REVIEW ARTICLE

Dimensions of Caregiving in Schizophrenia

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ABSTRACT

Family plays a vital role in the lives of individuals living with mental illnesses like schizophrenia. Schizophrenia is a severely disabling mental illness which affects the functioning of family caregivers. Family caregivers of individuals with schizophrenia have received significant consideration in recent years due to robust family involvement in caregiving of ill individuals. The family environment reflects the estimate of psychosocial factors that anticipate the prognosis of illness. Not surprisingly, family caregiving is a prominent support system that displays diverse roles regarding caregiving of individuals with mental illness; however, it has been stayed overlooked by the mental health practitioners. Family caregivers of individuals living with schizophrenia have to deal with a number of problems, such as associated stigma, burnout and reduced quality of life. These problems are result from apparent role of caring when combined with inefficient support system and unproductive ways of coping. Subsequently, may affect the biopsychosocial integrity and quality of life of caregivers. It is now well recognised concern for a mental health professional to acknowledge various dimensions of caregiving and cater the needs associated with family caregivers of individuals with schizophrenia. This review article used a descriptive approach to develop qualitative themes of different dimensions of caregiving from the review of literature. This is a retrospective study which has given an overview of different dimensions of caregiving in context of individuals living with schizophrenia. It is important to pursue further research on this neglected public health concern of caregiving.

Keywords: Caregiving, Schizophrenia, Express Emotions, Illness Perception, Caregiving Burden, Quality Of Life, Burnout, Stigma.

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INTRODUCTION

Globally, the mental health problems have been rising and impacting socio-economic, health care, and human rights of ill individuals and their families.¹ Schizophrenia is possibly the most vividly intense and miserable appearance of mental illness known to human beings.² It impacts those who are living with them as well as care for them.³ In fact, caring intended at schizophrenic ill individual is demanding and generally is not a matter of choice.⁴ The magnitude of care moved from hospitals to families, communities and society at large, after the deinstitutionalization.^{5,6} The lives of caregivers can be disturbed by providing more than usual care to ill individual suffering from schizophrenia. An augmented role of caregiving to previously existing family roles may become challenging, physically, psychologically and economically.⁷ The level of support and responsibility conveyed by caregivers varies, depending on the severity of the illness of ill individuals.⁸

Schizophrenia, being the most common functional psychotic disorder causes a wide range of symptoms, such as hallucinations, delusions, conceptual disorganization, and impaired cognitive ability.^{5,9,10} This is so disabling that schizophrenia has intensified many challenges in management and subsequent outcomes of illness. If not managed properly, they significantly affect the quality of life of ill individuals and their family caregivers.⁶ Evidence reveals that the perpetual and unintended cost of caregiving result in recurrent hospital admissions, need for continuous psychological and financial support, and reduced productivity for a long duration.¹¹ Subsequently, family caregivers feel an extensive array of emotions, such as grief, anger, denial, guilt isolation and stigmatization.¹²

Caregiving is now considered as a multidimensional health care assignment and becoming a growing part of health care system, worldwide. It is estimated that around one third to two third of ill individuals with schizophrenia are living with their family.¹³ Family

caregiving is described as connection of one family member with another on a regular basis in assisting tasks that are necessary for independent living. The main caregiver is considered the person who provides maximum support to the ill individual in the family, spends substantial period in taking care of the ill individual, on daily basis.¹⁴ The indented and unintended cost of caregiving may include recurrent hospitalization, lasting psychological & economic support, and lost productivity.¹¹ The add-on role of caregiving to the existing family roles makes caregiving a challenging task. It impacts on caregiver's physical as well as psychological health.¹⁵

The awareness regarding mental health aspects of caregiving is now expanding in high, low- and middle-income countries.¹⁶ It is observed that environmental revolutions in the region place significant demands on family caregiving. The urbanization in response to modernization transformed family systems into nuclear families which makes caregiving a difficult task. Subsequently, insufficient community support and limited access to resources while living in nuclear families in urban areas make caregiving challenging and mental health of caregivers at risk. The emotional and physical wellbeing of caregiver is meaningful not only for the caregiver but also for the care receiver.¹⁵

In most of the non-western countries, family caregivers are considered the primary care providers of individuals suffering with mental illnesses.¹⁵ Generally, women are considered the largest care providers for ill individuals with mental illness. Though, recent evidence indicates men progressively assuming the role of caregiver.⁷ Caregivers are usually parents, mostly mothers and occasionally spouse of ill individuals. Evidential data from India indicate that more than 90% of ill individuals are living with their families. In the process of caregiving, the family supposed to take care of assigned tasks including day-to-day care, managing medication, hospital visits and dealing with the financial needs.¹⁷

Caregiving trends indicate diverse cultural experiences related to people's perceptions and attitudes toward individuals with mental illness. In every culture, caregiving reflects prevalent social values associated with the perception of mental illness, for example, in Saudi Arabia mental illness is negatively perceived to appear due to evil eye, which consequently influence the public attitude towards mental illness and wellbeing.¹⁸ In developing countries, most of the individuals suffering from severe mental illnesses are living with their families. It is observed that strong family involvement is widespread in Asia, specially with respect to caregiving throughout the illness. In South Asian countries, over 70% of individuals with schizophrenia rely on their family caregivers, compared to 25–50% in Western countries.^{19,20}

There is now substantial clinical evidence indicates that impolite interactions between the ill individual of the family and the caregiver impact the symptoms severity of the illness and increase levels of distress.²¹ It seems that some of the caregivers are often not ready to assume the additional role of caregiving, which produces distress in them.²² However, typical responsibilities of caregiving involve providing emotional support such as careful listening, extensive companionship, and assistance in activities of daily living such as brushing, cleanliness and personal hygiene.² The above review of literature indicates that caregiving of individual with schizophrenia is a challenging task. This review article highlights the crucial dimensions of caregiving to acknowledge this neglected but important issue. Also, addressing the efforts and difficulties, they have experienced during the process of caregiving such as burnout, burden, and decrease quality of life.²³ This review article tries to answer the following research question:

To identify the various dimension that influence caregivers in the process of caregiving of individuals with schizophrenia.

The potential studies were approached according to the research question of the review article. The studies were retrieved via searching of electronic databases, internet search and bibliographic search of the recovered full articles. An efficient electronic database search was performed in the PubMed, Science-Direct, Psych-Info, and Google Scholar up till saturation. The search was conducted in the period from March 2020 to March 2021. The first author performed initial literature search and screening of the articles from the internet and electronic database sources. The second author made a further search to find if any potential studies have left out. Relevant articles published in the English language, available in an internet and electronic database sources in the form of journal articles were included. The following search terms were used to identify the potential studies: 'Caregiving', 'Schizophrenia', 'Express Emotions', 'Illness Perception', 'Caregiving Burden', 'Quality of Life', 'Burnout', 'Stigma'. A combination of words using Boolean operators 'AND' and 'OR'.

Following are the qualitative themes developed on dimensions of caregiving in schizophrenia collated from the analysis of literature:

Express Emotion

Express emotion is a qualitative measure of emotional expressions carried in the family environment, by caregivers in daily living.²⁴ Evidence indicates that express emotion is positively correlated with family atmosphere in course of schizophrenia.²⁵ It is suggested that express emotions are linked with several clinical and social factors associated with ill individual's and family caregiver's functioning, such as working position, cognitive functioning, number of hospital admissions, premorbid modification, duration of illness, duration of untreated psychosis, number of household members living with individuals with mental illness.²⁶

Literature suggests that high express emotion mainly involves critical remarks, emotional over-involvement, and hostile behaviour of family caregivers towards ill individuals in family.²⁷ The express emotion components such as critical comments, hostility and emotional over-involvement surface from different causes and have circumstantial effects on individuals with illness. The component of critical comments is a negative appraisal from the part of caregiver towards the behaviour of ill individual with mental illness. While, the component of emotional over involvement is related to the feeling and thought of selfless attitude, shielding the ineffectiveness of caregivers towards individuals with mental illness. However, the hostility component is usually associated with critical comments, and negative charges or contempt from the side of caregivers towards the individuals with mental illness.24

It is now documented that unfavourable family interactions, and relationships among individuals with schizophrenia and their caregivers reflect high expressed emotions in family. High express emotions are significant in predicting symptom severity and relapse associated with mental illness. It is now established that social and emotional environment inside the family plays a vital role in schizophrenia. Evidence indicate that family caregivers who display high express emotion of criticism report more burden than caregivers who display low express emotion of criticism.²⁸

On the other hand, it is indicated that ill individuals with positive perceptions of their family caregivers have a significantly lower rate of psychotic exacerbation of symptoms at follow-up. However, literature demonstrate the significance of expressed emotion in families where ill individual perceive criticism by their family caregivers tend to have more chances in predicting relapse.²⁹

Illness Perception

The concept of illness perception is a recent pragmatic approach, that belongs to individuals living with mental illness, their caregivers, and clinicians. Illness perception is stated as the self-definition of health position induced by illness-related experiences in the past. It was argued that people tend to think differently about specific diagnoses, in case of physical illness. There is a desire to identify or diagnose individual's illness separated from one's awareness about the self. The discrepancy between the illness and the perception about the self is often more blurred in psychosis, consequently, make the illness more difficult.³⁰

Illness perception is related to emotional distress, disability, adherence to treatment regime, recovery and engagement in psychological services for psychotic disorders. The understanding of illness perceptions and its incorporation in health care system is critical regarding improvement in treatment outcomes in individuals with schizophrenia. The perception of illness has been shown to vary across countries and culture. Nevertheless, evidence indicate that perceptions and experiences of individuals with mental illness have been neglected largely in Asian culture.³¹

Caregiving Burden

Caregiving burden can be identified as a mental state produced by the amalgamation of substantial emotional, social and financial difficulties arising from caregiving of mentally ill individuals of family. It often involves feelings of shame, self-blame and guilt. (Elegbede 6) Caregiving burden is generally observed in dealing with the ill individual's symptoms (Dennis 13), due to decreased quality in different domains of life, such as personal health, leisure time, daily routine, social activities, occupational functioning, and emotional coping and regulation of caregivers. Evidence suggests that they experience different types of burdens that may upset their biopsychosocial integrity, and associate with somatic, emotional, social, and financial burden.^{32,33}

Studies from South Asian countries like India document lack of sufficient health and community care, in different life areas such as resources, relations, and safety.³⁴ In a study conducted on caregivers of individuals living with schizophrenia found that spouses reported greater emotional burden compared to parents. It is also indicated that spouses used negative distraction whereas parents used denial as coping strategies. Literature suggests that caregiver burden depends on many factors such as caregiver's lesser level of education, coping skills, patient interaction,

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being a parent of ill individual, illness duration, need for hospitalization, financial instability, violence, personality factors such as male gender, age of onset of illness, unemployment and marital position.³⁵

Quality of Life

Health-related quality of life is defined as individual's perception of his/her position in life, in perspective of culture, values, goals, expectations, standards, and concerns. Caregivers deal with extensive challenges related to the quality of life of ill individuals living with schizophrenia while supporting them.^{36,37} Focusing on the quality of life of caregivers is a primary concern in evaluating the crucial outcomes of community care. Findings indicate that increase in the caregiver's quality of life improves an ill individual's psychotic symptoms.³⁸ The quality of life of family caregivers of individuals living with mental illness like schizophrenia has been increasingly documented. Although literature indicates that caregiving of ill individuals exhibits significantly lower quality of life when compared with general population.¹⁰ It may be the result of fear, discrimination, concern about the prolonged care of the ill individual and feeling of insecurity due to his/her mental condition. Recent findings on caregiving of individuals with schizophrenia report decrease quality of life, substantial caregiving burden, restricted activities, persistent symptoms of anxiety, depression and psychosomatic complaints.⁶

Stigma

Troubles and difficulties related to stigma do not only disturb individuals suffering from mental illness but their families are also affected by it. Stigma intensifies the struggles of caregiving and upset the lives of caregivers in multiple ways. The literature indicates that family caregivers experience more stigma and discrimination while living with individuals with mental illnesses. In South Asian culture, individuals with mental illnesses deem to be discriminated, stigmatized, socially isolated, and their needs are neglected.³⁹ For instance, a study from South India found that family caregivers of individuals living with schizophrenia often have concerns that other family members would not be capable of marrying, and friends and family may evade or consider them different. Comparable findings have been described from other low and middle income and several high-income countries.^{39,40}

Stress and Coping

Caregivers often encounter increased mental and emotional strain due to the financial, emotional, social

demands of the chronically ill individual in the family. Psychological stress is conceptually defined as a unique, discomforting, emotional state experienced by an individual, in response to a specific stressor or demand, that results in harm, either temporary or permanent, to the person. Depression is more frequently experiences by caregivers of individual with chronic mental illness. Caregivers deal with increase stress due to financial, psychological, and social challenges persistently faced due to ill individual in family. Caregivers who have a persistent high stress level are more likely to have a lower quality of life and greater physical health risks in comparison with the general population.⁶

Psychological stress can be defined as a unique, discomforting, emotional state experienced by an individual, in response to specific demand, that results in harm, either temporary, or permanent, to the person. Caring of individuals with mental illness produces conflicting feelings and emotions that can be stressful, especially if the caregiver does not have a sufficient support system. Globally, it is now recognized that caregivers are more vulnerable to stressful circumstances due to involvement in activities that requires care, especially when dealing with individuals suffering from chronic mental illnesses.^{41,42}

CONCLUSION

Family caregiving of individual with mental illness is considered as central support system in most of the developing countries. The family caregivers take multiple roles in providing care for individuals with mental illness. Analysis of literature on caregiving indicates that it incorporates both positive and negative aspects of caregivers. Unlike normal caring, caregiving for mental illness is different. Regular caring changes into caregiving when the tasks and responsibilities of ill individual of family go beyond ordinary expectation. This is usually a prolong process and caregivers may find this role undesirable. Consequently, it is associated with emotional distress among caregivers. Though, it can be a source of ecstasy and contentment on rare circumstances. So, it is important to discourse about the issues and difficulties faced by caregivers. Still, there is a scant literature available about the psychological structures of caregiver's sufferings. It is important to improve understanding and concerns of caregiving during the course of illness in schizophrenia.

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