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SCHIZOPHRENIA AND OTHER PSYCHOTIC DISORDERS (AK PANDURANGI, SECTION EDITOR)

The Family Support Movement and Schizophrenia in India

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Abstract

Purpose of Review To review the evolution of family support movement for schizophrenia in India and to report perspectives of family caregivers who are running family support groups across the country in the backdrop of recent legislations in India.

Recent Findings Family support movement started in the 1990s, mostly by family caregivers independently in multiple cities across the country. Apart from periodic support meetings, they have successfully influenced recent legislations to address the felt needs of families. Mental health professionals need to gain skills to work collaboratively with assertive family caregivers to develop services to support those diagnosed with mental illness.

Summary Though there is a need for such movement, funding is poor and very few caregivers of persons with schizophrenia are forthcoming to participate. The formation of national federation with government and non-government partnership could help give the required impetus to the family support movement for persons with schizophrenia in India.

Keywords Family support · Schizophrenia · India · Group meetings

Introduction

Family Support Movements can be traced back to families initially getting together for the cause of their disabled user to form peer family support groups or self-help groups [1]. In the West, these groups partner with family members to help share lived experience and provide peer family support through strategic self-disclosure technique and active acceptance in all interactions [2]. These platforms form the founding stones for the development of family support and advocacy movements and mental health and rehabilitation services for persons with mental illness.

Family participation and self-help nature of the movements are essential components that give impetus to the Family Support Movements. In the USA, family participation has evolved and matured in the last 30 years from 'relative lack of parental involvement in mental health care in the early 1980s, to a rapidly growing family movement in the 1990s, to providing family-driven care and mental health service delivery system today' [3].

Over the last four decades, The National Alliance on Mental illness (NAMI) in the USA has blossomed from a group of families to an association of 500 affiliates which shapes public policy, provides helplines, conducts public awareness activities, and offers the necessary information to families [4]. Another well-known organization is the Richmond Fellowship (RF) that started in the UK with over 30 branches across the world [5]. RF organizations operate in several locations in Australia and New Zealand, Hong Kong, Nepal, India, and in other parts of the world. They work on therapeutic community principles and offer a range of services, including family support, wherever required. The Schizophrenia Society of Canada offers a variety of mental health support services including educating families and working with them to facilitate recovery.

Importance of Family in India

In India, more than 90% of persons with mental illness live with their families [6]. Families perform the caregiving role

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24 h × 7 days × 52 weeks. Being a caregiver is neither chosen nor planned and preparation for role occurs after it has been acquired [7, 8]. In a 25-year follow-up of a cohort of 90 first episode persons with schizophrenia (ICD-9 criteria), all but two persons with schizophrenia lived with their families [9]. This is a testament to the resilience of Indian families. In addition to catering to basic (shelter, clothing, and food), emotional, and financial needs of the patient, the role of Indian family is all-pervasive: including decision of when, where, and how to seek treatment and need to continue/or not, with the treatment and also with issues pertaining to rehabilitation including employment and marriage [6]. The family members of persons with mental illness face various problems—financial, emotional, interpersonal, and social relationships—as a caregiver, which affects their day-to-day activities, health, and occupation [10].

Involvement of Family in Treatment of Mental Illness

In the 1950s, when families were considered 'toxic' in Western countries, Dr. Vidyasagar allowed family members of persons with mental illness to stay in open tents pitched in the hospital campus [11]. This helped family members understand illness, impact of treatment offered, and need for medication adherence and involved them to be partners in management plan. Persons with mental illness recovered fast and when discharged, the relapse rates were low [11, 12]. When discharged, persons with mental illness conveyed the message to the community that mental illness was treatable. The family members involved in treatment served as 'agents of change' in their community in identifying other persons with mental illness and guiding their family to seek treatment [11]. Based on this principle, family wards were established in Christian Medical College, Vellore, and NIMHANS, Bengaluru [11]. In India, it is common for most acute treatment facilities to admit the persons with mental illness along with a family member who usually stays with the person throughout hospitalization.

Impact of Crumbling Joint Family and Urbanization on Persons with Schizophrenia

Traditionally, Indian joint families and strong networks of kinship ties have provided economic and emotional support in caring for persons with mental illness [11]. Persons with disabilities would be accommodated in family and social networks to function according to their capacities [7].

Over the last 2 decades, the traditional support structures are breaking down in Indian family [7, 11, 12].

1. Urbanization
2. Shift from joint/extended families to nuclear families particularly in urban areas
3. Steady increase in the proportion of working women and both spouses working
4. Migration of younger generation (within and outside the country) in search of better economic opportunities.

In this context, family members are forced to make considerable compromises (including resigning from their job to assume caregiving as a career) or look for institutional placements to care for their family member with schizophrenia who requires additional support beyond what the family is able to provide.

It is paradoxical that while western countries are moving towards deinstitutionalization and family and community-based support, the reverse seems to be taking place in urban India [7] for caring for persons with mental illness.

Family Support Movement in India: Case Examples

In India, which has strong clan and kinship networks, the concept of reaching out to people outside the family for help (being a part of self-help group) was not considered in keeping with the cultural and family norms. However, given the need of the hour, several attempts have been made to form family support groups in different parts of the country, some of which have become family support movements for provision of mental healthcare services in the country.

A few of these family self-help groups go on to become family support movements. Family self-help groups are defined as 'voluntary small group structures for mutual aid in the accomplishment of a specific purpose' [10]. These groups are either run by the family members themselves, for example the Association for MENtally Disabled (AMEND) in Bengaluru, or are coordinated by mental health professional in mental health settings (outpatient clinics, inpatient, daycare, or a half-way home), for example Subitcham (translated as 'prosperity') which is mentored by MS Chellamuthu trust in Madurai, in South India, and take up themes like information about illness, practical difficulties, and strategies to handle the same. Participating in such meetings helps family members understand that they are not alone in the formidable task of caring for their loved one, besides giving them a platform to exchange helpful suggestions and coping strategies, reducing stress, isolation, and stigma [13]. Families with a higher level of education, especially parents, join such support groups [10]. After participation in meetings, families report better understanding, adaptive coping skills, and improvement in relationship [10].

Non-governmental organizations (NGOs) such as Family AllianCE on Mental Illness (FACEMI) (pan-Indian organization), Aasha (translated as 'hope', and headquartered in Chennai), Schizophrenia Awareness Association (SAA) (headquartered in Pune), and Sambandh (Translated as 'relationship', and headquartered in Delhi) are examples of emergence of family support movements which initially started as family support groups before going on to become community care providers to supplement the acute shortage mental health professionals and of care facilities. The emergence of the above family support movements, its challenges, and future directions are detailed in the following paragraphs:

1. Aasha Experience (Chennai, Tamil Nadu State, South India):

   Aasha was the 1st family support group to be founded in India in 1990, by a group of family caregivers from Chennai with the support of Dr. Sarada Menon (ex-director and founder of the Schizophrenia Research Foundation (SCARF)). Post formal registration, the group met once in a month (around 10–12 family caregivers) to discuss each other's problems and for emotional support. Over a period of time, the group got funds to conduct programmes on every 3rd Saturday in an auditorium where caregivers from all over Chennai would attend and a psychiatrist would be invited to talk on subjects such as medication adherence, marriage-related issues for persons with mental illness, role of family, and 'What after me issues'. Aasha further branched out to provide daycare services in 1999, residential services in 2001, and 4 shops where persons with mental illness are employed in the last decade. Monthly family support group meetings are conducted in the premises of the daycare centre. All the initiatives were run by family members of persons with mental illness. Currently, Aasha family support group has 300 family caregivers as its members. Ms. Ratna Chibber, who is the founding member of Aasha, states that families have different needs and when their needs are not met in the group, they exit the group. She reports having a number of members who have exited the group and re-joined based on their needs apart from many new members joining. The revolving nature of caregivers in the family support group causes a barrier in developing a sustainable model. However, Ms. Chibber feels that family support groups for caregivers of persons with mental illness are important and have a future in India, as Aasha has demonstrated, supported many families, and survived over the last 30 years.

2. SAA Experience (Pune, Maharashtra State, West India)

   SAA was founded, as family caregivers felt the need for a platform to discuss their own problems. Due to the paucity of mental healthcare professionals, especially counsellors and the inadequate time offered by the psychiatrists to provide psychosocial support, family caregivers took up the initiative to form an informal group in 1994. The group grew from 4 to 5 family caregivers to 10–12 members meeting once a month in Pune, Maharashtra. The members introduced new members to the group every month and shared their experiences and problems. Each month's meeting had a topic of discussions, like symptoms and marriage. In 1997, a structured family support group was initiated in various cities of Maharashtra state like Nagpur, Kolhapur, and Pune, where volunteers (family caregivers) from the SAA family support group helped form and conduct the family support groups in each of cities. Similar 6–7 family support groups were also initiated in Gujarat under the Quality Rights project which, unfortunately, did not sustain due to the lack of consistent availability of facilitators to sustain the groups. Currently, SAA-supported family support groups are running successfully in Kolhapur (1 group anchored by students), Pune (2 groups one for caregivers and one for clients with schizophrenia, anchored by SAA volunteers), and Nashik (1 group, anchored by SAA volunteers). Mr. Amrit Bakhshy, who currently is the president of SAA and also a family caregiver of persons with schizophrenia, stated that caregivers often are unable to participate actively in their family support groups on a continued basis due to burden of caregiving, work schedules, and the meeting location being far away from their place of work/residence. Mr. Bakhshy believes that the family support movement in India, though initiated in multiple places, can be considered successful only if it is anchored and sustained by family members themselves instead of professionals or organizations.

3. Sambandh Health Foundation Experience (Gurugram, Haryana State, North India):

   Ms. Rita Seth, founder of the Sambandh Health Foundation, Gurugram, Haryana, had a sibling with schizophrenia and noticed that her parents could not find any support for themselves in the community. When she took over the responsibility of caring for her brother with mental illness from her mother, she joined a Family Self Help Group in Delhi to help her take care of her own self-care needs, her guilt and, her anxiety of becoming a family caregiver. She believed that it was the only pathway for caregivers to learn from each other and learn from professionals on how to take care of their loved one with mental illness. As there were no family support services in Gurugram, Haryana state, she initiated a family support group for 20–25 caregivers staying in Gurugram who met once a month. After 6 months, two family support groups were running successfully in Gurugram and Delhi where family caregivers discussed agendas related to their self-care, information on latest recovery, medications, communication, treatment adherence, empathy and compassion, and mental health–related policies and laws such as the Government of India Mental Health Policy 2014 and the Mental Healthcare Act 2017, as well as understanding the rights and responsibilities of persons with mental illness, economic issues such as creating a financial trust, health, and other insurance. The group often invited professionals like psychiatrists or psychologists to answer various FAQs raised by the family caregivers. Family self-help groups also ran in four villages in Haryana and in Faridabad Civil Hospital. Ms. Rita Seth contends that there is a high need for family support groups, as it is only in such groups that hope gets built, family members start thinking positively, and there is a change in perception of the client. She strongly advocates that such family support platforms should exist even if the participation of family members dwindles, as these groups act as a platform to start family-led services and solutions for persons with mental illness.

4. FACEMI Experience (All India Family Caregivers Network):

   The Family Support Group Movement in Bangalore started with the formation of AMEND, at the initiative of a person with mental illness in 1992. The group was an emotional support group for persons with mental illness and family caregivers who shared their problems in managing their mental health issues. As there was a need for a separate advocacy group of family members which networked with state- and national-level stakeholders to bring about a change in the legal, family, and systemic level, ACtion for Mental Illness India (ACMI) was founded separately from AMEND in 2003 (e.g. establishing ambulance services in Bangalore, appealing for legal reforms of Mental Health Act, 1987). In 2013, as there was a need to have an all-India association to address the needs of persons with mental illness and family members, FACEMI was established. FACEMI is a national network consisting of regional family advocacy groups under its wing running independently in different parts of the country: [1] Saathi (translated as 'companion' or 'partner' and headquartered in Vadodara, Gujarat state) [2], Shakti (translated as 'strength' and headquartered in Kolkata, West Bengal state) [3], Trupti (translated as 'satisfaction' and headquartered in Lucknow, Uttar Pradesh state) [4], Maitri (translated as 'friendship' and headquartered in Bengaluru) [5], and Jagruti (translated as 'awareness' or 'watchfulness' and headquartered in Delhi). Dr. Nirmala Srinivasan, a parent of a person with mental illness, an academician turned mental health activist and the founder of AMEND, ACMI, and FACEMI, reports the following challenges in successfully running a family support movement across India: (1) The families shoulder the responsibility of care despite the deficits in the mental healthcare system and hence do not have resources or time to spare for activism. (2) As mental health and disability are under the control of state or provincial governments in India, NGOs are not forthcoming to help run a national body to reach to families in different states. (3) Technology is a big enabler for the new generation of caregivers to access support online. To organize support groups today needs different skill sets.

Impact of Recent Policies and Legislations on Family Support Movement

The National Mental Health Policy of India (2014) [14] elaborates on the following issues concerning family caregivers:

1. Support for families including 'caring for the carer', forming caregiver groups, financial support (including monetary and tax benefits) for caregivers, access to information, and assisted living services.
2. Involvement of family in designing, implementing, and monitoring mental health services
3. Simplifying procedure for disability certification and enhancing disability benefits and empowerment in education, housing, employment, and social welfare aspects for persons with mental illness
4. Assisted living services to address challenges faced by elderly caregivers including 'Who after me?' dilemma. A mix of community, institution, and home-based services are advocated.
5. Provision of home care and support for 'orphaned persons with mental illness' with high support needs when parents are no longer there
6. Addressing the needs of children of persons with mental health problems.

'The Rights of Persons with Disabilities Act 2016' [15•] has provisions for limited guardianship for persons with mental illness. 'The Mental Healthcare Act 2017' [16•] has specified representation in the Central and State Mental Health Authority to consist of 2 caregivers or organizations representing of persons with mental illness, 2 persons with mental illness, and 2 persons to represent NGOs providing services for persons with mental illness. The legislation has ensured that family caregivers, persons with mental illness, and NGOs will be equal or more in number than mental health professionals in the central and state mental health authority. This is expected to give families and persons with mental illness a greater say in designing, implementing, and monitoring mental health services.

Discussion

In India, there are strong vocal organizations for persons with visual, locomotor, and hearing disabilities who have voiced their demands and influenced policy. Family caregivers were successful in getting 'National Trust Act 1999' for the empowerment of persons with mental retardation, cerebral palsy, autism, and multiple disabilities. India has more than 200 parent associations for intellectual disability with more than 40,000 members who have formed a national federation called 'Parivaar' (translated as 'extended family') – National confederation of parents' organizations [17•]. The federation organizes annual national conferences for parents to identify needs and discuss it with the government to inform policy development [17•].

Most family support groups/caregiver groups for persons with mental illness are overwhelmingly based in urban India. This may be because of 2 possibilities and both may be simultaneously true:

1. The social fabric of rural areas (including culture, joint family, supportive neighbours, availability of informal employment opportunities according to patient ability, etc.) ensures that a person with mental illness is accommodated within the family/community, obviating a need for a more formal support group.
2. Due to social factors (poverty, illiteracy, villages scattered apart, etc.), rural families are unable to devote time and energy to come together and advocate for change.

The absence of strong lobby groups of persons with mental illness and family members has been acutely felt in following aspects:

1. Policy and legislation: Persons with disabilities act (1995) recognized 7 disabilities (including low vision, blindness, hearing impairment, locomotor disability, leprosy cured, mental retardation, and mental illness). But reservation in government jobs was provided only to visual, hearing, and locomotor disabilities. After passing this law, the inclusion of mental illness as a disability was reviewed for removal due to pressure from other (non-mental health) disability groups. Mental health professionals and family caregivers had to lobby hard, in order to retain 'mental illness' also as a disability [18].
2. Developing mental health services sensitive to the needs of families and persons with mental illness: the requirements of a therapist treating schizophrenia are different from felt daily needs of a family caregiver. The perspective of a family member is useful in deciding services/facilities to be developed within the budget allotted for mental health.

Family support movements have moved from knowledge, information, and support to advocacy. Indian family caregiver organizations have largely focused on support group meetings and advocacy to influence government policies. Family support movements have lobbied and been successful in inclusion of 'home based rehabilitation', 'provision of half-way homes, sheltered accommodation, supported accommodation', 'provision of mental health treatment, ambulatory services for the mentally ill' [19] and services free of charge in government-run or funded mental health establishments', and 'medical insurance for treatment of mental illness on same basis as is available for treatment of physical illness' in recently passed 'The Mental Healthcare Act, 2017' [16•]. The family caregiver organizations are lobbying for the implementation of such initiatives at ground level so that families can benefit.

Lessons Learnt and Way Forward

There are practical difficulties in bringing persons with mental illness and families together as a public organization, for a common cause. Many prefer to keep mental illness under wraps as they fear being 'labelled' if they are identified as part of family mental health organization(s). Besides, many rely on mental health professionals to enforce change and have not understood the power of family caregiver lobby. Over the last few years, people are gradually getting comfortable about discussing mental health–related issues in public forum.

In such a scenario, organizations run by families of persons with mental illness are bound by the common thread of creating a better life for a loved one with mental illness. In such groups, families are involved in more assertive, informed, and involved roles [20]. In many groups, there are more parents than siblings, spouses, or adult children which are indicative of the changing social fabric. There is a need for the family support movement to also address the diverse needs of children, spouses, and siblings of persons with schizophrenia.

The Indian family support movement is led by a few vocal family caregivers who, driven by their personal experience, have galvanized families together and lead them in pursuit of making the mental health system responsive to their needs. Many others are happy to outsource the responsibility to active members and confine themselves to participation in meetings or signing petitions. This group dynamics is not limited to family caregiver groups for persons with mental illness and is also true for many other groups (including for persons with physical disabilities and family caregiver organizations for persons with intellectual disability) as well. There aren't many instances of family members coming together to take care of a person with mental illness from another family even for a short duration.

There is a need for a single-family caregiver organization to spread across the country and democratically elect leaders for a specified term among members at district, state, zonal, and national level. This will strengthen the family caregiver lobby at grassroots level to speak for a common cause and more effectively advocate for change in mental health services and also groom new leaders across the country. There is a need to have term limits on office bearers. This will ensure that the movement is sustainable and not dependent on charismatic leaders alone.

In addition to educating themselves to care for person with mental illness, family members should also engage in healthy discussions with professionals about how to be more helpful to families [20]. Given the hierarchical nature in the health sector (doctor, nurse, social worker, family, patient), many mental health professionals baulk at the suggestion of 'listening' to the family members, in matters of health, especially in the area of mental health. Big attitudinal changes must take place if professionals and family members have to work together in the interest of persons with mental illness. Mental health professionals should be encouraged to attend meetings of support groups, listen, learn, and interact with family members during their training. What helps the patient and family lead a better life is also in the best interest of the mental health professional!

Conclusion

The Family Support Movement for persons with Schizophrenia is at its nascent stages in India. Though the need for such movements is high, the funds to develop and sustain such movements are meagre and very few caregivers of persons with schizophrenia are forthcoming to participate in micro- and macro-level family support movements. The formation of a national federation of family support groups with government and non-government partnership could help give the required impetus to the family support movement for persons with schizophrenia in India, which is currently struggling to find a foothold. This step could also help advocate for a number of policy changes, infrastructure, and services for the betterment of persons with schizophrenia and their family members at the national level.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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