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Engaging families to advance global mental health intervention research

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Across cultures, family members often play important and even critical roles in the lives of adults who suffer from depression and other chronic mental health conditions. These roles could be even more pronounced in low-income and middle-income countries (LMIC), where cultural values and norms might more strongly encourage family involvement and family is often the *de facto* provider of mental health care when mental health services are scarce. International guidelines and recommendations have attempted to draw attention to the evidence base supporting the need for family involvement.1, 2 Despite compelling reasons for adapting evidence-based treatments for adults to include families in LMIC, the topic has received surprisingly little attention in the literature about global mental health services and implementation, with with the exception of a few studies that have involved family in the treatment of patients with psychotic disorders,[3] substance abuse,[4] and dementia.5, 6 A review[7] of community and home-based interventions for people with neuropsychiatric disorders in LMIC showed that fewer than 10% of the interventions involved family members.

This gap is an important missed opportunity. A substantial body of literature, comprised predominantly of observational work in both the social sciences and the medical field, describes the roles of family members involved in the lives of persons living mental illness, which include providing practical support for illness management and treatment adherence in the home, influencing care-seeking pathways, and accompaniment and support during clinic visits and inpatient psychiatric hospitalisations. Family caregiving also has important moral and emotional dimensions with potential to both affirm and ameliorate suffering.[8]

Inattention to the role of family in the global mental health intervention field has several potentially important consequences. First, individually focused psychosocial interventions introduced within cultural settings in which a high value is placed on family involvement might separate the patient from naturally occurring social supports and increase social isolation or risk of stigmatisation. Second, psychosocial interventions focused solely in the individual might miss crucial opportunities to strengthen treatment through engagement and involvement of family. Third, a narrow focus on individual outcomes prevents broader

examination of the effects of psychosocial interventions (both positive and negative) on the family.

Engagement of family also highlights important challenges and caveats. From an ethical perspective, family-centred models must take into consideration the family resources and competing demands, and should protect families from undue burden. Issues to consider when families are involved are loss of economic engagement in other livelihood activities, interference with domestic duties, and secondary stigmatisation.[9] Particularly in LMIC, where resources are scarce, task sharing can easily become task dumping and place unrealistic demands on family members—especially women—who might risk harm. Furthermore, intervention models need to account for situations in which family relationships might be so strained or dysfunctional that involvement in mental health care could be counter-productive. In a previous work,[10] for example, we have highlighted the potential for families to both impede and facilitate depression care. In some situations, separation from the family might be necessary for mental health recovery, although it is especially complicated in situations where interpersonal violence is the primary driver of psychological distress. Finally, involving families has the potential to diminish the autonomy of individuals with neuropsychiatric disorders, particularly when the individual's preferences are not adequately assessed and addressed by treatment providers when the family is also present.

With the growing emphasis on integration of mental health in primary care, there is an acute need for work to adapt evidence-based treatments for depression, anxiety, and other non-psychotic disorders to include family members. For example, family can play various roles in depression treatment, such as providing collateral information to inform the initial assessment, promoting adherence to non-pharmacological treatment (eg, behavioural activation) or medications, monitoring symptoms and side effects, helping in relapse and prevention planning, or simply being a supportive presence during therapeutic sessions.[10, 11] Since people with neuropsychiatric disorders might have comorbid health problems and rely on family members for help in managing these conditions, engaging these family members as partners in the treatment of coexisting mental health conditions is often a natural extension of their caregiving role.

The issues we have raised have great relevance also for high-income countries. A 2016 report by the National Academies of Sciences, Engineering, and Medicine[12] highlighted how the US health-care system, for example, does not adequately support and involve family caregivers in clinical care. Evidence-based treatments developed in high-income countries reflect the broader limitation (ie, the existence of a bias toward more individualistic models of care) highlighted by this Comment, and present a challenge for LMIC as they seek to culturally adapt and scale-up these evidence-based treatment interventions. High-income countries might have much to learn from LMIC about innovative and family-based models. The entire field of global mental health, we argue, will be enriched and advanced by more explicit consideration of the role that family members can play in evidence-based psychosocial interventions (panel).

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Panel

Recommendations for involving families in interventions for adults with neuropsychiatric disorders

- Involve families in the design and adaptation process for interventions for neuropsychiatric disorders, including ongoing supervision and refinement of the intervention during implementation.
- When designing and offering interventions, consider that family members might often be present during clinical visits and available for participation.
- Identify a range of opportunities for family involvement, such as providing collateral information, participation in psychoeducation, personalising behavioural interventions to family context and circumstances, actively supporting behavioural interventions, promoting adherence, and relapse prevention planning.
- Balance benefits of family's active involvement in the intervention process with potential economic, time, and emotional burdens of caregiving and patient preferences.