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Understanding caregiver burden from a long-term perspective: The Banyan model of caregiver experiences

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Abstract

Purpose: A multiphase model for experiences of family members of persons with mental illness that considers both positive and negative aspects is proposed.

Design and Methods: Mixed methods (semistructured interviews, life history timelines, focus group discussions, and the Experience of Caregiving Inventory) were used with caregivers accessing outpatient services of a nongovernmental organization in urban and rural locations around Chennai, India.

Findings: Based on our results, we constructed a multiphase model, which we named The Banyan model of caregiver experiences. The phases are (1) manifestation of symptoms, (2) seeking help, (3) helplessness and attribution, (4) relative control and insight, (5) loss and worries, and (6) finding new meaning.

Practical Implications: Our multiphase model allows us to identify in more detail the needs of caregivers at various stages.

KEYWORDS

caregiver, experiences, family burden, India, mental illness

1 | INTRODUCTION

The experiences of caregivers of people with mental health issue have been described in a significant body of research, mostly from western countries,¹⁻³ and to a smaller extent from low-resource countries.³⁻¹⁰ Most studies focus on measuring the negative aspects of caregiving, called “family burden,” which is usually defined as the influence of giving care to a person with mental health problem on the living situation of their caregiver and the emotional, psychological, physical, and economic consequences thereof (Awad,¹¹ WHO^{12(p12)}). A distinction is often made between “objective” and “subjective” burden. Objective burden is the concrete and observable negative effect of mental illness, such as financial burden, time spent on care giving, disturbance of family life, and negative health outcomes of the caregiver. Subjective burden is defined as the extent of burden *experienced* by the caregiver as a result of caregiving.³

An alternative approach to understanding caregiver experiences was developed by Szmukler.¹³ The notion of caregiver “burden” was rejected and instead, a “stress-appraisal-coping” framework was developed, which encompasses both positive and negative experiences^{13(p138)}. Szmukler developed a 66-item Experience of

Caregiving Inventory (ECI) in consultation with caregivers, focusing on a wider variety of domains of burden as well as on positive experiences of caregiving. This is important because “the extraordinary power of love” is often a sustaining force to continue caregiving duties^{14(p16)}.

While love and positive experiences can be vital aspects of caregiving (Awad,^{11,15-17}) it is undeniable that caregiving can cause significant distress to family members. Tension, stress, anxiety, resentment, depression with feelings of hopelessness and powerlessness, a sense of entrapment, disruption in their family life and relationships, financial difficulties, physical ill health, restrictions in social and leisure activities, and an overall decrease in quality of life have been reported as aspects of burden.¹⁸⁻²² Despite family burden being studied frequently, there is no conclusive evidence of the extent of, and contributing or predicting factors of burden. This has been attributed to studies being conducted in different settings, varying instruments, and the lack of a uniform definition of burden. However, certain findings have been concluded across studies. Symptomatic behavior, for example, violence, excessive demands, and high dependency^{1,3,19,23} and low levels of functioning^{3,24} seem to be a major contributor to family burden. It is hard to link a specific diagnosis to higher burden, as most studies focus on people diagnosed with schizophrenia,^{25,26}

thereby making comparison difficult. Burden appears to be higher among female caregivers,^{3,27,28} caregivers with higher education,^{3,29} and young age of the person with mental illness.^{30,31}

The duration of illness as a factor influencing family burden is studied to a limited extent, with varying results. Some studies have shown that longer duration of caregiving indicates higher burden and lower positive coping abilities,^{29,32} Chakrabarti et al.,^{24,31,33,34} while others have not found a positive correlation³⁵ (Ricard³⁶).

In sum, while predictors for family burden have been studied, the outcomes are nonconclusive or contradictory and hence, do not produce a set of indicators useful for practical application. More research is warranted in order to gain deeper insight into caregiver experiences and potentially identify additional factors and patterns. Furthermore, duration of caregiving has emerged as a potential predictor of caregiver burden, but only to a limited extent has this been studied. It might be, however, a relevant factor; one could imagine that caregivers in different phases of caregiving, experience different levels and types of burden. Existing frameworks for phases of caregiving are predominantly from North America,³⁷⁻⁴² with one exception from a middle-income country, Botswana.⁴³

2 | CAREGIVER EXPERIENCES IN LOW- AND MIDDLE-INCOME COUNTRIES

It has been suggested that caregivers play a large role in non-Western countries in the resocialization, vocational, and social skills training of the person subjected to caregiving (hereafter referred to as "relative"), not only because of closer family ties that exist in many non-Western societies,^{44,45} but also because developing countries lack rehabilitation professionals to deliver these services.⁴⁶ There is a glaring lack of infrastructure, funds, and political support for mental health care in developing countries.^{47,48} In India, an estimated 90% of people with chronic mental illness live with their families.^{49,50}

Chadda⁶ showed that nonacceptance of the relative by members of society led to the feeling of isolations, including hiding the mental illness in order to preserve the chance of marriage. Blaming persons with mental illness and lack of appreciation from the society also contributed to caregiver burden. An ethnographic study in India by Addlakha⁵¹ illustrated interpersonal tension between siblings as a result of existing economic hardship being exacerbated by caregiving.

Since mental illness is often attributed to demon possession or black magic, the first course of treatment is frequently with faith healers. Some places require families to accompany their relative for extended periods of time, and rituals performed are often expensive. Many caregivers subsequently seek treatment at medical facilities, or continue treatment at both types of facilities simultaneously.⁵² In this context, it is important to understand the experiences of caregivers in a low-resource setting such as India, over a period of time.

3 | METHODOLOGY

The study employed a mixed-method research methodology, through semistructured interviews, life history timelines (LHTs), the ECI

administration, and focus group discussions in order to provide a multidimensional approach aimed at gaining insights in the burden experienced by caregivers of persons with mental illness.

3.1 | Sample

The study was conducted among caregivers of people accessing free mental health outpatient clinics of The Banyan in urban and rural location around Chennai, Tamil Nadu, India. The Banyan is a non-governmental organization, founded in 1993, which addresses issues of homelessness, poverty, and mental health through emergency mental health care, outpatient psychiatric treatment, social care, vocational training, research, and advocacy. A multidisciplinary team of psychiatrists, social workers, psychologists, occupational therapists, and community workers is available to clients, with or without the caregiver's presence.

The sample population of the interviews consisted of caregivers of women with severe mental health concerns from low socioeconomic groups. Of 29 caregivers from the qualitative sample, relatives of 24 access the outpatient clinics of The Banyan and five access government psychiatric services in Kancheepuram district, Tamil Nadu.

Maximum variation purposive sampling^{53(p73),54} was employed to select the participants, from four categories: (a) spouses, (b) adult children, (c) siblings, and (d) parents. Maximum variation purposive sampling has been chosen in order to gain a deeper understanding of the experiences of different types of caregivers of women with mental ill health. In order to choose caregivers who would be able to verbalize their experiences of caregiving, a minimum of 2 years of caregiving was required.

The ECI was administered to 117 caregivers of clients (male and female) accessing The Banyan's outpatient psychiatric clinics in urban and rural areas. The caregivers were selected randomly, choosing every second caregiver who attended the clinic. If a caregiver did not give consent to participation, the next caregiver on the list was approached. Caregivers of clients diagnosed only with an intellectual disability (and not a psychiatric illness) were excluded, as well as caregivers with less than one year of caregiving experiences.

The investigators developed the model of caregiving. In order to understand the more detailed experiences of caregivers during each phase, focus group discussions (FGDs) were conducted with different types of participants comprising caregivers accessing the Urban Mental Health Program of The Banyan (parents and spouses; $n = 12$), mental health professionals ($n = 8$), and NALAM community workers* from urban ($n = 10$) and rural areas ($n = 12$).

Finally, the findings of the modeling phase were consolidated and presented in two focus groups for validation. Participants of the FGDs were caregivers accessing the Rural Mental Health Program of The Banyan (siblings and adult children; $n = 8$) and mental health professionals ($n = 10$).

* NALAM workers, which means well-being in Tamil, are community level employees of The Banyan who have attended a 6-month training program. Their responsibilities range from identification, referral, and follow-up to facilitation of social entitlements for people with all disabilities, and addressing other issues in the community, such as substance abuse and domestic violence.

All caregivers participating in the study regularly access treatment at The Banyan or a Government hospital. All mental health professionals and community workers are employed at The Banyan. The methodology evolved over time, since queries arose during the analysis phase, which led to the theory building phase, followed by the validation phase.

3.2 | Data collection and analysis

3.2.1 | Understanding burden

Semistructured interviews were conducted with caregivers at their home or at a private place at the clinic. The interview schedule was prepared by the investigators, and was adapted from an interview schedule developed by The Banyan Academy of Leadership in Mental Health in 2009. The schedule was used as a topic guide for the interview. Appreciative inquiry⁵⁵ was used as a method to assist caregivers in framing their own experiences without the more rigid format of a structured interview. In addition, the investigators used LHT exercises to collect retrospective event data, as it has been shown that this method elicits more detailed data than regular semistructured interviews.⁵⁶ Participants created timelines with positive and negative events since the onset of the illness.

The interviews were audiorecorded and transcribed verbatim from Tamil or English to English by a professional service. Transcripts were read and coded through open coding by the first two authors, and verified by the third author. The coded data were then discussed to create a list of categories to be used in the phase of axial coding (Corbin and Strauss⁵⁷). The emerging patterns were used in the development of the phases of caregiving.

The ECI is a 66-item survey, with more conventional domains related to burden (difficult behavior, negative symptoms, effects on family), as well as problems with services, dependency, need to back up, and loss (Szmukler,¹³ in addition to two domains with positive experiences of caregiving (positive personal experiences and good aspects of relationship). Answers were rated on a 5-point scale (0 = never, 1 = rarely, 2 = sometimes 3 = often, 4 = almost always). The ECI has been shown to have good internal consistency^{13,58} and has previously been used in India.²⁹ However, the instrument has not been validated for use in India.

3.2.2 | Developing a model for phases of caregiving

The authors developed the phases of caregiving according to the analysis of the qualitative and quantitative data from the first phase by identifying common experiences and themes among caregivers and preparing names and descriptions for each phase.

Consequently, four homogenous focus group discussions were conducted at The Banyan locations to validate the structure and names of the phases. Participants prepared charts in small groups that elaborated on the feelings of the caregiver in each phase, the available treatment and information, needs and support structures.* The charts and discussions were analyzed by comparing the most frequent themes in the discussion with the model proposed.

Finally, two homogenous focus group discussions were conducted at The Banyan locations to validate the model by presenting a summary of the findings of the previous focus group discussions to participants, followed by a discussion on whether the themes and needs identified were congruent with their experiences.

4 | ETHICS

Approval for the study was obtained from the ethics committee of The Banyan, which consists of external reviewers. After explaining the details of the study, consent forms were signed by participants in Tamil or English.

5 | RESULTS

The study involved 29 caregivers in interviews, 117 in the Experience of Caregiving Inventory and 21 caregivers in the focus group discussions. Characteristics of caregivers, the person subjected to caregiving, and duration of caregiving are presented in Table 1.

The demographic details of the mental health professionals who participated in the study are presented in Table 2.

Next, we will report the findings of the Experience of Caregiving Inventory, followed by an explanation of The Banyan model of caregiver experiences.

6 | EXPERIENCE OF CAREGIVING INVENTORY

The findings of the ECI are presented as total scores of grouped domains. Since each domain has a different number of questions, and therefore varying possible total scores, the total possible score per domain is also presented in Table 3.

Overall, the results show that negative domains scored considerably lower than positive domains, indicating that being a caregiver has positive aspects in addition to burden. When examining individual items within domains, high scores were observed for a number of items within the categories "need to back up," "dependency," and "loss" domains, which are shown in Figure 1.

Regarding "need to back up" we observed a large difference between the items, explaining relatively low scores, while high scores have been observed for "have to support him/her," "backing up when he/she runs out of money," and low scores for "him/her keeping bad company" and "has difficulty looking after money." "Always at the back of my mind" and "having to help him/her fill in the day" scored high in the "dependency" domain. Similarly, in the "loss" domain, the overall score is low, while "what sort of life he/she might have had" and "thinking about lost opportunities" have scored high.

Even so, the levels of burden found through the ECI were relatively lower than expected. This positive result was not congruent with that of interviews conducted, during which, although positive aspects of caregiving were mentioned and caregivers generally expressed that they had a good relationship with the person subject to caregiving

* The latter two categories will be discussed in a separate article.

TABLE 1 Characteristics of caregiver, person subjected to caregiving and duration of caregiving

	Interviews (n = 29)	ECI (n = 117)	Focus group discussions (n = 21)
Mean age caregiver	48.8 (SD = 17.6)	47.3 (SD = 14)	52.4 (SD = 13.5)
Mean age relative	46.1 (SD = 11.8)	39.8 (SD = 11.7)	
Gender caregiver			
• Female (%)	62.1	57.3	61.9
• Male (%)	37.9	42.7	33.3
Gender relative			
• Female (%)	100	65.8	85.7
• Male (%)	0	33.3	14.3
• Unknown (%)		0.9	
Type of caregiver			
• Parent (%)	27.6	35.9	23.8
• Spouse (%)	20.7	30.8	38.1
• Sibling or sister/brother-in-law (%)	27.6	12	28.6
• Adult child or son/daughter-in-law (%)	24.1	15.4	9.5
Education caregiver			
• No education (%)	10.3	8.5	4.76
• Up to 5 years (%)	24.2	17.9	9.52
• Up to 8 years (%)	20.7	12	33.3
• Up to 10 years (%)	24.2	23.1	42.9
• Up to 12 years (%)	0	9.4	4.8
• Higher education (%)	20.7	17.1	
• Unknown		12	4.8
Marital status caregiver			
• Unmarried (%)	17.2	12	4.8
• Married (%)	48.3	62.4	81.0
• Widowed (%)	27.6	10.3	14.30
• Divorced or separated (%)	6.9	4.3	
• Unknown (%)		11.1	
Diagnosis relative	Unknown		Unknown
• Schizophrenia (%)		34.2	
• Psychosis NOS (%)		26.5	
• Depression (%)		17.1	
• Bipolar disorder (%)		13.7	
• Intellectual disability with psychosis (%)		3.2	
• Unknown (%)		1.7	
Mean duration of caregiving in years	14.2 (SD = 9.49)	8.3 (SD = 6.5)	14.0 (SD = 9.96)
Longest duration (years)	40 years	32 years	39 years
Shortest duration (years)	2 years	1 year	2 years

TABLE 2 Mental health professionals and community workers information

Participants focus group discussions	Mental health professionals and community workers (n = 39)
Location	
• Rural Mental Health Program	19
• Urban Mental Health Program	20
Occupation	
• Social worker	4
• Psychologist	2
• Senior community worker	2
• NALAM worker	21
• Nurse	2
• Occupational therapist	1
• Vocational trainer	2
• Healthcare worker	2
Mean years of experience	3.6 (SD = 3.09)
Mean number of clients assisted	241 (SD = 259.93)

(referred to as “relative”), aspects of burden, and at times high burden, were also undeniably present.

One reason for this discrepancy could be that the sample of the ECI consists of caregivers who regularly visited the health unit, and had done so for at least one year of caregiving. These conditions are expected to lead to most relatives being less symptomatic and caregivers more experienced in dealing with symptoms and crisis situations. Therefore, we can expect that the experiences and needs of caregivers evolve and change over time.

7 | PHASES OF CAREGIVING

Based on the timeline interviews, the ECI and the focus group discussions (FGDs), we constructed a multiphase model of caregiver experi-

TABLE 3 Results of the Experience of Caregiving Inventory (ECI)

Variables	Mean (SD)	Total possible score per domain
Negative domains		
Difficult behavior	5.87 (6.76)	32
Negative symptoms	8.06 (7.06)	24
Stigma	3.29 (4.16)	20
Problems with services	1.69 (4.17)	32
Effects on family	4.42 (5.60)	28
Need to back up	9.20 (4.72)	20
Dependency	8.51 (5.07)	20
Loss	7.80 (7.40)	28
Positive domains		
Positive personal experiences	18.27 (6.91)	32
Good aspects of relationship	17.06 (5.34)	24

ences, which we named The Banyan model of caregiver experiences. The model states that the experience of caregiving changes over time and is influenced by the psychiatric condition of the relative, the available medical services and information about mental illness, and the changes in the life of the caregiver as a result of caregiving. This process is not necessarily linear and depends on the individual's circumstances. As shown in Figure 2, the experiences of caregivers can follow various trajectories, and phases may recur over time. Some caregivers may not experience all phases and some phases may never be left behind.

The feelings and emotions outlined in Table 4 are as experienced in each phase by caregivers. They are described and illustrated in the next section.

7.1 | Phase 1: Manifestation of symptoms

As emerged from the analysis, the initial time when the mental health symptoms of the relative become manifest is experienced as confusing and frightening for caregivers because the cause for the changes in

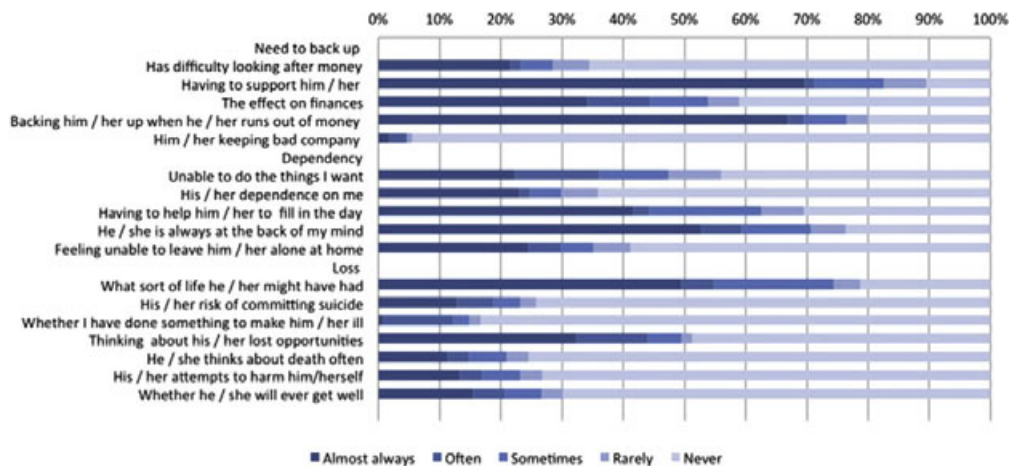


FIGURE 1 Experience of Caregiving Inventory (ECI) results per item in the domains of “need to back up,” “dependency,” and “Loss” [Color figure can be viewed at wileyonlinelibrary.com]

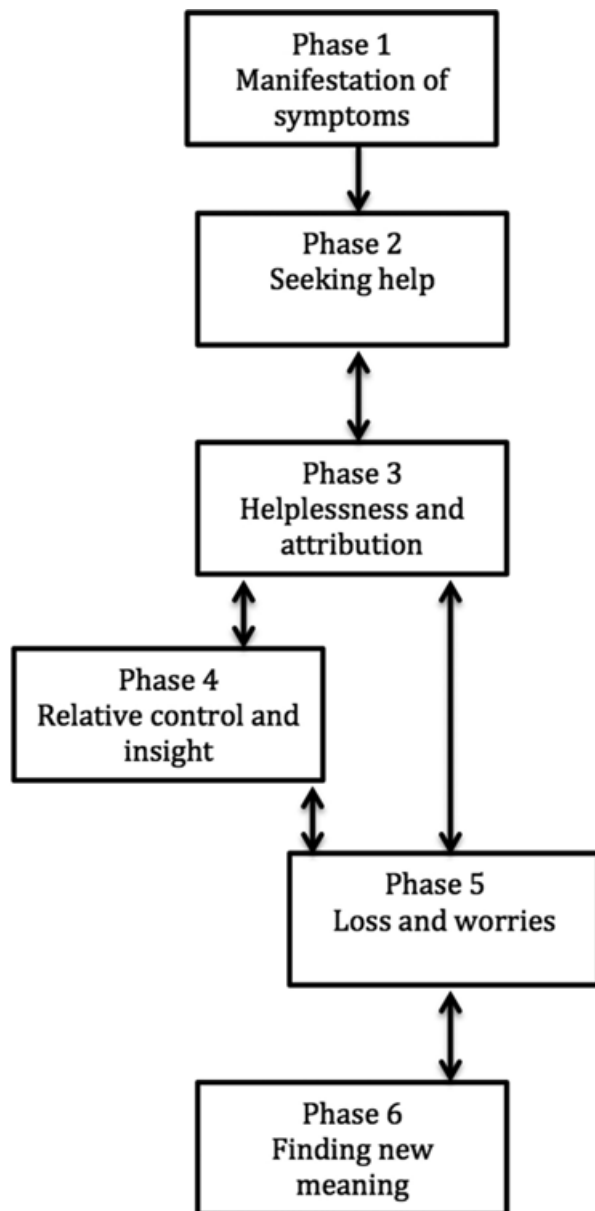


FIGURE 2 The Banyan model of caregiving experiences

behavior is unknown. One caregiver described the initial 2 years of his wife's illness as follows:

I used to wonder why she was constantly talking about unrelated things that do not make sense, did not talk to us and refused to eat. Staying with her for those initial two years has made me feel mentally sick too. The reason of her behavioral changes was unknown to me, which was annoying me very much. (Husband, 69 years old)

The changes were often attributed to religious reasons, black magic or fate or ascribed to personal traits of the relative, such as laziness, stubbornness, "being difficult." A mother and a husband recalled:

We saw that some black magic had been done to the food she had eaten. (...) She would run, laugh, beat others, shout, throw mud and stones on people and be irritated. (Mother, 65 years old).

I just ignored her strange behavior, thinking: "Ok, this is how she is." But I never knew that she was mentally disturbed. (Husband, 70 years old)

The first phase is also described as a time when the family experiences dishonor, since the behavior of the relative can be embarrassing at times. In some situations, family relations are disrupted, because caregivers cannot participate in events and celebrations. In addition, the employment of the caregiver is frequently disrupted, due to the need to stay at home to take care.

7.2 | Phase 2: Seeking help

After the manifestation of symptoms and the realization that the change in behavior indicates a serious problem, caregivers aim to seek help, at various types of facilities (faith healing centers, government hospitals, private practitioners, nongovernmental clinics). A brother remembers:

We went to churches where she was chained, and we visited temples, but nothing helped. When she was admitted to the Institute of Mental Health (IMH) (Government Hospital, MD) in Chennai, she recovered. But IMH was too far and we lost hope. (Brother, 51 years old).

Caregivers shared they had feelings of despair, frustration and a sense of loneliness during this phase. Caregivers expended time and money in order to seek help, which was often beyond their means, as was shared by a mother:

When she became ill in 1993, we spent a lot of money on her treatment, we even sold property. Even then, we had a lot of loans and debt. (Mother, 67 years old)

Some caregivers indicated that they experienced hope of recovery during this phase, considering the financial and time investments made, while also experiencing fear about the future. Some caregivers shared their strong determination not to abandon the relative.

During this time, the employment of the primary caregiver is often affected, since he or she needs to take time off work to travel to places of treatment. Most inpatient facilities require a caregiver to be present (including The Banyan) and faith healing centers can require people to stay for extended periods of time.

7.3 | Phase 3: Helplessness and attribution

Despite seeking help, a complete cure of mental illness is not always feasible, due to the nature of mental illness, delayed start of treatment and experimentation to find the right type and dosage of medicines. This can give rise to a feeling of helplessness, characterizing phase three, since the relative may not be recovering, as shared by two mothers:

She relapses every 6 months, treatment is not working for her. (Mother, 67 years old)

TABLE 4 Description of phases of The Banyan model of caregiver experiences

Phases	Feelings and emotions of caregivers	Phases	Feelings and emotions of caregivers
Phase 1	- Sleeplessness/agitation/nervousness/mental disturbance	Phase 4	- Self-confidence/confidence about how to administer medicines
Manifestation of symptoms	- Helplessness/confusion - Fear - Sadness - Loneliness - Anger - Loss of honor in society	Relative control and insight	- Faith in medication - Less experience of stigma - Hope - Relief - Positivity
Phase 2	- Anxiousness/depression/mental disturbance	Phase 5	- Hollow feeling/anxiety/sleep disturbance/frustration/loss of peace/depression / hopelessness/feel like giving up
Seeking help	- Feeling upset about employment disturbance - Questioning the possibility of a cure - Fear of stigma - Resolve that the relative should not be abandoned - Lack of knowledge about mental illness and available treatment facilities	Loss and worries	- Loss of relationships/loneliness - No freedom - Inferiority complex - Social fear/losing honor in society - Suicidal - Worries about potential suicide of the relative
Phase 3	- Depression/frustration/irritation	Phase 6	- Self-confident/feeling experienced and able to help others
Helplessness and attribution	- Anger about treatment not working - Guilt about not seeking help on time - Loneliness/inability to share experiences with others - Fear of chronicity of illness	Finding new meaning	- Feeling pride and accomplishment - Seeking to help others and share knowledge - Become active in the community - Desire to gain new knowledge

She used to beat me. I had no support from relatives and earning money was difficult. (...) Now I need to take care of her children as well. I tried fighting for her disability allowance, but that didn't work out either. (Mother, 80 years old)

After accessing several types of treatment and facilities, caregivers often lose the stamina to continue accessing treatment, given the paucity of money and time. A son recalls:

We tried many places for treatment, starting with the mental hospital in Chennai. That didn't help, so then we didn't go anywhere. Later she got shock (ECT) treatment, but that didn't help either. She relapsed in 2005 and again from 2013 onwards. (Son, 31 years old)

In this phase of helplessness, caregivers also try to find answers about what caused the mental illness. They attribute the onset of mental illness to a particular event in the life of the relative, such as losing a baby, domestic violence by a spouse or losing large amounts of money.

Family members shared their thoughts about possible causes:

She was married and her baby died when she was three months. After that, she became like this. (Brother, 50 years old).

She got mentally ill, because her husband used to beat her on the head often. (Mother, 80 years old).

In addition, in India, mental illness is often attributed to black magic, cast on the family because of jealousy about success or good fortune. Possession by demons is also cited as one of the reasons for mental illness.

7.4 | Phase 4: Relative control and insight

During this phase, caregivers experience a sense of control and stability, after the volatile phases described above. Stability is often aided by reduction of symptoms and increased self-confidence of the caregiver in dealing with difficult situations. The term "relative control" indicates that caregivers may not be able to exercise complete control over their situation, since circumstances such as mental health status of the relative, decisions made by the relative about his or her own well-being, the clinical decisions made by mental health professionals, and personal circumstances of the caregiver influence the sense of stability and control experienced by the caregiver.

At times, medication makes the relative more sleepy or less active, which contributes to the sense of relative control, even though this is not necessarily in the best interest of the relative. A mother and daughter-in-law shared their experiences:

When she takes medicines, she sleeps. If she doesn't take medicines, she screams with hair open and wanders. (Mother, 55 years old)

[S]he doesn't give me any trouble. She is always very silent and does her work and doesn't trouble anybody at all.
(Daughter-in-law, 26 years old)

Caregivers indicated that they gained self-confidence by living with the relative every day and dealing with situations as they arise. Learning by trial and error was identified as an important process in gaining self-confidence. Caregivers also indicated that they gained more insight in the nature of the mental illness, symptoms, warning signs and coping mechanisms, which helped with early identification of relapses.

Caregivers expressed hope in the effectiveness of medicines and felt life was normal again in this phase:

I have no problems with her. She helps us with the work in the field, just like others in the family. (Brother, 31 years old)

There is no problem now, because she goes to work and earns money. It is actually the other way around, she earns money and takes care of me. (Father, 60 years old)

Caregivers also seek to share their situation with relatives and hope for acceptance from society by inviting the relative for family celebrations and to their homes.

7.5 | Phase 5: Loss and worries

Even if caregivers experience relative control in phase 4, they shared that loss and worries can be felt simultaneously, which is not often acknowledged. Loss of the life the caregiver and client could have had, loss of relationships and fear for loss of life of the client can be part of the caregiving experience.

Loss and worries can be experienced in all phases, but are especially prominent after a longer duration of caregiving, when permanent changes in life become manifest.

A mother reflected on her particularly difficult life:

There is no happiness in my life, I have so many problems. It's better to die than to live. So I feel very exhausted and wish I was no more. (Mother, 55 years old)

Caregivers experienced various types of loss, including the loss of the opportunity to get married, to have children, to pursue higher education, to experience a regular life as spouses, loss of relationships with relatives and friends, loss of employment.

Caregivers reflected on their own loss of opportunities or that of others:

I think about my marriage and the need for a companion in my life who would take care of me. But people say that it is not possible in my life, so I feel constantly upset and depressed.
(Daughter, 26 years old)

My daughter and son wanted to study more after 10th Standard, but because of financial difficulties and loans for medical costs, they both have to work now. (Daughter, 37 years old)

Sometimes my friends ask me why I look like an old person. Friends my age have small children, while I have so many responsibilities. I am a fun-loving person, and like to joke and chat, but all that is for some time only. (Daughter, 36 years old)

Caregivers also grieve the loss of opportunities in the life of the relative, similar to their own losses mentioned above, and the kind of life they could have lived had they not experienced mental ill health. A mother and shares her worries:

I don't have income, no food and many things but all that does not worry me as much as my daughter's plight. She is very young, but she never lived her life. Seeing her like this is very difficult. (Mother, 60 years old)

Similarly, a husband expresses his grievance:

And now that we finally have enough money and live well, she is not able to enjoy this happiness. This bothers me very much. (Husband, 70 years old)

Almost all caregivers expressed worries about who will take care after the caregiver is no longer able to.

She is an orphan if I am not there. (Sister, 50 years old).

Caregivers worry about the physical safety of the relative, especially when he or she wanders out on their own without informing anyone in the family. Caregivers of women are especially afraid of physical or sexual abuse when she goes out on her own, or when she has to stay at home alone.

7.6 | Phase 6: Finding new meaning

Despite the distressing experiences described above, some caregivers were able to redefine aspects of their life positively, as a result of the caregiver role. First, many caregivers were seeking stability and a "manageable" relative who did not trouble anyone, even if that meant not being meaningfully engaged and always staying at home. However, caregivers who did manage to facilitate the independence and productivity of the relative, felt a sense of accomplishment and pride, thereby finding new meaning in their role as a caregiver.

A daughter shared her learning during the caregiving process:

She started having bath on her own. It was told to us in the meeting [at The Banyan] that we have to let them be independent and allow them to do their work on their own. (Daughter, 38 years old)

Second, some caregivers indicated that they helped others by referring them to mental health clinics, or gave others advice on how to deal with crisis situations or difficult behavior, both in their own communities and at the waiting rooms of the outpatient clinics.

A husband remembered:

The Banyan used to have a monthly support group. I was the president. I liked that work very much, because I could help people. (Husband, 70 years old)

Caregivers also expressed interest in increasing awareness about mental illness in the community, since they experienced the effects of lack of awareness and societal stigma personally. Some caregivers were able to put this in practice by becoming salaried community mental health workers with The Banyan, as one of them shared:

My life changed when I started working at The Banyan as a community worker. I always liked to help people and now I can do it every day. (Father, 59 years old)

This phase was recognized less than other phases, with some caregivers not observing any positive change. This could be explained by the poor living conditions of many caregivers when survival takes precedent over helping others and personal development. However, many derived strength out of the ability to facilitate changes in the life of their relative or to advice others.

8 | DISCUSSION

As other studies concluded, the experience of caregiving is a complex phenomenon to understand, especially when considering both negative and positive aspects of caregiving.

The ECI was earlier administered at a hospital in Chandigarh, India.²⁹ A difference in findings was observed in this study, with the mean scores for the negative domains lower in this study, and the positive domains higher. This could possibly be explained by the differing demographics of the sample population, or cultural differences between Chandigarh and Tamil Nadu. Another explanation for the difference could be that the sample in Chandigarh consisted of only caregivers of persons with schizophrenia, while the sample in Chennai consisted of caregivers of persons diagnosed with different types of mental illness.

When comparing other frameworks of phases of caregiving, common themes and differences can be identified. Certain frameworks (Gubman 1987,^{37,38,40,42} include the difficulties encountered by caregivers in accessing treatment and finding one's way in the mental health system, including financing the treatment. All four frameworks explain that caregivers sought more information about and involvement in the treatment, which was not provided by mental health professionals, thereby leading to a loss of faith in mental health professionals and the mental health system itself. This loss of faith was not reflected in our study, even though the lacunae in the Indian mental health system are well documented.^{47,48}

Other frameworks^{38,40-42} focus in more detail on the personal transformation of the caregiver over time. While The Banyan model does include "finding new meaning" as an integral phase, this aspect was not stressed upon in detail by many caregivers. This could be indicative of the low-income status of caregivers in this study, for whom making ends meet and curing the mental illness were the main priority, while personal growth and self-discovery are considered secondary or not at all. Karp and Tanarugsachock³⁹ stressed the importance of distancing oneself from the relative with mental illness, in order to maintain one's own mental and physical health. In the Indian

context, some caregivers did discuss the need for long-term facilities in order to reduce their burden, which may not be a realistic option, considering the lack of affordable long-term care facilities. Abandonment, possibly leading to homelessness, is then the only option, which is mostly unacceptable to caregivers. Instead, caregivers focused their energy on coping with the current situation, instead of seeking ways to distance themselves from the relative.

Compared to the phases frameworks developed in western countries, we found considerable differences, most notably in domains of losing faith in the health system, the importance of receiving a diagnosis, the emphasis on personal transformation of the caregiver and the need to distance oneself from the relative with mental illness.

The framework developed by Seloilwe⁴³ for caregivers in Botswana is similar to the framework proposed in this study, without the additions of phase five "Loss and Worries" and phase six "Finding new meaning." It was seen in this study that acknowledging the loss and worries of a caregiver is important, since their life altered drastically as a result of being a caregiver, while also emphasizing the possibility for positive change seen in phase 6.

The Banyan framework emphasizes that the experiences of caregivers evolve over time and are influenced by many factors: the availability of facilities and the quality of treatments, the psychiatric status of the person subject to caregiving, the personal capacity of the caregiver to acquire skills to handle difficult situations, the acceptance level of the family and community as well as the desire of caregivers to help others. It should be noted that the sample group exhibited specific characteristics, such as most relatives being women who were diagnosed with severe mental illnesses. This may have affected certain outcomes. For example, since women are usually not the main breadwinners in the family, a loss of income from the person with mental illness may have been experienced less severely, while the feelings of loss about the person subject to caregiving being divorced or never married may be experienced more acutely in this study population (see also Reference⁵⁹). Second, the caregivers in this study take care of women with severe mental illness, associated with symptomatic behavior and lower functioning, which has been shown to result in higher levels of burden among caregivers.³

Mental health professionals and community workers may use the framework to determine the type of support caregivers require, based on the phase(s) they are experiencing. However, the framework has not been tested for use as an assessment tool. The study was confined to caregivers who have sought help and are regularly accessing treatment. Studying caregivers who have not been able to take care of their relative would be valuable, in order to evaluate the applicability of this model.

The study was limited to caregivers in Tamil Nadu, which is culturally distinct from other parts of India. Studying caregivers in other resource-deficient settings, both in India and other parts of the world, would strengthen the model. Another limit of this study can be represented by not having applied the same multidimensional evaluation through different instruments (semi-structured interviews, focus group discussions and the Experience of Caregiving Inventory) to all caregivers involved in the study, in order to highlight correlations and differences of assessment.

9 | CONCLUSION

As is clear from the literature, caring for a person with mental health issue taxes caregivers in financial, emotional, and social domains of life. Even though many caregivers provide care out of choice, with love and affection, and positive aspects are experienced, the difficulties are also undeniable. In order to understand the holistic experience of caregivers of persons with mental health issue, we developed a framework of six phases that caregivers commonly experience over the years of being involved in the care for a person with mental health issue, which goes beyond the singular concept of burden, to include positive aspects of caregiving as well. When the caregiver experience is considered as a process that changes over time, support structures can be provided according to the requirements of a particular phase. It is our hope that this framework contributes to a more detailed understanding of the caregiver experience and can serve as a basis for an assessment tool to provide support to caregivers, tailor-made to their specific situation and circumstances.

10 | IMPLICATIONS FOR NURSING PRACTICE

Our multiphase model can be utilized in nursing practice to understand the experiences of caregivers, and their needs and potential aspirations for the future at different phases of caregiving. Attention for the caregiver experience by psychiatric nurses can improve the relationship with the patient and, at the same time, support coping mechanisms of caregivers, potentially contributing to mental illness recovery of patients.

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CONFLICT OF INTEREST

The authors report no actual or potential conflicts of interest.

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