

Perceived Barriers to Using Digital Mental Health Support Among Family Caregivers of Individuals with Schizophrenia

Gowri Hari K.

*M.Sc. Psychology, Centre for Distance and Online Education, Jain (Deemed-to-be University),
Bengaluru, Karnataka, India*

Abstract—Family caregivers of people with schizophrenia carry a heavy burden and have limited access to formal support, while digital mental health options are expanding. This qualitative study explored the perceived barriers to using digital mental health support among family caregivers of individuals with schizophrenia. A qualitative, exploratory design was used. Eight family caregivers were selected through purposive sampling and interviewed using a semi-structured interview guide. The interviews were audio-recorded, transcribed and analysed using reflexive thematic analysis. Five themes were identified: limited awareness and understanding; practical and technological constraints; trust, privacy and stigma; doubts about relevance and fit; and caregiver burden with lack of time and energy. The perceived barriers were personal, practical, social and related to how services are designed. The findings suggest that digital mental health support for caregivers should be available in local languages, simple to use, low in data cost, clear about privacy and combined with human contact. These findings add to the limited qualitative evidence on caregivers in India.

Index Terms—caregivers, digital mental health, barriers, schizophrenia, qualitative study, India

I. INTRODUCTION

Background.

Schizophrenia is a severe and long-term mental disorder that affects thinking, emotion, perception and behaviour. It usually begins in late adolescence or early adulthood and, for many people, follows a course of relapse and partial recovery over many years. The World Health Organization estimates that about 24 million people worldwide live with schizophrenia. Although it is less common than depression or anxiety, its effect on the person and on the family is far greater,

because it often interferes with education, employment, relationships and independent living. In India, the National Mental Health Survey of 2015-16 found that a large proportion of people with mental disorders did not receive any treatment, and that the treatment gap for psychotic disorders was substantial (Gururaj et al., 2016). Mental health services remain concentrated in cities and are limited by a shortage of psychiatrists, clinical psychologists and psychiatric social workers. Because of this, and because long-term inpatient care is no longer the norm, the day-to-day care of a person with schizophrenia falls mainly on the family. Parents, spouses, siblings and adult children provide supervision, medication reminders, financial support, transport to clinics and emotional support, often with little training and little relief (Chadda, 2014).

The caregiving role also changes over time. In the early years of illness, families often have to learn about the diagnosis, understand the treatment and cope with a relative whose behaviour may be unfamiliar and distressing. Over the longer course, caregiving can become a settled but demanding routine that continues alongside the caregiver's own work, household duties and health. This extended and shifting role is one reason why the needs of caregivers should be considered as a separate concern from the needs of patients (Chadda, 2014). Caregivers are often the ones who observe changes in sleep, withdrawal or suspiciousness at home and who must decide when to contact a clinic. In many families the first contact with services is made by a relative rather than by the patient, so the information and support given to caregivers can shape the whole course of care (Pharoah et al., 2010).

India has one of the largest numbers of mobile phone and internet users in the world, and government and private initiatives have expanded tele-mental health services, helplines and online platforms in recent years. However, access is uneven. Differences in income, education, language, gender and rural or urban residence mean that many families still lack a personal smartphone, affordable data or the confidence to use online services (Naslund et al., 2017). Even where a smartphone is available, it may be shared among several family members, used mainly for calls and messages, or limited by the cost of data. A service that requires private, regular and reliable access is difficult to use in households where the phone is controlled by someone else.

Caring for a person with schizophrenia carries a heavy burden. Caregivers report financial strain, disturbed sleep, restricted social life, worry about the future, fatigue and emotional distress, and rates of depression and anxiety among them are higher than in the general population (Awad & Voruganti, 2008; Caqueo-Uriazar, Gutierrez-Maldonado & Miranda-Castillo, 2009). Stigma adds to the burden. Studies in India show that families of people with schizophrenia often experience shame, blame and social avoidance, and may conceal the illness from relatives and neighbours (Koschorke et al., 2014; Thara & Srinivasan, 2000). Stigma lowers help-seeking and isolates caregivers. Psychoeducational and family interventions reduce relapse and improve family functioning (Pharoah, Mari, Rathbone & Wong, 2010), yet in most low-resource settings very few families ever receive them. Digital mental health support refers to the use of mobile phones, applications, websites, text messages, video calls, telephone helplines and online communities to deliver information, screening, counselling, self-help, peer support and clinical care. These tools can be used at home, at any hour and at low cost, which is why they have been promoted as one way to narrow the treatment gap in low- and middle-income countries (Patel et al., 2007; Naslund et al., 2017). Reviews suggest that apps and online programmes can be useful for a range of conditions, although the quality of the evidence differs and many apps are not backed by research (Torous et al., 2021). For schizophrenia, early studies show that people with psychosis can use smartphone tools and find them acceptable (Ben-Zeev et al., 2014; Alvarez-Jimenez et al., 2014). Most of this work, however, concerns

patients. Much less is known about digital tools designed for family caregivers, and still less about how caregivers in India view them.

Access to a digital tool does not mean it will be used. Systematic reviews of engagement have identified barriers at several levels: the person (low motivation, limited digital skills, privacy worries), the technology (poor usability, cost, unreliable connectivity), the content (lack of relevance, language mismatch) and the wider context (lack of professional endorsement, social stigma) (Borghouts et al., 2021). Groups who are underserved, including people with low income and limited education, are at particular risk of being left out (Schueller et al., 2019). Caregivers who have received advice from a psychiatrist or psychologist may be more willing to try a recommended tool, while those who rely on unfamiliar websites may be uncertain about accuracy and safety. Because treatment decisions in schizophrenia are sensitive, a caregiver's trust in a digital source may matter as much as its technical quality (Borghouts et al., 2021; Torous et al., 2021).

Theoretical background.

The Stress, Appraisal and Coping framework (Lazarus & Folkman, 1984) treats caregiving as a prolonged stressor, in which coping depends on how caregivers appraise demands and, on the resources, available to them. The Technology Acceptance Model (Davis, 1989) explains use of a technology through perceived usefulness and perceived ease of use. The Unified Theory of Acceptance and Use of Technology (Venkatesh, Morris, Davis & Davis, 2003) extends these ideas with social influence and facilitating conditions such as support and infrastructure. These frameworks were used as sensitising concepts rather than fixed categories, so that themes could emerge from the data. Because the Technology Acceptance Model and the Unified Theory were developed for general users, their application to family caregivers was examined rather than assumed.

Significance and aim.

Family caregivers of people with schizophrenia are a group with high need and low access to support. Digital mental health could reach them without travel, leave from work or public disclosure, but this promise will not be realised unless the barriers they face are understood. Most existing studies on digital mental

health in India are quantitative, focus on patients or the general public, or address depression and anxiety. The present study explored how family caregivers of people with schizophrenia perceive the barriers to digital mental health support.

II. REVIEW OF LITERATURE

A. Barriers to digital engagement.

Borghouts et al. (2021), in a systematic review, grouped barriers to engagement into factors relating to the individual, the intervention and the setting. These included low digital literacy, lack of motivation, privacy concerns, technical problems, content that was not relevant and lack of human interaction. Problems at one level often interact with problems at another. Poor usability may matter little to a confident user but may stop a caregiver with limited digital skills from continuing, and a lack of professional endorsement may reduce trust in a service that would otherwise be acceptable. Torous et al. (2021) concluded that apps, chatbots and virtual tools hold potential, but that evidence, safety and privacy standards must improve. Mohr et al. (2017) noted that real-world uptake of digital programmes is often much lower than in trials, which tend to involve motivated participants. Schueller et al. (2019) highlighted that digital mental health can widen inequalities if the needs of underserved groups are not considered in design, and Bucci et al. (2019) found that staff saw promise in digital tools while stressing that the difficulty lies in how services are organised.

B. Digital tools in schizophrenia and in low- and middle-income countries.

Alvarez-Jimenez et al. (2014) reviewed online, social media and mobile technologies for psychosis and found them feasible and acceptable to young people with psychosis. Ben-Zeev et al. (2014) tested a smartphone programme for people with schizophrenia and found high use and satisfaction. Firth and Torous (2015) found that the number of apps for schizophrenia was growing but that evidence of effectiveness was limited.

Naslund et al. (2017) reviewed digital technology for mental disorders in low- and middle-income countries, found promising early evidence, and noted that most studies were small and short and that access, language

and sustainability were poorly addressed. Torous, Wisniewski, Liu and Keshavan (2018) surveyed psychiatric outpatients, many of whom owned smartphones and were interested in mental health apps, yet had concerns about privacy and about being overwhelmed by information.

C. Caregivers, stigma and family support.

Nearly all the studies above involved patients rather than their families. Relatively little has asked how the people who support patients experience these tools, even though caregivers often decide whether a family member uses a digital service at all. Koschorke et al. (2014) documented experiences of discrimination among people with schizophrenia in several Indian sites, and stigma by association affects relatives, who may withdraw from social contact. Families who fear that a diagnosis will become publicly known may delay contact with services until a crisis has developed.

Chadda (2014) described families as the main providers of care in the Indian setting and called for services that attend to caregivers themselves. The Cochrane review by Pharoah et al. (2010) concluded that family interventions can reduce relapse and hospital admission, but that they need trained staff and regular sessions, which are scarce in low-resource settings. Caqueo-Uribe et al. (2009) found that caregivers' quality of life is lower than in the general population, with the poorest outcomes where social support is weakest. Awad and Voruganti (2008) reported that relatives experience considerable emotional, financial and social strain. Thara and Srinivasan (2000) found that stigma associated with schizophrenia was widespread in India and affected marriage prospects, social relationships and the way families spoke about the illness.

D. Research gap.

The literature shows that caregivers carry a heavy burden, that family support is effective but hard to access, and that digital tools are feasible and acceptable for people with psychosis. Barriers to digital use are well documented in general terms, but few studies have examined how caregivers themselves, particularly in India, understand these barriers in their own circumstances. The present study addresses this gap.

III. METHODOLOGY

A. Design.

A qualitative, exploratory design was used. Qualitative research suits questions about perceptions, meanings and experiences, where the aim is to understand a phenomenon from the participants' point of view (Creswell & Poth, 2018; Patton, 2015). The study followed an interpretivist position, which holds that reality is understood through the meanings people give to their experiences. Data were collected through in-depth semi-structured interviews and analysed using reflexive thematic analysis. The research questions were: what do family caregivers know about digital mental health support and how have they used it; what barriers do they perceive; and what changes or conditions would make such support usable for them?

B. Participants.

Participants were recruited from [study setting], where persons with schizophrenia receive outpatient treatment or rehabilitation, after permission was obtained from the head of the institution. Eligible

participants were family caregivers aged 18 years or above who had been the main unpaid caregiver of a person with a psychiatrist-diagnosed schizophrenia for at least one year, who lived with or were in regular daily contact with that person, who could communicate in English, Hindi, Kannada or another language known to the researcher, and who were willing to give written informed consent and to be audio-recorded.

Paid caregivers, caregivers with a serious physical or mental illness that would prevent participation, and caregivers in an acute crisis related to the patient's illness were excluded. Purposive sampling was used to select caregivers who could give rich information about the topic (Patton, 2015), and maximum variation was sought with regard to age, gender, relationship to the patient, education and place of residence. Recruitment continued until data saturation was judged to have been reached. Guest, Bunce and Johnson (2006) found that saturation was often reached within about twelve interviews in relatively homogeneous groups. Eight caregivers took part. Their characteristics are shown in Table 1.

Table 1. Socio-demographic profile of the participants (N = 8)

Code	Age / Gender	Relationship	Education	Years caring	Smartphone and internet use
P1	54 / Female	Mother	Secondary (10th)	8	Basic smartphone, shared with husband; uses WhatsApp occasionally
P2	42 / Male	Brother	Graduate (B. Com)	5	Personal smartphone; high digital literacy; daily 4G data user
P3	49 / Female	Wife	Higher secondary	11	Personal smartphone; uses YouTube and WhatsApp; limited mobile data
P4	61 / Male	Father	Diploma	14	Basic key-pad phone; no personal internet access
P5	38 / Female	Sister	Post-graduate	4	Personal smartphone and laptop; active daily internet user
P6	58 / Male	Father	Primary (7th)	9	Shares phone with son; struggles with typing and touchscreens
P7	45 / Female	Wife	Secondary (10th)	6	Personal smartphone; uses voice notes; limited data plan
P8	66 / Male	Father	Graduate (B.A.)	12	Personal smartphone; uses basic calling and news apps

Note. Ages ranged from 38 to 66 years and caregiving experience from 4 to 14 years.

C. Instruments.

Three instruments were used. First, a socio-demographic data sheet recorded caregiver and patient details, including age, gender, relationship, education,

duration of caregiving, smartphone ownership and internet use. Second, a semi-structured interview guide was developed by the researcher from the study objectives and the literature. The guide is not a standardised scale. It covered awareness and past use of digital support, perceived barriers (probing cost, time, skills, language and network), trust and privacy,

family and social influences, contact with professionals, relevance and suggestions. The guide was reviewed by the research supervisor and piloted with one caregiver, whose interview was not included in the final analysis. Third, an audio recorder was used with permission, and field notes were written after each interview.

D. Procedure and ethics.

Ethical approval was obtained from [institutional ethics committee] before data collection. Eligible caregivers were identified with the help of the treating team and approached by the researcher. The purpose of the study was explained, a participant information sheet was given, and written informed consent, including consent for audio-recording, was obtained. Participation was voluntary, and participants could withdraw at any time without any effect on the patient's treatment. Interviews were held in a private room at a time convenient to the caregiver, lasted about 30 to 60 minutes and were audio-recorded. Participants were encouraged to speak in the language they were most comfortable with. Interviews were transcribed verbatim and, where needed, translated into English, and translations were checked by a second bilingual person. Recordings were stored on a password-protected device, and transcripts carried code numbers in place of names. Confidentiality was maintained through code numbers and secure storage. Caregivers who became distressed were offered a pause and, if needed, referral to the treating team or a counsellor.

E. Data analysis and quality.

Reflexive thematic analysis followed the six phases described by Braun and Clarke (2006, 2019): familiarisation with the data through repeated reading of transcripts; generation of initial codes; searching for themes by collating codes; reviewing themes against the coded extracts and the full data set; defining and naming themes; and writing up. Coding was inductive and driven by the data, although the researcher remained aware of the theoretical concepts in Chapter 2. The transcripts were coded [manually / using software: specify]. The themes were discussed with the research supervisor to improve the clarity and depth of interpretation. The quality of the study was assessed against the criteria of Lincoln and Guba (1985). Credibility was supported by prolonged

engagement with the data, a pilot interview and discussion of codes and themes with the supervisor. Transferability was supported by a detailed description of the setting, participants and procedures. Dependability was supported by a clear record of the steps taken, and confirmability by field notes and a reflexive diary. Reporting followed the COREQ checklist (Tong, Sainsbury & Craig, 2007). The researcher is a postgraduate student of clinical psychology, and this training, together with an interest in making mental health care more accessible, could influence how questions were asked and interpreted. A reflexive diary was kept throughout, and neutral, open-ended prompts were used so that caregivers could speak freely.

IV. RESULTS

A. Participant profile.

The eight participants were all family caregivers of persons with schizophrenia, including mothers, fathers, brothers, sisters and wives of the patient. Smartphone access and internet use varied considerably, from personal smartphones with daily data use to a basic key-pad phone without internet access. Some caregivers shared a phone with a husband or son, and one had completed only primary schooling.

B. Themes.

Analysis of the interview transcripts produced five main themes that describe the barriers caregivers perceived. Table 2 summarises them with their sub-themes.

Table 2. Themes and sub-themes

Theme	Sub-themes
1. Limited awareness and understanding	Not knowing what digital mental health support is; no information from clinicians; confusion between reliable and unreliable sources
2. Practical and technological constraints	Cost of data and devices; poor connectivity; sharing of phones; low digital skills
3. Trust, privacy and stigma	Fear of information leakage; shame about the illness; doubts about unknown online helpers

4. Doubts about relevance and fit	Language and cultural mismatch; need for personal contact; belief that schizophrenia needs in-person care
5. Caregiver burden and lack of time and energy	Constant care duties; exhaustion; low priority given to own needs

Theme 1: Limited awareness and understanding.

Caregivers described little knowledge of what digital mental health support could offer. Many were aware of phones and video calls only as ways of staying in touch with relatives or of seeing a doctor in an emergency, and had not thought of them as sources of information or support for themselves. Several said that no clinician had ever mentioned an app, helpline or online group. Some who had searched the internet reported being confused by contradictory advice and unsure which sources to believe.

Theme 2: Practical and technological constraints.

Caregivers described cost, connectivity and skills as everyday obstacles. Mobile data was seen as an expense that competed with medicines and household needs. Some lived in places with weak network coverage. In several families one phone was shared among members, which made private use difficult. Older caregivers, particularly parents, said they were not confident using applications and relied on children or neighbours to help.

Theme 3: Trust, privacy and stigma.

Concerns about privacy and trust were prominent. Caregivers worried that information about the illness shared online could become known to relatives or the community, which they feared would harm the patient's marriage prospects, employment or the family's reputation. Some doubted whether unknown people or automated programmes could be trusted with sensitive information. At the same time, a few participants saw a private digital route as attractive precisely because it avoided being seen at a clinic or support group.

Theme 4: Doubts about relevance and fit.

Caregivers questioned whether digital tools would suit their situation. Language was a concern, since many applications were available only in English. Some felt

that schizophrenia is a serious illness that needs face-to-face assessment and that an app or screen cannot understand the family's circumstances. Many preferred to talk to a known professional and said they would be more willing to try a digital service if their own psychiatrist or psychologist recommended it.

Theme 5: Caregiver burden and lack of time and energy.

Caregivers described days filled with supervising the patient, managing medicines, handling crises and earning a living. Several said that they put their own needs last and had little time or energy to learn a new tool, even when they believed it could help. Digital support was therefore sometimes seen as one more task and not as relief.

V. DISCUSSION

Interpretation of findings. The finding that caregivers knew little about digital support, and had not been told about it by clinicians, agrees with the view that low awareness and lack of professional endorsement reduce engagement (Borghouts et al., 2021). It also fits the Unified Theory of Acceptance and Use of Technology, in which social influence, including advice from trusted professionals, shapes use (Venkatesh et al., 2003). Cost, connectivity, shared devices and limited digital skills reflect the concerns of Naslund et al. (2017) about access in low- and middle-income countries, and the warning of Schueller et al. (2019) that digital mental health can leave underserved groups behind. In terms of the Technology Acceptance Model, these constraints lower perceived ease of use (Davis, 1989), and in terms of the Unified Theory they are a lack of facilitating conditions. In the framework of Lazarus and Folkman (1984), caregivers with heavy demands and few resources may appraise a new tool as an additional demand rather than as a coping resource.

Privacy concerns, the role of stigma and the wish for support in the local language and from a known professional all point to the same conclusion: the barriers cannot be understood only as problems of technology. Privacy concerns are consistent with the survey of psychiatric outpatients by Torous et al. (2018) and with the broader concerns about data safety raised by Torous et al. (2021). The sense of exhaustion and lack of time supports the literature on caregiver

burden (Awad & Voruganti, 2008; Caqueo-Urizar et al., 2009; Chadda, 2014). Overall, the barriers arise from the interaction of caregiving strain, stigma, limited resources and the way services are organised, which suggests that solutions should combine technical, clinical and social measures.

Comparison with previous literature.

The finding that some caregivers saw privacy as an advantage differs from the survey of Torous et al. (2018), in which privacy was mainly a concern for outpatients. It suggests that digital support may help reduce stigma-related barriers if confidentiality is clearly assured. The wish for support in the local language and from a known professional is in line with the view of staff reported by Bucci et al. (2019), and with the observation of Mohr et al. (2017) that many tools show poor uptake in real-world settings.

The role of stigma also matches Indian studies showing that families of persons with schizophrenia often hide the illness (Thara & Srinivasan, 2000; Koschorke et al., 2014). Earlier studies reported that people with psychosis found smartphone and online tools feasible and acceptable (Alvarez-Jimenez et al., 2014; Ben-Zeev et al., 2014).

The present study shows that the carers who support them face a different set of barriers, related to time, shared phones, language and trust. This is consistent with the observation that caregiving is a heavy and continuing burden (Awad & Voruganti, 2008; Caqueo-Urizar et al., 2009), and it extends the call for services that attend to caregivers themselves (Chadda, 2014).

VI. IMPLICATIONS, LIMITATIONS AND FUTURE DIRECTIONS

A. Implications.

Clinicians can introduce suitable digital resources during routine visits and show caregivers how to use them. Support should be available in local languages, simple to use, low in data cost and clear about privacy, and involving caregivers in the design of tools is advisable. Digital services should be combined with human contact, such as helplines and peer groups, and with efforts to reduce stigma. Mental health professionals and students of clinical psychology may be trained in digital literacy and in guiding families.

B. Limitations.

The sample was small and purposive, drawn from a single setting, so the findings may not apply to all caregivers. Data depended on self-report. The researcher's interpretation shaped the analysis, although reflexivity and supervision were used to limit this. Interviews conducted through translation may have lost some nuances of meaning. The study explored the views of caregivers only; the views of patients, clinicians and app developers were not included.

C. Future directions.

Future studies could use larger and more varied samples, including rural caregivers; mixed-methods designs that measure the extent of the barriers found here; co-design and testing of digital tools for caregivers, with evaluation of their acceptability and effect; and studies that include the views of patients, clinicians and service providers.

VII. CONCLUSION

This qualitative study explored the perceived barriers to digital mental health support among family caregivers of individuals with schizophrenia. Five themes were identified: limited awareness and understanding; practical and technological constraints; trust, privacy and stigma; doubts about relevance and fit; and caregiver burden with lack of time and energy. Family caregivers of persons with schizophrenia face barriers to digital mental health support that are personal, practical, social and related to service design.

Awareness, access, trust, relevance and the capacity of an already burdened caregiver all play a role. The promise of digital mental health will be realised for this group only if these barriers are addressed together.

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