

## COMMENTARY

# Self-Help Efforts among Families Caring for Users with Severe Mental Illness: Some Concerns and Challenges

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## ABSTRACT

Given the dearth of information on mental health self-help groups in India as compared to the large volume of studies in the global north, this paper attempts to understand the caring context of families living with a seriously ill member in North India, while more specifically looking at the issues arising out of their involvement in such endeavors. With limited public and private family mental healthcare support services, families were seen to engage in similar self-help and advocacy efforts and in relentlessly trying to organize them. Also, despite of concerns and contestations related to support group participation, families expressed that such activities could be an alternative treatment and care possibility for their seriously ill members. Therefore, as family mental health self-help groups are present and operate, there is a need for health systems research in the country to critically examine these efforts.

**Key Words:** Self-help groups, Severe mental illness, Caregiving context, Family participation.

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## Introduction

There is limited information and research on mental health self-help groups in India as compared to the large volume of studies mostly conducted in the global north that attempt to establish its usefulness. Though much is known about mental health family self-help groups in the latter countries, literature is only recently emerging about these families and their self-help endeavors in the global south. With contemporary emphasis on an “empowerment-community integration” approach in achieving recovery and growth among users with Serious Mental Illness (SMI), family intervention predominantly in a group format using different modalities is seen to generally improve well-being for caregivers. Family based public mental health services in India are largely rendered by professionals using varying degrees of psycho-educational and behavioral practice approaches.<sup>1,2</sup> Non-Governmental Organizations (NGOs) are also seen to provide varying degrees of mental healthcare services in the country which has been highlighted by a few authors.<sup>3</sup>

Since the past three decades there has been a rise of published studies on mental health mutual support groups in reciprocally benefitting both families and users with SMI. However, they have largely come from the global north, such as certain European and North American countries.<sup>4-9</sup> Few Asian countries from the global south<sup>10-14</sup> including India<sup>15,16</sup> have started reporting into the potential benefits of self-help groups among this population. An attempt is therefore made in this paper to generally understanding the characteristics and context of both caring and mutual self-help efforts of families living with users with SMI. Some issues and challenges emerging out of their engagements in these endeavors have also been mentioned. Observations here were drawn from a qualitative study that involved attending support group meetings and interviewing caregivers of individuals with a serious mental illness in Delhi.

## Families' Context and Caring Challenges

A factor that affected the levels of caring for families was related to their material conditions of being able to afford the cost of treatment for their ill users. Thus, the increasing costs incurred toward their ill member's long term treatment and care was gradually being seen to financially destabilize families in this respect. Other factors which were related to increased levels of caregiving burden among families were having more than one member in the household with a chronic condition, while also being the only earning member. Caregivers were seen to care for their seriously ill relative for a considerable period of

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time and comprised of elderly retired fathers, mothers who were homemakers, and single siblings belonging to the middle socio-economic strata. Similar characteristics of families were also reported in a study<sup>15</sup> from the southern part of the country.

Families were also seen to experience varying degrees of caregiving burden as a consequence of the different levels of socio-occupational functioning of their ill members with a SMI who were single, unemployed, and largely dependent on them at an increasing age. Other challenging course of SMI; viz. intermittent exacerbations and relapses resulting in brief periods of hospitalization, and long term side-effects of medical treatment; were also related to increased burden of caregiving among study participants. The challenging context of caregiving that families find themselves differently in despite of a seemingly similar illness is further exacerbated by the lack of public and private (psychosocial) support services for individuals and their families with SMI. This, it appears has a bearing on families relentlessly trying to organize themselves through self-help group engagements and advocacy endeavors.

### Support Group Participation and Emerging Issues

Most families were involved in self-help advocacy endeavors for close to two decades, with some being involved for about a few years. Though fathers in most families actively participated in these efforts; mothers on the other hand did not partake in advocacy and support group activities. Families were also seen to be lobbying for community rehabilitative services for long stay residential homes, informal re-entry employment services for users, as well as seeking information on mental health treatment services. Study participants simultaneously participated in more than one support group organization or NGO, and were involved in efforts to build a national level federating body.

Families expressed resentment toward other support group members in terms of not being able to financially contribute to efforts in providing rehabilitative services for their ill members. Resentment by families were also expressed toward other members representing certain mental health organizations that left them (and the NGOs that they represented) out of the overall consultative processes of drafting a Mental Healthcare Bill in the country.<sup>17</sup> Though families were seen to collaborate with mental health professionals in support group activities, differences among them were seen to emerge as some resisted their involvement.

Contesting issues were seen within the disability sector as families felt that welfare benefits favor people with other physical disabilities rather than mental health disabilities, and that people with mental retardation within the latter group are favored rather than their ill members with SMI. Families also disagreed among themselves on the kind of advocacy efforts mental health NGOs were engaged in

with an emphasis being given to legal advocacy rather than to innovative treatment and rehabilitative care services. However, despite of emerging concerns and contestations related to support group participation, families expressed that such activities could be an alternative treatment and care possibility for their seriously ill members.

### Concluding Observations

Several studies in India<sup>18-20</sup> have examined the economic challenges of families caring for people with SMI. This however has to be further examined in the context where public and private, i.e. NGO, run long-term community rehabilitative services for this group with a disabling condition is unaffordable and almost non-existent. As information on mutual support groups among families living with users with SMI in India is only recently emerging,<sup>15</sup> it is encouraging to see that popular media reports are beginning to raise these issues.<sup>16</sup> In a scenario (as in India) where formal public mental health support services for users and their families with SMI is limited, an emerging narrative of informal self-help efforts as an alternative treatment and care possibility needs closer consideration from a health systems and research perspective.

As mutual support group endeavors among families with users with SMI as an approach to psychosocial support, care and treatment for them show promising results in countries of the global north, evidence on these still remain to be forthcoming from India. Given that these activities are beginning to be reported from other parts of the country,<sup>15</sup> this paper attempts to understand some of the issues among a similar population in another part of the country. However, beyond only raising these issues, it is premature to arrive at such conclusions in the absence of evidence that look into the long-term effects and consequences of family support group participation among its members as well as their seriously ill users. It would thus be prudent for current health systems research in India to critically examine family mental health self-help efforts.

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