Editorial

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Carers of persons with severe mental illnesses: an under recognised resource for mental health care

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Abstract

As community based mental health care has steadily grown all over the world, the number of persons with various types of mental illnesses who are cared for by their family members, relatives, friends, peers, and other non-professional, unpaid carers has also increased. In low-and-middle-income countries, the majority of persons with serious mental illnesses are looked after at their own homes by family members. The care and support provided by the family are often under recognised and undervalued. Families and carers experience various positive and negative (burden of care) effects on their well-being. There is an urgent need to provide pragmatic care, support and family psychoeducation at all mental health care settings.

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Introduction

During the past two to three decades, "recovery oriented mental health care" has become one of the most significant goals and guiding principles for mental health policy makers and mental health service providers all over the world (1). The concept of recovery, while easily understood in the field of physical medicine, has until recently been either neglected or received poor attention in the field of mental health care. The concept was initially introduced by persons who had used mental health services and had "lived experience" of mental illness – patients. Few published patient narratives of their lived experiences became powerful catalysts for the starting of the recovery model and movement in psychiatry (2). Recovery is described as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and or roles. It is a way of living a satisfying hopeful and contributing life even with limitations caused by illness" (1). Recovery model is now "reshaping our clinical and scientific responsibilities" (3). A supportive family as well as other caregivers such as friends and peers are important factors which contribute to good recovery. Explaining the amazing recovery of the 1994 economics Nobel prize winner, John Nash who famously suffered from chronic paranoid schizophrenia, Nancy Andreasen, the famous American Neuropsychiatrist and former Editor-in-Chief of the *American Journal of Psychiatry* (4) highlighted the role "a supportive family…and most importantly, a wife who loved him deeply and patiently, never losing sight of the goal of full recovery". Andreasen said about Nash's wife Alicia; "without her, there very likely would have been no recovery and no Nobel Prize". Carers and family members of persons with severe mental illnesses have an often under recognized but very significant role in their 'recovery'.

Deinstitutionalization and growth of community mental health

Beginning during the second half of the twentieth century (1950s to 1970s), numerous factors including public and professional perception that asylums (mental hospitals) were not therapeutic institutions contributed to the widespread downsizing and closure of mental hospitals all over the developed world. The serendipitous discovery of the first ever antipsychotic medication – chlorpromazine – and its steadily spreading use in developed countries hastened the process of moving severely mentally ill patients out of mental hospitals (followed by either partial, or full closure of those hospitals) and shifting their care to community-based settings – a process referred to as deinstitutionalization. While deinstitutionalisation occurred at varying paces in different western countries, the process of mental hospital reforms began much later in Asian and other developing countries and is still very much a work in progress.

Various alternatives to mental hospitals such as non-hospital community residential facilities (half-way-homes, hostels for mentally ill), different types of supported accommodation in the community, community mental health centres (in United States of America) and other

community-based treatment programs for severely mentally ill were developed (5). Multidisciplinary teams evolved in all developed countries for delivering comprehensive community-based care for patients with severe mental illnesses and complex needs living in defined catchment areas of the community. Different models of "case management" including "assertive community treatment" were developed.

Role of families in mental health

Early ideas about the role of families in mental health were largely postulated by psychoanalytically trained mental health professionals. Family influence was thought to be aetiological (causative) in serious mental illnesses. Family pathology arising from disturbed family relationships and faulty communication styles such as "double bind communication" (two or more conflicting messages in which one message negates the other described by English anthropologist, Gregory Bateson) (6) were blamed and thought to be causative for schizophrenia. Families were accused of inadvertently abusing their offspring. German psychiatrist Frieda Fromm-Reichman coined the term "schizophrenogenic mother" to describe mothers of persons with schizophrenia who she said were "dominant and overprotective but basically rejecting" (7). British psychiatrist, Julian Leff noted that "despite lack of confirmatory evidence, there was a pervasive climate among psychiatric professionals of blaming relatives and consequently ostracising them" (8). Psychiatrists tried to help families correct faulty communication styles through family therapy. By the 1970s, psychodynamic theories about causation of schizophrenia were in decline. Families and relatives of persons with serious mental illnesses who were naturally deeply hurt and resentful rejected their implication in the causation of mental illness. Mothers and other relatives of persons with schizophrenia organized themselves to form national advocacy organizations. A prominent example of such organization is: National Alliance on Mental Illness (NAMI) in the USA (www.nami.org).

Studies of the outcome of relocating long term seriously mentally ill patients from mental hospitals to community settings showed that a good interpersonal environment of the households where patients resided was an important predictor of good outcome. Worst outcomes were in environments where there was little or no warmth and support and critical comments by the relatives (8). A metric to assess the emotional responses and attitudes of relatives namely "Expressed Emotions" (EE) was developed (9). EE is a measure of one person's emotional response to another person who is suffering from a mental illness. Numerous studies of mentally ill persons living in the community with their families in various countries, cultures and languages showed that family members and relatives, depending on their EE, could influence the outcome of the illness in a positive or negative direction (10).

While optimal drug therapy is the cornerstone of the clinical management of persons with severe mental illness, substantial benefits occur with addition of family interventions including family psychoeducation. Ideal family intervention should include provision of information about all aspects of the illness, strategies for solving routine problems posed by the sick relative, learning to lower expressed emotions (EE), improving communication, and acquiring various stress-coping skills. Benefits of effective family interventions include greater symptom reduction, remission of residual symptoms greater medication adherence, possible dosage reduction, better social outcome, and economic benefits (11).

The concept of 'burden of care'

It is not very easy to take care of a mentally ill relative at home. Caring for persons with mental illness at home for long periods has physical, emotional, social, and economic impacts on care providers. The stress of caring is referred to as caregiver burden. The concept of "burden on the family" was first introduced by Treudley in 1946 (12, 13). According to him, "burden on the family" refers to the negative consequences of caregiving for those in close contact with a mentally ill person. Subsequently, a number of researchers (14, 15) have studied various aspects of burden of care by developing and standardising scales and instruments for measuring the burden. Caregiver burden has objective and subjective dimensions. The objective burden concerns the disturbing behaviour and symptoms of the person with mental illness which contribute to the changes in and disruptions to family routine, family relations, work, leisure activities, the financial constraints, and effects on physical health of carers. Relatives have difficulties in understanding illness related behaviour, and they often lack knowledge about the nature of illness; Subjective burden is the effects on mental health of carers. The subjective distress and worry among family members caused by stigma of mental disorders, feelings of shame, anger, perceived loss, and guilt (16, 17). Carers suffer physically, mentally, socially, and economically. Carers tend to often neglect their self-care. Many isolate themselves due to the stigma of mental illnesses. Many carers may manifest various bodily symptoms, and physical health problems, feelings of anxiety and depression and greater health service use.

Carers of persons with mental illnesses

All over the world, a substantial proportion of persons with serious mental illnesses rely on family members, relatives, and friends for various types of assistance, support, and care. In low- and middle-income countries

where organized and formal mental health care services and trained mental health workforce are vastly limited, the role of family, relatives, friends, and other informal carers is vastly greater. In most Asian countries such as India, and China, the majority of persons with severe mental illnesses are looked after by their family members (18, 19, 20). Literature has consistently shown that genuine caregiving makes significant difference for the quality of life of the recipient (4, 21).

What do carers do? The roles of carers vary from person to person and will depend on the nature and stage of the illness and symptomatology. The caring role will include monitoring the symptoms, supervising medication adherence, managing crisis situations, providing care and support for activities of daily living and routine chores, managing finances, helping with follow-up and review appointments, seeking employment etc. (22). Families and carers often tolerate a great deal and do not complain. They expect regular communication from the professional care providers and timely information about progress and outcome of treatment, medication changes, and other available support services. Most families and carers expect to meaningfully engage and involve in the ongoing management.

The value of carers of persons with mental illnesses who constitute an "informal workforce" and a support system is under-recognized all over the world. They should receive greater attention and recognition. Many carers may require psychological help themselves to cope with the burden they face. There is a need to provide pragmatic care provider/family educational interventions at all mental health care settings.

Conflict of interests

None.

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