

Experiences of Primary Caregivers of Persons Suffering from Severe Mental Illness: A Qualitative Narrative Inquiry

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Abstract

Background: Primary caregivers of persons with severe mental illness (SMI) in India work at the intersection of thin public mental health infrastructure, social stigma, and legislation that is progressive on paper but poorly enforced. **Objectives:** To document the psychosocial, economic, and legal experience of ten primary caregivers of persons with Schizophrenia or Bipolar Affective Disorder (BPAD), and to examine how far statutory protections under the Mental Healthcare Act (MHCA) 2017 and the RPWD Act 2016 reach their daily reality. **Methods:** A qualitative narrative inquiry was conducted with ten purposively selected primary caregivers attending psychiatric out-patient services at a New Delhi tertiary hospital. In-depth interviews were audio-recorded, transcribed, and analysed thematically. **Findings:** Seven themes emerged. Four extend known patterns - economic attrition, gendered role reorganisation, stigma management, and informal (spiritual/peer) coping. Three emergent observations warranting further study were identified: grief for a lost pre-illness identity, stigma intensification post-formal care contact, and gendered barriers to legal authority. **Conclusions:** Caregivers remain an unrecognised, uncompensated workforce whom current legislation does not yet reach in practice. Given the small sample, the three emergent observations should be read as hypotheses for confirmatory research rather than established findings.

Keywords: Caregiver burden; severe mental illness; narrative inquiry; Mental Healthcare Act 2017; RPWD Act 2016; India

Introduction

Schizophrenia and Bipolar Affective Disorder (BPAD) are among the most disabling non-communicable conditions worldwide. India's National Mental Health Survey (2015-16) estimated psychotic-disorder prevalence at 1.9 per 1,000 populations, with treatment gaps exceeding 70-80% for severe disorders, against a backdrop of roughly 0.3 psychiatrists per 100,000 people (Ministry of Health and Family Welfare, 2016, 2021).

Institutionalisation in India is both costly and stigmatised, so the family home becomes the de facto psychiatric ward and a relative becomes treatment coordinator, medication guardian, and crisis manager. The Mental Healthcare Act (MHCA) 2017 and the Rights of Persons with Disabilities (RPWD) Act 2016 (Government of India, 2016, 2017) both recognise community-based care and, in the MHCA's case, a 'nominated representative' role - yet whether caregivers know of, or benefit from, these provisions is under-researched. Indian caregiver research has also relied heavily on quantitative burden instruments (e.g., the Zarit Burden Interview), leaving the texture and legal context of caregiving underexplored.

This narrative inquiry addresses that gap through the first-person accounts of ten primary caregivers, aiming to: (a) document their multidimensional experience; (b) identify any emergent patterns not yet theorised in Indian caregiver research; (c) examine the gap between MHCA/RPWD protections and lived legal reality; and (d) generate recommendations for practice and policy. The sample is deliberately small and is intended to support narrative depth, not statistical generalisation.

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A narrative approach was chosen deliberately over the burden-score instruments that dominate the Indian literature, on the premise that a numeric burden score can indicate that caregiving is difficult without explaining how that difficulty is organised - the sequence in which resources are depleted, the specific mechanisms of stigma management, or the precise point at which legal protection fails to reach the person doing the day-to-day work. The ten cases reported here are offered in that spirit: as detailed, situated accounts capable of generating testable hypotheses, rather than as a representative cross-section of Indian caregivers.

‘Caregiver burden’ - objective disruption and subjective distress - was formalised by Grad and Sainsbury (1963) and Hoenig and Hamilton (1966); later meta-analyses (Pinquart & Sorensen, 2007) identified relationship quality, patient impairment, and social support as its strongest predictors. Indian studies since Verghese (1988) and the SCARF programme have documented sustained, high-intensity family caregiving, with Dsouza et al. (2020) noting that female caregivers report higher subjective burden and lower help-seeking. Qualitative work capturing legal awareness, identity change, and the meaning caregivers assign to their role remains comparatively sparse - the gap this inquiry addresses.

The MHCA 2017 replaced the custodial Mental Health Act 1987 with a rights-based framework: the right to community-based treatment (Section 19), decriminalised attempted suicide (Section 115), Mental Health Review Boards, and the ‘nominated representative’ mechanism. The RPWD Act 2016 extends parallel protections to psychosocial disabilities, including safeguards against institutionalisation and district-level grievance redressal. Both are widely regarded as the most comprehensive such framework in Indian history - yet, as this and prior studies suggest, an implementation gap separates statute from lived experience, particularly for low-literacy, low-income households.

This implementation gap has two distinct components that the present study tries to keep separate. The first is awareness: caregivers cannot exercise a right they do not know exists, and legal-literacy interventions address this directly. The second, less studied component is structural - whether the family and institutional arrangements around a caregiver actually permit her to exercise a right even once she is aware of it. Sections 4 and 5 below suggest that, at least in some of the ten cases studied, awareness and structural access are not the same problem and may need different remedies.

Methods

Design: Data collection took a narrative-inquiry stance (Clandinin & Connelly, 2000), inviting participants to narrate their caregiving experience in their own words; the resulting accounts were analysed using thematic analysis, with an interpretivist-constructivist stance treating meaning as co-constructed between narrator and listener

Setting and participants: The study was conducted at the Department of Psychiatric Social Work, ABVIMS-Dr. Ram Manohar Lohia Hospital, New Delhi. Ten primary caregivers were purposively sampled: inclusion required being the person providing the majority of daily care for a relative with an ICD-10 diagnosis of Schizophrenia or BPAD at least 12 months of caregiving, age 18 years and above, living with an individual with a severe psychiatric illness. Paid caregivers and those with an active psychiatric diagnosis of their own were excluded. Recruitment continued until thematic patterns began to repeat, judged to occur at the eighth participant, with two more recruited to check for disconfirming accounts; given the small overall sample, this is reported as indicative rather than definitive saturation.

Table 1. Sociodemographic Profile of Participants (N = 10)

Participant ID	Relationship	Gender	Diagnosis	Duration (yrs)
P1	Wife	Female	BPAD	7
P2	Daughter-in-law	Female	Schizophrenia	5
P3	Father	Male	Schizophrenia	12

Participant ID	Relationship	Gender	Diagnosis	Duration (yrs)
P4	Husband	Male	BPAD	9
P5	Wife	Female	Schizophrenia	11
P6	Wife	Female	Schizophrenia	8
P7	Father	Male	BPAD	15
P8	Brother	Male	BPAD	6
P9	Brother	Male	Schizophrenia	10
P10	Mother	Female	Schizophrenia	13

Note: Age, education, occupation, and household income were not systematically recorded for this study and are therefore not reported in Table 1. This omission is noted explicitly as a limitation below; descriptors used elsewhere in this paper (e.g., low-literacy, low-income) reflect participants' self-reported circumstances rather than measured demographic variables.

Data collection and analysis: Each participant completed one to two semi-structured interviews (60-90 minutes, Hindi or English), covering caregiving history, economic impact, social relationships, spiritual practice, legal awareness, and aspirations. Interviews were audio-recorded, transcribed verbatim, and back-translated where needed. Thematic analysis followed Braun and Clarke's (2006) six-stage process, from familiarisation to report production; candidate novel constructs were checked against disconfirming cases and reviewed by two senior psychiatric social workers. Ethical approval was obtained from the Institutional Ethics Committee, informed consent was obtained from all participants - in writing for literate participants, and via thumbprint with an independent witness for non-literate participants and were identified only by code (P1-P10).

Findings

Analysis identified seven major themes. Four themes (Themes 1-3 and 7) extended existing evidence on caregiving in severe mental illness, whereas three themes (Themes 4-6) represented potential theoretical contributions emerging directly from participants' accounts. Rather than occurring independently, the themes formed an interconnected process in which economic strain, changing family roles, stigma, and legal exclusion accumulated over time, contributing to caregiver burden and psychosocial distress. Spiritual coping and peer solidarity functioned as adaptive pathways supporting resilience. *Figure 1* illustrates this integrated conceptual model and the relationships between the empirically derived themes and the proposed theoretical constructs.

Theme 1: The Architecture of Economic Attrition

Caregivers described a sequential liquidation of assets - savings first, then jewellery, then productive assets - accelerated by unpredictable relapse cycles. Livelihood sacrifice was often irreversible: closed businesses could not simply be reopened once customers and capital were lost. Private transport, necessitated by the behavioural symptoms of the individuals with mental illness on public transport, added a recurring, unsubsidised cost.

"I had to sell my wife's gold bangles to buy the medicines. First the savings went, then the gold. I pray the house does not go next." - P3 (Father)

"I had to close my small grocery store. Now even if I wanted to restart, I have no money and I have lost the customers." - P8 (Brother)

"Public buses are not an option. He gets agitated and the other passengers complain. I have to take a cab every time." - P4 (Husband)

Read together, these three sub-patterns suggest that economic attrition in this sample was not a single shock but a slow-moving process with its own internal order - liquid assets first, then more consequential ones, with transport cost running underneath as a constant, largely invisible drain throughout. None of the three

participants quoted above described any subsidy, reimbursement, or formal financial counselling reaching them at any stage of this process.

Theme 2: Family System Reorganisation and Gendered Role Absorption

Wives described absorbing every household, financial, and parenting function previously performed by an unwell husband, without recognition or compensation. A second pattern involved scapegoating: wives and daughters-in-law were sometimes blamed - through folk explanations of curses or 'bad fate' - for causing the illness they were also caring for. Both patterns were reported exclusively by the female participants in this sample and were absent from the accounts given by the fathers and brothers interviewed, which is consistent with - though obviously not proof of - a gendered distribution of this particular burden.

"Now I do everything my husband used to do. Nobody asks how I am. I am just the person who brings him here." - P1 (Wife)

"My husband and in-laws blame me. They say I brought this curse into the family." - P5 (Wife)

Theme 3: Stigma Management and Social Capital Erosion

Concealment of diagnosis from neighbours and kin was deliberate and cognitively demanding, calibrated against risks to marriage prospects and reputation. Where concealment failed, progressive exclusion from community events followed - a pattern this study's source material terms 'social death' of the family unit, extending a concept usually applied to terminal illness.

"I never told anyone in the colony. I have told everyone he has a 'blood pressure problem'. I have to remember this lie in every conversation." - P6 (Wife)

"Neighbours stopped inviting us to functions. We have become invisible in the colony." - P9 (Brother)

The two accounts above sit at different stages of the same trajectory: one participant is still managing an as-yet-undiscovered diagnosis through active concealment, while the other describes the aftermath of exclusion once concealment had already failed. Considered together with Theme 5 below, they suggest that the risk of exposure, not only its eventual occurrence, is itself a source of chronic strain.

Theme 4: Grief for a Lost Pre-Illness Identity

One participant's account describes grief for her son's pre-illness identity - his personality, ambitions, and relational reciprocity - while he remains physically present. This resembles, but is distinct from, 'chronic sorrow' (Olshansky, 1962) and 'ambiguous loss' (Boss, 1999): here the person is present but experientially and relationally altered, and the grief carries no social sanction because there has been no death. As this pattern is illustrated by a single case in the present sample, it is offered as a hypothesis rather than an established finding.

"I grieve for my son every day, but he is sitting right there in front of me. There is no funeral. There is no word for what I feel." - P10 (Mother)

Theme 5: Stigma Intensification Post-Formal Care Contact

A single case describes stigma intensifying, not easing, after formal hospital contact: prescription bottles and visible OPD visits made a previously concealable diagnosis known to neighbours. This inverts an assumption built into the MHCA 2017 - that formal care contact protects families - and suggests that, without community-level destigmatisation, exercising legislated care rights can carry a social cost. Replication beyond this single case is needed before firmer claims can be made.

"After the first hospitalisation, everything changed in the neighbourhood. Before, we had problems but we were normal people. Now we are the family with the mad person." - P6 (Wife)

Theme 6: Gendered barriers to Legal Authority

Two participants - both women performing all functional caregiving - described the patient's nominated representative under the MHCA 2017 being a less-involved male relative rather than themselves. Because Section 2(n) of the Act leaves this nomination to the patient rather than the institution, the interview data cannot establish whether this reflected the patient's own preference, family pressure shaping that choice, or convention; whatever the mechanism, it produced concrete costs, including a week's delay in signing a treatment plan while a distant brother-in-law was contacted. If this pattern is confirmed at scale, it would point to gendered family dynamics shaping how a gender-neutral legal mechanism is used in practice, rather than to a flaw in the provision itself.

"I know every medicine, every dose. But when something needs to be signed, they call my father-in-law. He doesn't even know the names of the medicines." - P2 (Daughter-in-law)

"The hospital asked for a guardian signature. I am his wife, I take care of him. But they said my brother-in-law needs to sign. We had to wait a week." - P5 (Wife)

Theme 7: Spiritual Coping and Peer Solidarity

In the absence of formal support, faith provided both an explanatory frame and a daily emotional resource, though it occasionally delayed treatment-seeking. Hospital waiting areas also functioned as informal peer-support spaces, offering caregivers a rare sense of not being alone; participants described exchanging practical advice - which doctor to consult, how to manage a relapse at home, where medicines were available at lower cost - in a setting no formal service had designed for that purpose.

"I believe God is testing me, not punishing me. Prayer is my only strength now." - P10 (Mother)

Both forms of informal support appear to fill a gap left by the health system rather than substitute for professional care by choice; participants did not describe these as preferred alternatives to clinical support so much as the only resources reliably available to them between appointments.

Theoretical Synthesis

Three emergent observations help extend existing theoretical understanding. The observation of grief for a lost pre-illness identity builds on Doka's (1989) concept of disenfranchised grief by describing grief for a living person whose identity has been profoundly altered by illness. The observation regarding stigma intensification post-formal care extends Goffman's (1963) work on stigma by suggesting that formal contact with psychiatric services may, in some circumstances, increase rather than reduce social exclusion. Finally, the observation of gendered legal barriers draws on Fraser's (1995) concept of parity of participation to highlight how gendered family structures may prevent primary female caregivers from exercising legal rights theoretically available under the Mental Healthcare Act (2017). Because these observations were identified from single illustrative cases within a small qualitative sample, they should be viewed as tentative conceptual categories that generate new questions for future research rather than established theoretical models.

Discussion

The present study explored the lived experiences of family caregivers of persons with schizophrenia and bipolar affective disorder and found that caregiving extends well beyond managing psychiatric symptoms. Participants described caregiving as a process that gradually reshaped their financial circumstances, family roles, social relationships, and emotional well-being. These findings are consistent with previous studies

demonstrating that caregiver burden in severe mental illness is multidimensional, encompassing financial, emotional, physical, and social challenges (Awad & Voruganti, 2008; Grover et al., 2015; Kate et al., 2013). One of the most prominent findings of the present study was the gradual process of economic attrition. Rather than describing financial burden as a single event, caregivers narrated a progressive depletion of household resources, beginning with savings and extending to jewellery, productive assets, and livelihoods. Repeated travel for psychiatric follow-up further increased the financial burden. Similar findings have been reported by Grover et al. (2015) and Kate et al. (2013), who identified treatment costs, loss of productivity, and reduced family income as major contributors to caregiver burden among families of persons with schizophrenia in India. The present findings extend this literature by illustrating the sequential and often irreversible nature of financial decline.

The findings also demonstrate how severe mental illness reorganises family life. Female caregivers, particularly wives and daughters-in-law, described assuming responsibility for household management, finances, childcare, and caregiving while receiving little recognition for these additional roles. Some also reported being blamed for the illness itself. These observations are consistent with earlier studies showing that women frequently experience greater caregiving burden because of traditional gender expectations and unequal family responsibilities (Chakrabarti & Gill, 2002; Dsouza et al., 2020). The present study further suggests that gender inequalities may extend beyond caregiving responsibilities into legal decision-making within families.

Stigma management emerged as another central aspect of caregiving. Participants described continuously concealing the diagnosis from neighbours and relatives, carefully managing everyday interactions to avoid disclosure. When concealment was no longer possible, they experienced reduced social participation and progressive isolation. These findings are consistent with Goffman's (1963) theory of stigma and with Indian qualitative studies reporting concealment, discrimination, and social exclusion among families of persons with severe mental illness (Koschorke et al., 2017; Loganathan & Murthy, 2008). However, the present study adds a further dimension by showing that the anticipation of disclosure itself became a chronic source of psychological strain, even before overt discrimination occurred.

Participants consistently reported that psychiatric services focused primarily on treating the individual with mental illness, while their own financial, emotional, legal, and social concerns remained largely unaddressed. Similar unmet caregiver needs have been identified in previous research, which has highlighted the importance of caregiver psychoeducation, counselling, practical support, and family-centred mental health services (Saunders, 2003; Yesufu-Udechuku et al., 2015). These findings reinforce the need for mental health services that recognise caregivers as partners in treatment rather than solely as providers of care.

The present study also identified three preliminary conceptual contributions that may extend current understanding of family caregiving. One emergent observation reflects grief experienced for the altered identity of a loved one who remains physically present. Although this experience shares characteristics with chronic sorrow (Olshansky, 1962), ambiguous loss (Boss, 1999), and disenfranchised grief (Doka, 1989), the present findings suggest a distinct form of grief centred on the loss of a person's previous identity rather than physical death.

Similarly, the proposed construct of stigma intensification post-formal care suggests that engagement with formal psychiatric services may, in some circumstances, increase the visibility of mental illness and unintentionally contribute to social exclusion. While the Mental Healthcare Act (Government of India, 2017) aims to protect the rights of persons with mental illness and their families, the present findings indicate that legal protection alone may not reduce stigma unless accompanied by broader community awareness and anti-stigma initiatives. This observation aligns with evidence that structural stigma often persists despite progressive mental health legislation (Corrigan & Watson, 2002; Thornicroft et al., 2022). The proposed construct of gendered legal barriers highlights a possible mismatch between the gender-neutral provisions of the Mental Healthcare Act (Government of India, 2017) and everyday caregiving practice. Female caregivers described situations in which they performed nearly all caregiving responsibilities but were excluded from formal treatment-related decisions. Although observed in only two

participants, these findings resonate with Fraser's (1995) concept of parity of participation, which argues that legal equality alone does not guarantee equitable participation where structural social inequalities persist.

These proposed concepts should be interpreted cautiously. Two of the three constructs emerged from single illustrative cases within a small qualitative sample and therefore should not be regarded as established theoretical categories. Instead, they represent exploratory conceptual contributions that require examination through larger qualitative and mixed-methods studies involving more diverse caregiver populations. If supported by future research, these concepts may broaden current models of caregiver burden by incorporating identity-related grief, structural inequalities, and the unintended consequences of engaging with formal mental health services.

Taken together, the findings suggest that caregiver burden is not simply the sum of financial, emotional, and social challenges. Rather, these experiences appear to interact and reinforce one another over time. Economic hardship, changing family roles, stigma, legal barriers, and emotional distress formed an interconnected caregiving experience that cannot be adequately addressed through patient-centred treatment alone. A more comprehensive approach incorporating caregiver support, psychiatric social work, legal guidance, financial assistance, and community-based anti-stigma programmes may therefore be necessary to improve outcomes for both caregivers and persons living with severe mental illness.

Limitations and Future Directions

This study was conducted with a small sample of ten caregivers from a single tertiary-care psychiatric hospital, which limits the transferability of the findings. Two of the proposed constructs emerged from individual cases and should therefore be considered exploratory. In addition, the cross-sectional design captured caregiving experiences at a single point in time, and participants' accounts may have been influenced by recall or social desirability bias. Future research should replicate these findings using larger, multi-site, and culturally diverse samples. Longitudinal and mixed-methods studies are needed to validate these emergent observations, grief for an altered identity, stigma intensification post-formal care, and gendered legal barriers, and to develop evidence-based interventions and assessment tools that address caregivers' emotional, legal, financial, and social support needs.

Conclusion

This study highlights that caring for a person with schizophrenia or bipolar affective disorder extends far beyond managing psychiatric symptoms. Caregivers experienced interconnected financial, social, emotional, and legal challenges that were often overlooked within routine mental health services. Alongside confirming known aspects of caregiver burden, the study proposes three preliminary observations regarding grief for an altered identity, stigma intensification post-formal care, and gendered legal barriers, which offer new perspectives for understanding caregiver experiences. Although these concepts require validation in larger studies, the findings emphasise the need for family-centred mental health services that recognise caregivers as essential partners in care and address their support needs alongside those of the person living with severe mental illness.

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References:

- Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics*, 26(2), 149–162. <https://doi.org/10.2165/00019053-200826020-00005>
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Harvard University Press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

- Clandinin, D. J., & Connelly, F. M. (2000). Narrative inquiry: Experience and story in qualitative research. Jossey-Bass
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1(1), 16–20.
- Doka, K. J. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington Books.
- Dsouza, S., Karkal, R., Basavaraju, V., & Muliya, K. P. (2020). Understanding the burden and coping in caregivers of persons with schizophrenia and bipolar disorder. *Asian Journal of Psychiatry*, 51, Article 101987. <https://doi.org/10.1016/j.ajp.2019.101987>
- Fraser, N. (1995). From redistribution to recognition? Dilemmas of justice in a post-socialist age. *New Left Review*, 212, 68–93.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.
- Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet*, 281(7280), 544–547. [https://doi.org/10.1016/S0140-6736\(63\)91339-8](https://doi.org/10.1016/S0140-6736(63)91339-8)
- Grover, S., Chakrabarti, S., Ghormode, D., & Avasthi, A. (2015). Burden experienced by caregivers of persons with schizophrenia and bipolar affective disorder. *Indian Journal of Psychiatry*, 57(Suppl. 2), S224–S232. <https://doi.org/10.4103/0019-5545.161500>
- Hoening, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12(3), 165–176. <https://doi.org/10.1177/002076406601200301>
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in caregivers of schizophrenia. *Indian Journal of Psychological Medicine*, 35(2), 147–152. <https://doi.org/10.4103/0253-7176.116244>
- Koschorke, M., Padmavati, R., Kumar, S., Cohen, A., Weiss, H. A., Chatterjee, S., Patel, V., & Thornicroft, G. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science & Medicine*, 178, 66–77. <https://doi.org/10.1016/j.socscimed.2017.02.019>
- Loganathan, S., & Murthy, R. S. (2008). Living with schizophrenia in India: Gender perspectives. *International Journal of Social Psychiatry*, 54(3), 225–236. <https://doi.org/10.1177/0020764008090280>
- Ministry of Health and Family Welfare. (2016). *National mental health survey of India, 2015–2016*. National Institute of Mental Health and Neurosciences.
- Ministry of Law and Justice, Government of India. (2016). *The Rights of Persons with Disabilities Act, 2016*. Gazette of India.
- Ministry of Law and Justice, Government of India. (2017). *The Mental Healthcare Act, 2017*. Gazette of India, Extraordinary, Part II, Section 1.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43(4), 190–193.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 62(2), P126–P137. <https://doi.org/10.1093/geronb/62.2.P126>
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.
- Saunders, J. C. (2003). Families living with severe mental illness: A literature review. *Archives of Psychiatric Nursing*, 17(6), 285–294. [https://doi.org/10.1016/S0883-9417\(03\)00119-0](https://doi.org/10.1016/S0883-9417(03)00119-0)
- Thornicroft, G., Sunkel, C., Aliev, A. A., Baker, S., Brohan, E., El Chammay, R., Davies, K., Demissie, M., Drake, R. E., Gureje, O., Hanlon, C., Henderson, C., Jordans, M. J. D., Kola, L., Kulygina, M., Lund, C., Maulik, P. K., Semrau, M., Shidhaye, R., ... Sartorius, N. (2022). Ending stigma and discrimination in mental health. *The Lancet*, 400(10361), 1438–1450. [https://doi.org/10.1016/S0140-6736\(22\)01470-2](https://doi.org/10.1016/S0140-6736(22)01470-2)
- Vasudeva, S., Sekhar, C. K., & Rao, P. G. (2013). Caregivers burden of patients with schizophrenia and bipolar disorder: A sectional study. *Indian Journal of Psychological Medicine*, 35(4), 352–357. <https://doi.org/10.4103/0253-7176.122224>

- Verghese, A. (1988). Family participation in the care of the mentally ill. *Indian Journal of Psychiatry*, 30(4), 399–405.
- World Health Organization. (2021). *Mental health atlas 2020*. World Health Organization.
- Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E., & Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis. *The British Journal of Psychiatry*, 206(4), 268–274. <https://doi.org/10.1192/bjp.bp.114.147561>

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Fig. 1: Conceptual model of Family Caregivers' Experiences

