Engaging families and caregivers in mental health care – DS Raju Oration Award

I am extremely delighted with the great honor of Dr. D. S. Raju memorial oration bestowed on me and humbly express my gratitude to the AP Chapter of I.P.S. My presentation discusses various aspects of “ENGAGING FAMILIES AND CAREGIVERS IN MENTAL HEALTH CARE.” Over the past half-century, the model of mental health care has changed from institutionalization to a community care approach. The transformation is mainly due to the use of updated interventions and techniques with a tremendous advance in the management of psychiatric patients and to the respect for human rights. During the second half of the 20th century, a shift in the mental health-care paradigm took place largely owing to three independent factors: (1) psychopharmacology makes significant progress with the discovery of new drug and development of new forms of psychosocial interventions; (2) the human rights movements became truly international phenomenon; and (3) social and mental components were firmly incorporated in health by the WHO. However, deinstitutionalization has not been an unqualified success. Community care still faces operational problems. The main reasons are that governments have not allocated enough resources to community care; there are no adequate number of mental health professionals and mental health services in community care; the mental health professionals have not adequately prepared to accept their changing role; the stigma, misconceptions, superstitions, and prejudice remain high and strong in community with lack of proper awareness about mental illness.

The WHO developed the optional mix of services pyramid to guide countries on how to organize services for mental health. From the WHO pyramid, it can be seen that mental hospitals and specialist services present the highest cost, yet are the least frequently needed services. However, these are the most-often provided services to people in almost all countries. This is in contrast to self-care or informal community care, which has a high frequency of need and can be provided at a relatively low cost. This clearly shows the importance of informal community care, which includes mainly the family caregiving. In India, by all means, family caregiving is a norm. Families of Indian patients have always been partners in care for their relatives with mental illness and in many instances the mainstays in such care. The extensive involvement of families in care is driven both by choice and a compulsion. Culture, kinship obligation play important role in all decisions regarding treatment. In “cure versus care” dichotomy concept, the family members believe that it is the duty of the professional to cure the patient, while providing care is their responsibility. The compelling forces for their active role are the woefully inadequate mental health infrastructure and inadequate resources and extremely limited alternative institutional facilities and welfare supports for people with mental illness.

India is a secular and pluralistic society, characterized by tremendous cultural and ethnic diversity. In India, the family is the most important institution that has survived through ages. Like other eastern societies, India is a collectivist society with a sense of harmony, interdependence, and concern for others. It emphasizes familism, filial piety, family cohesion, and family integrity. More specifically, collectivism is reflected in a greater readiness to cooperate with others in various aspects.

Unfortunately, Indian families irrespective of their educational background malignantly harbor many wild superstitions and misconceptions. In general, people do not sympathize with the mentally ill person because they
impacts the will power to pull himself/herself up and is not making an effort. Many times, patients are ignored, isolated, or taken to faith healers. Mentally ill persons are treated with meaningless rituals rather than appropriate medications. There are various myths regarding the causes of mental illness such as the influence of evil spirits, witchcraft, loss of semen, the curse of God, and bad parenting. People do not accept medical reasons for mental disorders and hence criticize medical treatment modalities, particularly electroconvulsive therapy (ECT). Many people, especially from the rural community, believe that worship of God and prayers can reduce or eliminate the bad effects, and the influence of evil spirits can be removed by Tantric procedures. The majority of the patients are taken to faith healers, sorcerers, religious heads, or God-men. People continue to have an adverse and negative attitude toward psychiatry and psychiatrists with the fear of their close relative being labeled as “mad” and getting treated with sleeping pills. This sort of misconceptions and superstitions play a significant negative impact on caregiving.

ROLES OF CAREGIVER

The caregiver facilitates the mentally ill relative to approach the appropriate mental health professional. He/she provides the information about the illness behavior in treating psychiatrist. He/she assists the professional in management. The caregiver advocates on behalf of the ill relative and provides shelter and financial assistance. The caregiver monitors symptoms and supports adherence to treatment plans and thereby lessens the risk of relapse and improves the quality of life. The caregiver maintains records of previous treatment, medications, and hospitalizations. He/she also supervises the self-care, occupational activity, and social involvement.8,9

IMPACT ON FAMILY

The presence of a serious chronic mental illness can have significant consequences. Families experience the impact and the burden of mental illness in the role of the caregiver as well as simply by being a family member. Parents, partners, siblings, and children react and cope in different ways at different stages of mental illness. The chronic stress that family members experience along with the practical demands of caregiving for their ill relatives can have an impact on their day-to-day living, health, social, and family relations and financial situations.

IMPACT ON DAILY LIVING

Life becomes chaotic and unpredictable. Caregiving disturbs the entire family. Caregivers have less time to pursue their career and personal activities, as most of time is spend on caregiving. Life events which are normally a cause for celebration become a source of stress and conflict. Caregiving responsibilities interfere with their vocational responsibilities. They have to spend a significant amount of time in the caregiving role.

IMPACT ON HEALTH

Studies reported that one-third of the caregivers scored positive on G.H.Q. Feeling of confusion, anxiety, stress, guilt, shame, self-blame, depression, fear, and anger are common among caregivers. Over some time, families tend to experience changes in their health and well-being. Higher rates of anxiety and depression are reported in family caregivers.7 On the long run, it may cause burn out. Caregivers experience physical problems and it affects lifestyle diseases such as hypertension and diabetes.

IMPACT ON SOCIAL LIFE

When people are affected by significant physical illness, they seek support from relatives and friends. They often rally round to express concern and offer assistance whether or not support is required. However, the scenario is different when a family member is affected by a serious mental health problem. Feeling of stigma and discrimination comes in the way of sharing their problems. The fear of disclosure may lead the families to distance themselves from relatives, friends, and the wider community. The majority of caregivers report that they rarely or never get social support from relatives and friends. Siblings of a mentally ill person isolate themselves from friends and community because of embarrassment. Sometimes, they feel neglected as their parents focus on ill brother or sister. Families try their level best to conceal the mental illness with the fear of future marriage alliance problems to the affected individual and his/her siblings.

IMPACT ON CAREER AND FINANCES

Mental illness has an impact on a family’s employment and financial situations. If a person with mental illness is the sole earning member of the family, the financial problem becomes disastrous. Additional stress and the time demand of caregiving, as well as the actual costs for supporting an individual, can have a profound short-term and long-term effects on a family’s financial security. The career of the caregivers is significantly affected. On a few occasions, they may have to go on a long leave from the job and at times even lose the job. The children of parents with mental illness are particularly affected.
COMMON PROBLEMS OF CAREGIVERS

The impact of caregiving is related to the factors such as characteristics of the person with mental illness (PWMI); characteristics of the caregiver relationship between them; nature, severity, duration, Disability of mental illness and the available resources; and the available resources. A study conducted in Sri Lanka by an organization called “Basic Needs” has shown that stigma, discrimination, and exclusion livelihood hardship and difficulties in getting access to adequate treatment and care are the salient features of the problems expressed by caregivers. Families received little recognition for their valuable work and most countries fail to recognize the family contribution and to offer financial support.

FAMILY CARE GIVING

Families are the single largest group of care givers, often providing financial, emotional, and social support, although their role generally goes unrecognized. Family involvement in mental health services can take different forms, depending on the level of the needs and availability of services. In general, it can be conceived on a spectrum from more basic functions to specialized interventions. The basic minimum level includes the provision of general information on the mental health services and assessment. On a more complex and specialized level, services can offer a family with psychoeducation, consultation, family intervention, and therapies.

BARRIERS FOR FAMILY INVOLVEMENT

The common barriers for family involvement are caregiver understanding of illness and expectation of services; the awareness, acceptance, and acknowledgment from professional groups; the conventional constraints; caregiver burden; lack of interest; and lack of government support.

FAMILY CAREGIVER PROFILES

All over the world, women are the predominant providers of care for family members with mental illness. Worldwide caregivers of the elderly with dementia are usually their wives or daughters and the caregivers of patients with schizophrenia are usually their parents, mostly mothers. Most caregivers are middle age or elderly and commonly parents. Community based studies have shown dementia more common with increase in life expectancy in India. Like Western countries, Dementia patients in India have been older women who are wives dementia patients and younger women who are daughter of dementia patients.

FAMILY-BASED INTERVENTION

In the 1950s and 60s, Dr. Vidyasagar was the pioneer in family intervention, and in 1960s and 70s, the family participation studies were limited to large hospitals. Subsequent research on family-based interventions was scarce. Lack of enthusiasm is attributed to skepticism about the need for structured family interventions for Indian families. Critics have argued that day-to-day practice already involves family members. Structured interventions are expensive, time-consuming, and resource intensive, which makes them unsuitable for nonwest countries such as India.

FAMILY PSYCHOEDUCATION MODEL

There is enough evidence for the high prevalence of burden and distress among Indian family caregivers, and the usefulness of family-based interactions in lessening the negative caregiving outcomes is well established. Two major models developed and empirically tested are the (1) behavioral family management model and (2) family psychoeducation model. A subset of the family educational model is the consultant model, in which individual families meet periodically with a professional involved in the patient treatment to receive information, advice, and support. It has been suggested that the family educational model could be a more appropriate model for the Indian context. Another suggestion to adopt a needs-based approach with varying levels of interventions from simple to complex is also particularly apt one. Regardless of the model adopted, it is amply clear that relatively simple and inexpensive forms of these interventions, which emphasize ongoing contact, and medication adherence while offering emotional and practical support and which rely on nonspecialist professionals for delivery are more likely to succeed in the Indian context.

SOME NEW INITIATIVES

Several nongovernmental organizations have been working in the area of providing community support to persons with mental illness and their caregivers. Some of these are Ashadeep (ASSAM), AMEND (BANGALORE), AASHA (CHENNAI), SAA (PUNE), NAMI INDIA (MUMBAI), TURNING POINT (KOLKATA) AND SCARF (CHENNAI).

CAREGIVERS PERSPECTIVES OF MENTAL HEALTHCARE ACT [MHCA]

Sec. 18 (1) gives right to any person with mental illness (PWMI) to get free treatment from Government run or funded Hospitals.
Mental health care act has made modified electro-convulsive therapy compulsory which requires short general anaesthesia. It is beneficial for the patients it comes at an extra cost to economically deprived patient family.

Suicide is no longer a criminal offence as per section 115 of MHCA, the law presumes those who attempted suicide to suffering from severe mental illness. These modification in law has made caregivers to disclose true information about cause of suicide attempt and nature of mental illness

Changes in admission and discharge procedure may discourage admissions due to stigma and the caregiver has to carry the significant burden of caring for the acutely symptomatic state.

The advance directive becomes an important hurdle and burden to the family caregiver and the psychiatrist in the management of emergencies.

Mental health care Act 2017 has made provisions make it mandatory that mental health illness should be covered health insurance companies either run by the government or private and all government health schemes should treat mental illness at par with physical illness.

The MHCA ensures health care, treatment, and rehabilitation in the least restrictive environment, respecting the right and dignity.

The admission of children with mental illness is converted into a state-monitored tedious process, instead of simple parent consent and become troublesome to the family.

The act does not give clear guidelines regarding mental health care in general hospitals, which reduces stigma. These issues are to be actively taken into consideration for the amendment of the act in the future.

Thus, the caregivers and the family involvement in mental health care form the key support system and take multiple roles in the management of persons with mental illness. They suffer substantial burden and there is a great need for the research to introduce suitable interventions.

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