

# CAREGIVER EXPERIENCES OF SCHIZOPHRENIA PATIENTS WITH SELF CARE DEFICIT: A SYSTEMATIC REVIEW

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**Abstract:** Caring for individuals with schizophrenia is a demanding task that impacts all aspects in families, particularly primary family caregivers. Given that families are vital to patient recovery, it is important to help primary family caregivers improve their daily living activities. The two main objectives of the systematic review were to identify articles outlining the experience of caring for a person with schizophrenia and secondly to identify articles concerning factors that affect caregiver with schizophrenia. Targeted literature searches were conducted in Scopus, Sciencedirect and PUBMED, using a combination of keywords. They were searched for period from 2012 until 2018. These findings suggest that caregiver experience in treating schizophrenia includes challenges of care, support, and future care concerns. While affecting the increase of self care that is age, sex, job, personality, family relationship, economy, onset and ability of self care. The family has the function to preserve and maintain the health (health care function) for family members who suffer from a disease. We identified experiences as improving patient self-care behavior. Factors sociodemografi, personality, economy, onset and ability of caregiver need support and support from family and health officer.

## 1 INTRODUCTION

Schizophrenia is a disease that is disturbing and distressing for patients and their families (Wai-Tong Chien et al, 2004). A study showed that a heavy burden on the family in caring for family members with schizophrenia because the family needs is replaced by the patient.

Studies in Asia indicate that about 70% of people with schizophrenia live with their families and depend on family members for care provision (Chan & Yu, 2004; Sethabouppha & Kane, 2005). Suhita (2016) in his dissertation states that families who care for patients with schizophrenia experiencing anxiety and confusion in caring for a family member suffering from schizophrenia. Some families who care for patients with schizophrenia are older people, who prefer and protect the healthy family members rather than family members of schizophrenia, some families are not ready to become caregivers for relatives with schizophrenia (Yang et al., 2017). Other research found a family with a person with schizophrenia (ODS) have difficulty in maintaining them,

Disturbance in the process of thought resulting in decreased self-care wishes. Some self-care deficit problem in patients with mental disorders such as disorders of personal hygiene, inability ornate, inability to eat / drink with self-contained,

self elimination difficulties, this will require the help of family or other people to solve it (Keliat, 2010).

The family has an important role as the presence of people with schizophrenia in their families. Family support, treatment is relatively long, with the risk of recurrence (relapse) if psikofarmaka disconnected (Suhita, 2016). Caregivers are individuals, mostly family members of patients, who spend the most time caring for patients, providing support, and check medicines and other aspects of daily life of patients.

## 2 METHODS

This review was informed by three database searches: Scopus, ScienceDirect and PUBMED, using a combination of keywords. They were searched for the period from 2012 until 2018. Search terms included: caregiver or family members AND schizophrenia experience, family caregiver AND schizophrenia. Studies were included that focused on caregiver outcomes, the data collected from caregivers of Patients (of any age). Studies were excluded that caregivers recruited from out-patient settings or at home. A total of 25 journals are consistent with this theme. Literature with descriptive research design, qualitative, phenomenology and RCT.



### 3 RESULTS

#### Characteristics of caregiver

Caregiver characteristics presented in this article include age, gender, education level, occupation, relationship with the patient. On the characteristics of a family member with schizophrenia is a long illness. Overall caregiver is an adult as between the age of 17-65 years. Most of them are closely related to people with schizophrenia in their family-usually a spouse, parent or child (Wai-Tong Chien et al, 2004)

#### Experience

Parenting experience gained in schizophrenic patients that caregiver characteristics of women experience more burden than men, parents, especially mothers, had more of a burden than a spouse or other family members (Yanling Zhou et al, 2016)

More than a third of family caregivers report high levels of perceived burdens and difficulties facing their child or spouse disease (Alejandra Caqueo-Uriza et al, 2017). One of the most important aspects in response to the caregiver is the knowledge about schizophrenia. A negative perception relatives disease has been associated with high patient distress, shows the value of the assessment and understanding of adaptation caregiver to schizophrenia (Alejandra Caqueo-Uriza et al, 2017).

Different family environment affects families coping strategies used during episodes of acute schizophrenia. It can related with relapse episodes in the future and of course as a whole and the results of the disorder. attitudes towards patients. Psychosocial burden, level of social support, stigma experienced by family, financial condition.

Parents reported severe psychological distress when their child is diagnosed with schizophrenia, their deep sense of loss, followed by a reception. It arises because of feelings of love and responsibility of parents bore the meaning of concern in children with schizophrenia. Strategies and resources that assist caregivers in treating schizophrenia is an antipsychotic medication, social support, communication, fixed activity, knowledge, spirituality and adopt a positive attitude. The presence of a positive attitude is very important in the role of the participant as a nanny. Chang & Horrocks (2006) who also confirmed that adopt positive behaviors and attitudes that are important for the caregiver role as parents (Mc Auliffe et al, 2014).

Caregivers experienced emotional disturbance when a family member they become aggressive or abusive to them or their friends. This study reveals the challenges of the psychosocial, emotional, economic, physical and experienced nurses in

caring for their relatives who suffer from mental illness.

The majority of caregivers are women who are psychologically distressed as a result of the great responsibility they face when caring for a family member sikkofrenia. Poor emotional impulse can lead to depression which would have a negative impact on family (Ayuurebobi Ae-Ngibise, 2015)

Table 1. Review of Journal

The title, name of the researcher	Design, Sample, variable	Result
Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. Mirja Koschorke, 2017	Quantitative, Qualitative 282 caregiver age 16-60 years, dx ICD 10 schizophrenia, caregiver Family	The impact of stigma on the lives of families, need planning and intervention care for families. The interview describes the caregiver with stigma, the impact on relationships and emotional well-being is very high; blame experiences, comments and avoidance of others,
The experience of caregivers of people living with serious mental disorders: a study from rural Ghana Ayuurebobi Kenneth et al, 2015	qualitative 75 caregiver	Caregivers reporting burden, financial, social exclusion, emotion, depression, and a lack of time for other social responsibilities
Experiences and Influencing factors of caregivers of Patients with mental disorders Huang et al, 2014	Survey 139 caregivers	ECI score influenced age, gender, occupation, relationships with patients, caregivers economic status, and the first onset and patient self-care ability
Experiences of caring for a sibling with schizophrenia in a Chinese context: A neglected issue Cheng-I Yang, 2016	Descriptive, qualitative 10 caregiver	Step into a caregiver; parenting challenges; Support; and worry about future care.
Relationship between Mental Health and	cross sectional	significant care burden associated with mental health outcomes directly. personality, coping style, and family functions affect

Burden Among Primary Caregivers of Outpatients with Schizophrenia	355 primary caregivers	caregiver burden and mental health caregiver parents experiencing higher caregiver burden personality (extraversion / introversion and psychoticism) no direct impact on caregiver burden, but it has a direct effect on the functioning of the family, family function affects mental health as a result of caregiver burden	term schizophrenia in their families: a phenomenological study. Huang et al, 2009	10 caregivers	prevention of cognitive and religion).
Yu Wenjun, 2018			Emotions, Ideas and Experiences of Caregivers of Patients With Schizophrenia About "Family to Family Support Program" Bademli, 2015	phenomenological method	positive attitude to feelings, stress reduction family support. ideas, emotions, and experiences of caregivers
The Adaptation Model Of Caregiver In Treating Family Members With Schizophrenia In Kediri, East Java	cross-sectional design with nature explanatory research 135 respondents\	The results Showed caregiver self esteem (-0.25 <0.05), community resources (0.24 <0.05), self-efficacy (0.22 > 0.05), caregiver coping effort (12:17 <0.05), and the perception of caregivers about the family situation at this time (0:19 <0.05), the which means that adaptation of caregiver in treating Patients with schizophrenia is influenced by the characteristics of the family items, namely community resources, self-efficacy, coping caregiver effort, self-esteem and perception of family caregiver to the conditions experienced at this time.	Parents experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study Mc Auliffe et al, 2014	20 caregivers. Living caregiver burden with Schizophrenia	The psychological trauma of a parent (caregiver), caring activities, coping with enduring illness Feelings of love and taste the responsibility of creating awareness in schizophrenia. Family-centered approach at the core of the plan of care
Melda Byba Suhita, 2017	Schizophrenia, caregiver, adaptation		A randomized controlled trial of a mutual support group for family caregivers of Patients with schizophrenia a.	descriptive qualitative	
Family experiences of caring among caregivers of schizophrenia Patients Mohamad et al, 2013	- 154 caregiver	negative votes; the patient's young age, unemployment, income and low skills. Positive assessment: are married, have a skill, fixed income and urban residents. Life skills a strong predictor of the positive and negative ratings	randomized controlled trial (RCT)	48 caregivers. Family caregivers; schizophrenia	support group interventions can overcome / reduce the burden and distress (identifying problems parenting and problem-solving techniques). The experimental group showed a significant decrease in the duration of re-hospitalization of patients at 3 months compared with the control group.
Female Families' Experiences of Caring for Persons With Schizophrenia. Eriko Mizuno, 2013	- 11 family caregivers	Family experiences, perceptions and family relations, family burden, family attitudes, and knowledge of family	Wai-Tong Chien et al, 2004		
Effect of living with Patients on caregiver burden of individuals with Schizophrenia in China. Yanling Zhou et al, 2016	Comparative 243 respondents Living caregiver burden with Schizophrenia	living with a caregiver explained 6.7%, 8.3% and 6.7% of the variance in distress, disrupted routines and helpfulness. Living with patients is a strong correlation of the increased burden experienced by caregivers	The effects of group psychoeducational program on family burden in caregivers of Iranian Patients with schizophrenia a. M. Fallahi Khoshknab	randomized-controlled trial design 71 caregivers psychoeducational caregivers	Caregivers who receive psycho-intervention intervention do not suffer from heavy family burden anymore. Because of the inorganic enhanced as intervention groups Psychoeducative programs could be useful
The experiences of carers in Taiwanese culture who have long-	phenomenological qualitative	the burden of care (helping clients disease, lack of support professional and family conflict), the emotional burden (sad, worried and scared) and coping strategies (strategies			

et al, 2013		
Understanding the complex family experiences Of Behavioral Family Therapy	qualitative research 40 of participants (20 patient, 20 caregiver)	The most frequently associated with the open sharing information component about BFT and discussion of their family member's illness and a greater understanding of both mental illness
Brendan et al, 2016		
Family Support Mental Disorder Patients Treated With Health Promotion Model Approach	<i>cross sectional study</i> , 72 families of patients with mental disorders	Family perception of the benefits, the ability to care for patients and interpersonal factors have a significant influence on the support of family, while the family's perception of barriers, daily activities and situational factors do not have a significant influence of family support in the treatment of mental patients
Nirwan et al, 2016	family support, mental disorders	
Correlates of caregiving burden in schizophrenia: A cross-sectional, comparative analysis from India.	Quantitative cross-sectional 75 caregivers Caregiver burden, coping strategies that come into play, as well as social support	a high level of load, low social support, and poor tackle on caregivers
Stanley, 2017		

## 4 DISCUSSION

Schizophrenia is a severe mental disorder. This disorder is characterized by positive symptoms such as talks chaotic, delusions, hallucinations, impaired cognitive and perception, negative symptoms such as avolition (declining interest and encouragement), reduced desire to talk and poor contents of the conversation, show flat affect, and interrupted relations personal. Schizophrenia is a disease in parts of the brain that lead to persistent and serious psychotic behavior, concrete thinking, and difficulty in information processing,

interpersonal relationships, and solve the problem (Stuart, 2006).

The family is the unit closest to the patient, and is a "primary caregivers" for patients. Families must have an adaptive coping in overcoming or dealing with schizophrenia to determine how or the necessary care of patients at home. The family has the function to preserve and maintain the health (health care function) for family members who suffer from a disease. Stress that gave rise to the expression of emotion from the care giver will affect the way care giver in providing care for patients with schizophrenia (Suhita, 2017)

Involvement of all family members, including siblings, in the treatment plan for people with schizophrenia, and provide psycho-education appropriate for all family members to reduce not only the tension and stress of parenting today, but also anxiety about the future care (Cheng-I Yang, 2016 )

## 5 CONCLUSIONS

We identified experiences as improving patient self-care behavior. Factors sociodemografi, personality, economy, onset and ability of caregivers need support and support from family and health officer. Social support from the government and society to the caretakers will be very helpful in maintaining and improving the care of a caregiver to family members with schizophrenia (Ayuurebobi Ae-Ngibise, 2015)

## REFERENCES

- Bademli, K., & Duman, Z. Ç. (2016). Emotions, Ideas and Experiences of Caregivers of Patients With Schizophrenia About "Family to Family Support Program." Archives of Psychiatric Nursing, 30 (3), 329-333. <https://doi.org/10.1016/j.apnu.2015.12.002>
- Boyer, L., Caqueo-Urizar, A., Richieri, R., Lancon, C., Gutiérrez-Maldonado, J., & Auquier, P. (2012). Quality of life among caregivers of Patients with schizophrenia: a cross-cultural comparison of Chilean and French families. BMC Family Practice, 13 (1), 42. <https://doi.org/10.1186/1471-2296-13-42>
- Chien, WT, Norman, I., & Thompson, DR (2004). A randomized controlled trial of a mutual support group for family caregivers of Patients with schizophrenia. International Journal of Nursing Studies, 41 (6), 637-649. <https://doi.org/10.1016/j.ijnurstu.2004.01.010>
- Gater, A., Rofail, D., Marshall, C., Tolley, C., Abetz-Webb, L., Zarit, SH, & Berardo, CG (2015). Assessing the Impact of Caring for a Person with Schizophrenia: Development of the Schizophrenia Caregiver Questionnaire. Patient, 8

- (6), 507-520. <https://doi.org/10.1007/s40271-015-0114-3>
- Lauriello, J, Bustillo JR, KS (2005). Schizophrenia: Scope of the problem In: Saddock BJ, Saddock VA (eds) Kaplan & Sadock's Comprehensive Textbook of Psychiatry (8th Ed. Vo). Philadelphia: Lippincott Williams & Wilkins.
- McAuliffe, R. O'Connor, L., & Meagher, D. (2014). Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 21 (2), 145-153. <https://doi.org/10.1111/jpm.12065>
- Mizuno, E., Takataya, K., Kamizawa, N., Sakai, I., & Yamazaki, Y. (2013). Female Families' Experiences of Caring for Persons With Schizophrenia. *Archives of Psychiatric Nursing*, 27 (2), 72-77. <https://doi.org/10.1016/j.apnu.2012.10.007>
- Möller-Leimkühler, AM, & Mädger, F. (2011). Personality factors and mental health outcomes in caregivers of first hospitalized schizophrenic and depressed Patients: 2-year follow-up results. *European Archives of Psychiatry and Clinical Neuroscience*, 261 (3), 165-172. <https://doi.org/10.1007/s00406-010-0155-5>
- Stuart G.W & Laraia, M. . (n.d.). *Principles And Practice Of Psychiatric Nursing* (Ed.7). St Louis: Mosby.
- Suhita, BM, Catharina, U., Basuki, H., & Joseph, A. (2017). The Adaptation Model Of Caregiver In Treating Family Members With Schizophrenia In Kediri, East Java. *Nurses Journal*, 12 (37), 74-80.
- Varghese, M., Pereira, J., Naik, S., Balaji, M., & Patel, V. (2017). Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Social Science and Medicine*, 178, 66-77. <https://doi.org/10.1016/j.socscimed.2017.01.061>
- Yang, CI, Hsieh, MY, Lee, LH, & Chen, SL (2017). Experiences of caring for a sibling with schizophrenia in a Chinese context: A neglected issue. *International Journal of Mental Health Nursing*, 26 (4), 409-417. <https://doi.org/10.1111/inm.12269>
- Yu, W., Chen, J., Hu, J., & Hu, J. (2018). Relationship between Mental Health and Burden among Primary Caregivers of Outpatients with Schizophrenia. *Family Process*, x (x), 1-14. <https://doi.org/10.1111/famp.12340>
- Yusuf, Ah., Fitryasari Rizky, Nihayati, Hanik E. (2015). *Buku Ajar Keperawatan Kesehatan Jiwa*. Jakarta: Salemba Medika.