

# Factors Influencing Family Acceptance of People with Schizophrenia Receiving Care at Home: A Systematic Review

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## ABSTRACT

**Background:** People with schizophrenia require long-term care and treatment. The high cost of treatment for sufferers makes many families decide to do their treatment at home. Government programs and policies such as Community Mental Health Nursing (CMHN) are one of the hopes of families to help them. Changes in the situation due to caring for people with schizophrenia need to be balanced with psychological adaptation by family members so that family acceptance characterizes an adaptive response. **Objective:** This article will provide information about factors related to family acceptance. **Methods:** This research used the systematic review method by utilizing eight electronic databases such as Scopus, DOAJ, ProQuest, Web of Science, ScienceDirect, PubMed, and SAGE from January 2012 to 2022. Articles obtained from electronic databases are related to relevant topics in a total of 79 articles, displaying only 20 articles analyzed that meet the criteria. The keywords used are "family acceptance" and "schizophrenia", "schizophrenia OR family OR acceptance". **Results:** Acceptance is an essential aspect of the family's psychological adaptation journey. Acceptance is related to a person's ability to face and undergo situations that are presented to him voluntarily. Stigma can reduce family confidence in caring for sufferers, thus requiring expectations, attitudes, experiences, social support, and convenience in health services. **Conclusion:** Other efforts are needed, apart from the sufferer's family, but also the support of other people and the community. In addition, health professionals like physicians or nurses are needed as role models not to discriminate against and stigmatize families and sufferers.

**Keywords:** Factor; Influencing; Family Acceptance; Schizophrenia; Nursing

## INTRODUCTION

Schizophrenia is a form of severe mental disorder characterized by positive symptoms such as hallucinations and delusions (Carrara *et al.*, 2019). People with schizophrenia have to struggle with disorganization, or the inability to organize real events, and the emergence of negative symptoms such as fatigue, apathy, and emotional loss. Most people with schizophrenia have to take psychotic drugs and undergo various kinds of therapy to relieve the symptoms that arise. This condition makes it difficult for people with schizophrenia to socialize and find work (Aszrul *et al.*, 2018).

The global prevalence of schizophrenia is 1% of the total world population; 15% of them are children whose parents suffer from mental disorders, and 35% are children whose parents suffer from schizophrenia. According to data from 2010 to 2013, mental disorders can cause world economic losses reaching US\$16 trillion due to the decreased productivity of sufferers and their caregivers. (Naeim & Rezaeisharif, 2021). That is why, according to the World Health Organization Report (2015), schizophrenia is called one of the 'burden diseases' in the world or a disease that burdens countries globally. Previously, WHO said that cases of maternal and child mortality were a big burden for the country, but now the facts have shifted to mental disorders (Azrul & Syam, 2018). This disease is included in the burden disease group because of the overall impact caused by the disease, including physical, economic, and social impacts. And some sufferers with this condition will last a long time or even a lifetime (Buckley *et al.*, 2015).

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The existence of people with schizophrenia is often rejected by families and the health system. The rejection that occurs by families when caring for people with schizophrenia is due to the burden of their direct involvement in caring for sufferers on a daily basis. In addition, a difficult challenge for families is adjusting to the policies of the health care system because sufferers must continue to undergo treatment or medication. According to Aubeeluck & Luximon-Ramma (2020), the presence of schizophrenics at home makes the family worry about their own safety when the patient relapses and commits violence. In addition, families are often forced to avoid large events or social events that involve many people because they have to look after sufferers, and families are also experiencing financial difficulties. Naeim & Rezaeisharif (2021) stated that one of the criteria for a patient to recover is that there is no recurrence of symptoms within 2–5 years, such as hallucinations, delusions, and loss of motivation. This long and uncertain period of treatment often causes families not to accept people with schizophrenia (Azrul & Syam, 2018). Whereas the aspect of psychological adaptation of caregivers with schizophrenia that is characterized by this acceptance greatly determines their performance in performing the role during patient care (Naeim & Rezaeisharif, 2021). The existence of stigmatization and discrimination is also another reason for families not to accept sufferers. In the view of society in general, people with schizophrenia are perceived as someone whose behavior is strange, scary, unpredictable, aggressive, and poorly controlled (Carrara *et al.*, 2019). The difficulties of the family as the main caregiver in dealing with sufferers and their experience in dealing with difficult conditions can cause a burden. Besides, the burden can occur due to long treatment and high costs, so families care for people with schizophrenia at home. Which of these burdens can lead to wrong family actions by rejecting sufferers, causing a sense of insecurity, and other problems in the family (Sarrió-Colas *et al.*, 2022)?

Family acceptance is characterized by family attitudes and behaviors that do not feel ashamed to care for and do not make high demands on the achievement of behavior change shown by sufferers. The attitudes and behaviors of these families can increase the role of the family in preventing the recurrence of schizophrenia in sufferers through family involvement in treatment and helping sufferers socialize and work (Naeim & Rezaeisharif, 2021).

The purpose of this systematic literature review is to support families who decide to care for people with schizophrenia at home by providing important information from related articles about efforts to increase the acceptance of families caring for people with schizophrenia. So that sufferers get adequate care and have a good quality of life.

## **METHODOLOGY**

### **Search Strategy**

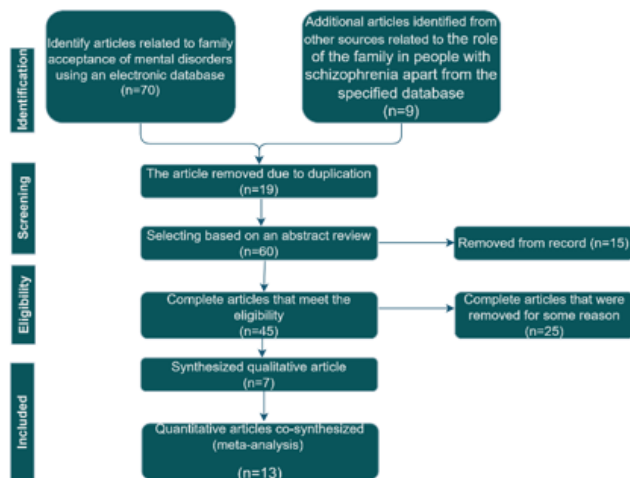
A search was carried out using the keywords "family acceptance" AND "schizophrenia" and "schizophrenia OR family OR acceptance" to find articles related to family acceptance of people with schizophrenia who are cared for at home and relevant to the research objectives.

### **Selection Criteria**

The research articles sought are limited by the inclusion criteria for articles published online, which are: research for the last ten years (2012–2022); presenting information about factors related to or influencing family acceptance and the effects of family acceptance for people with schizophrenia; and presenting empirical research, both qualitative and quantitative, related to family acceptance. Exclusion criteria are articles that do not use English; articles related to family acceptance other than those with mental disorders.

### **Data Extraction**

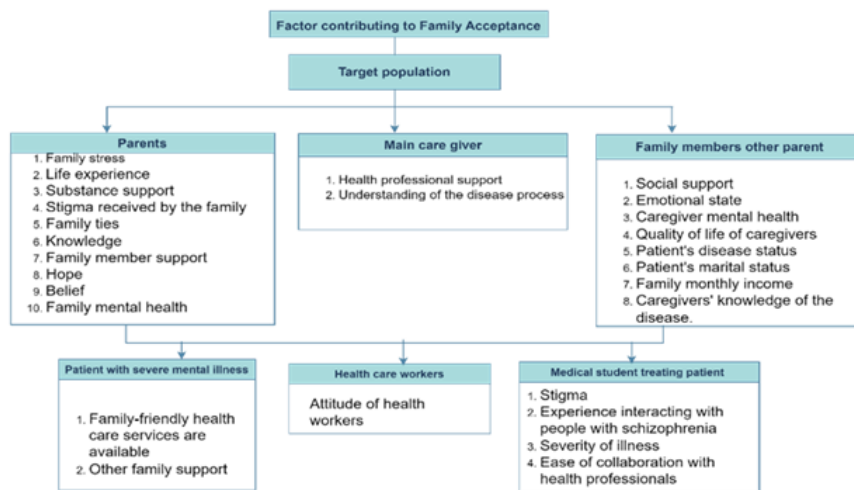
Articles obtained from the electronic database related to factors related to family acceptance totaled 79 and featured 20 articles analyzed. Researchers use advanced search features to eliminate articles and speed up the screening process. Furthermore, articles were compiled using observational research methods that follow PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-analyses). All articles, according to the topic, were fully meta-analyzed. The stages of the research include selecting literature, reading the full contents of the article, determining feasibility, extracting the central themes and concepts, and synthesizing (refer to Figure 1).



**Figure 1: Flowchart of Study Protocol**

**RESULTS**

Article searches were carried out by entering the keywords "family acceptance" AND "schizophrenia" or "schizophrenia OR family OR acceptance". They obtained 79 relevant articles from seven electronic databases: Scopus (12), DOAJ (8), ProQuest (8), Web of Science (7), ScienceDirect (9), PubMed (12), SAGE (14), and other databases (9). Furthermore, articles were reviewed following guidelines such as the flowchart above, and 20 relevant articles were obtained. Figure 2 shows the factors that affect family acceptance based on the point of view of the target population, which consists of people suffering from mental disorders and those who directly care for people with schizophrenia (refer to Figure 2).



**Figure 2: Factors Affecting Acceptance**

People caring for sufferers are families related by blood, other family members or relatives, primary caregivers, practicing students, and social workers in the health and medicine sectors. Some factors increase family acceptance, such as stress on the family, low family quality of life, communication barriers, shame, stigma, no help, and difficulty caring. While factors that increase family acceptance include family ties, hope, and trust, good medical services, family experience, knowledge, affect, or positive responses of people with schizophrenia, While Table 1 shows a summary of the selected articles (see Table 1 below):

**Table 1: Summary of the Analysed Articles (n=20)**

| No. | Study reference                        | Findings   |
|-----|--|--|
| 1   | Sarrio-Colas <i>et al.</i> , 2022      | Difficulties faced by parents in accepting people with mental disorders due to stress due to the emergence of new problems due to living with people with mental illness, life experience in dealing with difficult situations |
| 2   | Paul & Nadkarni, 2017                  | Family acceptance occurs because of the bond that begins before the child is born  |
| 3   | Gedik, Güntüßen, & Ince, 2020          | Families are willing to accept sufferers and take them to health services if hope and good health services are available.  |
| 4   | Carrara <i>et al.</i> , 2019           | Health workers are examples of positive behaviour for families and the positive views of others on sufferers   |
| 5   | Leng <i>et al.</i> , 2019              | Low quality of family life   |
| 6   | Azrul & Syam, 2018                     | The formation of family experiences about mental disorders itself affects the high level of acceptance   |
| 7   | Naeim & Rezaeisharif, 2022             | Family acceptance begins with the hope and belief that sufferers can recover, thereby helping to prevent a recurrence  |
| 8   | Vicente <i>et al.</i> , 2013           | Family acceptance is likened to a family that can break down a big barrier; health workers must accompany the family to achieve this.  |
| 9   | Gallaway, 2015                         | Acceptance includes both social and non-social; non-social parental acceptance is reflected in the mentality of parents who are healthy and not ashamed.   |
| 10  | Putra, Hamdani, & Supriati 2017        | Knowledge and ability of the family are essential in the care of sufferers. The family's ability to adapt quickly can prevent emotional and economic burdens   |
| 11  | Darni, Yusuf, & Tristiana 2020         | Psychological and behavioural support for families can accelerate family acceptance  |
| 12  | Agustina <i>et al.</i> , 2022          | Family acceptance positively affects the recovery time of patients who recover faster.   |
| 13  | Mamnuaah, 2021                         | Sufferers need family affection, the greatest affection in the form of family acceptance   |
| 14  | Chiles, Stefanovics, & Rosenheck, 2017 | Stigma in the family makes family acceptance difficult, but the experience of living with sufferers makes the family finally accept  |
| 15  | Bailey, 2020                           | Acceptance can occur if there is no anxiety or depression in the family  |
| 16  | Angermeyer <i>et al.</i> , 2021        | Feelings of helplessness and depression cause families not to accept sufferers   |
| 17  | Balon, 2023                            | Stigma causes delays in acceptance, and information can change the stigma  |
| 18  | Schomerus <i>et al.</i> , 2014         | Low family acceptance is associated with the occurrence of biogenetic beliefs that say schizophrenia is difficult to cure.   |
| 19  | Angermeyer <i>et al.</i> , 2011        | Family acceptance is influenced by public stigma, where there is a stereotype that sufferers are unstable, dangerous, and irresponsible.   |
| 20  | Langlois <i>et al.</i> , 2020          | Difficult care for patients causes families not to accept sufferers.   |

**DISCUSSION**

**Acceptance aspects in the target population of parents**

Parents, especially in India, who care for children suffering from schizophrenia state that stress that occurs in the family, social support, family life experiences, stigma, family ties, and support from family members affect family acceptance (Paul & Nadkarni, 2017; Sarrio-Colas *et al.*, 2022). In this study, it was explained that caring for family members who suffer from schizophrenia makes the family often ridiculed and often labeled as a 'crazy' family, which makes the family feel ashamed and want to separate themselves from family members who have mental disorders. In addition to ridicule, the family also received different or discriminatory treatment, such as not being involved in social

events, not being given information on social activities, and a lack of communication with the sufferer's family. This condition will make parents' lives more stressful when caring for their children who suffer from schizophrenia (Chiles, Stefanovics, & Rosenheck, 2017; Mamnuah, 2021).

In addition to stress due to stigma and discrimination, the family also feels burdened by the sufferer because the sufferer has not worked for a long time (Schomerus, Matschinger, & Angermeyer, 2014). Especially in families that have a large number of family members, of course, it will increasingly add to the burden on the family. Meanwhile, we all know based on family functions that the family is the main source of support physically and psychologically for other family members who are sick. The condition of the sufferer who is not working psychologically affects other family members so that they can no longer be expected to support each other in the family. So that the longer the sufferers suffer, the more the other family members become unsupportive of them because they feel the burden of life is very heavy (Agustina *et al.*, 2022; Gallaway, 2015).

In India, family ties, which are relationships between siblings, are very strong. It is even believed that this was formed before they were born. The different health conditions of schizophrenics cause siblings to want to separate themselves from sibling bonds (Paul & Nadkarni, 2017). Family acceptance is likened to a family that can break down a big barrier (Vicente *et al.*, 2013); however, the unpleasant experience can make the family want to build a dividing wall with sufferers even more. These four factors occur continuously and are interconnected so that the family ultimately chooses to reject or not accept the sufferer (Azrul & Syam, 2018).

The uncertain course of schizophrenia can cause the quality of life of caregivers or healthy families to decrease due to anxiety about the uncertainty of the sufferer's condition and depression due to various life demands on the family (Bailey, 2020). Declining family quality of life can cause the family's role to suffer. The physical, emotional, and mental health roles of the family also decrease (Aubeeluck & Luximon-Ramma, 2020; Leng *et al.*, 2019). However, having hope and belief that the patient can recover can initiate acceptance. In addition, it can help prevent recurrence in sufferers (Naeim & Rezaeisharif, 2021).

### **1. Acceptance aspects in the target population and caregivers**

The literature review results obtained mention the research results on the main caregivers, who are other families besides their parents but live in one house and visited the Maringa City Hospital, Parana, Brazil (2021). The article states that social support, emotional condition, caregiver mental health, quality of life, patient's disease status, patient's marital status, family monthly income, and caregiver's knowledge of illness affect family acceptance (Leng *et al.*, 2019). Social support from the community to families directly or to sufferers through simple ways such as the community being involved, paying attention to the needs of families and sufferers, and not carrying out social isolation or exclusion will increase family acceptance of sufferers. Acceptance is defined as understanding the condition of others. But on the contrary, low public acceptance of families or sufferers can cause family confidence to be low (Angermeyer, 2021).

The situation above is related to a condition called 'biogenetic belief', which is a person's belief that arises as a result of the previous behavior of others that raises expectations. When it is associated with social acceptance, what happens is that when a person feels high acceptance from their social environment, indirectly, the person gains confidence in something they are facing so as to form hope that the sufferer can recover. The emergence of hope in the family will ultimately make it easier for the family to accept the conditions it faces (Balon, 2023; Schomerus, Matschinger, & Angermeyer, 2014). Social support received by the family psychologically can reduce the emotional burden on the family so that the mental health of the family increases and it is easier to accept sick family members. However, the unstable condition of sufferers or the easily changing symptoms of schizophrenia often cause family uncertainty in dealing with all the challenges that can occur, especially if the sufferer is still not married. Then all the burden of his life becomes the responsibility of the family. It has an impact on the family's monthly income because there are family members who do not work. It is the difficulty of treating schizophrenics and the consequences they have in everyday life that sometimes makes it difficult for families to accept sufferers (Angermeyer, 2021; Langlois *et al.*, 2020).

## **2. Acceptance aspects in the target population of family member of other parents (other families who still have kinship but don't live in the same house)**

According to close relatives of sufferers who still have family relations, but they do not interact continuously and live at the same house, they also experience the effects of having family members suffer from mental disorders. They also feel they have an obligation to help, but sometimes the financial or substance constraints they experience also prevent them from providing social support. This situation makes them feel guilty and frustrated, thus affecting their emotional state. In addition, they said that they often become a reference for information or a place for families who live in the same house to ask questions about patient care. In addition, they are also often involved in decision making, especially in treatment, even though they do not have enough knowledge to deal with sufferers' problems. Families who live in the same house as sufferers will often do this to other families who do not live in the same house when they are unemployed and have no job or income. This situation occurs continuously and repeatedly, making them helpless, depressed, and want to ignore sufferers and their families (Leng *et al.*, 2019; Putra, Hamdani, & Supriati 2017; Sarrió-Colas *et al.*, 2022).

Acceptance of families who do not live in the same house as sufferers can occur if sufferers and families who live in the same house have sufficient finances. For example, a definite monthly income, the patient is married, and his partner has an income, so that it can help the patient to get adequate treatment, not have frequent relapses, recover quickly, and not cause a burden on other families (Buckley *et al.*, 2015; Leng *et al.*, 2019). In addition, according to the families who live at the same house, sufferers and their families need accurate information about mental illness. According to them, the campaign on mental health education by health workers is a very useful tool to increase family knowledge so that they can carry out care more independently (Cenat, 2020).

## **3. Acceptance aspects in the target population of people with schizophrenia**

Further interesting research is qualitative research on the main target population of schizophrenics in the Turkish region (2020), which states that they feel accepted by their families for two reasons: getting support from other people and getting health or care services that are easily accessible to the family (Gedik, Günüşen, & Ince 2020; Noh, Choe, & Yang 2018). Schizophrenia sufferers whose conditions are stable are very clear in describing their situation during the period of care by the family. The sufferers directly stated that in the early stages of the illness, the family refused their presence because of shame. However, along with the course of the disease, when the family was able to adapt to their environment and often received help from other people, including family neighbors, they could accept it. Apart from the experience that has been formed, the ease with which families provide medical care to sufferers will also make it easier for families to accept sufferers because families feel at ease knowing that there are other parties who can be relied upon when needed (Azrul & Syam, 2018; Gedik, Günüşen, & Ince, 2020).

## **4. Acceptance aspects in the target population of health care workers**

The results of the research on a target population of 54 health care workers in Canada in 2023 who work in families with family members suffering from mental disorders According to these health workers, families can accept sufferers if they get a good attitude from them. The results of this study state that families often receive unpleasant treatment from health workers because patients are noisy at health services or are not orderly. The family regrets the attitude of the officers, who were not kind to them or to the sufferers. So that makes the family think that if health workers can't accept sufferers, what about the general public? While it is known that the public picture of mental disorders is generally due to stereotypes that sufferers are unstable, dangerous, and irresponsible, in addition, it cannot be denied that humans have strong biogenetic beliefs, including families that also believe that schizophrenia is difficult to cure (Mamnua, 2021; Metzl & Hansen, 2018). This situation can be a trigger for families not to accept sufferers (Carrara *et al.*, 2019; Mamnua, 2021). But on the contrary, when the family gets convenience and a good attitude from health workers, it can convince the family to want to care for sufferers because the family feels that other people accept the patient (Metzl & Hansen, 2014).

## **5. Acceptance aspects in the target population of medical student treating patients**

Based on the research results of students who were involved in caring for schizophrenics at the hospital where they

practiced in the USA in 2017, it states that family acceptance of family members with mental disorders is influenced by stigma, experience interacting with schizophrenics, disease severity, and ease of collaboration with health professionals. The research data was taken through a quantitative approach with a questionnaire on 289 students. The results stated that students who had treated schizophrenics had interacted with the patient's family. The patient's family experienced a long journey until they finally accepted the patient's condition. Nearly 60% of families do not accept sufferers in the early stages of the disease, which is in the first 0–1 year. This is due to shame and failure because they fail to take good care of their families. Most of the families, 55% of whom have never cared for people with mental disorders, have cared for them. The results of this study explain that family experience is an important factor in accepting Families will not be affected by social stigma if they have the ability to care for sufferers because they feel they are not dependent on other people. especially if the family can easily access health services in their surroundings and receive treatment support from a psychiatrist (Cenat, 2020; Lidia *et al.*, 2022). Psychological and behavioral support for families can accelerate family acceptance (Chiles, Stefanovics, & Rosenheck 2017). Family acceptance has a positive effect on the recovery time of patients, which results in faster recovery (Darni, Yusuf, & Tristiana 2020).

## CONCLUSION

Based on the description of the results and discussion above, it can be concluded that family acceptance is influenced by social support, stigma, stress level, caring experience, knowledge, beliefs, and ease of access to health services. Social support greatly influences acceptance, so families need to be facilitated by being encouraged not to hesitate to seek social assistance and maintain social networks that have been built. Mental health education campaigns by health workers need to be done to reduce community stigma. These two factors can affect the experience, stress levels, and family beliefs in caring for sufferers. Health workers also need to provide information to increase the family's knowledge and quality of life as a provision in caring for sufferers. In addition, health workers also need to provide access to quality health services for families.

## Conflict of Interest

The authors state that no potential conflict arises in this study.

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