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Summary

Family caregivers are the main source of support for people with mental illness in India. Mental health care in India is often difficult and expensive to access (particularly in rural areas), and in many areas access relies on non-government organisations (NGOs). Caregiving often implies incessant anxiety, seeking help in various places, losing social connections and opportunities. The need for support in order to cope with the evident and multi-faceted distress caused by caregiving.

The loving connections between family members and the positive intentions to provide care and support over an extended period of time are equally important to recognise. While not all families continue to provide care for their relatives with mental illness, and abandonment does occur, family members more often consider it their duty to take care of them. They stand by their relative from the onset of symptoms and for many years, through many trials and tribulations. Most families are intimately involved in areas of the relative's life, including living together, providing or sharing finances, deciding on marriage partners, providing much social interaction, taking responsibility to find treatment, attending sessions with psychiatrists and social workers, learning about the symptoms of mental illness, paying for medication, ensuring medication compliance, and encouraging the relative to go to work. Different family members, such as spouses, parents, siblings and adult children, frequently end up being the primary caregiver for their relative, depending on family circumstances.

The experiences of caregivers of people with mental illness in India are lived out in the context of the country's very complex landscape of mental health. It highlights intersections of poverty and mental health, lack of mental health services, cultural and family structures and norms, the pressures of social interactions and expectations; high reliance on caregivers in the mental health services and/or strong family ties; and the emotional and practical challenges of family care. This means that any study on caregiver experience must take into account the complex intersections of numerous factors in addition to an individual's health.

In this thesis, I attempt to explore these intersections and the place of the caregiver in them. Study participants included caregivers and clients who access mental health clinics of The Banyan, a non-governmental organisation providing mental health care to low-income group in and around Chennai, Tamil Nadu.

I suggest that attending to the changing experiences of caregivers living in poverty is a rich site of study, in that it offers us the ability to consider changing needs of caregivers, and work towards developing adaptive, flexible, and inclusive support structures.

While studies on the experiences of caregivers have been conducted in various contexts, this thesis attempts to contribute to this body of knowledge by understanding and gauging the types of support structures caregivers need, and to examine the barriers to accessing them. The thesis will focus on a particular type of support structure, namely social protection measures, and also examine the role of community-based workers in minimising those barriers. The thesis will attempt to answer the following research question:

How can we understand the experiences of caregivers of people with mental illness in a low-resource context and address these with the design and implementation of support structures?

In order to answer the main research question, four sub-questions were addressed through the research presented in different chapters in this thesis. They are the following:

5. *How can the challenges faced by caregivers of people with mental illness from low-resource families be understood in the cultural context of India?*
6. *What is the nature of support structures required by caregivers?*
7. *What are the challenges in accessing social protection measures for people with mental illness and their family members?*
8. *Which strategies can be employed by community-based health workers to address the challenges of access to support structures for caregivers of people with mental illness?*

In order to address these sub-questions, the thesis largely employed mixed-methods, including semi-structured interviews, life history timelines, focus group discussions and surveys. In most studies, sequential methods were used to validate the findings of an earlier phase of data collection with another research method. The thesis aimed to achieve validity through methodological and investigator triangulation, piloting instruments, data saturation, and prolonged fieldwork and residence in the study area.

Study participants included caregivers and clients who access clinics of The Banyan, a non-governmental organisation providing mental health care to low-income group in and around Chennai, Tamil Nadu.

Findings

The thesis is divided into two parts. Part 1 explores the experiences of caregivers, including both negative and positive aspects, as well as the support structures needed during the long duration of caregiving. Part 2 considers the barriers to providing required services, in particular social protection measures, followed by an exploration of the community-based strategies that aim to address these barriers.

In **Part 1**, chapters 4, 5 and 6 set the scene of this study by offering a broad perspective on the experiences of caregivers in an urban and semi-rural area of Tamil Nadu, India. These chapters aimed to understand the lived experiences of caregivers and the aspects of Indian society and culture that contribute to the experiences of this particular group of caregivers. More specifically, these chapters aimed to address three key themes in caregivers' experiences that have hitherto been inadequately addressed in the literature: the importance of considering the changing nature of caregivers' experiences over time; how family structures affect these experiences and their positive aspects; and how caregiving can lead to personal growth. In this thesis, I aimed to gain more understanding of each of these issues.

In order to gain insights into the first issue, we developed a phase-based model based on the experiences of caregivers of persons with mental illness in Tamil Nadu, India. The resulting 'The Banyan model of caregiver experiences' outlines six phases of the caregiving experience.

The phases described in The Banyan model of caregiver experiences (Chapter 4) are:

7. Manifestation of symptoms
8. Seeking help
9. Helplessness and attribution
10. Relative control and insight
11. Loss and worries
12. Finding new meaning

The model (described in Chapters 4 and 5) elaborates on the lack of mental health awareness, which means that many family members are not aware that their relative's behaviour is a symptom of mental illness. Instead, many families attribute the behaviour to magico-religious reasons, which leads them to seek treatment in faith healing centres first.

The cultural manifestations of stigma result in lack of knowledge on mental health (phases 1 and 2), the hesitation of caregivers to ask extended family members for help because they fear negative reactions (phase 2), loss of relationships and worries about the safety of the relative (phase 5).

Personal change is described in phases 4 and 6 of the model, where we discuss how caregivers learn about how to deal with the challenges of caregiving and getting used to the treatment of mental illness (phase 4) and how caregivers use their experiences to find new meaning in life by helping others, becoming employed as a community mental health worker or experiencing positive change in their personality and character (phase 6).

We found that stigma played a large role in a plethora of consequences of caregiving, including loss of social relationships and loneliness (as described in Chapter 5). Loss of social relations, as a result of stigma and community members' lack of awareness of mental illness, affected families greatly. While not all caregivers reported loss of relationships, most families did and this resulted in loss of employment, the waning invitations to celebrations by extended family members, being shunned by neighbours and general isolation of the family by society.

Particularly painful experiences reported were related to marriage. Adult children and siblings of people with mental illness reported being unable to find a partner whether through an arranged marriage or a 'love marriage', since potential partners were unwilling to bear responsibility for the relative with a mental illness or were worried about whether mental illness was a genetic condition.

A general sense of shame and unwillingness to be associated with mental illness was also observed. This led to certain caregivers being unmarried against their wishes, even though they were at or past the eligible marriageable age. These manifestations of courtesy stigma were incredibly painful and life-altering for these caregivers.

Similarly, shame about the inability of the relative with a mental illness to attain certain social expectations, such as education, employment or marriage, resulted in embarrassment for some caregivers. Caregivers also shared embarrassment as a result of their relative's behaviour, such as verbal abuse of the caregiver or others, shouting, or public nudity. Public embarrassment caused families to perceive a loss of honour, which was a painful experience for caregivers.

In Chapter 6, we described four aspects of finding meaning as a result of being a caregiver, which includes the domains of personal strength, compassion, focusing on life's positives and effortful reinvention of the self. We also examined the caregivers' sources of strength in their life. We found that in many cases, religion was an important source of strength and resilience. In addition to religion, a sense of duty towards family members was mentioned as a source of strength. Caregivers said that their parents taught them that family needs to care for each other in all circumstances, which reflects the great importance placed on family responsibility in India. Lastly, caregivers described that they developed personal strength as a result of experiencing hardships.

We found that caregivers require a wide range of support structures, such as educational, psychological, social, financial and peer support. Since families included in the study are all from low-income groups, some of the support structures they need are related to general conditions of poverty and social deprivation. However, we found that being a caregiver of a person with mental illness compounded the challenges facing people living in poverty. The lack of support structures (medical, financial and social) for people with mental illness in India results in the accumulation of responsibility on the shoulders of family caregivers, which can be too much to bear for those who simultaneously experience poverty and social exclusion.

In **Part 2**, in **Chapters 7** and **8**, I examined barriers to accessing social protection measures and considered a strategy involving community-based people to improve access to support structures through the use of boundary objects.

The barriers described in Chapter 7 relate to policy decisions by state governments that exclude people with mental illnesses from being eligible for disability benefits, despite inclusion of mental illness as a disability in the Rights of Persons with Disabilities Act 2016. In addition, other social and stigma-related issues reduce access to social protection for people with disabilities, such as lack of awareness of application procedures, difficulties in travelling with the relative, caste-based discrimination, corruption and the low social status and power of people with mental illness. We have described these in an access framework that considers barriers from both the demand and supply perspective. Some of these barriers can be addressed by relatively simple assistance provided by a community-based worker, while others are systemic issues related to caste, class and bureaucratic processes, which are more complex to remedy.

We presented the *NALAM* worker model in Chapter 8 as an example of community engagement and people who aim to address a wide range of problems in the lives of families. *NALAM* workers act as boundary-spanners in order to bridge some of the gaps which become apparent when families are faced with caregiving responsibilities.

NALAM workers have a flexible mandate and are able to respond to families' specific needs in order to reduce their burden. These needs may span economic, medical, social and vocational domains, which *NALAM* workers are able to address by acting as boundary-spanners between families, communities, health care providers and government agencies. I described specific strategies, including information sharing, reframing, presence and facilitating inclusive physical spaces.

CONCLUSION

The answers to the sub-questions pertained to the importance of considering experiences of caregivers in a phases model, as their experiences and need for support structures change over time. I also described experiences peculiar to the Indian context, such as lack of mental health knowledge the search for mental health treatment across various belief systems and issues faced by siblings and children related to finding a marriage partner. I elaborated on the range of support structures required by caregivers in order to be able to provide care to their relative, which included the more obvious financial and medical support, but also described the need for social relationships, entertainment, and access to places of worship. In addition, I complement the answers to the sub-questions with three insights that contribute to answering the main research questions.

First, I found that new social support structures are required as a response to a complex process of the breakdown of existing social support structures that would normally be provided by relatives, neighbours, and friends, but which has often reduced because of stigma and social isolation. This does not necessarily make the provision of support structures resource-intensive or time-consuming. I aimed to showcase a wide range of options for support structures, of which some are one-off simple interventions that have the potential to make a large impact. An example of this is assistance provided by *NALAM* workers to obtain government benefits, such as a ration card for food staples, old-age or widow's pensions. Another example is securing educational scholarships for the children of clients, or referring

clients for employment. Obtaining a disability allowance proved to be more difficult, since the barriers to obtaining this entitlement were found to be systemic and were the result of exclusion of people with mental illness. This demonstrates and highlights the need for a responsive and inclusive government system that includes persons with mental illness as eligible for social protection measures. Other support structures are more long-term and require consistent investment of time and financial resources, such as vocational training, increasing social support and reducing stigma in the community. Providing adequate support structures has to overcome various types of barriers, including lack of financial resources, low literacy level among some caregivers, lack of trained professionals and lay people, and finally, stigma related to mental health.

Secondly, as my research has shown, the complexity of envisaging and implementing support structures, and the need for multi-faceted support structures, present both a challenge and an opportunity. Challenges include the need to address multiple crisis areas at once, which may seem like a daunting and overwhelming mandate. On the other hand, organisations or agencies committed to reducing the burden on caregivers have ample angles from which help can be offered, depending on the capabilities, resources, and organisational philosophy. This provides opportunities for experimentation, as well as of collaboration among various actors, including non-profit organisations, government agencies, private entities and individuals to address the burden borne by caregivers.

Finally, an important finding of the studies is that drawing on the strengths of caregivers, as well as community resources, is an important angle in envisaging support structures. Existing resources (such as medical care, social protection, vocational training) are available, but they need to be channelled to and tapped by innovative and inclusive strategies. Specific needs include counselling programs for caregivers, establishing peer support networks, as well as attention for the physical health issues of caregivers require dedicated support structures. I would suggest a system in which the needs of caregivers are assessed and planned for, independent from the needs of people with mental illness, while implementation may be mainstreamed in health and social protection programs, where appropriate.

From this perspective, appreciating the willingness of families to support their relative, as is common in India, is a valuable source of strength when considering the options for support for a person with mental illness. Considering the very important and prominent role that families play in decisions about treatment, providing financial aid and housing to the relative,

as well as providing most of the social support for a person with mental illness, supporting them is of vital importance. In particular, it is imperative to provide support structures that are appropriate and appreciative of their struggles and resilience in the face of distress and that aim to assist families in continuing their caregiving responsibilities.