

Caregiver Burden, Quality of Life and Empowerment Intervention in Caregiver Family with Schizophrenia *A Systematic Review*

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Abstract: Schizophrenia is chronically and schizophrenia suffer has duration of disease long time so that the risk of remission and relapse and quality of life is not well. Many factors that can lead to it occurs, among others, preparation and knowledge of care giver family and the availability of resources in society, of this care can lead to positive and negative impacts, include the care and quality of life of caregiver. This research aimed to review the 15 journals that discuss about caregiver burden, quality of life and empowerment intervention of caregiver family with schizophrenia. Methods: 15 journal articles in accordance with the purpose of writing. Results: From the results of the study it was found that the majority of care givers were women (82%) and housewives (67%) .The 60 samples of 40 care givers (67%) experienced a severe burden in caring for their families and 8.33% such as diabetes mellitus and hypertension (George Reena and Raju S., 2015). While physical illness and fatigue in care giver significantly associated with social support also correlates with the patient's negative symptoms (Kokurcan Ahmet et al, 2015). Conclusion: Each caregiver has different positive and negative effects, this is because many factors influence it.

1 BACKGROUND

Schizophrenia is a chronic mental disorder in which the patient experiences delusions, hallucinations, impaired thought processes, concentration and lack of motivation. With a wide variety of causes and symptoms for every schizophrenic (Vajeena Bhanu and Anuradha, 2017). Schizophrenia is one form of severe mental disorders and runs chronically even many patients have a long duration of symptoms. Several studies showed that about 20% of schizophrenics did not show improved symptoms and even increased symptoms of disability, 35% showed mixed patterns with different degrees of remission and exacerbations (Chien, Chan & Morrissey 2007 in Sally Wai-chi Chan , 2011). Approximately 25% - 50% of people with schizophrenia live with family and the care performed by the family depends on the symptoms and disability of each patient (Yip, 2000 in Sally Wai-chi Chan, 2011). Schumacher (2000) in Sally Wai-chi Chan, 2011 reveals various factors can affect the rehabilitation process of patients in families

and communities. Like the level of preparation, knowledge and skills of family caregivers and the support of resources in the community. If the caregiver does not have sufficient knowledge and skills and support, the caregiver may not perform well, causing relapse and hospitalization again (Chien & Chan, 2005 in Sally Wai-chi Chan, 2011).

These situations will affect the patient as well as the family especially the family members who have the duty as caregiver. The duties and responsibilities that the caregiver has to take can lead to a burden of upbringing. Caregiver, gender, patient relationships, education, economic status, severity of disease, ethnicity and culture of local communities, problem-solving skills, trust, social support, is a personal factor associated with parenting burden. Care will be done at all times, the risk of loneliness and often overcoming many new problems (Kerime Bademli and Neslihan Lök, 2015).

In the nurturing process for schizophrenics, family caregivers often bear economic and material burdens. In addition, psychosocial burden is also affected. Stigma is one of the greatest psychosocial

burdens faced by family members or caregivers of schizophrenics. Psychosocial burden on family members with schizophrenics negatively affects family members and their loved ones (Girma E., et al, 2014). Caring charges are classified as objective and subjective burdens. The objective burden is a burden on the cost of care. Subjective burden is an individual situation and an individual's assessment of emotional distress triggered by the disruptive behavior of the patient. Families often complain that they undergo a negative experience, which may lead to a decreased quality of life of caregivers and schizophrenics (Kerime Bademli and Neslihan Lök, 2015). The purpose of this article is to identify the caregiver burden, quality of life and empowerment intervention caregiver with schizophrenia.

2 METHODS

A systematic review of the much databases was carried out to access relevant articles published between 200 and 2018. Twenty-one articles met the conclusion criteria of this study.

3 RESULTS

The majority of caregivers are women (82%) and housewives 67% (Reena George & S. Raju, 2015), while in research Girma et al, 2014 caregiver is more dominated by men (70.38%). Psychological burden experienced by caregiver include stress from mild to severe, (67%) caregiver experience heavy burden in caring for schizophrenia (Reena George & S. Raju, 2015). Care giver's burden and quality of life are significantly worse for caregivers who treat patients with physical and mental illness (Amelia Rizzo, Marco Liotta, and Carmela Mento, 2014). 80% of caregivers experience moderate load levels, higher loads on older caregivers, caregivers and partners (Gupta A., et al, 2015). It was found that 8.33% of caregivers were treated with physical ailments such as diabetes mellitus and hypertension (Reena George & S. Raju, 2015).

In caregiver loads there are 5 dimensions of burden, nanny anxiety is the highest, then the dependence of the patient, feelings of shame and guilt and family ties. The stigma load level is the lowest. The three main things found in this study in parenting are: 'I worry about his safety when he's alone', 'I'm afraid he'll get sick all the time', and the patient's SRB score significantly indicates that patients are satisfied

with the support of medical staff, CHQ scores of significant nurses with caregiver load scores (Ying Hou, et al, 2008). In parenting, the most detrimental to caregivers are those who show the reason for caring for a sense of responsibility rather than out of compassion. As well as indicating that the load time required and quality of life becomes lower. (Amelia Rizzo, Marco Liotta, and Carmela Mento, 2014).

The majority (72%) carers use long distance and seek social support as their coping strategy. There is no correlation between perceived stress, coping and burden of care on schizophrenic caregiver. There was a significant negative correlation between income and stress perceptions As well as a significant positive correlation between stress perception and age and duration of care (Reena George & S. Raju, 2015). The low perceived social support scale is significantly correlated with all subscales of The Maslach Burnout Inventory for caregivers, resulting in burnout syndromes in caregivers correlated with perceptions of social support (Ahmet K., et al, 2015). In other studies conducted in two areas of the city and the village it was found that there was no significant difference in the psychological pressure of family caregivers between the town and village. But caregivers in Guangzhou were significantly able to adopt eight coping strategies: facing problems, distancing, controlling, seeking social support, accepting responsibility, no longer escaping, objective problem solving and positive reassessment, rather than caregivers in Hong Kong (Paul CW Lam, Peter Ng, Jiayan Pan, and Daniel KW Young, 2015).

Using bivariate analysis that factors of disability, frequency of schizophrenia recurrence, schizophrenia severity, residence, and socioeconomic status have a significant relationship with custody. Since disability factors are the highest, then interventions focusing on reducing disability in the management of schizophrenia can help reduce the burden of parenting care (Arun R, et al., 2018). The data analysis used multiple regression model to assess cost covariate, care provider burden, and QoL. Direct costs are medicine (50%) and transportation (27%). 49% of caregivers report a high burden. Better educated carers report lower indirect costs and better QoL. Caregivers with higher levels of depression, anxiety and stress report higher parenting burden and lower QoL. While the male caregiver has a better QoL (Yaw Nyarko Opoku-Boateng, 2017).

There are other factors associated with parenting burden: the negative symptoms that occur in the patient, the burden subdomain (burden on welfare, the burden of marriage, the burden of the relationship, and the load due to the perceived severity) is a

subjective load predictor. While the burden on the welfare and age of respondents is a predictor of psychological pressure (Elangovan Aravind Raj, Sahana Shiri, and Kavita V Jangam, 2016). In another study it was found that disease duration, psychopathology and disability factors were significantly correlated with total load scores; the perceived social support has a significant inverse correlation with the total load score. While psychopathology has a high relationship with disability. With separate regression analysis, indicating that duration of disease and perceived social support are significant predictors of burden in addition to psychopathology and disability (Aarti Jagannathan, et al, 2014).

Actions of parenting are not much different in patients despite different diagnoses, but the role of parenting will change from active involvement physically and medical care increases with social and psychological care during recurrence (Navaneetham Janardhana, et al, 2015). Lower psychological well-being is found in older caregivers and low education status. And psychological well-being is higher in siblings. A strong negative correlation was found between parental care and psychological well-being (Gupta A., et al, 2015).

In addition to the burden of care that is the impact of treatment of schizophrenia, stigma is also a condition that can occur due to schizophrenia. Significant differences in self-stigma scores between urban and rural respondents. Self-caregiver stigma shows a positive correlation with signs of perceived mental illness, a supernatural perception of mental illness, and psychosocial and biological perceptions of mental illness (Girma E. et al, 2014). Family caregivers in this case are parents, lack of education, and lower monthly household income, increased stigma and decreased quality of family-centered care experience of poor health-related quality of life. Especially in monthly household income, affiliation stigma and quality of family-centered care are the most important factors that lead to improved health-related quality of life (Chiu-Yueh Hsiao, et al, 2017).

Problems experienced by caregivers and families in running care for people with schizophrenia certainly makes the scientists interested in providing intervention to caregivers and patients, as well as many models of empowerment of caregivers who have been done. One of them is in community-based project MAANASI able to reduce the burden of care. The welfare factors of caregivers, marital relationships, appreciation for caregivers, severity of illness, and relationships with others are significantly correlated with the type of mental illness. The burden

on caregivers is generally lower than expected, probably due to interventions being undertaken at community-based MAANASI projects. (Swaroop N., et al, 2013). Other studies of carer-based empowerment interventions were conducted with a three-step approach: preliminary assessment of caregiver loads, caregivers in empowerment-based intervention sessions, and assessment of care expenses after empowerment interventions. Significant differences in the perceived burden between before and after intervention (S. Vajeaha Bhanu & Dr. Anuradha K., 2017).

Psychoeducation interventions also have beneficial effects on family cohesion, global family burdens, objective family burdens, and symptoms of family depression during the intervention period. However, it is not significant for the subjective burden of the family. The linear regression model revealed that family members of people suffering from schizophrenia for more than ten years showed the greatest increase while attending the psychoeducation group. Psychoeducation was a valuable nonstigmatization intervention and empowered family members with mental disorders (Palli A, et al, 2015). Another intervention that can be done in reducing the care burden is Clinician Supported Problem Solving Bibliotherapy (CSPSB). In this study, pre and post interventions were measured at months 1, 6 and 12 in either CSPSB or UOFS interventions (regular outpatient support). An intention-to-treat analysis is applied. The CSPSB group had significant improvements in family burden, experience of care, and decreased severity of psychotic symptoms and re-hospitalization frequency, compared to UOFS groups at months 6 and 12 (Wai Tong Chien, David R. Thompson and I. Lubman Terence V. McCann, 2016).

In other studies using empowerment interventions with counseling and psycho-education. The results of the study found that the majority of respondents using coping focused on problems to deal with aggressive behavior of patients. Most caregivers act by taking medication and talking about aggressive behavioral triggers to the patient calmly, lovingly and letting the patient alone. Nursing orders should focus on counseling and psycho-education to empower caregivers to utilize strategies to reduce the aggressive behavior of patients and ways to deal effectively with situations (Abin Varghese A., et al.2015).

There is also an empowerment intervention in the form of a family peer education program for mental disorders conducted in Japan. Group interviews were conducted with 27 facilitators from seven program

locations about their experiences before, during, and after becoming facilitators. Data are categorized into five stages of parenting: (1) attracting and suppressing negative experiences. (2) find comfort by listening to negative experiences; (3) supporting participants as facilitators; (4) understanding and affirming through experience sharing and (5) discovering social values and roles in one's experience. The third, fourth and fifth phases are experienced by the facilitator. The value provided by the facilitator on their parenting experiences changes from negative to positive (Kageyama M., et al., 2015).

4 DISCUSSION

Various problems arise and are felt by caregivers family who care for their own family members with mental disorders and some other pathological conditions. The burden of nurturing, stress, psychological well-being and quality of life of caregiver and patient is a frequent problem. Levels of burden, stress, psychological wellbeing and quality of life show varying results for each study as well as the factors that influence it. In the process of seeking help and care for patients with mental illness, family members or caregivers often bear economic and material burdens. They also experience psychosocial burdens, where stigma is one of the most challenging psychosocial burdens faced by family members or caregivers of people with mental illness.

Factors found in some studies that may affect parenting burden are 3 factors, ie factors derived from patients, environmental factors and factors of caregiver. Factors from patients can be concluded, among others, disability factors, frequency of schizophrenia relapse or duration of disease, and psychopathology or severity of schizophrenia symptoms. This is certainly related to the severity of caregiving activities that must be done by the caregiver. The more severe the symptoms of schizophrenia that arise, the more severe parenting activities that must be done. Likewise, the more severe the defect in schizophrenia, then the task of parenting is also increasingly complex, especially if people with schizophrenia often relapse (Arun R., 2018). While the environmental factors that may affect social and socio-economic support, the stronger the social and economic support available, the lighter the nurturing task (Aarti Jagannathan, et al, 2014). The factors of caregiver are age, sex, education level, occupation, depression level, anxiety and stress. Caregivers with higher levels of depression, anxiety

and stress are reported to have higher parenting burden and lower QoL. And in male caregivers it has a light parenting burden and a better quality of life than female caregivers (Yaw Nyarko Opoku-Boateng, 2017).

Caring and quality of life is a risk factor or a protection factor. This is in addition to factors from patients, the environment and caregiver itself, also depends on the intent and purpose of each caregiver. Whether caregiver carries out parenting because of compassion or merely a form of responsibility. If it is a form of responsibility, then the care of the schizophrenic becomes more severe than the feeling of affection. In addition, social support is needed by caregiver in carrying out their parenting activities.

Therefore, many studies are trying to provide intervention in empowering caregiver to reduce the burden of care, improve the quality of life of patients and caregivers, and improve psychological well-being. Several empowerment interventions were undertaken in several studies including Clinician Supported Problem Solving Bibliotherapy (CSPSB), community based MAANASI project, psychoeducation intervention, empowerment with counseling and psychoeducation, intervention by providing booklet for six weeks with face-to-face discussions, and peer program group education. Caregiver empowerment interventions are able to reduce the burden of caregiver, improve the quality of life, reduce stigma, improve psychological well-being, and increase cohesion in the family.

5 CONCLUSION

The findings of some of these studies will encourage mental health care professionals to be actively involved in the prevention of mental illness and the promotion of mental health through the assessment of stress felt by mentally ill sitters to help them become resilient and use more constructive treatment. strategy in stressful situations.

The nurse's self-stigma can negatively affect the patient's search, compliance, and rehabilitation processes, programs that improve coping strategies by strengthening self-esteem and empowerment by health care providers and forming family support groups can help to overcome self-stigma. between caregivers of people with mental illness.

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