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‘Bringing mental health care closer to home’
Understanding and improving continuity of care for homeless women with severe mental disorders in (South) India

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‘Bringing Mental Health Care Closer To Home’

Understanding and improving continuity of care for homeless women with severe mental disorders in (South) India

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geboren te Chennai, India

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TABLE OF CONTENTS

Account 9

Prologue 10

CHAPTER 1:

Introduction **12**

1.1 Background 12

1.2 Contextual Background 15

1.2.1 Mental Health 15

1.2.2 Homelessness and Mental Health 16

1.2.3 Gender, Homelessness and Mental Health 18

1.2.4 Mental Health Care in India 19

1.2.5 The evolution of mental hospitals 21

1.2.6 Community based mental health care 21

References 23

CHAPTER 2:

Theoretical Framework **33**

2.1 Fundamental human rights, the nexus of homelessness, stigma & mental illness. 33

2.2. Continuity of care for persons with chronic mental health needs 35

2.3. Integration of care in the community 36

2.3.1 Family Caregivers 38

2.3.2 Supported Housing Models 40

2.4 Mental health care approaches 41

2.4.1 The concept of Positive Psychology 41

2.4.2 Recovery 42

2.4.3 Strengths-based approach 43

2.4.4 Well-being in recovery 44

2.5 Innovation in mental health systems 45

2.6 Strategic Niche Management 45

References 47

CHAPTER 3:
Methodology **53**
3.1 Research Questions 54
3.2 Research Approach 56
3.2.1 Study context: The Banyan, Mental Health NGO 56
3.3 Research Methods: 59
3.3.1 Qualitative method 60
3.3.2 Quantitative methods 61
3.4 Validity 63
3.5. Ethical considerations 64
3.6 References 65

CHAPTER 4:
Beggary, the Law and People in Begging in India **67**
4.1 Abstract 67
4.2 Introduction 68
4.3 Need for the study 72
4.4 Methodology 73
4.5 Findings 77
4.6 Conclusions 92
References 95

CHAPTER 5:
Understanding the caregiver burden from a long-term perspective: The Banyan model of caregiver experiences **99**
5.1 Abstract 99
5.2 Introduction 100
5.3 Methodology 102
5.4 Results 106
5.5 Discussion 119
5.6 Implications for nursing practice 122
References 122

CHAPTER 6 :

Loneliness, stigma, lost opportunities and caregiver growth: understanding experiences of caregivers of persons with mental illness in Tamil Nadu, India **129**
6.1 Introduction 129
6.2 Background 130
6.3 Effects of caregiving on families 131
6.4 Methodology 134
6.5 Results 140
6.6 Conclusion 159
References 159

CHAPTER 7:

Reducing family burden: needs and strategies for responsive support structures for caregivers of persons with mental ill-health in Chennai, India **170**
7.1 Introduction 171
7.2 Background 171
7.3.Gaps in support structures for family caregivers in India 172
7.4 Methodology 177
7.5 Results 180
7.6 Discussion 197
7.8 Conclusion 200
References 201

CHAPTER 8:

Supported Housing as a recovery option for long-stay patients with severe mental illness in a psychiatric hospital in South India: learning from an innovative de-hospitalization process **211**
8.1 Abstract 211
8.2 Introduction 212
8.3The Banyan’s Supported Housing Model 216
8.4 Methodology 220
8.5 Results 222
8.6 Discussion 239
References 244

Chapter 9 :

Home Again : Effects of a Housing with Supportive Services Intervention For Homeless Women with Mental Illness in India **251**
9.1 Abstract 251
9.2 Introduction 251
9.3The Banyan’s study intervention 254
9.4 Methodology 255
9.5 Results 259
9.6 Discussion 263
References 268

CHAPTER 10 :

Discussion and Conclusion **271**
10.1 Homelessness, Mental illness and Jurisdiction 273
10.2 Family caregiving in India 275
10.3 Supported Housing - development and scaling up 280
10.4 Validity 284
10.5 Study limitations and ideas for future research 285
References 286

SUMMARY 290

ACKNOWLEDGEMENTS 299

Account

Chapter 4
Ravi, M., Padmakar, A., Mander, H. & Regeer, B. J. (submitted). Beggary, the Law and People in Begging

Chapter 5*
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Chapter 7*
Padmakar, A.Dijkxhoorn, M. A., Bunders, J., de Wit, E.E., Regeer, B (submitted)**.** Reducing family burden: needs and strategies for responsive support structures for caregivers of persons with mental ill-health in Chennai, India
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Chapter 8
Padmakar, A. de Wit, E.E., Mary, S., Regeer, E., Bunders, J., Regeer, B. (submitted). Supported Housing as a recovery option for long-stay patients with severe mental illness in a psychiatric hospital in South India: learning from an innovative de-hospitalization process

Chapter 9

Narasimhan,L.,Padmakar,A.,Mary,S.,Regeer,B.,Gopikumar,V. (submitted).Home Again: Effects of a housing with supportive services intervention for homeless women with mental illness in India

Prologue

As I worked on finalizing this thesis, and putting together the work of four years of academic work, and even more years of psychotherapeutic work with the Banyan, I found myself actively remembering the various accounts of personal stories that motivated me to begin this query. I would like to share the story of one woman whom I had met during this continuing journey with the Banyan, as I believe it expresses the complexity of mental health care in a context of family and social-cultural living, and the need for mental health responses to be more adaptive. The story of Ersheen is narrated below.

The story of Ersheen

> Ersheen is a 35-year-old woman and hails from Tamil Nadu. Since her childhood she has been very pious and talented. She was abandoned by her husband because of her mental health issues, so she returned to her parents' home and lived with her parents and siblings. Her family was unsupportive towards her. Initially, she particularly struggled with the reality that her illness had become her identity and the sole reason for rejection by her husband and his family. She was hospitalized at The Banyan in 2002, and for the past 17 years she has been accessing The Banyan's services. Multiple attempts to reunite Ersheen with her family have been unsuccessful.
>
> Ersheen attained puberty when she was 13 years old. She was instructed to be clean by her parents, especially during her menstrual cycle. She was excluded was very afraid, especially in the nights as she would sleep alone in the backyard of her house as it was a cultural taboo not to sleep inside the house during menstruation. Sleeping through the night in the pitch dark was scary; hearing dogs barking and footsteps walking on dry leaves would leave her trembling in fear, and she would close her eyes tightly. Ersheen hated herself as a woman and hated her body. She would get very stressed when anticipating her menstrual cycle again. She wished she were a man, as being a woman was associated with more responsibilities and rules to follow. She subsequently suffered an episode of schizophrenia

> with obsessive and compulsive traits. Meanwhile, her rituals of washing her hands repeatedly, getting totally drenched to clean herself, hallucinatory behaviour, and sleepless nights gradually increased. This was the first time the family took her to the nearest hospital to seek help. She was then referred to The Banyan for further treatment. Her family members were very embarrassed that Ersheen, a Muslim woman, also showed promiscuous behaviour at times, drawing attention from the neighbourhood, especially men. She was sent by her family back to The Banyan multiple times when she experienced a recurrence of symptoms secondary to psychosocial stressors in her home environment.

The story of Ersheen sheds light on the complexities involved in supporting persons with mental illness - understanding her symptomatology within her cultural and religious context and her own ways of coping with early life stressors. But how can we reformulate mental health in India in a way that it addresses, rather than negates, these complexities involved in the vicious cycle of mental illness, stigma, and homelessness or poverty? What sort of interventions are currently available that can carefully consider the needs of Ersheen as well as those of her family? Can the disparities between the needs of the individual, family and the availability of services be lessened? And what do we need to learn to deliver such care within the context of a low-resource country such as India? These were the questions that guided me throughout this study as well as the hope to create mental health services that feel more like home.

CHAPTER 1: INTRODUCTION

1.1 Introduction

Globally, mental health issues in the homeless population reflect a complicated mesh of socio-psychological, cultural, and economic issues, and much has been written about the relationship between homelessness and SMDs. Mental disorders include such general conditions as depression, anxiety, alcohol and substance abuse, but also more severe and disabling disorders such as schizophrenia and bipolar disorder (WHO, 2014). According to Rathod et al. (2017), 80% of all mentally ill people are born in low- and middle-income countries (LMICs). Some 23% of the world's mentally ill population comprises persons living in the South Asian region - India, Bangladesh, Bhutan, Maldives, Nepal, Pakistan, Sri Lanka, and Afghanistan (Bax, 2007; Borenstein, 2009). These numbers show the extent to which problems of a political, socioeconomic, and cultural nature contribute to the onset and expression of mental illness in people, as well as the risk of increased poverty and homelessness.

The problem of homeless persons with mental disorders (HPMD) is a complex issue within the Indian context, connected as it is to stigma, gender inequality, deficiencies in mental health awareness and support, and a gross neglect of their rights (Swaminath, Enara & Rao, et al., 2019). Although the consequences of SMD are serious, mental health care for the homeless population has not been treated as a serious problem by many health systems. According to a study by Fazel, Khosla, Doll & Geddes (2008), about 3 to 42 percent of homeless people in high-income countries live with psychotic disorders, compared to about 1 percent in the general population. In low-income countries the numbers are likely to be even higher, with estimations varying from 8 to 47 percent (Smartt, Prince, Friss et al., 2019). At least one-fifth of the homeless population in India could be diagnosed with a mental disorder as evaluated by the National Mental Health Survey (2016). Most countries in the South Asian region are developing countries, such as India, and are faced with limited resources, including a lack of economic support, health infrastructure, and professional stakeholders in the health sector (Ranjan and Asthana, 2017). In a meta-analytical study conducted in 1998, Reddy and Chandrashekar reported that the prevalence of mental disorders in India is 58 per 1000 population (48.9 per 1000 in rural areas and 80.6 per 1000 in urban areas). Historically, homeless people were legally punished for their status, through laws such as the vagrancy and beggary law. There is a paucity of interventions and strategies to care for HPMDs within the mental health care system (Gowda et al., 2019).

The role of society to protect human rights is often negated in India, and HPMDs have been generally at the receiving end of indignities and violations of their basic human rights. Numerous practices of life-long incarceration in mental hospitals, jails, or beggar homes have been reported, reflecting a lack of awareness and professional care at several system levels (e.g. Gostin, 2008). Recently, however, increasing efforts have been made to enforce the rights of persons with mental health needs, protecting and promoting their right to healthcare and services, e.g., through the Mental Health Care Act of 2017 (Namboodiri et al., 2019). This act is described by Math, Basavaraju & Harihara et al. (2019) as *'progressive, patient centric, and rights-based*', and a leap forward from earlier legislation concerning disability and mental health, which involved the judiciary and reinforced stigmatizing practices. Nonetheless, the act has also been criticized for being selectively focused on the rights of persons with SMD as part of their hospitalization period, and failing to provide scope for the participation of various other stakeholders, including the family of MHC users (or other caregivers) and lay mental health workers (Narayanan et al., 2014, 2015). It also remains relatively silent on delivering care in the community, which seems to be the most pressing need in India (Swartz and Swanson, 2014). Math et al. (2019) explained that the act reflects the notion that persons with SMD are more often harmed than supported by family caregivers and mental health professionals, which then negates the fact that India's key resource in the context of economic hardship is actually the family. It is a common practice in India for family members to take on the role of caregivers, as alternative care options are few, due to the scarcity of trained mental health professionals able to serve a large population of persons with SMD, and as part of the collectivist culture in which one is expected to care for close relatives. Mental health care in India is more sustainable if there is an effective collaboration with the community and particularly ways to nurture supportive relationships with family caregivers.

Community-Based Mental Health (CBMH) has been drawing increasing attention in the recent past following the positive results of more general community-health models (Castillo et al, 2019; Srivastava et al., 2016, Sidana, 2018). Although awareness about mental health care is still relatively low, there is increasing recognition of the utilization of communities (e.g., families) to improve mental health care for persons with SMD, both to relieve the professional health system and as a way to approach mental health as part of human life. Indeed, an increasing number of small-scale but promising studies are being conducted in India as well as other LMICs, indicating the potential scope of alternative community-based (mental) health models, including halfway homes, daycare centers, or supported home facilities and clustered group homes (Swaminath et al., 2019). However, the gap between institutional models (e.g., hospitals) and user-centered models in the community is still relatively large, partly due to a lack of knowledge on how to develop CBMH models and implement them on a larger scale (Brenman et al., 2014). More research is needed to understand how models (including private-public partnerships) can be sensitively developed in the context of India (Swaminath et al., 2019). Similarly, in the absence of current knowledge on caregiver support for persons with SMD in India, in-depth studies are needed to understand how families can be supported to relieve their burden of caring for family members with SMD.

The aim of this thesis is to gain more understanding about the way health care can be delivered to support persons with SMD in and with the community, with a humane approach. The focus will be on the professional strategies and psychosocial interventions required to support MHC users and families of MHC users in the community setting, as well as the organizational processes that are needed to support innovative intervention models.

This study also emphasizes the need for developing user-centric mental health services and a range of interventions required for homeless persons with chronic mental health needs along with continuity of care in the community. This thesis employs the following main research question:

Main Research Question: How can mental health systems in India become more adaptive to serve the needs of those with chronic mental health needs in the community, and to support caregivers in delivering continuity of care

1.2 Contextual background

1.2.1 Mental Health

Mental health is an important global health concern and an integral component of holistic health (Saxena et al., 2007). In India, Neuropsychiatric illness accounts for 10.8% of the global occurrence of mental illness (Seby et al, 2011). According to the National Mental Health Survey (NMHS, 2016) the incidence rate of mental disorders in individuals above 18 years is 10.6%. The lifetime prevalence in the surveyed population was 13.7%. This proportion of the population requires active mental health intervention.

Severe Mental Disorders (SMDs)

In India, the prevalence rate of SMD is 0.8% (NMHS, 2016). Bihar state in India has the highest number of people suffering from schizophrenia, even higher than the entire number of Mental health care users (MHC) users in North America (Adams et al., 2006). SMDs include psychotic disorders and bipolar disorders, while common mental disorders (CMD) include unipolar and anxiety disorders. The manifestation, outcome, and impact of SMDs are very different from those of CMDs. Though the prevalence rate of SMDs is lower than that of CMDs, SMDs must be treated with urgency. In urban metro cities, the prevalence rates are 2 times higher than in rural places, with schizophrenia and other psychoses (0.64%), mood disorders (5.6%), and neurotic or stress-related disorders (6.93%).

Common Mental Disorders (CMDs)

Nearly 10.0% of the Indian population has CMDs such as depression, anxiety disorders, and substance abuse disorders. There are significant variations in the overall morbidity observed in 12 Indian states (NMHS, 2016), ranging from 5.8% in Assam to 14.1% in Manipur. Three states (Assam, Uttar Pradesh and Gujarat) reported prevalence rates less than 10%; in 8 of the 12 states, the prevalence varied between 10.7% and 14.1% (NMHS, 2016). In India, 12 million disability-adjusted life years (DALYs) in 2010 were caused by unipolar depression. Anxiety disorders caused nearly 4 million DALYs in 2010 (WHO, 2004).

Suicide

Suicide is a public health problem which has detrimental socioeconomical, political, and emotional consequences (Armstrong and Vijayakumar, 2018). The National Crime Records Bureau (NCRB) of India states that the suicide rate in India is 10.6 per 100,000 population (WHO, 2014). The NCRB publishes statistics based only on police information, which results in under-reporting and misclassification of suicide deaths (Patel et al., 2012).

Psychiatric Comorbidities:

MHC users with psychiatric comorbidities are associated with poorer outcomes in various domains. Hence, there is a greater need for a proactive mental health care system aimed at this population. The presence of comorbidity increases the likelihood of the following: recurrence of symptoms, rehospitalization, increased negative life events and family discord (RachBeisel et al., 1999), suicide and violence, homelessness, and eventually all of this leads to a socioeconomic and public health care delivery burden (Hartman and Nelson, 1997; Quinlivan and McWhirter, 1996).

1.2.2 Homelessness and Mental Health

Homelessness is an outcome of the interaction between intrapersonal and structural factors (Fazel et al. 2014) with mental illness. Poverty, mental illness, addiction, lack of affordable housing, and socioeconomic inequities lead to homelessness (Bird et al., 2010; Perrisini, 2009; Somers et al., 2016). The prevalence rates of mental illness are high among the homeless population (Evans & Wells, 2003: Forchuk et al, 2007), while factors such as socioeconomic disadvantage, childhood adversity, trauma, and domestic violence are inherently involved in the trajectories between mental illness and homelessness (Shelton et al., 2009). Homeless persons with mental health issues encounter ostracization, social rejection, and stigma (Rae and Rees 2015; Siskind et al. 2014). Poorer physical and psychological health, social exclusion, victimization, increased disability, and greater mortality are significant among the homeless (Fazel et al. 2008; Keogh et al. 2015; Martens

2001). Indeed, the situation of homelessness for persons with SMDs should be understood in relation to the diverse etiological factors that can lead to homelessness, such as those mentioned above.

Stigma and exclusion play a significant part in rendering people homeless, and can be especially damaging to those who belong to a minority race or ethnic origin, or with a past experience of mental health issues. Conceptually, it is debatable whether social causation or social selection supports this notion (Dohrenwen, 1992; Kroger et al., 2015; Hoffmann et al., 2018). There is an increased risk of clinical psychopathology when a person is from a lower socioeconomic status, according to the social causation hypothesis (Wadsworth and Achenbach, 2005). The social selection hypothesis, on the other hand, explains that worsening of mental health leads to deterioration in social and economic conditions (Kessler et al.,1995). Persons with SMDs are more vulnerable when they are socially excluded from income and housing and experience any significant negative life event, which further supports the social selection hypothesis (Philippot et al., 2007). Life on the streets increases one's vulnerability to the lack of basic needs, social support, and participation in the society, which can lead to precipitating the onset or an episode of SMD (MacKenzie, 2013).

Criminalization of homeless people

India's vagrancy and beggary laws reflect the sociopolitical environment of homeless people and represent the after-effects of colonialism, leading to a highly controlling and punitive society. The first Vagrancy Act (1939) was established to control any form of idleness and unruly behavior and made into laws in the Beggary and Vagrancy Act (Raghavan and Tarique, 2018). This also indicates the double hypocrisy confronting the poor and homeless as they are from a deprived environment, which is similarly an indicator of the failure of governance (Chambliss 1964; Beier and Ocobock 2008), and leaves them not just without a home, but also punished for the same reason. The Bombay Prevention of Begging Act (1959) criminalizes homeless people or people on the streets who do not have employment (Goel, 2010). There has been an oversight in judging 'seeking alms' behavior instead of focusing on the actual reasons of why homeless people have been engaging in begging (Raghavan and Tarique, 2018). The causal relationship between poverty and thus limited outcomes such as illiteracy and lower-paid jobs is insufficiently recognized. Poverty, migration, and urbanization have led to the abandonment of family members. This is more prevalent in specific categories such as the sick, aged, and those with physical and mental illness (Ramanathan, 2008).

It is also necessary to understand that the physical health condition of the homeless population is very much at risk, in addition to their mental health issues. Extreme weather conditions and overcrowded places precipitate increased physical and mental health risks due to insecurity and personal loans (Broadway. Street to home bulletin, 2012). Physical injuries, respiratory infections, malnutrition, and winter mortality are common ill health ailments seen in the homeless population. There are also higher rates of tuberculosis and HIV in the homeless population (Centers for Disease Control and Prevention, 2011).

1.2.3 Gender, Homelessness, and Mental Health

There are gender differences in mental disorders that also extend towards differences in the stages of disorders, such as onset of illness, which could possibly increase the risk of vulnerability, diagnostic profile, and treatment adherence (Astbury,1999). Compared to men, women are relatively more affected by mental health issues and also increasingly vulnerable to mental disorders due to genetic factors, societal roles, marital status, education, and work (Murthy, 2016; Dennerstein, 1993).

Gender inequality has a significant impact on the societal disadvantages of women in society (Doyal, 2001). Women are deprived of job opportunities and are usually paid less if they hold a job. Compared to men, they are denied basic rights such as property ownership and are more conveniently abandoned by spouses. Women are also more susceptible to becoming homeless because they lack family support (Caton, 2017). They are more vulnerable to physical and sexual assault (Upshur, Jenkins, Weinreb, Gelberg, & Orvek, 2017).

Women are also denied economic autonomy and resources, rights to education, health services, inadequate physical and mental nutrition, they are overworked and succumb to different forms of abuse throughout their lives (Ahmad et al., 2000). The level of stress is therefore often higher in women compared to men (Gajendragad, 2015; Kumari, 2008). The impact of mental illness on women also extends further due to common experiences of rejection, stigmatization, limited or no access to care, and poor access to general health interventions (Moorkath, 2018). Economic hardship, lack of education, intimate partner violence, family dysfunction, and the demise of the primary caregiver contribute considerably towards the trajectory of a homeless woman with mental illness (Gopikumar, 2014; Chatterjee and Hashim, 2015). There is an increased chance for a woman to become homeless in the absence of or weak government systems plus hampered family support in the face of poverty and migration (Sikich, 2008). Although the above clearly indicates a need for care specifically focused on women, community-based rehabilitation and long-term care options are often absent or fail to fulfill the needs of women who have SMDs (Moorkath et.al , 2018).

1.2.4. Mental Health Care in India

In India, mental illnesses are part of a larger public health burden (Zeeman et al., 2017). There are barriers in mental health care in India due to a discrepancy between the services required and the availability of resources according to the National Mental Health survey (2015-2016). The inefficient mental health system has left 150 million people in urban and rural India who are still in need of mental health services. Health systems are integral to delivering evidence-based mental health care (WHO, 2000). The unavailability of infrastructure to provide inpatient and outpatient services is a significant barrier to responsive care and the availability of specific interventions. The physical and social infrastructure of the mental hospitals are highly unsatisfactory (Murthy,2011). The living conditions in the hospitals are very poor and evidently isolate MHC users further. There are no interventions designed for those who recover, and they continue to stay in the hospitals. The biomedical approach benefits only those who have acute symptoms, but for those who have long-term and chronic needs, there is a lacunae of interventions to continue treatment in a community setting. The concept of a multifaceted approach does not exist to engage with families, skills building, employment options, linkage to voluntary organizations, and access to contact families to enable strengthening of family ties (Murthy et al., 2005).

The treatment gap for mental disorders in developing countries is 76%-85% according to the WHO study (Demyttenaere, 2004). In India, the treatment gap for mental disorders is 83% (Prashanth et al., 2019). MHC users there often face discrimination by their own communities, which continues to pose challenges for accessibility to mental health facilities, even if they do exist. The treatment gap in the mental health care system has deprived individuals with SMD from receiving care (Kaur and Pathak, 2017). Lack of awareness, stigma, accessibility or availability of health care services, non-medical explanations, scarcity and unequal distribution of resources are some of the barriers (Saxena, 2007) that confront beneficiaries (National Commission of Macroeconomics and Health 2005; Working Group on Disease Burden for 12th Five Year Plan 2011; Reddy et al 2013). Stigma and discrimination also affect the treatment gap in a mental health care system (Lal and Vashisht 2002; Working Group on Disease Burden for 12th Five Year Plan 2011; Shidhaye and Kermode 2013).

There is also a great paucity of mental health human resources. According to Gururaj et al. (2016), there is only one psychiatrist for every 250,000 population, and the availability of <1 mental health workers per 100,000 population (psychiatrists, psychologists, and psychiatric social workers) is very low.

The District Mental Health Programme (DMHP) was initiated under the National Mental Health Programme (NMHP) to deliver services to the community by integrating the mental health system and the general health system (Ved et al., 2019). The implementation of DMHP (1996) was not very effective due to a constricted inflow of funding, insufficient human resources, and poor motivation in service providers across levels. In India, there is a discrepancy in health care between the central and state government with regard to budget allocation, perspective towards policy, and process of implementation (Gopikumar et al., 2015). MHC users do not access treatment due to poor motivation, perceived stigma, inability to understand the need for treatment, tedious process, and lack of awareness (Dhawan and Pattanayak, 2012). There is a huge discrepancy between the public policy and the health systems that specifies the need for improving mental health wellbeing. There is a significant paucity of MHPs, especially in rural areas (Rao et al, 2011).

1.2.5. The Evolution of Mental Hospitals

There was a significant evolution in mental health to its present status in India due to the establishment of mental hospitals (Daund et al., 2018). Originally, isolation was perceived as a recovery-oriented approach (Bhugra, 1996). In India, during the medieval period, mentally ill persons were secluded by keeping them in temples (Bhugra,1996). Early mental institutions in India were a response to the mental health needs of European MHC users residing in India. The colonial period was generally characterized by neglect and a lack of interest in caring for people with mental health issues.

The first mental hospital in India was established in Bombay in 1745. The first Lunacy Act was enacted in 1858 (Ernst, 1990). From 1745 to 1912, mental hospitals were founded in India and Bangladesh. Gradually, the population with mental health disorders increased despite there being so many mental hospitals. There was a gradual deterioration in hygiene and health in the hospitals. The physical infrastructure of these hospitals needed constant repair and renovation (Brunton, 2015). The deterioration in the state of the mental hospitals was a cause of great concern in both India and abroad (Daund et al., 2018). Specialists in psychiatry were appointed as full-time officers, and the in-charges of hospitals were civil surgeons, and all responsibilities were removed from the inspector general of police. The central supervision system was finalized to keep a watch over these hospitals, and the Indian Lunacy Act was formulated in 1912 (Healy, 2014).

After India’s independence in 1947, there was a significant change in the development of mental hospitals. Due to poor conditions and inadequate resources, deinstitutionalization was initiated globally while the government of India focused on creating general hospitals with psychiatric units. The number of mental hospitals increased from 31 to 45 (Sax, 2014). The number of MHC users in these hospitals increased, leading to a surge of interest in community-based interventions.

1.2.6. Community Mental Health Care

Mental illness affects individuals, their families, and the community due to disability and cost implications. In LMICs, mental disorders are major contributors to the global health burden and are usually associated with comorbidity with communicable and noncommunicable diseases (Prince et al., 2007; Moussavi et al., 2007). Some 90% of persons with mental disorders in LMICs do not receive basic mental health care services. In most LMICs, mental health is considered to be of low priority, and the needs of mental health treatment are becoming pervasive (Bruckner et al., 2011; Patel et al., 2010). The neglect of mental health treatment is evident despite evidence that mental health services are feasible and cost-effective and can be integrated with primary health services (Prince et al., 2007; WHO, 2004; Patel et al., 2007).

Many initiatives were started in mental hospitals in India through the participation of families of MHC users in the inpatient setting. Families were involved in taking care of persons with mental health issues. Caregivers would stay with the MHC users inside the hospital setting. This was initiated in the 1950s at Amritsar Mental Hospital, followed by the Mental Health Centre at Christian Medical College, Vellore, and the All India Institute of Mental Health, Bengaluru, in the 1960s (Isaac, 2012). Ties with MHC users were strengthened through marriage, joint family system, and close-knit community, there was increased tolerance of inappropriate behavior by the larger community, and faith & religion-based healing places were considered as large care systems in the community (Isaac, 2012).

Globally, the closure of mental hospitals took place between 1960-1980 due to repeated hospitalizations, geographical and professional isolation of human resources and institutions, poor treatment of MHC users, inadequate inspection, and failure of management and leadership (Thornicraft & Tansella, 2002). In India, downsizing of inpatient services was initiated, and outpatient services were expanded with community care (Phadke,1998).

In the 1980s, the emphasis was placed on the integration of mental health services with general health care services. The most important development during this time was the initiation of the National Mental Health Programme (NMHP) of India in 1982, followed later by the District Mental Health Programme (DMHP) from 1996 onwards (Murthy, 2012). These programmes were launched to enable mental health services to reach the most underprivileged and marginalized populations who were unable to access mental health care

(Murthy, 2012; Murthy et al., 2005). But the community mental health services faced several challenges, such as a lack of funds and human resources, system rigidity, stigma, less mental health awareness in the community, and inconsistency in continuing care in the community. Though the community mental health services were initiated in response to improving the quality of care, systemic rigidity and poor understanding and implementation of the model destabilized its sustainability (Anant Kumar, 2005; Kumari et al., 2007; Krishnamurthy et al., 2003; Jain and Jadhav, 2009; Waraich et al., 2003; Kapur, 2004; Jacob, 2001; Jacob et al., 2007; ICMR, 2009).

There is a dearth of exploration and understanding of continuity of care for persons with SMDs and of their long-term needs. The Banyan, a mental health NGO, an expert pioneer in the field of homelessness and mental health, has explored innovative strategies to deal with the complex mental health needs of homeless people and continuity of care. The research world has yet to impart knowledge for solution-based strategies to provide continuity of care through user-centric interventions. Hence, this thesis explores innovative models and strategies of care so that an adaptive framework of the mental health system can be designed for homeless persons with SMDs.

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CHAPTER 2: THEORETICAL FRAMEWORK

Life inflicts the same setbacks and tragedies on the optimist as on the pessimist, but the optimist weathers them better - Martin Seligman

In this chapter, I am particularly concerned with the continuation of care of persons with severe mental disorders (SMDs) in the context of deprivation, homelessness and stigma. As I am intuited to believe that such continuity of care is mostly found with and within the community, I look for theories and models that will help me understand how to study the involved phenomena most effectively. Moreover, this study is embedded in an organization focused on the improvement of care (The Banyan), and as an (action) researcher, I am similarly interested in stimulating adaptation and change (e.g. de-hospitalization in mental health care). In this context, I will also look for theories that support me in understanding innovative processes in health care settings. The theories discussed in the first part of this chapter will thus involve concepts, therapeutic approaches, and models of care that focus on the *continuity of care* (in the community). In the second part, I will move to describing the concepts related to health system change, processes of innovation in health care and transition management, to inform the study at hand.

Main research question: How can mental health systems in India become more adaptive to cater to the needs of (homeless) persons with chronic mental health needs in the community, and to support caregivers in delivering continuity of care?

2.1 Fundamental human rights, and the nexus of homelessness, stigma and mental illness.

Before moving into the main focus of this thesis, which concerns the continuation of care for persons who are challenged by a complex mesh of homelessness, moderate to severe mental health disorders, poverty and stigma, I want to devote some attention to the broader socio-political context in which this thesis takes place. As mentioned earlier, a large part of the population in LMICs such as India, find themselves caught in the nexus homelessness, stigma and mental illness, with few opportunities to live humanly dignified lives. While the preamble to the Constitution of India is based on universal human rights, and upholds the equality of opportunity and status for all citizens, it is important to embed this thesis in the complete understanding of how these basic human rights principles are translated and actually practiced when they reflect the most vulnerable populations in the country.

According to the World Health Organization (2012), mental health and well-being are fundamental to quality of life, enabling people to experience life as meaningful, and become creative and active citizens. Persons with mental illnesses have the same basic rights as any other person in India, but in the context of homelessness and family alienation (often due to stigma), these people are systematically criminalized under e.g. the Bombay Prevention of Begging Act (Mander, 2017). As such, while the International Covenant on Civil and Political Rights (ICCPR) and the Declaration on the Rights of Disabled Persons (ratified since 1996 in India), condemn discrimination on the basis of mental illness, many find themselves discriminated on the basis of being homeless (Poreddi, Ramachandra, Reddema et al., 2013).

The negation of fundamental human rights for persons who are homeless, merely perpetuates and exacerbates the personal and societal problems they already experience as a result of poverty and stigma (Swaminath et al., 2019). Politics and the translation of constitutional rights to legal processes in India have a fundamental impact on human rights. This thesis therefore starts by questioning to what extent the fundamental rights of homeless persons are at risk and what happens with homeless persons who are challenged by mental illness, when (continuation of) care is not organized within the current healthcare system. When institutional care is absent, what role do current politics play in conceptualizing and dealing with the aforementioned group of people? I ask this question as an introductory inquiry into the current state of affairs, before making my way to understanding how continuation of care for (homeless) persons with SMD could be better organized. Similarly, I act on the intuition that the answers to this question will provide extra motivation for the main objective in this thesis, which is to leverage change in the nexus of homelessness, mental illness and stigma (and to break the vicious cycle involved), by finding ways to improve and sustain continuation of care in India.

2.2. Continuity of care for persons with chronic mental health needs

Achieving continuity of care (COC) for persons with severe mental disorders is a significant indicator of a well-functioning health system, and, as a concept, has gained considerable significance in the process of de-hospitalization (Sweeney, Davies & McLaren, et al. 2016). COC has, historically, been difficult to define, although it is intuitively understood as a concept that deals with the sustainability of support for persons that require long-term care, including a range of relatable concepts such as integration and cohesion (Biringer et al., 2017). Joyce, Wild & Adair (2004) define the construct as '*underdeveloped, vague and over-inclusive'*, and difficult to evaluate or develop. Essentially, COC includes a variety of aspects that establish *connectedness* in care: responding to patients' individual needs in a multidimensional way over time (Wierdsma, Mulder & de Vries et al., 2009). COC has often been described to play a central role in mental health, and is linked to enhanced quality of life, community functioning, and reduction of illness related symptoms. Improved COC has also been related to higher levels of patient satisfaction and fewer hospital referrals (Kim, Jang & Lee, et al. 2018).

Traditionally, COC has predominantly been explored from the perspective of health professionals and care providers (Sweeney at al. 2016; Joyce, Wild & Adair et al., 2004), and identified as, for instance, having '*a continuous caring relationship with an identified health professional'* (Gulliford, Naithani & Morgan, 2006, p. 248). This was before multidisciplinary holistic models for care were developed, and other paradigms to COC were identified, such as the recent 'Partnership Paradigm' care which is co-constructed between professionals, more informal members of the care network and the patients (Heaton, Corden & Parker et al. 2012). Joyce et al. (2004) emphasize the need for patient's experiences of COC, as well as those of their families, as they are the sole parties in a position to judge the continuity of their care setting.

In the context of chronic illness, particularly in the case of discharging patients with chronic mental disorders, there has recently been more recognition of the experiences of those on the receiving end of the care system. In general, there has been a shift from disease-focused care to 'person'- centered care, which is compelling in that it underscores the unique nature of each individual's attributes and how integral overall well-being is to their care-path (Jiloha and

Shekhawat, 2010). User-centered research studies suggest that persons with SMD also emphasize other aspects such as *relationship* (wanting to feel safe in ongoing personal relationships), *choice, mutuality* & *knowledge* (wanting to feel a sense of autonomy in day-to-day activities, as well as the care process, and being well informed), *peer support* and *service avoidance* (see e.g. Biringer et al., 2017; Sweeney et al. 2016; Joyce et al., 2004). In more general terms, clients were also instrumental in framing issues of *comprehensive services* (including care in natural and culturally sensitive environments, such as independent housing, enabling work and recreational activities), *individualized care* (including flexibility in service provision, family and client involvement in treatment and decision making) and *community-based service models* (with fewer hospital admissions), on the research agenda (see Joyce et al, 2004; WHO, 2018). At the same time, COC has been adapted to be understood 4s a *long-term* and *contextual* process, wherein people are enabled to sustain *social relationships* and a reasonable *quality of life* (Crawford et al, 2004).

2.3 Integration of care in the community

The WHO (2018) wrote a compelling report based on fundamental human rights to address continuity and coordination of care through integrated people-centered health services, including also a distinct focus on developing support services in marginalized and impoverished settings. In an introductory remark to their framework on care it states that:

> *"All people have equal access to quality health services that are co-produced in a way that meets their* ***life course needs*** *are coordinated across the continuum of care and are comprehensive, safe, effective, timely, efficient and acceptable; and* ***all carers are motivated, skilled and operate in a supportive environment."***

The framework similarly helps to conceptualize the continuation of good care across the lifespan of people, with emphasis on creating an enabling environment through five parameters **(figure 2.3 a).**

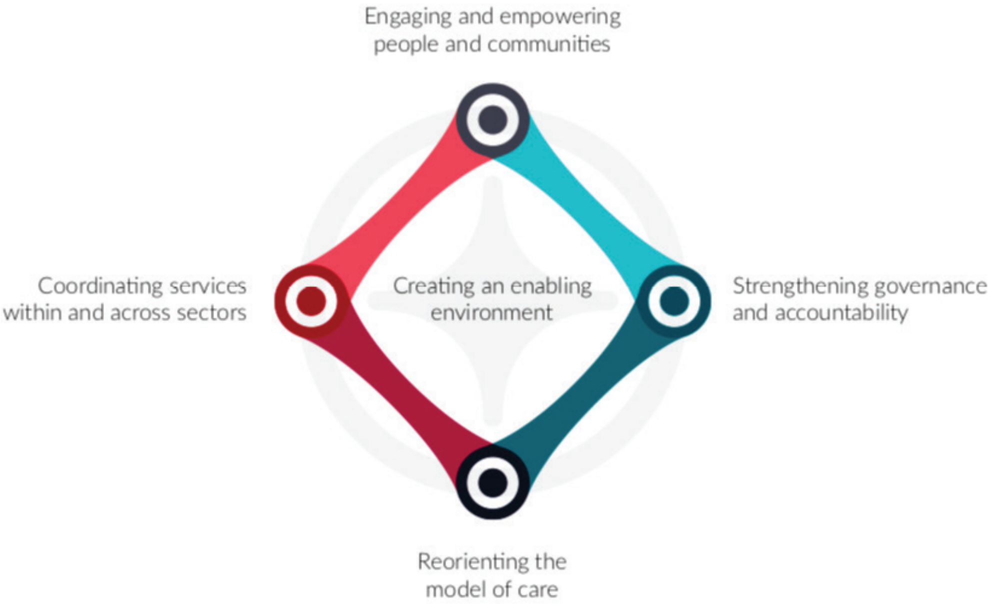

Figure 2.3a: *The five interdependent strategies of the WHO Framework on integrated people- centred health services (IPCHS)*

At the top of the figure, the importance of engaging and empowering people and communities is described. This parameter is of particular importance in LMICs, as the continuity of care is heavily reliant on the contribution of informal caregivers and family support. Indeed, as often attested by scholars, LMICs are often dealing with shortages of health care workers and lack of accessible infrastructure. The reorientation of care models includes collaborative approaches in health care services, and the need for patients and informal care workers to participate in decision-making processes and to be supported in more out-patient settings. Similarly, strong and accountable governance and coordination of services across different sectors and levels of governance are needed to secure continuity of care (WHO, 2018). Included in the suggestions that are offered by a variety of interventions related to family, community & social networks, and enabling care in the setting of a home (see table 2.3b). In this thesis, I will specifically focus on two of the listed out options:

1) support for caregivers and family centered care

2) housing for care.

Table 2.3b. drivers of continuity of care according to WHO (2018).

Practice interventions
• Peer support, befriending and community social networks
• Community connectors
• Education and support for caregivers
• Community health agents and family-centered care
• Workforce education for holistic practice
• ***Patient-centered medical homes***
• Housing for care
• Family health teams
• Health navigators
• Case management or guided care
• Health promotion, prevention and enablement approach
• Collaborative and anticipatory care planning
• Personal outcome focus and goal-centered care
• Tailored health literacy and self-management coaching
• Interdisciplinary team-based practice
• Collocation of services
• Intermediate care, “hospital at home”, transitional care
• Care pathways, guidelines, care coordination agreements • Clinical or care networks
• Single or shared electronic care records
• Information governance and data-sharing protocols
• Technology-enabled care and decision support
• Risk prediction tools to target interventions

2.3.1. Family care(givers)

Studies suggest that a model of COC that exclusively incorporates hospital based, professional support for clients will be deficient in providing long-term care to those with chronic illness and/or disability (Thornicroft et al, 2016). A balanced care model, in which both the community (including family caregivers and informal caregivers) as well as professionals work together, is more likely to induce positive outcomes for persons with SMD over time. Family and family caregivers have been found to play a significant role in securing COC (including treatment adherence and rehabilitation) and overall integrative community care (Freeman & Hughes, 2010). Understanding their perspectives and experiences in how COC can be achieved is essential (Herder-van-der-Eerden, Hasselaar & Payne et al, 2017). Again, this is particularly true in LMICs where family's form the cornerstone of securing care for persons with SMD and long-term disability. In the context of de-hospitalization, reintegration with the family is still one of the more conceivable options, even when families are not always ready to accept the patient. Particularly in the mindset of person-centered care, the family offers the best opportunity for persons with SMD to still live a normal, humanly dignified life. Besides offering pure emotional support, family caregivers are also instrumental in providing practical support, such as assistance in day-to-day activities and chores, medical treatment procedures and financial support (Monyaluoe, Mvandaba & du Plessis, et al. 2014). The embedding of persons with SMD in a familiar environment can improve the outcomes of COC, particularly if the care delivered by the family is constructive.

However, there are also challenges and limitations to family care, particularly as insufficient support is provided to the family. A number of studies show that families, although they are likely to be attentive and accepting towards their family members with SMD, can also experience a lot of stress and significant burden as a result of their (new) role. Families experience many challenges in their caregiving, ranging from *subjective* concerns (related to one's' way of thinking, the ability to recognize and accept the new situation and the loss experienced), to significant *objective* burden (including economic setbacks, stigma from the community, difficulties in dealing with illness- related behaviours, etc.). These burdens drain the quality of life of family caregivers, ultimately reducing the quality of care as well (Murthy, 2014; Jagannathan et al., 2010). Both internationally, as well as in India, the mental health of caregivers is generally not addressed as an integral component of mental health care, despite evidence that caregiving can impose an emotional burden, manifesting itself in the form of anger, irritability and depression, ultimately leading to poor care provision (Steele et al.,2010; Awad, 2008; Lauber, 2003, Tsang, 2003). To support families in their important role of providing long-term care to persons with SMD, more knowledge is required on how to understand family care (*what are the experiences of family caregivers)* and how they should be supported (*what strategies are needed to improve their quality of life, as well as their caregiving).*

2.3.2. Supported Housing Models

Historically, patients with SMD were kept in hospitals for as long as needed until they fully recovered. In the new paradigm of person-centered, integrated COC, issues related to the science of living (human dignity, quality of life, wellbeing and independent decision-making) have been recognized as important parameters in the treatment of patients. Supported Housing (SH) is a relatively recent intervention that fits really well within the paradigm of integrated community-based COC, as well as in the mental ill health-poverty-and-homelessness-nexus. Supported housing provides structured, non-institutional, and independent living arrangements along with supportive services aimed at medical attention, rehabilitation and the attainment of life skills (Lipton, Siegel, Hannigan, Samuels, & Baker, 2000; Padgett, Stanhope, Henwood, & Stefancic, 2012). These projects enable people to lead a **functional** and **independent life** with support, ultimately aimed at rehabilitation and integration into society (Lipton et al., 2000). As advocated by the WHO, SH projects are user-centered, and applies a strong philosophy with emphasis on the residents' independence, freedom of choice, independent life skills, individualized services, and ultimately, community integration (Culhane, Metraux, & Hadley, 2002).

SH projects can differ in quality and model, as housing can be provided in many ways, ranging from independent apartments to communal forms of living. Likewise, supportive services vary in the trade-off between fixed structure and independence; for example, whether the resident or the healthcare provider is responsible for medication management, living arrangements, activities and personal income responsibility (Lipton et al., 2000). The so-called 'Treatment First' projects emphasize that residents have to show a certain level of living skills and commitment to take part in the treatment prior to admission into the supported housing initiative (Padgett et al., 2006). However, practice has shown that this level of independence and commitment are difficult to reach without stable housing (Pearson et al., 2009). Therefore, more and more projects prefer the 'Housing First' approach, placing people in supported housing without requirements, supporting them to develop key skills and levels of independence as they go (Pearson et al., 2009). As this is still a relatively new approach, questions remain as to which models are best suitable to implement in the context of LMICs, such as India, and how to develop and scale-up sustainable models that are sensitive to the various challenges that may exist in these local contexts (including e.g. societal stigma, religious dispositions, challenges related to social-economic and stakeholder participation, forms of informal and professional support that is required to sustain COC). These questions will be addressed during the course of this thesis.

2.4 Mental health care approaches: Positive Psychology

Besides looking at the structures and models in which COC can be organized for persons with SMD, it is also important to conceptualize mental health in more therapeutic terms. In the past few decades, in the field of social work, psychology, and general mental health, there has been a stronger recognition of constructive approaches to strengthen a person's capacity for well-being. While there was a strong tendency to base professional therapeutic practices on a medical, disease-based model, often focusing on healing deficiencies, current approaches to mental health acknowledge and utilize the strengths of both patients, as well as families caring for a mentally ill family member. The focus here is to reflect with families not only on their need for support, but also on their strengths and how they can use them to cope with negative experiences. Similarly, community mental health care focuses not only upon people's defects and disabilities (**an illness perspective**), but also upon their strengths, capacities and aspirations (**a recovery perspective**). Services and supports thus aim to enhance a person's ability to develop a **positive** identity, to frame the illness experience, to self-manage the illness, and to pursue personally valued social roles.

2.4.1 The concept of Positive Psychology (PP)

Seligman and Csikszentmihalyi define positive psychology as the "scientific study of what goes right in life, from birth to death and all stops in between" (Peterson, 2006). Huppert (2009) states that psychological well-being is about lives going on well, and it is a mix of good feeling and effective functioning. PP is a comprehensive approach to mental health that emphasizes positive emotions and human strengths over dysfunction and mental illness (Norrish and Vella-Brodick, 2009). Within the field of Psychology, PP is an approach that examines the optimal experience of people and their best doings (Peterson, 2006; Csikszentmihalyi and Seligman, 2000; Park and Peterson, 2003). The disease model is challenged in PP. According to PP, the essence of living a good life is more important than avoiding or undoing problems. PP as a positive and subjective experience, emphasizes positive individual traits and positive institutions in order to improve quality of life especially when life seems to be void and meaningless. Pathology has dominated the model of human life, neglecting the positive attributes of making one's life worth living. In general, mental health and mental illness are conceptualized as two opposite polarities; mental health care systems are designed to reduce mental illness which will subsequently improve mental health (Lasiello et al., 2019). Hope, wisdom, creativity, future mindedness, courage, spirituality, responsibility, and perseverance have been largely ignored. PP takes a harmonizing stance, in which there is more focus on the strengths rather than weaknesses of an individual, and principles of PP takes great interest in fulfilling the lives of distressed persons (Park et al., 2016; Andrews, Issakidis, Sanderson, Corry, & Lapsley, 2004; Cuijpers, van Straten, SMDt, Mihalopoulos, & Beekman, 2008). It argues that mental health services require PP as it employs good components of life which continue to exist in the lives of those living with mental illnesses (including e.g. particular relationships, unique personal resources, etc.), and are perceived to be the leverage point to better health (Slade, 2010).

2.4.2. Recovery

In line with the paradigm of PP, recovery has also been a well discussed concept which has subsequently influenced mental health policies and mental health services (Castillo et al., 2019). Recovery is defined as *"the process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential"* (Substance Abuse and Mental Health Services Administration (SAMHSA). Braslow (2013) explains three broad categories of recovery: 1) recovery as a mental health outcome, 2) recovery as a subjective experience and recovery as a system of values that adds life to mental health systems, and 3) clinical care processes. From the viewpoint of recovery, efforts have been made to shift the focus from only symptom reduction to an overall improvement of clinical care with components of social inclusion, belongingness and well-being in patients (Jose et al., 2015; Windell et al., 2012). An effective mental health system needs to have a recovery framework that is inclusive of community network and policies. (National Academy of Science, 2016).

In recent years, however, despite a transition from institutionalized mental health care to community-based interventions, there has been less focus on factors such as support from social networks, participation in decision making, recovery and quality of life (Mental health Commission of Canada, 2009). *Shared decision-making* is one of the collaborative efforts to facilitate recovery (Coleman, 1999). These components need to be an integral part of mental health services. Many MH users feel ambiguous about the way their care is delivered (Deegan,1988), as well as about the interpersonal conflicts that arise as part of these unsolicited clinical decisions (Fisher, 1994). In contrast, the recovery model provides a more participatory and holistic view of a person’s mental illness. Recovery focuses on the person and not only on their symptoms (Davidson, 2005; Bonney and Stickley, 2008). Recovery needs to be understood from the perspective of the individual rather than looking at larger outcomes which align with societal and or medical norms. The manifestation of recovery may differ from person to person and as such recovery is not guided by golden standards. A mental health system which comprises of access to care, care packages that are individualized, continuity of care and long term options can but enhance the recovery journey of an individual. There need to be multiple stakeholders of mental health system, family, support from friends and mental health professionals (Jacob, 2015) contributing towards recovery. The mental health system as such is required to find creative ways of working towards recovery of the MH user.

2.4.3. Strengths based approach (SBA)

Mental health is often portrayed pessimistically in the arena of health, with limited scope for recovery. The medical model has depicted SMDs as chronic and irreversible changes in neuropathological patterns and deficits in information-processing (Farkas, 2007). The medical model has failed to identify and acknowledge strengths in individuals that can facilitate recovery. Certain individual attributes in a person are worth appreciating and can bring about meaningful recovery, which is in contrast with clinical recovery with a stringent and skewed perspective. This field of SBA encourages one to perceive mental health issues as part of one's normal life (Shanley & Shanley, 2007). SBA shares aspects of PP, and upholds the basic principle of mental health recovery, with a belief in people's ability for self-care, and working on one's self confidence to progress towards getting well (Xie,2013). An individual's abilities are given more importance than flaws and deficits, thus aiming to inculcate a sense of resilience in MH users.

The notion to foster resilience has several advantages. Resilience helps people to prepare for and face adverse life events with better coping mechanisms. Perceptions of adverse life events are much better, and acceptance of such situations is much better in people who are resilient (Bonanno,2004). During hard circumstances, resilience tends to act as a guard shield by protecting from psychological and physical health problems (Rutter, 1985; Yi, Vitaliano, Smith, Yi, & Weinger, 2008). Within the SBA framework, fostering resilience is an integral shift in care processes as it specifically helps people who are burnt out and mentally exhausted due to multiple stressors in life. People with less resilience tend to fail in innovation, creativity, sustaining a positive environment for oneself. There could be several fluctuations in resilience levels but the larger outcomes of resilience are vital for a person with mental health issues. This thesis maintains that a strength-based approach will be very effective in designing user centric interventions for COC by family members as caregivers, to protect the dignity of homeless persons, and to create interventions for persons with chronic mental illness.

2.4.4. Well-being in recovery

Finally, in this thesis I involve the overarching objective of wellbeing in recovery. Good quality of life also helps to build resilience against stressors, have fulfilling relationships, and experience a meaningful life. There have been many attempts to understand mental wellbeing as it presents itself as a complex, multidimensional and dynamic concept (Ryff, 2014). Subjective well-being includes psychological and social well-being (Ryan and Deci, 2001). Well-being and recovery are closely related concepts in Positive Psychology. There is a dire need for mental health care delivery services to create innovative packages for COC, and long-term options with well-being as a guiding principle for those who are homeless. Disorder specific interventions may bring clinical recovery outcomes to some degree but social wellbeing outcomes are necessary to understand as well. Recovery can be measured with visible outcomes with regard to reduction in symptomatology and functioning capacity, but it is essential to use approaches that enhance the quality of an individual's life (Thieme et al., 2015).

2.5. Innovation in (mental) health systems

In the preceding sections of this chapter, I delineated the concept of COC, elaborated on the ways to further improve upon COC as integrated in the community (e.g. in the forms of family care and supported housing), and outlined the psychotherapeutic approaches that form the fundamentals of quality care, according to contemporary science and practice. I end this chapter by describing how such approaches and alternative models could be developed, improved and sustainably incorporated in the current mental health systems.

A key lesson learned from studies on system change is that sustainable innovations are embedded in a social context; meaning that they are developed and evaluated in interaction with the society. This means that new interventions, projects or models are not worked out in isolation, but in close connection to the context in which they are meant to gain their value. Similarly, it has become broadly understood that top-down approaches (e.g. by governments and corporations) are more reactive than proactive, and have failed to modernize and improve healthcare systems (e.g. Chowdhury, 2012; Bengoa, 2013; Thakur, Hsu & Fontenot, 2012). Instead of employing a top-down approach to implementing change, a more bottom-up or integrated approach is preferred to achieve sustainable societal transformation.

2.6 Strategic Niche Management

Strategic Niche Management (SNM) is an approach that aims to investigate how social-technical innovations can be introduced as societal experiments (e.g. pilot studies on niche experiments) with the objective to improve the way these innovations achieve their inherent objectives in the context of the larger system (Schot & van Geels, 2008; Loorbach, 2006). It stimulates the embedding of new ideas in a ‘protected’ space, often at a grassroots level, that is less rigidly directed by the tendencies of a larger system. It is within these protected spaces that there is room to experiment and learn, and adapt to a new product, process or technology. There is a need to blend the new environment to the social-cultural and psychological needs of the individual so that one can interact with the components of innovation (Raven, Weterings & van den Bosch, 2010). Similar to many contemporary models for managing change, SMD involves a process of experimenting, evaluating, adjusting and re-evaluating. Non-Governmental Organizations (NGOs) can play an important role in creating and managing protected spaces in which new ideas can be implemented and evaluated, before they are adopted by the ‘regime’ (the institutional level of government bodies) and put into practice on a larger scale (Marinova, Annandale & Phillimore, 2008). In India, NGOs have also been lauded for their ability to evolve and perfect quality programs that pose models of care and sustainability for governments to adopt and implement on a larger scale, because they are more sensitive and accountable to grassroots contexts (Thara & Patel, 2010). The principles of SNM as part of sustainable transition management are therefore included to guide this thesis. Innovative strategies suggested to improve COC for persons with SMD are paralleled with the aim to: 1) interactively learn about in the desirability of the innovation in the local context, 2) articulate the strategies and adaptations that are required to make the innovation feasible, and sustainable over time, and 3) to stimulate changes in social organization that are important to widely diffuse the innovation (Loorbach & van Raak, 2006).

Overall, SNM concepts in this thesis explore and facilitate an understanding of the demonstration of new models within the context of user’s needs, including cultural, political and environmental factors. SNM also facilitates a framework for clinicians, users and policy makers to be engaged in the development and diffusion of an implementation process.

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CHAPTER 3: METHODOLOGY

In the previous chapters, I aimed to describe the problem that this thesis is dealing with and the context in which solutions to this problem will be sought. I delineated the nexus of poverty, homelessness, stigma and mental illness, and emphasized the need for care systems in which persons with mental illness are continuously cared for in a humanly dignified manner. With the first two chapters, I hope to have effectively emphasized the importance of understanding and addressing the issue of continuation of care (COC) in a context of deprivation and low resources for a highly vulnerable population. Through this thesis, I am also concerned with finding solutions that are *sustainable, context-sensitive, community-based* and *person-centered*. The underlying therapeutic paradigm which will form the fil rouge of this action-oriented research is strengths-based and leans on the principles of positive psychology. Building and/or strengthening alternative pathways of COC will therefore generally be focused on stimulating constructive educational, therapeutic or practical support for all stakeholders involved. Similarly, I acknowledge the approach that there are various strengths, assets and resources that exist in the people and communities we work with to build positive change, which are considered in the philosophy of action-research (AR) as partners or agents of change, rather than passive recipients of support.

Action Research (AR), in the broadest sense, differs from other types of research that just look to describe and understand the current status quo. AR usually follows a simple sequence of steps in which understanding is followed up with phases of *preparation, planning, acting and observing and reflecting and re-planning* (Kemmis and McTaggert,1988) **(see figure 3.1).** Similarly, this thesis will aim to answer questions related to the phenomenology (experiences, perceptions, strengths and challenges) as currently reflected in the ‘way things are now’, as well as questions that relate to how the situation can be improved.

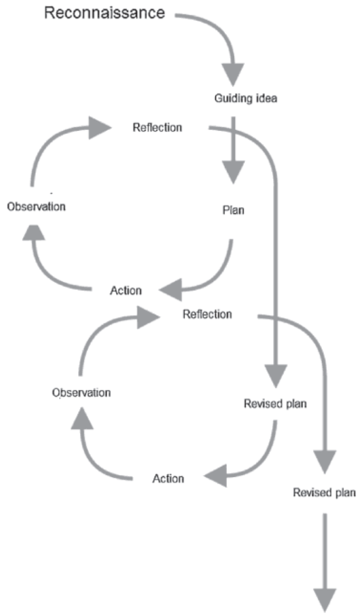

Figure 3.1. Action research spiral (Kemmis and McTaggert,1988)

3.1. Research Questions

The main research question of this thesis was formulated as follows:

> **How can mental health systems in India become more adaptive to cater to the needs of those with chronic mental health needs in the community, and to support caregivers in delivering continuity of care?**

Three sets of research questions are derived from the theoretical framework, aimed at understanding (1, 2a & 2b), and adapting the system (3a & 3b):

***Sub-question 1**: How can the experiences, dignity, and aspirations of homeless persons with mental illness be understood in the current context of India's political system and legislation processes?*

***Sub-question 2a:** In the context of de-hospitalization, how can we understand the experiences of family caregiving as an integral part of COC for persons with chronic mental health needs?*

***Sub-question 2b**: How can family caregivers be better supported in their caregiving role, in order to preserve and improve COC for persons with chronic mental health needs?*

Sub-question 3a*: How can alternative COC programs, modelled on housing first principles, be developed in the context of South India, for persons with chronic mental health needs?*

Sub-question 3b: *How can sustainable models of supported housing be scaled-up and implemented in different parts of the country?*

The answers to these questions are provided in three parts. In the first part, I respond to the first sub-question to sketch the broader social-political situation in which homeless persons with SMD construct their lives.

In addition, chapter 8 also gives insight into finding an innovative way for the homeless people when they have lean or completely no options to join their families. This article also reflects on the continuity of care within the social context. In the second part, I look extensively at sub-question 2a and 2b, as one pathway to improving COC. The articles involved here particularly focus at ways of systematically enhancing and supporting a very common and natural way of organizing COC through family caregivers. Finally, in the third part, I look at an entirely new model of COC in South India, in order to understand how feasible models can be developed and evaluated in comparison to other models of care **(see table 3.1).**

Table. 3.1

Part	**Research question**	**Chapters**					
		4	**5**	**6**	**7**	**8**	**9**
1 Understanding social-political context.	*1. How can the experiences, dignity, and aspirations of homeless persons with mental illness be understood in the current context of India's political system and legislation processes?*	🟩				🟩	
2 Understanding and enhancing COC through family caregiving	*2a: In the context of de-hospitalization, how can we understand the experiences of family caregiving as an integral part of COC for persons with chronic mental health needs?* *2b: How can family caregivers be better supported in their caregiving role, in order to preserve and improve COC for persons with chronic mental health needs?*		🟩	🟩	🟩		

3 Introducing and scaling-up alternative models of COC through supported housing	*3a: How can alternative COC programs, modelled on housing first principles, be developed in the context of South India, for persons with chronic mental health needs?* *3b: In the context of preparing alternative COC models such as Supported Housing for upscaling, how can we understand its basic outcomes in comparison to care as usual?*					🟩	🟩

3.2. Research Approach

This thesis uses an action research approach to answer the main research question and sub-questions, using both qualitative and quantitative methods. Action research also aims to contribute to addressing practical problems in the field of social science. The goal here is to study a system in-depth and concurrently collaborate with members of the system to create suitable adaptations to the system and develop best practices to enable the care system to be more sustainable, effective and efficient. Hence, action research is a collaborative effort by the researcher and the members of the ecosystem, and emphasizes co-learning (Boog et al.,1996).

3.2.1. Study context: The Banyan, Mental Health NGO

This study is embedded in the context of a Mental Health NGO, called The Banyan. Located in Chennai, South India. Founded in 1993 by Dr.Vandana Gopikumar and Vaishnavi Jayakumar, The Banyan focuses on designing innovative and comprehensive mental health services in both institutional and community settings, to people who suffer from poverty, homelessness and mental illness in the states of Tamil Nadu (since inception), Kerala and Maharashtra. Since its inception with crisis intervention and rehabilitation for homeless women with mental health issues, the Banyan has expanded its support programs with three major care models: **Emergency Care and Recovery Centre, NALAM: Community Mental Health Programme** and **Home Again.**

While the Emergency Care and Recovery Centre (ECRC) continue to provide comprehensive and multidisciplinary biopsychosocial packages, as well as reintegration and aftercare services to, till date, about 2500 homeless women with mental illness, reintegration interventions help women to find employment, engage in daily activities and live with their families again. About three-quarters have encouragingly gone back to their families. For those who have no option to reintegrate with their families, Inclusive Living Options (ILO) - Home Again and Clustered Group Homes provided by The Banyan focussing on finding alternative housing options with personalized and graded supported services to those with mental health needs, aiming as much as possible to empower them live independently. Some of the interventions (e.g. clustered group homes and home again but also support services for family caregivers) that are currently running in Chennai, and adopted in three different states **(see figure 3.3 and 3.4),** were developed and evaluated as part of this thesis. NALAM, finally, which in Tamil stands for 'wellness', is a community-based mental health program that delivers care at the grassroots level, mobilised by primary health- or community centers across the country. The services have been accessed by about 10,000 people so far, and include a range of interventions, such as e.g. inpatient- and outpatient clinical care, home-based services, social entitlement facilitation, livelihood interventions, education and housing support (Narasimhan et al., 2019).

The NALAM workers are largely trained by the Banyan Academy of Leadership in Mental Health (BALM), which offers master level programs in Social Work and Applied Psychology. The NALAM mobilizers are instrumental in a range of activities **(Box 3.2),** and also form an important part of this research work, as co-creators in the development of interventions, as well as important reflections of how care continues to be practiced and improved.

Box 3.2 NALAM mobilizers activities

NALAM Mobilizers:

- Build rapport with community members, especially those who may have a mental illness
- Provide supportive counselling in different settings
- Facilitate issue of disability certificates and access to social entitlements (e.g. income-generation activities) for persons with mental illness
- Initiate innovative programmes in response to the needs of the community

Replication of The Banyan Models And Partnership with State Governments

Tamil Nadu – ECRC (5 Districts)
Kerala – ECRC, Home Again (3 Districts)
Maharashtra – Home Again

● - ECRC

▲ - Home Again

Figure 3.3 indicates the replication of The Banyan services in Tamil Nadu, Kerala and Maharashtra

Emergency Care and Recovery Centre replication (5 Districts) with National Health Mission – Government of Tamil Nadu

1. Vellore
2. Tirupur
3. Vilupuram
4. Tiruvanamalai
5. Theni

● ECRC

Fig. 3.4 indicates The Banyan's ECRC model replicated across 5 districts in Tamil Nadu

In this thesis, my articles are a reflection of The Banyan's services which are responses to the complexity of mental disorders within an unadaptable mental health system which lacks innovation and sustainability.

3.3 Research Methods:

Throughout the thesis a variety of different methods were employed to collate data on the aforementioned problems. Mixed methods research refers to an emergent methodology of research that advances the systematic integration, or "mixing," of quantitative and qualitative data within a single investigation or sustained program of inquiry. The rationale behind this approach is that through the integration of different sets of data, both depth and width in understanding can be achieved (qualitative methods being more focused on in-depth exploration and qualitative to generalize and find more validity in general patterns). Mixed methods research originates in social sciences and was later generalized to health and mental health research (Creswell and Plano Clark, 2011).

In general, I employed more qualitative research methods to deeply understand what the perspectives of multiple stakeholders were on a particular issue, while questionnaires were instrumental in getting a broader perspective as put forward by a larger number of people involved in the study. See figure **3.5** for a quick visual overview.

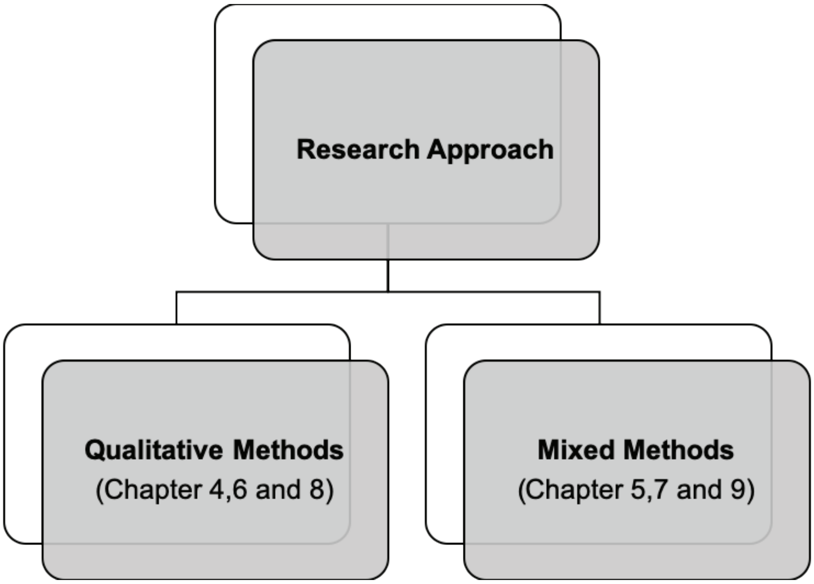

Figure 3.5. Overview of how methods were integrated in the thesis.

My thesis comprises 6 research studies out of which 3 were based on a strictly qualitative approach and in 3 studies mixed approaches (qualitative and quantitative) were applied. Qualitative methods included in-depth interviews, naturalistic observations, fieldnotes by Banyan employees and Focus Group Discussions (FGDs). Quantitative methods included questionnaires, as well as validated therapeutic scales.

3.3.1 Qualitative methods

In-depth interviews formed a big part of this thesis to explore the perceptions, experiences, needs, challenges, strengths and aspirations of stakeholders involved. The interviews ranged from being open to semi-structured, as commonly used in qualitative research (Edwards and Holland, 2013), and were conducted by myself or by co-researchers as indicated in each study. All interviewers adhered to the basic principles of Appreciative Inquiry (AI), focused on taking a positive approach to organize and understand someone's reality, practice and/or organization. AI moves beyond problem-focused inquiry, and focuses the data collection more primarily on what works, rather than on fixing what does not. This is not to say that in the interviews challenges and negative experiences are negated or avoided, but that the interviewer will take care to build up and organize the interview in a way that it empowers the respondent, and enhances their sense of self-esteem, rather than bringing it down (Ashford & Patkar, 2001). Sometimes, Time-line interviews (Adriansen, 2012) were also employed to gain a picture of how a particular reality developed over time (e.g. chapter 7 on support strategies for caregivers). FGDs were useful in understanding how a selected group of people construct a certain reality together, when the discussion is facilitated by a moderator. The purpose is to understand how a group of people give meaning to a particular topic (e.g. homelessness, the concept of 'home' or 'caregiving'), by systematically engaging the participants in a series of exercises that support brainstorming and reflection (Nyumba et al., 2018). FGDs are often used by action researchers for its empowering, participatory and transformative potential (Chiu, 2003). By structuring the FGDs in a logical series of analytical steps, it allows participants to not only function as respondents to 'status-quo' type of questions, but to be active in voicing dreams or aspirations for the future, prioritize them, and participate in comparing and linking these to earlier mentioned problems or challenges. The analysis thus becomes shared, rather than conducted solely by the main researchers (Nyumba et al., 2018). Finally, naturalistic observations are a very important primary tool for qualitative researchers interested in understanding behaviors and other phenomena in a particular social environment (Salkind, 2010). Observational notes were used throughout the thesis, both intensely and systematically as data collection tool in some of the chapters, as well as more informally throughout the thesis to make sense of the connections between the chapters. Field notes were collected both by NALAM workers, as well as the primary researchers involved in this thesis, and include reflections and observational notes on the reality and practice of Banyan workers as well as the experiences as reflected by clients.

3.3.2. Quantitative methods

For the quantitative part of this thesis, a variety of questionnaires and validated therapeutic scales were used. Validated scales included instruments such as the Experience Caregiver Inventory (ECI), Community Integration Questionnaire to assess emotional competencies of clients, the WHO Quality of Life (QOL) scale to assess quality of life across four domains, and a variety of specific psycho-social scales to test the mental health status of clients whenever this was deemed relevant. The purposes of these scales are explained in more detail in each chapter.

An overview of methods employed in this thesis and the number of participants involved in each study, is given below:

	Explorative Study	Methods	No:of participants
Chapter 4	Understanding the social-political context of incarcerated homeless persons	Qualitative research, convenient sampling, semi-structured interviews	Semi-structured interviews with 24 participants, including 4 detailed key informants who were legal professionals, social work practitioners and service providers

Chapter 5	Understanding the experiences of family caregivers through a phases model	Mixed methods, maximum variation purposive sampling, life history timeline, focus group discussion, ECI inventory	Survey of 117 caregivers from mental health clinics, interview with 20 caregivers from mental health clinics, 40 mental health professionals and NALAM workers
Chapter 6	Understanding caregiver experiences through lost opportunities, stigma and caregiver growth	Qualitative research, semi-structured interviews, life history timeline and focus group discussion	Survey of 117 caregivers from mental health clinics, interview with 20 caregivers from mental health clinics, 40 mental health professionals and NALAM workers
Chapter 7	Strategies to reduce caregiver burden through responsive support structures for caregivers	Mixed methods, semi-structured interviews, life history timeline and focus group discussion. Triangulation - caregivers, mental health professionals and community based` workers	29 caregivers from mental health clinics, 39 mental health professionals and NALAM community workers
	Intervention Study		
Chapter 8	Supported Housing as a recovery option for persons with SMD and chronic needs	Qualitative research, in-depth interviews	59 participants were screened, 11 in supported housing and 14 health care workers from ECRC
Chapter 9	Effects of a Housing intervention with supportive services as a recovery option and social inclusion persons with SMI and chronic needs	Non randomised controlled two-group trial, mixed-methods approach, ethnographic observations,	126 participants, 53 in Home Again intervention arm and 53 in Care as Usual arm

3.4 Validity

Although social researchers to some degree denounce the idea of objectivity as an attainable goal, through the rigor of both collection tools and ways of analysis, I have tried to reduce the possibility of biases as much as possible to improve the validity of this study. I would like to address a few aspects that help to decrease the influence of biases.

The first advantage of this study is the *triangulation* of various methods, as well as respondents to ensure that our notion of reality was verified through different means and with different people, hence boosting the dependability of the data (Zohrabi, 2013). Gathering information from one technique only, as well as deriving it from one group of people exclusively, can create blind-spots. By triangulation of data sources, I could confirm my findings in various ways, thus feeling more confident that the results I found were reliable. Similarly, I found that the observational notes that were compiled were useful in continuously checking how and why certain questions were asked in my studies, and whether they could be complemented with other inquiries/ insights. In fact, Merriam (1998) also states that observation is a type of data triangulation that helps to substantiate core findings.

Another way of securing validity is the way I engaged people in co-creating knowledge. Most of the Banyan workers were co-participants in this study, and took part in constructing the aim of the separate studies, as well as in collecting data. Because many workers in the Banyan are continuously involved in conducting research besides their professional work, and some of their work is included in this study, observations are also long-term focused and very much overarching the separate studies. This, as well as analysing data in teams of researchers, helped to increase the validity of the data as well (Nunan, 1999).

External validity (enhancing the level of replicability) was protected through thick description of participants (including information on their social-economic background, relevant mental health status, history of treatment, etc.), as well as health workers involved (years of experience, personal information, etc.). Similarly, the qualitative descriptions of the environment, the research procedures involved, and the social-political context of South India, as well as the therapeutic principles of the Banyan, increase the transparency and thus replicability of the study.

Finally, I find it important to reflect on my own role as a researcher in this study. My background is in Clinical Psychology. I have worked with the Banyan as a clinician and lead at ECRC, faculty at BALM (specialisation in Clinical Psychology) for several years. Initially, when I started working with the Banyan I tried to strictly adhere to the professional and ethical principles of detachment and objective neutrality as derived from my educational and clinical training. While these are still important fundamentals of my professional work as a therapist, as well as a researcher, I also learned, through my work with the Banyan to be more personally engaged, and to reflect on the way the relationships I have with MH users continue to shape me as a person, as well as a researcher. I realize that as a qualitative researcher and therapist involved in understanding the real experiences I will always be somewhat skewed in my interpretations. In order to sharpen myself 'as an instrument', I tried to have many conversations with co-therapists and other researchers about both the personal and professional content that was relevant to this study, and to learn where my own blind-spots might be. This sense of self-validation and reflection also helped me in remaining emotionally balanced whenever insecurities would arise, to ensure it would not negatively affect the research. Similarly, qualitative research scholars in the mental health commonly support the notion that the best research is conducted in close connection with practical therapeutic concerns, and explores the issues that are most relevant to what is happening in a real context (Bowers, Minichiello & Plummer, 2007). In the way that the therapeutic and clinical practices of my work is combined with academic support as organized in this study (through Banyan Academy of Leadership in Mental Health and collaboration with the Vrije University) I feel confident that the validity of the current study content is largely guaranteed.

Ethical considerations

All studies were evaluated by the Institutional research review board by The Banyan and BALM. For all studies participants received written, as well as verbal, information regarding the objective, content and length of the study.

Participants were also reminded of their ‘voluntary’ participation and their right to leave the study at any point of time. For all studies, verbal and written consent were also received prior to the data collection procedures. Lastly, to protect the privacy of all study participants, anonymity was always maintained by disconnecting their names to the data through the use of subject codes. During the focused group discussions and semi-structured interviews, participants were allowed to leave the study whenever they decided to and during the housing interventions great care was taken to keep in mind the choice of the participants during the screening and transition process.

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Chapter 4

Beggary, the Law and People in Begging in India

4.1 Abstract

This paper examines the problems with laws which criminalize begging in India, and considers possible reforms, from the perspective of both experienced and senior social workers and jurists, and people who live by begging. To this end, interviews took place with four key informants, as well as 24 persons who are detained by state authorities in custodial beggars' homes where persons convicted for begging were involuntarily housed under the beggary law, inquiring about their assessments of the current legal framework, the proposed new law, and other legislative, policy and programme changes that they would recommend. It was observed that laws that make begging a punishable crime have their origins in India's recent colonial history, and are often used to criminalize and lock away very vulnerable urban populations, especially targeting homeless populations who are aged, disabled and/or mentally ill. This law, the paper describes, was challenged by the third author in the High Court of Delhi, which allowed his petition and declared the beggary law to be unconstitutional. This paper also describes a significant new legislative initiative by the Government of Delhi (now abandoned) to reform the legal approach towards people who live by begging from one that criminalizes them to one that creates obligation on state authorities to assist and rehabilitate them.

4.2 Introduction

In recent years, there has been growing support in India for the opinion that colonial-era laws which criminalize begging are not just wanting in compassion and humanism, but contravene the guarantees of India's constitution. This slowly-gathering support among legal, public policy and social experts, and destitute people themselves, does not still mean that there is unanimity; indeed, there continues to be widespread prejudices against beggars. The Delhi High Court in August 2018 has resolved the legal question by striking down all provisions of the anti-beggary law in Delhi which criminalize and penalize begging as unconstitutional. However, there has been much less informed discussion about the alternatives to beggary laws which criminalize beggary; about what legal or policy regime, if any, should fill the vacuum created by the abrogation of laws which criminalize beggary. This paper attempts to seek the views of people who live by begging; as well as a few selected 'experts' who are actively working with the current anti-beggary act, and the new destitution bill, together with service providers, and individuals in law enforcement. This paper explores their views on the existing, proposed and desired law, policy and programmes with a bearing on the lives, work and social protection of destitute people including those who beg for a living.

This article is entirely based on the Indian experience, but the questions it raises echo and resonate in various parts of the world, both in richer and less endowed countries. A recent article in the Guardian[1] highlights how the debates and controversies that this present article addresses regarding begging resonate with similar unresolved debates in many parts of the world. It observes that in the US, the National Law Centre on Homelessness and Poverty found in its study of 187 US cities in 2015 that 76% prohibit begging in specific public places, while 24% impose city-wide bans. Many local governments, as in India, urge people not to give alms to beggars. In England, for instance, in 2016, the Southampton city council ran a poster campaign not dissimilar to the one run by the Delhi state government from time to time, 'begging you for lasting change', saying people should give to charities not individuals. Some governments are more drastic, with the Nigerian senate, for instance, debating a law to ban the 'menace of street begging' in cities in the country. In the UK, the Anti-social Behaviour, Crime and Policing Act

2014 targets even ‘nuisance street entertainment’ in a similar manner as India’s begging law. Also, as in India, some governments are exploring ways to ‘rehabilitate’ beggars.

Origins of the law

Laws to criminalize beggary were enacted in India for the first time under colonial rule, overturning a very different civilizational tradition which taught the giver to treat persons seeking food and other charity with respect even while giving them alms. Some of India’s greatest thinkers, like Gautam Buddha, begged to instil humility, a tradition carried on by Sufi and Bhakti saints in medieval times. The idea that begging is a punishable crime is part of India’s much later colonial legacy.

The first law on beggary and vagrancy in India was the European Vagrancy Act, 1869 that dealt with vagrants of European descent., enacted immediately after the revolt of 1857 that had rendered several European men and women homeless. Assertions about white superiority and civility by the British Raj to sustain dominance over the Indian people were shaken in the wake of the revolution, necessitating a legislation to institutionalise vagrants of European descent and set up workhouses for their rehabilitation. This act was revised in 1874 to create more stringent punishments and deportation consequences for ‘vagrants’ of European origin. These, legislations introduced colonial attitudes about vagrants and beggars, which moved away from traditional cultural perspectives which were more tolerant and inclusive of people who lived on alms, setting the stage for beggary laws in India (Ganachari, 2002).

Provisions in the Criminal Procedure Code of 1898 for preventing the commission of offences were also used to initiate proceedings against vagrants, beggars, and other categories of ‘status offenders’. Additionally, ‘vagrants’ and ‘beggars’ were subject to penal provisions under local laws in diverse fields such as police acts, municipal acts as well as the national Indian Railways Act, 1941, which prohibited begging in railways. It was only in the 1940s that separate laws on begging were enacted, such as the Bengal Vagrancy Act of 1943, The Hyderabad Prevention of Beggary Act 1941 and The Madras Prevention of Begging Act 1945.

The writers of this article hypothesise that beggary laws to criminalize the poor were enacted for the following reasons: (1) the poor were perceived to be inferior or subhuman; (2) the way of life of the poor was considered the antithesis to a civilized way of life; and (3) the poor needed to be disciplined and educated in order to be converted into a productive resource for the larger society.

The tacit and mostly unstated underlying social philosophy was of blaming the victim, and especially the ultra-poor for their situation.

In the following section, we will observe that in free India, despite a progressive constitution that protected individual rights as well as advanced redistributive justice, laws which criminalized both begging and destitution persisted.

Beggary Laws After Independence

The fundamental premises and many of the provisions of the colonial laws that were enacted before independence were retained after Independence in the Bombay Prevention of Begging Act, 1959. This law is the model for a range of state acts which are still in force in 20 states and 2 Union Territory Administration including Andhra Pradesh, Assam, Bihar, Goa, Gujarat, Haryana, Himachal Pradesh, Jammu & Kashmir, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Punjab, Tamil Nadu, Uttar Pradesh, West Bengal & Union Territory Daman & Diu and Delhi. The state of Rajasthan and the Union Territory of Pondicherry have enforced anti-beggary measures by executive orders. Certain State Governments are tackling the problem under the provisions of the Police Acts and the Municipal Acts in their respective jurisdictions.

‘Begging’ under all these laws is defined expansively to bring within their ambit not only beggars, meaning thereby involved in soliciting alms, but also others who, due to their destitute status (such as the elderly or mentally ill) or street-based vocations, are presumed to be beggars. Typically, a beggar is defined in most of these laws to include anyone without ‘ostensible means of livelihood’ which really means that these laws make destitution not a subject of social assistance but of crime (Goel, 2010).

The penal consequences of begging in public places vary from release after admonition or personal bonds for first time 'offenders' to detention for up to 10 years. The offence of beggary is established on the basis of summary trials in designated 'beggars' courts' that are presided by a first-class special magistrate. After summary trial, beggar offenders are detained in custodial beggars' homes (often called observation homes). These are not officially jails, but in practice they have functioned like poorly resourced jails, or poor houses (Mander, 2016). The writers of this paper have observed in the many beggars' homes that they have visited that typically the social architecture of these settings resemble that of a maximum-security prison with barracks (instead of dormitories), with few or no opportunities to be exposed to the outside world. Barracks contain cells similar to those seen in jails "Inmates" are allowed to step out into common areas for 40 minutes to one hour per day, sometimes not even this. Few centres have rehabilitation facilities that offer vocational training, and pay Rs. 5/- to Rs. 10/- per month (or between 2-4 percent of statutory minimum wages) which serve little to no purpose in today's economy. 'Repeat offenders' or those persons who do not fall in line with the rules of the home are subjected to verbal and physical abuse. In some cases, these violations have led to deaths in the home. Monitoring mechanisms and human rights watch in these institutions are restricted to administrative oversight, and rarely involve feedback from inmates. In these ways these beggar's homes established under laws which criminalize beggary deny both freedom and dignity to the most destitute.

In response to a writ petition filed by the third author in the Delhi High Court which challenged the constitutional validity of criminalising begging (details will be provided later), and another petition by Karnika Sawhney (which sought more effective and humane implementation of anti-beggary laws but not their abrogation) the union government informed the court that it was considering the passage of a law which should replace the existing anti-beggary law. With experts and also representatives of the Delhi government, it drafted The Protection of Rights of Persons in Destitution Bill, 2016. This draft bill includes persons in begging in a larger category of 'persons in destitution', a condition in which the destitute person requires support to move out of destitution. It envisages the survey and identification of persons in destitution; and their referral to various schemes or legislation from which they can benefit, including social protection schemes such as pensions, insurance and shelter; and rehabilitation centres to ensure their basic literacy and train them for suitable livelihoods, while also extending nutrition and medical support. In the later stages of the hearings of the case, the union government informed the court that it had withdrawn its proposal for passing this law, but did not assign any reasons for this.

4.3 Need for the study

Research on begging in the social and development context, of India and empirical evidence on incarceration, rehabilitation methods, and systemic reforms have been limited. Fewer studies have sought the opinion of key constituents on their reasons for begging, experiences on the streets, their needs and aspirations, and perception of inclusion and participation. Therefore, it was felt important to speak both to people who have been criminalized and incarcerated under the beggary laws and judges and social workers who work closely with these populations to understand the problems with the existing law, and what if anything should replace it in order to ensure for destitute people, including people in begging, their fundamental right to a life of dignity. This paper seeks to understand from the perspectives of technical and experiential experts the relevance of the beggary law, its impact on their lives and perceived impact on the lives of thousands of inmates stuck in similar facilities, alternatives to the beggary law if needed, and how they may be constructed to fulfil fundamental rights of justice, dignity and the right to life as guaranteed in the Constitution of India.

Research Questions

This paper first asks if the beggary laws which criminalise begging should be abrogated. It then asks the further question that if it is accepted that beggary laws violate the constitutional rights of citizens who live by begging and therefore must end, then what could possibly replace this law.

The questions that this paper seeks to answer are as follows:

1. To what extent do professionals, courts and people in begging consider beggary laws in India to violate India's constitutional guarantees to people who are alleged to, or actually live by, begging?
2. If a law on begging is not required to criminalise begging, are the rights of people in begging adequately met simply by abrogating the law and by not replacing it with any other law related to begging? Or is a law or programme required to create positive duties on public authorities for persons who are engaged in begging due to a variety of circumstances?
3. If so, then what are these positive duties that the law should create, and by what processes?

4.4 Methodology

A qualitative research methodology was adopted, consisting of a series of semi-structured interviews with professionals and with persons incarcerated under beggary laws, combined with detailed desk studies of various petitions challenging the beggary law and the proposed The Persons in Destitution Bill, 2016 being considered by the Ministry of Social Welfare, Government of India, as a possible law to replace existing beggary laws. The following sections provide detailed information about the interviews and the study population.

Semi-structured interviews with persons currently or in the past incarcerated under beggary laws

The study seeks out the views and perspectives of vulnerable populations who have been convicted under existing beggary laws. The objective of the research is to understand how people who have been convicted and incarcerated for the 'crime' of beggary evaluate the role of the state in their lives, including a) the present legal arrangements; b) the proposed Destitution law; and c) any other assistance or support that they would desire from state authorities.

The study employed convenience sampling method to select centres for conducting interviews, and only sought those that granted permission for entry. These are mostly opaque institutions, and non-official researchers and social workers are usually denied entry to these homes and access to the residents of these homes. The study sample constituted residents from the Beggars' Homes in Bangalore and Hyderabad, and persons released from Beggars' Homes in Patna. We enquired from our colleagues across cities we work in if they could help us to meet with persons who were detained in beggars' homes and are now released and homeless. Social workers in the city of Patna were affirmative, and this is why this location was also included.

Interviewees were selected based on the following inclusion criteria: men and women without disabilities, men and women with physical disabilities, men and women with mental disabilities, transgendered people and women with children. A total of 24 respondents participated in the study (13 males and 11 females) between ages 30 and 70; Since neither of the shelters housed transgender people or women with children, they were therefore not interviewed.

The attempt was to hold the interviews in a private space unsupervised by Beggars' homes staff, but this was not always possible, as some staff members were unwilling to allow the residents to speak without being monitored. The researcher, sometimes with these limitations, would explain to the interviewee the purpose of the interview, and seek informed consent. The responses were matched under each of the major points of analyses of the thesis – the perspectives about beggary laws and especially of incarcerating people in begging. A semi-structured interview schedule prepared by the authors was employed for this study, with questions pertaining to the inmates' demographic details, details of their incarceration, employment status prior to incarceration, their feedback on the services provided at the beggars' homes, experience with reintegration, their opinion of the beggary law, and recommendations for the new bill. Each interview took an average of 40 minutes to complete. The questionnaire was administered in Hindi, Tamil, Telugu and Kannada, based on inmates' preferences and translated by the first and second authors. Questionnaire is presented as under:

1. Do you have a family?
2. Do you have active bonds with your family?
3. Before you were detained, were you supported or did you work?
4. If work, details?
5. Did begging in cash/kind constitute part of your survival strategy?
6. Details of your arrest, trial and conviction
7. Is this your first arrest? If not, details of history
8. Experience in beggars' home, including daily routine, food, counselling, livelihood training, violence, recreation, friendship, attitude of staff, visits by families, and so on?
9. What is your views about the Beggary Law and its implementation?
10. If the proposed Destitution Law was in place, would it have been better, and in what ways?
11. How would you like government to treat persons who are in your situation?

Coding was done manually by the authors. The responses were categorised under demographic details, time spent in the institution, and their feedback on the institution, and recommendations. For the purposes of this article, their feedback and recommendations have been highlighted.

Since this is an intensely vulnerable population, there were many ethical concerns of the study:

1) the resolve to keep the identities of the respondents completely confidential
2) not to press the respondents to respond on sensitive issues when officials insisted to be present in the interview process
3) not to press any question if it caused the respondent any visible emotional distress.
4) The interviewers to listen without being judgmental

Semi-structured interviews with legal professionals, social work practitioners and service providers

We are convinced that the greatest experts about begging would be those who live in destitution and live by begging. But to illuminate many complex legal and constitutional question in relation to the research questions raised above, this study also sought the views of a series of legal and social key informants on the beggary laws in India as well as the proposed Protection of Rights of Persons in Destitution Bill. Interviewees were stakeholders who have helped draft the Bill, and others who work closely with the vulnerable groups who are the subject of this research, namely persons who beg, persons who are homeless, disabled and mentally ill.

Four detailed key informant interviews were conducted by the researchers with key informants selected because of their engagement with these issues Three of the stakeholders were either leading and nationally acknowledged experts who had worked with destitute homeless persons for decades, or had contributed to the idea of a law to replace the anti-beggary law. One was a retired pro-poor judge who was willing to speak to us.

Informant 1 was Justice Prabha Sridevan, a retired judge of the High Court in Chennai. Informants 2 and 3 were service providers running organisations for homeless persons with mental health issues: Vandana Gopikumar, founder of Banyan, an organisation which works persons poor and mentally ill, and Sarbani Dasroy, who founded an organisation *Ishwar Sankalpa* which works with homeless mentally ill men and women in Kolkata. Informant 4 was Mohammed Tarique, founder of *Koshish*, an organisation that works for the human rights of people in begging, and who was part of the team of experts who authored the Protection of Rights of Persons in Destitution Bill.

The interviews took place in person or by Skype between August and September 2018, and lasted around one and a half hours each. Interviews were audio-recorded and transcribed verbatim before qualitative data analysis took place.

Study of Proposed Legal Cases Challenging Beggary and The Persons in Destitution Bill, 2016

A systematic and detailed analysis of the constitutional validity of the Begging Act was conducted through a desk study, comparing the Constitution to the Begging Act[2]. Moreover, there are two major legal cases challenging beggary and these were analysed to answer the question: to what extent courts consider beggary laws in India to violate India's constitutional guarantees to people who are alleged to, or actually live by begging. Both the petitions and the judgements upon them were analysed, alongside the interviews with people incarcerated under beggary laws and with professionals. Similarly, the proposed persons in Destitution Bill were analysed as well, regarding ways in which it accommodates the difficulties of the former laws and creates effective rights of social protection for destitute people.

4.5 Research Findings

Perspectives of People Incarcerated for Begging on Beggary laws' constitutional violations

Of the 24 people we spoke to who were detained in certified institutions in Hyderabad, Bangalore and Patna, 12 (half the sample) felt that beggary laws are wrong and unfair; four did not respond to the question; whereas eight (a third) felt that arresting beggars is a good thing for a range of reasons. This despite that fact that 90 percent of them spoke of these as jails, and all of them reported involuntary admissions to them. None of them were told where they were being taken or why.

When we asked a homeless man with a long-injured leg who begged outside a temple in Patna if there should be a law that the persons who are begging should get locked up in jail, his response was categorical: 'No, this should not be happening. When people have no alternative, they are compelled to beg to get food, but for this they are taken away and locked up.'

There were diverse reasons for those 12 interviewees who felt the beggary law is wrong and unfair. A young man from Hyderabad said, 'They should lock up people who are creating problems like riots or crimes and then put them in the jail and then in the shelter. And not the people who are just living quietly and only begging. They should not lock them up.' Others agreed, that politicians, corrupt people, thieves, murderers should be arrested, not those with no alternative but to beg for sustenance. Yet others held that the government has violated their rights by arresting them, that they should help people who have nothing, not put them behind bars.

Among those who felt arresting beggars is a good thing different reasons were given. First, it offers rehabilitation for many who use money earned from begging to drink. Two of the residents with substance use issues talked about how it was an alternative to a rehabilitation home for them to stop drinking and have asked their family to not take them back as they felt they were finally changing. Second, for elderly and disabled people it offers a roof and food. Two residents said it is a good law because it provides a food and a place to stay, reiterating the need for positive and not punitive responses by the state, which currently does not offer comprehensive welfare programmes for destitute individuals. Finally, and somewhat paradoxically, the same two respondents expressed that they considered arrest and detention a fitting punishment for individuals who pick up the habit of begging and subsequently make it their livelihood.

Views of Other Key Informants

Law scholar Usha Ramanathan argues that that laws aimed at preventing begging do exactly the reverse - i.e. they criminalize extreme poverty by criminalizing destitution, or as she puts it criminalizing 'ostensible poverty'; as observed by the Delhi High Court in *Narendra v State [of] Delhi*: 'No doubt poverty is a curse and a poor man has to suffer in society at different fronts, but I cannot consider that despite poverty being a curse, poverty cannot be made a crime.' According to Ramanathan, the beggary act 'demonstrates how laws may be made, continued, expanded and practised on a group that is powerless - so rendered by the illegality that the law visits on them, the prejudice that poverty provokes, the distance between privilege and poverty, and the vanishing obligations of the state' (Ramanathan, 2008; 33-44).

A significant proportion of persons living on the streets (who may or may not be engaging in begging) are persons belonging to ultra-vulnerable categories, such as those with physical and mental disabilities and the elderly. Owing to over-inclusive definitions of beggary in the BPBA, they are arrested and sent to observation homes that are ill equipped to offer any beneficial and therapeutic interventions.

That laws that ostensibly criminalize begging actually in effect criminalize extreme poverty and destitution is a theme which recurs in our interviews with other key informants The key informants we interviewed were all in agreement that the existing swathe of beggary laws in India violated the constitutional rights of destitute persons, persons alleged to be in begging and those who were actually dependent on begging for their livelihoods. Justice Sridevan describes as 'very unjust' that beggary laws criminalize people because they don't have money, a view interestingly echoing those of many people arrested for begging interviewed in our study. She makes a distinction between beggary per se, and beggary plus. The latter is beggary combined with crimes like kidnapping and trafficking. She says that the Indian Penal Code is adequate to put away kidnappers, traffickers and those who maim people for purposes of begging. There are enough nets in the law to catch these offenders and stop these offenses. Mohd Tarique points out that an unintended consequence of the law would be that traffickers, or persons committing more serious crimes, 'would be happier to be charged under the beggary laws' (which provide for a maximum punishment of 3 years) compared with other penal laws for which the punishments can be as high as 10 years. Vandana Gopikumar also reiterates that begging is not a crime, and the right to pursue vocations needs to be protected. She also points to the class-bias of the law against begging. 'In the earlier times, you live your life on the basics …So you're not criminalised, but you're respected, you're welcomed into homes, you're not shunned… (with) a sense of inclusiveness, from which we've moved into a sense of othering people who look different, who seem different, and who engage in beggary'. adds that beggars are entrepreneurial, a strength which needs to be built on. 'Take cognisance of the fact that the person's reality is different from yours', she says. 'And accept that reality and embrace diversity - which they (the state officials and judges) don't do'. Further, Gopikumar compares the argument that beggary laws should be retained because of the dangers of forced begging by criminal syndicates, with the argument against decriminalising suicide because some women commit suicide because of dowry harassment. But the answer to this is not criminalising suicide but strengthening dowry violence laws; likewise make laws penalizing forced begging more robust, if needed, but that should not be used as an alibi to continue to criminalise begging.

Perspectives in Public Interest Litigation: Violations of Constitutional Rights

As stated earlier, the third author of this article filed a Public Interest Litigation[3] WP (C) 10498/2009 challenging the constitutional validity of the Bombay Prevention of Begging Act, 1959 (hereafter called the Beggary law) as extended to the Union Territory of Delhi (hereafter described as the Begging Act). He argued that poverty can never be a crime; that if a person is destitute and begs for a living such a person cannot be treated as a criminal; hence seeking the decriminalisation of the act of begging. The High Court took up his petition with another petition filed by Karnika Sawhney. This second petition did not seek the decriminalization of begging, but instead more effective implementation in the national capital of anti-beggary laws, including better conditions in beggars' homes, more effective vocational training of detained persons, and increasing mobile raiding squads on beggars.

The Delhi High Court in a historic order of August 8, 2018, declared that criminalizing beggary is unconstitutional, and it struck down all sections of the law which regard begging to be a crime.

The first petition demonstrated many ways in which the Bombay Prevention of Begging Act, 1959 violates a range of constitutional rights: the Right to Equality guaranteed under Article 14 of the Constitution; the Right to Freedom of Speech and Expression guaranteed under Article 19(1) (a); the Right to Free Movement throughout the Territory of India guaranteed under Article 19(1) (d); the Right to Practice Any Occupation, Trade or Business guaranteed under Article 19(1) (g); the Freedom from Multiple Prosecutions for the Same Action guaranteed under Article 20(2); and the Right to Life guaranteed under Article 21 of the Constitution; the Right to Personal Liberty guaranteed under Article 21.

Article 14 lays down that the State shall not deny any person equality before the law. People in very unequal and different situations and treated in the same way by law, such as those who solicit and those who simply receive alms; disabled and non-disabled persons; those who 'have no visible means of subsistence' and those who actually don't have means of livelihoods but do not appear so. On the other hand it does not treat equally those who solicit alms and those who receive alms as tips, such as luggage handlers, gatekeepers, security guards, waiters and guides; and private organisations who solicit for alms and private individuals; and so on.

Article 19 protects the fundamental right to freedom of speech and expression. The Beggary law renders illegal the 'soliciting' of alms, which maybe verbally articulated, or through gestures. If people cannot make requests for alms, some may successfully struggle to survive, but large numbers may not. Their freedom of speech may literally be a matter of life or death to them.

Article 19(1)(g) guarantees the right to practice any profession, or to carry on any trade or business. The inclusion of singing, dancing, fortune-telling, performing or offering articles for sale in the Begging Law as a pretence for begging entails a careless disregard by the legislature of the right to practise any profession, or to carry on any business or trade.

Article 21 of the Constitution states that 'no person shall be deprived of his life or personal liberty except according to procedure established by law.' In *Francis Coralis Mullin v. Administrator, Union Territory of Delhi [(1981) 1 SCC 608]*, Justice Bhagwati interpreted the right to life as 'the right to live with human dignity and all that goes along with it, namely, the bare necessaries of life such as adequate nutrition, clothing and shelter.' Under this interpretation of the Right to Life, Article 21 translates into a right to beg when there is no social safety net, employment opportunities, or state support. For if the government does not provide one with the bare necessities of life, one has the right to engage in non-harmful behaviour to ensure that he is provided with the bare necessities of life.

The incarceration under the Beggary law amounts to absolutely disproportionate punishment which betrays a lack of official value placed in the lives and aspirations of those detained. It is informative to consider that the maximum sentence for a first-time begging offence is three times longer than that for voluntarily causing hurt under section 323 of the IPC and for subsequent begging offences the maximum sentence is three years longer than the maximum for voluntarily causing grievous hurt under section 325 of the IPC. Even if the Government's contention that these Certified Institutes are centres for rehabilitation were true, the time periods and indeed the very idea of detention is draconian. In reality, rehabilitation programmes in certified institutions created under the Beggary Law are few and inadequate; most detainees simply languish in conditions worse than jails.

In a landmark judgment, *Ram Lakhan vs State* on 5 December 2006, Justice Badar Durrez Ahmed of the Delhi High Court confirmed many of the claims of the constitutional invalidity of the beggary laws. He observes: '…begging involves the beggar displaying his miserable plight by words or actions and requesting for alms by words (spoken or written) or actions. Does the starving man not have a fundamental right to inform a more fortunate soul that he is starving and request for food? And, if he were to do so, would he not be liable under the said Act for being declared as a 'beggar' and consequently being deprived of his liberty by being sent for detention at a certified institution? Does this not mean that the said Act leads to deprivation of liberty on the basis of a law which runs counter to the fundamental right of freedom of speech and expression? Does this, therefore, not mean that even the fundamental right of protection of life and personal liberty, which is enshrined in th Constitution, is also violated ?' He adds that since the law has penal consequences and effecting the liberty of individuals, the restrictions it imposes on fundamental rights must be reasonable. There should be an evaluation of 'necessity; a situation where the person had no legitimate alternative to begging to feed and clothe himself or his family. Similarly, where it is apparent that the person was found begging under the exploitative command of others, he ought not to be deprived of his liberty by being sent to a Certified Institution for detention'.

In similar terms, the judgement of the Delhi High Court in *Harsh Mander and Kanika Sawhney* of 8 August 2018 does not make any distinction between voluntary or involuntary begging. The fact that this broad definition allows the state to treat homelessness and begging synonymously by detaining the homeless as if they were begging and implementing the penal provisions of the act against them. One could argue that this interchangeability has little or no analytical or empirical basis, as not all people in begging are homeless, and not all homeless people beg (indeed the large majority do other work). ‘These may be daily wagers and/or having family members to support’ the court observes. ‘As a result of the detention of the bread earner of the family, the entire family may be reduced to financial deprivation and penury. Such can never be the object, spirit and intendment of a welfare state by way of what is touted as a social benefit legislation’. On these grounds it finds the statute to be unconstitutional for being violative of Article 14 of the Constitution of India.

It quotes a number of judgements of India’s superior courts which interpret the fundamental right to life under Article 21 of the Constitution of India guaranteeing Right to Life to include *inter alia* the right to shelter, education, healthcare and clean environment. It goes on to observe that it ‘remains a hard reality that the State has not been able to ensure even the bare essentials of the right to life to all its citizens, even in Delhi. We find reports of starvation deaths in the newspapers and ensuring education to the 6 to 14 year old (sic.) remains a challenge’.

There may be many reasons that compel people to beg.A significant number of people may beg because they have no other option except begging to survive. In its Preamble, the Constitution of India identifies justice, liberty, equality and fraternity as foundational principles of the Indian State. Additionally, the Directive Principles obligates the State to secure for its citizens the right to an adequate means of livelihood, the right to work, as well as the right to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want. Therefore we could look at begging as a failure of the state rather than the individual who begs. Further the Supreme Court in various judgments, has recognized that poverty is not a crime.

It goes much further in its judgment of 8 August 2018 in *Harsh Mander and Kanika Sawhney Ka*where it concludes that ‘People beg on the streets not because they wish to, but because they need to. Begging is their last resort to subsistence, they have no other means to survive. Begging is a symptom of a disease, of the fact that the person has fallen through the socially created net. The government has the mandate to provide social security for everyone, to ensure that all citizens have basic facilities, and the presence of beggars is evidence that the state has not managed to provide these to all its citizens. If we want to eradicate begging, artificial means to make beggars invisible will not suffice. A move to criminalize them will make them invisible without addressing the root cause of the problem'…

Discussion: State's Positive Responses and Responsibilities

If a law on begging is not required to criminalise begging, are the rights of people in begging adequately met simply by abrogating the law and by not replacing it with any other law related to begging? Or is a law or programme required to create positive duties on public authorities for persons who are engaged in begging due to a variety of circumstances?

Among the interviewees, those who had been detained under existing begging laws articulated their positive expectations from the government. But they did not have a view if this should be embodied in schemes or in an alternate law. Only one said clearly that the best that the government could do for her was to give her back her freedom. To the same person with a chronically injured leg who begged in Patna, we asked: If the begging law was removed, what if anything should the government do for you? He replied, 'They should help us. They should help us build a life, build a home, give us some money so that we do not have to beg anymore'. Others suggested provision of homes, skills training, employment facilitation and pensions from the government, especially for persons with mental and physical disabilities who have minimum access to support networks. Persons who were detained for selling items on the streets or simply because they were sitting on the road felt it was unfair and unnecessary for them to stay in such a home, and instead suggested that the government should focus on taking care of destitute persons. One resident spoke about initiatives such as 'Amma Canteens' benefitting poor and destitute persons to be expanded across the country. Most residents reiterated the importance of permanent housing for persons with mental health issues, irrespective of whether or not they were homeless owing to the perception that they will not be able to take care of themselves in the long run.

Among the professionals interviewed for the study, Justice Sridevan is of the firm opinion that the repeal of beggary law should not be linked to passing of any form of a destitution bill. She pointed out that people for whom social justice schemes needs to be initiated need not necessarily be beggars, so there's no need for it to be linked to the ending of beggary laws. By linking these, she says, there will be an excuse to stall the repeal of the beggary act. ~~(~~It is true that the courts did not dispose of the petition because they awaited the alternative law draft from the union government; and it was after the union government informed the court that it had dropped this plan that the court finally disposed of the petition~~)~~. Vandana Gopikumar agrees that the repeal of the beggary law should not be contingent on any new bill to replace it. 'What should it be contingent on?' she asks. 'It should be contingent on our referring to our Constitution, our referring to various policies that we have with regard to people who are below the poverty line, and people who are deprived, and equal opportunity has to be promoted for all such people'. The repeal of the beggary laws are imperative because the state must stop criminalizing poverty. She agrees that the government should take proactive steps to protect vulnerable populations. But for this a new law is not necessary. What is required is that the government should repeal the old act and create provisions to protect destitute people through other schemes; and penalize crimes against children such as trafficking for begging.

Tarique Mohd on the other hand is convinced about the absolute need for a new law (he was indeed on the drafting committee of the union government for the model Bill that the union government at that time was considering submitting to the High Court). In his view, the beggary law was being rolled out more as a law and order problem. The new law would be about freeing vulnerable and destitute people from police and lawyers, and at the same time assuring people that they would be taken care of.

Justice Badar Durrez Ahmed of the Delhi High Court in Ram Lakhan vs State in 2006 was mindful that the petition before him did not challenge the constitutional validity of the beggary law. He still found that aspects of how the law was framed and implemented did violate constitutional rights, but he did not call for the abrogation of the law. He asks: 'Why does a person beg? There are various reasons for a human being to solicit alms. Firstly, it may be that he is down-right lazy and doesn't want to work. Secondly, he may be an alcoholic or a drug-addict in the hunt for financing his next drink or dose. Thirdly, he may be at the exploitative mercy of a ring leader of a beggary 'gang'. And, fourthly, there is also the probability that he may be starving, homeless and helpless.' We have already noted that he ruled that the third and fourth situations are forms of coercion, for which it is unjust, indeed unconstitutional, to punish the person who begs. He goes on that if 'the person was found begging because of his addiction to drinks or drugs, not much purpose would be served by sending him to a certified Institution which does not provide for detoxification or de-addiction. So, in such cases the court, after due admonition ought to release the beggar on a condition that he shall go in for detoxification or de-addiction at an accredited institution'. It is only for the first category of beggars, who he describes as 'Professional beggars who find it easier to beg than to work' that he finds it lawful and constitutional for them to 'be appropriately dealt with by passing orders under Section 5(5)4 of the said Act for their detention in Certified Institutions'. In this sense, he calls for the writing down of the law, but not its abrogation.

If a new law is required, then what are these positive duties that the law should create, and by what processes?

Protection of Rights of Persons in Destitution Bill

In response to the petition filed after this judgment (in 2009) by the third author for the abrogation of the beggary law, the union government assured the court that it was committed to decriminalising beggary. For this, while it would abrogate the existing law, it would in its place bring in a law for the comprehensive rehabilitation of persons in begging and destitute persons. It worked on a draft legislation - a model The Persons in Destitution (Protection, Care and Rehabilitation) Model Bill, 2016, which it would commend to state governments to adopt. This includes persons in begging in a larger category of 'persons in destitution', who include also homeless persons, persons with physical and mental disabilities, the old, infirm and other such persons who are above 18 years of age and 'in a state of poverty or abandonment arising from economic or social deprivation and sustained unemployment'… 'which requires support for the person to move out of it'. The law defines begging in the same way as existing beggary laws. However, after over a year of work on the Bill, the central government suddenly informed the High Court that it had dropped the idea of drafting this law to replace the beggary laws[4].

Positive Features of the Draft Bill:

The design of the draft Bill is that state governments shall constitute Outreach and Mobilisation Unit in districts, which shall survey and identify persons in destitution and mapping areas where they live, 'with a special emphasis on identification and rehabilitation of persons engaged in begging at Bus Depots, Railway Stations, platforms and inside the trains'. It would mobilise such identified people, refer them to various schemes or legislation from which they can benefit, including social protection schemes such as pensions, insurance and shelter; and assist them with the paperwork and procedures to access these benefits. It would run rehabilitation centres to ensure their basic literacy and train them for suitable livelihoods, while also extending nutrition and medical support. It would also refer them where necessary for de-addiction and mental health services.

A key positive feature of this draft was its emphasis on accountability across multiple levels. The bill aimed to establish within three months of its enactment, a monitoring and advisory board, headed by the principal secretary of social welfare, that would monitor, review and coordinate implementation of schemes and advise government on matters related to care, protection, welfare and rehabilitation of its constituents. The board would also act as a review committee for budgetary allocations and fund releases towards the implementation of the new bill. It would in addition, appoint smaller inspection committees for a state or district that would report back to them after periodic reviews. Reports prepared by the board would be available to the public on an annual basis.

Significant emphasis was also laid on record keeping, wherein all requests for support, assistance and referral services will be registered, and individual records maintained at rehabilitation centres. In addition, this information would be made available to the public, with the Outreach and Mobilisation Units serving as nodal agencies that would furnish information under the Right to Information Act of 2002. Despite expressed need for positive responses from the state, this bill has been dropped by Parliament for unexplained reasons.

Defining Destitution and State Responses to the most marginalised:

Tarique Mohd , who was closely associated with the drafting of the Bill explains that the definition of 'destitute persons' who are to be covered by the Bill seeks to include those who need and seek state support to get out of begging. It entails that state authorities look into the reasons why they are in a state of destitution and help them out of it by addressing the causes of their destitution. Vandana Gopikumar says destitute people are those who are excluded from a safe, caring, resourced family with both the desire and the capacity to protect them; persons deprived of material resources and networks of support. This echoes Barbara Harriss White (2002) who speaks of destitution as an *individual* phenomenon because by the time a person is destitute they are usually an individuated remnant of a collapsed household; and of destitute people as not just passively socially excluded but actively 'socially expelled'[5]. Sarbani Dasroy, founder of Iswar Sankalp, an organisation working with homeless mentally ill persons in Kolkata, agrees with the definition of destitute persons in the Bill, especially those who need state support to survive with dignity. Justice Sridevan agrees again on the need for support as the key to define a destitute person: people in socio economic deprivation and continued unemployment who cannot be lifted without state support. She feels the Bill should clearly spell out what support means in a separate clause.

Most experts agree on the other hand that the definition of begging should be restricted to soliciting and receiving alms, and nothing else; because the expanded definition criminalises simply having no means to earn a livelihood, or those who earn their livelihoods by selling things, street acrobatics, dancing, and singing.

Mode of Entry and Exit into Rehabilitation Centres:

Although the language and spirit of the Bill seems to suggest that these rehabilitation centres will be open and voluntary, there is a contradictory clause that 'If a person is found to be engaged in begging repeatedly in spite of undergoing rehabilitation and counselling, the assistance of Police Authorities may be sought and the person may be detained in the Rehabilitation Centre up to a time as may be deemed fit in the interest of the person as regards his/

her rehabilitation (sic.)'. This is feasible only if these rehabilitation centres are at least partly custodial and involuntary.

There were differences among the key informants about what the process for admission into the rehabilitation centres under the Bill should be. There are three possibilities. One is that it should be entirely voluntary, with no gate-keeping. One is that it should be voluntary, but there should be an evaluation of whether the person is genuinely destitute before she is admitted. A third is that the state should have the right to forcefully admit persons into these centres. Justice Sridevan is clear that any gatekeeping leads to corruption. Anyone who claims to be destitute should be admitted. She maintains that inclusion errors are acceptable but there should be no exclusion errors. Instead of squads going out to arrest beggars they can do outreach and inform people about the services offered under the new law. Entry should be entirely voluntary. 'If they don't want your kindness or offer for rehabilitation, so be it'. Tarique Mohd too agrees that the use of services should be entirely voluntary. It should be available for anyone who seeks to use it. Gatekeeping, he says, should be 'to bring the most vulnerable populations in, not to keep people out'.

Dasroy agrees that 'there can't be coercion at any cost'. There can be some negotiation between the system and the individual, because for people who have been in destitution for a long time getting into these systems and centres maybe a challenge. So mutual trust needs to be built. And she believes that some amount of practical targeting is necessary otherwise the state will not have the resources to support everyone who feels they require state support. 'We work only with the homeless people with psychosocial disability. (When people with other needs come to us) the first thing that many of them say is 'but … she's homeless, she doesn't have her parents …her brothers are not looking after her'…There is therefore the need 'demarcate the … boundary to which the state can actually work in…(E)ntire dysfunctional families (may) tend to put the entire burden onto the state, and then the whole system will probably become a little too burdened to carry it through. So, if we can be a little more pragmatic in the way that we define destitution.'. Gopikumar affirms that for those without mental health issues entry must be voluntary. But persons with mental illness may in some cases need involuntary admission and rehabilitation through the mental health care act (2017) and other supportive laws. Dasroy also agrees with voluntary admissions and exits except in the case of persons with mental health issues who are currently symptomatic

None of the professionals agreed with the provision in the Bill for involuntary admission of persons who are 'repeat offenders' by persisting with begging even after passing through or being offered the state's rehabilitation services. Although Tarique was associated with the drafting of the Bill, he affirms that this clause needs to be removed from the bill. By no means should any resident be involuntarily custodialised. 'If people go back to begging or do not avail of the rehabilitation services', he says, 'it is the failure of the program, not the people'.

Support Services:

We also asked the key informants the kinds of services, if any, that the redesigned open spaces for safety and rehabilitation of destitute persons should contain. Gopikumar believes that the rehabilitation centres should provide an extensive range of services: medical, de-addiction, mental health services, education, skill hubs for jobs, soup kitchens, shelter, vocational training, employment opportunities, legal aid, social protection schemes of government; basic income in the absence of a job, with the right to spend and to choose what to spend on. She emphasizes on the importance of basic income also as an effort to reduce State spending on resources people may choose to not access or deem unnecessary, whereas money in hand will place the citizen at the centre of the decision making process.

Tarique believes that what the Bill provides is adequate, but it is critical that fundamental rights should be made available for those who chose to exit the institution as well. Social entitlements such as pensions must also be made available for those who have been incarcerated (under the beggary act or otherwise). He enunciates the important principle that what is available for all citizens should be made for those in destitution. He also says that for some populations, the state must recognize the need for life long care, which could be met by establishing long-term centres for elderly, and people with disabilities presenting with high needs.

Dasroy agrees that referral services are very critical for destitute people with HIV, TB, mental health issues, pregnant women, new mothers etc. They may require long-stay homes, and old age homes for destitute older persons should be permanent. She adds that with old age homes however a mixed population will help with inclusion, participation and quality of life. This would mean including younger destitute populations in these homes as well. 'There is a hunger for relatedness' she says. It will also help build accountability. Gopikumar also speaks of permanent homes that accommodate 4-5 people with mixed disabilities living together like a family and its positive effects on social participation, reduction of disability and improvement in quality of life.

The residents of the beggars' homes had a similar set of expectations from the state as did the key informants we interviewed. These included clothes, food, psychiatric care permanent homes for the elderly and disabled, skills training and employment provision. Many could not understand a question that they should imagine and caring state, and then think of what it should do for them. We could learn therefore from their expectations from those 15 interviewees who spoke of positive experiences in the beggars' home. They spoke of good food, daily routine, opportunities for work and recreation. People with substance use problems said that it was an ideal place for them to quit drinking as it was a very strict atmosphere with no option of leaving. Two of them felt that the centre works better than a drug-rehabilitation home because they are not drowsy with medicines, walk and exercise every day and engage in manual labour. But among those who were unhappy, felt it was unfair to be detained despite providing details of the family, and one of them said it is unfair to be detailed purely because he does not have a family or anyone to pick him up.

One young man in Hyderabad beggars' home spoke of the kind of centre he would like: 'There should be a good place with better conditions with better food and living conditions….I want to move around according to my choice…. I want to have these facilities and freedom too…It's all about choices and freedom. If I have a good relationship (with the staff in the home), I will come back….If they trust me enough that if I go I will come back. I would like to go to such a place'.

Some respondents also emphasised the need a state-run places of safety for people with severe mental and physical health challenges who have been abandoned by their families. One said, ‘Whatever laws offer protection for disabled and mentally ill people is good. They don’t have anyone to care for them. They need food, water and a place to stay for the rest of their lives’. Another said, ‘This law is good for disabled people. Their families don’t want them so government should provide refuge’.

4.6 Conclusion

To start with, we need to note some limitations of the study. One is that the responses of many residents was possibly coloured by the fact that at times, we were unable to get permission from the jail authorities to speak alone with them. The second limitation was that we were not permitted free access to the residents, which did not allow us systematic sampling. The absence of extended and free access to the residents also did not allow us to interview the residents of the homes with the depth that we would have liked, nor to make some of them partners in the research to give it sufficient authenticity. But despite these limitations, the feedback from the residents were always interesting, some counter-intuitive, and at all times useful to answer some of the questions of the study. The limitations were partly overcome by triangulation with interviews with people who have spent many years working directly and closely with similar populations.

In the course of the final writing of this paper, the petition filed by the third author was allowed by the Delhi High Court, which held as we have seen, that legal provisions which criminalize begging violate the constitutional rights of some of the most vulnerable and disadvantaged citizens, and therefore are struck down.

This question has therefore been settled finally by India’s highest courts. But beyond this, as the article reveals, there is much less agreement about whether the law which criminalizes begging should be abrogated, or portions of it retained, and if it is abrogated, should it be replaced by another positive law to deal with the state’s duties towards the same vulnerable and dependent populations that are freed from the stigma of being criminals. Justice Badar

Durrez Ahmed of the Delhi High Court makes a useful classification, reminding us that people in begging are not a homogenous category of people. He speaks of people who might beg because of the coercion of desperate poverty and unemployment. A second category are people who might be compelled to beg by criminal gangs. We believe that the first cover conceivably the large majority of people in begging; and the second a small fraction, if at all, but this requires further studies to establish empirically. However, regardless of their numbers, we believe that there can be little disagreement with Justice Ahmed's observation that there is no justice in punishing people who are acting as the result of coercion. He then points to a third category of people, who beg because of drug addiction. Once again, he believes that they need treatment in drug rehabilitation centres, not incarceration in jail-like beggars' home.

This leaves only the fourth category, of people who beg not because of coercion or drug-usage, but because this is a profession they choose to pursue. Justice Ahmed seems to have no problem with the application of beggary laws to this one category. But in his judgment, he adds the disclaimer that he is not evaluating the constitutional validity of the beggary law. If he did, he may have concluded as we do in this paper that the law violates many fundamental rights of the person who chooses to beg, including the right to choose one' vocation, of freedom of expression and above all the right to life and liberty. Justice Ahmed describes such persons as 'lazy', while Gopikumar describes them as 'entrepreneurial', exercising legitimate rights of the way they wish to earn their livelihoods.

However, professionals and persons who have been incarcerated in certified institutions established under beggary laws are not in agreement about what if any should replace existing beggary laws. The authors of this paper tend to agree that the people in begging are only one section of destitute people who require state support, therefore whether or not we should have a law which creates positive duties for the state for destitute people (and what such a law should contain) must in fairness be delinked from the annulment of the beggary laws. Else the lack of consensus about the alternate law can – and is – being used as a reason to stall the revocation of laws which criminalize both beggars and destitute people and violate their constitutional rights. The idea of creating voluntary safe spaces for destitute people who seek such sanctuaries has wide acceptance with both professionals and people incarcerated for begging. The services that these should provide, including food, health care, counselling and vocational training and placements are also not controversial. Whether these should be binding in law or just programs are where debates continue, but we put our weight behind a law, because without it states are unlikely to commit the resources required by these highly invisible, vulnerable and stigmatised populations that survive at the further edges of society.

This article has been primarily concerned with questions of law. But there is, both underlying the law and traversing beyond this: larger questions of social morality, of the imperative of a compassionate, caring and just social order that we must be mindful of. Can we renegotiate a social contract that does not judge and treat its most dispossessed people as criminals? One that instead sees them without judgement and behaves towards them as human beings who are enduring enormous odds, people who deserve to live a life with the dignity they intrinsically and equally possess; and for this deserve to receive state (and social) support.

The Delhi High Court in its historic judgment of 8 August, 2018 in *Harsh Mander v State*, places these questions and those raised in this article in perspective. The question before them, the judges say, is simple. 'In our constitutional framework that promises every person the right to live with dignity, can the State criminalize begging?' In its answer to this, it lays out a very important principle. This is that the 'social contract between the citizen and the State is a contract by which in exchange for the citizen ceding her autonomy partially, the State promises her security over her person and a life with dignity'. This is reflected, the court points out, in India's constitutional framework, 'guaranteed by Part III which enjoins the State not only to protect life but also to advance it, and Part IV which mandates that the State shall allocate resources so as to further the common good'. It concludes that 'the constitution envisages the vision of a society that is humane, just and fair'.

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[5] Barbara Harriss-White *QEH Working Paper Series – QEHWPS86 Page 1.* Working Paper Number 86. A Note On Destitution

CHAPTER 5

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

5.1 Abstract

Purpose: A multi-phase 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 (semi-structured interviews, life history timelines, focus group discussions and the Experience of Caregiving Inventory) were used with caregivers accessing outpatient services of a non-governmental organization in urban and rural locations around Chennai, India.

Findings: Based on our results, we constructed a multi-phase 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 6. Finding new meaning.

Practical implications: Our multi-phase model allows us to identify in more detail the needs of caregivers at various stages.

5.2 Introduction

The experiences of caregivers of people with a mental health issue have been described in a significant body of research, mostly from western countries (Baronet 1999, Rose 1996, Chan 2011), and to a smaller extent from low resource countries (den Hertog 2016, Bhandari 2015, Chadda 2014, Monyaluoe 2014, Chan 2011, Mavundla 2009, , Nyati 2002, Ohaeri 2001). 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 a mental health problem on the living situation of their caregiver and the emotional, psychological, physical and economic consequences thereof (Awad 2008, WHO 2004:12). A distinction is often made between 'objective' and 'subjective' burden. Objective burden are the concrete and observable negative effect of the 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 (Chan 2011).

An alternative approach to understanding caregiver experiences was developed by Szmukler (1996). The notion of caregiver 'burden' was rejected and instead, a 'stress-appraisal-coping' framework was developed, which encompasses both positive and negative experiences. (Szmukler 1996: 138). Szmukler developed a 66-item Experience of Caregiver 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 (Karp 2002).

While love and positive experiences can be vital aspects of caregiving (Awad 2008, Liu 2007, Chen 2004, Schwartz 2002), 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 of quality of life have been reported as aspects of burden (Yin 2014, Grandon 2008, Magliano 2000, Jungbauer 2003, Lauber

2003). 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 (Baronet 1999, Chan 2011, Shibre 2003, Grandon 2008) and low levels of functioning (Chan 2011, Tarricone 2006) 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 (Lowyck 2004, van Wijngaarden 2009), thereby making comparison difficult. Burden appears to be higher amongst female caregivers (Chan 2011, Flyckt 2011, Hsiao 2010), caregivers with higher education (Aggarwal 2011, Chan 2011) and young age of the person with a mental illness (McDonell 2003, Harvey 2001).

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 (Aggarwal et al 2011, Lim 2003, Chakrabarti et al 1992, Tarricone 2006, van der Voort 2007, Harvey 2001), while others have not found a positive correlation (Ricard 1999, Schene 1998).

In sum, while predictors for family burden have been studied, the outcomes are non-conclusive 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 (Gubman 1987, Tuck 1997, Karp 2000, Muhlbauer 2002, Rose 2002 and Milliken 2003), with one exception from a middle-income country, Botswana (Seloilwe 2006).

Caregiver experiences in low- and middle-income countries

It has been suggested that caregivers play a large role in non-Western countries in the re-socialization, 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 (Avasthi 2010, Faqurudheen 2014), but also because developing countries lack rehabilitation professionals to deliver these services (Kakuma 2011). There is a glaring lack of infrastructure, funds and political support for mental health care in developing countries (Gopikumar 2015, Saraceno et al 2007). In India, an estimated 90% of people with chronic mental illness live with their families (Thara 1994, Chadda 2001).

Chadda (2014) showed that non-acceptance of the relative by members of society led to 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 Addlakha (1999) 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 (Lahariya,2010).

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.

5.3 Methodology

The study employed a mixed-method research methodology, through semi-structured interviews, life history timelines, the Experience of Caregiving

Inventory (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.

Sample

The study was conducted amongst 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 multi-disciplinary 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 socio-economic groups. Out 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 (Padgett 2012:73, Palinkas 2013) was employed to select the participants, from four categories: a) Spouses, b) Adult Children, c) Siblings, 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 two years of caregiving was required.

The Experience of Caregiving Inventory (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 groups (FGDs) were conducted with different types of participants, comprising of caregivers accessing the Urban Mental Health Program of The Banyan (parents and spouses) (n=12), mental health professionals (n=8) and *NALAM* community workers[1] from urban (n=10) and rural areas (n=12).

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

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.

Data collection and analysis

Understanding burden

Semi-structured 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 inquiry (Regeer 2009) 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 Life History Timeline (LHT) exercises to collect retrospective event data, as it has been shown that this method elicits more detailed data than regular semi-structured interviews (Axinn 1999). Participants created timelines with positive and negative events since the onset of the illness.

The interviews were audio-recorded and transcribed verbatim from Tamil or

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[1] *NALAM* workers, which means wellbeing in Tamil, are community level employees of The Banyan, who have attended a six-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.

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 was then discussed to create a list of categories to be used in the phase of axial coding (Strauss and Corbin 2008). 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 (1996), 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 (Szmukler 1996, Joyce 2000) and has previously been used in India (Aggarwal 2011). However, the instrument has not been validated for use in India.

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 amongst 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[2]. The charts and discussions were analysed 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.

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[2] The latter two categories will be discussed in a separate article.

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.

5.4 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.

Table 1 Characteristics of caregiver, person subject 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	17.2%	12%	4.8%
Unmarried	48.3%	62.4%	81.0%
Married	27.6%	10.3%	14.30%
Widowed	6.9%	4.3%	
Divorced or Separated		11.1%	
Unknown			
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	40 years	32 years	39 years
Shortest duration	2 years	1 year	2 years

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

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 Programme	19
Urban Mental Health Programme	20
Occupation	
Social Worker	4
Psychologist	2
Senior community worker	2
NALAM worker	21
Nurse	2
Occupational therapist	1
Vocational Trainer	2
Health Care Worker	2
Mean years of experience	3.6 (SD=3.09)
Mean number of clients assisted	241 (SD=259.93)

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

Experience of Caregiving Inventory

The findings of the Experience of Caregiving Inventory (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.

Table 3. Results of the Experience of Caregiving Inventory (ECI)

Variables	**Mean (SD)**	**Total possible score per domain**
Negative domains		
Difficult behaviour	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

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',

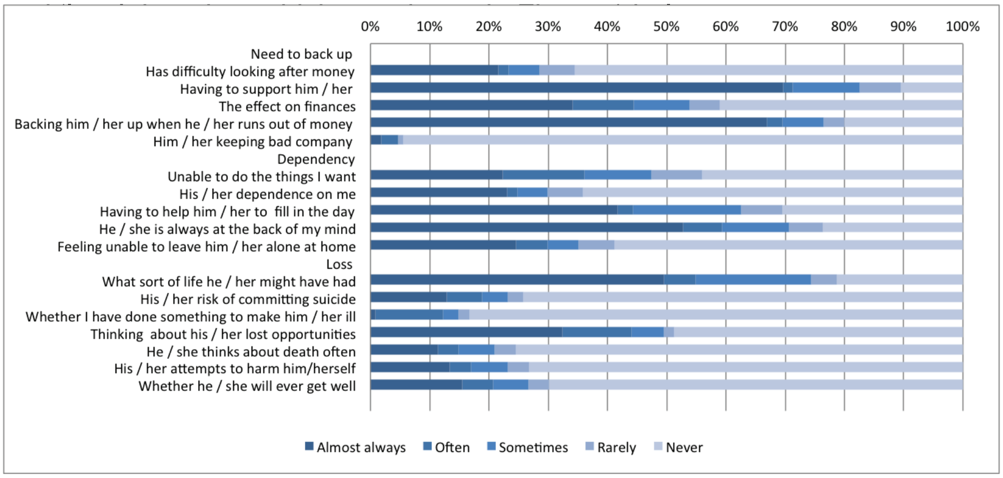


Figure 1: Experience of Caregiving Inventory (ECI) results per item in the domains of 'Need to back up', 'Dependency' and 'Loss'

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 (referred to as ‘relative’ below), aspects of burden, and at times high burden, were also undeniably present.

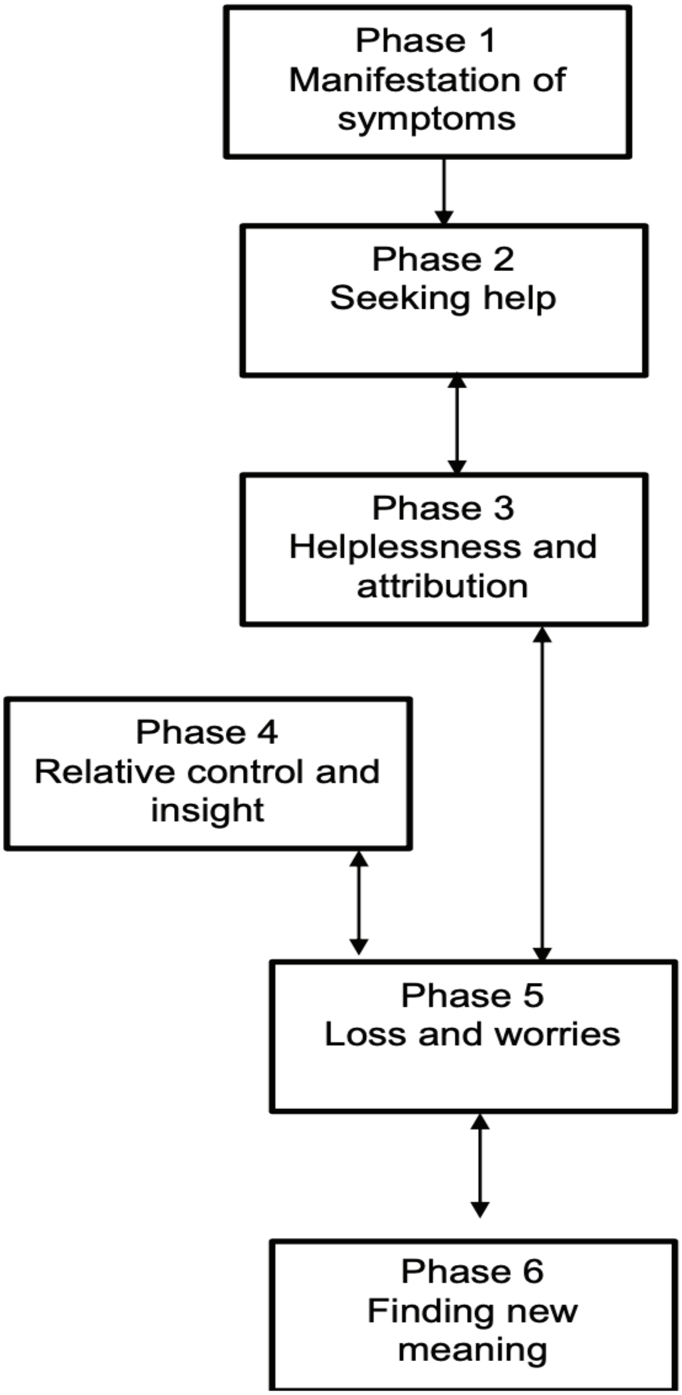
One reason for this discrepancy could be that the sample of the ECI consists of caregivers who regularly visited the health unit, and had done so for at least one year of caregiving. These conditions are expected to lead to most relatives being less symptomatic and caregivers more experienced in dealing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

Phases of caregiving

Based on the timeline interviews, the ECI and the FGDs, we constructed a multi-phase model of caregiver experiences, 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

Fig.2 The Banyan's phases model for caregivers



experience all phases and some phases may never be left behind.

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 Manifestation of symptoms	- Sleeplessness/agitation/ nervousness / mental disturbance - Helplessness / confusion - Fear - Sadness - Loneliness - Anger - Loss of honor in society	Phase 4 Relative control and insight	- Self-confidence / confidence about how to give medicines - Faith in medication - Less experience of stigma - Hope - Relief - Positivity
Phase 2 Seeking Help	- Anxiousness / depression/ mental disturbance - 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	Phase 5 Loss and worries	- Hollow feeling / anxiety / sleep disturbance / frustration / loss of peace/ depression / hopelessness / feel like giving up - Loss of relationships / loneliness - No freedom - Inferiority complex - Social fear/ losing honor in society - Suicidal - Worries about potential suicide of the relative

Phase 3 Helplessness and Attribution	- Depression / frustration / irritation - Anger about treatment not working - Guilt about not seeking help on time - Loneliness / inability to share experiences with others - Fear of chronicity of illness	Phase 6 Finding new meaning	- Self-confident/ feeling experienced and able to help others - Feeling pride and accomplishment - Seeking to help others and share knowledge - Become active in the community - Desire to gain new knowledge

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

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 behaviour is unknown. One caregiver described the initial two 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 dishonour, 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.

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, non-governmental 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 centres can require people to stay for extended periods of time.

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)
'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 loose 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.

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 wellbeing, the clinical decisions made by mental health professionals, and personal circumstances of the caregiver, all 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.

Phase 5: Loss and Worries

Even if caregivers experience relative control in phase four, 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 all 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, have children, pursue higher education, 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.

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. Firstly, 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)

Secondly, 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 behaviour, 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.

5.5 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 Experience of Caregiving Inventory (ECI) was earlier administered at a hospital in Chandigarh, India (Aggarwal, 2011). 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 and Tessler, 1987, Tuck 1997, Muhlbauer et al 2002, Milliken 2003) 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 (Saraceno

2007, Gopikumar 2015).

Other frameworks (Tuck et al 1997, Muhlbauer 2002, Rose 2002, Milliken et al 2003) 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 Tanarugsachock (2000) stressed the importance of distancing oneself from the relative with a 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 a mental illness.

The framework developed by Seloilwe (2006) 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 six.

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 Thara 2003). Secondly, 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 amongst caregivers (Chan 2011).

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.

Conclusion

As is clear from the literature, caring for a person with a 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 a 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 a 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.

5.6 Implications for nursing practice

Our multi-phase model can be utilized in nursing practice to understand the experiences of caregivers, and their needs and potential aspirations for the future at difference 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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CHAPTER 6

Loneliness, stigma, lost opportunities and caregiver growth: understanding experiences of caregivers of persons with mental illness in Tamil Nadu, India

6.1 Introduction

In India, caregivers of family members with mental illness provide invaluable and irreplaceable support for an estimated 90% of persons with mental illness (Thara 1994, Thara 2004). This dependence on the family for care and support is a result of both a lack of mental health services in India as well as close-knit and dependent family structures (Aggarwal 2011, Faqurudheen 2014). The absence or collapse of family support has been shown to lead to disastrous consequences such as homelessness and dire poverty (Gopikumar 2015), for persons with mental illness, especially in contexts where mental health services are inaccessible or non-existent.

India adopted a well-thought out and comprehensive mental health policy in 2014, which includes a mention of potential support structures for caregivers (Government of India 2014). In practice, the policies are not fully adopted or poorly implemented. India is a large country with enormous cultural, socio-economic, and rural-urban disparity in medical and social services and improvement in services across the country is expected to be a lengthy process. In the meantime, care for persons with mental illness falls upon family members, who lack necessary support structures since the needs of caregivers are often ignored or given scant attention in clinical practice (Jagannathan 2011). It is equally important to design the right kinds of structures for caregivers, in a culturally sensitive manner, taking into account the social relations and lived conditions that frame family life. In order to design appropriate support structures for caregivers, qualitative understanding of the lived experience of caregivers, both in terms of burden and personal growth, as well as their relationship, as it changes over time in the cultural context of Tamil Nadu is required. This is precisely the gap that this study tries to fill with a specific focus on one region of India, namely urban and rural areas in and around Chennai, Tamil Nadu.

6.2 Background

When faced with the reality of a family member with mental illness, caregivers experience both positive and negative changes in their life. The extent of the impact has been established in numerous studies, which have investigated the scale of burden in various domains (physical, social, financial, emotional) (e.g. Hsiao 2017, Joy 2017, Shah 2010, Chan 2011, Awad 2008) or have compared burden for different illnesses (Hastrup 2011, Nehra 2005). Others have widened the scope to understand potential gains to caregivers (Monyaluoe 2014, Aggarwal 2011, Chen 2004, Szmukler 1996). Theoretical models of caregiver experiences generally follow a stress paradigm, describing themes such as the changing relationship with the relative, requirements of time, money and emotional resources, interactions with mental health professionals, worry, loss and society's reaction to mental illness. The results of these studies point to demonstrable differences between high- and low-income countries. Studies in European and North-American settings identify issues such as lack of involvement of caregivers in the treatment process (Friedrich 2014, Chen 2004, van der Voort 2007), impact of deinstitutionalisation (Blanthorn-Hazell 2018, Awad 2008), high financial burden (Ignatova 2018, Perlick 2007), difficulties related to dealing with behaviour of the relative (Blanthorn-Hazell 2018, Perlick 2007, Magliano 2005) and emotional reactions of caregivers to the trajectory of mental illness of their relative (Dharmi 2017, Dunkle 2015, Karp 2000). On the other hand, within the significantly smaller body of work on caregiving in LMIC countries, the concerns focus on the involvement of other community members in care (den Hertog 2016, Monyaluoe 2014, Seloilwe 2006), families seeking out varying systems of treatment for the person with mental illness (religious, private and government) (Azman 2017, Faqurudheen 2014, Monyaluoe 2014, Jack-Ide 2013, Quinn 2010), religious coping strategies (Azman 2017 Chadda 2014), lack of locally available treatment (Chadda 2014, Jagannathan 2011), high levels of stigma and social exclusion (Jack-Ide 2013, Chang 2006, Thara

2003), and financial circumstances limiting access to mental health services for the affected person (Chen 2019, Addo 2018, Quinn 2010, Seloilwe 2006). The next section will look at India specifically and the special contextual factors related to family structures, stigma and aspects of caregiver growth.

6.3 Effects of caregiving on families in India

Negative effects of caregiving

Caregiver experiences are shaped by the cultural context, family structures and societal perceptions of mental illness. This section focuses on caregiving in the Indian context, and explores the special contextual and cultural factors that impact caregivers' lives.

Caregivers and stigma

In many parts of India, stigma related to mental illness is still a major concern, affecting persons with mental illness, as well as their family members. Courtesy stigma, as described by Goffman (1961, in Angermeyer 2003), also called affiliate stigma (Mak 2012), is an important aspect of caregiver burden. It refers to stigma experienced by someone who is associated with another person affected by stigma, such as someone with mental illness. Despite providing essential financial, physical and emotional support to their relatives, many family members report experiencing disapproval and devaluation by society (Lauber 2007, Thara 2003). The effects of stigma on caregivers however remains understudied in many LMIC countries, including India, and negative consequences for family members as a result of stigma have been less well understood (Tanaka 2018, Semrau 2015, Koschorke 2014, Loganathan 2008, Lauber 2007)

In India, mental health stigma is related to lack of awareness about mental illness, as well as various religious and magical explanatory models for the causes of mental illness, such as demon possession and black magic (Lahariya 2010, Padmavati 2005). The incidence, predictors and consequences of stigma include social ostracisation, loss of relationships and the inability to marry (Ergetie 2018, Wong 2018, Mishra 2012, Chan 2011, Macleod 2011, Chien 2004). The inability to marry can have severe consequences for a caregiver of a person with mental illness, particularly for for female caregivers. The expectation of marriage for women is high in India, with almost 95% of women marrying by age 35 (Yeung 2018). Arranged marriage, while on the decline, is still the most prevalent system of finding a spouse in India (Allendorf and Pandian 2016). Seeking a spouse for arranged marriages in India is based on considerations of the persons getting married as well as their family members. Caste endogamy is still highly prevalent (Allendorf and Pandian 2016) and class, education, income, health status and family structure of the future spouse are important considerations. In a Bangalore-based study conducted by Weiss et al (2001), it was found that individuals living with a person with mental illness in the family faced greater hurdles to be able to get married.

Positive effects of caregiving

Negative effects of caregiving have been the main focus of studies on caregiver experiences and are important to recognise as a crucial part of the caregiving experience. Meanwhile, positive effects of caregiving or growth as a result of caregiving are equally important to take into consideration. It was found that negative effects of traumatic experiences are a necessary aspect of posttraumatic growth and must occur before growth can take place (Shakespeare-Finch and Copping 2006).

The relation between caregiver burden, positive aspects and personal growth is conceptualised in several models, of which we will discuss a selection below.

One example of a model that includes the positive aspects of caregiving was developed by Szmukler (1996), namely the ‘experience of caregiving model’. This model goes beyond the commonly used ‘stress-burden-coping’ model, which focusses on negative aspects of caregiving and includes two areas of gains, namely ‘positive personal experiences’ and ‘good aspects of the relationship’.

Moving beyond the identification of positive experiences, theories of posttraumatic growth conceptualise domains of personal growth following a traumatic experience.

Posttraumatic growth

Posttraumatic growth (PTG) is defined as ‘positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events' (Calhoun & Tedeschi, 1999, p. 1 in Hallam 2014). Several studies show that the concept of posttraumatic growth is not only relevant for people experiencing traumatic events themselves, but also for caregivers (e.g. Hallam 2014, Cormio 2014, Thombre 2010, Cadell 2006).

Theories of posttraumatic growth are based on core assumptions about the self, general benevolence and the meaningfulness or predictability of events (Splevins 2010). When unexpected or unanticipated events disrupt life, one's worldview and anticipated life path may need to be revised (Triplett et al 2012).

Analysing posttraumatic growth in specific cultural contexts is highly important, since posttraumatic growth is intrinsically linked to the sense of 'self' of a person. In more collectivistic or interdependent societies such as India, the 'self' is generally more defined in relational terms linked to family members and others in society instead of considering the individual as the primary entity of consideration of growth (Splevins 2010). Behaviour in such societies is driven by the goal of upholding expected social norms as a means of maintaining social harmony (Splevins 2010). In this context, not reaching society's expected milestones and adjusting one's life path can be considered a life major disruption and a cause of great distress to the individual.
A majority of the literature on posttraumatic growth, however, is based in western and high-income settings, where growth is considered an individual process. For instance, a framework for posttraumatic growth, contextualized by Shakespeare-Finch and Copping (2006) for the Australian context, does not only comprise the concepts of 'compassion' and 'focus on life's positives', but also 'personal strength' and 'effortful reinvention of self'. In a more collectivistic society, like India, the self and personal growth may acquire a different meaning and urgency, which we will examine in this study.

Aims of the study

Considering the knowledge gaps related to the social and cultural aspects of the caregiver experience in India, we aim to investigate the lived experiences of caregivers of people with mental illness in a low-income setting, across the stages of their care journey, with particular focus on stigma, loneliness, lost opportunities and caregiver growth.

6.4 Methods

Study setting and population

The study was conducted among caregivers of people with mental illness in a rural and urban area of the South Indian state Tamil Nadu (TN). In social and economic terms, Tamil Nadu is often considered to be an outlier among states in India. It has a population of 72.15 million people, with a sex ratio of 996 females per 1000 males, which is well above the national average of 943 females per 1000 males (Government of India Census 2011). Tamil Nadu's literacy rate was 80.09% in 2011, which is higher than the national literacy rate of 74.04% and the poverty headcount ratio at 11.71% is lower than India's rate of 21.9% (National Sample Survey 2011-2012). While not at the same dramatic levels as certain states in North India, son preference and daughter aversion was observed in rural areas, due to drastically falling fertility rates and increased dowry demands over the previous decades (Pande et al 2012, Diamond-Smith et al 2008). In general, Tamil Nadu is a patriarchal society, which manifests in division of labour in the household and workforce, patrilocal practices, as well as domestic violence patterns (Chokkanathan 2012). Women in low-income households work mostly in informal jobs in agriculture, construction and home- or factory-based manufacturing (Government of India 2014, Keiko 2011). 34.82% of the workforce comprises of women in TN. Women make up 89.13% of the agricultural labour force, and 53.31% of the household industry labour force in rural areas (Government of India Census 2011).

According to the National Mental Health Survey of India 2015 – 2016 (NIMHANS 2016), Tamil Nadu has reported a higher suicide rate than the national average, namely 23.4 per 100,000 population versus 10.6 for India. Tamil Nadu also reported a high prevalence of mood disorders and depressive disorders (4.62%), compared to the national prevalence of 2.8% (NIMHANS 2016).

The District Mental Health Program (DMHP) is operational in 16 districts in Tamil Nadu, including Kanchipuram district, but excluding Thiruporur block. As has been reported in other parts of India, the DMHP is not consistently functional and provides psychiatric services in limited locations in districts

(Gupta 2018, Jacob 2017, Hanlon 2014, Jain & Jadhav 2009). Mental health services are available at the Kanchipuram and Chennai government hospitals, the Institute of Mental Health in Chennai and at private clinics. Despite relative proximity to Chennai, parts of Thiruporur block are remote and not serviced by public transport, thereby making access to healthcare facilities expensive and time-consuming.

Several mental health NGOs are operational in Chennai and Kanchipuram district, offering services ranging from clinical treatment and community awareness, to vocational training and advocacy. Limited long-term care facilities are available in Chennai and Kancheepuram district, but they charge high rates that are unaffordable for many of the families included in this study.

The caregivers who participated in this study make use of the free outpatient clinics provided by The Banyan, a non-governmental organisation (NGO). The aim of the organisation is to offer comprehensive care by a multi-disciplinary team, including medical treatment, emergency and long-term care, psychological services, employment and skills development, as well as facilitating access to social entitlements. The Banyan's free outpatient psychiatric clinics are located in various locations in Chennai and Thiruporur block, and in the Kanchipuram district in Tamil Nadu. The clinics treat people with psychiatric disorders, substance use disorders, intellectual disability and dementia. In 2018, 959 (402 male and 556 female) people accessed the rural clinics and 1323 (698 female and 625 male) accessed the urban clinics. All 29 participants in this study had been caregivers for at least two years and lived with the relative.

Study design

This study used a qualitative methodology, with semi-structured interviews, life history timelines and focus group discussions (FGDs) (Padgett 2012), in order to provide specific information that could provide an in-depth understanding of the lived experiences of caregivers in Tamil Nadu. In order to examine how caregivers give meaning to the experience of caregiving, the phenomenological perspective was used. In this perspective, human experiences are viewed as dynamic, complex, and continually moving (Gray 2018). The phenomenological perspective also provides opportunities to consider the cultural context as an influence on the human experience. This approach suited the aim of this study, which included understanding the cultural meaning of being a caregiver of a person with mental illness in a low-income family in India, and the changing nature, in both positive and negative terms, of caregiver experiences over time.

Semi-structured interviews were conducted with 29 caregivers who make use of the free clinics provided by The Banyan using an interview guide prepared by the researchers. Questions pertained to financial, social, emotional aspects of caregiver burden; stigma and social life; positive aspects of caregiving; relationship with the relative with mental illness; the trajectory of illness; requirements from the relative for care; help from other relatives or community members; treatment sought; long term care plans; support structures required. The guide was piloted with five interviews, after which the researchers discussed the interview guide and restructured questions that were misunderstood and added items for additional information. Most interviews were conducted at the participant's homes, with the exception of five conducted at a private place at The Banyan clinic.

Life history timelines for the period of the mental illness of the relative were prepared with the 29 participants. Caregivers were asked to indicate positive and difficult experiences and events during this time. Life history timelines have been shown to be an effective interview technique to help participants to remember past events (Adriansen 2012). The events in the timelines were then used as a starting point for additional questions about the experiences of the caregivers. Appreciative inquiry (Whitney 2019, Regeer 2009) was chosen as a result of ethical considerations related to the chosen methodology. The caregivers were given the chance to share both negative and positive experiences during the interviews and focus group discussions. This aim was not only to gain a multi-faceted understanding of the caregiver experience, but also to provide the caregivers an opportunity to share positive experiences and strength derived from their experiences, as opposed to singularly reliving distressing memories.

Based on the interviews and life history timelines, the authors developed a model of phases of caregiving, which is described elsewhere (Author et al. 2018) and in the data analysis section below. Following this, six focus group discussions (FGDs) were conducted with caregivers (n=21), mental health professionals and grassroots workers (n=39). The aim of the FGD was to verify the accuracy of the phases of caregiving and to understand the feelings and experiences of caregivers in each phase, since this was not included in the interviews.

Data collection

For the interviews and FGDs, purposive sampling (Gray 2018) was employed to select participants from caregivers making use of The Banyan's outpatient mental health clinics. Maximum variation sampling (Padgett 2012) was chosen to include four types of caregivers of people diagnosed with mental illness in the interviews, in order to gain a variety of perspectives: a) parents; b) adult children; c) spouses; and d) siblings. All relatives with a mental illness of the caregivers participating in the interviews were female. The aim of the first study phase was to understand the experiences of caregivers of women exclusively. After the development of the model of caregiver experiences, caregivers of men were included in the focus group discussions to elicit a broader perspective of caregiver experiences and to make the model applicable to caregivers of persons of both genders.

The interviews were conducted in the homes of participants, or at a private space at The Banyan clinic.

After conducting the interviews and the development of the model of caregiver experiences, six FGDs were conducted with caregivers of men and women diagnosed with mental illness making use of The Banyan's Urban Mental Health Programme (parents and spouses (n=12)) and Rural Mental Health Programme (siblings and adult children (n=8)), mental health professionals and NALAM[1] community workers from urban (n=10 and n=10) and rural areas (n=8 and n=12).

During the FGDs, the investigators explained the phases of caregiving model, following which participants created charts in small groups of two or three participants that detailed their feelings and experiences during each phase, which were then discussed in the larger group.

The first two authors, a social anthropologist and a clinical psychologist respectively, conducted the interviews and FGDs. In addition, a social worker

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[1] NALAM community workers are laypersons from the community who have received six months training in mental health care and social entitlement facilitation and employed by The Banyan to

address mental health in assigned villages around their residence.

employed at The Banyan conducted 12 interviews together with MD or AP. The first author (MD) is a social anthropologist, of Western origin and has lived in India since 2006. She has a basic understanding of Tamil. The second author (AP) is a clinical psychologist from South India and speaks Tamil fluently. The last two authors (JB and BR) are from the Netherlands and have spent extended periods of time in LMICs as researchers.

Data analysis

All interviews and FGDs were audio recorded and professionally transcribed, and if not in English, translated from Tamil to English. In addition, notes were taken during each interview and FGD. Inductive coding was employed by the first two authors and a codebook was developed using Dedoose software. After creating codes individually for five interviews, the authors compared codes and discussed the final codebook. Thematic analysis was conducted in order to identify common themes that caregivers indicated were most important in their experience (Gray, 2018). Relevant codes were then assigned to each theme after discussion between the authors, and the themes were examined in more detail to describe the most important aspects of each theme. Data saturation was discussed.

The charts prepared in the FGDs with feelings and experiences of caregivers in each phase were tabulated and items with the highest incidences were included in the description of the phases, in addition to identification of codes and quotes that corresponded with each phase. Frequently recurring themes that spanned various phases were identified from the data.

The results were analysed using a framework developed by the authors, named '*The Banyan's model of caregiving experience*' (Dijxhoorn et al. 2018), which emphasises the different phases caregivers experience over time. Six phases were identified as is shown in Figure 1 and described in table 3. Phases do not necessarily follow a linear succession. Moreover, not all caregivers experience all phases, and certain phases may never be left behind.

This model of caregiver experiences is a useful framework for analysing changes in experiences over time, as well as identifying common themes across phases. Whereas the purpose of the first study (Author et al 2018) was to construct and present a phased model of caregiving experiences, the purpose of this study is to gain in-depth insight in the lived experiences of caregivers, how experiences change over time, which themes are common across phases and how experiences relate to each other.

We will also use the posttraumatic growth framework developed by Shakespeare-Finch and Copping (2006) to examine whether and how the four domains identified in their model are described by caregivers in the Indian sample of this study and/or whether other areas of personal growth are relevant in the context of this study.

Figure 1 The Banyan's model of caregiving experiences (Dijkxhoorn et al 2018).

Ethical considerations

The Institutional Review Board of The Banyan approved the study before commencement (Approval number: EEC-2015-2). The purpose of the study was explained in writing or orally to participants in Tamil or English and written consent was obtained after the option of non-participation or refusal to answer certain questions was explained to the participants. If a participant was non-literate they gave their thumbprint and a witness signed. All data was anonymised during data analysis and the hardcopies of interview notes were stored in locked cupboards.

Table 1 Example of coding and thematic development process

Original text	Codes	Theme
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. In that case I feel constantly upset and depressed.	Life changes because of caregiving Psychological problems of the caregiver	Lost opportunities

Results

The characteristics of caregivers, mental health professionals and community workers who participated in the interviews and FGDs are recorded in tables 2 and 3.

Table 2 Characteristics of caregivers

	Interviews (n=29)	Focus Group Discussions (n=21)
Mean age caregiver	48.8 (SD=17.6)	52.4 (SD=13.5)
Mean age relative	46.1 (SD=11.8)	
Gender caregiver		
· Female	62.1%	61.9%
· Male	37.9%	38.1%
Gender relative		
· Female	100%	85.7%
· Male	0%	14.3%
Type of caregiver		
· Parent	27.6%	23.8%
· Spouse	20.7%	38.1%
· Sibling or sister/brother-in-law	27.6%	28.6%
· Adult child or son/daughter-in-law	24.1%	9.5%
Education caregiver		
· No education	10.3%	4.76%
· Up to 5 years	24.2%	9.52%
· Up to 8 years	20.7%	33.3%
· Up to 10 years	24.2%	42.9%
· Up to 12 years	0%	4.8%
· Higher education	20.7%	
· Unknown		4.8%
Marital status caregiver		
· Unmarried	17.2%	4.8%
· Married	48.3%	81.0%
· Widowed	27.6%	14.30%
· Divorced or Separated	6.9%	
· Unknown		
Mean duration of caregiving in years	14.2 (SD=9.49)	14.0 (SD=9.96)
Longest duration	40 years	39 years
Shortest duration	2 years	2 years

Table 3 Characteristics of mental health professionals and community workers

Participants Focus Group Discussions	**Mental health professionals and community workers (n=39)**
Location	
· Rural Mental Health Programme	19
· Urban Mental Health Programme	20
Occupation	
· Social Worker	4
· Psychologist	2
· Senior community worker	2
· NALAM worker	21
· Nurse	2
· Occupational therapist	1
· Vocational Trainer	2
· Health Care Worker	2
Mean years of experience	3.6 (SD=3.09)
Mean number of clients assisted	241 (SD=259.93)

All participants in the study are from low- or middle-income households (with monthly family incomes of INR 1500 (approximately USD 21) to INR 15,000 (approximately USD 210)[4]. The family income was self-reported and not independently verified.

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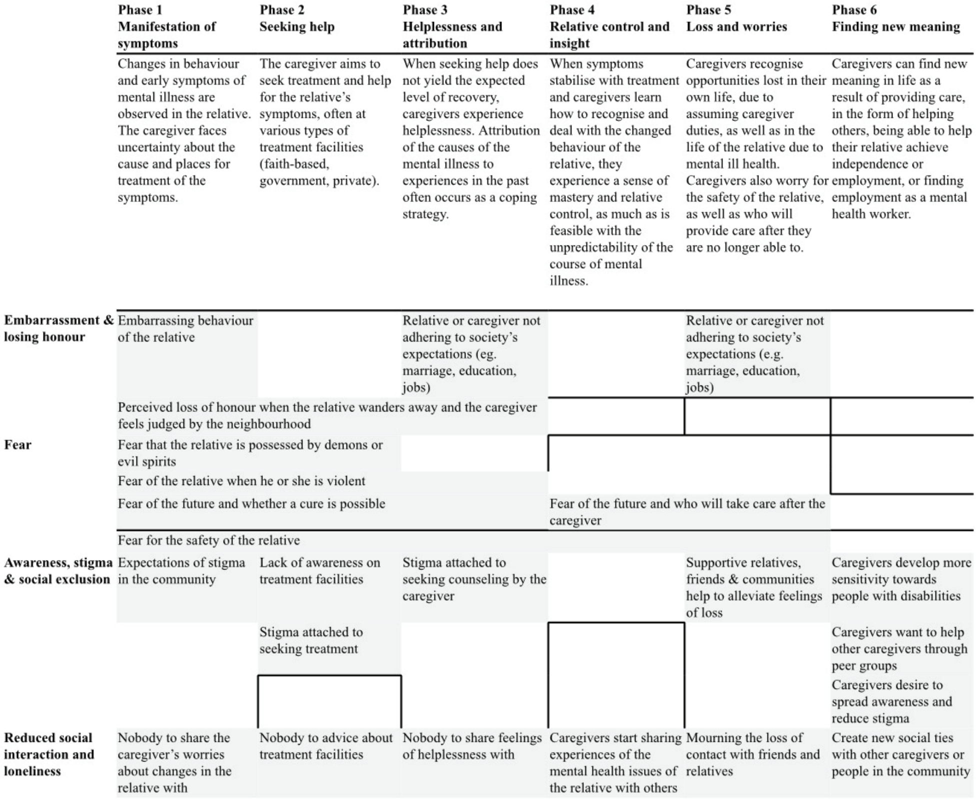
[4] Below Poverty Line certification is provided to households with incomes of INR 27,000 (INR 2250 per month) or less per annum (Source: Government of India – Ministry of Electronics and Information Technology. https://digitalindia.gov.in/content/below-poverty-line-certificate)

When analysing the experiences of caregivers, four themes were identified, namely embarrassment & losing honour; fear; awareness, stigma & social exclusion; and reduced social interaction & loneliness. The themes and manifestations in the different phases are shown in Table 4 and explained below. We describe how embarrassment, fear and stigma manifest in the daily life of caregivers, and how these issues lead to reduced social interaction.



	Phase 1 **Manifestation of symptoms**	**Phase 2** **Seeking help**	**Phase 3** **Helplessness and attribution**	**Phase 4** **Relative control and insight**	**Phase 5** **Loss and worries**	**Phase 6** **Finding new meaning**
	Changes in behaviour and early symptoms of mental illness are observed in the relative. The caregiver faces uncertainty about the cause and places for treatment of the symptoms.	The caregiver aims to seek treatment and help for the relative's symptoms, often at various types of treatment facilities (faith-based, government, private).	When seeking help does not yield the expected level of recovery, caregivers experience helplessness. Attribution of the causes of the mental illness to experiences in the past often occurs as a coping strategy.	When symptoms stabilise with treatment and caregivers learn how to recognise and deal with the changed behaviour of the relative, they experience a sense of mastery and relative control, as much as is feasible with the unpredictability of the course of mental illness.	Caregivers recognise opportunities lost in their own life, due to assuming caregiver duties, as well as in the life of the relative due to mental ill health. Caregivers also worry for the safety of the relative, as well as who will provide care after they are no longer able to.	Caregivers can find new meaning in life as a result of providing care, in the form of helping others, being able to help their relative achieve independence or employment, or finding employment as a mental health worker.
Embarrassment & losing honour	Embarrassing behaviour of the relative		Relative or caregiver not adhering to society's expectations (eg. marriage, education, jobs)		Relative or caregiver not adhering to society's expectations (e.g. marriage, education, jobs)	
	Perceived loss of honour when the relative wanders away and the caregiver feels judged by the neighbourhood					
Fear	Fear that the relative is possessed by demons or evil spirits					
	Fear of the relative when he or she is violent					
	Fear of the future and whether a cure is possible			Fear of the future and who will take care after the caregiver		
	Fear for the safety of the relative					
Awareness, stigma & social exclusion	Expectations of stigma in the community	Lack of awareness on treatment facilities	Stigma attached to seeking counseling by the caregiver		Supportive relatives, friends & communities help to alleviate feelings of loss	Caregivers develop more sensitivity towards people with disabilities
		Stigma attached to seeking treatment				Caregivers want to help other caregivers through peer groups Caregivers desire to spread awareness and reduce stigma
Reduced social interaction and loneliness	Nobody to share the caregiver's worries about changes in the relative with	Nobody to advice about treatment facilities	Nobody to share feelings of helplessness with	Caregivers start sharing experiences of the mental health issues of the relative with others	Mourning the loss of contact with friends and relatives	Create new social ties with other caregivers or people in the community

Table 4 Changes in themes over time in The Banyan model of caregiver experiences
(Please see the image above)

Embarrassment and losing honour

Caregivers expressed apprehension about losing honour (மரியாதை- *mariyathai* in Tamil) in phases one (manifestation of symptoms), two (seeking help) and five (loss and worries). In particular, certain public behaviour caused embarrassment, such as verbal abuse of the caregiver or others, shouting, or going outside naked.

> *'[S]he was asking everyone for money, which is very embarrassing. Sometimes when she gets angry, she verbally abuses and even beats us.'* (Sister, 50 years)
>
> *'It happened when we were travelling in the bus. She refused to sit in the seat, stood up the whole time. She also shouted at someone really badly. I felt embarrassed that time.'* (Son, 19 years)
>
> *'She used to dance, with her clothes in disarray. The house owner asked us to vacate the house, because if anything happens we might blame the house owner.'* (Husband, 57 years)

Loss of rented housing as a result of having a family member with mental illness was a common occurrence for many families, following complaints by neighbours or worries by house owners about their property. In extreme cases, families had to move multiple times every year.

In addition, when the relative did not attain normal social expectations, such as marriage, having children, employment, education, or if the caregiver's expectations for the relative are not met, the family perceived a loss of honour. Being married is an important social status, as it is considered necessary to fulfil one's social and religious duties ("*dharma*"). Therefore, the inability to marry as a result of mental illness can in itself be a form of stigma. The family as a whole can also experience loss of honour when siblings of the relative with a mental health issue become less eligible for arranged marriages, because of stigma, worries about the hereditary nature of mental illness and having to accept caregiving duties. Some caregivers shared that having a person with mental illness in the family was considered a sign that the family as a whole had bad luck (*thurathishtam* - துரதிர்ஷ்டம் in Tamil) or was surrounded by bad spirits (*ketta katru* - கெட்ட காற்று).

Wandering from home and getting lost or walking around the roads the whole day by the relative was also mentioned as a cause for loss of honour, because others in the community consider this a sign of inadequate care.

Honour was not just considered an individual issue by caregivers; actions of one family member affect others in the family too. Family members shared that the need to discipline the actions of the person with mental illness is not only in the interest of the individual, but is aimed at maintaining the honour of the whole family. Loss of honour has potentially devastating consequences, such as social isolation and loss of relationships, as is described later in the article, in addition to potential loss of housing.

Fear

Caregivers experience fear and worries in almost all phases, namely one (manifestation of symptoms), two (seeking help), three (helplessness and attribution), four (relative control and insight) and five (loss and worries). Caregivers expressed fear of the relative being possessed by demons or evil spirits in the first and second phase, since they did not know what caused the symptoms. Signs of mental illness are often attributed to demon possession and black magic in Tamil Nadu. Some caregivers mentioned that seeking medical treatment and observing improvement in the symptoms of the relative helped in reducing the fear of possession.

In the first phases (one, two and three), some caregivers shared being fearful of the relative when s/he is violent. In the initial stages, caregivers also experienced fear of the future and whether the relative would ever recover. Since they did not know what to expect about the course of treatment, or the final outcome, they feared the worst. The safety of the relative is a constant worry. Caregivers of female relatives worry about sexual assault when they are alone at home or out on their own.

> *'Safety is a major concern. We are scared to leave her alone anywhere, because she is a woman'* (Sister-in-law, 29 years old)

A mother shared her worries about her son who has seizures.

> *'My son once had a seizure on the street. People thought he was drunk, so nobody helped him. Once the seizure stopped, he was able*

> *to come home, but I was very scared, because he could have gotten injured.'* (Mother, 42 years)

In the later stages (four and five), caregivers experience fear of the future and uncertainty about who will take care of the relative when they are no longer able to. Caregivers often have no plan for who will take over in their absence, especially if there are no close relatives or if relatives have disengaged. Some caregivers expressed the hope that an NGO like The Banyan would take care of the relative and some left the future up to fate or God's will, without having concrete plans for an alternative arrangement. The options available are limited, due to lack of resources for paid facilities and scarcity or low quality of free long-term care facilities.

> *'After me, I don't know who will take care of my wife. My son and future daughter-in-law may not take care of her. Because we are not able to say how people will change in the future.'* (Husband, 70 years)

Awareness of mental illness in the community, stigma and social exclusion

Since awareness of mental health issues is generally low in Indian society, and there is a great stigma associated with having a relative with a mental health issue, caregivers often do not share their struggles with other family members.

A daughter shared her wish for community acceptance:

> *'If people understood that she is different than others, but they do not need to be scared or ignore her, life would be much easier for me'.* (Daughter, 32 years)

Family members also experienced courtesy stigma because of their family members. A husband describes the impact of his wife's illness on their son:

> *'My son is the most affected person. The people around keep talking to our son about our state and tell him that we are sinners and that's why we are being punished like this.'* (Husband, 56 years)

The nature of associate stigma ranged from exclusion from family celebrations, loss of relationships with family and friends, and branding the family of the person with mental illness as sinners.

Reduced social interaction and loneliness

Reduced social interaction, fear of social situations and loneliness were dominant themes for caregivers, also described by community workers and professionals. Loneliness can be a result of a breakdown in family relations or, more subtly, as a result of ceasing to receive invitations to family functions or no longer receiving visitors at home.

At times, caregivers exhibit signs of self-stigma by avoiding social gatherings.

> *'My relatives do invite me to celebrations. But if we go there, they might talk about mother, so I do not go to such programmes.'* (Son, 31 years)

In other cases, they miss social events because of caregiving duties, which could lead to loss of relationships.

> *'I explain to my friends about my wife's condition and tell them that she is psychologically affected and that is the reason I will not be able to come to the function, they understand. Even if I go to any function, I return early.'* (Husband, 57 years)

Almost all caregivers interviewed spend the entire day with the relative, except when going to work or on an occasional outing. In many cases, the relative preferred the caregiver to be at home at all times, and in some cases, there were concerns of seizures or potential problems with neighbours that prevented the caregiver from leaving the relative alone.

> *'I spend the entire day with her attending to all her needs. I cook for her, boil water for her bath. She goes on asking for food, which I make for her.'* (Mother, 55 years)

> *[I spend the whole day, 24 hours with her. I put a chair next to her and sit down.* (Daughter, 38 years)

The claim on the caregiver's time was related to the need of the caregiver to keep the relative happy and avoid violent outbursts or mental health relapses. While this may not be in the best interest of the relative, because independence is not fostered, caregivers felt it was necessary to keep the peace. In addition, caregivers, and in particular female caregivers, shared that it was their duty to do whatever necessary for their relative, even if that meant putting their own lives on hold.

Loneliness was also voiced in the context of receiving family support. In the first three phases, caregivers described how they felt lonely in the process of caregiving, finding treatment and dealing with recurrent crises. 'Nobody to help', 'nobody to guide', 'nobody understands the mental strain', were frequently used phrases. The feeling that they are solely responsible for finding successful treatment and the financial resources, without having information about mental illness or sources of support, caused them distress. Due to lack of awareness about the nature of and sources of treatment for mental illness among the general public, family members of caregivers are unable to provide support in this area, as are most community health personnel and village leaders. Similarly, peer support groups for caregivers are virtually non-existent in India.

However, not all caregivers voiced loneliness. Some did not lose relationships with family members or friends and said that their social life was not affected. In some cases, the relative with a mental illness was the only person in the family to face stigma.

> *'Everything is normal. We go to all functions and family members come home to visit. Sometimes she also comes with us.'* (Brother, 30 years)
>
> *'[W]e do go together. There she will sit talking to herself and I just tell the person sitting nearby that she is mentally ill and that they don't have to panic because of her behaviour.'* (Husband, 63 years)

Lost opportunities

In addition to the four themes identified above, we found that lost opportunities were a result of certain caregiver experiences. Lost opportunities took various forms for different kinds of caregiver. We will first describe the experiences of adult children, since their life trajectory seemed invariably affected. Reasons included interrupted education, having to take care of themselves from a young age, or because they had not been able to get married. In a country where arranged marriages are common, finding a spouse, in particular for female caregivers, was problematic because of various reasons. The first reason is the older age of the caregivers when they might initiate the search for a spouse, since they spent their earlier years providing care. Mid- or late 20s is considered an advanced age for marriage for women by many. After this, finding a spouse is not impossible, but poses more challenges. Secondly, having a relative with mental illness carries a stigma that affects all relatives. Lastly, in the patriarchal and patrilocal kin structures in Tamil Nadu and most other states in India, women are expected to live with the husband's family after marriage and prioritise the needs of the husband's family over her own. In this scenario, finding a spouse who takes full responsibility for his mother-in-law can be considered nearly impossible.

Adult daughters shared their feeling about their inability to marry:

> *'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. In that case I feel constantly upset and depressed.'* (Daughter, 26 years)
>
> *'I have got many proposals [for an arranged marriage], but I have told them that I will get married only if I can keep my mother with me. Another problem is that I am getting older and there is no need for me to get married. Now my thought is only about my mother and brother and I will lead my life by taking care of them.'* (Daughter, 38 years)

Disrupted education was another lost opportunity. Some adult children were forced to abandon the education of their own children because of financial difficulties:

> *‘Because we have a lot of debt for my mother’s medical expenses, my children could not study after 12th standard and they had to start working.’* (Daughter, 37 years).

> *‘Because of this, our sons had to change their school from private to government schools’.* (Sister, 30 years)

Others could not obtain the grades they desired, because of distractions at home. One daughter commented:

> *‘I was a very bright student. But in the public exam I did not score well, because my mother was unwell on the day of the exam. I couldn’t concentrate on the exam at all’.* (Daughter, 23 years)

Moving frequently, because of the mother’s illness, also affected the children’s education.

> *‘I always wanted to finish higher studies, but it never happened. My mother used to come to the school and create problems, because of which we had to move to a village from the city. I would like to finish my Master’s degree, but I do not have money now, because I need to take care of my mother’.* (Daughter, 25 years)

This inability to continue education and obtain well-paying jobs was a particular loss for sons, and daughters who were not married, since they were often the sole breadwinners for their family.

Many caregivers lost their jobs as a result of being a caregiver, either because their presence was required at home or as a result of taking time off to seek treatment. In other cases, the relative created embarrassing situations at the caregiver’s workplace. A mother explained:

> *‘I lost my job, because my daughter behaved badly when I was there’.* (Mother, 59 years)

Two husbands pondered on their change in life plans as a result of losing employment:

> *'Sometimes I feel bad, because I used to have a decent income and a good life. Now I have lost everything, because I have to take care of my wife'.* (Husband, 67 years)

> **'***I had plans in my life about what kind of work I wanted to do and how to live. I always wanted to buy a house. But when my wife fell sick, I had to constantly look after her and search for her when she wandered away. So I don't think I will be able to buy a house.'* (Husband, 57 years)

Caregiver growth

Even though caregivers most frequently described aspects of burden, and some caregivers reported no gains at all, positive aspects and perceived personal growth were also shared. We will describe these positive aspects in the framework by Shakespeare-Finch and Copping (2006), which consists of the domains personal strength, focus on life's positives, compassion and effortful reinvention of self.

Increased personal strength and confidence, as a result of providing care and facing difficulties in life was an aspect of growth often mentioned by caregivers:

> *'[Being a caregiver] has made me strong, because I had to overcome a lot of problems. I feel good when I think about what I was able to do for my family.'* (Daughter, 37 years)

> *'I have more patience now, and I am more thoughtful about the way I do things in life'*. (Sister, 36 years)

Caregivers focussed on positive aspects of caregiving by appreciating praise or being able to learn from mistakes made by their relative. Two daughters share their experiences below.

> ‘*We recently had a family celebration and many relatives praised me for the way I take care of my mother. They said she looked much better than before and that it is admirable that I am able to handle her. That made me very happy*.’ (Daughter, 38 years)

> *[My mother’s] life has been a big example for me, because I now know how not to lead my life. (….) She got severe depression, because my father betrayed her and spoiled her life. So I do not want to choose a wrong person like my father and I want the support of my family when I choose someone to marry.’ (Daughter, 26 years old)*

These aspects of perceived personal growth and strength linked to adverse experiences indicate the building of resilience among caregivers. Caregivers referred to resilience as a necessity to survive being the sole caregiver for their relative. Personal growth and resilience were positive side effects of an otherwise distressing situation.

Another positive aspect of growth was strengthening of the relationship between caregiver and relative. We observed that caregivers in this particular sample (who have continued caregiving responsibilities) also showed love, affection and a sense of responsibility as a constant drive for continuing. The main reason why most caregivers took care of and did not abandon the relative was because they felt love and affection for their relative. In addition, a strong sense of familial responsibility was observed, and caregivers considered providing care as natural and expected, instead of an extraordinary altruistic effort, despite the often great cost to their personal lives. Siblings and adult children emphasised that their parent had stressed the importance of being a caregiver to them over the years. Most spouses considered caregiving a normal consequence of being married and would have expected their spouse to do the same if the situation was reversed.

Caregivers also found that they had more compassion for and desire to help others in similar situations:

> ‘*When I see someone in a similar situation, I try to speak to them and tell them to get treatment as soon as possible.*’ (Brother, 51 years)

> ‘*While we are waiting at the clinic, I talk to new families and try to answer their questions. I like to help others, because we all had so many questions when we first came to the clinic.’* (Husband, 58 years old).

Reinvention of self was the domain that was least discussed by caregivers. During the interviews we found that many caregivers expressed difficulties with reflecting on how caregiving affected their sense of self and how they changed as an individual. Most caregivers in the study live in poverty and are struggling to survive and manage their daily lives. In those circumstances, expending efforts on personal growth and reinventing oneself were not priorities. In addition, many caregivers described changes in terms of the impact on the whole family, not on them as individuals.

Nevertheless, some caregivers were able to reinvent themselves and their careers by obtaining jobs in mental health, as nursing assistants or community outreach workers (see also Dijxhoorn et al.,2018).

‘I have learnt a lot about mental stability and psychiatric problems by observing my mother. Now I work as a nursing assistant with people with mental illness and it helped me that I had personal experience with mental illness’ (Daughter, 26 years old).

We found that, although caregiver experiences differ among individuals and families, we found common themes across phases. We also found that these themes are highly intertwined. Many of the experiences result in reduced social interaction and lost opportunities, both leading to experiences of loneliness (see Figure 2). Decreased social interaction was preceded by fear of social situations, social exclusion, stigma, time to be spent with the relative, embarrassment and losing honour, which in turn could lead to loneliness. Aspects of lost opportunities (inability to get married and loss of employment) were found to contribute to loneliness. Caregiver gains included more personal strength, compassion for others who experienced the same, focussing on life’s positives and reinvention of the self, which all resulted in a sense of meaning.

To conclude, we will reflect on the divergent experiences we observed in different types of caregivers.

Divergent caregiver experiences

The interviews and FGDs showed that the experience of being a caregiver broadly differed between parents, spouses, siblings and adult children. Selected categories are highlighted and explained below.

Elderly mothers who are widowed or divorced and whose daughter has mental health issues all shared being heavily burdened, both by their financial situation, hardships in life (widowed or abandoned by their husband) and by the strain of taking care of their daughter.

> *'Are you asking whether there is anything good in my life? There are no good things in my life. Not when I was married and not after my husband has passed away, every day is miserable for me.'* (Mother, 65 years)
>
> *'Nothing good has happened. I have faced all possible difficulties. My husband left me when my daughter was 23 days old. And now she is like this. (…) I got a lot of beatings from her earlier. Now she is better. (…) I will take care of her as long as I am alive. After that, it is God's will.'* (Mother, 59 years)

Siblings who are primary caregivers and live with the person with mental illness said they experienced low levels of stigma and isolation. They often did not experience loss of relationships, were not shunned from family functions and had the same social life as their peers or as before being a caregiver.

A mental health professional suggested a possible explanation:

> *'Siblings are busy with their own lives, especially when they are married and have children. They do take responsibility and care well for their sibling, but they do not spend as much time with them. When we ask about personal traits of a client, or their preferences, siblings are often unaware, which is not the case as much with other types of caregivers'*. (Social Worker, 26 years)

Caregiver burden was especially high in families with several persons with mental illness, where one family member often shouldered the care burden. Moreover, multiple family members with mental ill health added to financial burden because of treatment expenses, as well as loss of income from those affected. In addition, worries about the wellbeing of multiple ill family members caused high levels of distress among caregivers. A sibling who cares for three people with mental illness in her family shared:

> *'I have to take care of another sister and brother too. I am not so worried about one sister who lives with me, but I am always thinking about the other sister and brother. [T]hey insist on staying on their own. The brother wanders away from home often, and sleeps on the streets, so then we have to search for him.'* (Sister, 36 years)

Adult children caring for their mentally ill parent were mostly affected by lost opportunities in their lives, related to education, employment and marriage, as described above.

Discussion

This study adds to the existing empirical work on caregivers' experiences by considering the context of South India and how family structures and stigma influence caregivers' life experiences and decisions. In particular, we described the changing experiences of caregivers over time in a phase-based model.

Losing honour and embarrassment have been described in the context of mental illness as a factor of burden among caregivers. The relative's embarrassing behaviour has commonly been identified as a source of losing honour (Awad 2008, Chang 2006, Thara 2003). Caregivers in this study uniquely identified wandering, which caregivers perceived as causing gossip amongst neighbours about lack of care, as a source of embarrassment and losing honour, as well as the perception that the relative does not comply with social expectations of education, employment and marriage. A study by Thara and Srinivasan (1997) showed a marriage rate of 70% among persons with schizophrenia in Tamil Nadu over a 10-year period, which is high compared to studies conducted in western settings. Pinto (2011) described the fraught relationships between families and women with mental illness, and in particular scrutiny of families related to love and marriage. Both studies indicate the importance of marriage within families, as was conveyed by caregivers in this study; both related to attributing mental illness to marriage troubles, as well as considering of the unmarried status of their relative a failure. The high importance given to fulfilling societal expectations in some cases trumps the needs of the individual (Thara and Srinivasan 1997, Pinto 2011).

Courtesy stigma was observed to affect all family members across the world. Studies in China (Hsiao 2017), Sweden (Östman 2002) and a review of studies among caregivers of persons with bipolar disorder (van der Voort 2007) revealed the presence of courtesy stigma. Public stigma (Corrigan 2004) was experienced by caregivers in the form of difficulties in finding a spouse, branding the entire family as sinners, stigma in interpersonal interactions and disintegration of social connections (Angermeyer 2003). Aspects of public stigma often lead to reduced social interactions and loneliness. Studies on stigma conducted in India mostly focus on the effects on people with mental illness, instead of the stigma experienced by families (Koschorke 2014, Loganathan 2011, Loganathan 2008). We found that courtesy stigma affected families in various ways: lack of community awareness on mental illness and stigma related to cultural beliefs about causes of mental illness, such as black magic, demon possession and bad luck caused loss of relationships, due to the inability to participate in social events and cessation of visits by family members and friends. Some family members lost their employment as a result of stigma, which created great financial hardship.

Another aspect of stigma was a sense of loss of honour by families, since the relative with mental illness did not comply with societal expectation. We found that this stigma also reflected on other family members, either in their inability to find a partner for their relative, or inability of family members to marry themselves, because of courtesy stigma linked to having a relative with mental illness.

Since marriage is an important aspect of the expected life path of both men and women in India, the inability to marry caused great distress to caregivers, which has not been prominently described in studies in high-income countries.

Loneliness as a result of reduced social interactions was an important theme shared by the participants, which is consistent with other literature (Chan 2011). Reduced social support networks have been shown to increase the burden on caregivers (Brijnath 2014, Grandon 2008, Chan 2011, Chien 2007, Chen 2004). Unlike findings from studies in South Africa and Botswana (den Hertog 2016, Seloilwe 2006), which showed that family and community members often share care for a person with mental illness, caregivers in this study mostly lacked such support. This could be related to an increase in nuclear families and decline of extended family ties in India (Chadda 2013).

Studies in both high- and low-income settings show that female caregivers experience greater burden (e.g. Mathias 2018, Joy 2017, Brijnath 2014, Chan 2011, Hsiao 2010) than male caregivers. Elderly caregivers (>60 years old), and in particular mothers, were frequently identified as primary caregivers (Janardhana 2011, Awad 2008, Thara 2003). We found that female caregivers experienced high burden, either because they were elderly single mothers, as was found in Ethiopia (Shibre 2013), or because they were daughters of a mother with mental illness and they were unable to marry due to stigma and demands of caregiving. We did not find that stigma directly lead to lost opportunities (except when related to marriage) and instead were a result of the demands of caregiving and time and resources required to provide treatment and care for the relative with mental illness, which is similar to findings in North India among caregivers of people with dementia (Brijnath 2014).

As was observed in this study, siblings in other studies have been shown to be less emotionally involved in caregiving or long-term care provision, and experience lower levels of burden (Hsiao 2017, Zauszniewski 2014). Siblings expected to provide more social and emotional support, while parents expected to provide more practical support (Hatfield 2005).

The acceptance of the caregiver role by husbands in this study is not necessarily the norm. Abandonment or domestic abuse of wives upon the onset of mental illness is common across India, as is remarriage by men after women become homeless (Gopikumar 2015a).

Caregivers identified aspects of posttraumatic growth, which, as expected, in this setting focussed more on family relationships and needs of others then on the development of the individual. Accordingly, the theme of ‘compassion’, entailing an increased empathy for others in the same situation and the willingness to help them, was most prominent in the caregivers’ stories. In addition, earlier untapped ‘personal strength’ was developed as a result of the caregiver experience. Together with love for their relatives, ‘personal strength’ provided an important resource for perseverance and to carry out familial duties. In this context ‘personal strength’ did not lead to a process of ‘reinventing the self’, unlike findings in western settings. The fact that ‘effortful reinvention of self’ was least mentioned by caregivers, can also be explained by the larger focus on the needs of family members than focusing on investing time and energy in reinventing the individual (Bauer 2012, Shakespeare-Finch and Copping 2006, Chen 2004). The love shown by caregivers to their relative was similar to the findings of Brijnath (2014) among families of people with dementia in India, even though the participants in her study were from middle and upper class backgrounds.

The findings of this study warrant new avenues for further longitudinal research on caregivers’ experiences, in order to develop and test support structures that address the main issues they face (fear, stigma and loneliness) and to prevent lost opportunities as a result of caregiving. The extent to which new social relationships (e.g. in the context of helping others, or peer support structures) can contribute to a greater sense of meaning and counterbalance loneliness needs to be further investigated. Since the study was conducted with caregivers who have continued to provide care for their relative/s, understanding the lived experiences of caregivers who have stopped providing care would be informative, in order to understand how similar life experiences have led to different caregiving circumstances and in order to devise strategies to prevent negative consequences of lack of care by family members.

Limitations

While lack of access to mental health care is a major concern for large number of families of persons with mental illness, particularly in rural areas of India (Gupta 2018, Jacob 2017), this particular sample accesses services of the

NGO. Therefore, the experiences shared here exclude current issues with access to mental health care, even though they shared past struggles of finding appropriate treatment centers.

Conclusion

Providing care for a person with mental illness has the potential to alter the course of the caregiver's life drastically, including lost opportunities and reduced social interactions, resulting in loneliness. The consequences of these lost opportunities can be particularly profound for families living in poverty. Lack of awareness and stigma impact caregivers, and in particular female caregivers, in different ways, including loss of employment, housing, inability to marry. It is important to understand how these losses occur in daily interactions, and how the burden of caregiving changes over time. Nevertheless, the opportunity to help others, love and strong family ties have the potential to create positive experiences for caregivers and support structures can therefore be designed to strengthen these areas.

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Chapter 7

Reducing family burden: needs and strategies for responsive support structures for caregivers of persons with mental ill health in Chennai, India

7.1 Abstract

Family caregivers are still the primary source of support of people with mental illness in low-income countries such as India. However, without guidance and support, there is a risk of families becoming fatigued, and in no shape to provide the care their loved ones need. In the context of social-economic deprivation, social stigma regarding mental illness, the plurality of cultural and religious approaches, and a slowly developing mental health system in India, organizing support for families is urgently needed, but also complex. Appropriate timing of a range of sources of support to family caregivers is important, but too little is known about the needs of Indian families as they initially encounter, and then proceed to seek help for, dealing with mental illness in the family context. This study aims to explore when and how to support families in their process of understanding and taking care of mentally ill relatives, and what specific strategies might be employed throughout the caring process. The study was conducted in the context of a mental health organization in South India, The Banyan. In-depth interviews and focus group discussions (FGDs) were held with some 29 caregivers, and five senior mental health professionals (MHPs). The results depict the intricate experiences, ways of interacting, and need for support in the caretaking process of families, particularly in relation to earlier phases. Although the caretaking process is often chaotic, the results reveal a progressive line in the type of psycho-education and therapeutic support as families advance in their caretaking experience. The article concludes by

sharing strategies on how mental health-care systems can further improve family-based care in India.

7.2 Introduction

Family caregivers of relatives with mental illness provide invaluable support, especially in low- and middle-income countries (LMICs) where mental health professionals and inpatient mental health services are scarce or non-existent. In the Indian context, where the development of mental health system has been relatively poor (Srivastava, Chatterjee & Bhat, 2016), family caregivers are a given, but neglected, form of support. Ninety per cent of people with mental illness live with their family (Thara 1994, 2004), often due to the lack of alternative options for mental health users (MH users). The literature also shows that families in India commonly maintain a collective orientation to life, within which they can be relatively tolerant of persons with mental illnesses (Heitzman & Worden, 1995; Avasthi, Kate & Grover, 2013). Indeed, as described by Jiloha & Kukreti (2016), Indian families may '*regard their caregiving as a reflection of the cultural ethos of interdependency and reciprocity*'.

Still, the burden of family caregiving is often incredibly high, as well described by Chadda (2014); in their caring roles, families generally take on the full responsibility of responding to the day-to-day needs of their relatives with mental health issues, trying to understand patterns of early onset, relapse, and decline, and finding access to services, looking for employment options – sometimes to the extent of taking over their own lives. Studies in India find that the proportion of caregivers experiencing moderate to severe burden varies from 55% to 90%, while in some studies all caregivers express at least some degree of burden in giving care (e.g. Gautum & Nijhawan, 1984; Moily, Murthy & Nagarajaiah, 1997; Nehra, Chakrabarti, Kulhara, et al., 2006). Related to caregiving, the *objective* and the *subjective burden* can be distinguished (Hoenig & Hamilton, 1966). Objectively, or more directly, families experience the impact of caregiving in issues such as everyday practical problems, dealing with symptoms, greater domestic responsibilities, less leisure time, reduced social engagement and hobbies, etc. Few caregivers are able to sustain their job, social and/or leisure activities and make progress in life. Financial debts arise from the unemployment of the caregiver and due to the fact that they have huge debts as well as finding access to treatment for their family members (Chakrabarti, 2013). In India, there is also considerable social burden for families as there is little awareness of mental health issues while there is a high level of stigma (Kishore, 2011; Chowdhury, 2001; Thara, 2000).

In the context of families' objective and subjective burden, various studies have suggested that mental health professionals should be more sensitive and inclusive with regard to the social, cultural and spiritual context of the families that they aim to support (Basheer et al., 2015; Buhse, 2008). The mental health of caregivers is often not addressed as an integral component of mental health care in India (Chadda, 2014), despite the evidence that caregiving can impose an emotional burden, manifesting itself in the form of anger, irritability, depression, and ultimately lead to bad care provision (Steele, 2010; Awad, 2008; Lauber, 2003; Tsang, 2003). To complicate matters further, there is a lack of understanding of how support should ideally be provided to meet the specific needs of families, particularly as these needs (e.g. for knowledge, therapeutic help, socioeconomic or legal support), might vary from family to family, depending on where they are in the caregiving process. This study aims to look at the patterns of coping and adjustment in marginalized caregiving families in South India, and understand the various different types of support that can be provided to effectively help them.

7.3 Gaps in support structures for family caregivers in India

Family caregivers are members of any primary intimate group who take care of a person to whom they are directly related (either through blood or intention), mostly parents, spouses, adult children and siblings. Support for caregivers is a complex issue that requires exploration of both their needs and their strengths. Perceived strengths and positive experiences can give meaning to life and encourage caregivers to continue providing good care (Dijkxhoorn et al. 2018; Chadda, 2014). The combination of reduced family incomes and increased expenditure on care is obviously particularly stressful in LMICs, where so many households exist at or near subsistence level. Poverty can be a very severe and significant problem in addition to the absence of family support (Prince, 2004). In India, marginalized populations with mental health issues need financial assistance but there are limited welfare schemes for the caregivers of those with a chronic mental and physical health illness. There is a clear distinction between needs for individual agency and personal resources regarding the caregiving needs. Individual agency involves the level of control caregivers experience with regard to the situation. Caregivers would prefer to have an active role and be informed, rather than being spectators during a clinical consultation, which requires psycho-education and early counselling for the family (Kulhara et al., 2009). Jagannathan, Hamza, Thirthalli et al. (2010) found that Indian caregivers would prefer to understand the nature of illness, social stigma, and ways to manage the behaviour of their loved ones (including, for instance, symptoms related to hallucinations, excessive spending, decreased appetite, behavioural problems, poor concentration, inappropriate sexual behaviour, and the like). The impact of caregiving on one's personal (tangible and intangible) resources is crucial and requires social support, and also guidance about how, for example, to increase financial stability by using public support schemes, how to find work again, how to maintain and enrich the quality of life (e.g. through marriage), especially in the face of stigma and discrimination (Murthy, 2011; Jagannathan et al., 2010). The required resources are related to the phases of caregiving, i.e. the duration of caregiving as well as how the caregivers currently view their role and the impact of the illness on their everyday life. Still, in India, professional support for the such needs is rarely available (Chadda, 2014; Jagannathan et al., 2014).

7.3.1Relationship between caregivers and mental health professionals

The availability of mental health care and for the caregivers of those with mental illness is underdeveloped in India. Although family interventions commenced in the 1950s in India (Chadda, 2013), and more recent efforts have been made to understand how families' can be supported (e.g. through self-help groups and family intervention experiments), most of the pilot studies refer only to a few selective centres (e.g. NIMHANS) and too little has been implemented to an effective scale (Shankar & Rao, 2004). An additional problem is the quality of mental health care, as in India there is a range of different belief systems and approaches to psychological suffering. In this context of diversity, the interactions between caregivers and mental health professionals becomes problematic when professionals employ either a '*laissez-faire*' model, to avoid disagreement, or hold on too tightly to a one-dimensional (Western) explanation of health and neglect the potential power of embedding psychotherapy in the religious context of the patients and their caregivers. According to Murphy (2011), caregivers require dialogue and more exploration of their own needs so that mental health services can be adapted appropriately. There is often a lack of information about mental illness provided to caregivers and a failure to involve them in the treatment process. Globally, caregivers are unaware of what a diagnosis means, the scope for recovery, and the appropriate use and side-effects of medication (Seloilwe, 2006; Ohaeri, 2003; Lim, 2003; Karp, 2000). Similarly, caregivers are found to have little involvement in the treatment process (van der Voort, 2007; Rossler, 2006; Chen, 2004; Milliken, 2003). Caregivers have expressed the wish to participate in decision-making of the treatment process at the time of admission and being available during consultations (Chadda, 2014; Srinivasan & Thara, 2002; Nunley, 1998).

7.3.2Caregiving phases and needs for support

In the wider literature on caregiving it has been well documented that caring for a person with mental illness can give rise to varying degrees and types of burden and support needs, largely depending also on how far they are in the process of coping with their (new or more established) role as a caregiver (Hsiao, 2017; Joy, 2017; Lloyd, 2013; Chan, 2011; Steele, 2010; Awad, 2008; Nehra, 2005; Jungbauer, 2003). A model that explains this well is the ‘Timing it Right-model’, developed by Cameron and Gignac (2007), to understand the needs that arise over time in families taking care of stroke survivors. Although this model has not been employed directly to understand the (more complex) nature of caring for mentally ill relatives, it does a good job depicting the various stages of, for instance, intense concern, uncertainty, grief and slowly developing confidence, that families go through when progressing in their role as caregiver. It also sheds light on the importance of various types of support required to accommodate families in their caregiving journey (Cameron & Gignac, 2008).

It follows five stages:

1. Event/diagnosis (*requiring diagnosis, prognosis and someone to talk to*).
2. Stabilization (*requiring information on cause of event and current needs,*

someone to talk to, and some initial training).
3. Preparation (*information on available treatment and rehabilitation support, increased emotional support, training and appraisal*).
4. Implementation (*requiring information on everyday management, potential impact of caregiver's role*).
5. Adaptation (*supporting the family's interest in maintaining their own life, future planning activities, support groups for emotional support, training in continuing family integration, and appraisal*).

Although it is useful as it is based on a review of caregiver's needs, this model is limited in the sense that it focuses on caregiving specifically in relation to stroke, and is embedded in the socioeconomic and political context of a high-income, western country, very unlike that of low-income families in South India.

A study conducted in India by The Banyan (Dijkxhoorn et al., 2019) captures the various phases of caregiving that can be inferred from the experiences of Indian families. It was observed that most caregivers enter an intense process of grief as they first encounter mental illness in a family member (Table 1: phase 1), and realize they might be the only person able to help this person (potentially for a lifetime) (Abdollahour et al.,2010). This grieving process is similarly described in many other studies as an ongoing process (Ponder and Pomeroy, 1996; Liew, 2017)) but varying in intensity. The information- and help-seeking (phase 2) that follows involves the various ways in which families aim to understand and find help for the problem, and can cause much confusion and often various moments of disappointment. Subsequently, the burden of taking day-to-day care of a family member with mental problems and sometimes lack of progression or change (phase 3), can lead to fatigue and desperation in families. With the first signs of stabilization or even some improvement (phase 4), families might (re)experience a sense of control and greater insight. With the stabilization, however, families might also gain more time and space to live through a sense of loss connected to the illness (e.g. a job or sense of childhood) (phase 5). Finally, as caregivers continue to take care of their relatives, they may find different ways to give meaning to their role, and thus experience more positive emotions as well. The Banyan model thus emphasizes the positive and negative experiences of caregivers over time, but does not claim that the phases necessarily follow a linear model.

Indeed, not all caregivers experience every phase, and some might continue to stay in the same phase for a longer period of time for various reasons.

Table 1. The Banyan model of phases of caregiving (adapted from Dijkxhoorn et al., 2019)

Phase 1 Manifestation of symptoms	In the initial phase, changes in a relative's behaviour and early symptoms of mental illness are observed. The caregiver is uncertain about the cause and available treatment for the symptoms.
Phase 2 Seeking help	The caregiver aims to seek treatment and help for the relative's symptoms, often at various types of facilities (faith-based or psychiatric treatment at government and private facilities).
Phase 3 Helplessness and attribution	When seeking help does not yield the expected level of recovery, caregivers experience helplessness. Attributing the causes of the mental illness to past experiences is often a coping strategy.
Phase 4 Relative control and insight	When symptoms stabilize with treatment and caregivers learn how to recognize and deal with the relative's changed behaviour, they experience a sense of relative control, to the extent possible given the unpredictability of the course of mental illness. Caregivers also have more knowledge of and insight into mental illness and medication, which contributes to a sense of mastery.
Phase 5 Loss and Worries	Caregivers recognize their own lost opportunities due to assuming caregiver duties, as well as in the life of the relative due to mental ill health. Caregivers worry about the relative's safety, and about who will provide long-term care after they can no longer do so.
Phase 6 Finding new meaning	Caregivers can find new meaning in life as a result of being a caregiver, in the form of helping others, being able to help their relatives achieve independence or employment, or finding employment as a mental health worker themselves.

It is in relation to the caregiving phases as depicted by Dijkxhoorn et al. (2019), and in spirit of the ‘Timing-it-Right’ model, that this study aims to derive useful strategies and responses to the needs of family caregivers in India. The study hopes to understand (1) the strengths that are experienced by caregivers in their role; (2) the specific needs that come up in each phase of the caregiving process; and (3) how health professionals might best respond accordingly, in the context of low-economic status in South India.

7.4 Methods

This study was guided by the following research questions:

1. *What are the experienced strengths and most commonly practised coping strategies of Indian caregivers in the study context?*

2. *How can we understand the specific needs of caregivers in different phases of their caregiving process?*

3. *What support strategies exist, and are preferred in different stages of the caregiving process?*

The study was conducted among family caregivers and mental health care providers associated with a non-government organization (NGO) called The Banyan in the Indian State of Tamil Nadu. The Banyan was founded in 1993 and provides emergency, rehabilitation and long-term services for homeless persons with mental illness, as well as free community mental health clinics in urban and rural areas, mental health awareness, facilitation of social entitlements, peer-support groups, skills development, employment programmes and advocacy (Narasimhan et al., 2019). The Banyan employs mental health professionals (MHPs), as well as community-based *NALAM* (*Nalam* means wellbeing in Tamil) workers, who are community members who have received six months training in mental health care and facilitating access to social entitlements.

The study used a mixed methodology, in order to understand the need for support structures, as articulated by various stakeholders in mental health. Support structures here are considered sources provided by MHPs that could possibly benefit the caregiver. Both data-source triangulation (semi-structured interviews, survey and focus group discussions (FGDs)), as well as triangulation of participants in the study (caregivers, mental health professionals and community-based workers) were employed.

First, semi-structured interviews as well as historic time-line interviews (Carey, 1997), were conducted with 29 caregivers of women with mental health issues, using a guide developed by the researchers. We recruited 24 caregivers who attend the outpatient services of The Banyan, as well as five caregivers who are supported by government mental health services, in order to grasp the experiences of caregivers who access different types of services. Interviews were conducted in January and February 2015. Maximum variation purposive sampling was chosen for the semi-structured interviews and the FGDs, recruiting families who were in different phases of the caregiving process, in order to gain a deeper understanding of the development of needs in family members caring for a person with mental ill health (Padgett, 2012). Caregiver participants included spouses, siblings, adult children and parents.

Second, based on the findings from the qualitative interviews, the researchers developed a list of potentially beneficial support structures, which was then member checked by ten mental health professionals and community workers. One hundred and seventeen caregivers attending the free outpatient clinics of The Banyan in urban and rural areas were asked which support structures they most need. In addition to the list of support structures generated by researchers the list was shown to caregivers so that they could possibly add other support structures. The data were analysed using percentages. The survey was conducted from January to March 2016. Every second caregiver attending the clinic and meeting the criteria was requested to participate. If a caregiver refused, the next person on the attendance list was approached. Caregivers of relatives with an intellectual disability were excluded from the sample, and a minimum of one year as a caregiver was required. Two graduates in development studies and in social work administered the survey, after being trained by the first two researchers.

Subsequently, we aimed to understand the necessary support structures in the context of the phases model. To this end, nominal group interviews (Rice et al., 2018) were conducted with caregivers accessing the Urban Mental Health Programme (parents and spouses) (n=12), mental health professionals (n=8) and NALAM community workers from urban (n=10) and rural areas (n=12) to validate the phases model and to elicit the needs and required support structures for caregivers in each phase. Participants were asked to list support structures for each phase, in order to verify the most urgent needs at each stage. A second round of nominal group interviews was held with caregivers attending the Rural Mental Health Programme of The Banyan (siblings and adult children) (n=8); and mental health professionals (n=10) to verify the findings of the first round. The FGDs were held between September and November 2016.

Finally, in addition to interviews with caregivers, semi-structured interviews with five senior mental health professionals were conducted to understand the support structures offered by The Banyan in more detail, including successes and learning experiences (December 2016–January 2017). This was in order to understand the significance of support structures from the perspective of practitioners who have been part of the system offering services to caregivers.

All interviews and FGDs were transcribed from Tamil or English to English by a professional transcription service. The transcripts were read and coded by the first two authors. For the qualitative analysis thematic analysis was done using open coding (Gray, 2018) which was employed in order to identify recurring broad themes in the transcripts, followed by axial coding (ibid.) to identify more detailed patterns in the types of support structures needed. The data was analysed by two independent researchers to derive categories and themes, and discussed in various meetings before writing up the results. The quantitative data were analysed using SPSS 22.

Ethical considerations

The institutional review board of The Banyan approved the study (Approval Number EEC-2015-2). All participants signed translated consent forms after being informed about the content of the study. The voluntary nature of participation and the possible effects were explained in Tamil or English. If written consent could not be given because a participant was non-literate, oral consent was given in the presence of a witness, who signed, in addition to taking the participant's thumbprint.

7.5 Results

The study involved a number of caregivers and mental health professionals, whose demographic characteristics are presented in Tables 1 and 2.

Table 1. Caregivers' demographics

	Interviews (n=29)	**Support structures survey(n=117)**	**Focus Group Discussions (n=21)**
Mean age caregiver	48.8 (SD=17.6)	47.3 (SD=14)	52.4 (SD=13.52)
Mean age relative	46.1 (SD=11.8)	39.8 (SD=11.7)	45.3 (SD=12.01)
Sex of caregiver			
· Female	62.1%	57.3%	61.9%
· Male	37.9%	42.7%	33.3%
Sex of relative			
· Female	100%	65.8%	85.71%
· Male	0%	33.3%	14.29%
· Unknown		0.9%	
Type of caregiver			
· Parent	27.6%	35.9%	23.81%
· Spouse	20.7%	30.8%	38.10%
· Sibling or sister/ brother-in-law	27.6%	12%	28.57%
· Adult child or son/ daughter-in-law	24.1%	15.4%	9.52%
Education of 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%	33.33%
· Up to 10 years	24.2%	23.1%	42.86%
· Up to 12 years	0%	9.4%	4.76%
· Higher education	20.7%	17.1%	
· Unknown		12%	4.76%

Marital status of caregiver			
· Unmarried	17.2%	12%	4.76%
· Married	48.3%	62.4%	80.95%
· Widowed	27.6%	10.3%	14.29%
· Divorced or Separated	6.9%	4.3%	
· Unknown		11.1%	
Diagnosis	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	14.2 (SD=9.49)	8.3 (SD=6.5)	13.98 (SD=9.96)
Longest duration	40 years	32 years	39 years
Shortest duration	2 years	1 year	2 years

Table 2. Mental health professionals' and NALAM workers' demographics

	Focus group participants: Mental health professionals and community workers (n=39)	**Interview participants:** Mental health Professionals (n=5)
Location		
· Rural Mental Health Programme	19	2
· Urban Mental Health Programme	20	3
Occupation		
· Psychiatrist	4	1
· Social Worker	2	3
· Psychologist	2	1
·Senior community worker	21	1
· *NALAM* worker	2	
· Nurse	1	
· Occupational therapist	2	
Mean years of experience	3.6 (SD=3.09)	13.6 (SD=12.4)
Mean number of families assisted per participant	241 (SD=259.93)	2160 (SD=1681.7)

7.5.1 Caregivers' strengths

When considering caregivers' needs for support structures, it is important to approach the issue from a multi-dimensional perspective. In addition to understanding their burden, the caregivers' existing strengths should be considered, in order to design appropriate and helpful support structures. Therefore, before describing the support needs, this study looked into the strengths caregivers experienced in their role.

First, with regard to their subjective burden, an apparent strength was finding a way to give meaning in adopting the role of a caregiver. Caregivers find different ways of approaching their role, but the strongest asset here was their relationship with God. Spirituality and religious faith were the most frequently mentioned sources of strength, and sometimes the only source of emotional support available. As expressed by two caregivers:

> *'I am able to face all the troubles in my life, only because of the courage God has given me.'* (CG 9, daughter, aged 38)
>
> *'God will take care of us.'* (CG 18, brother, aged 51)

Caregivers also identified 'reflecting positively on their own character' as a source of strength, which they developed as a result of dealing with adverse circumstances in their own lives. Taking pride and confidence from their ability to take care of another person in complex situations helped them. Two caregivers explained this:

'Three people in my family are affected [by mental illness]. I had to manage and look after all three on my own without anyone's help. It was only possible because of my own self-confidence and courage.' (CG 1, mother, aged 58)

> *'My heart gives me courage and I console myself and try not to let the difficulty make me a coward. That is the reason I am still with her […]. I feel like I am the sole king of my life.'* (CG 7, husband, aged 70)

Further reflection on individual strengths, a number of participants stressed the role of social values instilled by their parents. Family-related values were carried out in action through caregiving responsibilities. This included being responsible to care for the person with a mental illness and express worry about long-term care options after the parents died. Again, knowing that caregiving makes you '*a good person'* helps caregivers continue to take on their role with greater responsibility:

> *'From childhood my dad taught me that no matter what comes in your life, you should […] always look after your mother to the best of your abilities. According to God's word, we will be happy only if we look after our parents and I believe in that strongly.'* (CG 10, daughter, aged 25)

> *'My parents always told us that we must support each other. So, I will always take care of my sister, no matter what happens.'* (CG 22, brother, aged 30)

Objective burden was countered by a variety of different and unique sources of support. Many caregivers experience economic hardship and have difficulties in making ends meet. Still, there were various ways family members were able to cope financially, e.g. through accessing a network of friends and extended family, finding access to small monthly allowances, managing to find a part-time job or even starting a small enterprise for their mentally ill relative. Stigma and coping with the illness-related behaviour was considered very difficult, but some caregivers found strength in meaningful relationships with sometimes just one friend or a family member. As one caregiver explains:

> *'My own family disowned me and my siblings wanted me to abandon my wife. As I did not do so, they cut off all family ties. My mother supported me for a year by taking care of my wife and having one parent to support me was of great help!'* (CG, husband, aged 70)

7.5.2. Needs as experienced by caregivers in each phase of the caregiving process

The personal resources and strengths experienced by caregivers notwithstanding, there were also various needs for external support structures. This study elaborates on the needs families experienced from the moment they encounter symptoms of mental illness in their relative towards a more advanced stage of the caregiving process. As mentioned earlier, the caregiving process is often messy and chaotic, and the needs of caregivers do not progress as neatly as delineated in the six phases of caregiving. Indeed, we see that certain questions or requests for support are maintained, while families also tend to regress from time to time in their development (e.g. finding acceptance but also continuing to grieve and/or falling back into denial). Still, we see that some needs are most vital at the beginning, while others become more important in later stages. This is clearly expressed in the stories of one family and their caregiving process, as depicted in Box 1, and reflected on by a mental health professional.

Box 1. Ms Sneha, aged 27

Sneha is a 27-year-old woman who was diagnosed with Psychosis Not Otherwise Specified (NOS) and Dull Normal Intelligence at the age of 17 years. In her family in Tamil Nadu there is a history of alcohol abuse (the father) as well as a highly critical attitude on the part of the mother and the older (experienced by Sneha as the 'preferred') sister. The family was a typical patriarchal household, which was later described by Sneha as '*a nightmare to live in'*. The family was concerned about her when she would leave the house occasionally to seek out physical intimacy from strangers. Over time, she started to show symptoms of severe mental health issues independent of the behavioural issues. Like many families in Tamil Nadu, Sneha's family first looked for consultation and healing from faith healers to *'make her normal again'*. This did not help, and Sneha started to wander away from home, until she was eventually brought to The Banyan. The Banyan's mental health-care team worked with Sneha intensively until her family expressed the wish to take her back home as they saw considerable improvement in her. She then went through multiple re-admissions, particularly as the family had great difficulty in accepting and understanding her behaviour, both as expressed by her illness and also because of the complex family dynamics. They would say: '*we didn't raise her to behave this way, please take her back'*. There was a great need to contextualize Sneha's behaviour, particularly her sexual promiscuity, which brought shame and harmed the family's reputation. There was a great need for psycho-education for the family, as well as positive reframing, emotional support and brainstorming ideas along with the family to deal with these issues. This increased the family's tolerance and acceptance. Currently, Sneha lives with the family and again it is going relatively well. At times, her distress is manifested through pseudo-symptoms in order to be re-admitted to the Emergency Care and Rehabilitation Centre (ECRC) of The Banyan, which is a safety net to protect herself from the hostility of her family and neighbourhood. Therefore, there are currently discussions about trying to get Sneha to talk about marriage, how to cope with this new relationship and her new role, understand the shift in roles and the consequences of getting into a long-term relationship, as she believes that marriage will bring her a great sense of social identity.

Reflection of a mental health professional (MHP)

With regard to Sneha's story, as well as many other such cases, the MHP explains that the aim of work based on principles of *positive psychology* is to stimulate acceptance and a sense of well-being in the present situation. The family initially felt it was easier to accept Sneha when she could be considered as having been punished by God, and looked for various ways to 'quickly fix' her (phases 1 and 2). When this did not work, the family felt hopeless and fatigued (often seen in phase 3). There was a great need for mental support, psycho-education and positive feedback on their caregiving abilities. The MHP said: '*When families are burnt out, they have difficulty to assimilate practical solutions immediately, they need somebody to actively and empathetically listen to them'.* Also hearing back from the MHP that Sneha was doing relatively well, and that the intensity of her symptoms had reduced, was helpful. There was also a need to understand Sneha's physiological needs and to perceive and understand these from a non-judgmental perspective. The Banyan repeatedly met the family to explain the difference between illness-related behaviour and behaviour that was secondary to her personality, complex family dynamics and human needs for intimacy. The sessions always ended with brainstorming strategies to reduce the objective burden, such as the possibility for marriage for Sneha. This case illustrated that discussions about marriage can be an important part of user-centred care packages in a mental health-care system, particularly in a country like India, where there are high social expectations tht women will marry.

According to MHPs, the needs of the family caregivers should not be perceived in isolation but as inherently related to what is needed to sustain and improve their caregiving. In other words, understanding and supporting the needs of family caregivers should eventually and ideally lead to enhanced caregiving and a more wholesome family experience. Implicit to this ideal the MHPs considered that several principles of caregiving were important, including '*helping caregivers understand and accept the behaviours of the patient as expressed both as an 'illness' (e.g. such as diabetes) but embedded in a context (e.g. of certain family dynamics)*, *encouraging the creation of a safe environment, stimulate autonomy and independence, sustain continuity of care as long as needed (including medical care), and understanding the bodily needs of clients*.'

According to the MHPs, caregivers often struggle to realize that their own role as well as the family culture can be a conducive or obstructive factor in the mental health status of their relative. Family members have often experienced pain and adversity in their own history, which influences how family dynamics develop. Therefore, family caregivers often need individual interventions and emotional support themselves. Personal behavioural patterns are difficult topics to discuss, but support cannot easily be provided without looking at the family as a whole. In fact, as one MHP says:

> *‘Clients and their families need psycho-education, but when it is done as it is usually executed, by giving information about statistics and symptoms, it is a waste of time. It only helps to look at what is happening in the family dynamics, and what they need to understand their situation in a helpful way. Sometimes this means you first need to conceptualize what is happening as a normal illness, before moving on to a diathesis-stress model where families can reflect on their own role. Especially when families are holding on to finding quick healing through faith healers, you first need to talk to them about alternative ways of looking at the situation and their role. It takes a lot of time and diligence’.*

Although each story is unique, we find some common features among families in their caregiving needs. These are depicted in Table 3.

Table 3. Caregivers' Support Needs

Phase of caregiving	Commonly found needs in caregivers
1. Manifestation of symptoms	- Finding a cause for the situation (often sought in religious context) - Needing more information about the illness and prospects of recovery
2. Seeking help	- Finding a 'quick fix' or way to heal the situation - Finding ways to give responsibility to an external institution - Finding socioeconomic support (e.g. to compensate for loss of income, parental role, etc.) - Receiving financial and medical support
3. Helplessness and attribution	- To be attended by listening and given emotional support - Positive feedback and reframing - Rejuvenating positivity - Finding more sustainable, explanatory models that match the situation of mental illness - Need to overcome '*learned personal and universal helplessness'*
4. Relative control and insight	- More insights into possible alternatives to solve small day-to-day problems - Finding ways to better live together in the current situation - Need to focus on themselves again, besides being a caregiver - Need to rebuild a life for themselves
5. Loss and worries	- Need to talk to others in a similar situation - Need to mourn lost childhoods, lost opportunities (such as education or career, married life) - Continued need for practical support such as economic and psychological
6. Finding meaning	- Need to share new insights with others - Need to find ways to continue care after the death of the primary caregiver

7.5.3. Suggested and currently practised support strategies by phase

To understand the support structures ideally provided to family caregivers at various stages, we first look again at the qualitative data to understand the complex combination of psychotherapeutic, medical, social, economic and legal support that is required to help caregivers in their role. The previous section shed light on caregivers' needs, and this section describes the strategies that mental health professionals use to meet these needs effectively, as well as what might still be missing. In the first two phases, MHPs agreed that it is important to provide psycho-education to families in a way that meets their needs. This is when information about symptoms of mental illness, availability of treatment centres and side-effects of medicines is shared. Similarly, plans are devised on how to obtain access to continuous care and counselling sessions. NALAM workers emphasize the need for psychosocial support (to complement faith healing, in cases where families also have recourse to it).

For people who were homeless, were admitted at the ECRC and are then prepared to return to their families, many adjustment issues arise. Both families and patients often require monthly counselling sessions, with the aim of optimizing reintegration. Issues addressed include stigma in the society and within the family (see Box 2). In such situations, MHPs need to offer a positive, patient and creative approach to maintain hope of recovery in the family. This is vital, as one MHP expressed:

> *'Family caregivers are an incredibly important stakeholder in the caregiving of patients. In the end, it is the most natural place for people to be. So, we will have to keep making that effort'.*

Box 2. Mrs R, aged 48

Mrs. R was diagnosed with paranoid schizophrenia and has many delusions about being married to a film celebrity. She was hospitalized at the ECRC of The Banyan and, when she was more stable, was reunited with her family. The reintegration was troublesome for a long time, because her mother and her brother were initially very resistant to her return. They were ashamed by her behaviour and perceived it as damaging their family's reputation. In addition, Mrs R refused to work, because she believed she was rich, which intensified the family's animosity towards her. The Banyan designed family interventions during monthly meetings and in phone conversations to help the family to better understand their daughter's symptoms. In order to show the family how well she was doing in The Banyan, where she was supported properly, the MHP showed them a video of her working at the ECRC. The video included positive testimonials by other patients and staff, which helped the family to feel less helpless and more positive about their ill family member.

The importance of counselling for families who are ready to take on more responsibility in caring for their mentally ill family member (often starting from phase 3,with acceptance of the illness, overcoming helplessness, and then increased control in phase 4), is also depicted in the story of another woman with mental illness and her family (see Box 3). Here again, the creative, patient and empathic approach required in counselling families shines through, as well as the ability to time various types of support appropriately. In the case described in Box 3, the mother was raised by very authoritarian parents, and was married to a man whom she disliked. She had a hard life, and was therefore very critical of her daughter. The MHP said about this: '*Softening' in attitude is very important, so that parents can move forward in a more positive manner'.*

Box 3. Mrs D, aged 55

Mrs D is the mother of Yazhini, who is 32. Yazhini was diagnosed with paranoid schizophrenia. Mrs D was open to having her daughter reunited with the family, but she was initially very resistant to understanding her own role in her daughter's recovery. She could not understand her daughter's slow progress and during counselling sessions accused her of procrastination. The mother referred to her daughter in negative terms, both during the sessions and to her daughter directly, which distressed Yazhini. During initial sessions, Mrs D. was very irritated with the MHP, saying: '*Who are you to give me advice? I curse you and your family!'* The MHP gauged that it was important for the mother to understand that her negative attitude could contribute to her daughter's slow progress, so she included role play in the sessions. The mother would play the daughter, and the MHP would take on the role of a mother. When the MHP played the role of a mother who is rejecting her daughter, Mrs D said: '*This mother should not exist. She should be more considerate!'* This provided an opportunity to reflect on her own patterns of communication. In later sessions, the MHP included Yazhini in the role-play sessions. During one session, she told her mother: *'But mummy, I only have you'*, after which the mother's attitude towards her daughter softened and their relationship improved.

The support structures currently in place at The Banyan are depicted in Table 3.

Table 3. Needs and strategies at each caregiving phase

Phase of caregiving	Commonly found needs in caregivers	Support structures offered by The Banyan
1. Manifestation of symptoms	- Finding a cause for the situation (often sought in religious context). - Psycho-education	-Empathetic listening - Unconditional attitude towards redundant complex problems within the socio-cultural context - Providing information about symptoms of mental illness, information, on the availability of other treatment choices and

Phase of caregiving	Commonly found needs in caregivers	Support structures offered by The Banyan
		centres, availability and side-effects of medicines - Stimulating and enhancing holistic understanding of the 'illness'
2. Seeking help	- Finding a 'quick fix' or way to heal the situation - Finding ways to give responsibility to an external institution - Finding social-economic support (e.g. to compensate for loss of income, parental role, etc.) - Receiving financial and medical support	- Being available whenever there is a crisis - Offer relevant skill-development training - Help making plans for continued (medical) care - Help in access to financial allowances for marginalized families - Create more awareness of potential stigmatizing practices of extended family and society and strategies to generate coping mechanisms - Formulate plans for continued psychosocial care - Helping families to reframe their expectations
3. Helplessness and attribution	- To be attended by listening and to be given emotional support - Positive feedback and reframing - Rejuvenating positivity - Finding more sustainable, explanatory models that match the situation of mental illness - Need to surpass '*learned personal and universal helplessness*[3]'	- Acknowledge their state of helplessness and understand the different styles of attribution - Reassurance and positive feedback on the competence of caregivers - Capacity-building sessions of caregivers - Intense dialoguing with caregivers to enhance their ability to face challenges

Phase of caregiving	Commonly found needs in caregivers	Support structures offered by The Banyan
4.Relative control and insight	- More insights into possible alternatives to solve small everyday problems - Finding ways to better live together in the current situation - Need to focus on themselves again, besides being a caregiver - Need to rebuild a life for themselves	- Assist the caregiver to enable the relative to improve skills of emotional regulation and decision-making - Share strategies to assist the relative in recovery (*MHP's discuss strategies with caregivers at clinics and during home visits*) - Brainstorm on strategies to relieve caregiver's burden (hobbies, time out, etc.) - Facilitate local peer groups
5.Loss and worries	- Need to talk to others in a similar situation - Need to mourn lost childhoods, lost opportunities (such as e.g. education or career, married life) - Continued need for practical support	- Facilitate local peer groups - Stimulate meaningful relationships between family members - Channel loss into a productive situation through skill-building or offering support to re-initiate lost opportunities such as employment, educational support etc. - Discussions with caregivers by community-based workers and mental health professionals on options for long-term care in their absence - Offer capacity-building sessions to caregivers towards self-efficacy
6.Finding meaning	- Need to share new insights with others - Need to find ways to continue care after one's own death	- Long-term care options - Facilitate local peer groups

Peer-support groups can be an important support structure for caregivers in the later stages (phases 4, 5 and 6). People in the later phases have a greater need to share their lessons with others, which can be met through peer groups.

Weekly discussions in peer-support groups include a range of topics, including sexuality in ill relatives, stigma, arranging extra funds, mourning loss, starting enterprises, etc.

7.5.4. Support as explained and emphasized by caregivers

Finally, the importance of particular support structures in general and as emphasized by caregivers was understood by analysing survey data (prioritization of support structures), and later on in the FGDs and interviews (particularly reflecting on the required strategies for each phase). The most prominent findings from mixed-methods analysis are described below.

1. Visiting places of worship and entertainment
Given that religion is an important source of strength for caregivers, being able to go to a place of worship can be a powerful support structure, as requested by 98.3% of caregivers. In phase 3, due to the state of helplessness, there was a need to vent by visiting religious places. Barriers to visiting a place of worship are financial constraints and being unable to leave the relative alone at home; 76.9% of caregivers indicated that a 'buddy system' would be helpful, as would organizing joint outings of peer-support groups. Similarly, requests for recreation for the caregiver and relative (70.9%) indicate the need for joyful activities, as well getting outside the home, often small and congested. In phase 5, the need for entertainment and recreation was expressed due to feeling house-bound.

2. Alternative arrangements for respite and long-term care
Many caregivers spend most of their time with the relative. In phases 4 and 5, caregivers expressed a need for temporary respite care, either with family members (58.1%) or at an institution (29.1%). In phase 5, caregivers raised long-term care in their absence ('who after me') as an important issue since affordable quality long-term care facilities are very scarce in India. Hence, assistance to plan for the future (financially and to identify those who can provide long-term support) (91.5%) or long-term care facilities for the relative (90.6%) were frequently requested.

3. Financial, employment and government assistance

Caregivers emphasized that free or affordable general health services for all members of the family (87.2%), financial support (87%), being a member of a micro-finance self-help group (76.1%), facilitation of government entitlements (68.6%), housing support (67%), access to loans with reasonable interest rates (65%), free products provided by the government (kitchen appliances, TV, groceries) (61.5%) and employment facilitation (for salaried jobs or self-employment, both for the relative (59.8%), and for the caregiver (60.7%) are important from the first phase onwards. Many caregivers preferred home-based work to salaried jobs or starting a business for the relative.

Financial strain on the family is experienced from the manifestation of illness onwards, due to the loss of employment of the relative or the caregiver, the need for the caregiver to spend time with the relative, and the cost of treatment. While most government services (and some non-profit services) are free, seeking treatment involves transport and medical costs as well as forgone wages. Going to faith-based healing centres is often very expensive and can require long periods of stay. In phases 3 to 6, financial support and employment facilitation continued to be important.

4. Peer and social support

Caregivers indicated the need for support structures that increase social interaction beyond family members, such as a peer-support group (69.2%), more visitors (65%), andn more home visits (53%) from representatives of the organization. A husband shared how social interaction helps:

> '*We get mental relief and peace when we come out of the house and speak to people.'* (CG 14, husband, aged 63)

Relatives were mentioned as useful sources of support, but some caregivers shared that they did not expect much financial or emotional help from them:

> *'Expecting help from relatives is foolishness. Some people might offer help financially but nobody will give the moral support that I need.'* (CG 10, daughter, aged 25)

> *'My relatives … taunted me for looking after my wife. [They said:] "What good is it for you to have a wife like her." They kept saying that, so I completely stopped seeing my relatives.'* (CG 4, husband, aged 57)

5. *Increasing awareness*

Community awareness about mental health issues was considered important in the early phases (1 and 2), in order to create an environment where there is no need for secrecy about mental illness, and stigma, social exclusion and abuse are reduced. In addition, caregivers seek to avoid the breakdown of meaningful relationships with friends and families, especially in phase 5. Helping others in the community (82.1%), being part of an advocacy group (82.1%) and peer support (69.2%) were identified as priorities. Generating awareness, helping others and being part of an advocacy group are deemed important mostly in phase 6, while peer support was requested in phases 4 to 6, when the volatility and uncertainty of the first three phases have stabilized.

6. Mental health education and information

Among caregivers, 51.3% indicated requiring more information about the nature and symptoms of mental illness. In the first three phases, caregivers primarily require information about mental illness, as well as about available treatment centres, medication and side-effects. In stages 4 and 6, caregivers need education about strategies to facilitate the relative's recovery (including employment and independence).

Given that caregivers were unable to seek help or information from relatives or community members, due to stigma and lack of awareness, they experienced loneliness, mostly in the first three phases. Caregivers expressed the need for informed local persons who could be consulted about the symptoms, and who could refer the family to a suitable place of treatment.

7. Treatment and care

Caregivers expressed the need to be treated with dignity while seeking treatment, as well as wishing to be involved in the treatment process. *'Being spoken to with love'* (அன்பான வார்த்தைகள் in Tamil) or '*be spoken to politely'* contribute to the perception of being treated with dignity. Reassuring caregivers during crises and stressing that mental health professionals and community workers are available for help, as well as appreciating and recognizing the caregivers' efforts, can help in ensuring that the caregivers' dignity is maintained. A husband shared how dignity influenced his experience:

> *'The services from The Banyan are very helpful. I don't know how to read and write, (…) and at The Banyan they clearly write the prescriptions and give us the medicines sorted out already. And unlike at the government hospital, they don't confuse us with which room to go to. They treat everyone with love and kindness, like relatives and friends.'* (CG 21, husband, aged 70)

8. Counselling and other mental health services for the caregiver
Among caregivers, 68.4% said that focused attention and therapeutic interventions to address their experiences and distress are required in all phases, and 72.6% also identified learning about breathing and relaxation techniques as a helpful strategy. Support is especially needed during the first two phases of the illness, when caregivers experience uncertainty, confusion, loneliness and denial. In the third phase, caregivers require assistance to deal with feelings of helplessness and with addressing the irrational attributions of the cause of mental illness, which may hinder acceptance. Similarly, in the fifth phase, caregivers are helped when their sense of loss is acknowledged and with strategies on how to deal with loss and regain hope. Lastly, addressing suicidal ideations in all phases is vital.

7.6 Discussion

While support structures for caregivers of people with mental illness are described in the literature (Akbari, 2018; Walke, 2018; Worall, 2018; Purba 2017; Bhandari, 2015; Jeon, 2005) this study adds to the current body of knowledge by recognizing the strengths of caregivers, their evolving needs and strategies for support structures in a low-income setting. We recognize the complexities and ambiguity of the burden on caregivers and the various aspects of life that are affected.

Caregivers' strengths were identified as being connected to religion and having a relationship with God; personal strength and character; and values of continued care for the person with mental illness instilled by the parents of the current caregivers. These strengths are also reflected in other studies (e.g. Pearce, 2005; Banjeree & Dixit, 2012; Mehrota & Sukumar, 2007; Walke, Chandresekaran & Mayya, 2018), but this study emphasized how these sources of strength played a distinct role in relieving the subjective burden of caregivers through the positive self-appraisal of their role. We would add to this that these sources of strength show up differently throughout the caregiving process. While in the first phase, spirituality is mainly sought as potential explanatory model for the mental illness of a family member (and so causes ambiguity and confusion when these explanations do not fit the concrete reality of the disease), during the third phase caregivers start to rely on their faith for strength to continue giving care. It is important for mental health professionals to be able to make such distinctions in order to know how to complement these strengths effectively, rather than negate them. While other studies (e.g. Grover et al., 2015), emphasize the need for clinicians to systematically assess and support the wide range of coping mechanisms caregivers employ, this study thus provides more insight into the variety of strengths used over time.

This study also brought to the fore the variety of needs that are experienced by caregivers as part of their trajectory of caregiving. While every family is unique, and the caregiving process is far from linear (see Dijkxhoorn et al., 2018), families generally feel a strong need to find a quick solution for the situation in the first and second phase. This is when mental health professionals should be present to provide psycho-education (when the caregiver is ready), listen emphatically, and slowly help the caregiver to reach more long-term understanding. While this is somewhat similar to the phases described in the 'timing it right' model by (Cameron et al., 2008), the specific context of mental illness in an Indian social-cultural context requires more sensitivity from clinicians to work with the explanatory models that are most comfortable for families. In the first stages, it is not advisable to employ a strictly psycho-medical model, which will alienate the family from the mental health system, but to be able to offer different frames as complementary. Other studies confirm the benefits of such integration, such as cultural acceptability, increased accessibility, less stigma, and better use of services by patients and their families (e.g. Gurejee, Nortje & Makanjuola et al., 2015).

This study furthermore found that the third stage of helplessness, though intuitively this phase seems most dysfunctional, is a good starting point for a better therapeutic relationship between caregivers and professionals. At this stage, there is a need for psychosocial support to the family, and strategies to relieve their subjective burden. The mental framework of families in the third stage is of universal helplessness (nothing works) or personal helplessness (I cannot make it work). It is at this stage that caregivers are more likely to abandon their role, either actively or passively (Contador et al., 2012). It was deemed important for mental health professionals to be receptive to the caregiver's need for listening, reassurance, positive appraisal, and perhaps more personal counselling to increase their well-being. In the third stage, there is little scope for practical solutions, which becomes more sensible when caregivers feel more confident again and have moved into the fourth or fifth stage. Again, while this is also described in the preparation phase of the 'timing it right' model (Cameron et al., 2007), the needs for psychosocial support were much more emphasized, and the strategies employed by The Banyan are more focused on increasing the caregivers' personal and subjective well-being. It is important to highlight here that a positive attitude is not reinforced by negating the pain or suffering of caregivers, but, on the contrary, by showing compassion and offering encouragement for what is still going well. As stated by Fernandez-Calvo, Castillo, Campos et al. (2016):*'the intention is to care for the caregiver by increasing his or her subjective wellbeing'.*

Finally, this article displays how mental health strategies can reinforce the more problem-solving and meaning-focused coping that become more actively accessible to caregivers in the last two stages, by giving more support to the positive beliefs and existential goals that motivate and sustain their role. This is the time where many practical support strategies can be offered to relieve caregivers of their objective burden, including help with obtaining financial support, employment, marriage consulting, etc. The role of mental health professionals from various disciplines in the Indian context is experienced as being more versatile. This is also described in van Ginneken et al. (2017), which addresses the multifaceted nature of mental health-care provision in

India and other LMICs. Within a country as complex as India, it is unlikely that more specific roles for mental health workers will work at present, and there are various studies that emphasize the need to expand the roles of both professional and lay-workers to work effectively in the face of limited resources (e.g. Kohrt et al., 2018; GOI, 2014).

However, besides relying on creative and versatile mental health workers, caregivers also benefit from being part of peer-support groups (particularly in the last few stages), which other studies have found improved relationships between family members and the mental ill relative (Worrall et al., 2018; Brister, 2012; Chien, 2009; Heller, 1997). Despite the known benefits, peer-support initiatives are scarce in India (Hanlon, 2014) and not an integral element of care provision. Strategies found useful in this study for peer-support groups include organizing local meetings, which are facilitated by community workers and caregivers themselves, discussing employment opportunities and having the chance to share problems.

Limitations and suggestions for further research

This study was conducted with caregivers who already receive psychiatric treatment and other support at The Banyan's free clinics. Hence, the support structures identified often exclude basic requirements of psychiatric treatment and the results may not be generalized to populations who have no access to any services, or who have ceased to provide care for their relative. Possible further research includes evaluating the reduction of the burden on caregivers through the suggested support structures, such as local peer-support groups and facilitation of social entitlements, as well as developing and evaluating an assessment tool for caregivers' needs in the phases framework.

Conclusion

The needs of caregivers of those with mental illness are often not recognized or addressed in low-income settings, due to the lack of human and financial resources. At the same time, particularly in such settings, people with mental illness depend heavily on their family members (caregivers). It is suggested that support structures should reflect these needs by addressing various domains of caregiving (financial, social, psychological, spiritual and related to long-term care), as well as considering the phases of caregiving experienced at the time and offering support from the first phase onwards. In addition, designing support structures in order to build upon the strengths and positive experiences of caregivers and strengthen family support is vital in a low-income setting. Locally trained community-based lay-workers could facilitate this support, in addition to that provided by mental health professionals.

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[1] Chadda (2013) explains that *‘the belief in the supernatural causation, the curse of God or evil spirits, is even more predominant in mental illness as compared to physical illness’*, and ‘*leads them first to temples and religious leade*

Chapter 8

Supported Housing as a recovery option for long-stay patients with severe mental illness in a psychiatric hospital in South India: learning from an innovative de-hospitalization process

Abstract

Individuals with severe mental illness have long been segregated from living in communities and participating in socio- cultural life. In recent years, owing to progressive legislations and declarations (in India and globally), there has been a growing movement towards promoting social inclusion and community participation, with emphasis on the need to develop alternative and inclusive care paradigms for persons with severe mental illness. However, transitions from inpatient care to community settings is a complex process involving implications at multiple levels involving diverse stakeholders such as mental health service users, care providers, local communities and policy makers. This article studies how the transition from a hospital setting to a community-based recovery model for personals with severe mental illness can be facilitated. It reflects on the innovative process of creating a Supported Housing model in South India, where 11 MH Service users transitioned from a psychiatric ECRC to independent living facilities. Experiences in various phases of the project development, including care provider- and community level responses and feedback were scrutinised to understand the strategies that were employed in enabling the transition. Qualitative methods (including in-depth interviews and naturalistic observations) were used with residents and staff members to explore the challenges they encountered in stabilizing the model, as well as the psychosocial benefits experienced by residents in the last phase. These were complemented with a WHO Quality of Life scale to compare baseline and post-assessment results. Results display the challenges encountered in the current context, and strategies that were used to respond and adapt the model to address these concerns effectively. Positive behavioural and psycho-emotional changes were observed amongst the residents, significant amongst those being enhanced in their mobility and participation. The article concludes by discussing the implications of this study for the development of innovative community-based models in wider contexts.

Introduction

For many years, individuals with severe mental illness (SMI) were excluded from the community and confined in institutions. This isolation happened for various reasons, including, for example, '*a) the general attitude of the public about people with mental illness, b) a belief that the mentally ill could only be helped in such settings, and c) a lack of resources at the community level*' (Patrick et al., 2006). With time, the institutional approach of segregation was much criticized during the 1950s and 1960s (Chow & Priebe, 2013). Institutions were criticized for functioning like warehouses, in which SMI were kept for long periods of time with no expectation of improvement or reintegration into the family and/or community (Kliewer, Melissa & Trippany, 2009).

In India, mental hospitals were introduced by the British as part of the psychiatric system, and as a way to purposely *'segregate the mentally ill from the community and not treat them as normal but rather detention away from the community'* (Daund, Sonavane, Shrivastava, Desousa & Kumawat, 2018). Mentally ill people were considered dangerous and were kept away from society (Sharma, 2006). In the 1970s, encouraged by the wave of de-institutionalization that had started in the West, development of psychiatric drugs, economic stagnation, lack of resources and gross understaffing problems, de-institutionalization took off in India, resulting in the decline of large psychiatric hospitals (Daund et al., 2018). The process of de-institutionalization, defined as '…*the practice of caring for individuals in the community rather than in an* *institutional environment*' (Shen & Snowden, 2014), gave rise to more interest in community-based mental health care (CBMHC) for people with severe mental illness, as well as a widespread urgency to develop alternative models (Chow & Priebe, 2013). A new Mental Health Act in 1987 paid more attention to treatment and care, and mental hospitals were encouraged to function as active therapeutic centres, providing mental health services and community mental health.

The main argument advanced for this shift was that access to health care for people with longer-term mental disorders is much better addressed in community-based services than in the traditional psychiatric hospitals (Thornicroft & Tansella, 2003). It would also be easier to promote the continuity of care and flexibility of services, making it possible to identify and provide timely treatment for relapses, and to increase adherence to treatment (Thornicroft & Tansella, 2003; Killaspy, 2007). The community-based services, when well embedded in professional mental health care, are also found to better protect human rights of people with mental disorders and prevent stigmatization (Thornicroft & Tansella, 2003). Studies comparing community-based services with other models of care consistently also show significant better outcomes regarding adherence to treatment, clinical symptoms, quality of life, housing stability, and vocational rehabilitation (Braun, 1981; Conway, Melzer, Shepherd & Anglia, 1994; Bond, Drake & M).

Even so, with the positive outcomes of CBMHC models, there has been greater recognition of the need to approach innovative strategies from a broader cultural and institutional perspective, particularly taking into account the organizational and strategic processes that play a role in implementation of CBMHC models in India and in other low- and middle-income countries (LICs and MICs), and adopting various ways to dynamically implement and adapt to contextual factors in moving towards well-grounded community-based support user.

Community-based health models and supported housing (SH) in India

The state mental health system is the formal source of mental health care in India. However, due to poor resources and allocation of services, it is lacking in many ways (Patel, 2007; Shields, Molloy & Smyth, 2013). Less than 1 per cent of health expenditure is devoted to mental health care, in common with many LICs and MICs . As many mental hospitals still have large numbers of long-stay patients, leading to diminished recovery and reduced quality of life, community-based alternatives in mental health care are persistently advocated (Shields et al., 2013; Harcourt, 2011).

In India, CBMHC commonly focuses on reintegrating persons with SMI into their family. Such an approach, however, denies support to a large population who have been abandoned by their family or, for many reasons, cannot return (Goel, Agarwal, Ichhpujani & Shrivastava, 2004). As there is a vicious cycle between mental illness, poverty, homelessness and stigma (Johnson & Chamberlain, 2011; Malhotra & Shah, 2015; Gilmoor, Adithy & Regeer, 2019), many people remain excluded from long-term community care (see Figure 1). In most cases, homeless people are referred to homeless shelters or incarcerated in homes for beggars. Similarly, the commonly held belief that Indian culture is collectivist and therefore ready to support each other in distress is often not the case when stigma is involved (van Ginneken et.al., 2017).

Women are particularly vulnerable to being abandoned by their marital family, as '…*homelessness, vulnerability to sexual abuse and exposure to HIV and other infections contribute to the difficulties of rehabilitating women*' (van Ginneken et.al., 2017). It is essential to understand the challenges involved when there is no concept of 'home' to such a large population. Few existing programmes support those who have lost their home and therefore their identity in a community setting (Lipton, Siegel, Hannigan, Samuels & Baker, 2000; Goel et al., 2004; Pleace & Wallace, 2011). Similarly, CBMHC will need to be broadened to provide person-centred services for people with diverse experiences and histories of, for instance, homelessness, stigmatization, or gender-based violence (GBV), and so on (Padgett, Stanhope, Henwood & Stefancic, 2011).

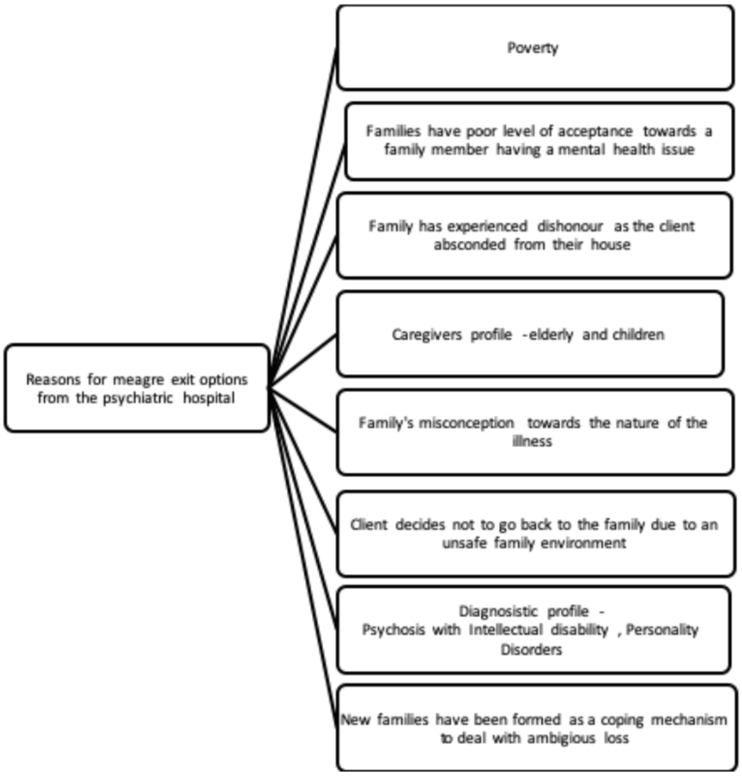

Fig 1. List of reasons for prolonged stay at Psychiatric Hospitals

It is in this context that supported housing (SH) emerged as an alternative that could meet the needs of SMI in order to better focus on functional impairment, social relationships, daily living skills and to promote recovery and self-reliance (Culhane, Metraux & Hadley, 2002). Supported housing provides structured, non-institutional, and independent living arrangements along with supportive services aimed at providing medical attention, rehabilitation and the attainment of life skills (Padgett, Gulcur & Tsemberis, 2006; Pearson, Montgomery & Locke, 2009). These projects enable people to lead a normal and somewhat independent life, with support, ultimately aimed at rehabilitation and social reintegration (Padgett et al., 2006). Supported housing projects are user-centred, and place a strong emphasis on the residents' independence, freedom of choice, independent life skills, individualized services, and ultimately community integration (Thornicroft, Deb & Henderson, 2016;

Narasimhan, Gopikumar, Jayakumar, Bunders & Regeer, 2019). Several studies have shown that homeless people with mental disorders who take part in a supported housing initiative show greater housing stability, make less use of shelters, are less often admitted and stay for less time in hospital, are less often imprisoned, and less substance abuse (de Wildt-Liesveld, Bunders & Regeer, 2015; Narasimhan et al., 2019). Since this model is not often described in the context of India, this study aims to understand how moving towards SH may support people with severe SMI. More specifically, it hopes both to shed light on how SH functions in a specific context in India, and also how to develop the concept of SH in a sustainable, sensible matter in the broader context of de-hospitalization.

The Banyan's Supported Housing Model

The Banyan is an organization that provides comprehensive mental health services in institutional and community settings for people experiencing poverty and homelessness (for a full description of the evolution of The Banyan, see Nowotny, Scott & Gibbons, 2013). Starting in 1993 with a crisis intervention and rehabilitation centre for homeless women with mental illness in the city of Chennai, The Banyan has grown to provide wellbeing-oriented mental health services, including emergency, open shelter and street-based services, long-term and alternative living options, and social care. Some 20 years ago, The Banyan also began to focus on catering to people as part of the community, shifting from long-standing institutional care to a model of community-based care. Since 1993, The Banyan has supported 1,691 homeless women with mental illness: 1,065 have been reunited with their family or community of origin; and 80 women access SH through a housing-style open facility in the community. Almost 2,500 have attended community clinics and associated social care services (such as livelihood and welfare facilitation in rural areas and towns).

The Banyan has explored housing options at different stages in its trajectory as a response to the complexities in mental health services. It started its first housing options for homeless women in 2003, intended exclusively for women who were completely functional and recovered. In 2007, long-term residents were moved to a quasi-institutional living arrangement situated at a Banyan facility. Independent living in the rural location was initiated in 2008 and was conceptually similar to the urban project. In hindsight, a systemic change can be observed in how after-care was organized for patients with chronic needs. Though institutional care has a range of services and support systems catered for in a user-centred environment, there was a strong need to understand and accelerate the slow progress of residents where negligible or no qualitative gains were seen in terms of personal recovery, and/or progress in participation. Accordingly, The Banyan undertook a pilot study with a supported housing facility near the Emergency Care and Recovery Centre (ECRC), where residents were selected and moved to live together with health care workers (HCWs) (see Figure 2).

Fig 2. History of The Banyan working towards Supported Housing

Study objective: learning from niche experiments

To our knowledge, little has been written on how to move from an undesirable situation (e.g. prolonged hospitalization of chronically ill patients) to a community-embedded care model in India. Indeed, as described by Thornicroft et al (2016) and Lewin (1996) on CBMHC, the transition of people from long-stay wards to community-based care (particularly in LICs and MICs) often faces various challenges and obstacles, such as stigma and discrimination both in society and by primary health staff, old or inappropriate programmes and legislation, inadequate alignment between the intended services and outcomes, feasibility problems, poor uptake by various (non-) professional stakeholders and potential collaborations, high staff turnover and/or burnout, etc. In order to create models that foster sustainable community care (and deal with the complexities involved), there is a need to learn from pilot studies or *niche experiments* (Kotter, 1996) in which new approaches to embed patients in a community setting are developed, practised and reflected upon. This study aims to contribute to filling this gap in socially robust knowledge (Brown et al., 2014) by describing the development of an SH project in India in the context of The Banyan's practice.

To understand how transitional processes work, and what can be learned from them, several models have been proposed in the field of change management, including Lewin's change model (Lewin, 1996), Kotter's theory of change (Kotter, 1996), as well as more recent ones such as the Stages of Implementation Completion (SIC) model developed by Brown, Chamberlain & Saldana (Brown et al., 2014) . Managing change generally starts with a period of *'unfreezing'* (Bridges & Hallinger, 1991) or *'pre-implementation*' (Brown et al., 2014), including the development of urgency, vision and alignment. Consequently, a period of *'change'* (implementation or empowering actions) commences, usually including both *confrontation* (frustration and anxiety) and *adaptation* (strategies to respond to barriers). As the change becomes increasingly integrated, a more *stable* phase of sustained change is reached (see all phases in Figure 2). Bridge's Transition Model (Bridges & Hallinger, 1991), finally, helps to emphasize the identity transitions (for instance of health workers and patients) that are involved in processes of change (Bridges & Hallinger, 1991). According to Bridges, as transitions materialize, feelings of disorientation, fear, uncertainty and frustration may initially arise. People are in a process of (slowly) letting go of a particular practice and getting used to the idea of a new beginning. Particularly during the implementation phase, feelings of resentment or anxiety about the new roles may be involved, but also great creativity, innovation and new ways of thinking about dealing with the situation (strategies). The final stage is a time of acceptance and new energy, where all stakeholders have embraced the change, and built on the skills that were required to make the new model work (Bridges & Hallinger, 1991).

In Figure 3, the earlier theories are combined to visualize how three stages in the change process towards community-based mental health (or more specifically, SH) can be followed to understand the transition process. In documenting how residents and staff perceive the current approach of community-based mental health care, it is important to consider all sides of the experience (Adriansen, 2012), starting with residents' initial transitions into housing. This is especially true, as the experience of transition can be stressful for all concerned, especially for residents who have a history of homelessness, the revolving-door syndrome, and continuous psychiatric health problems.

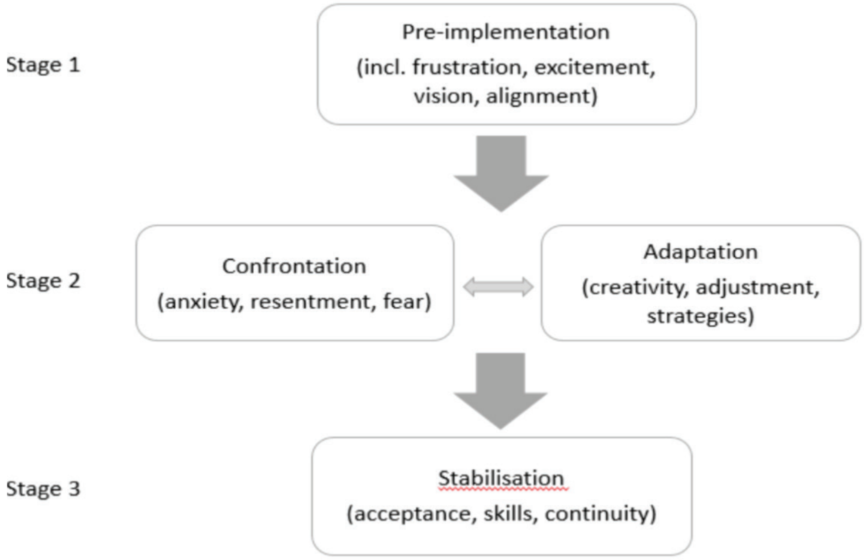

Fig 3. A model to evaluate the three stages of transition towards supported housing

Methodology

This study was primarily qualitative in nature. In order to understand how The Banyan worked towards establishing the SH housing project, data was drawn from various sources at different phases of the project. In order to understand the process of shifting and recovery from ECRC towards supported housing, the following questions were addressed:

1) How did the selection process of residents, house and HCWs take place? What were the steps involved in the pre-implementation phase? (Stage 1: pre-implementation)

2) What challenges were faced by the residents and the HCWs after moving into the supported housing? And, what strategies were employed to deal with the challenges? (Stage 2: confrontation and adaptation)

3) What were the components of recovery that were observed in the residents after moving to the shared house? (Stage 3: stabilization)

A large part of the data was collected throughout the development of the project, such as observational notes and daily log book records, mostly produced by HCWs and case managers in the SH setting. Great care was taken to report systematically on residents' activities of daily living, interactions, non-verbal communications, etc. (hereafter referred to as residents of SH). Log books were maintained by the HCWs in the SH, when other staff would visit the facility. Visitors and other colleagues were encouraged to write in their comments for feedback and also reflected on areas to improve. Information contained in the log books also gave feedback regarding the structure and working pace of each individual. Significant incidents and behaviour were thus recorded. Also, Appreciative Inquiry (AI) conversations were also held with 11 SM residents and noted by the HCWs.

Before and after the project, In-Depth Interviews (IDIs) were held with 14 members of staff involved in SH, including: healthcare workers, community workers, case managers, project managers, and management members.

The individual interviews were conducted to understand how the different stakeholders experienced the transition from ECRC towards SH in The Banyan. Using a timeline interview format, the participants were asked questions related to the definition of SH, the development of the concept, various SH practices, as well as the challenges they encountered and successes they achieved. In addition, the timelines were used to identify and characterize the different strategies used to improve the SH project and stabilize its positive outcomes. Such interviews, semi-structured as timeline histories, are useful to identify the sequence of events and the rationale behind this development, as well as the experiences and perceptions of the people involved (Pope, Ziebland & Mays, 2000). As more data was collected, the interview questions became more specific, and more attention was given to the support of the organization to facilitate the SH, as well as to identify crucial aspects in the SH approach. The interviews were conducted in Tamil and transcribed verbatim. Three independent researchers worked on analysing the data, first by reading the transcripts and the notes, then performing open coding to derive themes and sub-themes. The researchers began the bottom-up phase by reading the transcribed interviews carefully and identifying relevant text fragments, i.e. words and phrases that were meaningful to the research focus. Each new perspective on recovery of mental health was given a new code. Text fragments which expressed a common idea were grouped into categories. For example, categories such as ‘feeling happy’ and ‘feeling connected as a family’ reflected emotional and social aspects of wellbeing respectively. Systematic comparison helped to identify associated categories (Crabtree, 1999). The categories were then organized according to the four phases of implementation. The authors and a research assistant conducted the analysis in regular meetings to check each other’s assumptions and resolve disagreements before writing up the results.

Finally, the qualitative data was complemented with some clinical measurements, such as the World Health Organization Quality of Life scale (WHOQOL) to measure four conceptual domains of the quality of life, including: Physical Health, Psychological, Social Relationships and Environment. The measurement was administered as baseline and post-assessment, as well as three intermittent measurements (three in total), with 11 residents. The outcomes on this scale were evaluated by performing a paired t-test in

SPSS, to detect any significant differences between the baseline and final measurements, using a probability of $p < .05$.

Ethics

The study proposal was reviewed and approved by The Banyan's Research Review Board (RRB). Participants were informed about the purpose of research and of their right to confidentiality and to refuse to respond to any or all questionnaire items. Informed consent was obtained from all participants prior to the interview, and personally identifiable names or details were removed.

Results

In order to move towards realizing the SH concept, The Banyan took a number of preparatory steps. Although the concept of SH was quite well developed in theory, the way this vision would be shared with and for whom it would be implemented, and how the different ideas and challenges regarding the realization of SH in the given context were to be negotiated, was learned during the process. Second, as the team moved to implement the concept, various activities helped to mediate the challenges in the confrontation phase, and to facilitate successful adaptation. The analysis of interviews with health workers and residents, as well as the naturalistic observations and field notes, give insights into what came up during these phases.

Stage 1: **pre-implementation**

Selection of residents

Stage 1 started with selecting those who would be eligible to move to the SH facility and would thus be offered this option. Eligibility was based on two main criteria: first, they needed to be living in the ECRC for a period of five years or more, and second, they needed to have shown limited improvement in their mental illness over a prolonged period of time. The Banyan already had a decade of experience with independent living arrangements for high-functioning residents and few possibilities for reintegration. This pilot study focused on those with chronic needs and who required a high level of HCW support. The team looked at clients who had little to no possibility of reintegration with their family and community. One HCW reflects on the selection process:

> *We took residents who were really not doing well. Some residents could not even take a bath by themselves. We took residents like that to think about supported housing.*

A project manager reflects on the complexity of profile of residents as follows:

> *These were people with chronic symptoms. They showed less progress, may be due to prolonged periods of hospitalization. [You need to] understand the profile, it's a complex category.*

Fifty-nine of the 110 individuals who were initially identified as meeting both criteria (i.e. they had lived in the ECRC for five years or more and had not shown much progress). The mental health status of this group of people was evaluated using the BPRS, and scores higher than at least 41 (moderately ill) were considered. Most clients had scores of over 50, which is considered markedly ill.

As a way to discuss the SH concept with mentally ill residents, the staff decided to work with drawings and word associations, and stimulate the discussion from here. The staff member would draw an independently standing house, with windows, a living room, and separate bedrooms, and ask the residents what this picture meant to them. The reactions were varied. Some said: '*this is my home*' or *'this is ECRC'.* Others said it was family, or that they had lost their home. Through this bottom-up approach, the staff members were able to explain what the SH concept would look like and that some of them perhaps would like to move there. Some were immediately opposed to the idea, and felt the risk of being abandoned. One resident would ask: '*don't you like me any more?'*. But others felt open to thinking about the idea, especially as it could create more silence and privacy for them. As one resident said: *'In ECRC I have to share my food plate and sometimes my stuff gets stolen, and then I have to find it. I am too old for such things'*.

As a next step, interviews with each of the eligible residents were conducted to find out about their preferences, specifically with regard to living with four other housemates and their living arrangements.

> *We asked them how they would want to live, what kind of food they want to eat, what kind of clothes, what are their work pursuits, what are their interests. And we also informed them about the supported housing option and asked them whether they would like this kind of choice.*

Pre-engagement sessions were organized to discuss and negotiate the potential changes this initiative might bring and what challenges they might face. The sessions were also used to discuss what living in a supported house entailed and to encourage them to discuss any questions they might have with staff, case managers and among themselves. The respective case managers also had a debriefing meeting with them as necessary. As a case manager reflects:

> *It was very direct and open conversation, asking a client about the shift, who would you like to stay with. And then they would come back with their ideas saying; 'this is what I would want to do'. The dialogues were very open, in terms of what fears they might have, how they would want to live, how much personal space they want, how would they make this home life for themselves. So other things were also discussed other than just structural relocation.*

Out of the 59, eventually 20 residents agreed to move out to the SH facility. Again, they were asked about their preferences and especially with regard to their choice of housemates.

> *They would need to have something in common, it could be affiliation, familiarity, age, language and regionality, it could be based on preference and shared interests. Whatever the connecting component might be, they all decided whom they would share their home with. There was no coercion. They would all say, 'yeah, I would like to stay with them, I would be happy there'. So there was some kind of affinity, camaraderie, friendship that determined who will stay with whom.*

Selection of the house

Finding a house for residents to live in a community was the biggest challenge faced by The Banyan, but an important step. Property owners were unfamiliar and uncomfortable with the notion of SH for the mentally ill. The process of finding the first house took about four months, because some of the landlords' dogmatic attitudes towards renting out their house to the organization, and the social stigma related to mental illness. They argued that they would fail to find future tenants if people knew that residents with mental illness had lived in the house. House owners also believed that people with mental health issues need to be locked up in homes or hospitals. Moving them out into the community was considered too risky.

Property owners had a preference for functional and mobile residents. Some landlords also had difficulty in accepting that persons with mental health issues can live as families within a community setting.

One property owner was finally prepared to support the approach and decided to let out his house. The project manager remembers the conversation with him. (see Box 1).

Box 1. Reflection of a project manager concerning the house

[...] so this was one particular gentleman who knew The Banyan's work, and he also struggled with the concept in the beginning. I [project manager] had explained this concept to him […], so he didn't understand the fact like, why are you moving out people, why not keep them here? […] I had another admin person next to me, so we said we are doing this as a trial […], we want to work this option out, and see if it is going to work for residents first, and secondly for us. So, he said, it is a good initiative, at least you are thinking out of the box. […] he understood what it was and, he also asked for few terms as in, you shouldn't make too much noise, you should keep the house clean, which is very normal things to ask […] then we said, can we have an extra bathroom and all that, and then he was very willing to help us with that. So, he took us around […], he did it in a very nice way, that we felt it was a nice place, […] we felt it was safe, so we saw the infrastructure first, we were convinced that, okay, this is a good place to live in, that's when we started speaking, […] to residents as well.

Selection of the health care workers

The SH arrangement required two HCWs to work in shifts in one house for five residents. Individual and group sessions were done with The Banyan HCWS to discuss their change of role and they were given time to decide if they wanted to work in this new setting.

The training session included information on the components of the SH model as an alternative approach to care and the innovative role of HCWs. Also, before accepting to live in the SH property, the HCWs visited the house in order to get acquainted with the residents who would be moving there with them.

Two HCWs volunteered and were willing to commit to the concept. Despite not being familiar with the idea of supported housing, they were enthusiastic to explore how it would work. The other HCWs preferred not to move for different reasons, the main one being that if they lived in the SH facility, they might not be able to see their colleagues and friends frequently.

Table 2: Overview of factors that enabled the selection process

With residents	With house owners	With HCW's
1. Systematic process to identify the potential population who require long-term support 2. Creative and accessible way of explaining the housing model 3. Opportunity to make a preference list (people, housing arrangement) 4. Opportunity to take time to think and take a decision 5. Provide an environment that accommodates changes in decision regarding going back to ECRC	1. Finding a property owner who is aware of the organization's work 2. Finding someone who understands the need for innovation at ECRC 3. Accommodating to property owners' concerns	1. Debriefing on the new role 2. Training sessions for the HCWs 3. Visit to the supported housing 4. Address challenges by brainstorming strategies to resolve any issues

Stage 2: confrontation and adaptation

Residents encountering confrontation and adapting to the new situation

According to HCWs, particularly in the first period after the move towards supported housing, there were many transitions back and forth between the SH and ECRC. Some residents were ambivalent about moving into the supported housing and moved in and out, in some cases multiple times within the span of six months. For some, the process of final transition took three months, while others continued to stay and enjoyed having a space of their own and living in a less crowded environment. This eventually led to only 11 residents living in the supported housing.

These 11 residents were all women over the age of 40. Some eight women were married, one widowed, one divorced and the marital status of one was unknown. One of the residents had no formal education, one went to primary school, two to middle school, and seven to high school. Five of the women spoke Hindi, three of them Tamil, one Bengali, one Telugu and one Malayalam. Seven were diagnosed with schizophrenia, three with psychosis and one with a mood disorder with psychotic symptoms. Four of the residents had been hospitalized for six to 10 years, six of them for 11–15 years and one for 16–20 years.

Table 3. Socio-demographic characteristics sample (N= 11)

Age (In years)	
Mean Age	56
Age range	
40–49	3
50 and over	4
60 and over	4
Sex	
Women	11
Marital status	
Married	8
Divorced	1
Widowed	1
Unknown	1
Duration of stay at the psychiatric hospital	5 years and over

During the confrontation and adaptation phase, different reactions were observed among the residents. ‘Separation anxiety’ from a known environment was commonly seen, as one HCW reflects:

> *They got a bit anxious in the new environment. Those residents who lived at ECRC for more than 10 years got worried in a new environment.*

A fear of ‘losing the familiar’ was noted by the CHWs, in response to which a supportive strategy was developed. Residents could visit or return to the ECRC whenever they wished. The close vicinity to the ECRC made it particularly easy to arrange the logistics. Residents were again reassured that they would be receiving the same care programme during their stay in the SH facility.

If residents had already moved but showed an unwillingness to stay in the SH facility, the HCWs addressed their concerns immediately and residents returned to the ECRC. This also made it clear to other residents that they had the choice of moving out and could come back again, which helped in reducing separation anxiety.

One interviewee described how residents could change their mind and decide to move back to the ECRC, a step that was not perceived as regressive or poor decision-making as an individual’s free choice:

> *… [some] wanted to go back to the secure [safe environment] of the ECRC, not really because they were ill, but they just felt that they were, you know, ECRC is their home. We didn’t see it as regression into something, if that is where they feel they belong and they want to be, because they are otherwise well, and they have friends there, they like several things out over there, so we must give them the liberty to go back, and not see it as going back to institutional care.*

Though the ‘fear of losing the old identity’ among residents was prevalent, there were also themes regarding ‘fear of the new environment’. In the supported housing, it was less crowded and quieter. To make the residents familiar with the new environment and make clear that it would be a personal choice to move, The Banyan initially organized weekend trips to supported housing. Residents stayed at the SH facility during the weekends. As the SH facility was situated only a kilometre away from the ECRC, they felt a greater sense of safety and comfort.

As one of the HCWs reflects:

> *I gave them lots of activity in a good way. We called a social worker who gave them orientation in Hindi, this is our home. We all can live together, so we all can love each other and be friendly.*

Despite the fact that the house was situated in a known locality, differences in the environment seemed insurmountable for some residents. Most residents had experienced abandonment by their family and were thus sensitive to relocating. This made it crucial for the staff to communicate clearly that SH is geared towards a recovery approach and that the transition could be reversed at any time. The residents were also comforted in their fear of being left behind through clear communication and arranging visits by their friends.

Staff working in the supported housing were encouraged to observe and directly address feelings of anxiety in the residents and to try to find solutions fit for each individual person. HCWs assisted in following the treatment plans developed for each resident living in the home.

Table 4. Challenges faced and strategies employed to address these (stage 2)

Challenges (confrontation)	**Strategy (adaptation)**
Fear of losing the 'known'	· Residents could visit ECRC whenever they liked, including for celebrations /festive days · Residents can relocate to the ECRC at any time · Residents are reassured about receiving similar care as at the ECRC · HCWs assisted in following the treatment plan developed for each resident
Fear of abandonment	· Regular visits by residents' case managers and friends from the ECRC and clear communication addressing their autonomy and independent decision-making regarding the move
Fear of the 'new'	· Exploration of the environment by residents along with staff · Constant reassurance by case managers and HCWs
Condition of resident	· People with an intellectual disability found it particularly difficult and there was greater moving to and forth among them

Health care workers confronting and adapting to the new situation in stage 2

HCWs also experienced challenges in the process of adaptation (see Table 5). Only two HCWs were initially willing to take on the new role. There was a high sense of uncertainty and apprehension associated with the new role, and also with the community and social environment.

The core concept of integrating residents back into the community posed great challenge to HCWs. One HCW reflects how much she was overwhelmed during the initiation of the project:

> *It was very difficult; I had to do most of the household work, the residents would help me at times. I also wanted to leave the facility at some point. But slowly there was improvement in residents. In the beginning, neighbours used to come and ask me why they are shouting and behaving in a different way. Once even, I cried because they could not understand my feelings. I told all the neighbours that residents here […] are in training to get back to their usual life. This training will make them independent. And they can live on their own without depending on others. So, I used to beg them 'please understand' and sometimes I felt like running away from supported housing. Some residents had disturbances in the night and had interpersonal issues with the neighbourhood.*

She continues by describing how things gradually changed after some time:

> *Later on, I spoke to the residents. Even they are persons like us, not good to avoid them, try to talk to them. Also, I informed the neighbour about this model. Slowly residents started to socialize and visit neighbours' place and started spending time together*.

Some HCWs expressed discomfort about sharing space with residents who would occasionally engage in hostile behaviour. This was aggravated by the fact that the HCWs could not ask colleagues for help as they would do in the ECRC, as only two of them lived and worked in the supported housing. As one HCW reflects:

> *It's a new environment; that could be the reason why residents got emotionally disturbed. I was alone and I was in charge of 2 x 5 residents. Then there was also an incident when a client assaulted me.*

Moreover, the HCWs felt much ambivalence about their new role in the SH model. As one interviewee reflects:

> *Good care is not driven by a set of protocols, so there was a lot of confusion in the beginning among the health care workers; can we allow them to have social transactions, […] what if they are not dressed well, you know, or not brushing their teeth, what if they don't take their medication, what if they get lost when they are out in the community, those were challenges that we were tensed thinking about, but I think they have learned only by doing.*

To support the CHWs, capacity-building sessions were held, particularly focusing on how to provide care while empowering residents to live together independently. The training aimed to support HCWs in finding a balance between 'protecting residents (from other residents and from themselves)' and 'stimulating their autonomy in a gradual manner'. One interviewee explains:

> *And, of course, we had to, we couldn't leave them [the residents] entirely on their own as they did still need a lot of support. So, we had HCWs, who were trained on care processes, purpose of exercising autonomy in a home setting, to go and do what they want to do, and yet be there as, like, you know, carers in a home setting.*

Another challenge that some of the HCWs experienced related to their changing role was their feeling that they had to explain or even justify living in the community as unmarried women. HCWs were reassured not only by creating safety measures and financial reimbursement, but also by offering extended support to explain to their families about their (new) professional role and associated responsibilities. This helped to make the HCWs feel more comfortable with their work.

Among the HCWs in the ECRC, there were some who felt that the SH work was less demanding and so should be reflected in a lower salary. As a strategy to deal with this demand, the intense nature of work in the supported housing and the change in care model was explained to all HCWs.

Table 5. Challenges faced by HCWs and strategies employed to address them

Challenges (confrontation)	**Strategy (adaptation)**
Apprehension about the new job role and environment	● Before accepting their new role, HCWs visited the supported housing ● Training was conducted and researchers were supportive to address any issues ● Support was provided to HCWs to make their own conscious decisions regarding their new role
Independently handling residents' care and anxiety due to living with residents in a home setting	● In individual and group sessions the HCWs were prepared; illustrations of residents' behaviour and hypothetical situations were discussed
Difficulty in accepting the model as a form of transition towards community integration	● Dissemination of information on the SH model as an alternative approach to care. Training components included: a) Innovative care model of supported housing – focus on preference, shared decision-making and HCWs as well as deliberately unstructured environment b) Aligning this care model to the strategy and vision of The Banyan, also bringing about staff changes in the organization c) Role of HCWs in supported housing
Families of HCWs had apprehensions about them living in a home setting	● HCWs were assured of job security, pay scale and a job role equivalent to those who were working at the ECRC. Also, in certain situations the researchers intervened and convinced family members.

Sharing common space	- This was the first time that living space was shared between residents and staff members in a home setting. Hence, certain challenges such as sorting out personal spaces in the rooms, roles and responsibilities in keeping the living space organized were prevalent and immediately dealt with by the HCWs.
Job role and description differs between hospital setting and supported housing	- The nature of work in the supported housing and the shift in treatment was explained, and the intensity and the depth of the work were emphasized

Stage 3: stabilization phase

The stable phase describes the outcomes observed when most of the changes were integrated and the project required only maintenance. It is during this phase that some of the intended outcomes (e.g. better quality of life, independent living capacity, and lessening of symptoms) could be evaluated, and strategies to sustain successful change could be addressed.

Among the residents, several social and behavioural changes were witnessed, after a period of adjusting to the new environment. Positive changes at various levels were observed in the SH residents. Here, we present one resident, Ms M., to illustrate the developments that many non-progressive residents went through after moving to the supported housing in the stable phase.

Before Ms. M moved to the SH facility, she showed poor social skills, functionality, participation and was highly withdrawn. After three months of continuous stay in the supportive housing, she showed significant progress in every dimension. While at first Ms M. would keep to herself most of the time, she somehow gradually started socializing, such as making tea for her housemates and staff and going out for walks with others. She showed greater physical mobility, her self-care improved (also needing less assistance), sharing food, and even showing interest in cooking (see Table 6).

Table 6. Comparison of social and behavioural outcomes in Ms M.

No	**INDICATORS**	**Observations during pre- and post-housing intervention**	
		During stay at ECRC	**After 6 months in supported housing**
1.	*General Behaviour*	- She prefers to sleep and lie down during the most of the day - She was irritable	- She continues to sleep and lie down during the most of the day - She is less irritable - She appears to be cheerful
2.	*Self-care*	- She required several prompts to focus on self-care	- She was able to take care of herself without any prompts and also started bathing on her own
3.	*Mobility*	- She would refuse to get out of her bed to eat - Ms M usually requests the HCW to serve her food and prefers to eat in bed	- She would walk to the dining table to get her own plate and serve her own food
4.	*Daily Chores*	- She required several prompts to work and to engage in any activity	- She started showing interest in washing clothes, drying and folding them - She started cooking by making chapati dough and makes tea in the evening for everyone at home - Started watching television

5.	*Earning*	-There was no means of payment	- After several prompts she was able to engage in activities - Engagement in social enterprise (selling rice batter) increased as it was yielding a profit
6.	*Social Skills*	- She does not socialize spontaneously, only when someone tries to socialize with her - Socializes in a minimal, monosyllabic manner	- She speaks very politely to HCWs and to her housemates - She also initiated very limited conversations with her daughter

Similar developments were observed in the other residents since moving into the SH facility. For the other residents, for instance, improvements in self-care were particularly noticeable, as some started to take a bath by themselves and wash their own clothes. Many such changes were manifested because residents felt more at home, and so also took better care of the house. It was no longer only the HCWs who were cleaning the house as some residents also did so. Some also started cooking meals and serving tea to each other and to their occasional guests. One resident had the habit of spitting, but she managed to spit into the sink rather than on the floor or elsewhere. This change happened after HCWs had explicitly mentioned to her that this is her space, i.e. her own home. The other major change relates to engaging economic activities as many women started to sell vegetables, flowers and different kinds of batter, in the vicinity. Most residents seemed more relaxed and generally expressed feeling better in a non-hospitalized environment.

Based on the HCWs' notes, subtle changes were also seen in the roles that residents took on in their new environment. As one HCW reflects:

> *I see certain changes when I visit these two houses. Earlier as I would work in the hospital, it would be, 'give me this, give me that', no reaction, or just a smile. Whereas over here, I receive a smile, but it is a very encouraging smile and they have started communicating in simple ways by saying; 'Can I make you some coffee/tea? 'Have you*

> *eaten your breakfast?' You can see how they are playing the role of provider whereas earlier they would be very passive in the hospital setting. There is a change in identity in my opinion; very uplifting and very indicative of hope.*

Naturally, a culture of 'family' and a simulation of a 'household' was developed. It was observed that there was more acceptance of each other and residents were also more likely to perceive HCWs as family members. As two HCWs mentioned:

> *Each of the houses had the same philosophy; let's try and weave in a thread of what a family stands for. Typically, the resident would refer to the HCW as [very few would refer to them as staff] my daughter, my daughter-in-law, which actually here is good as it fosters a bonding with the HCW which are typically familiar relationships in many ways.*
>
> *In supported housing we all sit together and have our food while in ECRC, the residents and workers will have to eat separately.*

Gradually, the quality of life for residents in the SH project seemed to mirror that of a home-like environment. Such improvements were also reflected in the quantitative results. Outcomes on the WHOQOL scale show an initially steep incline and then a gradual stabilization of quality of life across four dimensions, including Physical Health, Psychological, Social Relations and Environment (see Table 7). The physical health of residents seemed to have been improved significantly **(p <.042)**, as well as the impact on social relations **(p < .02)**. It can also be observed that quality of life for most residents declined after the first month, pointing perhaps to initial adjustment issues with the transition. Then it seems there was a visible trend that reflected regarding their new situation, which then gradually stabilized over the remaining three months.

Table 7. Scores on QOL of the 11 residents measured six times over a period of six months (with month 4 missing)

	QOL Scale Domains			
	Physical Health	**Psychological**	**Social Relations**	**Environment**
1	37.7	38.7	26.9	44.3
SD	23.1	23.7	21.8	24.5
2	38.9	25.6	26.2	29.4
SD	22.2	25.0	28.5	25.8
3	69.2	50	47.6	67.6
SD	10.8	29	23.6	14.7
4	NA	NA	NA	NA
5	53.5	43.6	25	41
SD	5.17	5.2	2.6	8.62
6	54.3	54.3	41.6	58.3
SD	12.1	17.1	2.8	14.8

Regarding the adaptation to the new environment, residents mentioned experiencing several differences between their new way of living versus ECRC (see Table 8).

Table 8: Residents' reflections on how they perceive the SH project during the stabilization phase

Intrusion of privacy	• Some residents perceived their privacy to be less intruded upon • Residents felt comfortable with fewer people staying with them • There was less chaos with regard to their personal belongings • There was a sense of personal space in the house
Crowding and noise	• Fewer people living together makes a huge difference and makes residents feel more comfortable • Their home had a quiet environment
Routine in an institution	• No strict regime is enforced in the SH facility, which gives a feeling of home

One- to-one attention	• There is more focused attention in the SH facility
Triggers	• Residents said there were more triggers in the ECRC (*boredom, frustration*) provoking painful feelings than in the supported housing
Episodes of disturbed behaviour	• Transition to the SH supported housing facility led to a decline in the number of incidents
Profile of residents	• Residents with an intellectual disability, behavioural and personality issues had far more adjustment issues than the others

Discussion

Purpose of housing intervention in the context of homelessness population

‘Home’ or ‘family’ is an important place for identity formation, and integral to how behaviour becomes normalized and embedded in one’s personality. When people lose their home, they are not just homeless, but are equally at risk of losing an important frame of reference for how to function in the world. To be ‘home’ is not necessarily to be located in a particular geographical space, but to be at ‘home’ with oneself and with others. To understand the complexities of recovery processes for people with SMI, is to appreciate how their life histories are often fraught with trauma, stigma and abandonment. To rebuild their sense of dignity requires an environment for them to (re)-experience the organic evolution of a family. This is also emphasized by Wright & Kloos (2007), who show that micro-level living contexts, including one’s experience of family, strongly affect wellbeing outcomes in persons with SMI and should receive adequate attention in recovery processes. Similarly, Adair et al. (2016) found in their work with homeless individuals with SMI that the aspects of the ‘unit’ (e.g. the type of room and how it is shared with roommates) is experienced as most valuable.

During the stability phase of this current SH project, residents in this study also shared what it meant for them to be part of ‘natural’ family setting and to experience both more privacy (having a room) and togetherness (sharing a home) in their current living situation. Residents expressed various parameters of improved quality of life, by experiencing more rest, silence, attention and less intrusion in the SH facilities. This sense of being at home was translated into a greater sense of responsibility towards themselves and others. Indeed, as emphasized by Wong & Solomon (2002), people with SMI are likely to assume roles as participating members of a community when provided such an opportunity and adequate support. Being able to call a place your home is therefore seen as one of the hallmarks of recovery and being well (Carling, 1993; Tsemberis & Eisenberg, 2000; Rudkin, 2003), which is also confirmed by this study.

Shifts in operation and care in SH housing

Changing from an institutional living arrangement to a non-institutional environment had important implications regarding the functioning of the existing operating teams and guidelines. The current project emerged from the need to move some residents of The Banyan out of the ECRC, and provide support to them as part of the community. While this was a stand-alone project, it is clear that there is a wider need to support homeless individuals with mental illnesses in many parts of India (Gopikumar, 2014). For scaling-up purposes, it was deemed useful to learn from this particular transition period as experienced by The Banyan.

A few important lessons can be drawn from the different development phases. The managing team learned that it is important to move towards creating a sustainable concept of SH with the stakeholders involved, including the HCWs, the SH residents and the community. In the first phase, these stakeholders were instrumental in co-creating the vision of SH by sharing their concerns, dreams and ideas. Indeed, as shown by Acharya et al. (2017), inclusive partnerships with various stakeholders can help to produce more culturally sensitive and sustainable CBMHC programmes. With regard to this study, the residents who were given a chance to move out were supported in expressing their views on the concept of 'home' and SH through the initial brainstorms and drawing exercises. What emerged from these preparations were their expressed fears of being 'left behind', but also their wish to have a home of their own, connected to dreams of the family. Some other studies confirm that in transitions to community care, people with SMI often experience fear of insufficient support once they move out, stigma, loneliness and isolation (Hannigan & Wagner, 2003; Israilov & Cho, 2017). The current study results show how these fears can be addressed appropriately to help residents make the move at their own pace, which are largely in line with more current views on clients as empowered co-creators of care (Tabol, Drebing & Rosenheck, 2010; Acharya et al., 2017). Indeed, although the term facilitative support is not found in the literature, the underlying rationale is mentioned in similar case studies, using terms like empowerment (Kloos, 2005), viewing residents as persons rather than patients, freedom of choice, and facilitative rather than restrictive (Kloos, 2005; Padgett et al., 2006; Tsai, Mares & Rosenheck, 2012).

Similarly, in selecting the HCWs it seemed important that the operating team carefully delineate the implications of supporting individuals with SMI in a community setting, which requires a shift in professional responsibilities. Doing this at a very preliminary stage when little is yet clearly defined, was important for HCWs to feel comfortable enough to assume the change. The HCWs who eventually moved were given autonomy in this project to co-create the concept in a way that felt good to them. As such, they took much responsibility in how they cared for the residents, addressing numerous daily issues, such as social matters of hygiene, property, meditation processes, and interactions with the community. In this, the managing team provided supportive training but also deliberately provided more freedom to HCWs and residents to work through these issues. As such, during the adaptation and confrontation phase, various strategies were employed to deal with initial incidents of ambivalence among the residents, mainly involving various trips back and forth to the ECRC, as well as visits from well-known ECRC figures to the SH facilities. The HCWs played a key role here in building trust and bridging the gap during the transition period, and being sensitive to the residents' needs for confirmation and connection. Supporting residents in their transition, also through linking them with the community, is described by Johnson & Chamberlain (2011) as a core element of community-based support programmes. It is important to emphasize these shifts in roles for staff, as supporting links with people in the community is not always considered part of mental health (Nelson, Hall & Walsh-Bowers, 1998). As seen in this study, HCWs expressed their initial discontent with some of their new responsibilities, but creating boundaries was an important strategy to help the project move into a stable phase.

Finally, the selection of the housing facility itself proved to be both challenging and critical. Finding a landlord who appreciated the intentions of CBMHC and willingness to fight stigma turned out to be an uphill task. However, renting a space in which there is sufficient leeway to experiment with slowly integrating individuals with SMI is a prerequisite for SH projects to work. As described by Tsai et al. (Killasypy et al., 2016), positive connections with landlords can improve the residents' experience of social integration, housing stability, rehabilitation and successful community living. In some sense, the selection of appropriate housing deserves primary attention in the first stages of the deinstitutionalization process.

Implications for scaling up

Mental health services in India for those living in poverty and homelessness are largely organized around the tertiary state mental health hospitals. The district mental health programme (DMHP), the state's community mental health initiative, operates in only 125 out of 640 districts. Even where the DMHP runs, it primarily provides psychiatric medication, with no other interventions. Overburdened public infrastructure, lack of ongoing training and poor social care integration sustains the lack of appropriate care, especially for the poor. In facilities such as The Banyan's, while a majority choose to and are able to go back home, 10% remain in the institution. In order to implement the SH project more widely in India, it is imperative that mental hospitals broaden their perspective, and expand their network of linkages with significant community stakeholders such as block development offices, local panchayats, village health nurses, and government bodies. Few studies on SH report on the importance of networks, but Nelson et al (2014) indicate the significance of, for instance, government officials as beneficial to supported housing. In the current project, we saw that the more hands-on responsibility of interacting with the community lies largely with the HCWs, as well as the managing team. As explained also by Chen (2019) this means that for the development of sufficient insight into the residents' status to facilitate community integration, HCWs are required to be close to the residents, and ideally to live with them most of the time.

Although this seems like a costly project, the actual cost–benefit ratio seems to be lower in the case of The Banyan in Chennai. The cost per client in an ECRC is 20,980 INR while the cost per resident in an SH facility is 10,179 INR. So, in addition to the shift in conceptual and care paradigm, there are also substantial financial benefits. Although the cost–benefit literature for SH shows diverging results, most studies report higher costs due to the intensified care in high-income countries (Harkness, Newman & Salkever, 2004; Patel et al., 2015). In India, salaries are relatively low, which makes this transition more economically viable. Also, cost savings in mental health care associated with favourable outcomes for residents may also balance out the per capita costs of developing and implementing more intense care paths (Aveling, Martin, Herbert & Armstrong, 2017). Still, while implementing SH in different market conditions in India, it might be more difficult to find affordable rental spaces, affecting its efficiency in relation to financial costs.

Limitations and further research

This study is unique in exploring the challenges and strategies that emerged in working towards SH in an Indian setting. The exploratory design, including a range of stakeholders who were employed during the transition period, helped to develop socially robust knowledge, derived from contextual practice. At this stage of the project, the sample size was relatively small, and more research could be done to fully grasp the long-term benefits of SH at a micro level (for the residents, the community members, etc.) as well as macro level (economic and organizational benefits). At present, The Banyan has registered interest from other partners to scale up the SH project in several other states. This will provide the researchers with the possibility to innovate further and gain more understanding of its working mechanisms.

Finally, this pilot study relied quite heavily on the ECRC as a solid platform from which to transition. While it remains unclear from this study whether SH projects can be independently developed, it seems reasonable to assume that homeless individuals with SMI could also more directly be accommodated in SH facilities. The pioneering work with lay workers by Patel et al. (Patel, 2007) could be particularly useful here to understand how SH might function with different readily available stakeholders (including private-sector actors, for instance). It would be valuable to conduct future research on the development of SH as independently run, and so potentially different from the current context.

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Chapter 9

Home Again: Effects of a Housing with Supportive Services intervention for Homeless women with mental illness in India

9.1 Abstract

The issue of long stay in institutional mental health facilities presents an important social justice challenge that needs to be addressed. A non-randomised controlled study was conducted to examine effects of housing with supportive services – Home Again – for women with mental illness and long-term care needs. Home Again was found to have a significant effect on their community integration and disability. The implications of these findings are discussed with regard to potential scale up of intervention.

9.2 Background

Neuropsychiatric disorders in low and middle-income countries (LMICs) account for nearly three-quarters of the global burden of disease (WHO DALYs). The Indian subcontinent is particularly vulnerable, and neuro-psychiatric disorders in the region alone contribute to 34.1% of the global burden of disease (WHO Mental Health Atlas, 2011). Less than USD 2 per capita is spent on mental health by governments in LMICs, a majority of which is assigned to inpatient care (WHO Mental Health Atlas, 2014). Within this context, people with mental illness living in homelessness and poverty are marginalised the most, with little or no options for their care.

People accessing treatment at tertiary care settings, particularly those with antecedents of homelessness, are often at risk of long-term institutionalisation, due to the conspicuous absence of pathways for reintegration into society. Globally, of the persons with mental illness who are admitted to psychiatric hospitals for treatment, nearly a quarter (23%) of them continue to stay there for more than one year (WHO Mental health Atlas, 2011). Estimates for long term admissions in psychiatric hospitals vary widely among countries, from 15% in Pakistan to 65% in Japan to 72% in the Netherlands (WHO Mental Health Atlas, 2011).

Repeated reports in mainstream news and evaluations by the National Human Rights Commission (1999, 2008, 2012), throw light on prevailing undignified living conditions in these spaces, the persistent problem of lack of rehabilitation options and long stay users in several state hospitals across India. The National Human Rights Commission report of 2016 reports that an estimated 3100 people are living for five or more years in state mental health hospitals in India, resulting in compromised quality of life, reduced mental health outcomes, high disability burden and significant experience of human rights violations. In addition to compromising rights of people with mental illness, persistent long stay populations affect the ability of the tertiary centres to efficiently perform their function as acute care service providers as beds and resources are applied towards continued care for long-term service users.

In facilities run by The Banyan, a non-profit in India that caters to homeless women with mental illness, while a majority choose to and are able to go back home, a small percentage remain in the institution. In the last twenty-five years of running a restorative care service focused on personal recovery for homeless women with mental illness, The Banyan has found that approximately 11% of such individuals do not exit the system in any way, a majority of whom are those with high clinical needs and/or concurrent intellectual disability who are unable to inform about their family, while some have no family or choose not to go.

Therefore, a critical emerging need is the development and study of sustainable, dignified and well-being oriented options for people with mental illness with long term care needs. Community mental health initiatives need to cross integrate with options for stable shelter as an intervention for people who need long term care. The capabilities approach conceives development as substantive freedoms, which are choices people exercise to achieve ‘functionings’ that they have a reason to value – which may range from ‘elementary ones’ such as adequate nourishment, to ‘complex activities and personal states’ such as self-respect, political participation and so on (Sen, 1999). Therefore, the conceptualisation of social integration as processes by which people with mental illness are able to experience interpersonal reciprocity and citizenship as an indicator of quality of life (Ware et al., 2008) offers directions in development of interventions that address the complex needs of long stay populations.

There is evidence to support potential gains arising out of a stable housing condition. Supportive housing approaches have been used for addressing homelessness in the West. In the US, there is existing evidence from a small number of controlled trials that supports positive benefits arising out of housing. Since the 1980s, Pathways to Housing has been offering unconditional subsidised choice of housing to homeless people with assertive community treatment (ACT). Based on several studies that examine the effectiveness of this intervention, Pathways to Housing is acknowledged as an empirically supported intervention for homeless people, including those with mental health needs (Tsemberis 2000; Tsemberis 2004; SAMHSA, 2007). Rosenheck and colleagues (2003) compared a variant to this approach that uses a more cost effective case management support with housing rather than ACT and found positive evidence with those in intervention demonstrating fewer hospitalisations and greater housing stability.

Given this background and evidence, we implemented a housing with supportive services intervention as an approach to gauge possible effects of such an intervention on homeless women with mental illness who continue to live in The Banyan’s institutional facilities.

Study Intervention

Home Again is a complex housing with supportive service intervention that fosters choice based, inclusive living spaces through rented homes in rural or urban neighbourhoods with a range of supportive services for people with persistent mental health issues living long-term in institutions. People come together to form affinity groups and live together in homes in a community, creating a shared space of comfort, that mimics a familial environment. Along with housing, the intervention features allied supportive services including social care support and facilitation (opportunities for a diverse range of work, facilitation of government welfare entitlements, problem solving, socialisation support, leisure and recreation), access to healthcare, case management (detailed biopsychosocial assessments and personalised care plans), and onsite personal assistance. It also focuses on lived experiences where health is one amongst many priorities to live well and not central to the array of supportive services offered.

Home Again is executed by a multidisciplinary team, a majority of whom are non-specialists trained to function in this context as personal assistants. A typical home has 4-5 women with 1-2 onsite personal assistants visiting or living with them based on expressed need. Personal Assistants (PAs) are women, predominantly from rural backgrounds with no formal education in mental health, who are trained and supervised to support service users through individualised processes to achieve recovery consistent with service user priorities. Personalised supports are planned and derived from processes of dialogue between service users and staff, individually and in groups. Social visits are undertaken weekly by the case managers, with Masters level training in social work, who work with a case load of 20 service users. A nurse visits all homes weekly once to follow up on general health issues. Weekly meetings with the PAs, representatives from service users are used to collaboratively analyse Home Again, synthesise significant learnings, problem solve, and co-plan individual and group level interventions and activities. Collaborative plans are further discussed through quarterly individual sessions with service users, the project lead (a senior level social worker or psychologist with at least ten years of experience), personal assistant and the service user. The project lead also undertakes social visits to all the homes on a quarterly basis and conducts focus group discussions with service users and personal assistants. Multi-stakeholder engagements and discussions facilitate co-learning and are key to the Home Again intervention.

Methods

Design

We used a two-group quasi experimental design with one group receiving the housing with supportive services (HA) intervention and the second comparison group receiving care as usual (CAU) at The Banyan institutional facilities. A mixed methods approach was applied combining quantitative and qualitative methodologies. Participants in both arms were prospectively followed up over an 18-month period on a range of quantitative repeated measures. Participant and nonparticipant ethnographic observations and descriptive notes of project review meetings and case conferences were used for gathering qualitative data. In this article, the quantitative repeated measures are analysed and discussed.

Location and Population

Home Again was implemented in Tamil Nadu, India for formerly homeless women with mental illness, who were residing at The Banyan's institutional facilities for 12 months or more. The study was undertaken between December 2015 to September 2016. The Banyan, established in 1993, is an organisation that offers comprehensive services for the most marginalised to address complex issues and needs at the intersection of homelessness, mental ill health and poverty. The Banyan's Emergency Care and Recovery Centre (ECRC) located in urban Chennai and the Health Centre (HC) located in a rural village 40 kilometres south of Chennai, offer critical time interventions, care and reintegration services for homeless women with mental illness. In addition to these transit services, the organisation's Clustered Group Homes (CGH) project offers long term care in a cottage style institutional facility colocated with The Banyan Academy of Leadership in Mental Health (BALM) campus for higher education in social sciences. Home Again's broader vision is to address long term needs of people living with mental disorder who are currently in institutional spaces. Therefore, for the purpose of this study, the inclusion criteria were that participants:(i) are women living with a mental disorder; (ii) have a duration of more than 1 year of stay at any of The Banyan's institutional spaces. A small number of women live independently in homes rented by them as a peer group in proximity to The Banyan's rural Health Centre. For this study, women in such independent arrangements were included if they used inpatient services for more than 6 months in the last one year.

The intervention was implemented in one urban community in Chennai (Mogappair) and three rural communities south of Chennai (Thiruporur taluk. All communities are proximal to The Banyan's community mental health programme with weekly clinics, skills development units and social care.

Screening and Allocation

Recruitment for the study took place in December 2015. A file review of all women residential at The Banyan with 12 or more months of stay, covering socio-demographic features, years of association, work status and reintegration history, was undertaken. This was followed up with a face to face interview of all potential participants that elicited women's prospects and preferences for living (n=194). In particular, they were explicitly offered the choice to move into a home with friends/others or remain in the facility. Women who expressed a preference to move into a home in the community were allocated to HA, the intervention arm (n=67). Participants in HA were matched with women, who remained in the institutional facilities, based on disability and years of association to derive the CAU or comparison arm. All participants allocated to HA underwent a pre-engagement period of seven days with individual and group sessions, focussed on addressing concerns regarding shift into new environment, anticipating challenges, problem solving, planning for the new environment, social interactions with women currently living in shared housing arrangements and facilitating activities such as home furnishing and decoration.

Figure 1. Screening and Allocation

Measures and Data collection

At the participant level, our outcomes of interest were: (i) community functioning; (ii) psychological health; and (iii) quality of life. Community functioning, or integration in home, workplace and social life, was measured using the Community Integration Questionnaire (CIQ) (Willer et al, 1993). This was informed both by the client and the personal assistant. Psychological health was informed by the WHO - Disability Assessment Schedule 2.0 (WHO-DAS) 12 (WHODAS 12) for disability and Brief Inventory of Thriving (CIT) (Su et al, 2014) for psychological well-being. Quality of life was measured Quality of Life Inventory (QoLI - 20) (Uttaro et al, 1990; Lehman et al 1996) rated by the participants in the absence of all staff. Participants were prospectively followed up over 18 months with face to face administration of scales every 6 months. Measures were collected by three research associates including the Co-Principal Investigator, all with masters level training in psychology, social work and public health. Participants were met face to face at 6 months, 12 months and 18 months from baseline on approximately scheduled dates of appointments, with a tolerance of +/- of a week.

Background characteristics such as age, years of association, diagnosis and reintegration history were drawn from file records maintained by staff at The Banyan over the years. Diagnoses were drawn from the working diagnosis assigned by clinical staff as noted last in the file.

Data analysis

We used a modified intent to treat approach towards analysis. The final dataset used for analysis consisted of 106 participants (Figure 8.1). All participants who were allocated to and received at least 6 months of the Home Again intervention (n=53) and their matched controls from as usual care (n=53) were included in the final analysis. Our primary aim was to examine efficacy at this pilot stage. Since most participants who drop out of the intervention, move back into the institutional facility, typical intent to treat may not be a useful approach in determining actual efficacy of the intervention. We examined differences between background characteristics and baseline values of the groups using t tests/Mann Whitney U for continuous variables and chi square test for categorical variables. Generalised estimating equations were used to examine differences between HA (Home Again intervention) and care as usual (CAU) arms, controlling for baseline values of respective outcomes.

Ethical considerations

Participants were informed about the purpose of the study in addition to their rights. These included the right to choose intervention, to refuse to answer any part of the instruments, the right to leave interviews/focus group discussions/other workshops at any point and the right to decide to withdraw their information at a later point. They were given the contact details of a researcher in case they have further questions about the study or their data. Informed consent was obtained in writing – either signature or thumbprint – from all participants.

Protection of rights such as choice within care including exit from intervention, adverse events such as death or interpersonal violence necessitate ongoing ethical oversight mechanisms for work with marginalised populations. For this purpose, a three-member team of service users assessed and audited the intervention every quarter.

Table 8.1: Background characteristics of participants by arm

Characteristic	Home Again (n=53)		Care as Usual (n=53)			
	M	SD	M	SD	t	p-value
Age	46.09	9.9	46.98	11.45	0.43	0.67
	Mdn	IQR	Mdn	IQR	U	p-value
Years of association	11.17	5.25	11.08	5.88	1375	0.85
	N	%	N	%	X2	p-value
Diagnosis					1.49	0.47
Schizophrenia/Psychosis NOS	33	62.26	36	67.92		
Intellectual disability	17	32.08	12	22.64		
Others	3	5.66	5	9.43		
State of origin					1.19	0.76
Tamil Nadu	30	56.6	25	47.17		
Andhra Pradesh	6	11.32	6	11.32		
Others	7	13.21	8	15.09		
Not known	10	18.87	14	26.42		
History of reintegration attempts					0.53	0.47
No	41	77.36	44	83.02		
Yes	12	22.64	9	16.98		
History of living in a shared accommodation independently						0.437
No	48	90.56	51	96.23		
Yes	5	9.43	2	3.77		
Co-morbid chronic physical health conditions					7.53	**<0.005**
No	30	56.6	16	30.19		
Yes	23	43.4	37	69.81		

Significant differences are in bold

9.5 Results

Background characteristics of participants : The sample consisted exclusively of women, with a mean age of 46.53 (SD=10.66), median 11.13 (IQR=1.95) years of association and median disability score of 13.68 (SD=12.39) as measured by WHODAS 12. Participants were predominantly diagnosed with schizophrenia and psychosis nos (65.09%), followed by intellectual disability with psychosis (27.36%), with a minority with other diagnoses (7.54%). Reintegration was not attempted for 80.19% of the participants. No significant differences were found between both the arms at baseline on any of these background characteristics (Table 8.1). However, participants from the CAU arm had a greater proportion of co-morbid chronic physical health conditions in addition to their psychosocial disability compared to those in the HA arm (p<0.005).

Table 8.2 compares participants in HA and CAU on the baseline values of outcome measures. No significant differences are noted in any of the outcomes of interest at baseline.

Table 8.2: Outcome measures at Baseline

Measure	Home Again (n=53)		Care as Usual (n=53)			
	Mdn	IQR	Mdn	IQR	U	p-value
Community integration (CIQ)	2	5.6	3	3	1357.5	0.764
Home integration	0	0	0	0	1386.5	0.872
Social integration	1	2	1	1	1220.5	0.218
Work integration	0	3	3	3	1202	0.161
Disability (WHODAS 12)	12	18.5	9	23.5	1330	0.636
Quality of life (QOLI 20)						
General life satisfaction	5	2.5	5	1.5	1177.5	0.326
Social contacts	1	0	1	0		
Psychological well-being (BIT)	39		37		1146	0.389

Participant Outcomes

Table 8.3 summarises results of GEE models comparing both the groups over time with one another in pairs. There is a significant main effect of Home Again on Community Integration, with participants in Home again experiencing greater improvements in CIQ scores; β = 5.976; S.E. = 0.761; Wald 95% CI = 4.485, 7.468; p <0.001. In pairwise comparisons using Bonferroni correction, participants in Home Again experience an increase in CIQ scores with a mean difference of 6.25 (SE=0.71; 95% CI 4.86,7.64) between the two arms (p<0.001). These main effects are observed in each of the sub-domains of community integration measures indicating greater involvement in home and household activities (p<0.001), more social activities such as shopping/leisure and social contacts (p<0.001) and participation in work (p<0.001). Similarly, a main effect of Home again is observed the frequency of social contacts sub-scale item in the quality of life measure (p<0.005).

There is no main effect of Home Again on disability; β = -0.13; S.E. = 0.087; Wald 95% CI = -0.301, 0.041; p=0.136. However, there is a significant interaction effect of Home again and time (p<0.05). In pairwise comparisons with Bonferroni correction, we observe that participants in Home Again decreased more over time with a mean difference of -6.58 (SE=1.89; 95% CI -12.14, -1.09) between both arms at 18 months (p<0.05).

No effects of Home Again are observed in the quality of life measure (general life satisfaction) (p=.0.922) and subjective psychological well-being scores (p =0.116).

Table 8.3: Regression analysis (generalised estimating equations) for effects of arm and time on outcomes

Outcome	Parameter	B (SE)	95% Wald Confidence Interval	p-value
Community integration (CIQ)	Arm=Home Again	5.976 (0.761)	4.485, 7.468	**<0.001**
	Time=18months	0.566 (0.474)	-0.362, 1.494	0.232
	Time=12months	0.934 (0.596)	-0.233, 2.101	0.117
	Home Again*18months	0.392 (0.820)	-1.216, 1.999	0.633
	Home Again*12months	0.443 (0.836)	-1.196, 2.083	0.596
Home Integration	Arm=Home Again	1.373 (0.348)	0.691, 2.055	**<0.001**
	Time=18months	-0.566 (0.249)	-1.053, -0.079	**<0.05**
	Time=12months	-0.33 (0.265)	-0.85, 0.189	0.213
	Home Again*18months	0.976 (0.396)	0.201, 1.752	**<0.05**
	Home Again*12months	1.085 (0.361)	0.377, 1.793	**<0.005**

Social Integration	Arm=Home Again	2.377 (0.330)	1.731, 3.024	**<0.001**
	Time=18months	0.113 (0.218)	-0.314, 0.54	0.603
	Time=12months	0.226 (0.229)	-0.222, 0.675	0.323
	Home Again*18months	-0.189 (0.355)	-0.883, 0.506	0.595
	Home Again*12months	-0.245 (0.337)	-0.905, 0.414	0.466
Work Integration	Arm=Home Again	2.226 (0.321)	1.598, 2.855	**<0.001**
	Time=18months	1.019 (0.277)	0.477, 1.561	**<0.001**
	Time=12months	1.038 (0.280)	0.489, 1.586	**<0.001**
	Home Again*18months	-0.396 (0.419)	-1.218, 0.425	0.344
	Home Again*12months	-0.396 (0.401)	-1.183, 0.39	0.323
Disability (WHODAS 12)	Arm=Home Again	-0.13 (0.087)	-0.301, 0.041	0.136
	Time=18months	-0.141 (0.055)	-0.249, -0.033	**<0.05**
	Time=12months	-0.021 (0.036)	-0.091, 0.049	0.557
	Home Again*18months	-0.185 (0.088)	-0.358, -0.013	**<0.05**
	Home Again*12months	-0.027 (0.066)	-0.156, 0.102	0.684
Quality of life (General life satisfaction)	Arm=Home Again	-0.005 (0.053)	-0.109, 0.099	0.922
	Time=18months	-0.142 (0.041)	-0.222, -0.063	**<0.001**
	Time=12months	-0.17 (0.046)	-0.261, -0.08	**<0.001**
	Home Again*18months	0.063 (0.058)	-0.052, 0.177	0.283
	Home Again*12months	0.063 (0.065)	-0.064, 0.19	0.33
Frequency of social contacts	Arm=Home Again	0.278 (0.090)	0.102, 0.454	**<0.005**
	Time=18months	-0.014 (0.059)	-0.131, 0.102	0.812
	Time=12months	-0.071 (0.057)	-0.183, 0.041	0.216
	Home Again*18months	-0.066 (0.107)	-0.275, 0.143	0.536
	Home Again*12months	-0.132 (0.102)	-0.333, 0.069	0.197
Psychological well-being	Arm=Home Again	3.57 (2.270)	-0.878, 8.018	0.116
	Time=18months	-2.207 (1.468)	-5.085, 0.67	0.133
	Time=12months	-2.002 (1.140)	-4.236, 0.232	0.079
	Home Again*18months	-1.174 (2.055)	-5.201, 2.852	0.568
	Home Again*12months	-1.572 (1.789)	-5.077, 1.933	0.379
Significant differences are in bold				

9.6 Discussion

Feasibility and Efficacy

Home Again demonstrates feasibility and process of transition for people with complex needs with antecedents of homelessness and long stay within a hospital environment. Participants were heterogeneous in their levels of disability with diverse clinical and social needs. All women who made a choice to live in a home irrespective of their levels of symptoms or disability were unconditionally offered a home in a community. With appropriate support and adequate linkages to escalate to inpatient care when necessary, women with mental illness with long term care needs were able to sustain such a living arrangement and experience gains in their social integration and disability as a result. The sustenance of homes over time in communities offers evidence of feasibility of establishing housing within low resource contexts with adequate supportive services and linkages to health and social care services.

This pilot study indicates the efficacy of Home again in comparison to institutional care for people with mental illness, with long term care needs, particularly on social well-being, in a low resource setting. Existing literature on housing for homeless people with mental illness is heavily inclined towards housing stability and therefore homelessness prevention as an outcome. There is a small body of published literature that considers social inclusion, participation or community integration of users of housing services. Further, studies indicate that persons with mental illness experience only low to moderate levels of social integration (Gerber et al., 2003) and particularly low levels of integration when compared to controls in the neighbourhood (Aubry & Myner, 1996). Tsai and colleagues (2012) examined social integration for 550 chronically homeless people with mental illness who participated in the 11-site Collaborative Initiative and found that while substantial improvements were achieved in housing, people remained socially isolated and experienced limited improvement in various domains of social integration. In our current evaluation of the Home again approach, we have found substantial gains on social integration.

Ethnographic observations gathered as part of the study reveal an emphasis on a sense of family that offers social support, and fosters hope, and independence. It was observed that reduced supervision and the interdependence that arises from this liaison of familial bonding nurtured social well-being. Families were formed between members of a home who adopted different roles such as the ‘carer’, ‘worrier’, ‘mother’, ‘grandmother’, and the ‘child’. Personal assistants, who are onsite staff to assist member of the home with their living also became a part of the notion of family. Thus, social interactions and bonds within and outside the home feature widely in the ethnographic observations – a motherly relationship is forged between a participant and a personal assistant; memories of a recipe from childhood inspires a woman to cook; young pups in need are adopted into the family; phone calls are made if a member of a home is hospitalised or returns late from work; women demand and secure relief offered for floods by the local government; children visit regularly to learn, play or be taken care of while parents run errands; dinner invitations are exchanged; milk, considered auspicious, from a cow that has given birth in the neighbourhood is shared; a neighbour visits regularly to learn basket weaving and converses in the process; another offers help to a shared housing user in finding a suitable spouse. Qualitative data that we gathered also reveal that inclusion experiences are complex and coloured by various actors’ sense of social norms and order that are applied to judge people, their ‘normality’ and abilities. Despite the apparent acceptance of women who may be symptomatic and organic interactions in the neighbourhoods, conformity to social identities as a yardstick to designate ‘normal’ versus the ‘abnormal’ were observed. Understanding such complex factors will add more substantively to unpacking social inclusion pathways for people with mental illness.

No effects were noted in self-reported quality of life or the psychological well-being measure. This may perhaps be reflective of the quality of care offered at The Banyan or maybe the consonance users are able to perceive between their preferences and their living arrangements. Another explanation may be that transitions into the community either initiate recollections of relationship losses from the past or lead to growing aspirations that are still out of reach. Probing conceptualisation of psychological well-being and quality of life in the local socio-cultural context may offer directions for future research and interventions.

A possible unexpected outcome on account of Home Again is the improved reintegration rate at The Banyan's Emergency Care and Recovery Centre (ECRC). While in 2014 only 20.51%, reintegrated back to the family within the first year of their admission to ECRC, by 2017 54.29% of women, who sought admission, recovered and reunited with their families, coinciding with decrease in proportion of long stay population from 80% in 2014 to 19% in 2017. While it may be too early to conclusively attribute this improved efficiency in the institutional facility to Home again, the trend and concomitant occurrence may be further investigated for associations.

Ensuring fidelity to ethos of care among staff

Pressure to conform to established social identities, forms of control and exclusion may occur as much in a home in the community as it may in any other setting. Pat Capponi recollects depressing narratives of social indifference, despair and unchanged conditions she experienced and witnessed as a service user who was shifted to a group home as part of the deinstitutionalisation process, illustrating the complexities involved in actioning interventions as intended in their true forms. Further, managing clients with ongoing disabilities is challenging job. Evidence suggests that deinstitutionalisation contributed to burnout among staff who felt overburdened by the complex needs of service users discharged from tertiary settings (Edwards, Burnard, Coyle, Fothergill, & Hannigan, 2000; Evans et al., 2006; Morse, Salyers, Rollins, Monroe-DeVita, & Pfahler, 2012).

Supervision to navigate day to day complexities and reiterating ethos of care may be critical to ensuring that a sense of home, interdependence and choice for users to pursue what is personally meaningful, features central to the Home again intervention, are retained. In this experience of implementing the Home Again intervention, we found it essential to offer concrete, consistent on the job support for staff to acquire over time tacit knowledge involved in playing the role of a facilitator of lived experiences, balancing personal responsibility for safety with client freedom, engaging with community as a stakeholder and formulating one's day to day work beyond activities of daily living. Further personal assistants themselves come from a background of extreme personal distress, sometimes dropping out of higher education and joining the job in order to mitigate family poverty. Personal narratives of these women also feature gender-based discrimination and violence at a very young age. Supervisory relationships needed to be additionally cognisant of these challenges and offer support for personal and professional development of Personal Assistants.

Translating to scale

Home again may potentially translate into wider implications for a very vulnerable population if scaled up to address the issue of long stay among people with mental illness in institutional settings. This may be furthered to alter the paradigm of institutional mental health care, with a particular focus on transformation gains to accrue beyond immediate service users of Home Again or the institutional facilities, to include mental health system gains on account of rationalised acute care resources and increase in recovery-focused human resources and practice. But how can complex interventions such as Home Again scale? What are the significant enablers and barriers to scale?

In this pilot, evidence has emerged from Tamil Nadu, a relatively progressive state in the India. This necessitates firstly a process of broadening with demonstration initiatives in diverse socioeconomic and cultural contexts and a process of developing the intervention further to be responsive to these many realities. Secondly, neighbourhood deprivations and social contexts have been implicated in determining illness and recovery pathways in mental health. In broadening Home Again, understanding the social, economic and cultural setting and its interactions with intervention effects will be an important agenda.

In the Indian context, budgetary allocations in the health sector for mental health are concentrated largely in institutional mental health care. While resources may be reapplied in the process of transitioning people into housing in the community, social justice and health are administratively divided into different departments in India, both at the Centre and State levels. In the absence of collaborative agreements and service delivery between social welfare and health departments and ministries in the Governments at state and central level, budgetary redirections are not straightforward. This may present as a significant barrier to securing more enduring investments in the Home Again intervention even if readiness to transition to scale is indicated.

Differential experiences of deinstitutionalisation worldwide are necessary to consider in terms of the criticality of creating not just adequate community supports (Thornicroft & Tansella, 2002) but services that are appropriate and resonant with the professed ethos. Scale up without transfer of intervention's value base may increase risks of intervention descent and morphing into smaller microcosms of facilities with poor quality of care and lack of user centredness. Values may be necessary to achieving the cross-site motivation for intervention fidelity, resource sharing and knowledge co-production across domains and sustenance of stakeholder networks. The necessity of retaining the intervention's core at scale indicates the need for explicating underlying values and transactional processes of re-experiencing and learning involved in diffusion to other contexts. Concrete identification and articulation of processes that enable value-based diffusion and may influence the extent of fidelity to Home Again intervention, will be necessary to implement housing with supportive services across distributed geographies at a nationwide scale. In this regard, policy recognition of housing with supportive services may offer a standardized oversight system that ensures fidelity to non-negotiables while allowing for freedom of implementers to innovate in their contexts and allaying hesitations of potential partners and implementers on account of risks.

Conclusion

This pilot study of a housing with supportive services intervention, Home Again, undertaken in Tamil Nadu, India offers promising evidence of intervention's effect in increasing social integration of people with enduring psychosocial disabilities and history of homelessness. Understanding value drivers of the intervention and pathways for diffusion of these values may prove necessary in the process of transfer to other contexts. Examination of particular factors and the process through which gains in community integration for people with mental illness were achieved will have broad ranging consequences for tailoring of services for people with mental illness.

Limitations

This evaluation used a quasi-experimental design, due to anticipated ethical issues of denying the choice to move out for people who wanted to and potentially separating friends. We did not randomise the participants and although we used matching on specific, this limitation must be kept in mind as a potential source of bias while reading the results. Cross sectional data at baseline and endline have been compared for outcomes at the level of intermediaries and community. We enrolled lower participants (n=67) than originally planned (n=80). This may have prevented other effects on other outcomes from being adequately tested. We did not gather data on neighbourhood variables such as quality of neighbourhood, presence or absence of services, poverty and so on that may have influenced some of the outcomes.

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Chapter 10 Discussion and Conclusion

We think sometimes that
poverty is only being hungry, naked
and homeless. The poverty of being
unwanted, unloved and uncared for is the
greatest poverty - Mother Teresa

The objective of this thesis was to understand how change in the mental health system in India could potentially be leveraged to improve continuity of care (COC) for persons with severe mental health disorders (SMDs). Especially in recognising the perpetuity of homelessness, poverty and mental illness, finding ways to improve and sustain care was considered as an important quest. Throughout the thesis I particularly tried to employ a research and innovation approach that is constructive, user-centric and focused on dignified living for all people. This means to move away from social exclusion, practices of criminalization (of begging) and incarceration but also from prolonged inpatient treatment and hospitalization, towards models that improve quality of life for persons with SMI. Thus, the questions asked in this thesis focused on understanding how COC can be improved through better family caregiving and alternative models, specifically Supported Housing. The main question asked in this thesis was:

> **How can mental health systems in India become more adaptive to cater to the needs of those with chronic mental health needs in the community, and to support caregivers in delivering continuity of care?**

The specific sub-questions asked were:

Sub-question 1*: How can the experiences, dignity, and aspirations of homeless persons with mental illness be understood in the current context of India's political system and legislation processes?*

Sub-question 2a: *In the context of de-hospitalization, how can we understand the experiences of family caregiving as an integral part of COC for persons with chronic mental health needs?*

Sub-question 2b*: How can family caregivers be better supported in their caregiving role, in order to preserve and improve COC for persons with chronic mental health needs?*

Sub-question 3a*: How can alternative COC programs, modelled on housing first principles, be developed in the context of South India, for persons with chronic mental health needs?*

Sub-question 3b: *In the context of preparing alternative COC models such as Supported Housing for upscaling, how can we understand its basic outcomes in comparison to care as usual?*

The answers to these questions are provided in three parts. In the first part, I respond to the first sub-question to sketch the broader social-political situation in which homeless persons with SMI construct their lives **(chapter 4)**. In the second part, I look extensively at sub-question 2a and 2b, as one pathway to improving COC. The articles involved here particularly focus at ways of systematically enhancing and supporting a very common and natural way of organizing COC through family caregivers **(chapter 5, 6, 7).** Finally, in the third part **(chapter 8 and 9)** I look at the new model of COC (supported housing) in South India, in order to understand how such innovative interventions can become sustainable and implementable in various other sites.

10.1. Homelessness, mental illness and jurisdiction in India

Chapter 4 critically evaluates the destitution bill which for a long time failed to adhere to the basic rights and autonomy of an individual. This chapter also sheds light on the complex relationship between homelessness and its causes and consequences of incarceration in relation to begging. The article shows that homeless people are often perceived as a threat to society. The state and the legislation respond to the complex issue of economic deprivation, the failing infrastructure of public services and its social consequences by negating and reinforcing it. Law and order are given priority over care and concern. The most vulnerable people are thus being penalized for ‘crimes’ that are often the only alternative left for people to survive in a context of deprivation and lack of safety.

Indeed, this chapter shows that for homeless people it is highly possible to encounter incarceration. The chapter portrays the exploration of views and perspectives of vulnerable persons who have been convicted under the current system of the ‘Bombay Prevention to Begging Act’, their perception of the current legalities, the proposed destitution law and the support systems that they require from the state. The semi-structured interviews of 24 respondents who were incarcerated for begging and currently residing in beggar homes revealed that they were not informed about the reasons for being incarcerated and were taken away without their consent or voluntary participation. The findings revealed that the majority of them said that the proposed destitution bill was unfair and needed to be abrogated. Some also revealed that they desperately want to contact their families even as the benefits of continuing to stay in beggar homes outweighed their emotional needs with regard to their family. In particular, women expressed a great sense of safety from sexual assault and domestic violence. This also resonates with the current literature that reveals that homeless people are at a greater risk of violence and women are more vulnerable to sexual violence (Heslin, Robinson, Baker, & Gelberg, 2007). It was stated by one of the experts that the policies should be contingent to the Indian Constitution; to basic fundamental human rights of equality and that address poverty, rather than criminalize it.

Most strikingly, the views of the respondents interviewed for this study show that besides the more deontological arguments provided for abolishing the anti-beggary act, the criminalization of begging homeless people also practically holds little ground. Incarcerating persons might result in additional trauma, and also certainly does not solve the problem that started the vicious cycle of homelessness, mental illness and social dysfunction. As rightfully described by one magistrate in chapter 4, it is highly unlikely that people beg out of free will and laziness. As also found by Padgett & Priyam (2017. p. 75); *'day-to-day lives of homeless persons are characterized by the near-constant demand to generate income for sustenance'*, for which begging becomes a key tool to survive. . Homeless persons are most likely to be coerced into begging by hunger or addiction to substances. In the latter case, there arises the question whether it is useful to send 'patients' or to prison, where there is no program for detoxification or mental health support is available as yet.

Finally, the chapter sheds light on the question what alternatives might be available to possibly substitute the anti-beggary law. In response to the question what the government could do for them, after the removal of the beggary law, one of the respondents answered that the government should help them build a life, a home, and provide financial support. Experts discussed the possibility of basic income, but also the need for mental health services, education, and other basic activities that help people live a dignified life. Hence, this chapter, as I intuited from the beginning, also gives prompt answers towards the need to understand what it means to care for people, in the community, with sensitivity to their unique (mental) health needs and in a sustainable manner. In addition to also build trust and to reverse downward spiral that homeless people find themselves in India. As well described by Padgett et al. (2016):

> *Greater attention to enforcing "below poverty line" entitlements in medical care would help to close the gap in health care delivery as well as reduce distrust in the health professions. Finally, decriminalization of the activities homeless persons carry out to survive—including begging, selling legal goods, and sleeping outdoors—would remove the onerous burdens of fines and incarceration….. Increasing and sustaining public assistance programs for homeless people can build on their hard-earned resourcefulness and substantially enhance their health and well-being.*

10.2. Family caregiving in India

10.2.1. Strengths and challenges experienced by caregivers.

Based on the findings in **chapter 5,** I will be discussing in detail the intense experiences and psychological processes as observed in family caregivers taking care of their family members with SMDs. Family caregiving, as described in the introductory chapters of this thesis, plays a key role in COC in LMICs such as India. Understanding what constitutes family caregiving in this specific context was considered important in improving COC structures.

First, as observed in both **chapter 5** and **chapter 7**, caregivers, besides experiencing a great deal of burden in their role, also show various important strengths that are often ignored. Indeed, while caregivers are able to describe their deep concerns and feelings of anger, loss and resistance, they often also talk about the positive sense of meaning they derive from their role as a caregiver. This is often overlooked by research, as '*we have not really looked at what caregiving means to the caregivers'* (Murphy, 2016, p. 14), and it is time that we begin to understand both the strengths and weaknesses as observed in Indian families taking care of persons with SMDs (Murphy, 2016; Myers, 2003) explains that focusing on stress and burden only, without noting the various strengths of caregivers can lead to an overmedicalization of care. The understanding derived from the three studies on family caregiving in India confirms that in only looking at the burden of families, we might run the risk of losing powerful leverage for enhancing support structures, as we fail to reinforce and empower people's natural ways of deriving strength; potentially through religion, positive habits or through culturally and family-induced value systems.

Strengths that were found in this study somewhat overlap with other studies and indeed confirm meaning-based coping, both from personal-cultural value systems (e.g. *I feel good when I'm taking care well of my loved ones, as I've been taught to take care of my relatives)* or faith-based sources (see also e.g. Murphy, 2016; Malhotra, 2015; Hebert, 2006; Thombre, Simonton & Sherman, 2010). In the context of coping mechanisms, many respondents mentioned praying to God and visiting religious places helped them to cope better and give them a sense of hope during distressed situations. Religion thus also plays an important role in meaning-focused coping, as connected to post-traumatic growth. Post-traumatic growth is a concept we found to in **chapter 6** on cross-cutting issues in caregiving. Indeed, in **chapter 6,** it was quite clear that over a period of time there was a sense of growth in the caregivers despite all the hurdles that one underwent during the journey of caregiving. In the caregivers of The Banyan, we found a similar pattern of post-traumatic growth, which includes a process of self-reflection that the caregivers were quite aware of after a reasonable period of caregiving. This also resonates well with the empirical research evidence that after devastating losses in life, caregivers recognize that the caregiving experience has not been without joys, achievements and opportunities for growth, both personally and spiritually (Clipp et al., 1995; Folkman, 1997; Folkman, Moskowitz, Ozer, & Park, 1997; Garfield, 1995; Moskowitz, Folkman, Collette, & Vittinghoff, 1996; Viney, Crooks, Walker, & Henry, 1991). This also further connects to the principles of positive psychology focused on enhancing resilience, hope and meaningful life.

Secondly, it is important to address the difficulties that are encountered by caregivers, in a systemic manner (as done in **chapters 5-7).** Caregiving is a meaningful process and a powerful journey of an individual and family, but is often increasingly burdened by several personal, psychological and socio-economic factors affecting the process. In India, there are extreme limitations of alternative support facilities and welfare measures for those with long term illness, such as mental disorders and chronic physical illnesses. Urbanization and nuclearization of families have resulted in greater burden on caregiving. As delineated in the introduction of this thesis, families do experience a range of challenges connected to stigma, poverty and lack of information and support to deal with mental illness. The studies in my thesis expand this initial understanding of family caregivers' burden to more analytical understanding of how the caregiving process takes place and actually includes several stages (well connected to the stages of grief as depicted in Kubler-Ross model of grief). While most studies study caregiver's burden as commonly experienced by caregivers regardless of their learning curve, **chapter 5** sheds light on how the experiences of caregivers change over time, and concludes with the notion that these 'stages' should be acknowledged in creating support strategies (**chapter 7)**. The final model that was derived includes six distinct stages which can influence each other and are contingent on one's experiences and reinforcements/losses during caregiving. While the stages are separately observable, and useful to consider by mental health professionals, I do not content that this is always a linear process for each family history (**chapter 7)**. The Banyan's phases model of caregiving starts with the 'manifestation of symptoms' (1), then 'seeking help' (2), helplessness and attribution (3), relative control and insight (4), loss and worries (5) and finally finding new meaning (6). Each phase is a dynamic mechanism that propels movement through the caregiving process.

How can we understand these phases? Indeed, most families when confronted with mental illness tend to seek for quick solutions, and finding ways to stop the embarrassment of having a mentally ill person in the family. Either the 'illness' has to be removed (e.g. through religious rituals or medication) or the family member runs the risk of being alienated. In the Indian context, the role of the family's reputation and pressure to function as a family unit within norms is very important. This is not just related to positive events in life but even with regard to illness, reputation and honor of the family are quite powerful in controlling family members and decision-making to a great extent. In **chapter 6,** it was found that caregivers were most embarrassed and experienced fear of losing family honor/reputation was more pressurizing than the illness itself. The stigma associated with mental health continuous even after the recovery of the individual. Labelling stands as a 'stop sign' for both the MH user and their families with regard to their identity and opportunities. 'Label' becomes the social identity of the individual with a mental health issue. As a result, the caregivers are prone to develop 'self-stigma' and make attempts to reduce social interaction in view of fear and anxiety of being socially discriminated. This was also found in studies conducted by e.g. Grover (2017) and Koschorke et al (2017), and also resonate with the theoretical framework of COC which emphasizes the need to stimulate an enabling environment with connectedness and partnership with caregivers (WHO, 2018). The mental health care system needs to be people-centered with continuity - interpersonal, longitudinal, management and informational, for stigma to be reduced (WHO, 2018).

After families understand the long-term implications of caring for a mental ill person, despair and a sense of helplessness can occur **Chapter 5**. Family members feel fatigued and in no position to continue caring. **Chapter 6** shows the importance of leveraging this stage in family caregivers by providing listening space, and help families reshape their frame of understanding and connected expectations. Psycho-emotional support becomes increasingly important, before the family caregivers can move into more advanced stages of the caregiving process and post-traumatic growth. This is also in alignment with the literature that highlights the resilience, optimism, and sense of coherence as three of the most important personal strengths exhibited by caregivers that assist in adaptation to caregiver stress (Fernández-Lansac, 2012; Ekwall et al., 2007). It is particularly in the last three stages of the process that professionals can support with a varied mix of practical (problem-solving oriented) as well as psychosocial support strategies to help relief respectively objective and subjective burden. Hence, the third point to discuss in this context, relates to the importance of creative and multifaceted health workers, and strategies that follow the stages of caregiving concurrently.

10.2.2. Strategies to support caregivers.

In **Chapter 7**, the aim was to build on the gained knowledge from the previous studies and follow with an assessment of how strategies can respond to the needs of caregivers according to the Banyan caregiving phases. In general, it was observed that at the start there is a need for information, for psycho-education, and practical help. It becomes particularly salient here for mental health professionals to be unconditionally open to the family (and stay in close proximity), offer information about the mental illness, and slowly stimulate a more holistic picture of the more chronic state of the patient. Formulating plans for continuous treatment might also be done at this stage. As earlier mentioned, when caregivers fall into the third stage of universal or personal helplessness, it is important for mental health professionals to recognize this stage, and focus on capacity building and providing psycho-emotional support to the family. **Chapter 7** gives a picture of the sensitivity and creativity (in dialogues, role-plays, positive reframing, etc.) counsellors and health workers require to empower caregivers at this stage, but also how this is naturally practiced by the NALAM and Banyan workers. The complexity of their work-profile becomes further enhanced when supported families in the fourth to sixth stage, as here the families require both action-oriented support (with e.g. support in accessing financial schemes, employment plans, or marriage counselling), complemented by support focused on family and individual wellbeing (stimulating leisure time, hobbies). If anything, **chapter 7** displays the resourcefulness and diversity of the involved health workers in supporting family workers. I would like to discuss this a bit further in a broader context, with particular reference to the fact that this study was conducted in a low-resource setting.

It seems that generally, but particularly in high income countries (in the West) it is more commonly practiced to separate evidence-based therapies from more lower level care (see e.g. Barnett, Gonzales & Miranda, et al., 2018). In our setting, although individuals with severe mental health needs are treated by professional psychiatrists and psychologists, a relatively large part of the care responsibilities falls on the shoulders of lower- educated community health workers (HCW's), who are trained and supervised by the Banyan. In the context of family caregivers, HCW's may take up a variety of different roles, but within that often offer case management and therapeutic support as well. In the context of low-resources, the effectiveness and efficiency involved in capitalizing on lower educated professionals or 'lay workers', has often been described (see e.g. Patel et al. 2010), and even be the sole therapy provided (Bolton et al., 2014; Murray et al., 2015). As such, it has been suggested by Barnett et al (2018) that roles and responsibilities of HCW's in certain regions may be expanded to meet the needs of communities with lack of access and infrastructure, but even in higher resources may be able to play a role in delivering care in culturally and socio-economically diverse settings (such as e.g. in the US). We also find that HCW's are more likely to deliver care in an engaged and culturally sensitive way. This was also found in a study in India by Chatterjee, Patel & Chaterjee (2003) in which lay health workers were more able to communicate with the local community, leading to better psychosocial support. Similarly, van Ginneken et al. (2017) found that lay health workers were better positioned to deliver support because of their stable community residency.

Naturally, it thus becomes important to look more carefully at what types of training and supervision are actually needed to find an optimum equilibrium between costs and benefits, evaluating the costs of training and support of HCW's in relation to mental health professionals, in combination with care outcomes. Finally, it would be useful to shed more light on how care is effectively coordinated between easier and more severe cases (van Ginneken et al. 2017), also for families who provide care to a relative with chronic mental health needs. The WHO framework (2018) on continuity and coordination of care also emphasizes the role of community health agents in family care. Traditional practices of care rely heavily on health care professionals ignoring the innovative and creative perspectives that field workers can bring into care services. The Banyan's continuity of care program also used NALAM workers to meet families and this brought about a closer network and alliance between caregivers and specialized care. Since the NALAM workers were from the same community and local village, there was access to them immediately and caregivers identified themselves more easily with NALAM workers. When it is not possible to have qualified professionals to cater services, instead the studies in this thesis show that services can be expanded by empowering community mobilisers as a form of reorienting the model of care (van Ginneken et al. 2017).

10.3 Supported housing: development and upscaling

In the previous part of the discussion, I address how my thesis focused on understanding, improving and supporting family caregiving, as an existing form of COC, and how my findings can be understood in reference to other studies. In the final section, I would like to give answer to the questions raised about alternative forms of COC, and more specifically the model of Supported Housing. Supported Housing has come up as an important intervention for people with chronic mental needs, also in response to increasing critic on the hospitalization of persons with SMI. In the introduction of **chapter 8**, I describe the history of hospitalization, globally and in India and how the mental system has evolved in acknowledging the importance of quality of life, and continuation of care in a humanly dignified way (e.g. with the community). While earlier medical models focused entirely on 'treating' sick people, community- and person-centered models of care recognize the need to focus on concepts of wellness and wellbeing as intrinsically important to any person suffering from mental illness (Connell, Brazier & O'Cathain et al., 2012). Thus, there has been more attention for the living- and working conditions of persons with SMI, translating to studies that focus on community integration, personal relationships, autonomy, social skills, physical health, belonging and satisfaction, etc. (Goldfinger,1996; Connell, Cathain & Brazier, 2014; Slade, 2010).

With the attention for wellbeing, there was also a need to develop care models in which 'patients' could be treated, and live relatively normal. To provide the opportunity for persons with mental illness, to still live a life outside of the hospital and in the community, required a flexible and person-focused type of support, operating to address the needs of service users (McPherson et al.,2018). 'Housing First', a model developed in the US, responds to this movement by placing an emphasis on delivering mental health care for homeless persons in the community, and as an alternative to a 'stepped' model in which persons gradually move up through different institutions towards independent living. The 'treatment' approach that says; '*independent living when they are ready',* is contrasted in this model of Housing First, which seeks to provide independent housing as a starting point. This US-based model, but also other models of Supported Housing have been applied in many different settings in the past decades, but failed to really take root in India. In **chapter 8** and **9**, I describe the results of the Home Again model of the Banyan in reference to how we can develop such models in a sustainable manner in South India, and how to implement the same model in other contexts as well. I will discuss the key findings of these studies a bit further.

10.3.1. Developing a Supported Housing model in South India.

The Banyan, in response to the need for designing a novel community intervention for homeless women with chronic and long-term needs, initiated the SH model in the close proximity of the ECRC. The study described in **chapter 7** focuses on an implementation process that led to innovation in the care systems of homeless persons with chronic needs. The implementation process was understood as three stages - (i) pre-implementation, (ii) confrontation and adaptation phase and (iii) stabilization phase. This intervention also provided scope to understand both MH users, community and the role of HCW's from a mental health system reform point of view. What emerged clearly from the study on the innovation development is that, although there was some clarity on the direction (e.g. more autonomy for clients, independent living, building strong relationships among clients and with the community, etc.), the technicalities as well as the cornerstones of the concept (For whom? Under what conditions? For how long?) were yet to be built.

In the development, the Banyan, as part of their person-focused approach decided to include all the stakeholders in most of the decision-making processes. In Strategic Niche Management (SNM) such co-creation processes are also recognized as important ways of leveraging organization's ability to innovate, optimize processes, adapt products and services to user's actual needs, and thus create a more sustainable positioning by being more flexible in the development process (Hurni & Grosser, 2017). Service-users, as part of the selection process, were invited to brainstorm on the concept of 'home' and what it would look like to live independently. They connected home to the idea of 'family', and the participatory process helped them also reflect on potential fears, and reasons to 'not move out'. While this process could be considered tiresome, or unnecessary, **Chapter 7** shows how much of the initial fears (which can form obstacles to the development process) could be understood and better handled. When stakeholders are involved, they can also participate in creating more value, and act collectively to mitigate uncertainties. Apart from the service users, community members & landlord, this process of sharing responsibility was particularly useful in working with the HCW's. In all the steps of the development process, they were consulted and encouraged to take decisions and create strategies. The HCW's had many queries and their complete novice became their strength to sustain a community-based approach. For instance, in response to the HCW's's observations and sensitivities, during the earlier phases of the Supported Housing model, the service users could still move back and forth to the ECRC, which helped to build trust. Including health workers in health innovation was also seen as one of the key factors for successful development in a review by Cyrill, Smith & Renzaho et al. (2015), emphasizing particularly the need for HCW's that understand the culture of the community. Similarly, engaging HCW's in the development process turned out to be important to motivate and inspire them to be part of the process, and even live with the service users. Again, the review by Cyrill et al. (2015) warns that programs often fail due to lack of means to motivate HCW's, confirming the importance of participatory and co-creation approaches.

While this participatory approach is inherently a characteristic of The Banyan, the outcomes of the SH model also show the relative effectiveness of co-creation and mutual learning. Because of the time taken to develop this model together, aligning research and service development, the SH model could move towards a stable phase with relatively little trouble. Thus, we found that there were significant changes in the social relationships and physical health in the women who moved from a hospital setting to supported housing. Such results were also seen in other studies (e.g. McPherson et al. 2018), but are new in this particular context in South India. Finally, this study is remarkable in the sense that it decided to employ the SH alternative for people with severe mental health problems, instead of those with mild issues. The positive results that were gained here are therefore particularly unique, and motivated The Banyan to scale-up the project. The next question was thus how to implement the project in different regions in a sustainable manner, and test how SH functioned in comparison to other care models. I end the discussion by exploring the findings related to this question.

10.3.2. Supported Housing compared to care as usual.

Scaling-up of services for persons with mental health issues is one of the most important priorities for global mental health, particularly for LMICs and '*more attention needs to be directed to implementation science'* (Patel, 2010, p. 1977). One step towards better implementation is to actually work towards evidence-based knowledge, such as achieved in RCTs. As mentioned in the introduction to this thesis, an important step in the 3T's roadmap to transform healthcare systems comes after clinical efficacy research (*testing what works such as in chapter 8*), and involves testing who benefits from promising care (outcome and comparative research) (Dougherty & Conway, 2008). **In chapter 9,** the Banyan's supported housing model got translated to a larger project of 'Home Again', and was systematically evaluated in comparison to Care as Usual (CAU). The model showed significant impact on community integration and disability. There is a significant impact on community integration when compared to a matched cohort of users from CAU, especially in sub-domains including e.g. greater involvement at home and in household chores. There was an increase in social activities such as shopping, leisure and social contacts, increase in work participation. In addition to quantitative data results, ethnographic observations highlighted the concept of family at Home Again through offered social support between family members fostering hope and independence. It was also observed that reduced supervision and the interdependence that arises from the familial bonding further nurtured social well-being. Families were formed between members of a home who adopted different roles in the family. Personal assistants who offered support also became a part of the family. Especially since the outcomes show that persons with severe mental health issues can continue to be cared for in independent living facilities, and do not regress in their psychosocial status as compared to CAU in hospital settings, the outcomes can be considered promising enough to be implemented and tested in other settings (Dougherty et al. 2008).

10.4 Reflections on validity

In order to reduce any threat to internal and external validity, various methods and co-researchers were used to further validate the data collected in this thesis.

10.4.1 Internal Validity

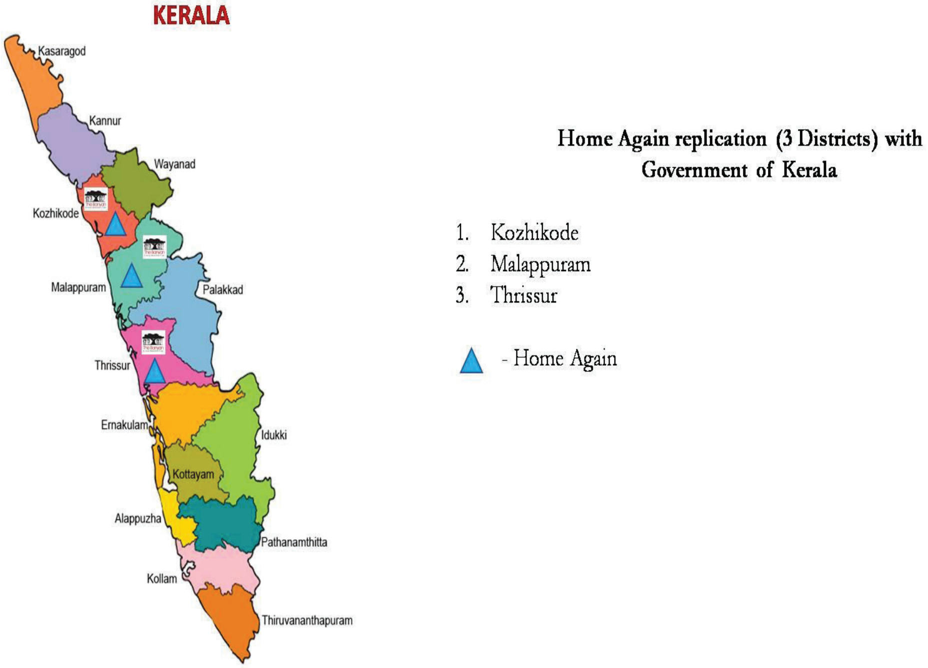
All instruments were translated in the local language and back translated before data collection. Member checks were done by the participants to reconfirm that the information that was collected was the actual representative of their views. Information was also cross checked with field experts, professionals and grass root workers involving multiple levels. Finally, triangulation was achieved by using at least multiple data-collection instruments and physical data records during research. A combination of individual interviews, group interviews, and surveys could substantiate information retrieved through one instrument.

10.4.2 External Validity

The thesis is placed in the context of The Banyan's work in South India and keenly focussed on homeless with SMI. The external validity of the study relates to the extent to which the results of the study may apply to other organisations and communities in Tamil Nadu and other parts of India. To enhance the external validity of the findings, some exploratory interviews were conducted involving members of the community, professionals, and public officials. Alternatively, the unique aspects of homeless women such as their power relations, gender roles and social practices reinforces the fact that The Banyan has MH users from diverse cultures and geographical areas. Exploratory method were used to understand the findings with less specificity and more generality.

10.5 Limitations of the study and ideas for future research

Globally the overall volume of mental health services needs to increase but especially in low-income and middle-income countries the availability and the need for care is disproportionate. Scale-up projects might help to bridge this gap, and promising projects such as Home Again might be adopted at municipality and state level. There is a need for multiple stakeholders such as the government, donors, agencies, public health organizations and consumer group to represent collaboratively as mental health stakeholders to facilitate scaling up of mental health care interventions. As far as pharmacological and specific psychological interventions are concerned there is adequate information from LMICs and MICs but with very poor outcome indicators. As mental health organizations and research scientists, there is a significant need to research pilot studies and scale up innovations for sustainable models of care. Till date, the Banyan managed to scale up Home Again in various parts of India with partnership with the state government. Home Again has been extensively replicated in Tamil Nadu Chennai, Tirupur and Trichy with MH users who are long stay and have chronic needs at the ECRC (Emergency Care and Recovery Centre). In Kerala (3 districts) and Maharashtra (Ratnagiri), Home Again has been replicated in partnership with the State Government to end incarceration in state mental hospitals(see figure10.4.1).



In the context of this PhD doctorate it was not feasible to study the implications of these scaling procedures, especially as most of these activities occurred after most of the data collection had finished. My study was therefore limited to understanding how Family Care can be improved, and SH can be developed in the local context of the Banyan sites in Tamil Nadu. In the future, I believe there is a scope to understand how interventions such as SH are actually adopted and adapted in different settings, and how they are successfully sustained.

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Summary

The global burden and magnitude of disease attributable to mental disorders has drawn significant attention in the recent years, emphasising the immediate urgency for better systems of prevention and treatment of these disorders. The problem is more acute in low- and middle income countries, where there is acute crisis, lack of treatment and poor accessibility of care, widespread stigma and prejudice. Globally, 450 million people suffer from mental illness as a major concern. 75% of these individuals are from middle-and-low income countries (WHO, 2018) In India, 150 million people are suffering from mental health disorders and are in need of regular treatment (NIMHANS, 2019). More than 50% of individuals are deprived of treatment for mental health disorders and this rate increases in countries with inadequate resources such as India (Saxena et al., 2007). According to Rathod et al. (2017), 80% of all mentally ill people are born in low- and middle-income countries (LMICs). Globally, mental health issues in the homeless population reflect a complicated mesh of socio-psychological, cultural, and economic issues, and much has been written about the relationship between homelessness and SMDs. The problem of homeless persons with mental disorders (HPMD) is a complex issue within the Indian context, connected as it is to stigma, gender inequality, deficiencies in mental health awareness and support, and a gross neglect of their rights (Swaminath, Enara & Rao, et al., 2019). Although the consequences of SMD are serious, mental health care for the homeless population has not been treated as a serious problem by many health systems.

Homelessness is an outcome of the interaction between intrapersonal and structural factors (Fazel et al. 2014) with mental illness. Poverty, mental illness, addiction, lack of affordable housing, and socioeconomic inequities lead to homelessness (Bird et al., 2010; Perrisini, 2009; Somers et al., 2016). The prevalence rates of mental illness are high among the homeless population (Evans & Wells, 2003: Forchuk et al, 2007), while factors such as socioeconomic disadvantage, childhood adversity, trauma, and domestic violence are inherently involved in the trajectories between mental illness and homelessness (Shelton et al, 2009). Homeless persons with mental health issues encounter ostracization, social rejection, and stigma (Rae and Rees 2015; Siskind et al. 2014).

This thesis emphasizes the need for developing user-centric mental health services and a range of interventions required for homeless persons with chronic mental health needs along with continuity of care in the community. The objective of this thesis was to understand how change in the mental health system in India could potentially be leveraged to improve continuity of care (COC) for persons with severe mental health disorders (SMDs). Especially in recognising the perpetuity of homelessness, poverty and mental illness, finding ways to improve and sustain care was considered as an important quest. This thesis particularly tried to employ a research and innovation approach that is constructive, user-centric and focused on dignified living for all people. This meant moving away from social exclusion, practices of criminalization (of begging) and incarceration, but also from prolonged inpatient treatment and hospitalization, towards models that improve quality of life for persons with SMI. Thus, the questions posed in this thesis focused on understanding how COC can be improved through better family caregiving and alternative models, specifically Supported Housing. The following main research question was asked, based on the innovative intervention models of The Banyan, a non-profit organisation based in India, which has been working with homeless people with mental illness since 1993:

> **Main Research Question:** How can mental health systems in India become more adaptive to serve the needs of those with chronic mental health needs in the community, and to support caregivers in delivering continuity of care ?

The answers to these questions are provided in three parts. Part 1 considers the broader social-political situation in which homeless persons with SMI construct their lives. Part 2 understands the pathways to improving COC. It also particularly focuses at ways of systematically enhancing and supporting a very common and natural way of organizing COC through family caregivers. Finally, in Part 3 one of the complex problems of homeless people is understood based on a new model of COC – supported housing in South India, in order to understand how such innovative interventions can become sustainable and implementable in various other sites.

The main question was thus approached with the following sub-questions:

Sub-question 1: How can the experiences, dignity, and aspirations of homeless persons with mental illness be understood in the current context of India's political system and legislation processes?

Sub-question 2a: In the context of de-hospitalization, how can we understand the experiences of family caregiving as an integral part of COC for persons with chronic mental health needs?

Sub-question 2b: How can family caregivers be better supported in their caregiving role, in order to preserve and improve COC for persons with chronic mental health needs?

Sub-question 3a: How can alternative COC programs, modelled on housing first principles, be developed in the context of South India, for persons with chronic mental health needs?

Sub-question 3b: In the context of preparing alternative COC models such as Supported Housing for upscaling, how can we understand its basic outcomes in comparison to care as usual?

This thesis used an interactive approach combining quantitative and qualitative studies to answer the main question, and associated sub enquires. Continuity of care (COC) is used as a theoretical concept to gain more understanding of persons with severe mental disorders as a significant indicator of a well-functioning health system. The COC framework helps to conceptualize the continuation of good care across the lifespan of people, with emphasis on creating an enabling environment. Recovery is not to be understood based on the journey of an individual but caregiving itself is a process of recovery. Both caregiver and MHC user perspectives are to be taken into consideration, stressing the importance of wholistic care systems in the face of significant social and economic barriers. Transdisciplinary research process was applied as it presents a critical alternative to conventional methods of problem-solving for complex, persistent issues. Strategic niche management and Positive Psychology theories were used to analyse mechanisms for knowledge co-production, integration and radical system change within the framework of recovery.

In **Part 1 - Chapter 4** throws light on the destitution bill which fails to adhere to the basic rights and autonomy of an individual. It sheds light on the complex relationship between homelessness and its causes and consequences of incarceration in relation to begging. This chapter also explores on what are the possible alternatives might be available to substitute the anti-beggary law. The possibility of financial support through basic income, housing options, and the need for mental health services, education, and other basic activities were emphasised. In this way, this chapter, attempts to understand sustainable approaches to care, in the community, that are sensitive to diverse (mental) health needs. This chapter also examines the bill, critiques the incarceration model, and offers alternative ways to respond to beggary and homelessness in law and policy that emphasise care and rehabilitation. This chapter portrays the exploration of views and perspectives of vulnerable persons who have been convicted under the current system of the 'Bombay Prevention to Begging Act', their perception of the current legalities, the proposed destitution law and the support systems that they require from the state. The semi-structured interviews of 24 respondents who were incarcerated for begging and currently residing in beggar homes revealed that they were not informed about the reasons for being incarcerated and were taken away without their consent or voluntary participation. The findings revealed that the majority of them said that the proposed destitution bill was unfair and needed to be abrogated. Some also revealed that they desperately want to contact their families even as the benefits of continuing to stay in beggar homes outweighed their emotional needs with regard to their family.

In **chapter 5** and **chapter 7**, the role of caregivers is often associated with burden and their strengths is usually ignored and not considered significant to understand the positive gains of caregiving. This is explored in this chapter based on research done on three studies on caregivers and their caregiving process. The process of caregiving journey need not necessarily get associated only with negative terms but can also be viewed through the lens of strengthening virtues of a caregiver, protective factors that has helped in continuing caregiving and the possible strengths that are derived due to caregiving. Results indicated that post-traumatic growth and the crucial role of religion in meaning-focused coping, as connected to post-traumatic growth were key factors. **Chapter 5** also sheds light on how the experiences of caregivers change over time, and concludes with the notion that these ‘stages’ should be acknowledged in creating support strategies (**chapter 7)**. The final model that was derived includes six distinct stages which can influence each other and are contingent on one’s experiences and reinforcements/losses during caregiving. While the stages are separately observable, and useful to consider by mental health professionals, I do not content that this is always a linear process for each family history (**chapter 7)**. The Banyan’s phases model of caregiving starts with the ‘manifestation of symptoms’ (1), then ‘seeking help’ (2), helplessness and attribution (3), relative control and insight (4), loss and worries (5) and finally finding new meaning (6). Each phase is a dynamic mechanism that propels movement through the caregiving process.

In **chapter 6,** it was found that over a period of time there was a sense of growth, which includes a process of self-reflection, in the caregivers despite all the hurdles that one underwent during the journey of caregiving. Caregivers recognized that the caregiving experience has not been without joys, achievements and opportunities for growth, both personally and spiritually. In the context of coping mechanisms, many respondents mentioned praying to God and visiting religious places helped them to cope better and give them a sense of hope during distressed situations. It was also found that caregivers were most embarrassed and experienced fear of losing family honor/reputation was more pressurizing than the illness itself. The stigma associated with mental health continuous even after the recovery of the individual.

In **chapter 7,** the aim was to understand the role of the phases and the strategies in each based on the needs of the caregivers during each phase. There was a great need for information, specific information about the illness and need for practical help. It becomes particularly salient here for mental health professionals to be unconditionally open to the family (and stay in close proximity), offer information about the mental illness, and slowly stimulate a more holistic picture of the more chronic state of the patient. Formulating plans for continuous treatment might also be done at this stage. As earlier mentioned, when caregivers fall into the third stage of universal or personal helplessness, it is important for mental health professionals to recognize this stage, and focus on capacity building and providing psycho-emotional support to the family. **Chapter 7** gives a picture of the sensitivity and creativity (in dialogues, role-plays, positive reframing, etc.) of lay workers require to empower caregivers at this stage, but also how this is naturally practiced by the NALAM and Banyan workers. The complexity of their work-profile becomes further enhanced when supported families in the fourth to sixth stage, as here the families require both action-oriented support (with e.g. support in accessing financial schemes, employment plans, or marriage counselling), complemented by support focused on family and individual wellbeing.

Chapter 8, describes the history of hospitalization, globally and in India and how the mental system has evolved in acknowledging the importance of quality of life, and continuation of care in a humanly dignified way. Earlier medical models focused entirely on 'treating' unwell persons, but the community and person-centered models of care recognize the need to focus on concepts of wellness and wellbeing as intrinsically important to any person suffering from mental illness. With the attention for wellbeing, there was also a need to develop care models in which 'patients' could be treated, and live relatively normal. To provide the opportunity for persons with mental illness, to still live a life outside of the hospital and in the community, required a flexible and person-focused type of support, operating to address the needs of service users (McPherson et al.,2018). This chapter laid out the processes in pre-implementation of a supported housing facility for long term MHC users in a psychiatric hospital. Qualitatively, behavioural observations showed a significant improvement in activities of daily living and social relationships. There was also great insights in the observations that were made by the health care workers based on pre and post observations that they have seen of the MHC users while they stayed at the hospital and after they shifted to a housing facility.

In chapter 9, the Banyan's supported housing model got translated to a larger project of 'Home Again', and was systematically evaluated in comparison to Care as Usual (CAU). The model showed significant impact on community integration and disability. There is a significant impact on community integration when compared to a matched cohort of users from CAU, especially in sub-domains including e.g. greater involvement at home and in household chores. There was an increase in social activities such as shopping, leisure and social contacts, increase in work participation. In addition to quantitative data results, ethnographic observations highlighted the concept of family at Home

Again through offered social support between family members fostering hope and independence. It was also observed that reduced supervision and the interdependence that arises from the familial bonding further nurtured social well-being. Families were formed between members of a home who adopted different roles in the family. Personal assistants who offered support also became a part of the family. Especially since the outcomes show that persons with severe mental health issues can continue to be cared for in independent living facilities, and do not regress in their psychosocial status as compared to CAU in hospital settings, the outcomes can be considered promising enough to be implemented and tested.

This thesis summaries the complex challenges homeless people face in addition to mental health issues. Gender and mental illness also have high correlation with regard to the homeless population. There is a need for more sensitivity in understanding the homeless population. The destitution bill criminalises begging by completely ignoring several other factors such as poverty, social isolation and poor support systems. Homeless persons with mental health issues are either incarcerated for begging or continue to be homeless with high disability profile. There is a need for innovative and sensitive models to cater services to the homeless population. Supported housing models and innovative care packages for continuity of care is very essential to reduce homelessness. Mental health systems have a dogmatic approach to care processes which hinders recovery in a meaningful way.

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Archana Padmakar

About the Author

Archana Padmakar did her PhD at Vrije University, Amsterdam. Her PhD thesis focusses on Bringing mental health care closer to home: understanding and improving continuity of care for homeless women with severe mental disorders in South India. She has completed M.Phil in Clinical Psychology. She is a licensed Clinical Psychologist certified by the Rehabilitation Council of India. She has been working in the Mental Health Sector for 13 years. She has specialization in treating homeless women and women, children and adolescents with mental health issues. She has practiced utilizing a wide range of holistic psychological interventions and techniques that can provide every mental health user with an individualized experience.

She has experience in working in diverse clinical settings including inpatient and outpatient centres - expertise in working with homeless women with mental health issues and also working with support groups comprising of caregivers. She is also practising low-cost therapy for individuals, couples and families. She currently heads Emergency Care and Recovery Centre at The Banyan and it has been adopted in few states across India. Her expertise in recovery pathways for people with mental health issues led her to research models of long term care, continuity of care and support structures that families would require as part of her PhD and user-centric models of care.

She also heads the department of Clinical Psychology at The Banyan. She is also faculty at the Dept. of Applied Psychology at Banyan Academy of Leadership in Mental Health (BALM) teaching students of Masters of Clinical Psychology and Counselling Psychology.