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## FAMILY RESISTANCE ON FAMILY CARE GIVER OF SCHIZOPHRENIA, JEBRES DISTRICT, SURAKARTA, INDONESIA

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### ABSTRACT

Family caregivers are people or groups who volunteer their time to assist in caring for family members who are dealing with mental health issues. It is also hoped that the family caregiver would be able to support the patient's recovery both financially, emotionally, and physically. This study examines the vulnerability of family caregiver schizophrenia and analyze the family resilience of family caregiver schizophrenia in Jebres, Surakarta. The goal of this study is to examine the vulnerability of family caregiver schizophrenia, how family caregiver dealing with vulnerability and how family caregiver builds resilience. I utilized a qualitative technique with a case study approach to preparing this paper, looking at primary material from interviews and field observations. I presented secondary data, those were, information obtained from books, manuals, and written reports, as proof. According to research on family resilience after taking on the role of the informal family caregiver, informal family caregivers believed that People with Schizophrenia (ODS) had had a positive or negative impact on their lives, hence family resilience had a more positive impact, such as believing they would be able to survive because they are a family member or relatives. In addition, the ability of family caregivers to adapt and survive in the face of vulnerabilities or problems could create resilience. Meanwhile, family caregivers who were unable to adapt and survive in the face of problems made their families more vulnerable than before.

**KEYWORDS:** family caregiver, schizophrenia, family resilience, vulnerability.

### 1. INTRODUCTION

The 2018 Basic Health Research (Riskesdas) data had showed that 7 out of 1000 households have family members with Schizophrenia/Psychosis. More than 19 million people over the age of 15 are affected by mental and emotional disorders, more than 12 million people over the age of 15 are estimated to have experienced depression. According to WHO, Global Health Estimates, the death

rate due to suicide in Indonesia in 2016 was 3.4 per 100,000 population. The data showed that males 4.8 per 100,000 population higher than females 2.0 per 100,000 population. (Ministry of Health, 2019)

In 2017, viewed from the calculation of the burden of disease in Indonesia, there are several types of mental disorders estimated to be experienced by the society, including depression, anxiety, schizophrenia, bipolar, behavioral disorders, autism, eating behavior disorders, intellectual disabilities, and attention deficit hyperactivity disorder (ADHD).

In Surakarta, Central Java, in 2016, approximately 2,095 people suffering with mental disorders consisted of 760 patients with severe mental disorders and 1,325 patients with mild mental disorders. Data at the Regional Mental Hospital Surakarta in 2016, showed the fact at least 4000 people were visiting as outpatients or undergoing as inpatients.

Schizophrenia is a global health problem that has serious implications not only for patients, but also their families who Caregiver certainly cannot be separated from confusion and anxiety feeling in providing care where the role of the family is needed to become a sustainable Caregiver because of a self-care deficit. People with schizophrenia experienced a decrease in the ability to do self-care activities independently such as maintaining body hygiene, bathing, dressing, decorating, toilet activities to eating and drinking. The World Health Organization explains the clinical manifestations of people with Schizophrenia in addition to self-care deficits are also experiencing life fantasies, hallucinations, experiencing mental disorders, difficulties in expressing emotions, loss of motivation, withdrawal, lack of interest in activities in their daily lives. People with schizophrenia who had decreased ability to carry out daily activities, required them to depend on the help of others, such as family caregivers who live together under the same house. (Hartanto, 2018).

A good caregiver must be prepared with uneasy process of caring for someone. The caregiver will definitely go through various experiences such as feelings of difficulty, anxiety, fear, doubt or even feelings of pleasure, considering they are more trained in caring for and feel happy when clients experience several developments (Niman, 2019).

Fadli's research (2013) showed that the better the attitude and support of the Family Caregiver, the less frequency of client relapses. On the other hand, there was a connection between the increased expression of Family Caregiver, thus increasing the frequency of client relapses. The longer the treatment, the wearier the Caregiver in facing the client's treatment process. Families are estimated reach weary feeling after caring for more than 5 years (Swardiman, 2011). The characteristics of a good Caregiver are having patience, being creative in supervising treatment, and supporting activities that help with treatment. Meanwhile, an example of a lousy caregiver is the one who shackles the client and does not take steps in the healing process (Keliat, 2005). (Nim, 2019)

Being a family caregiver means being a family with responsibilities and burdens heavier than any other ordinary family. This leads to a condition where vulnerability can be experienced by caregivers of schizophrenic families. The vulnerability occurs when family caregivers experience limited access to livelihoods such as access to health, economy, employment, and education. They have to nurse ODS, family caregivers have to pay the ODS costs of living, the difficulties of social stigma, and to take care of their mental burdens while nursing ODS. This responsibility requires the dedication and sacrifice of family caregivers for their time, costs, and activities if they are not responsible for ODS.

Family members with psychiatric problems will experience disturbances in activities of daily living, impaired in interpersonal, social, and practice relationships. On the other hand, families found stigma, a sense of helplessness, lethality, fatigue, a decrease in meeting personal needs and even the ability to develop personal resources (Suryaningrum in Niman, 2019).

In addition, families will feel the increasing of economic and family emotional burden, stress over the behavior of family members who suffer from mental illness, burdened in carrying out daily household activities even social activities caused by the arising of social stigma due to their family's member mental problems (Ngadiran, Yani & Daulima in Niman, 2019) In caring for family members who suffer from mental problems, families likewise will face limited health facilities and services, constrain in financing, and even inadequate information access (Wardhani, 2013). Absolutely, the families' choice who want to care for and live together with family members who suffering schizophrenia is not an easy thing, problems often arise that are experienced by family members in it. Families must be able to handle the stress caused by changes of their family members' behavior who experience psychiatric problems such as schizophrenia. It is common that families often frighten because of the society's stigma on their judgement given to their families, from judgement of family members who have mental problems to concerns over changes in relationships with the environment such as friends and neighbors. These fears create social stigma which is impacted family members choose to distance themselves from family members who have schizophrenia illness from the surrounding environment. As a result, the family became uncomfortable and even felt guilty by alienating their own family members (Lefley 1989 in Koolae et al, 2009). Both those who has been suffering from mental problems and their families experiencing the same difficulties living in society. Families are the most affected socially and economically. In the midst of the Covid-19 condition where it is required physical distancing, families must face this condition 24 hours continuously together with their family members who have mental problems. In addition to the health crisis, the family is also experiencing an economic crisis which makes meeting health needs and services even more difficult

(Munawar, 2020)

In dealing with vulnerabilities or problems in life as a family caregiver, several strategies are needed, therefore family caregivers can deal with problems well. This strategy will bring up the concept of family resilience, which is where the family is able to survive and adapt in facing problems and become a prosperous family.

Based on this social fact, the author would like to conduct further research related to how family resilience strategies acted as Family Caregiver for schizophrenia.

## 2. RESEARCH OBJECTIVES

- To analyze the vulnerability experienced by families with roles as family caregivers for schizophrenia.
- To analyze the resilience of the family that was formed after acting as a family caregiver for schizophrenia.

## 3. METHODOLOGY

This study used a qualitative approach in the case study variant. A case study is a research method or strategy as well as research results in a case

## 4. DISCUSSION

### 4.1 Family Caregiver

Caregiver is an individual who helps patients with special conditions and limitations to carry out their daily lives such as helping to bathe, eat, walk and protect them to always be in a safe state and so on. Caregiver is a term often used to define the role of individuals who provide care for people with disabilities such as People with Schizophrenia (ODS). In Indonesia, caregivers are generally a family, consist of husband and wife, their children, in-laws, grandchildren and relatives who live together in the same house. Caregivers have a role as emotional support, providing care for patients (bathing, dressing, preparing food, supervising and giving medicine), managing finances, making decisions related to care and communicating with formal health services (Kung, 2003: 3).

Doctor Susi as one of the doctors at the Surakarta Regional General Hospital explained what is meant by Family Caregivers are those who really understand and live together with patients. Family Caregivers do not always come from an elementary family. Support come from Family Caregivers is very much needed to improve the patient's healing process, where Family Caregivers are also expected to be able to understand how the patient's illness and drugs that support healing.

Furthermore, Caregivers are divided into two types, namely formal and informal caregivers.

#### 1. Caregiver Formal

Formal caregivers are professional care provided by hospitals, treatment centers, psychiatrists or other professionals who are provided and make payments. (Sarafino, 2006: 55).

## 2. Caregiver Informal

Informal caregivers are people who help with home care, they do not consist of professional health workers and there is no payment burden (voluntary). This is usually done by families whose household members are sick such as husband or wife, son or daughter and other family members outside the elementary family (Sarafino, 2006: 55). Family Caregiver itself is part of the informal type of Caregiver, where they consist of family members of the patient himself, friends, friends and neighbors around the patient's house (Reinhard, 2008). Become an informal Family Caregiver, they definitely need a formal Caregiver such as a doctor, nurse, or psychologist who provides training in the form of psychoeducation.

Based on the classification of the periodization of time in the parenting process providing care to household members who experience schizophrenia, Family Caregivers are divided into 3 namely full-time, part-time, and freelance:

### 1. Fulltime Family Caregiver

Full-time Family Caregivers are families who live together and live together to provide care to family members who have ODS. They are not only provide attention, financing, but also prioritize their lives to fully care for their family members who suffer from schizophrenia.

### 2. Part Time Family Caregiver

Part-time family caregivers are families who take care of their family members who have schizophrenia with the help of professional medical personnel who come to the house to treat. It is as well as the community to provide assistance or assistance such as household assistants who are devoted to providing care and treatment because their time is divided for other life demand that cannot be left behind, such as working as a Civil Servant with strict scheduled working hours, or as an office worker who only has time to rest at home after work.

### 3. Freelance Family Caregiver

Freelance family caregivers are those who have household members with mental problems, hence do not have the time to provide care and nurse to family members with mental problems yet provide the financial ability to take care of household members with schizophrenia in private homes, RSJD, within a certain period of time. The other hand, there are also Family Caregivers who do not have the ability both in terms of time and funding because of their difficult economic life and being squeezed out of poverty.

#### 4.2 Vulnerability of Family Caregiver of Schizophrenia

Vulnerability is a condition determined by social, economic, psychological, environmental factors, as well as processes that increase the society's vulnerability to the impact of a danger. In addition, spend time caring for schizophrenic patients, family caregivers need to pay for patients' lives because of their inability to work. In addition, caring for patients with mental disorders is not easy, there must be limitless patience in dealing with the patients themselves as well as dealing with problems arise such as society stigma, economic deficiencies, limited space for movement, and the possible stress faced in treating patients. These problems will lead to family vulnerability that is more severe than the previous condition if they cannot dealt with properly.

In this section, the author will present various problems that must be faced by schizophrenic family caregivers.

##### 1. Social Stigma

Negative stigma against people with mental disorders such as schizophrenia is common to be found. Society still considers all people with mental disorders as "insane". This is in accordance with Mr. Yanto's statement as a nurse at RSJD Surakarta who stated that there was the use of the word "insane" by public security officials who disciplined people with mental problems on the street. (Research data, December 2021)

##### 2. Social Problems

In addition to the stigma in society, family caregivers also have to face social problems such as lack of relationships with surrounding neighbors or community, poor communication with family, unbalanced roles in the family where it is only one person bears the burden as a family caregiver. The lack of understanding of the surrounding community about mental illness and the negative stigma of the community regarding mental illness, especially in case studies of schizophrenia patients, is one of the problems that must be faced by family caregivers. This is experienced by the Palupi family caregiver when nursing for her mother who is a schizophrenic patient. Palupi's neighbors still call her mother "insane". (Research data, December 2021)

##### 3. Economy Problem

In addition to having to support themselves and their families, family caregivers have to bear with the living costs of schizophrenia patients which increasing their economic burden. Due to their inability to meet their daily needs, family caregivers even have to give up their assets to cover their needs. This is also done by Arif as a family caregiver for his mother. Arif was forced to sell his mother's land to cover the shortage of daily necessities. (Research data, December 2021)

##### 4. Psychic Problems

Caring for people with mental disorders requires a lot of dedication. It is not uncommon for family caregivers to feel tired because of the burden they are experiencing. This is in accordance

with the statement of the RSJD nurse, Pak Yanto who told about the double burden experienced by a family caregiver who has to take care of his brother while he also has to responsible for his own family. The demand to be able to share time, energy, and costs makes him tired and feel unable to deal with his family's problems. (Research data, December 2021)

### **4.3 Family Resilience of Schizophrenia Family Caregiver**

After facing a crisis or life problem, some families in Walsh's (2003) research could actually became strong and achieved more positive things in dealing with life's problems, yet some others become more vulnerable than before. This was also supported by research conducted by Patterson (1983) there were stressing factors (causes of crisis) able to affect social life both in the environment and in the family (in Walsh, 1998). Family resilience is defined as the process of each family for problem solving and adjustment as a functional unit (Walsh, 1998). According to the expert (Fraser, M & Galinsky, 2004) which stated that family resilience can include "the ability to improve themselves" and "respond beyond the usual". In order to become a resilience each member must be willing to face risks and respond to success.

Talking about family resilience, it is certainly cannot be separated from risk and protective factors (Walsh, 2006). A risk factor is said to be a factor that encourages negative things to appear in the family while a protective factor is the opposite where it becomes a factor that reduces the possibility of negative outcomes (Mackay in Wandasari, 2012). As well as for Walsh (2003) how to reduce negative outcomes is said to be a component of resilience and the family itself can be a protective factor. The components of family resilience are belief systems, organizational patterns and communication processes.

#### **A. Family Caregiver Belief System**

Being a Family Caregiver is not an easy thing, sharing personal life with other people is certainly not easy for anyone to do. But this is a must for the Family Caregiver where they has to share their life with the patients he cares for. At first, of course, there was a feeling of tiredness, sadness and did not think that in the end their life dedicate into a Family Caregiver for both his family members and the environment. This is because he as a Family Caregiver must fight for themselves as well as fight for their family members and patients.

The steps of Family Caregivers go through to form a family belief system as described by Walsh are as follows:

#### **1. Able to give a meaning to every difficulty faced**

Giving a meaning to every moment experienced by Family Caregivers is important because this will support how a person will behave to be able to solve a problem. The Family Caregivers at the beginning was not easy to be able to provide meaning regarding a problem they were facing, everything at first certainly felt heavy because the Family Caregiver is a normal human being who

shared their time for the patient. In the end, they seemed to have two sides of life that must be borne when there was a problem.

## 2. Have positive outlook

For Family Caregivers, especially those who have played the role of Family Caregiver for a long time, the various problems along the nursing in it are able to provide a positive view and the orientation. They are no longer blaming the situation or the cause of the problem but the focus has changed to how to solve it and take lessons. Family Caregivers feel that the way we view problems will affect our daily activities. In the theory of family resilience, having a positive view is actually able to build initiative and persistence to be able to solve the problem. Almost all of the Family Caregivers were hesitant at first because of their lack of knowledge and this was also their experience in caring for schizophrenic patients. But in the end, by the encouragement of their extended family and the environment, they finally made the Family Caregivers more confident about their ability to become nurses for patients after a dozen years of struggling to learn to be a Family Caregiver. This is also experienced by Arif, a family caregiver for his mother. After a dozen years as a family caregiver and with the support of his big family, Arif feels he can pass the years ahead in caring for his mother. (Research data, December 2021)

Having a positive view is also evidenced by the informants in this study, namely Dinar. Dinar is as a person who has mental problems and his son also has similar problems, finally made Dinar compelled to build a community which contains Family Caregivers and provides space for Family Caregivers to share knowledge and tips in dealing with the relapse of the schizophrenic patients. Dinar did not lock herself up and was sad because she had to deal with herself and his son who has a mental disorder. Dinar was able to build a strength whose source came from various problems. This is formed Dinar's positive thinking as a Family Caregiver in looking at the problems that are present.

## 3. Transcendent support and spirituality

Transcendent or support from outsiders is able to form a new hope becomes the main thing when living life as a Family Caregiver. There are many cases where Family Caregivers end up feeling stressed because they do not get support from anyone outside of themselves or their families. Therefore, when Family Caregivers tell their complaints to other families and the surrounding environment such as neighbours and the community, they finally get support. This is making Family Caregivers stronger and better in living their life as Family Caregivers. The next is spiritual aspect that Family Caregivers do. This exactly what Arif did, he invited his mother as a schizophrenic patient to participate in religious activities such as recitations in his environment. The aspects of spirituality are felt to be able to provide inner peace for the perpetrators, they feel comfortable because in it they feel like getting inner peace of life wisdom from the things they believe in and also meeting other people as a means of socializing as well as being a reinforcement that the power of God will heal the disease. there is. (Research data, December 2021)



Belief can be formed through various fears that come from the problems at hand. However, this is what makes Family Caregivers survive because of the problems and urgency. Family Caregivers use all their minds to find a way out as described by Dinar's family caregiver who uses various ways in an effort to solve her family problems. (Research data, December 2021).

The result is belief built a positive thought. Family Caregiver over time can overlook the problem from the positive side, and feel that being a Family Caregiver is an extraordinary experience because the knowledge of taking care schizophrenic patient is not easy. This was told by Arif's family caregiver who felt that he had received additional knowledge about being a family caregiver and about psychological problems. (Research data, December 2021).

### **b. Family Organization Support for Family Caregiver**

The family as an organization is a discussion of how a family is able to solve a problem systematically and support each other similar to a structured organization. Families in the elementary family line consist of father, mother and children certainly have main duties and their respective portions in carrying out tasks in the family. The formation of organizational behavior in the family must go through repeated habits by the actors in it. The informants in this study received various supports from their extended families, although most of them did not live under the same roof and even in different cities. By Wlash, 1998 is said to be able to make Family Caregivers able to easily manage resources, manage pressure comes from themselves and their surroundings, and restore harmony pace of living that occurs as a result of a problem. Informants told how they were often helped by the other when they needed first aid or when they had to take patients to the hospital.

Besides, it is common among family members to experience several contradictions or paradoxes, where however families must still try to adapt themselves to maintain stability from the crisis, which certainly gives a little shock to the development of family patterns and will also provide even more pressure. Sasa, as a Psychologist at the Surakarta Hospital, explained this is a family task who have to nurse schizophrenic patients. In addition to Family Caregivers, families from the smallest line to the extended family must support each other and lighten each other's burdens. (Research data, December 2021) In addition to the extended family, Family Caregivers usually help each other with the surrounding environment, either with their peers, neighbours or social environment as well as with the community where the Family Caregivers join. All of these are things needed by the Family Caregiver such as various supports, both time, effort and material where they get from the family and community organization patterns. Those supports are able to maintain a balance between the Family Caregiver's personal life as well as their family organization to support each other for schizophrenic patients healing process.

Support from extended families can be of various kinds, one of which is providing material assistance such as funding for treatment (Research data, December 2021).

Hana as a Clinical Psychologist and former head of KPSI said that another form of support is having a family who is ready to be contacted anytime and anywhere. This certainly makes Family Caregiver nursing easier where they have been busy sharing their life with schizophrenic patients. (Research data, December 2021). In addition to the extended family, the social environment around the Family Caregiver's residence also provides various supports. As told by Arif when he was not at home, his mother as a schizophrenic sometimes left unnoticed, fortunately the neighbors already knew each other. Therefore, if his mother travels to a place, Arif will be notified soon. (Research data, December 2021)

### **c. Family Resilience Through Family Caregiver Communication Patterns**

Family Caregiver is not an easy work to do, because they have to share their life with the patients they care for. Previous research had revealed that there were Family Caregivers whose lives became vulnerable because they did not get support from their families and the surrounding environment. It turns out that communication is the main skill in solving a problem from every side.

Arif, an informant, told how the communication built within the family ultimately really helped the work of the Family Caregiver. It happens when the Family Caregiver is not alongside with the patient, other family members will help monitor the schizophrenic patient such as asking for treatment, reminding him to take medication and other activities. (Research data, December 2021).

Communication is used as a medium for the Family Caregiver to convey and express emotions related to what they feel as a Family Caregiver. As a result, communication is able to build a sense of togetherness, mutual care and mutual support in solving problems and providing critical thinking for Family Caregivers and their environment. The communication culture is able to provide an analysis and clarify solutions in facing problems and create a belief to make decisions.

Communication is also carried out by their health assistants from medical experts, i.e. Clinical Psychologists where many patients and Family Caregivers exchange ideas and ask for solutions related to the problems they are experiencing. (Research data, December 2021).

As told by an informant, Babay, after finding out he was a Family Caregiver, he contacted his husband for strength and support immediately. This kind of communication is very effective to make the Family Caregiver does not feel alone to face the fact they are caring for Schizophrenic member and has to share their life with them. (Research data, December 2021).

However, there is the story of a Family Caregiver who has a disreputable relationship with their extended family. The Dinar informant's extended family only found out she was a Family Caregiver and also a schizophrenic only a few months when this research was conducted. Because her extended family did not give a good response and instead blamed past circumstances and was associated with several stuff she had been done in the past. (Research data, December 2021).

This is a common phenomenon in our society, because not everyone is able to understand the position of the Family Caregiver, and moreover many of the people do not understand the terms of the disease explanation. But this is a strength in itself to able to survive and even make a big impact by providing knowledge about schizophrenia to the general public.

### **4.3 Schizophrenia Family Caregiver Resilience**

In this study, researchers will map out the family caregiver schizophrenia process to realize family resilience. From the field findings, we found out the recognition of informal family caregivers of schizophrenia related to the importance of cooperation in all lines of family, relatives, community, and government in order to create a better life for family caregivers who have double roles. They have to care of their life and on the other hand they have to nurse ODS in the family for uncertain long term. (Research data, December 2021)

Being a family caregiver is vulnerable to rejection, including rejection of suggestions, advice and recommendations. That kind of rejection eventually make family caregiver tired psychologically, moreover they have to undergo double role between personal needs and ODS needs whom they treated. (Research data, December 2021)

Palupi, as an informal schizophrenic family caregiver for her mother, revealed the negative impact of her role as a schizophrenic family caregiver is so much thoughts she have to bear and somehow it makes her overthinking. (Research data December 2021)

In this study, researchers want to examine the process of family caregiver resilience. Informal schizophrenic family caregivers who are dedicated to caring for full-time, part-time and freelance, certainly have differences in utilize their strategies to build family resilience. Based on field research, researchers found there were statements from family caregivers regarding the importance of family cooperation to create a better life as expressed by the Palupi as family caregiver. Due to her proactive nature and continuing to maintain her kinship, she felt helped at the lowest points. (Research data, December 2021)

### **4.4 References**

Number citations consecutively in square brackets [1]. The sentence punctuation follows the brackets [2]. Multiple references [2], [3] are each numbered with separate brackets [1]– [3]. Please note that the references at the end of this document are in the preferred referencing style. Please ensure that the provided references are complete with all the details and also cited inside the manuscript (example: page numbers, year of publication, publisher's name etc.).

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### Author Profile



**Triana Rahmawati** received the S.Sos. and M.Si. degrees in Sociology from Universitas Sebelas Maret in Environment in 2015 and 2022, respectively. Has achievements and awards in the field of entrepreneurship such as being a Social Entrepreneur Diplomat Success Challenge Grand Finalist in 2018 and Runner Up of the Smeska Solo Technopark Business Incubation in 2021. Then she became an extracurricular entrepreneurship teacher at SMP PK Muhammadiyah Surakarta since 2020 and Guest Lecturer in Entrepreneurship at UNIBA Surakarta since 2022 until now. At the national level, Triana is a mentor for the entrepreneurship program owned by PT UNITED TRACTORS Tbk and PT ASTRA DAIHATSU. Entrepreneurship programs that are implemented online and offline. Offline activities are carried out in four cities, namely Jakarta, Bandung, Bogor and Tangerang. Currently she is actively running her own business, namely Youth Project, Givo Souvenir, and Humie Essential Oil. As well as being active as a mentor for the entrepreneurial community owned by PT UNITED TRACTORS Tbk, namely Berdaya Bersama.