

## Psychological Wellbeing of Family Caregivers with Schizophrenia Patient

Nurdinie Asfa Frizzell & Zainal Madon

Department of Human Development and Family Studies, Faculty of Human Ecology,  
Universiti Putra Malaysia, 43400 UPM Serdang, Selangor, Malaysia  
Corresponding Author Email: zainalm@upm.edu.my, nrdnie.asfa@gmail.com

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### Abstract

A person with good psychological wellbeing is a person who able to live with positive impression and can work well in their daily life (Huppert, 2009). This study aims to explore the challenges, support system and coping mechanism of family caregivers who are taking care of their family members with schizophrenia living in Klang Valley. Nine caregivers have participated in an in-depth interview session through online platform. Five themes have been generated consisting of 11 sub-themes. Five themes generated are such as guardian role, challenges faced by caregivers, emotion expression, support system and coping mechanism. Caregivers have been facing with various challenges with some are lacking with efficient support system. Caregivers did not get enough information related to schizophrenia from professionals that led them to search that information by their own. As a conclusion, caregivers need more information and guidance from professionals in order to allow them to provide better care for patient and at the meantime, able to help them in getting better psychological wellbeing.

**Keywords:** Schizophrenia, Psychological Wellbeing, Family Caregivers, Support System, Coping Mechanism

### Introduction

Family is an important basic unit in the society as they will provide support towards their own family members for both, mentally and physically. Commonly, family members are those who are the closest person that every individual usually seek for help and guidance. In certain culture, taking care of their sick family member is an essential responsibility and they should accept one another. Therefore, a lot of people who are sick, they will be taken care by their own family members. Schizophrenia is a chronic illness as there are neither technology nor medication that can cure the illness that led them to live with the illness for their entire life. Statistically, there were 20 million registered schizophrenia patients worldwide (World Health Organization, 2019). Due to their unstable emotion, it can lead to sudden behavior changes such as from being passive to aggressive. Due to their seemingly out-of-reach action for other

people to understand, it can contribute to stress for people in their surrounding (The National Institute of Mental Health, 2020).

According to Young et al (2019), caregivers with lack of support system and low life quality have high tendency to develop health issues. Devoting oneself to be a caregiver will demand them to sacrifice a lot in order to take care of their schizophrenic family members. Other than external challenges such as society's stigma and workplace stress, dealing with schizophrenic patient will challenge caregiver's physical, emotion and mental. In order to have a stable psychological wellbeing, caregivers need to have a lot of support, knowledge and self-understanding, to deal with all the challenges that they are facing. A person with good psychological wellbeing is a person who able to live with positive impression and can work well in their daily life (Huppert, 2009). Caregivers with good psychological wellbeing are able to deal with the negativity in their life.

Although mental health awareness in Malaysia has been arising, there are not much of awareness being spread related to schizophrenia and the society do have stigma against schizophrenic person. It might be due to the lack of knowledge being spread and not much of research has been done in Malaysia. Due to that, the public does not aware of the struggle facing by family caregivers and schizophrenic patient. For the past five years, there are limited amount of study has been done in Malaysia related to schizophrenia especially about family caregivers. Increasing the awareness about mental health patient is a great intention but, on the other hand, attention need to be given to family caregivers too as they need support and understanding from the general public. Understanding caregivers' situation can help to lessen their burden and prevent them from isolating themselves from society's judgement.

It is important to give more attention to the wellbeing of family caregivers of schizophrenic patient and educate the public more about their condition as it might be able to reduce the stigma against schizophrenia. In addition, more knowledge about the challenges facing by family caregivers will be able to develop more empathy towards patients and caregiver. Hence, this research will be exploring deeper about the challenges, support system and coping mechanism of family caregivers with schizophrenic patient to understand their psychological wellbeing.

## **Literature Review**

### *Challenges as Schizophrenic Caregiver*

Lerner et al (2018) conducted an online survey that involved caregivers who did not get paid to take care of schizophrenic patient. They discovered that family caregivers in the United States often faced distress throughout their caregiving period due to lack of their own individual time. Focusing on giving care for schizophrenic patient demands a lot of effort, energy and time from caregivers. Caregivers find it as a burden to take care of schizophrenic patient as they have lesser time to socialize and some even faced job loss (Tarmizi et al., 2019). Twelve informants participated in this study that have their family member admitted to psychiatric hospital located in Tehran. Tarmizi et al (2019) also mentioned about caregivers facing insufficient knowledge from medical sector staff. It was also supported by a study conducted by Young et al (2019) which resulted with patient's psychiatric did not provide sufficient information about schizophrenia and suitable caregiving method. They were using Qualitative Evidence Synthesis that focuses on parent caregivers with adult schizophrenic

child. Other than that, caregivers have tendency to be exposed to mood disorder as this research resulted with 37% of the caregivers got diagnosed with anxiety and depression (Xiaoyun et al., 2016). Caregivers from this study were family caregivers from Shandong Province Mental Health Center in China that fulfilled the inclusion criteria to be eligible to participate in their cross-sectional research. Mental illness has become the synonym of stigma among society. Lastly, a study conducted by Zhang et al (2017) has adopted cross-sectional design in order to determine affiliated stigma and life quality of 350 primary caregivers who are taking care of patients that seek service from Singapore's Institute of Mental Health. This study resulted with caregivers, aside from other challenges, need to deal with stigma from surrounding people.

### *Support System*

Park et al (2018) cited from Orrell and Hancock (2014) about caregiver's unfulfilled needs might lead to challenges as they do not have adequate helps and support. Sometimes the existing support system that caregivers have are no necessarily helping caregivers. There are a few caregivers, out of 15 caregivers, who participated in the qualitative descriptive research done by Huang et al (2020) that portrayed themselves as a failure when at the time they were not being supported in terms of knowledge and understanding from their family member's psychiatry team. They also had limited treatment choices due to their demographics that forced request for lesser time for appointments as some of them also facing financial problems. Huang et al. conducted their research at Changsha, China while using convenience and purposive sampling in selecting informants. In addition, Sufficient support system able to enhance caregiver's wellbeing especially if they get a strong social support from others as it can help to lessen their burden (Leng et al., 2019). This study was held in Jinan, China with a total of 180 participants who willing to be interviewed and met the criteria. In research that was using literature review method, they found out that caregivers need a strong financial support and healthcare workers should also monitor and guide caregivers to improve their life quality (Kamil & Velligan, 2019). In Tukey, a study led by Bademli and Duman (2016) was using phenomenological method that consists of eight sessions of "Family to Family Support Program" at Izmir Schizophrenia Support association that was participated by 20 caregivers. The purpose of this study was to analyze caregivers experience and idea when participated in it. The study proved that having sufficient social support and knowledge can increase caregiver's ability to face their problems.

### *Coping Mechanism*

Most caregivers used social coping and problem based as their coping mechanism (Rao, Grover, & Chakrabarti, 2020). They also discovered a correlation between caregiver's financial condition with the types of coping mechanism being used. Due to lesser options, caregivers with financial problems implemented escape-avoidance and negative religion coping. In a descriptive correlational study conducted by Rahmani et al (2019) in Iran, they found out that most of caregivers tend to use emotion-coping such as avoidance to deal with their situation. This coping mechanism do not solve the problems, rather, it will only cause more pressure in future. Caregivers with longer caregiving period implemented different approach as they are focusing more on creating a strategy based on their patient and failing it and they will use a new strategy until they found the suitable method (Poonnotok et al., 2018). This research was focusing on the caregivers with > 5 years of caregiving experience which does not really discover the challenges being faced by caregivers with minimal knowledge and experience.

Malaysian researchers, Ong, Norhayati Ibrahim and Suzaily Wahab conducted research in 2016 at Psychiatric Clinic of Hospital Canselor Tuanku Muhriz that was participated by 200 outpatient caregivers. The research resulted with Malaysian family caregivers implemented coping strategy the most followed by emotional-based and substance used. However, this research was conducted in 2016, way before the pandemic of Covid-19. Due to the different situation and living style, researching on current situation of schizophrenic caregivers are essential. On the other hand, an explorative qualitative approach has been done by Iseselo, Kajula and Malima (2016) that resulted with family caregivers of schizophrenic patient mostly were using religion coping mechanism by accepting it and regular prayer.

### **Methods**

This study adopted purposive sampling method to screen caregivers in ensuring only eligible caregivers participated in this study. Due to COVID-19 pandemic, online platforms such as Facebook groups and Twitter were being used to reach out to caregivers and encourage them to participate in this study. Caregivers who were eligible to participate in this study needed to fulfill below criteria.

- i. Must have at least 10 months experience as main caregiver
- ii. Lives in Klang Valley
- iii. Able to speak and understand English and/or Malay language
- iv. Patient under their care need to be diagnosed by psychiatrist
- v. Family caregivers need to be 18 years old and above

After approaching caregivers who volunteered themselves to participate, I did a screening to ensure that caregivers fulfilled the criteria mentioned. Before each interview session, ethical consideration form was shared and explained to caregivers in ensuring caregivers to understand about the research and about their rights on keeping their identity private and confidential. Ethical consideration form was reviewed and approved by Associate Professor Dr. Zainal from Department of Human Development and Family Studies. Each interview session estimated took up to one-hour, through online meeting platform due to Movement Control Order (MCO) in Malaysia, which was consider as an effective time range to allow caregivers to share their experiences. Transcript was generated after each interview and being analyzed. Important information was highlighted during first transcript reading to allow researcher to focus information that were related to the topics. Subsequently, information identified was classified into suitable themes. After thorough screening, all data in each theme that carried same meaning were classified into related sub-theme. This analysis process is known as thematic analysis which allow researcher to classify information into suitable and relatable theme. Aside from transcripts, recorded videos were being used during analysis process in order to recall caregiver's face expressions and voice intonations.

### **Findings**

Family caregivers that participated in this research live in Klang Valley. Based on Table 1, a total number of nine caregivers have participated in this research which consist of eight female and one male. There are two caregivers who have retired while the rest are still working. Results revealed that majority parents will take the responsibility to take care of their children despite their working status. Majority of family caregivers are taking care of their schizophrenic patient together with other family members and their partner. Five

themes have been generated in this research followed by 11 sub-themes that help to explain in detail about each theme.

**Table 1**

*Demographic information of family caregivers*

Caregiver	Caregiver Age	Caregiver Gender	Caregiving Period	Work Status	Relation With Patient	Patient Age	Patient Gender
C1	31	Male	10 years	Working	Son	54	Female
C2	30	Female	1 year & half	Working	Sister	38	Male
C2	30	Female	1 year & half	Working	Daughter	65	Female
C3	61	Female	15 years	Not Working	Mother	39	Female
C4	30	Female	10 months	Working	Sister	32	Male
C5	69	Female	10 years	Not Working	Mother	28	Male
C6	43	Female	20 years	Working	Daughter	68	Female
C7	44	Female	1 year & half	Working	Mother	22	Female
C8	57	Female	8 years	Working	Mother	28	Female
C9	32	Female	8 years	Working	Wife	40	Female

**Guardian Role**

**Figure 1: Caregiving Role**

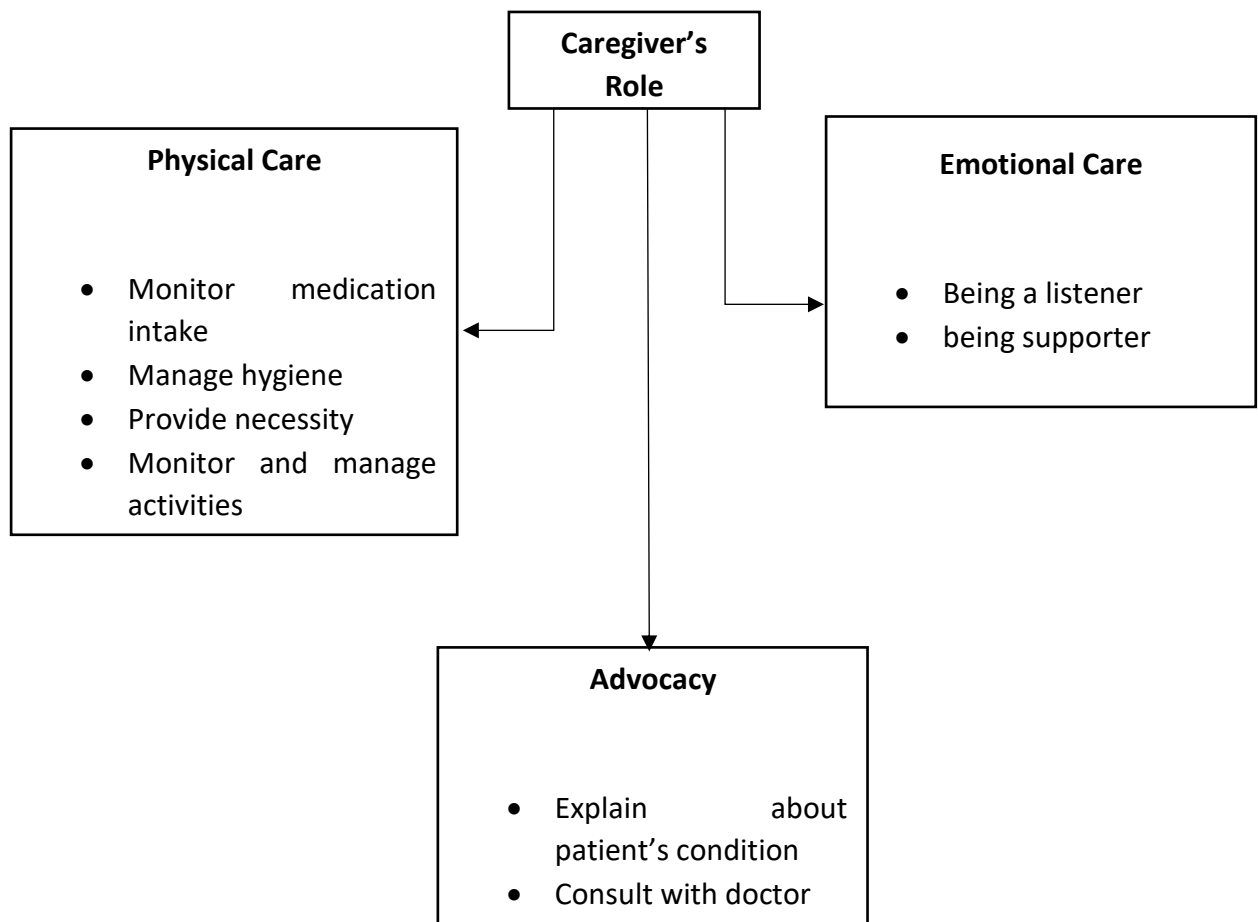


Figure 1 shows caregiver's role in managing their schizophrenia family member. During the interview session, caregivers mentioned about these three main cares needed by patient that demand caregivers to help them. Due to patient's limitation, caregivers need to make sure certain aspect need to be done to support patient and to ensure they are in good condition. Three main aspects that caregivers need to assist patient are physical care, emotional care and advocacy.

Due to patient unstable mental condition, caregivers need to step in and take care of patient's physical needs. Caregivers need to manage patient's hygiene and provide necessity for them. Aside from that, it is important for caregivers to manage and monitor the activity and medication intake of their family member with schizophrenia due to their inability to remember and think wisely.

Aside from physical care, patients also need caregivers to manage their emotion needs. Due to their hallucination and delusion, they seem to be 'not-fit' with other people as they view and understand the world differently. Schizophrenia patients have the same social needs as other people. Therefore, a lot of caregivers will be there to listen and support patient's emotion needs.

As the person who take care of their family member with schizophrenia, caregivers are the one who will be communicating with the doctor especially when they need to point out about the effectiveness of the medication prescribed to patient as some prescribed medications do cause harm than good to patient.

### Emotion Expression

Table 2

*Emotion expression*

<b>THEME: EMOTION EXPRESSION</b>	<b>FREQUENCY</b>
Worried	5
Stress	4
Burnout	3
Fear	2
Mixed Feelings	2
Sad	2
Pity	2
Skeptical	1
Restless	1
Happy	1
Grateful	1

Table 2 shows the emotion that caregivers expressed during interview session. Providing care for schizophrenic patient will always plays with emotion as sometimes they can be in unstable condition. Not to forget about caregivers who need to deal with aggressive patient. Most of the emotion being expressed by caregivers were negative and it really give huge impact in their life such as constantly feeling worried and stress due to lack of resting time for themselves. On the other hand, there are also caregivers who expressed positive emotion at

certain situation as they felt happy with the progress of their family member and also feeling grateful to be the selected person to take care of their sick family member.

### **Challenges Faced by Caregivers**

There are numerous challenges that caregivers need to deal when they are caring for their schizophrenic family members. The challenges are various caregiving task, neglected educational needs, inefficient services and limited access to services.

Majority caregivers who participated in this research are working and they mentioned about the never-ending task that they need to do alongside with other responsibilities such as work demand and parenting responsibility. Having multiple responsibilities do put a lot of pressure on caregivers.

*“I am working and responsible to manage the school including the marketing. At the meantime, I also need to take care of my toddler and psychotic mother and brother. It was super demanding especially during MCO that caused me to experience miscarriage in July 2021” – C2*

Schizophrenia is not a common mental illness especially when mental awareness in Malaysia is not high. Dealing with schizophrenia patients is hard if you do not have any knowledge about it as you will not understand patient’s situation and ways to deal with it. Quite a number of caregivers touched about their neglected information needs. Caregivers need to find their own medium to understand patient’s illness and ways to deal with it.

*“When my mother was diagnosed with schizophrenia, the doctor only mentioned about the diagnosed name and how it happened to my mother. I only got to know more about schizophrenia when I got married to my wife” – C1*

Caregivers also often feeling uncertain with the effectiveness of the medication that psychiatrist prescribed for their family member as some medication can affect patient’s health. Aside from that, there is a caregiver who experience ‘psychiatrist cycling method’ that being implemented in government hospital. Changing psychiatrist will lead to lack of rapport between patient and psychiatrist that demand caregiver to explain patient’s condition repeatedly.

### **Support System**

In this theme, there are three sub-themes consisting emotional support, instrumental support and information support.

Caregivers mainly will seek for emotional support to channel their emotion in caring for their schizophrenic patient. Caregivers tend to only trust their own family members to express their emotion as they think that only family members can understand their situation. Aside from that, some caregivers also seek for support from professionals such as attending counselling session while a small number of caregivers will only keep it by themselves.

*"I had no knowledge about any mental illness. Therefore, I went to not only one but several counselling sessions even to marriage counselling..." – C7*

*"I do not think that they can help me... They never witness any caregiver handling patient with schizophrenia." – C9*

When it comes to instrumental support, most of caregivers do seek for it as in certain situation, some caregivers could not handle the situation by themselves and need help from other people. Caregivers get a lot of instrumental support from people around them such as family members, neighbors and spouse.

*"Alhamdulillah, my husband participated in taking care of the house chores together with me and I also exposed my children in how to manage my schizophrenic mother when she has become more stable. They helped me a lot." – C6*

Knowledge is the strong element that all caregivers need to have in order to be able to provide appropriate care towards their family member with schizophrenia. It can be challenging if one is not equipped with sufficient knowledge and it can impact caregiver's psychological wellbeing. Caregivers have been using various connection and platform to learn and understand more about schizophrenia due to lack of information from professionals.

*"... I read often. Even in the support groups in Facebook, sometimes other participants share useful research articles about schizophrenia." – C3*

*"In YouTube, there are several professional doctors that shares about schizophrenia and mental illnesses. His videos are easier to be understood." – C7*

### **Coping Mechanism**

There are four sub-themes in this theme which are escape-avoidance, problem-focused, self-control and religious coping.

Mainly, caregivers are using problem-focused in their caregiving style to encounter the stress that they are facing. Some of them seek for alternative medication and trying and error approach. Caregivers with children tend to expose their children about their schizophrenic family members to allow them to learn on managing patient and accepting patient's condition.

*"I am... sort of making a trial. I tried this and that and figure out what can and cannot be done." – C3*

*"Once my children reach certain age, I will explain it to them. They need to know the needs for their grandmother." – C1*

At the meantime, there are also a lot of caregivers who manage their situation using escape-avoidance mechanism. Majority caregivers isolate themselves from the public to prevent others from talking about their sick family members. There are also caregivers who displaced their emotion by writing their experiences to express themselves.



*“How do I deal with it? The answer is I did not meet people. People do not understand their condition... People who do not know them, I can never shut their mouth.” – C3*

Dealing with schizophrenic patient can impact caregiver’s psychological wellbeing. That is why caregivers should always beware of their own capability. A few caregivers use self-control as their coping mechanism where they will deal with the situation based their ability at that particular time.

*“Previously, I always forced myself to try hard despite me being drained. But now, I will only deal with it based on what I can do” – C2*

Majority of caregivers exposed their coping mechanism using religious coping which they will pray and self-reflect in Islamic ways.

*“Allah test my family with this situation. However, I hold to my mom’s saying about Allah will give us a lot more ‘nikmat’ and ‘rezeki’ from what we have now.” – C7*

## **Discussion**

Majority of caregivers mentioned that they need to handle numerous tasks once they became a caregiver especially those who work. Due to that, caregivers spend lesser time for themselves and it led to them being stress. Lerner et al (2018) mentioned that caregivers suffer each extra time in providing care to patient. Meanwhile, half of caregivers feel stress being a caregiver for schizophrenic patient (Xiaoyun et al., 2016). However, in present study, caregivers who have knowledge about schizophrenia faced minimal pressure mentally and physically.

A study done by Shah et al (cited by Young et al., 2019) resulted with caregivers were supplied with minimal information about schizophrenia from professionals. A number of caregivers are facing the same issue as they faced difficulties in caring for schizophrenia patient because they do not understand patient’s condition. Initially, majority caregivers did not have the knowledge about schizophrenia and they needed guidance. Tarmizi et al (2019) cited that family caregivers were lacking information and consciousness, method to overcome stress and show their care towards patient. In addition, caregivers also facing ineffective services from professionals. Medication being prescribed were tested at first to know its suitability with the patient. Professionals are using the try and error method until they find the suitable medication for schizophrenia patient. Lerner et al (2018) mentioned caregivers feeling distress thinking about patient’s medication effectiveness. Other than that, government hospital in Malaysia implementing the psychiatrist rotation method which lead to different psychiatrist will be assign for a patient after a few periods. There was also psychiatrist who prescribed new medication despite being informed by caregivers about the effectiveness of previous medication.

According to Iseselo et al (2016); Huang et al (2020); Pompeo et al (2016), caregivers faced some financial difficulties during their caregiving period. On the contrary, in present research, caregivers did not consider financial as a challenge. It is most probably due to lower medication cost at government hospital and the privileged given for mentally ill patient that

owns '*Orang Kurang Upaya*' card that is eligible for RM300 every month, provided by the government.

Present study shows that almost all caregivers are support seeking which is the opposite of a study done by (Anli et al., 2019). In present study, most caregivers tend to only seek for emotional support from their family members or other schizophrenic caregivers. They fear of being judge by others. However, despite them experiencing stigma, some caregivers took the opportunity in various platform to spread awareness about schizophrenia. This outcome is parallel with a study in Singapore conducted by (Zhang et al., 2018).

Caregivers need to have instrumental support to help them especially those who are caregiving an unstable patient. Most caregivers seek support from their family and other social support. According to Pompeo et al (2016), social support has the ability to help and lessen caregiver's burden.

Due to lack of information from professionals, caregivers seek for informational support on other platforms. A number of caregivers seek for more information in support group as they can exchange information and express their thoughts with someone who understand them. It was proven that meeting and communicating with other caregivers can result to positivity as they able to encourage each other (Bademli & Duman, 2016).

A decent number of caregivers in this research implemented problem-focused method especially those with more than 10 years of caregiving experience or those who actively seeking for self-help. Poonnotok et al (2019) supported the point as caregivers in their research have more than 10 years of experiences deal with their problem by using try and error method.

At the meantime, escape-avoidance mechanism has been commonly implemented by caregivers in this research. Rao et al (2020) stated the same result with their caregivers as they constantly using escape-avoidance as their coping mechanism. Caregivers tend to isolate themselves from others. The term of "They do not understand our situation" has been mentioned several times by various caregivers. Rahmani et al (2019) highlighted that their research resulted with avoidance as caregiver's strategy. However, they did not suggest using it due to its inability to solve any problems arise.

A study done by Iseseo et al (2016) mentioned that caregivers creating their own method to deal with their own situation through religious coping. Gojer et al (2017) also stated that caregivers expressed positive impression when referring to their religion ways to manage their stress. In this research, almost every caregiver, either directly or indirectly, being seen to be using religious coping as their coping mechanism.

## **Conclusion**

Overall, there are various challenges that caregivers need to face and it differs based on their situation. Challenges that being mentioned the most by caregivers are numerous caregiving task and lack of knowledge that can lead to overwork and stress. Other than that, support system gives huge impact on caregiver's life. However, sadly, some caregivers did not get enough support from professionals in understanding about schizophrenia. To overcome their

challenging situation, caregivers will implemented coping mechanism to deal with stressor and challenges. In Malaysia, most of caregivers been using problem-focused and escape-avoidance coping mechanism throughout their caregiving period. This research aims to provide more knowledge about caregivers who are taking care of their schizophrenic family members. Through that, it can increase awareness and being a reference by respective representative from government or any NGO to explore about the needs of family caregivers. Due to time limitation to complete this research, it prevented researcher's ability to explore deeper about caregivers' experience in caregiving for patient with schizophrenia although a lot of essential information have been collected through this study. Future research could take a longer period of time in discovering caregivers' experience through in-depth interview with minimum two interview sessions for each caregiver as it will build a better rapport between caregivers and researcher. Through that, researcher would be able to get a better understanding about caregivers' caregiving experience. In addition, despite the thorough screening has been done to ensure diverse participation from caregivers, the was not much of a number of male caregivers that participated in this research. Participation from both genders will gives a wider view about the challenges, coping mechanism and support system experienced by caregivers as both genders have different ability in terms of psychologically and physically.

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