

Children of Parents with Mental Illness: The Need for Family Focussed Interventions in India

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ABSTRACT

Family interventions have been an integral part of mental healthcare in India for several decades. This paper highlights the need for an emerging change in the nature of family interventions in India—from generic interventions for heterogeneous caregiver groups to interventions addressing particular needs based on family stages and structures. It makes a case for recognizing the experiences and needs of one such group, that is, families affected by parental mental illness with children in their care and summarizes the current status of research on this topic in the Indian and global context. It presents implications for future research in India and discusses preliminary ideas for professionals working in adult mental health settings to address the needs of children and families affected by parental mental illness.

Key words: *Family intervention, parenting, parents with mental illness*

The formal involvement of families in mental healthcare in India can be traced back to the 1950s, with pioneering works at the Amritsar Mental Hospital; the Mental Health Centre, Vellore; and the National Institute of Mental Health and Neurosciences, Bangalore.^[1] Although these early experiments showed that the involvement of families did lead to better patient outcomes, they also highlighted the burden and stress faced by the families and the importance of providing them support and education.^[2,3]

Since then, rigorous studies have established the effectiveness of family interventions for various

psychiatric disorders. These interventions have traditionally included a heterogeneous group of caregivers comprising predominantly of parents and spouses and sometimes, siblings and adult children.


RECENT TRENDS IN FAMILY INTERVENTIONS IN INDIA

In the last few years, there has been an increasing recognition that the needs of caregivers might vary based on the structure of the family or how the caregiver is related to the person with the illness. For instance,

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Amaresha *et al.*^[4] reported that siblings of persons with schizophrenia have distinct needs compared with other caregivers, such as a need for brief interventions, telephonic services, and support groups, with a higher focus on illness management and functionality. Similarly, Pashapu *et al.*^[5] explored the marital needs of couples where one of the spouses has schizophrenia and found that they specifically face issues in family communication, role functioning, sexual relationship, and legal issues. Philip^[6] reported that aging parents of persons with schizophrenia had particular concerns related to future, including the ill member's self-management of the illness and handing over of caregiving after their death. These studies developed and tested psychosocial interventions addressing the unique needs of these caregiver groups.

Another such group, with distinct experiences and needs, is children who have a parent with mental illness. Although they have long been known to be at high risk genetically and environmentally,^[7] it is only in recent years that research into preventive mental health for this group has emerged. An encouraging development in this field in India has been the growing movement around perinatal psychiatry, with interventions addressing the parenting needs of mothers with mental illness and their infants.^[8,9] However, studies focusing on older children and adolescents affected by parental mental illness are fewer. Children of varying age groups have differing needs; therefore, the impact of parental mental illness and the opportunities for intervention with them can be diverse.^[10]

The rest of this paper reviews the existing research on this topic, both from the global and Indian context. Findings from studies on parents with mental illness and their children are briefly summarized, followed by descriptions of preventive interventions developed for the children. The last section discusses how these findings can inform future research and service development for this population in India.

CHILDREN OF PARENTS WITH MENTAL ILLNESS: THE GLOBAL CONTEXT

Globally, 12–45% of mental health service users are reported to be parents.^[11] The experiences and needs of families affected by parental mental illness have been predominantly studied from the perspective of the parent with mental illness and their children. These findings are reviewed in the following sections.

EXPERIENCES OF PARENTS WITH MENTAL ILLNESS

Studies done around the world with parents with mental illness have described their challenges.

Parents have reported that the illness interferes with parenting and have described parenting as stressful and burdensome.^[12-16] A two-way relationship between parental mental health and the parent–child relationship has been proposed, wherein parental psychopathology can strain parent–child relationships and possibly lead the child to distance from the parent emotionally, thereby further disenfranchising the parent, increasing their distress, and impeding recovery.^[17]

In addition to the direct impact of the mental illness on parenting, parents have described other circumstances that add to their vulnerability. Mental illness often co-occurs with other psychosocial adversities such as poverty, marital discord and separation, and downward social and economic mobility,^[18,19] thereby increasing the patients' need for support. There is also stigma and discrimination in relation to parenthood experienced by those with mental illness, including being stopped from having children, being seen as unfit parents, being separated from their children, and being blamed for their child's difficulties.^[20] Parents have reported that the fear of losing child custody prevents them from seeking treatment, disclosing to professionals that they are parents, and discussing parenting difficulties.^[21,22] The stigma of “failing as a parent” has been described as perhaps greater than the stigma of mental illness itself.^[21]

Despite these negative experiences and effects, many parents have also described parenting as a “road to recovery” as it enriches and provides a structure to their lives^[23] and motivates them to seek treatment.^[24] Therefore, there is a need to expand our understanding of parenting with mental illness. Instead of focusing exclusively on deficits and impairments in parenting, which leads to further marginalization and exclusion,^[14] there is a need to pay equal attention to the individual strengths and motivations of parents and also to the structural barriers that increase their vulnerability.^[25] They need to be provided with ongoing instrumental, emotional, and social support so that they can be better parents.^[26,27]

EXPERIENCES OF CHILDREN OF PARENTS WITH MENTAL ILLNESS

Studies exploring children's experiences of living with a parent with mental illness have also described both positive and negative aspects. Children have identified concerns such as lack of information, disruptions in the family, having to take up caregiving roles, and lack of support services. Children also have difficulties in managing their emotions and experiences of stigma and social isolation.^[28] At the same time, children have also reported positive gains from these experiences, such as

becoming more mature and responsible, and they report wanting to be involved in the care of their parent.^[29-31]

Recurring themes in these narratives are the children's need for information and support. Children have talked about the need for education about parental mental illness, improved coping skills, and support from mental health professionals and schools.^[32,33] Many children have reported feeling apprehensive about visiting their parent in the hospital and expressed that the - hospitals need to be "family friendly" and accommodate needs of the children of parents with mental illness, and at the same time acknowledge their caring efforts.^[34,35]

INTERVENTIONS FOR FAMILIES AFFECTED BY PARENTAL MENTAL ILLNESS

Based on the needs that have emerged from these studies, several interventions have been developed for families affected by parental mental illness. Some interventions include only the parents or the children, but with a focus on the family, whereas other interventions involve the whole family. Interventions with parents predominantly focus on training in parenting skills^[36,37] or psychoeducation and peer support.^[38] Let's Talk about Children^[39] is one such psychoeducational intervention that involves 15–45 min discussions with the ill parent and his/her partner, to assess the child's situation and empower the parents to talk to their children about the illness.

Interventions targeted at the children are mostly aimed at providing psychoeducation, peer support and respite, in individual or group formats.^[40-43] Some also provide skills training^[44,45] and resource coordination.^[46] Although some of these activities are delivered in a clinic setting, others are designed as after-school workshops,^[47,48] camps,^[49,50] or online interventions,^[51,52] to make them more accessible for children.

A third set of interventions targeting the whole family involve interventions such as psychoeducation; cognitive restructuring; teaching communication skills, problem-solving and parenting strategies; and case-management strategies. One of the earliest and most researched is Beardslee's preventive family intervention or "Family Talk."^[53] This was originally designed for parents with affective disorders and their children aged 8–15 years and involved 6–10 sessions with a clinician. Separate sessions with parents and children focus on gathering history, psychoeducation, and preparation for a joint session. The joint session focuses on initiating and enhancing communication

about the illness between the parents and the children. This intervention has been adapted to include other age groups and diagnoses.^[39,54,55]

Other family interventions entail child-inclusive discussions to generate care plans and discuss parenting issues.^[56-58] Some interventions have used the cognitive-behavioral approach in a single family format^[59,60] or a multi-family group format.^[61,62] Studies also highlight community and home-based interventions-including services that link families with environmental supports and provide access to financial resources and liaison and advocacy services.^[63-65]

A recent systematic review reported that preventive interventions with this population lead to significant improvement in parenting behaviors,^[66] and a meta-analysis reported positive effects on the children's behavioral and emotional health, with interventions that jointly addressed parents and children yielding larger effects.^[67] However, they also pointed out a lack of high-quality studies and recommended adoption of more rigorous research methods to test the interventions^[66-68]

CHALLENGES IN WORKING WITH FAMILIES AFFECTED BY PARENTAL MENTAL ILLNESS

Various challenges in working with this population have been identified within adult mental health systems, including the complexity of the issue;^[69] a lack of attitude, knowledge, skill and confidence for working on parenting and family issues;^[70] a lack of clarity about staff roles; and limited options of referral services.^[71]

It has also been suggested that mental health systems often operate from an individual level, problem/deficit-focus approach, where preventive interventions are not given priority. Hence, issues of parenting and children are addressed only if abuse or neglect is identified or if the child develops a diagnosable disorder.^[72]

To overcome these challenges, Maybery and Reupert^[73] recommend the adoption of family-sensitive policies at the organizational level, coupled with ongoing workforce training. Such a system would set up processes to routinely identify a service user's children, assess the family's parenting and child-related needs, and provide psychoeducation to each family member and have a clear system of referrals. Additionally, the agency would have more specialized family services, such as family therapy, where families with more intensive needs can be referred.

Several interventions have been designed for professionals in adult mental health settings to sensitize and equip them to work with children and families affected by parental mental illness.^[74-76] Other measures include having designated “child representatives”^[77] or “child-responsible personnel”^[78] in adult mental health settings.

In addition to improvements in adult mental health services, other recommendations include increasing investment in child and adolescent mental health services, creating adequate community support for families, building intersectoral collaborations such as with child-protection agencies, and lobbying governments to recognize this group of vulnerable children.^[10]

CHILDREN OF PARENTS WITH MENTAL ILLNESS: THE INDIAN CONTEXT

There are no large-scale epidemiological studies from India that report the prevalence of parenthood among persons with mental illness, but a few clinic-based studies provide an approximate picture. A study of persons with schizophrenia found that about 49% of them had children,^[79] and a study of female inpatients in a psychiatric hospital reported a figure of 66%.^[80] Another recent study reported that despite stigmatizing experiences related to marriage and childbirth, 57% of the participants with mental illness were married, and many of them had children.^[81]

Studies done in India with children of parents with mental illness have found that they use maladaptive coping strategies^[82] and have higher levels of internalizing and externalizing problems.^[83,84] Adult children of parents with mental illness have reported that they had experienced many disruptive experiences in their childhood, such as unstable families, parental discord, and having to discontinue education to go into employment.^[85] Many of them, though resilient, reported burden and lack of support^[86] and lower levels of psychological well being.^[87]

It has been reported that children are negatively affected by poor information about parental illness and inadequate role functioning in the ill parent.^[5] Spouses of persons with mental illness have reported concerns about the effects of parental mental illness and the ways to support their children.^[88]

Much of this literature focuses on deficits and risks, and there is little published literature in the Indian context about how ill parents perceive their parenting role, how children experience growing up with an ill parent, how families navigate parenting challenges, and what support they need.

IMPLICATIONS FOR THE INDIAN MENTAL HEALTH SETTING

Due to the lack of literature from India, our current understanding of these topics rests predominantly on western studies. Although western studies set a precedent for the conceptualization of preventive interventions for children and families with parental mental illness, local studies are needed to contextualize these findings to India—both to the culture of Indian families and to the way Indian mental health services are organized.

Research with family caregivers in India is still predominantly limited to concepts such as stress and burden,^[89] and there is a need to shift the focus to understanding their experiences as a whole and to explore themes related to parenting and children. Several characteristics of Indian families, such as rigid hierarchical structures and an emphasis on kinship obligations, might affect the way parents and children relate and communicate with each other.^[1,89] As formal foster care is uncommon in India,^[81] some children are likely to be in the informal care of extended family members. These features of the Indian context could alter the experiences of families with parental mental illness.

Additionally, these interventions need to be adapted to suit the way Indian mental health systems are organized and the resources that are available. Research is also needed to identify how other agencies such as child protection systems, schools, and general healthcare settings can play a role in supporting children, parents, and families affected by parental mental illness. The inadequacy of resources is a major barrier in not prioritizing preventive child and family mental health in India.^[90] Therefore, in addition to studying outcomes, rigorous studies examining the cost-effectiveness and returns-on-investment of preventive interventions with this population are needed, to support policies and services for this population.^[65] In building workforce capacity, training a few specialist professionals who can go on to provide consultations and carry out advocacy and further capacity-building programmes^[10] may be an efficient option.

Some ways to increase visibility for this population within adult mental health services would be to routinely assess if service users are parents and if so, to document information such as the children’s age and living and parenting arrangements. It would be useful to keep in mind that persons with mental illness and their families might be apprehensive in initiating discussions about parenting and children.

Children themselves might have concerns about inheriting the illness from the parent and might feel anxious at the prospect of meeting with mental health professionals. This reiterates the need for professionals to raise these topics in sensitive ways. When children accompany or visit their parent in the hospital, professionals could encourage them to share their experience and concerns and appreciate them for their contributions to the care of the parent. Where appropriate, and when families and children are willing, children could be invited to participate in routine family interventions or referred to specialist child and family psychiatric services.

CONCLUSION

Despite a long tradition of involving families in mental healthcare in India, more attention needs to be focused on the diversity among families affected by mental illness. There is a growing understanding of the unique vulnerabilities and needs of children and families affected by parental mental illness. This highlights the need to take forward research in this area and for developing preventive child and family mental health interventions.

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Conflicts of interest

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