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Exploring family resilience in a community mental health setup in South India

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Abstract

The purpose of the study is to identify the socio-demographic characteristics and understand the level of family resilience of clients and their caregivers seeking treatment for mental illness within a community mental healthcare set-up. The sample consists of 60 respondents from impoverished urban and semi-urban families whose family members are currently undergoing treatment at the community mental health clinic run the Mental Health Action Trust (MHAT), a local NGO based in the northern region of Kerala in South India. The methodology requires the participants to report the current symptom severity for their family members suffering from chronic mental illness, using the 18-item Brief Psychiatric Scale. They were then interviewed about how different aspects of family resilience applied to their own lived experiences as primary caregivers using Sixeby's Family Resilience Scale based on Walsh's conceptual framework of family resilience. The study is expected to contribute to understanding how families might be nurtured and strengthened using Walsh's family resilience approach in an Indian cultural context.

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Keywords: mental illness; family resilience; community mental health; caregivers; strengths-based approach; vulnerability; poverty

1. Introduction

Resilience is referred to as the ability to bounce back from adversity or crisis. Bonanno et al (2001, as quoted in

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Bonanno, 2004) defines resilience as being about more than just the absence of psychopathology, but as a "stable trajectory of healthy functioning across time as well as capacity for generative expressions and positive emotions." This characterisation of resilience is in line with the WHO (2005) definition of health, i.e. health being the composite of an overall wellbeing in physical, mental and social dimensions of the person and his/her life, and not merely the absence of any disease, infirmity or injury. Luthar et al (2000) provide a historical overview of the evolution of the concept of resilience, the beginning of which can be traced back to research on schizophrenia, especially with children of mothers diagnosed with schizophrenia and children who had been considered as high-risk for developing psychopathology but had proven to grow up to be responsible and productive adults (O'Dougherty Wright, Masten and Narayan, 2013). Throughout the subsequent decades, the focus has shifted from risk to resilience (Coleman and Ganong, 2002; Rutter, 1999).

In the Indian context, family members may assume the role of primary caregivers for two main reasons: firstly, the cultural customs of interdependence and collectivism that encourage a joint effort in taking care of relatives with mental illness, and secondly, the shortage of professionals, services, and facilities to administer to a vast majority of the Indian population requiring psychiatric treatment and mental healthcare (Avasthi, 2010). This is echoed by Rammohan et al (2002) and Zauszniewski et al (2010) who also discussed some notable features of caregivers in families which had a member with mental illness. Studies that describe risk factors affecting resilience of caregivers and their families have noted that the paucity of accessible, available and affordable mental health services can unfavourably alter outcomes. The same review also found mention of certain socio-demographic factors that can influence a caregiver's perception of family resilience, such as age and education. That is, there was a connection between the caregiver having more health problems or facing more issues in family functioning if the caregiver was significantly older or if the caregiver had obtained little education.

This study will aim to identify socio-demographic characteristics of clients and caregivers and understand their levels of family resilience seen, within two clinics (one in an urban setting, the other in a semi-urban setting) in a collaboratively-run community mental healthcare set-up. The methodology uses a structured interview method of data collection, using the Brief Psychiatric Ratings Scale (BPRS) to measure the client's current level of symptom severity as reported by their caregiver and the Family Resilience Assessment Scale (FRAS) to assess levels of family resilience perceived by the same caregivers for their families. The data is analysed to understand the caregiver's perception of how their family is able to cope with adverse events and whether they display high levels of family resilience and in what component areas of the framework does the family do well with regards to family resilience.

2. Review of literature

One of many definitions commonly cited when explaining resilience is the following: 'the capability to flourish despite normative fluctuations that take place throughout the life span' (Bonanno, 2004; Seligman and Csikszentmihalyi, 2000, as quoted in Marin and Vazquez, 2012), and has been of increasing interest in the social sciences for many decades. As Marin and Vazquez (2012) mention, resilience was considered a trait inherent to an individual, or considered to be influenced by a number of personality characteristics that allowed certain individuals to achieve success despite facing adversity (Higgins, 1994). Later research came to show that resilience can be learnt over time. That it can be grown through supportive and fostering social ties and bonds form the basis of building wider social networks of support encompassing not only individuals but families and communities too. In recent times, it has evolved to be inclusive of the larger social policies that shape the local and global public health responses to disparities in healthcare.

Bronfenbrenner (1994) put forward the definition of the "microsystem" as the innermost level of the ecological environment. The family unit is an example of a microsystem. In this perspective of human development, the family is the stage upon which all family members play out their roles and responsibilities towards one another (McCubbin & McCubbin, 1991). Resilience is then the cumulative effect of the interactions between protective and risk factors as well as the subsequent effects of such factors on the individual's wellbeing. Factors might include personality

traits, cognitive thought processing styles, concepts of self, and physical health at the individual level, while family-level factors can include attachment and parenting styles, family structure and communication patterns, and social support systems or networks outside of the family. At the environmental level, factors affecting resilience include social exclusion, social conditions, education, health, and community participation (CAMH 2007).

In its initial avatar as 'relational resilience', resilience within the family unit was described by Jordan (1992) as involving components such as family organizational patterns, communication and problem-solving processes, access to community resources, and affirming belief systems held by the family unit. Walsh further developed these ideas into a framework of family resilience (1996, 2002, 2003, 2012) seeing it as being integral to providing "psychological inoculation" for the members of the family unit. Black and Lobo (2008) described the characteristics of resilient families in terms of the protective and recovery factors that contribute to optimum family health: a positive outlook on life, shared spirituality, accord between family members, flexibility of roles allowing for adjustments as per need, clear and open communication between family members, sound financial management, quality time spent with each other in both daily activities and recreational activities, steady routines to give a sense of stability even when the family is in crisis, and access to and availability of individual, familial, and community networks that provide resources and social support. Similarly, Benzies and Mychusiak (2008) assigned three domains of resilience: individual, family, and community. Factors considered to be related to family resilience were family structure, intimate partner relationship stability, family cohesion, supportive parent-child interaction, stimulating environment, social support, family of origin influences, stable and adequate income, and adequate housing. Looking at family resilience in practical application in social work practice is about using a strengths-based approach to help the family resolve the problems that threaten the equilibrium of the microsystem. Table 1 demonstrates the differences between traditional and resilience-based approaches in counselling and therapy for families, as explained by Simon et al (2005).

Table 1: Simon et al (2005) summarising differences between traditional and resilience-based approaches

Aspect	Traditional approach	Resilience-oriented approach
Focus and purpose	Diagnose and correct family dysfunction	Identify and utilize family resources
Role of diagnosis	Prerequisite for effective treatment	Unnecessary for effective treatment
Role of assessment	Gather information from the past to identify pathology	Identify current and potential family strengths and resources
View of problem	Problems indicate underlying family pathology (i.e., family is sick)	Problems indicate unsuccessful solution attempts (i.e., family is stuck)
View of family	Family is deficient and requires extrafamilial expertise and intervention	Family is resourceful and capable of marshalling their own resources
Role of practitioner	Expert	Collaborator
Language	Deficit-oriented	Strength-oriented
Source of treatment	Interventions originate from the practitioner	Interventions originate from the family's strength and resilience
Nature of treatment	Problem-focused, pathology-driven remediation	Solution-focused, strength-driven empowerment
Use of external support	Minimal use of external supports and resources	Liberal use of external supports and resources
Desired outcomes	Decrease family dysfunction	Increase family resilience

There have been interventions conducted based on the strengths-based approach in both the global and Indian context, and family resilience seems to show theoretical validity across cultures and borders (Patterson, 2002). While prevention of mental disorders and promotion of mental health are distinct but overlapping aims, resilience is a concept that forms the kernel of mental health promotion efforts (CAMH, 2007). Within a public health framework, creating and improving upon resilience would allow amelioration of not just medical and psychiatric factors but also of social, environmental and cultural factors among others. As part of the public health approach to mental health, emphasis on community mental health care is vital (Davydov et al, 2010; Friedl, 2009; Seccombe,

2002). Saraceno and Barbui (1997) found in their review of epidemiological data from the international literature that poverty was a risk factor for negative outcomes for persons with mental illness and that lack of access and/or availability of psychiatric or mental healthcare services and facilities might have an impact on outcomes as well.

With regards to measuring resilience, a number of scales are in existence but there is no 'gold standard' as such (Windle et al, 2011; DeHaan et al, 2002). Most measures look at resilience at the individual level rather than at a family level. In a methodological review of resilience measurement scales done by Windle et al (2011), three (out of 15) received the best psychometric ratings, but in the larger picture, these - the Connor-Davidson Resilience Scale (CD-RISC), the Resilience Scale for Adults (RSA), and the Brief Resilience Scale (BRS) - can be considered as only being moderately valid, as they are suited only to certain settings/populations or requires further theoretical development. Sixeby (2005) developed a Family Resilience Assessment Scale (FRAS) based of Walsh's theoretical framework, and splitting the concepts into six subscales of family communication and problem-solving, maintaining a positive outlook, utilization of social and economic resources, family connectedness, family spirituality, and family ability to make meaning of adversity. Due to the open-ended nature of the final item on the scale, and thereby qualitative nature of the question, it can be left out of quantitative data analysis or not used in data collection. Kaya and Arici (2012) adapted the same questionnaire into a Turkish version in order to explore its psychometric properties and concluded that the family connectedness and family spirituality subscales could be excluded as well. This brought down the number of subscales to four and total number of questions to forty-four.

While some studies have shown that using Walsh's framework for research and clinical practice is beneficial, such a study is yet to be conducted in this particular region (South India) or setting of services and practice (community mental health clinics run in and managed by semi-rural, semi-urban, and urban communities).

3. Methodology

The Mental Health Action Trust (MHAT) is a not-for-profit organisation that provides free, comprehensive, community-based, volunteer-led, cost-effective mental health care to the poorest people of the localities they serve, including the wandering homeless mentally ill. It aims to provide long-term management of chronic mental disorders through a system of community-owned and managed care, supervised and run by MHAT within three districts of Kerala. Since its founding in 2008-09, the organisation has delivered treatment and interventions to 2500 clients. The interventions range from weekly outpatient psychiatric clinics in the local communities to initial and follow up assessments by the MHAT team comprising psychiatrists, clinical psychologists and social workers, psychotherapy and locally-based rehabilitation programmes, and provision of home-care visits by the clinical team when necessary. Each client in this model is looked after in the community by a trained volunteer care worker from the same community, who acts as his/her care coordinator.

The study seeks to reveal respondents' experience as a starting point to future research on family resilience in the Indian context. Purposive non-random sampling was done to identify sixty respondents who were primary caregivers for clients seeking treatment for mental illness at two of MHAT's collaboratively-run community mental healthcare clinics (30 from each clinic) in Malappuram district of Northern Kerala. The respondents were administered the self-prepared socio-demographic questionnaire, the Brief Psychiatric Rating Scale (BPRS) and the Family Resilience Assessment Scale (FRAS) by the researcher in Malayalam, the local language in Kerala. Socio-demographic data collected included the following items of both the primary caregiver and client: age, gender, religion, level of completed education, marital status, employment status, family details (nature of residence – own house/renting/staying with family or in ancestral home; joint family or nuclear family; number of members in the household – in case the primary caregiver was not a member of the client's household/residence). The caregiver was asked to answer the following items as well: their relationship to the client, whether there were other family members being treated for mental illness, number of family members who support the primary caregiver in caring for the member with mental illness – up to 3 members can be recorded), number of years of mental illness of the client, number of years the client has been undergoing treatment with the community mental health clinic, the caregiver's current perception of the client's symptom severity, and the time period for which the caregiver

considers the client to be without symptoms of their mental illness.

The BPRS consists of 18 symptom constructs and takes 15-20 minutes for the interview and scoring. Each item was scored from 1 (not present) to 7 (extremely severe) and 0 was entered if the item was not assessed/not known. The scale was scored by adding each item score for a range of 0-126. The Cronbach's Alpha measure for this tool when administered in Malayalam was found to be 0.787. The FRAS measure uses a 4-point Likert Scale that ranges from 1 (strongly disagree) to 4 (strongly agree), with items 42, 48, 57, and 62 being reverse scored; i.e. from 4 (strongly disagree) to 1 (strongly agree), and contains 6 subscales. The overall internal consistency of the FRAS is $\alpha = 0.96$ and has good criterion validity with three well-known instruments (Sixeby, 2005; Plumb, 2011). A higher score indicates a high level of family resilience, and a low score indicates a low level of resilience. The FRAS consists of sixty-six questions and one open ended question (not used in this study). For this tool which was also administered in Malayalam, it was found that the Cronbach's Alpha measure was 0.925 for the FRAS (consisting of 54 items), and 0.935 for the further-shortened version of 44 items and 4 subscales as suggested by Kaya and Arici (2012).

4. Results

Table 2 summarises the socio-demographic data for the clients and caregivers who formed the sample for the study. The clinic in the semi-urban community setting was designated as Clinic 1 and the one in the urban community setting as Clinic 2.

Table 2: Socio-demographic data for clients and caregivers

Socio-demographic Category	Clients Frequency (%)	Caregivers Frequency (%)
Age		
0 – 19 years	0 (0)	3 (5.0)
20 – 29 years	9 (15.0)	7 (11.7)
30 – 39 years	22 (36.7)	16 (26.7)
40 – 49 years	15 (25.0)	12 (20.0)
50 – 59 years	9 (15.0)	11 (18.3)
60 – 79 years	5 (8.3)	11 (18.3)
Gender		
Male	40 (66.7)	24 (40.0)
Female	20 (33.3)	36 (60.0)
Education		
Illiterate	13 (21.7)	8 (13.3)
Primary school (up to VII)	23 (38.4)	20 (33.4)
High school (up to X)	20 (33.3)	30 (50.0)
Higher secondary (up to XII) or Undergraduate degree	4 (6.6)	2 (3.3)
Marital Status		
Unmarried	16 (26.7)	6 (10.0)
Married	29 (48.3)	49 (81.7)
Separated/Divorced	12 (20.0)	0 (0)
Widowed	3 (5.0)	5 (8.3)
Employment Status		
Unemployed	41 (68.3)	39 (65.0)
Employed	19 (31.7)	21 (35.0)

Table 3 summarises the distribution of responses for the diagnosis of the client, the relationship of the caregiver to the client, and the details regarding mental illness, treatment and symptom severity of the client. The diagnosis of the mental illness of clients was taken from the case files maintained at each clinic for the particular client, as well as corroborated with regards to the current medications being taken by the client.

Table 3: Client-specific information

Client-specific information	Frequency (%)
Diagnosis	

Bipolar Affective Disorder (BPAD)	34 (56.7)
Recurrent Depressive Disorder (RDD)	4 (6.7)
Schizophrenia	13 (21.7)
Psychosis (not specified)	9 (15.0)
Caregiver's relationship to client	
Father	1 (1.7)
Mother	14 (23.3)
Siblings (brother/sister)	14 (23.3)
Husband	4 (6.7)
Wife	16 (26.7)
Offspring	4 (6.7)
Second-degree relatives (aunts/uncles, grandparents/grandchildren, nephews/nieces)	2 (3.3)
Affinal relatives (in-laws)	5 (8.3)
No. of years of mental illness of client	
0 – 5 years	11 (18.3)
6 – 10 years	11 (18.3)
11 – 15 years	8(13.3)
16 – 20 years	18 (30)
21 – 30 years	11 (18.3)
30+ years	7 (11.7)
No. of years the client has been availing treatment	
Up to 1 year of treatment	8 (13.3)
1 year – 2 years	16 (26.7)
2 years – 3 years	17 (28.3)
4 years – 5 years	19 (31.7)
Caregiver's perception of client's symptom severity (is the client currently symptomatic?)	
No	46 (76.7)
Yes	14 (23.3)
Since when has symptoms abated or reduced markedly?	
Currently symptomatic	14 (23.3)
Less than 1 month	8 (13.3)
Less than 6 months	12 (20.0)
6 months – 1 year	10 (16.7)
More than 1 year	16 (26.7)

Table 4 summarises the respondents' scores for the tools of data collection into distinct categories. Based on the recommendation by Kaya and Arici (2012), when excluding the subscales for Family Connectedness and Family Spirituality (a total of 10 items thus removed), a few more families make the jump from a medium level to a high level of family resilience. The scores for the individual subscales that make up the Family Resilience Assessment Scale are shown in Table 5.

Table 4: Respondent scores and categories

	Frequency (%)		
Questionnaire tool score ranges	Low	Medium	High
Brief Psychiatric Rating Scale	59 (98.3)	1 (1.7)	0 (0)
Family Resilience Assessment Scale-54 items	0 (0)	39 (65.0)	21 (35.0)
Family Resilience Assessment Scale-44 items	0 (0)	34 (56.7)	26 (43.3)

Table 5: Family Resilience Assessment Scale subscale scores and categories

	Frequency (%)		
Family Resilience Assessment Scale – subscale scores	Low	Medium	High
Family Communication and Problem-Solving (FCPS)	0 (0)	40 (66.7)	20 (33.3)
Utilisation of Social and Economic Resources (USER)	3 (5.0)	41 (68.3)	16 (26.7)
Maintaining A Positive Outlook (MPO)	2 (3.4)	38 (63.3)	20 (33.3)
Family Connectedness (FC)	3 (6.0)	54 (90.0)	3 (5.0)
Family Spirituality (FS)	1 (1.7)	32 (53.3)	27 (45.0)
Ability to Make Meaning of Adversity (AMMA)	1 (1.7)	28 (46.7)	31 (51.6)

Table 6 shows the comparison of means for the two clinics for the Brief Psychiatric Rating Scale (BPRS), the Family Resilience Assessment Scale (FRAS), the 44-item FRAS (FRAS44), and the categories for each of the six

subscales of the FRAS. Clinic 1 mean scores are higher than Clinic 2 mean scores except on the subscale of Family Connectedness. That is, the clients from the semi-urban clinic score higher on all the tools (except for the exception of the subscale mentioned). This may be indicative of caregivers in the semi-urban setting perceiving themselves as being more isolated within their family structures as well as in the larger community setting.

Table 6: Comparison of means on Family Resilience Assessment Scale subscales by clinics

Clinic ID	BPRS	FRAS	FRAS44	FCPS	USER	MPO	FC	FS	AMMA
1	26.73	161.13	132.83	2.4000	2.2333	2.3667	1.9667	2.5333	2.6333
2	25.83	156.47	127.87	2.2667	2.2000	2.2333	2.0333	2.3333	2.3667

5. Discussion

The data analysis shows that the average primary caregiver of a client with mental illness in the community mental health setting for the given sample was likely to be aged between 20 – 55 years, was likely to be a woman who might be the mother or spouse of the client, and most likely had completed their education up to the high school level. Clients, on the other hand, were more likely to have not gone beyond the primary level of schooling, were aged between 30 – 50 years, and were more likely to be a man who had lost his position as the primary breadwinner for the family unit. This is in line with previous findings in the literature that have sought to describe the population most vulnerable to being marginalised as a consequence of mental illness and poverty. However, the small sample size of the study prevents further generalization especially with regards to the gender composition of participants in the study. A greater proportion of clients in this study were likely to be illiterate. While this is indicative of the levels of poverty prevalent among low-income communities in this area, it is also connected to the marginalisation resulting from not being able to access psychiatric services and treatment that might help the client return to a normal life. Being unable to access treatment can lead to lost opportunities in many facets of life, such as education, employment/productive work, and income generation capacities. The study also found that a majority of clients were unemployed, as were a majority of female caregivers. In the case of the female caregivers, larger societal influences may play a role, where cultural expectations regarding traditional gender roles may prevail. For clients, it is more likely that the symptoms of their mental illness may prevent them from fully engaging in productive work, and the client may be in need of a gradual re-induction into the workforce after months or even years of being unemployable or unable to work.

When it comes to marriage and family, the study has found that many clients are either unmarried or divorced/separated from their partners. This relates to the stigmatisation that many persons with mental illness still continue to face even with the many advances in understanding mental disorders. Commonly related stories in the community about mental illness are those of incidents of men and women who have been abandoned by their spouses as they could not handle the burden of care. This has often meant that clients are cared for by their parents in their old age, increasing the burden of care for the family. In the case of men, it was more likely that their wife would be the primary caregiver than vice versa. Part of the stigmatising effect of mental illness is also that even when clients show considerable reduction in symptoms of mental illness, the ‘tag’ never really goes away, so it is seen that many clients continue to be cared for by their parents or siblings, and also face separation from their offspring in such situations. Only 1 or 2 respondent caregivers said that they lived separately from their wards, and in those instances, both the client’s and caregiver’s families lived in close proximity to one another (within the same compound or separated by an adjacent wall). The study found that most families in the sample were nuclear in type, often consisting of up to 5 members, a finding that might be taken to be representative of most families in the coastal belt of northern Kerala. In addition to this, the scores seen on the family connectedness subscale of the Family Resilience Assessment Scale (FRAS) for the semi-urban clinic were lower than that for the urban clinic. Given that many studies previously deem urbanisation as a contributing factor to marginalisation due to mental health, this seems counter-intuitive. As per previous studies, the level of education of the caregiver has a positive interaction with the level of family resilience reported on both the FRAS and the shortened 44-item version (.347, p= .007 and .369, p= .004 respectively). The study did not find any association between caregiver’s age and family resilience.

The duration of mental illness and the duration of treatment in the MHAT community mental health clinics are representative of the history of illness and the family's attempts to resolve this issue. Quite often, clients end up at the community mental health setup many years after the onset of illness, after having exhausted most other options within their grasp, which often includes faith-healing, time-consuming travel to private or government facilities and service providers, and resource-draining treatment – often in the form of direct costs such as transportation charges, expensive psychiatric medications, extensive hospitalisations in the case of severe mental illness, and indirect costs such as productive days lost or income lost in the face of heightened symptom severity. It was considered that there might be some interaction between symptom severity and family resilience, but this has not been borne out by the study's findings. Using the Brief Psychiatric Rating Scale (BPRS) may not have been completely appropriate to the aims of the study, as it included participants whose wards had already been receiving treatment for mental illness and did not allow for a baseline comparison to gauge improvements or worsening in symptom severity of clients. It would be interesting to look into whether there might be a protective factor afforded by the ongoing availability of mental health services within the community.

Due to the smallness of the sample size, comparison of means was only attempted for the clinics in order to ascertain if there were any differences in how different communities might deal with the burden of caregiving and how this might impact family resilience levels. While the semi-urban clinic scores higher in terms of clients being more symptomatic when compared to clients availing treatment from the urban clinic, the caregivers participating from the semi-urban clinic also score higher on the components of the FRAS except for the Family Connectedness subscale. Why this comes about is not conclusive, but may tie into factors such as living in a more isolated community (as compared to urban communities that tend to be densely packed), less access to community resources, gender role expectations regarding how help is sought and returned, and the family composition and number of members available to help alleviate the burden of caregiving. .

6. Conclusion

The Family Resilience Assessment Scale (FRAS) has potential to be used on a large sample as in order to further explore the application of the theoretical framework to social work practice especially in the community mental health setting. The socio-demographic profile helps to clarify characteristics of the persons most likely to be designated as primary caregivers for persons with mental illness in a family. Limitations of the study include the time taken to administer the FRAS as well as language barriers in interviewing the respondents. Being able to assess family resilience qualitatively would be beneficial and can be executed by creating an analysis format for the inclusion of the open-ended question originally part of the FRAS as envisioned by Sixeby (2005). Another limitation of the study is that in using an inventory administered by the interview method might bias the participant towards providing socially acceptable or desirable answers. However, using the tool as a self-report inventory would have been impossible to do given the educational levels of many participants due to illiteracy and minimal schooling being predominant in low-income communities. Further research might consider comparisons of family resilience levels between caregivers of clients who have not yet been inducted into the community mental health setup versus those of a client population already availing of mental health services. Though this study did not find any evidence to extensively look into whether the client's mental illness might be impacted on by the components of family resilience or vice versa, given the small sample size, it bears significant implications. Given that different mental disorders have differential impact on clients' lives and functioning and interactions with others in their midst, it might be plausible to study the interaction between specific mental disorders and family resilience as well. Similarly, future research into family resilience in the community mental health setting might find whether having to care for more than one family member with mental illness might also have impact levels of family resilience.

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