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A Review on Quality of Life for the Caregivers of Schizophrenic Patient

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Abstract: ***Schizophrenia is a disturbance in thinking, emotions and volitions. Schizophrenia is characterised by significant impairments in the way reality is perceived and changes in behaviour related to: persistent delusions, persistent hallucinations, disorganized thinking, highly disorganized behavior, negative symptoms. Schizophrenia causes psychosis and is associated with considerable disability and may affect all areas of life including personal, family, social, educational, and occupational functioning. Caregivers play an important role in the support, management, recovery and care of schizophrenia patients throughout life. Caregivers not only manage the patient in home situation but also help in improving the condition and prevent from further relapse. While supporting the patients emotionally, financially and socially it often results in feelings of burden in caregivers. This affects the caregiver's overall life and specifically their quality of life adversely. The objectives of the review to evaluate the quality of life and social support system among family caregivers of a family member with schizophrenia and to identify factors associated with the quality of life. Caregivers should be encouraged to request assistance from other family members and friends in providing care, especially when caregivers are unemployed or long-time carers. This review shows that caregiver to seek support from other family member and friends and mental health care provider and helping families to maintain and enhance a supportive social network may provide useful means to improve caregivers' quality of life and minimizes factor that factors associated to quality of life.***

Keywords: Significant impairment, care-givers, quality of life, schizophrenia

1. Introduction

People with schizophrenia often also experience persistent difficulties with their cognitive or thinking skills, such as memory, attention, and problem-solving. Schizophrenia is frequently associated with significant distress and impairment in personal, family, social, educational, occupational, and other important areas of life. Schizophrenia affects approximately 24 million people or 1 in 300 people (0.32%) worldwide. This rate is 1 in 222 people (0.45%) among adults (2). It is not as common as many other mental disorders. Onset is most often during late adolescence and the twenties, and onset tends to happen earlier among men than among women. People with schizophrenia are 2 to 3 times more likely to die early than the general population as per World Health Organization, 2022. As per survey in duration of 1990-2017, globally there were 1.13 million incident schizophrenia cases and 12.66 million DALYs (disability adjusted life years) due to schizophrenia in 2017. The incident rate and DALYs rate were highest among the age group of 20–29 and 30–54 years, respectively.

Caregivers are defined as persons caring for patients, most of whom are relatives of the patients. Family members are the pillars of strength in their patients’ lives. They provide practical help, personal care and emotional support to the patients. Care giving is difficult and demanding and can affect the caregiver’s physical and emotional health resulting in financial and social constraints. The severity of care giving burden has been linked to patient’s disease, meeting the patient’s needs, patient’s lower global functioning and quality of life. Family members of persons with serious mental illness felt stress and burden that has effect on their own health and quality of life and impair the functioning of the family.

National Mental Health Policy (2014) highlighted universal access to the integrated mental health care services including promotive, preventive, supportive treatment and care for all. Families are the main-stay of long term care for persons with mental health problems. Such families bear direct financial costs of treatment as well as associated indirect costs such as loss of wages consequent to having to give up employment to look after sick family member. The emotional and social costs of providing care for a family member with mental illness cannot be quantified but exacts a huge toll on families.

Quality of life

Wei Y et al. (2022) explored the sequential mediating effect of expressed emotion and perceived expressed emotion on the relationship between care burden and quality of life among 135 Chinese families having schizophrenia patients. Result showed that care burden was negatively related to patients’ QoL, including physical, psychological, and social relationships domains, with patients’ sex, age, educational level, employment status, and medication-taking as covariates. The sequential mediating effects of criticism and perceived criticism between care burden and QoL were not significant. However, the sequential mediating effects of emotional over-involvement and perceived emotional over-involvement (EOI) between care burden and QoL (including physical and psychological domain) were significant.

Meng Na MM et al. (2021) explored the association between family functioning and quality of life (QOL) among 121 family caregivers of patients with schizophrenia in a cross-sectional study. Regression analysis showed that poorer physical health of family caregivers was significantly associated with the lower educational level of caregivers, the closer kinship with patients and the multiple episodes schizophrenia and better family adaptability and affective responsiveness were significantly associated with the better mental health of family caregivers. Family functioning is associated with mental health rather than the physical health of family caregivers.

Gelaye H et al. (2022) conducted an institution based cross sectional study among 398 caregivers of Schizophrenia using a consecutive sampling technique. Logistic regression was performed and statistical significance was declared at a p-value < 0.05. 189 (47.5%) of family caregivers had poor quality of life. Being divorced, unable to read and write, primary education, being spouse, sibling and children of the patient, poor social support and high perceived stigma were significantly associated with the outcome variable. Because the magnitude of poor quality of life among family caregivers was high, family intervention programs are highly recommended to improve quality of life among caregivers.

Leng, A et al. (2019) conducted a cross-sectional study, where participants were recruited and independently interviewed using a questionnaire, consisting of demographic characteristics, the Medical Outcome Survey SF-36 form, and social support rating scales. Multiple stepwise regression analysis was used to analyse the factors related to QoL. Results: 181 family caregivers were recruited in Shandong province, China. On a composite QoL score, family caregivers perceived that their QoL was poor (68.3), especially in the aspects of role-physical (61.3), role-emotional (57.6) and mental health (63.0). We also found family caregivers received low social support, especially in objective support and utilization of social support. Patient's illness state, care time, financial burden and objective support were significantly correlated to caregivers' QoL in the physical component score (PCS). Patient's illness state, patient's marital status, family monthly income, caregiver's knowledge about the illness, caregivers coordinating caring, life and work, subjective support received and utility of support were significantly associated with caregivers' QoL in the mental component score (MCS).

Shuet C N et al. (2018) conducted a cross-sectional study on 221 randomly recruited patients and their caregivers. These caregivers were interviewed face-to-face using WHOQOL-BREF questionnaire to evaluate their quality of life. Results showed that Caregiver’s single, widowed and divorced status (ANOVA=3.09, p=0.029), lower level of education (ANOVA=4.18, p-value 0.017) and Chinese race (ANOVA=6.98, p-value<0.001) were significantly associated with the poor QOL. Whereas, the patient’s Chinese race (ANOVA=10.17, p-value<0.0001) and profession (ANOVA=3.15, p-value<0.002) were significantly associated with the caregiver’s quality of life

A study conducted by Mondal A et al. (2023) on quality of life in the caregivers of schizophrenic. 40 **s**chizophrenia patients, 20 inpatient and 20 outpatients, along with their caregivers were selected by using purposive sampling technique. Brief Psychiatric Rating Scale (BPRS) was administered on the patient to assess the severity of the symptoms and WHO-Quality of Life-Brief was administered on the caregivers to assess the quality of life. The study showed that the caregivers of inpatient schizophrenic patients face problems in the social functioning area, personal relationships and support system in comparison to the caregivers of outpatient schizophrenic patients. Caregivers also exhibited problems in their physical health as the severity of symptoms in schizophrenic patients increase.

Factors associated with caregivers’ quality of life

It is often found that Caregivers’ health was highly deteriorated. Stress, anxiety, and depression were observed in several studies. It is found that caregivers catch infectious diseases. This could have occurred due to a deterioration in the caregiver's immune system. Working life was also significantly affected. Caregivers must leave their jobs, modify their working hours or change to another job. Moreover, in some cases, stress seemed to be associated with a triple shift: job, household duties, and care for a patient. The last dimension evaluated was economic burden. Economy issues produce concern in caregivers due to expenses in different areas, e.g. drug therapy and treatment. Regarding this, there is a difference between developed and developing countries. In countries such as Chile, Nigeria, and India caregivers expressed more concern in this dimension, likely caused by scarcity of community and health resources. Family dynamics were affected due to the presence of disagreements, conflicts, and even violence among its members. In addition, some close relatives might go away avoiding having to take care of the patient. It was found that Quality of life in caregivers of patients with schizophrenia: as revealed from the Alejandra CU et al in the year 2009.

Social support system

Social support refers to the resources available to an individual, which are provided by members of their social networks, including friends, family members, acquaintances, and health-care professionals. Caregivers may feel isolated from friends and family owing to the time and effort spent in care provision. Several previous studies have identified reduced social support available to these families. It is important to note that a significant positive correlation has been reported between social support and quality of life. It was found that family care giving in schizophrenia: do stress, social support and resilience influence life satisfaction. (Selwyn S et al. conducted in the year2022).

Relationship between caregivers’ quality of life, factors associated with caregiver quality of life and social support based on demographic profile:

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2. Discussion

Caregivers play important roles in care of person with mental illness. They are responsible for day to day care, proper medication and to meet basic needs of the patients. They face lot of challenges as caregivers such as physical and emotional distress, financial problem, and lack of social support.

The review has been proven that most of the caregivers had poor quality of life especially in physical and emotional domain. They received low social support. Quality of life is associated with patient's illness state, care time, patient’s marital status, family monthly income, caregiver's knowledge about the illness, social support.

3. Conclusion

Decreased QOL may be associated with caregivers' burden, lack of social support, course of the disease and family relationships problems. In developing countries, QOL is affected by caregivers' economic burden. High quality research is needed in order to identify factors associated with QOL over time and testing the efficacy of interventions aiming to improve QOL in caregivers of patients with schizophrenia. Social support had a significant correlation with caregivers' quality of life. Caregivers should be encouraged to request assistance from other family members and friends in providing care, especially when caregivers are unemployed or long-time carers. Mental health education campaigns and helping families to maintain and enhance a supportive social network may provide useful means to improve caregivers' quality of life. Considering the management of patients with psychiatric illness is moving from institutional care to community care it is imperative that health care providers and policy makers are aware of these factors because decreased quality of life of caregivers may impede the quality of care patients may receive from their caregivers. Caregivers of persons with schizophrenia do perceive burden, on account of which and along with lower socioeconomic status they experience poor quality of life and compromised mental health. The results of the literature highlight the suffering in terms of burden and quality of life of caregivers that all operators should consider in the therapeutic process in order to prevent as far as possible the development of responsive diseases. It is also important, as we have seen, to pay attention and allow caregivers to express their motivations for care and the role of kinship that covers towards the patient in order to use these personal resources in the patient integrate management. The investigation of the motivational aspects of the caregivers and the increased knowledge of the differences between the emotional experience of parents and children can contribute to the definition of more specific psycho-educational interventions and support.

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