

Lived Experiences of Families With a Schizophrenic Member: A Phenomenological Study

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Abstract. Limited existing studies in Pagadian City explored the experiences of families with schizophrenic members, which led to a lack of knowledge about schizophrenia and mental disorders in general. Thus, this phenomenological study aimed to explore the lived experiences of five family members with schizophrenic members in Pagadian City, Zamboanga del Sur, to fill the gap in people's knowledge about how families go through their lives with schizophrenic members. The study focused on the behaviors the participants observed in their loved ones before the diagnosis, their emotions upon knowing the diagnosis, their concerns and challenges, and their coping strategies. Information was gathered by interviewing the participants. Using Moustakas' transcendental phenomenological analysis, the researchers were able to determine that the families noticed the reserved personalities, shifting personalities, staring into blank space, delusional thoughts, and being temperamental of their schizophrenic members before they were diagnosed. They felt fear and anxiety, immense sorrow, pity, sympathy, and hope as they knew about the diagnosis. The study highlighted concerns such as uncertainty about the future, the propensity to harm themselves and others, and the tendency to leave home. Furthermore, financial hardships, communication difficulties, and deprioritization of other family members became challenges for them. The families coped by praying, supporting one another, and having more patience. The implications of this study included understanding the families' concerns and coping strategies, helping schizophrenic members understand interventions, and assisting educators and therapists in tailoring their approaches. Additionally, the findings of this study can contribute to the knowledge of the schizophrenia field and potentially influence practice and policy.

Keywords: Lived experience; Schizophrenia; Schizophrenic family member; Phenomenology.

1.0 Introduction

Schizophrenia is a severe brain disorder that causes people to perceive reality incorrectly. Schizophrenia is characterized by delusions, hallucinations, abnormal physical behavior, and disorganized thought and speech (Substance Abuse and Mental Health Services Administration, 2023). Following the psychiatric revolution and deinstitutionalization policies, mental health care shifted from hospitals to families, causing challenges for family caregivers who had to take full responsibility for patients (Tamizi et al., 2020). Adjusting to a new family life ecology and dealing with social dishonor is marked by strength, sacrifice, and the search for meaning in an uncertain environment. According to Wan and Wong (2019), caring for a family member with schizophrenia leads to increased stress and psychosocial burden. A family member with schizophrenia may lead to high financial, emotional, as well as physical stress among their families (Ranjan et al., 2022). Family members experienced stigma and negative consequences (Young et al., 2019).

Approximately 24 million people, or 1 in 300 people (0.32%), worldwide have schizophrenia. Adults (2) make up 1 in 222 of these rates, or 0.45% (World Health Organization, 2022). The National Alliance on Mental Health estimated the prevalence of schizophrenia among adults in the United States and was estimated at 1.5 million people per year (Team et al., 2024). According to a global trends report released in 2020, China has the highest age-adjusted schizophrenia rates, followed by the Netherlands and Australia. These findings are consistent with a 2018 systematic review, which found that schizophrenia was most common in East, South, and Southeast Asia, Western Europe, and high-income North America (Gillette, 2023). The Department of Health report shows that 1 million Filipinos (1% of the population) are affected by this disorder each year (Maravilla & Tan, 2021).

For more than 60 years, psychiatric services have gradually transitioned from an asylum to a community model. This change has resulted in the emergence of a deinstitutionalization movement (Salime et al., 2022). As a result, most patients now live in the community with their families rather than in mental health facilities (Di Lorenzo et al., 2021a). An unpaid family member, friend, or neighbor who provides care to a person with an acute or chronic condition and requires assistance with various tasks, such as dressing, bathing, and medication administration, as well as tube feeding and ventilator care, is referred to as an informal caregiver or family caregiver (Jegermalm & Torgé, 2021).

Chen et al. (2019) stated that family caregivers play crucial roles in taking care of people experiencing schizophrenia in the community since the caregiving process is complex, with both negative and positive emotional reactions, societal barriers like stigma and isolation, and unmet needs (Cleary et al., 2020). Previous studies have shown that people with schizophrenia are negatively affected when they live in a family environment with high levels of criticism, whereas living in an environment with encouragement and praise from family members can improve the life satisfaction of schizophrenia patients. Furthermore, family dynamics refers to how family members are linked, so family members' attitudes and attributions toward people with diseases influence the occurrence and progression of mental illness (Wang et al., 2019).

According to Sharifi et al. (2023), the experiences of the parent caregivers can be divided into two main categories: The "burden of care" and "negative attitude and inefficient performance." The former encompasses three subcategories: disrupted social and family interaction, helplessness, and poor support quality. At the same time, the latter incorporates two: negative attitude and poor performance by those responsible for caring for such a person and negative attitude towards patients from caregivers. Due to their old age and medical needs, older parents should carry an extra burden of care. Among the top priorities for improving the situation of caregivers and patients with schizophrenia were the government's increased efforts to provide patients and caregivers with multifaceted support, the development of an integrated team of specialists, and acceptance and improvement of public attitudes against stigma and explicit discrimination in society (Sharifi et al., 2023).

Participants described the diagnosis of schizophrenia for a relative as a heartbreaking experience. In contrast, some participants controlled the experience with a sense of relief at finally recognizing the condition and gaining access to care. Before learning the diagnosis, the caregivers' experiences and representations significantly impacted how the "news" was digested. The sharing of the diagnosis served as a starting point for the participant's acceptance of the illness's reality. Participants reported various unmet needs related to the diagnosis, including individualized support, detailed explanations of the disease, and direction on their caregiver role (Forcheron et al., 2022).

Families who care for schizophrenic patients go through loss and cope with social stigma and isolation, which can make them feel ashamed or guilty and hurt their physical and mental health. Although most of the effects of caring for a patient with schizophrenia are unpleasant, some family caregivers have recently begun to recognize more advantageous and positive features of this position (Darban et al., 2021). In addition, a study by Glecia and Li (2023) presented that parents reported mixed emotions, providing insight into the severe psychological distress they experienced after their child was diagnosed with schizophrenia. The period immediately following diagnosis can be especially stressful. On the contrary, parents experienced acceptance of their new caring role, which was supported by their love and responsibility for their child with schizophrenia.

Despite the primary role that family serves in the lives of people with serious mental illness, it is an understudied source of support (Chronister et al., 2021). According to some studies, it showed that family caregivers of individuals with schizophrenia complain of a heavier burden than those who care for an individual with a chronic medical illness (Di Lorenzo et al., 2021b). While barriers differ depending on their location, both Filipinos in the Philippines and overseas are hindered by self-stigma, social stigma attached to mental illness, and cultural values that prioritize conformity and discourage seeking help. Filipinos living in the Philippines face financial constraints and limited access to services, while those overseas experience difficulties due to immigration status, lack of health insurance, language barriers, discrimination, and lack of acculturation. Filipinos tend to use formal help only as a last resort or when problems become severe (Martínez et al., 2020). According to the World Health Organization (2020), there is limited data on Filipinos' mental health help-seeking behavior. Due to the comfort, camaraderie, trust, maturity level, and validation of their informal sources of support, adolescents favored them above official ones. It was discovered, specifically, that when Filipino youth seek mental health assistance, they do so through friends, peers, family, and online support groups (Villamor & Dy, 2022).

In Pagadian City, there have been no existing studies exploring the experiences of families with a schizophrenic member. Therefore, there is a lack of knowledge about schizophrenia and mental disorders in general. Thus, this study aimed to explore the lived experiences of families with a schizophrenic member to fill the gap in people's knowledge about how families go through their lives with a schizophrenic member. Furthermore, this study was supported by the Family Systems Theory of Murray Bowen (1966). The Family Systems Theory provided an understanding of what happens with relationships and family dynamics when a family is disabled due to the challenge of caring for a member diagnosed with schizophrenia. From the Family Systems perspective, all family members are viewed as an emotional system deeply built with interconnected and interdependent behaviors. When one of the members is diagnosed with schizophrenia, the roles, styles of communication, relations, and emotional climates may change dramatically (Minuchin, 1974).

Thus, this study was conducted in the 2nd semester of the academic year 2023-2024 to answer the question, "What are the lived experiences of families with a schizophrenic member?". In addition, it also answered the following questions: "What are the behaviors the participants observed in their loved ones before they were diagnosed with schizophrenia?" "What are the emotions of the participants upon knowing that their family member had been diagnosed with schizophrenia?" "What are the concerns the participants experienced about their schizophrenic members?" "What are the challenges that participants have faced after the diagnosis of schizophrenia in their family members?" and "How did the participants cope with the challenges of living with a schizophrenic member?"

2.0 Methodology

2.1 Research Design

This study used a qualitative research design, with a phenomenological methodology in particular. The researchers chose to use a qualitative research approach and conducted a factual study to explore the subjective experiences of families with schizophrenic members. The purpose of this study was best addressed through phenomenological research, which mainly focused on the transcendental phenomenological approach. As Moustakas (1994) highlighted, the transcendental phenomenological approach calls for one to put aside judgments, prejudices, and preconceptions to see the phenomenon through "fresh eyes." It allowed researchers to explore how family members lived and constructed their views, which disclosed the emotional and relational forces at play. In so doing, the research looked at these families' admittedly complex everyday worlds and how they managed things within their family setup.

Furthermore, an aspect of this method was that prior assumptions were put between brackets to involve the participants in a more sincere discussion by allowing for trust and openness. This phenomenological approach demonstrated numerous enlightening points of understanding about the experiences of these families and culminated in better-targeted support and resource development.

2.2 Research Locale

This study was conducted in Pagadian City, Zamboanga del Sur. According to the Philippine Statistics Authority (n.d.), Pagadian City, located in the Zamboanga Peninsula of the Philippines, had a population of 210,452 as of

2020. The city is characterized by its hilly terrain and tropical climate, which can influence agricultural practices and resource access. In addition, the city's economy is primarily driven by agriculture, trade, and small-scale industries. Moreover, many households engaged in farming, fishing, and various forms of local commerce, reflecting a rural lifestyle intertwined with urban elements. These environmental conditions may impact the community's mental health, as socioeconomic stressors can exacerbate mental health issues.

Furthermore, the research locale has limited access to formal mental health services for families supporting schizophrenic individuals. Due to this shortage of professional resources, a closer look is necessary at the peculiarities and adaptive strategies at the level of these families in their cultural environment. Based on the social landscape of Pagadian City, which incorporates aspects such as strong family relations, religious sentiments, and quasi-social stigma surrounding mental illness, is likely to contribute to the role in shaping the experiences as well as the coping mechanisms among families struggling with schizophrenia.

2.3 Research Participants

In this study, the researchers utilized snowball sampling to identify participants within a specific community dealing with a sensitive topic like schizophrenia. The method relied on referrals from initial participants, which helped reach individuals who may have difficulty identifying through other sampling methods. Given the stigma surrounding mental illness, this sampling allowed for a more organic and trustworthy recruitment process, encouraging individuals to share their experiences in a supportive environment.

Five participants from Pagadian City were involved in the study, each having a family member diagnosed with schizophrenia for at least one year. The first participant was a mother of two children. The second participant is a grandmother of a schizophrenic patient. The third participant was the eldest brother of a schizophrenic member. He is married with five children. The fourth participant is also a sibling of a schizophrenic member. She is the younger sister to her brother, who was diagnosed with schizophrenia. Lastly, the fifth participant is the eldest sister of a schizophrenic patient. She is married and has five children. All participants were given the choice of whether to participate in the study, and a time and place were agreed upon for their interviews.

2.4 Data Gathering Procedure

The data gathering was based on the standards of qualitative research. Initially, the researchers made a formal letter asking for permission from the families involved in the study, which was signed by the researchers and noted by the research adviser and the Dean of the College of Teacher Education, Arts, and Sciences (CTEAS). Upon approval, the researchers went to the respective houses of the participants according to their agreed date and time. Informed consent and permission letters were also obtained before the interviews. Each of the interviews conducted had a minimum of 30 minutes and a maximum of 1 hour and 30 minutes. The participants were assured of the secrecy of their personal information, which would not be disclosed at any point in the study.

In the research process, the researchers identified a phenomenon to study, bracketed out one's experiences, and collected data from several individuals who experienced the phenomenon. The researchers started with transcription of the interviews and horizontalization (Moustakas, 1994). The common or shared experiences of the family members were identified so that the researchers would understand how the participants were experiencing the phenomenon. Next, the researchers developed a cluster of meanings and themes from these significant statements. Open codes were temporarily assigned. Afterward, similar codes were grouped and assigned to a logical category. The categories were further analyzed to determine overarching themes that provided insight into the experiences of families with schizophrenic members. Finally, the panel members of this study reviewed the themes created by the researchers to ensure their validity and relevance to the participants' lived experiences.

2.5 Ethical Considerations

Ethical considerations were critical in research due to the need to secure and protect study participants. At all times, the researchers ensured that participants were safe from harm and protected from unnecessary stress. The obtained informed consent ensured by the researchers that all potential risks—physical, social, and psychological harm—were disclosed to participants before the study and kept to an absolute minimum. Moreover, written consent was given to the participants who chose to participate in the study. When gathering data, privacy was

maintained by only asking questions required for the study. The interviews were conducted in private settings where the research participants felt at ease.

3.0 Results and Discussions

The participants consisted of siblings, a mother, and a grandmother of a schizophrenic member from the City of Pagadian. They have years of experience taking care of their family member who has schizophrenia. The participants' years of experience in taking care of their loved ones helped the researchers capture the genuine and authentic experiences of families living with schizophrenic members. Each participant was designated with a code of P1, P2, P3, P4, and P5 to maintain the confidentiality of their profiles.

3.1 Behaviors of the Schizophrenic Member Observed Before the Diagnosis

The data gathered by the researchers during the interview revealed the different observations of the family before the diagnosis of their loved ones. Upon reading and rereading the transcripts of the interview, four themes were revealed regarding the behaviors the participants observed in their loved ones before they were diagnosed with schizophrenia. These themes were Having Reserved Personalities, Shifting Personalities, Staring into Blank Space, Having Delusional Thoughts, and Being Temperamental.

Having Reserved Personalities

During the interview, most of the participants shared a common response in which their loved ones, before being diagnosed with schizophrenia, were observed as being reserved. This raises the question of whether these subtle changes could be early signs of the condition. With this category, the respondents narrated:

"As I have observed, she was very quiet in elementary when she was still little. Unlike other kids who were talkative, she was just quiet. If you will not call her first, she will not answer." – P2

"What we observed when he was still a child is that he is shy, and he did not want to approach others." – P5

According to Peters (2020), social withdrawal is a common observation made by family members who have schizophrenia. It is also a predictor of psychosis in the future in children who are more susceptible to the illness. The social withdrawal could be a subtle manifestation of the underlying psychotic process beginning to develop.

Furthermore, Camisa and her colleagues (2005) suggested that the symptoms of schizophrenia were frequently associated with decreased extraversion aside from the increasing rate of neuroticism. This result was consistent with the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) (2024) description of the symptoms of individuals with schizophrenia. Accordingly, individuals with schizophrenia often exhibit reservedness characterized by a significant withdrawal from social interactions and a diminished desire to engage with others.

Shifting of Personalities

Families of individuals with schizophrenia often grapple with a heartbreaking paradox: living with someone you have known for a long time. However, it seems like they are already a completely different person. The illness can cause dramatic personality shifts, leaving loved ones struggling to connect with a seemingly "different" person.

"Yes, she was diligent. I did not expect it. At fourteen, she seems different; she is not who she was. She became aggressive." – P1

"It is like he is different from others. Because he easily gets angry and insults others. And then he stares. It seems different. His eyes look aggressive." – P3

"I witnessed even before when his brain was still not damaged; he was very caring and generous. Then, when his brain was damaged, his personality changed. Very aggressive. Him being good, he turned aggressive." – P5

Personality changes are a fundamental feature of psychotic disorders; it is most typical of schizophrenia and has been used to differentiate schizophrenia from other severe mental illnesses (Conneely et al., 2020). Furthermore, some studies have found that untreated psychotic symptoms, especially delusions and hallucinations, tend to be

a source of aggression in people with schizophrenia. Coid et al. (2021) recorded persecutory delusions as strong risk factor for violent crime properties. Similarly, Volavka (2014) also stated that the high rates of violent behavior in schizophrenia were largely associated with acute psychoses situations during which delusional thoughts are intertwined with paranoid feelings.

Staring Into Blank Space

When witnessing a schizophrenia patient, one noticeable sign is their tendency to appear to be staring into space. This empty glance, separated from the immediate surroundings, can be a subtle yet deep indicator of the complicated inner workings of their mind.

"At times when she is thinking deeply, I do not even have any idea about what it could be, but she seems to be looking at a distance." – P1

"His actions are unusual and difficult to comprehend. At times, he always appeared to be looking far away." – P4

Blank stares or blank facial expressions are said to be caused by psychotic diseases such as schizophrenia and associated disorders (StÖppler, 2022). According to WebMD (2024), people with schizophrenia struggle to organize their thoughts. They may not be able to follow along when you speak to them. Instead, it may appear they are staring into space or being distracted. When they speak, their words can become jumbled and difficult to understand. Additionally, there were also individuals diagnosed with schizophrenia who may have experienced catatonia. During this situation, individuals will have prolonged periods of immobility or repetitive, purposeless movements often accompanied by vacant stares (Tandon et al., 2008).

Having Delusional Thoughts

For families of individuals with schizophrenia, dealing with their loved one's delusional thoughts can be emotionally draining. They may feel helpless and confused about how to respond, torn between confronting the delusions and trying to redirect the conversation. There is also a sense of grief for the person they once knew. With this category, the respondents narrated the following:

"Sometimes, when parents fall asleep, she might go out. She already went to the road and waited for a car because she said there is someone who wants to get her, she will ride in the truck." – P2

"I felt so scared when there was a moment that.. what was it? He tried to kiss me because he assumed I was his wife. That was my fear, and I ran fast to our neighbor. If it was you- I was really scared that time and ran to our neighbor." – P4

These statements showed how delusional thoughts affect schizophrenic patients' actions and goals. They reveal a mix of imagination and reality, where desires and ambitions can be unclear. Whether it is sneaking out at night because of fear, wanting to leave while feeling restless, or dreaming big but struggling to act, these experiences highlight how confusing delusions can be. Delusions are a hallmark of schizophrenia, deeply influencing patients' perception of reality (Hany et al., 2024). These delusions, often fixed and resistant to logic or contradictory evidence, can range from paranoid thoughts to grandiose or somatic beliefs, profoundly shaping the individual's behavior and cognitive processes.

Being Temperamental

One of the most challenging aspects of schizophrenia is its unpredictable and often tempestuous nature, which can manifest in various ways, from erratic behavior to volatile mood swings. These temperamental fluctuations not only present significant challenges for individuals with schizophrenia but also for their families, who must maintain a delicate balance of support, understanding, and coping with the illness's unpredictable nature. The respondents had common similarities when it came to this category. The responses were as follows:

"There are instances that she suddenly gets irritated." – P1

"Yes, she does get silent and has a sudden reaction to become irritated, throwing tantrums that are evident in her expression." – P2

"He would get upset and even tries to insult us to make it seem that he is against us." – P5

A study conducted by Dib et al. (2021) stated that patients with schizophrenia exhibited considerably higher mean depressive, cyclothymic, irritable, and anxious temperament ratings than healthy controls. These responses were agreed by Dib et al. (2021), who conducted a study about patients with schizophrenia. Accordingly, these patients exhibited considerably higher mean depressive, cyclothymic, irritable, and anxious temperament ratings compared to individuals not diagnosed with the said illness.

3.2 The Emotions of the Participants When They Learned that Their Family Member Has Schizophrenia

Family members experienced various emotions upon knowing that their loved ones were schizophrenic. The emotions they felt were similar to those of other participants. The themes acquired from their responses were the following: Fear and Anxiety, Immense Sorrow, Pity and Sympathy, and Hopeful.

Fear and Anxiety

The family members had similar feelings of fearfulness and anxiety upon hearing the news about the condition of their loved ones. The participants were anxious because they saw that their loved ones were different from the others. The family members were anxious as their loved ones tended to isolate themselves and did not want to interact with others. Additionally, the thought of schizophrenic members being left with no one in the future made them worried. The respondents said:

"I am worried because she is different and then what will she do if she is left all alone." – P1

"I felt so scared when there was a moment that.. what was it? He tried to kiss me because he assumed I was his wife. That was my fear, and I ran fast to our neighbor. If it was you- I was really scared that time and ran to our neighbor." – P4

The development of a schizophrenic disorder, as well as acute episodes in the later course of the disease, caused significant emotional suffering to the family members who also act as caregivers to their schizophrenic members. It was emphasized that the families of schizophrenic individuals experienced burden on a practical, financial, and emotional level, and the level of burden is positively associated with the frequency of symptomatic behavior of the said individual (Lowyck et al., 2020).

Sadness

It was inevitable to feel so much sadness when hearing sad news about a family member. While doing the interview, it revealed that some of the participants could not stop themselves from crying because it made them reminisce about the moments when they heard about the diagnosis of their loved ones. While doing the interview, it revealed that the family never experienced true happiness because they had to deal with so many obstacles in their lives ever since.

"I was sad, of course, because it is my grandchild, right? I was really sad as to why this child turned like that... Those times when she cannot take medicine, I can feel very sad." – P2

"I shed tears at that time because when Dad returned from the doctor, he told us about Nuning's situation. I shed tears because he was so close to me... However, it is so painful to think about. This disorder is intentional by him; this disorder is intentional." – P3

"We do not have happiness. We are very sad at this time. It seems we are very down, and my father is always absent-minded while driving... When I, in those happenings, crying- I was crying, I will cry." – P5

Family caregivers living with schizophrenic members face tremendous stress and a high level of burden. These major responsibilities include physical discomfort, changed regular habits, tension, aggression, immense sorrow, enormous stigma, role changes, social withdrawal, and financial/career difficulties, typically with a lack of resources and support (Chen et al., 2019).

Pity and Sympathy

During the interview, it revealed a feeling of pity towards their family member with schizophrenia. The participants felt a deep collective sympathy as they saw their loved ones battling schizophrenia daily. Their emotions were deeply impacted as they knew the diagnosis and the sight of their family member's suffering elicited a painful feeling. The researchers gathered the following responses:

"Well, in my case before, I feel sorry for my younger brother... I am looking at him, and he is pitiful because he is inside there. He cannot go outside, I feel sorry because he has been in the cage for several years." – P3

"What we feel for our younger brother is pity, pity." – P5

Witnessing their loved ones suffering in pain and being locked up inevitably elicited sentiments of pity. This theme emphasizes the realization that their family member will not get better and will always be caged and hindered from exploring life. The weight of this emotion was evident to the family members as they carried the reality about the condition of their loved ones with schizophrenia.

Hopeful

The participants expressed a shared belief in God following the diagnosis, finding solace in prayer, and seeking spiritual guidance to support their family members during their illness. They hope their loved ones regain a sense of normalcy, as they perceive them as abnormal.

"I asked God for help." – P2

"Before, I just prayed to the Lord, hoping that he would help Nuning so that he would return to being a normal individual. I prayed I prayed that the Lord would help him to think that in his heart and mind, nothing is impossible to God with his plans for the person." – P3

In the lives of those families with family members who have mental disorders, faith can have a significant impact. Praying to a Supreme Being played a significant role in processing the emotions of families dealing with schizophrenic members as it gave a glimmer of hope in alleviating the condition of the affected family member.

3.3 Concerns The Participants Had About Their Schizophrenic Family Member

It is unavoidable for participants to have worries and concerns about their loved ones who have a mental disorder, especially schizophrenia, which causes hallucinations, delusions, and disorganized behavior and thinking. Upon bracketing the data gathered, the researchers developed three themes: Uncertainty of the Future, Propensity to Harm Self and Others, and Tendency to Leave Home.

Uncertainty of the Future

The ambiguity of the future life of individuals who have schizophrenia and their ability to live in a society in the absence of family members had caused many concerns among the participants.

"What if.. we do not know the future.. for instance, we will no longer be around because we are already old." – P1

"...his security in his life, it is unclear. I am concerned about him that his- his result in life." – P3

"I am worried about him because of what might happen to him. I am worried about his future because he is a bachelor, and if he is already old, he has no child. He has no family. If his parents die, who will look after him? We have our own family, so I worry about his future. What will happen if he is all alone." – P4

During the interview, the participants shared common responses, such as uncertainty about what may come in the future for them and their loved ones. A participant who is the mother of a schizophrenic patient highlighted the thought of what will be the future of her daughter if the time comes when she will not be around anymore. Other participants were also worried about their siblings since they needed to prioritize building their own family.

Propensity to Harm Self and Others

People with schizophrenia act aggressively and have the possibility to cause harm to others and themselves. When left alone, people with this illness can see opportunities where they could hurt themselves.

"She even took an action of... that necklace she keeps wearing. I noticed she was like that (choked herself using the necklace). It was a good thing I noticed. She tied it tightly on her neck." – P1

"He wanted to commit suicide. Then, when he gripped the electricity, he thought that he did not have anything in his life and that he did not have any chance. Commit suicide. I said do not be like that because it is a sin when you take your own life, committing suicide." – P3

"I was apprehensive that he would hurt other people because it was what he felt that he tended to harm. He burns his back with a candle." – P4

It has been observed that individuals with schizophrenia may try self-harm as a result of command hallucinations, catatonic excitement, or because of associated depression (Bhat et al., 2011). They also have a higher suicide risk than the general population (Jakhar et al., 2017). Although command hallucinations were not an independent risk factor, they did raise the risk in people who were already inclined to commit suicide (Pompili et al., 2007). These actions of their loved ones continue to worry the participants because there are times when they are at a loss for what to do, and their responsibilities as parents and siblings are constricted because they have to give full attention to their loved ones to avoid bad situations.

Tendency to Leave Home

The participants observed instances when their loved ones left their homes several times without asking for permission. This was reflected in their responses:

"...that was the time when she suddenly walked away. She suddenly walks away bringing a bag." – P1

"I worry. Sometimes, when their parents fall asleep, she may come outside. She had already gone to the road and waited for a car because she had said that someone would get her, and she would get in the truck. It was a good thing they noticed (her parents); the father went to the kitchen and went outside when he saw his daughter on the road... She goes out in the evening, so I was really scared. I can say to God, look after her." – P2

"He is different when he is triggered. He will go anywhere. We have a hard time looking for him." – P4

Hallucinations were considered as one of the symptoms of schizophrenia. They were hearing voices instructing them to stray around. Any sense may trigger a hallucination, but hearing voices is the most common. When speech is disorganized, it develops disorganized thinking (Mayo Clinic, 2024). The participants continue to worry about the security and well-being of their loved ones because, if left unchecked, their frequent attempts to run away could result in serious circumstances.

3.4 Challenges Faced By The Participants Following Their Loved Ones' Diagnosis of Schizophrenia

It was not an easy journey for families with a schizophrenic member to navigate life. After the diagnosis of schizophrenia, their life path took an abrupt turn. This posed challenges for the person with the diagnosis and the people surrounding them, especially the family. These families faced many challenges as they dealt with complex emotions and adaptations. To support the individual who has been diagnosed with schizophrenia, family members must make their way through a new environment. The challenges they faced were numerous, and the researchers developed three themes: Financial hardships, communication difficulties, and deprioritization of other family members.

Financial Hardships

One of the challenges common to the participants shared was a lack of financial resources when caring for a schizophrenic member, as it can affect the well-being of their loved ones. Unavailability of funds could delay medication since it prevented them from acquiring the patient's prescribed medicines. Hence, it could affect the condition of the person with schizophrenia and could worsen the symptoms.

"There is a difficulty because he will also maintain a medicine, and then where do we find that? We also help them and provide support. It has a very big impact, especially in terms of finances. It was hard to seek money. It is really hard. You have to take his medicine first because it is important. If he is not able to drink it, he will be... triggered." – P4

"I look at the difficulty because there is nothing to buy medicine, nothing to go back to the hospital just to make him normal. That is what I feel of difficulty that I cannot help any because at that time, my job there at the barangay, the salary is very low." – P5

Living and caring for an individual with schizophrenia was a burden to the families, particularly if they were struggling financially. Struggling with the financial aspects of purchasing the medicine was quite challenging. In dealing with schizophrenia, financial capacity was critical as it played a big role in the treatment of the illness. The participants disclosed that, due to their limited financial resources, they faced difficulties in continuing their loved ones' medication after receiving the diagnosis.

Communication Difficulties

Schizophrenia often leads to cognitive impairments, which could affect a person's ability to process information, maintain a conversation, or express their thoughts clearly.

"At times when she cannot drink medicine, her symptoms would come out. She would just lie in her room. When you call her, she will not respond. Will not communicate with us. I am also sad because she does not respond when being called." – P2

"...when he is triggered, he will scream and scream." – P4

"He will not be able to talk to, then sometimes he is asked to talk, he will suddenly get angry." – P5

The participants disclosed that they are having difficulties talking with their loved ones because they will not receive any response or the patient will respond aggressively. Difficulty in communication can create barriers to expressing themselves effectively. Furthermore, the emotional expression difficulties and social withdrawal tendencies of those with schizophrenia can further complicate interactions.

Deprioritization of Other Family Members

Family members of a schizophrenic patient who has their own family frequently experience disruptions in their responsibilities to their own family because the schizophrenic patient requires constant care and attention. It is challenging for them to continually look after their loved ones with schizophrenia since they also have to look after the well-being of their own family.

"It is there that you cannot take care of your own family, to my children... because he is there... we will take care of him because he is pitiful if we neglect him... because he will be the priority. Just like when he was imprisoned, we give... food and water because he is pitiful if we neglect him. Our eyes are always on him." – P4

The participant revealed frustrations as they have to give more attention to the diagnosed family member than their own family. Supporting a family member who has schizophrenia entails assisting them in receiving necessary medical and psychological care. However, it also entails looking after oneself equally (WebMD, 2022). The familial dynamics surrounding the care of a schizophrenic patient often necessitate a shift in focus that can lead to the deprioritization of one's own immediate family. The constant care and attention required by the patient often overshadow the needs of the caregiver's family, leading to feelings of frustration and imbalance.

3.5 Participants' Coping Strategies For Living With Schizophrenic Family Member

Living with a schizophrenic member presents a unique set of challenges to their families that can significantly affect their well-being and their daily lives. Coping with these challenges requires resilience, understanding, and often a profound adjustment in one's perceptions and expectations. The participants' responses created three themes: Praying, Supporting One Another, and Having More Patience.

Praying

The importance of faith and spirituality emerged as a prominent theme throughout the statements. The families repeatedly turn to prayer, seek support from religious figures such as pastors and nuns, and rely on their belief in a higher power to navigate through difficult circumstances. They found solace and strength in their relationship with God, trusting in His guidance and finding comfort in the power of prayer.

"All I do is to pray to God that he will help me get through the challenges I am facing." – P2

"There is no one else. Only God can help us. We ask for his guidance so that he would give us an open heart and open mind and that he would answer when we call his name." – P3

"For me, so I will not get stressed easily, I chose to strengthen my stewardship to God. Because if you stray away from God, you will easily get exhausted due to the stresses of life." – P4

"Our faith in God had helped us overcome our challenges, and we managed to get through our problems." – P5

Spiritual coping (SC) can assist families that serve as caregivers to better deal with stress and emergencies by mobilizing beliefs and practices. The literature demonstrated a growing body of research that confirmed the relationship between SC and improved health outcomes among caregivers. Research also indicated that families or caregivers who do not employ spiritual coping mechanisms have an increased risk of depression and anxiety (Rohmi et al., 2023).

Supporting One Another

Supporting One Another. Another recurring theme was the significance of family support and unity in facing challenges. Despite the hardships the families encounter, there was a strong emphasis on coming together as a family and offering each other emotional, moral, and sometimes financial support. The families communicated openly, shared responsibilities, and worked together to overcome obstacles, demonstrating resilience and the power of open communication in strengthening family bonds.

"We would help each other in supporting him. When he takes his medication, I always check on him to see whether he has been taking his medicines. In dealing with his issues, I always remind him to maintain his medication. Maintaining his medication will help his illness not reoccur." – P2

"Of his needs? We would have a budget, a budget of the money, of our expenses to accommodate all his needs... If he needs anything, I will give it to him. I am the one who will lend him his medicines. I am also the one who is assigned to give him his food and water while he is imprisoned in his compartment... My spouse and one of his siblings take turns in watching and taking care of him." – P3

"We help each other as a family so that no one would be pressured to take all the responsibilities. We would also converse with him from time to time." – P4

"We would collaborate through communication with my parents. We would still give our support even though we have a sibling who is like that, and we are still here, as well as their grandchildren, because if we do not support them, they will become weaker, knowing they are getting old. We will still support him, especially me, because I am his sibling. I am still going through a problem because it is something other people do not understand. All I did was make sure I could support myself financially, morally, and spiritually and pray for my family. So that we can overcome all our trials." – P5

Family members have an important role in providing care and support to relatives suffering from mental illnesses. This is especially true in Asian countries, where cultural norms lay the responsibility for providing care to the ill person's next of kin. Sociocultural expectations view the caregiving function as typically being discharged by parents, children, or the spouse and as a family obligation with morally binding undertones (Stanley et al., 2016). The study of Darban et al. (2021) also highlighted that when one family member is diagnosed with schizophrenia, the other family members actively engage in caring for the family member to alleviate the burden of the situation. This collective effort promoted a sense of shared responsibility and led to stronger family ties that reinforced the bonds among family members as they navigated the challenges together.

Having More Patience. Coping mechanisms and resilience were evident themes as families discussed strategies for managing stress, handling difficult emotions, and navigating tough times. The participants stated that having perseverance, patience, and determination were important to overcome obstacles, even when faced with overwhelming challenges. Through prayer, communication, and seeking professional help, they demonstrate a commitment to maintaining mental and emotional well-being amidst adversity.

"A long patience because if you do not have patience, you will get bruised because you will get back at him and when you get hurt, always doing play fight so if she gets hurt, you will get hurt too... That is why I do my best so I can handle it." – P2

"Lengthen your patience because if you do not have any patience, you will not understand. You need to understand him. You need to be understanding because if you do not have enough patience and understanding, you are going to lose attention for him because it will come to a time that you will have enough because of his attitude." – P3

One positive outcome that also became a coping mechanism for families with family members with schizophrenia is the cultivation of patience (Darban et al., 2021). In these families, caring for the individual with the illness fosters a deeper sense of patience that evolves over time. This growth in patience can enhance family dynamics and improve the overall supportive atmosphere within the household. Coping and resilience are one of the important aspects to be applied when caring for a schizophrenic member. The participants have reported having long patience and understanding of their family member with schizophrenia so that it would help them to endure the caregiving situation. Resilience and social support also mediate between the caregiving burden and positive aspects of caregiving (Wang et al., 2019).

4.0 Conclusion

The data gathered from this study revealed the different and authentic stories of lived experiences of families with schizophrenic members. The results highlighted the various experiences before the diagnosis and after the diagnosis of their loved ones. The participants experienced different emotions and challenges as they dealt with the mental disorders of their loved ones. In addition, the challenges unveiled the participants' hardships and their effects on their loved one's well-being. Furthermore, despite everything that happened to their family since the diagnosis, they were still hopeful to see their loved ones turning back to normal, and their faith in God became even stronger as time went by. They have been coping by thinking positively and putting trust in the Lord.

In the responses of the families and the related literature, it was implied that families are affected by the mental illness that their family members are experiencing. These were connected to Murray Bowen's Family Systems Theory, which suggested that families function as emotional units where individual behavior is intertwined with family dynamics. The theory also emphasized role flexibility and adaptation, as families with schizophrenic members experienced significant changes in roles as they navigated the illness. Emotional reactivity and fusion were also crucial aspects of the theory, as family members became emotionally entangled, making it difficult to maintain autonomy and boundaries. Upon examining these emotional dynamics, the study uncovered the emotional toll of schizophrenia on family members and identified coping strategies for fostering healthier emotional boundaries and coping mechanisms.

This study aimed to understand the struggles and fears faced by families caring for a member with schizophrenia and how society perceives these families. The implications of this study included understanding the families' concerns and coping strategies, helping patients understand interventions, and assisting educators and therapists in tailoring their approaches. Additionally, to equip mental health professionals with better interventions, advocate for better resources and support services for families with schizophrenic patients, and reduce stigma by raising public awareness.

Furthermore, the result of this study emphasized the substantial demands of caregiving of families and pointed out that it likely takes a toll on family members providing care to their loved ones with schizophrenia. Families also may benefit from additional support, such as in mental health, as this study has revealed that they are a population at risk for burnout if provided with inappropriate or no support at all. Therefore, mental health interventions should target both the needs of individuals with schizophrenia and the well-being of the family

caregivers in order to deliver effective care. Lastly, this study's findings can contribute to the knowledge of the schizophrenia field and potentially influence practice and policy. They can also benefit advocacy organizations and support groups, reducing stigma and building a more welcoming social response to mental health.

5.0 Contributions of Authors

The authors confirm their contributions to the paper: Alfanta, JV and Rodrigo, JD—study conception, data collection, analysis and interpretation of the result, and draft manuscript writing and preparation. Guinea, JMR— manuscript editing, writing, and supervising.

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7.0 Conflict of Interests

The authors declare no conflict of interest with the publication of this paper.

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9.0 References

- Bhat, P., Pardal, P., & Diwakar, M. (2011). Self-harm by severe glossal injury in schizophrenia. *Industrial Psychiatry Journal*, 20(2), 134. <https://doi.org/10.4103/0972-6748.102524>
- Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, 7(5), 345–374. [https://doi.org/10.1016/S0010-440X\(66\)80065-2](https://doi.org/10.1016/S0010-440X(66)80065-2)
- Camisa, K. M., Bockbrader, M. A., Lysaker, P., Rae, L. L., Brenner, C. A., & O'Donnell, B. F. (2005). Personality traits in schizophrenia and related personality disorders. *Psychiatry Research*, 133(1), 23–33. <https://doi.org/10.1016/j.psychres.2004.09.002>
- Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., Chen, C., & Lu, X. (2019). The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: A qualitative study. *BMC Psychiatry*, 19(1), 75. <https://doi.org/10.1186/s12888-019-2052-4>
- Chronister, J., Fitzgerald, S., & Chou, C. (2021). The meaning of social support for persons with serious mental illness: A family member perspective. *Rehabilitation Psychology*, 66(1), 87–101. <https://doi.org/10.1037/rep0000369>
- Cleary, M., West, S., Hunt, G. E., McLean, L., & Kornhaber, R. (2020). A Qualitative Systematic Review of Caregivers' Experiences of Caring for Family Diagnosed with Schizophrenia. *Issues in Mental Health Nursing*, 41(8), 667–683. <https://doi.org/10.1080/01612840.2019.1710012>
- Coid, J. W., et al. (2021). Psychotic disorders and violence: a systematic review of the evidence. *The Lancet Psychiatry*, 8(4), 357–371.
- Darban, F., Mehdipour-Rabari, R., Farokhzadian, J., Nouhi, E., & Sabzevari, S. (2021). Family achievements in struggling with schizophrenia: Life experiences in a qualitative content analysis study in Iran. *BMC Psychiatry*, 21(1), 7. <https://doi.org/10.1186/s12888-020-03025-w>
- Di Lorenzo, R., Gironi, A., Panzera, N., Fiore, G., Pinelli, M., Venturi, G., Magarini, F., & Ferri, P. (2021). Empathy and perceived burden in caregivers of patients with schizophrenia spectrum disorders. *BMC Health Services Research*, 21(1), 250. <https://doi.org/10.1186/s12913-021-06258-x>
- Dib, J. E., Nehme, I., Haddad, C., Azar, J., Hallit, S., & Obeid, S. (2021). Affective temperaments of Lebanese patients with schizophrenia: Comparison by gender and severity of psychosis. *BMC Research Notes*, 14(1), 430. <https://doi.org/10.1186/s13104-021-05854-8>
- Forcheron, V., Sacureau, E., Bourgeois, J., Pouchon, A., Polosan, M., Gaboreau, Y., & Dondé, C. (2022). Experience, impact and needs of informal parental caregivers around the communication of a diagnosis of schizophrenia. *International Journal of Social Psychiatry*, 69(1), 101–110. <https://doi.org/10.1177/00207640211068978>
- Gillette, H. (2023). An easy guide to the epidemiology of schizophrenia. Retrieved from <https://tinyurl.com/yc4vzbz2>
- Glecia, A., & Li, H. (2024). Mental health and wellbeing in family caregivers of patients with schizophrenia disorder: A literature review. *Current Psychology*, 43(12), 10914–10941. <https://doi.org/10.1007/s12144-023-05220-w>
- Hany, M., Rehman, B., Rizvi, A., & Chapman, J. (2024). Schizophrenia. StatPearls - NCBI Bookshelf. <https://www.ncbi.nlm.nih.gov/books/NBK539864/>
- Jakhar, K., Beniwal, R. P., Bhatia, T., & Deshpande, S. N. (2017). Self-harm and suicide attempts in Schizophrenia. *Asian Journal of Psychiatry*, 30, 102–106. <https://doi.org/10.1016/j.aip.2017.08.012>
- Jegermalm, M., & Torgé, C. J. (2021). Three caregiver profiles: who are they, what do they do, and who are their co-carers? *European Journal of Social Work*, 26(3), 466–479. <https://doi.org/10.1080/13691457.2021.2016647>
- Lowyck, B., De Hert, M., Peeters, E., Wampers, M., Gilis, P., & Peuskens, J. (2004). A study of the family burden of 150 family members of schizophrenic patients. *European Psychiatry*, 19(7), 395–401. <https://doi.org/10.1016/j.eurpsy.2004.04.006>
- Maravilla, N. M. A. T., & Tan, M. J. T. (2021). Philippine mental health act: Just an act? A call to look into the bi-directionality of mental health and economy. *Frontiers in Psychology*, 12, 706483. <https://doi.org/10.3389/fpsyg.2021.706483>
- Martinez, A., Co, M., Lau, J. Y. F., & Brown, J. (2020). Filipino help-seeking for mental health problems and associated barriers and facilitators: a systematic review. *Social Psychiatry and Psychiatric Epidemiology*, 55(11), 1397–1413. <https://doi.org/10.1007/s00127-020-01937-2>
- Minuchin, S. (1974). *Families and Family Therapy*. Cambridge, MA: Harvard University Press.
- Moustakas, C. E. (1994). *Phenomenological research methods*. Sage Publications, Inc.
- Peters, E. A. (n.d.). Motivation and social withdrawal in schizophrenia: factors related to passive social withdrawal and active social avoidance (Master's thesis). University of Connecticut
- Ranjan, L., Gupta, P., Kiran, M., & Singh, N. (2022). Family care burden and its association with psychological distress among caregivers of chronic patients with schizophrenia. *Journal of Public Health and Primary Care*, 3(3), 81. <https://doi.org/10.4103/jphpcjphpc.16.22>
- Rohmi, F., Yusuf, A., Fitriarsi, R., & Agustinus, H. (2023). What benefits might a family expect from using spiritual coping mechanisms when providing care for people with schizophrenia? Literature review. *SAGE Open Nursing*, 9, 23779608231214935. <https://doi.org/10.1177/23779608231214935>
- Salime, S., Clesse, C., Jeffredo, A., & Batt, M. (2022). Process of deinstitutionalization of aging individuals with severe and disabling mental disorders: A review. *Frontiers in Psychiatry*, 13, 813338. <https://doi.org/10.3389/fpsyg.2022.813338>
- Sharifi, M., Younesi, S. J., Foroughan, M., Safi, M. H., & Khanjani, M. S. (2023). The Challenges of Caring for an Adult Child with Schizophrenia in the Family: An Analysis of the Lived Experiences of Older Parents. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 60, 469580221148867. <https://doi.org/10.1177/00469580221148867>
- Stanley, S., & Balakrishnan, S. (2022). Family Caregiving in Schizophrenia: do stress, social support and resilience influence life satisfaction? - A quantitative study from India. *Social Work in Mental Health*, 21(1), 67–85. <https://doi.org/10.1080/15332985.2022.2070051>
- StÖppler, M. C. (2022). Blank stare (Eyes), blank stare (Face), compulsive behavior and confusion. Retrieved from <https://tinyurl.com/f9dbnuvh>
- Tamizi, Z., Fallahi-Khosknab, M., Dalvandi, A., Mohammadi-Shahboulaghi, F., Mohammadi, E., & Bakhshi, E. (2020). Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. *Journal of Education and Health Promotion*, 9(1), 12. <https://doi.org/10.4103/jehp.jehp.356.19>
- Tandon, R., Keshavan, M., & Nasrallah, H. (2008). Schizophrenia, "Just the Facts" What we know in 2008. 2. Epidemiology and etiology. *Schizophrenia Research*, 102(1–3), 1–18. <https://doi.org/10.1016/j.schres.2008.04.011>
- Team, S., Team, S., & SingleCare. (2024). Schizophrenia statistics 2024. Retrieved from <https://www.singlecare.com/blog/news/schizophrenia-statistics/>
- Villamor, A. M., & Dy, M. F. (2022). Benefits of and barriers to mental health help-seeking of selected Filipino college students. *International Journal of Arts Humanities and Social Sciences Studies*, 7(4), 78. <http://www.ijahss.com/Paper/07042022/1179451642.pdf>
- Volavka, J. (2014). Violence in schizophrenia and other psychoses: a review. *Acta Psychiatrica Scandinavica*, 129(3), 233–244.
- Wan, K., & Wong, M. M. (2019). Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. *Internal Medicine Journal*, 49(S1), 9–15. <https://doi.org/10.1111/imj.14166>

- Wang Jun-ping, Wang Xiao-yu, Wu Jun, Ye Dong-qing (2019). The pioneer of mental health: Philippe Pinel. *Chinese Journal of Disease Control & Prevention*, 23(12), 1539–1542.
<https://doi.org/10.16462/j.cnki.zhjbkz.2019.12.021>
- Young, L., Vandyk, A., Jacob, J. D., McPherson, C., & Murata, L. (2019). Being Parent Caregivers for Adult Children with Schizophrenia. *Issues in Mental Health Nursing*, 40(4), 297–303.
<https://doi.org/10.1080/01612840.2018.1524531>