Review Article

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Homecare: a strategy to ease the burden of Family Care Givers of clients with mental disorders: an overview

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ABSTRACT

Mental disorders are the second leading cause of disease burden in terms of Years Lived with Disability (YLDs) and the sixth leading cause of Disability-Adjusted Life-Years (DALYs) in the world in 2017. Mental disorders can lead to extreme physical, psychological, social and financial burden among the caregivers. Family is a basic unit of caring for the mentally ill. Empowering the family caregivers on caring their mentally ill client at home is an effective strategy in rehabilitation as the mental health facilities are limited in India. Home based care is known to reduce burden among the caregivers. Homecare includes various components that help in caring and managing clients with Activities of Daily Living (ADL), supervision and administration of medication, recreation and leisure activity, stress management, regular follow up with mental health professional, social skill training, management of psychiatric emergencies, management of potentially harmful behaviours such as suicide and anger management. The outcome of the home care of mentally ill depends on the willingness and cooperation of the family and continuous support and monitoring by the mental health team. It is cost-effective and implies the shift of responsibility not only on the hospital but on the family caregivers and the health professionals in the community.

Keywords: Home care, Burden, Family care givers, Mental disorders

INTRODUCTION

Mental disorders were the second leading cause of disease burden in terms of Years Lived with Disability (YLDs) and the sixth leading cause of Disability-Adjusted Life-Years (DALYs) in the world in 2017. Epidemiological studies conducted in India have highlighted the prevalence rate of mental disorders between 5.82% and 7.3%.

The treatment gap between the burden of disorders and the facilities available is more than 75%.² The inpatients and outpatient services for the treatment of the mentally ill are few as compared to the burden of illness. Very few

addiction and counseling centres are available for the treatment of substance abuse. However, the majority receive little or no care and in a developing country like India, only 15-25% of the affected persons receive treatment.³

Even though limited centres are available for treatment, lack of adequate infrastructure, trained workforce, insufficient funds hamper the treatment process. Other factors like lack of motivation, perceived stigma, long duration of illness, poor insight, poor prognosis, and lack of knowledge predispose people not to seek treatment.⁴ Due to these factors, either not treating or mistreating the occurrence of mental illness exacerbates medical, functional, and social problems leading to an increase in

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caregiver burden.⁵ The WHO states caregiver burden as the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends, or other individuals involved with the individual outside the healthcare system.⁶ A study on prevalence of burden among 368 family care givers revealed 85.3% of total objective burden and 84.2% of subjective burden. This study also concluded that family care givers require comprehensive intervention in order to reduce the growing incidence of chronic enduring diseases burden which may lead to mental disorders among FCG's.⁷

To address these problems of caregiver burden, mental health professionals need to plan strategies to empower family caregivers on homecare to fill the gap between the hospital and home. Home care is termed as a non-residential multidisciplinary psychiatric service that aims to treat patients outside the hospital or nursing homes to enable them to stay in their usual place of residence as long as possible. Homecare applies to individuals of all ages and in physical or mental illness.

Due to the deinstitutionalization of the mentally ill patients, the role played by the family caregivers is significant especially reducing the number of hospital readmission, role in the maintenance of treatment and rehabilitation of patients.⁹

THE MAGNITUDE OF BURDEN ON FAMILY CARE GIVERS

Family members are the primary caregivers of Individuals with mental disorders in most of the non-western world. In India, more than 90% of patients with chronic mental disorders live with their families.¹⁰

Literature highlights that caregivers of mentally ill individuals undergo a lot of burden, which accounted for 40.9% of the severe burden. The highest areas of burden were seen in the areas of physical and mental health, spouse-related, and external support.¹¹

The burden of mental disorders is estimated as 14% globally, with the highest-burden in developing countries, leading to continued economic burden and suboptimal productivity at the individual and national levels. ¹²⁻¹⁴ A study concluded that poor social support and severity of illness have a major role in determining the amount of burden on a caregiver. ¹⁵

CATEGORIES OF CAREGIVER BURDEN

Family members play important roles in the care of the sick and those unable to take care of their own needs. Caregivers are at risk of caregiver burden.

The burden perceived is one of the important prognostic factors in the history of the disease and a critical determinant for negative care giving outcomes.¹⁶

Changes seen in various aspects of the care giver's life and household (e.g. **OBJECTIVE** anxious, irritable, extra BURDEN responsibilities on the care giver, evidence of weight loss). • The emotional reactions of the care giver to the caregiving experience. It **SUBJECTIVE** measures emotional **BURDEN** impact of caregiving on the caregiver (Sadness, crying, blaming oneself). • The care giver feels that the **DEMAND**

Figure 1: Shows the categories of burden of FCG's.

responsibilities are overly

placing demand on them.

DETERMINANTS OF FCG'S BURDEN

Several studies have identified a number of determinants of family care givers among mentally ill patients are associated with caregiver burden. They are classified as follows-

Disease related determinants

BURDEN

Studies have identified the following disease related determinants such as the duration of mental disorder, number of psychiatric hospitalizations, degree of functional impairment and neuropsychiatric symptoms and crisis situations or problem behaviors.¹⁷

Clinical and socio-demographic determnants

Literature has shown that variables related to the patient and caregiver include young age, male gender, and presence of other comorbidities (physical and/or psychiatric) of the patient increases caregiver burden.¹⁸

Caregiver-related determinants

Studies have suggested older age, female gender, high household income, level of education, degree of kinship with the patient history of physical illness such as hypertension and diabetes mellitus, and or mental co morbidities such as anxiety and depression as well as low quality of life.¹⁹

Social psychological determinants

It includes low social support and family dysfunctionality.²⁰

Other determinants positively associated with burden of care givers include residence and days of contact with the patient.²¹

CONSEQUENCES OF BURDEN ON THE CARE GIVERS

The burden on the FCGs has a significant impact not only on the individual's health but on the health and integrity of the family. A systematic review concluded that the impact of mental illness had multidimensional, long-term, and generational impacts on family members.²²

The physical consequences of care giving have received less attention than psychiatric outcomes. One study indicated that caregivers often experience several physical problems, including back injuries, arthritis, high blood pressure, gastric ulcers, and headaches.²³

Some studies show multiple consequences of caregiver burden, such as mental-health problems (e.g., depression, anxiety, stress, and burnout syndrome), physical health deterioration (e.g., diabetes), and other negative effects (e.g., family dysfunction, social isolation, excessive use of health services, and financial problems). Some evidence indicated significantly higher scores of overload in caregivers of psychiatric patients when compared to other conditions, such as other chronic diseases.¹⁸

Studies indicate that caring for an ill family member at home is negatively related to physical health.²⁴ A study concluded that family care givers require comprehensive interventions in order to reduce the growing incidence of chronic enduring disease burden which may lead to mental disorders among FCG's.⁷

These findings highlight the need for interventions to support people with mental disorders and their caregivers.²³

Table 1: Consequences of burden on the caregivers of mentally ill patients.

Physical impact	Psychological impact	Social impact	Financial impact
	-Depression		
-Exhaustion	-Anger and frustration	-Social exclusion	
-Lack of sleep	-Worry of future especially	-Poor cooperation by	
-Neglect of own health	the death of a caregiver	neighbors	-Had to forgo basic needs to buy
-Need to take additional	-Safety problem especially	-Stigma in the society	medicine
medication	breaking of home items,	-Disruption of social life	-Incurred additional bank loans
-High blood pressure	rape by others	as no replacement to look	-Taken hand loans from relatives
and heart disease.	-Fear of suicidal ideations	after mentally ill.	and neighbours
-Loss of appetite	-shame and low self-esteem	-Stressful family	-Had to sell ornaments
-Frequent headaches	-Embarrassment due to	environment	
-Gastric ulcers	societal attitude		
	- Burnout		

HOMECARE: A TECHNIQUE TO EMPOWER FCG's

The availability and integration of mental health services into communities can promote accessibility, acceptability, affordability, and scalability of services, as well as promote adherence to treatment and increase the likelihood of positive clinical outcomes.²⁴

The enormity of the mental health gap has necessitated introduction of innovative methods of care delivery. ⁴² Various innovations were successfully tried to fill the gaps in the delivery of mental healthcare in India. But these efforts are scattered and not enough to address the dire demand. It is important for the mental health professionals to identify the extent of burden among the family care givers of the patients they treat.

Early identification and specific interventions would help in empowering the FCG's in formulation of an intact support base which is healthy and effective. Understanding existing community perceptions of mental health is vital to establishing successful practices.²⁵ Homecare needs to be looked at as a multidisciplinary approach so as to support the family not by an individual but collective effort. It is a known fact that the FCG's may want to have information about the disease condition and to be involved in treatment decisions. ²⁶ Home care can help in management of day-to-day problems that can be discussed, and simple and practical solutions can be offered to the FCG's. Family care givers who are in contact with treatment teams for a long time learn to develop healthy coping methods to deal with the burden of caring for relatives with severe mental illness by both experience and prolonged therapeutic contact with the mental health team. ¹¹

SERVICE PROVIDERS OF HOMECARE IN THE COMMUNITY

Collaborative care model (psychosocial services, nonspecialist care and specialist services) has been found beneficial as mental health services are made available at community and primary healthcare level that is not only acceptable but effective in reducing treatment gaps, improving treatment adherence and quicker rehabilitation of mentally ill patients in their family and the society. Homecare multidisciplinary teams working in several health areas provide more benefits to users than traditional care by a single professional.²⁷

According to the literature, more effective teams generate better treatment outcomes and greater satisfaction among users. Effective teamwork also reduces health costs and medical errors. Treating mental disorders as early as possible, and close to the person's home and community can lead to the best health outcomes.²⁸

Non-professionals workers are first level providers who have received general rather than specialist mental health training. Tasks such as providing community level basic health education, education regarding disease, need for

drug compliance, monitoring adherence and side effects etc., could be undertaken for various periods of time. This would free up the resources especially the specialist to take care to those who needed most.²⁹

A study concluded that faith healers in many conditions and situations became the first point of contact as the faith of the community in these faith healers is deeply rooted. Since the traditional and faith healers have lived in the community and people constantly rely on them to meet their needs, their services can be made useful by taking them into confidence, imparting education on mental health and mental illness, so that they can be service providers of mental health in the right direction rather than misleading the community on mental illness.

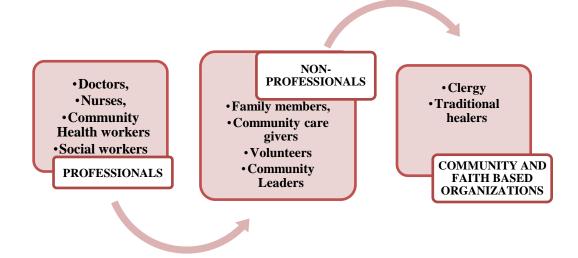


Figure 2: Multidisciplinary team in home-based care.

COMPONENTS OF HOME CARE



Figure 3: Shows the components of home care.

Activities of Daily Living (ADL)

Personal hygiene tasks such as eating, toileting, bathing, dressing, rest and sleep, leisure activities, exercise, etc are used as an indicator of a person's functional status. Activities of daily living (ADL) impairment can have significant ramifications for patients and their caregivers, as it can lead to caregiver burnout and institutionalization.³¹

Medication adherence

The prevalence of non-adherence to antipsychotics ranges from 20 to 89% for patients with schizophrenia or bipolar disorders. Non-adherent behavior increases the risk of relapses and rehospitalization.³³

Literature has highlighted that psychotropic medication non-adherence can lead to exacerbation of the illness, reduce treatment effectiveness, or leave them less responsive to subsequent treatment. Other consequences of non-adherence include re-hospitalization, poor quality of life or psychosocial outcomes, relapse of symptoms, increased co-morbid medical conditions, wastage of health care resources, and increased suicide.³⁴

Recreation and leisure activities

A study pointed that involving clients in recreational and physical activities has been shown to reduce stress, anxiety, and depression during the process of recovery. Physical activities have been shown to have numerous psychological benefits. Recreational activities lead to improvement in mood and reduced depressive symptoms.³⁵

Stress management

Stressors have a major influence on mood, sense of wellbeing, behaviour, and health. The long-term effects of stressors can be detrimental to the health of the patient. Various techniques such as progressive muscle relaxation, autogenic training, relaxation response, biofeedback, guided imagery, diaphragmatic breathing, transcendental meditation, cognitive behavioural stress reduction, and mindfulness-based stress reduction without any side effects have proved to be beneficial. Individually these techniques have been tried in depression, anxiety-related disorders, personality disorders, adolescent aggression, etc.³⁶

Follow-up of treatment

Timely follow-up after hospitalization can reduce the duration of disability and for certain conditions, the likelihood of rehospitalization. For these reasons, the time between inpatient discharge and outpatient follow-up is considered an important indicator of health system quality.³⁷

Social skill training

Social skill training equips the patient to deal with stressful life events, daily hassles, problem-solving capacity, reduce exacerbations, etc. In addition to this, the protective effects of social skills training help individuals stabilize their illnesses, improve adherence to medication and psychosocial treatment, and promote progress toward recovery.³⁸

Management of emergencies

Tackling emergencies at home is a challenging situation for family caregivers. In rural communities, the trend is specialist care consultation which is available only once a week and the access available is limited.³⁹

Suicide is among the top three causes of death among youth worldwide. Extensive stress and inability in managing stress pushes persons to suicide.⁴⁰ It must be reinforced to the family care givers to look out for the warning signs and early follow up is essential to reduce suicidal attempts.

Hence prevention of suicide is a matter of great concern at home since the home cannot be perfectly safe. 41

Psychoeducation programs

A systematic review suggests that psychoeducational approaches are useful as a part of the treatment program for people with schizophrenia and related illness. A study highlighted that the psychoeducation group reported greater improvement in family and patient functioning, family's burden of care, and the number and length of patient re hospitalization over the 12-month follow-up.⁴²

Rehabilitation services

These are services that facilitate opportunities for patients to reach their optimal level of independent functioning and for improving the quality of life activities. 60 Activities such as yoga, light physical exercises, group discussion, training for daily living skills, social skills, life skills, vocational training, individual, and family counselling are included. Studies have highlighted the importance of rehabilitative services immediately after the discharge of patients from the hospital. 43

Anger management

Among psychiatric patients, anger is one of the strongest predictors of aggression. 44

Anger may be shown towards health care professionals, family members, and oneself. Hence training family caregivers in identifying early symptoms of anger and preventing de-escalation of symptoms is foremost in handling anger.⁴⁴

IMPLICATIONS FOR PRACTICE

The concept of home care has been highlighted in literature for decades. High rates of functional loss and mortality are reported among patients with mental illness. It also leads to social and economic loss. ⁴³ A patient with mental illness is not able to fulfill all the roles and responsibilities which he used to do before his illness. Hence family caregivers need to meet all the needs which burden the caregivers.

A study found that a higher percentage of patients who took part in collaborative discharge planning meetings became involved in aftercare services compared to those who did not attend such meetings.⁴⁴ Home care helps to reduce readmissions to the psychiatric unit by not permitting the use of active inpatient beds by chronic or recovered patients.

Family caregivers are empowered to look after their family members in their familiar setting and economical in terms of cost and distance. The responsibility of looking after the patient can be shared by all family members rather than shunning the responsibilities. Home care establishes a strong relationship between the client and the health team. Thus, family caregivers can identify early symptoms of the onset of the disease without undue

delay. Educative programs can be planned and implemented depending upon the felt needs of the family, availability of caregivers and the family caregivers are at ease at home rather than the hospital to actively participate in the group sessions.

PROBLEMS ENCOUNTERED IN-HOME CARE

Home care has its disadvantages. As health team members, we need to be proactive in anticipating problems and to be ready to tackle them. All family members may not cooperate as it is a burden for them to look after the client at home. Within the family is

essential to achieve the goal of home care. Family members may have fear and uncertainty to handle emergencies. It is difficult to have full control over the therapy session as patients and their caregiver may not be focused. Educative programs once planned may not be conducted on the scheduled dates and time due to time constraints and the programs tend to be postponed. Distance and traveling constraints hamper home care. Moreover, the houses may be located quite far from each home. Hence health practitioners take a lot of time for traveling. Health professionals may not feel safe in the patient's home. 45

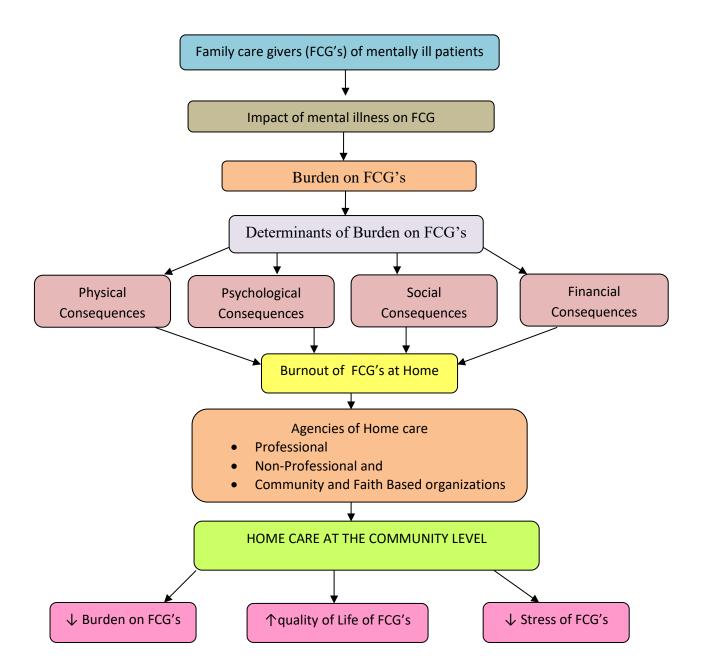


Figure 4: Model of homecare management for reducing burden of FCG's of mentally ill patients.

CONCLUSION

Home care is a strategy for monitoring continuous care after discharge. It is cost-effective and implies the shift of responsibility not only on the hospital but on the family caregivers and the health professionals in the community. Families of Indian patients have always been partners in care for their relatives with mental illnesses, and in many instances, the mainstays of such care. It appears that this extensive involvement of families in care is driven both by choice as well as a compulsion. Home care services have negative and positive effects for caregivers, patients, and their families. Victor Hugo says that helping families in providing care is an idea whose time has not yet come in India. However, if the slow yet steady progress of these Indian efforts continues, its time will surely come, perhaps sooner than later.

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