5 DISCUSSION

5.1 Designing caregiver-centred support

Our findings add to a growing body of work that shows that accessing well-designed peer support has enormous potential to help caregivers in low- to middle-income countries (LMIC) where the health system lacks the capacity to provide the services PSMI and their families need [80]. Caregivers are overloaded with caring responsibilities and day-to-day challenges, which put their own health and well-being at risk and reduce their capacity to provide care. Our caregiver interviews and professional workshops suggest several ways we can design reciprocal peer support spaces that bridge service gaps by helping with the physical/mental health burden, emotional distress, managing stigma and supporting PSMI's recovery.

5.1.1 Supporting caregivers' physical and mental health.
The peer support spaces facilitate an understanding that "*you are not alone in the duty of caring for a loved one*". The caregivers need support through the information that others can share with them and social and emotional support to mitigate the physical and mental health burdens they face, which will subsequently reduce barriers to recovery of PSMI. More generally, a space needs to be given to escape the stigma they experience routinely. Such a space can also mitigate the issues in their existing support systems. With many PSMI being ill for a prolonged period of time, our findings revealed the long-lasting and severe negative impact of caregiving on the carers' physical and mental well-being. Many PSMI have lived with their condition for years, however, they are usually left untreated due to inadequate healthcare provision, lack of information, and social stigma [69]. Similar to earlier studies [55, 126], our research confirmed the considerable negative impact on caregiver-PMSI relationships, their emotional well-being, and the experiences of being blamed, criticised and neglected by others, which were all linked to emotional distress, hopelessness and social withdrawal.

5.1.2 Supporting caregivers' emotional safety.
Digital support networks cannot take a one-size-fits-all approach to manage their user's confidentiality but instead must strike a delicate balance. They need to find a way to support flexible, caregiver-determined anonymity where appropriate to allow participants to vent while feeling safe and avoiding pervasive social stigma but, at the same time, allow caregivers to find each other and come together to share support in the real world when they choose to. Caregivers in this study experience worries ranging from reputation damage (more applicable for urban participants) to cultural misconceptions (applicable to rural populations) that stopped them from getting a diagnosis, intervention and treatment in a timely manner. Our work adds to a body of literature that has found mixed differences in rural and urban settings in developing contexts. While Jadhav et al. [46] suggested their Indian participants felt more socially excluded in a rural environment, urban residents in Vietnam reported more stigma in terms of social exclusion [122]. In our work, the fact that urban participants reported facing judgements from relatives and friends, whereas rural participants described family and neighbours as being supportive and tolerant highlights the similarity to the study in Vietnam, which speculates that LMIC needs comparable solutions.

5.1.3 Supporting caregivers' sharing lived experience.
Our interview participants expressed their strong desire to give back to their communities by sharing their lived experiences and

perspectives and shared that attending meetings provided them with a greater comprehension of the problems they must face, gave them adaptive coping abilities, and built meaningful relationships. This is consistent with the helper-therapy paradigm, claiming that assisting others can boost self-esteem and reduce self-stigma [15]. We also observed that having more knowledge about illness leads to less stigma, which is corroborated by other research [48, 126]. The workshop findings show that the experts established a link between challenges experienced by the caregivers (i.e. extreme burdens, barriers to recovery and stigma) and a desire to share their lived experiences. This is consistent with previous research, which acknowledged that digital peer networks could alleviate stigma and provide supportive information to people dealing with similar challenges [19, 21, 45, 47, 105, 118], underlining the need to reduce stigma so that PSMI can live safer, more meaningful lives [13, 133, 137].

5.2 Designing support for the recovery of PSMI mediated by caregivers

The amount of expertise needed to navigate the complexities of mediating recovery for a PSMI in India is hard to overstate, and the pragmatic lessons, experiences and skills that caregivers develop are of enormous value to other caregivers. While recovery is a systemic challenge in high-income countries, this challenge is amplified in LMIC [93]. The findings in this study show an extreme lack of support from the healthcare systems, leaving the caregivers becoming the primary source of support for PSMI's recovery. This complex situation warrants design considerations that support caregivers as mediators for the recovery of PSMI. We should ask how can a network be built by the caregiver and what role technology needs to play in supporting its creation? While there is no universal concept of recovery, the consensus is that the recovery process is to increasingly empower caregivers to have hope and a sense that it is possible to regain meaningful life while managing persistent symptoms [44].

5.2.1 Holding onto hope in recovery.

Holding onto hope and supporting PSMI in the face of extreme burden, various barriers, stigma, and an ill-equipped existing healthcare system can be very difficult for caregivers who, in the majority of cases, have not undergone the needed training, as demonstrated in our findings. The most prominent barrier to recovery, as articulated by the caregivers, is their lack of knowledge about the diagnosis and about the subsequent steps related to how to take care of supporting the PSMI. A peer support group, as articulated by the experts in the workshop, has the potential to gather lived experiences where informational support can be provided with empathy as the sharing is coming from someone's own experience in caregiving. Sharing and learning about others' experiences can also cultivate a sense of belonging, as described by the workshop participants, enabling caregivers and PSMI to develop a sense of self-efficacy through the feeling of "I am not in this alone, if others can do it, maybe I can do it too". This sense of belonging can be achieved through group configuration design, where people who share certain similarities can be grouped together (See section 5.3.1).

5.2.2 Early empowerment for recovery.

Our work showed that the earliest stages of SMI onset are amongst the most challenging, as stigma and limited awareness of mental health issues delay diagnosis and hinder the process of recovery in LMICs such as India. As such, online peer support has to be particularly attentive to the way that a new user is welcomed to the community - they are likely to be at the point of greatest need with the least expertise as they are stuck trying to support recovery for the PSMI from a condition that they don't understand. Fortunately, purposely designed peer support can provide new caregivers with the information, network and social-emotional support needed to better take care of themselves and their loved ones because experienced carers have accumulated considerable knowledge and skills needed to make the most of the limited support available in the current health system (e.g. finding a good doctor) and the skills to cope with and manage the stigma from their social networks and at a societal level.

5.2.3 Social movements to promote awareness.

There was a clear appetite in the participants we interviewed to try to effect wider social change and reduce the amount of stigma associated with mental health illness in India. Designing for social support and acknowledging the non-professional caregiver's expertise in supporting PSMI's recovery not only supports caregivers at an individual level but can empower them to contribute to social movements that attract attention and effort in supporting caregivers at a societal level [1, 39, 98, 110]. Hughes et al. [43] used an ethnographic approach to gain a deeper understanding of the social issues faced by caregivers and to explore how they can be addressed using technology. This approach revealed new insights that expanded participants' conceptions of support beyond mere information and belonging networks to include instrumental support. This is driven by the need for tangible aid and aspirations to advocate together for structural reforms, such as strengthening family rights, disability compensation, and rehabilitation facilities, as well as fulfilling the social needs of PSMI, as it was stressed that isolation exacerbates their condition. This concentration on relationship development is consistent with HCI studies [17, 135] that leveraged social media for advocacy campaigns and political discourse. Future research should focus on developing a safe space for SMI caregivers to share their experiences and aspirations while facilitating three types of influence, namely emotional support, informational support, and tangible support, to strengthen social bonds and promote digital activism.

5.3 Designing for a technology-mediated peer group

The final design implication focuses on the technical design that allows for the caregiver and recovery-focused support articulated earlier to be operationalised. This includes the design of group configuration, group moderation, group facilitation and accessibility. Green et al. [32] suggest that harnessing the potential of digital technologies is one effective approach to allow services to reach individuals. This is consistent with this paper's findings that human connections can be embedded into digital peer networks to facilitate caregiver and recovery-centred support. However, from a logical stance, as Salovaara et al. [104] argued, a limited understanding

of a tool constitutes a significant barrier for users to make use of it. This demonstrated a clear need to leverage existing technical literacy, such as using social media applications or telephone-based services to engage and sustain peer support participation.

5.3.1 Group configuration design.

In relation to group configuration design, two key considerations are abstracted from the finding, with one being grouping people based on shared similarities and their dynamic of interaction. A determinant that emerged in the requirement elicitation was the differences in how participants conceptualise the expectations from the support group in terms of their individual requirements. Many participants sought that would enable them to identify peers based on more nuanced characteristics beyond the diagnosis of the PSMI, such as shared emotions, treatment experiences, health knowledge, roles, and lifestyle, which is in contrary to traditional techniques that organise health communities on diagnostic labels. This consideration is consistent with suggestions made by Hartzler et al. [37] for people with various forms of cancer, Park et al. [79] for people with depression, and [128] for caregivers of people with cognitive impairment, who advocate engaging peers in online communities based on similar other than disease label. This is a departure from the current practices of peer support services in the Indian context, which predominantly employed homogeneous groups, or the "one size fits all" approach based on the diagnosis of the illness or conditions [113]. Furthermore, studies [35, 56] have recommended accommodating target users' dynamic interactions and unique characteristics to influence motivation in using digital solutions.

5.3.2 Group moderation design.

A common factor in the failure of several support groups has been a lack of continuous availability of moderators who can administer the groups [113]. Some workshop participants described that engaging in online mental health networks can be distressing due to unsupportive members or inappropriate content. This requires intentional moderation design, as observed in related work on mental health support groups [11, 20, 51, 58, 111, 123] that demonstrate perpetuating negative online community behaviours impedes PSMI recovery. Our workshop findings showed that seeking emotional support necessitates sensitive disclosure and more implicit than explicit requests, which necessitated a well-moderated safe space for community members to take part.

5.3.3 Group facilitation design.

Group facilitation is another key aspect of the technical design, emphasising on who and how to facilitate the group interactions. The NGO professionals who participated in the workshops argued that it is ideal for caregivers to be in-charge of their interaction with other peers and influence features of the tool's administration for its continuous development. The approach of centring caregivers as both the owners and recipients of a digital support tool corresponds to the concept of mutual aid, in which self-help groups are established to fulfil marginalised communities' needs [52]. This demands exploration into models for training and encouraging caregivers, especially experienced caregivers who are willing to volunteer. Peer support facilitators have promoted recovery-focused improvements when given appropriate training, supervision, and management [95]. These design considerations do not disregard the significance

of clinical expertise. Instead, they suggest the following stages in establishing scalable systems where peer expertise can evolve and thrive with the assistance of professionals to strengthen caregivers' interpersonal relationships. A cooperative communication channel led by caregivers can facilitate both the provision of professional support and collaboration with other caregivers in integrating techniques for daily caregiving routines with PSMI. Likewise, it was advocated by Moulder et al. [67] that instead of the active involvement of professionals, their advising techniques should be used to provide participants with a holistic understanding of the problem as well as possibilities to alleviate it.

5.3.4 Group accessibility design.

Participants in this study interpreted personalised digital services to include accessibility and the capacity to engage with technology. This study used technology affordances as a lens for analysing the data [107], which provided a deeper insight and revealed diverse needs and difficulties with current communication practices for participants. There was a common consensus that people struggled with using the keyboard function to express their emotions through reading and writing. At the same time, people in rural areas favoured communication through audio technologies, while those in metropolitan regions preferred support through visual channels reasoned to socioeconomic factors like literacy rates and associated technological costs, which were relatively low in rural areas. This differential access to technology is supported by Toyama [129]'s amplification theory to alleviate the digital divide with the notion that progressive technology provision can effectively lessen societal inequities [134]. Existing literature illustrates using social media platforms [4, 24, 72], and IVR systems [41, 53, 94] incredibly beneficial as informal peer support sources in related areas of illness, through utilising multimedia to simple phone calls. Therefore, these findings emphasise the significance of designing peer support technologies with media accessibility preferences, such as video or audio, to accommodate caregivers' specific needs and pain points, in addition to broad illness diagnoses to remove traditional barriers to support and provide greater assistance.

6 CONCLUSION

This study reports challenges experienced by mental health caregivers in urban and rural India, including considerable physical and mental health burdens, barriers to supporting PSMI's recovery, stigma, and issues in the existing support systems. It presents a framework of design considerations for online communities that provide peer support to caregivers and is informed by direct engagement with them as well as professionals from NGOs who contributed their current work practices. Our findings suggest designing innovative peer support systems by leveraging existing digital platforms powered by social media or telephone-based platforms to mitigate the caregiving burden and foster the recovery of people with serious mental illnesses (PSMI). This work provides a valuable example from HCI for SMI caregivers in India and LMIC in general. We outlined opportunities for future work to establish peer support networks that can empower caregivers to support themselves and care for their loved ones while forming meaningful connections with peers. This connection has great potential to create a

social movement that could lead to healthcare system changes that provides more systematic support for families in need.

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