Caring in the Shadows: Exploring the Lived Experiences of Indigent Primary Caregivers of Patients With Schizophrenia in Rural Philippines

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Abstract

Diagnosis within the schizophrenia spectrum places a huge burden not only on the patients but also on their caregivers, who live with them and interact with them regularly. This qualitative phenomenological study is about the lived experiences of indigent primary caregivers of patients diagnosed with schizophrenia spectrum disorders in General Luna, Quezon Province, Philippines. Ethical standards of trustworthiness and rigor were followed. The data gathering was accomplished through unstructured one-on-one interviews with seven (7) participants, who were purposively chosen using criterion sampling. Narratives were transcribed and analyzed using Smith et al.'s (2009) interpretative phenomenological analysis. The study revealed four (4) major superordinate themes: (1) Guided by Culture: Embracing the Caregiving Journey with Filipino Values; (2) Emotions Unveiled: Mapping the Emotional Trajectory of Caring; (3) Unseen Warriors: Fighting Silent Battles and Overcoming Untold Struggles; and (4) Boundless Devotion: Navigating the Altruistic World of the Primary Caregivers. Findings showed that participants' experiences underscore the profound impact of Filipino cultural values on the caregiving experience and emphasize the emotional complexity of caregiving for individuals with schizophrenia. There were also challenges and difficulties faced by the participants. Their altruistic world involves the immense sacrifices they make, the transformative impact on their identities, and the coping strategies they employ to navigate the challenges they face. The insights gained from the participants can inform tailored support systems and interventions, benefiting similar caregiving situations. The study has implications for improving mental health programs and aiding both patients and caregivers.

Keywords: Schizophrenia Spectrum Disorders, Primary Caregivers, Mental Health, Indigenous Psychology, Interpretative Phenomenological Analysis, Philippines

1. Introduction

Schizophrenia is the most debilitating of all mental health problems in its most severe form and is also the most expensive mental disorder per person from an economic standpoint (World Health Organization [WHO], 2022). According to the Global Burden of Disease Study 2019, which was published by the WHO (2022), the global prevalence of schizophrenia is 2.5%, affecting 24 million of the global population and approximately 1 in 200 adults, making it the primary concern of mental health services in all countries. Since it is the most impairing of all mental health conditions in its acute states, schizophrenia places a huge burden not only on the individuals afflicted but also on the people closest to them, most specifically the caregivers who live with them and interact with them regularly. The global trend of deinstitutionalizing mental health and prioritizing community-based care resulted in making family caregivers indispensable in the management of schizophrenia (Hajebi et al., 2019). In the majority of underdeveloped and developing countries like the Philippines, community care services are inadequately prepared to meet the needs of these patients and their families, or informal caregivers. With that, not only patients but also their caregivers experience different problems and challenges along the way. The researcher found it significant to understand and go deeper into the lived experience of the primary caregivers of patients diagnosed with schizophrenia spectrum disorder, especially those who are from low-income families in rural areas of the Philippines. Particularly, the researcher purposively chose the beneficiaries of the “We Care Program”, a local government of General Luna Quezon initiative program launched in 2020. The program aimed to support indigent families in caring for their loved ones with mental health conditions (Mallari, 2020). The research paper intends to determine insights from the experiences of the indigent primary caregivers from which themes will emerge as the findings of the study. The findings of this study aim to inform mental health care practices to support not only patients but also caregivers. The results and output of the study can be used to improve the current implementation of different mental health programs in the province and can be used as a basis for improvement to help not only the patients but also the primary caregivers.

2. Literature Review

2.1 Family Caregiving of Patients With Schizophrenia

Due to deinstitutionalization and the rise of community-based mental health services, primary caregivers have assumed greater responsibility for individuals diagnosed with schizophrenia. This shift has considerable effects on families, involving both emotional and financial strains. A quantitative study by Rahmani et al. (2022) investigated the caregiving burden and its determining factors among family caregivers of schizophrenia patients. The findings indicate that a substantial caregiving burden was experienced by family caregivers, with 38.2% reporting a severe burden. The responsibility of caring for a relative with schizophrenia gives rise to emotional shock and burden, inadequate understanding of the illness and care techniques, challenges in patient medication adherence, interpersonal difficulties, conflicts in family or work settings, financial strain, and the necessity for robust social support (Iswanti & Pandin, 2022). Recent investigations have also delved into the requirements, obstacles, and techniques for managing challenges among primary caregivers of individuals with schizophrenia. Isaac et al. (2022) conducted a comprehensive review and meta-synthesis encompassing 38 studies involving 543 participants. The findings reveal that the primary caregivers' necessities encompassed rehabilitation and job training centers, informative resources, support groups, improved healthcare provisions, and enhanced communication and cooperation (Isaac et al., 2022).

Furthermore, Isaac et al. (2022) highlighted those difficulties such as "treatment expenses, unconventional beliefs, self- and other-related harm, noncompliance with therapy, demanding caregiving duties, strained family relationships, misunderstanding and bias, and self-stigmatization" were encountered. Additionally, they observed that problem-focused coping, emotional coping, behavioral strategies, reliance on social support, religious coping, and cognitive reevaluation were the mechanisms adopted (Isaac et al., 2022). Stanley and Blakrishnana (2022) conducted a study focusing on the pivotal role of family caregivers in supporting individuals with mental health conditions like schizophrenia. Through a quantitative approach, they assessed the stress levels, perceived social support, resilience, and life satisfaction of caregivers responsible for individuals diagnosed with schizophrenia. The study involved 75 caregivers from southern India and employed standardized assessment tools to gauge these essential factors. Regression analyses indicated that while social support doesn't directly alter the impact of stress on resilience, resilience functions as a mediator between stress and life satisfaction.

In caring for a loved one with schizophrenia disorders in a Filipino family setting, Martinez et al. (2020) found that despite facing significant levels of psychological distress, Filipinos across the globe typically steer clear of formal help-seeking avenues and possess a generally unfavorable perspective towards such options. They tend to lean toward seeking assistance from close friends and family members. While Filipinos living in the Philippines mention barriers related to finances and service accessibility, overseas Filipinos face additional challenges related to immigration status, absence of health insurance, language barriers, instances of discrimination, and challenges in adapting to the host culture. Both groups encounter the stigma associated with mental illness, along with concerns about preserving their reputation, feelings of embarrassment, and adherence to cultural values that prioritize conformity to norms, making mental illness socially unacceptable.

2.2. Conceptual Framework

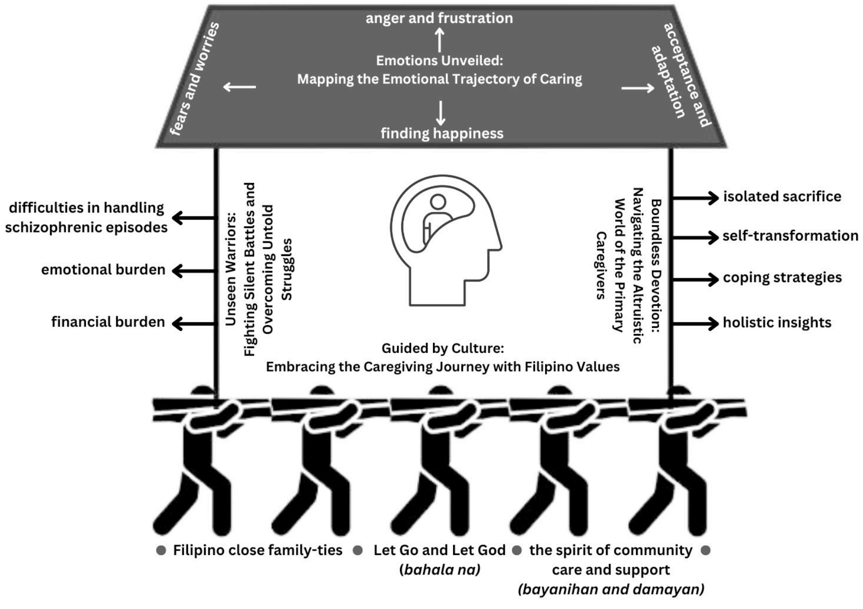

Figure 1. Thematic Scheme of the Lived Experiences of Indigent Primary Caregivers of Patients with Schizophrenia

This study explored the experiences of indigent primary caregivers of patients with schizophrenia disorders, resulting in a conceptual framework inspired by the traditional Filipino Bahay Kubo (Nipa Hut). This framework highlights the economic, emotional, and cultural challenges faced by caregivers, emphasizing the need for greater support.

Guided by Filipino values like close family ties, let go and let god, ('bahala na'), and community spirit ('bayanihan'), caregivers navigate a complex emotional landscape. They experience anger, fear, and frustration, but also find acceptance, adaptation, and moments of happiness.

Despite facing schizophrenic episodes, emotional strain, and financial burdens, caregivers persevere as 'unseen warriors'. Their altruism leads to profound self-transformation and the development of coping strategies. While their sacrifices can lead to isolation, caregivers ultimately gain deeper insights, empathy, and personal growth. This study underscores the challenges faced by this marginalized group and advocates for increased resources and understanding of their experiences.

3. Methodology

The study employed a qualitative phenomenological research design to delve into the lived experiences of primary caregivers of schizophrenia patients. The data were analyzed using interpretative phenomenological analysis (IPA) based on the methodology and principles constructed by Smith et al. (2009. Seven (7) participants were chosen through purposive and criterion sampling. In line with the IPA's best practice guidelines on the idiographic principle, this study worked with a small sample size that is homogenous in characteristics (Pietkiewicz & Smith, 2012). In this way, the generalizability of the findings was limited, but a richer, more in-depth case-by-case analysis would be gained (Smith et al., 2009). Participants were selected using the following inclusion criteria:

1) A primary caregiver (18 years old and above) of a patient diagnosed with schizophrenia spectrum disorder.
2) Be able to communicate efficiently and be willing to participate in research.
3) Comes from an indigent family and is a beneficiary of the We Care Program.

Unstructured interviews, which lasted from 30 minutes to 2 hours, were conducted, recorded, and transcribed. IPA seven-step data analysis, as shown in Figure 2, involved immersing in the data, identifying emergent themes, and developing superordinate and subordinate themes across cases (Smith et al., 2009). The analysis deepened themes with literature, conceptual frameworks, and symbolic representation. The study adhered to ethical guidelines and aimed to understand the experiences of primary caregivers of patients diagnosed with schizophrenia in General Luna, Quezon, bridging broad knowledge with individual perspectives.

01 **Reading and re-reading**
Immersing oneself in the original data.

02 **Initial noting**
Free association and exploring semantic content (e.g. by writing notes in the margin).

03 **Developing emergent themes**
Focus on chunks of transcript and analysis of notes made into themes.

04 **Searching for connections across emergent themes**
Abstracting and integrating themes.

05 **Moving to the next case**
Trying to bracket previous themes and keep open-minded in order to do justice to the individuality of each new case.

06 **Looking for patterns across cases**
Finding patterns of shared higher order qualities across cases, noting idiosyncratic instances.

07 **Taking interpretations to deeper levels**
Deepening the analysis by utilizing metaphors and temporal referents, and by importing other theories as a lens through which to view the analysis.

Figure 2. The seven steps of IPA Data Analysis
Source: Charlick, McKellar, Fielder, & Pincombe (2016), adapted from Smith et al. (2009)

4. Findings and Discussion

Themes

Superordinate Theme 1: Guided by Culture

This superordinate theme highlights the interplay between Filipino cultural values and the caregiving experience through identification from three subordinate themes: (1) Filipino Family-Ties (2) Let Go and Let God; and (3) The Spirit of Community Care and Support.

Filipino Family-Ties. As immediate family members, several participants believe that no one else but them is responsible for caring for the patients. Mutya, who has been caring for her brother because their parents are both deceased, fully embraced the responsibility as the eldest. Makisig, who has been caring for her mother for more than a decade, further elaborated that:

> *"The immediate family of people with schizophrenia should understand their situation with patience, empathy, and compassion more than anyone else. The first ones to provide care and understanding for them [patients] should be their children, parents, or siblings; it's their responsibility, no one else's. It's our familial obligation that we should not escape from."*

Let Go and Let God. It is common among the participants to surrender their worries, anxieties, and burdens to a higher power. Participants acknowledge that when caring for a family member with schizophrenia, accepting the limitations of one's control is crucial. The phrase "bahala na" was often mentioned in the participants' verbatim. Ligaya shared that:

> *"I accept that there are things beyond my control, so I entrust them to God. I pray, 'Lord Almighty, I let go and surrender this to you.' My faith in God helps me care for my daughter."*

The Spirit of Community Care and Support. This subtheme addresses the Filipino values of "bayanihan" and "damayan", and how the participants attribute this to their caregiving journey through practical assistance and local government mental health advocacy. Narda recalled how the neighbors, barangay patrols, the barangay captain, and the police helped her bring her daughter to safety, where the doctor injected the patient with antipsychotics. She further elaborated on how reliable the community was in her situation at the onset of her son's schizophrenia symptoms.

> *"I ran, asking for help from... the police... I asked for help from the police. And I had someone from DSWD (Department of Social Welfare and Development) with me. There were escorts—two police officers and one DSWD personnel. Free transportation, free food, and free medical assistance. I'm grateful to them because they didn't abandon me. Especially Mayor. It really just takes one call for help. He gave me money, and I went home late at night, so happy. "Thank God" I keep saying that because I was able to buy medication."*

Superordinate Theme 2: Emotions Unveiled

This theme explores and maps the emotional trajectory that the participants have been going through while caring for a loved one with schizophrenia. Four (4) subordinate themes emerged under this theme: (1) anger and frustration; (2) fears and worries; (3) acceptance and adaptation; and (4) finding happiness.

Anger and Frustration. In the early phases of taking on the caregiving role, anger and frustration were expressed by the primary caregivers, mostly toward other people, the patient, and the situation. Ligaya shared:

> *"I was angry and annoyed at my co-parents-in-law. It seemed like they didn't care about their daughter's-in-law's illness. They left me alone and didn't provide any form of support. I was so frustrated."*

Participants who are the primary caregivers of their married son with schizophrenia mentioned how angry and frustrated they were with their daughters-in-law. In their narratives, they described how their daughters-in-law neglected rather than cared for their sons, leaving them with no choice but to assume the responsibility.

Fears and Worries. Several participants described having fears and worries as they navigated the care and support of their loved ones. They worry about the patient's risk of self-harm or harm to others. Maya further elaborated that:

> *"He started feeling uneasy back then, and he lost significant weight. He wouldn't eat, rarely took a bath, things like that. And sometimes, he would spit at people who passed by... That's when I started worrying, and we sought help. I had him confined in a psychiatric ward. I was afraid he might harm others or himself, so I asked the police for assistance to take him because he didn't want to come along."*

Acceptance and Adaptation. Participants eventually reached a point of acceptance and adaptation. Their experiences lead them to acknowledge the reality of the situation as they accept it. Maya shared:

> *"Sometimes, of course, there are times when you get angry, but afterwards, I realize that it shouldn't have been that way. Because that's what the doctor told me. His doctor advised me never to make him angry, and never scold him, so he won't become aggressive... [His condition has been explained to me.] I've been taking care of him for a long time, on and off schizophrenic episodes. He gets better, then he relapses. It's a cycle, as the doctor said.] I've become accustomed to it, in a way, because if that's how it is, there's no one else to take care of him but me."*

Finding Happiness in Small Moments. One of the common shared experiences among the participants is finding happiness in small moments in their caregiving journey amidst the unique challenges of caring for a family member with schizophrenia. They take time to appreciate the small things that bring them joy and a sense of relief, like a moment of connection or a day without an episode. Makisig finds joy in moments like sharing a meal or being silly and playful with her mother. In those moments, his bond with his mother grows. Some participants find happiness on days when the patient is in a good mood or on a day without an episode. Maya expressed appreciation toward his son and shared that:

> *"He can be affectionate sometimes, [he'll say], 'Mama, I bought you food' ...Sometimes I see him washing the dishes, I'd say to myself, "oh thank goodness, his mood is good!" Sometimes he voluntarily takes a bath. He'll say, 'Ma, I already took a bath, give me some money.' He does those things. I find precious joy with those moments."*

Participants also find happiness in witnessing a positive change in their loved one's condition. Tala described the feeling of knowing there's a positive change in his son's condition as feeling like "a large thorn was removed from her chest".

Superordinate Theme 3: Unseen Warriors

This third superordinate theme contains the difficulties and burdens the participants face in the caregiving role. This theme arises from three subordinate themes: (1) Dealing with Schizophrenic episodes; (2) Emotional burden; and (3) Financial burden.

Dealing With Schizophrenic Episodes. Participants had to handle schizophrenic or psychotic episodes where the patients exhibited aggression and violence, delusions, paranoia, hallucinations, or social withdrawal. It manifested differently among the patients, but it certainly was challenging and distressful for all the primary caregivers. Narda shared:

> *"Oh my God! I tell you; I melt down and cry uncontrollably! Oh mother! There are times that I could not sleep, especially when she doesn't have her medication, because her psychotic episode involves punching and slapping me when I'm fast asleep at night. It scares me! Oh my God, she even pulled me and dragged me on the floor once!"*

Emotional Burden. Caring for a family member with schizophrenia is emotionally challenging for the participants. Feelings of helplessness and sadness are common, further increasing the emotional burden and negatively impacting the caregiver's mental well-being. Coming from low-income households, providing care leads to exhaustion, burnout, and neglect of one's own needs, further adding to the emotional burden. Due to her heavy emotional burden, Perla thought of giving up. She elaborated:

> *"I get stressed but even if I'm stressed, I can't neglect him because if I do, things might get worse. I want to end the burden, all of it. I thought about ending my life, but then I thought if I'm gone, my poor son, my daughters will be left alone. If I kill myself, how about him? No one would take care of him. So, I still worry about him... his future. Honestly, I'm exhausted from taking care of him. I'm so tired, it's so hard to cope. I just thought, if I do that thing [suicide], first and foremost, it's a sin... it's a sin against God... so I ignore everything, and I just continue even if it's challenging, for my son's healing as well."*

Financial Burden. Participants emphasized how caring for a family member with schizophrenia significantly contributed to their already existing financial difficulties, given that they are from a low-income class. It is a constant struggle to make ends meet, especially since maintenance medications are needed for an illness with a lifetime course. Tala said:

> *"The most difficult part is first, finding money for his treatment in the psychiatric ward. Second, the expensive maintenance medication that he needs to take for the rest of his life. That's what concerns me, I keep on worrying about it. There's nothing left to sell, not even a single livestock. Right now, only the maintenance medication is what he needs to alleviate his symptoms and make him high-functioning, and I think about it especially when it's the start of a new month. I think about where I can get that much money because I have no source of income, considering how expensive the medication is."*

Due to financial constraints, Narda shared that asking for financial and medical assistance from government agencies has been part of her routine.

Superordinate Theme 4: Boundless Devotion

This superordinate theme was unfolded from the four subordinate themes under it, such as (1) Isolated Sacrifice, (2) Self-transformation, (3) Coping Strategies, and (4) Holistic Insights. This superordinate theme highlights the altruistic nature of being the primary caregiver of a family member suffering from schizophrenia.

Isolated Sacrifice. Assuming the responsibility of caring for their loved ones with schizophrenia means sacrificing. In this way, participants often experience a sense of isolation in their caregiving role. Caregivers may have limited opportunities for social interactions outside the caregiving context. Maya stated that:

> *"I really should not be here; I should be retiring in my other children's homes in Manila. I just can't leave him behind because there's no one else to take care of him but me. No one else can cook him food, take care of him, or even do his laundry. It's all me who does that, so he can be safe from the psychotic episode's triggers. It's a real sacrifice. Even my sibling invited me to go to another country for a vacation, but I couldn't do it because of him. I can't leave him. I really do need a break. Oh, I can't even do it because I have to take care of him."*

Self-Transformation. Despite the immense challenges and sacrifices involved in the caregiving journey, participants have undergone significant changes within themselves that shape their perspectives, strengths, and abilities. Makisig shared that:

> *"Before, my patience was short, but now I've stretched it as long as I could."*

Maya also shared that the caregiving role also brought changes to her identity:

> *"The old me is gone. I used to be happy. I was cheerful, and I used to have a stall in the wet market where I was doing good, but now I can't leave him on his own, and it's like I'm focused on him because he is dependent on me due to his illness. My attention is solely on him."*

Coping Strategies. Participants shared various mechanisms they employed to navigate and cope with the demands and stresses associated with caring for a family member with schizophrenia in a low-income household. Participants reach out to friends, family members, or support groups. Taking time to prioritize their own physical, emotional, and mental well-being is crucial for maintaining resilience. Tapping on their inner strength helps them cope. Tala shared that:

> *"But what if I get sick too? If the one I'm taking care of is already sick, then we'll both be sick. I just strengthen my mind, body, and spirit because I think if I give in, if I let it overwhelm me, then what will happen to us? We'll have nothing left... That's the end of it."*

Holistic Insights. In this subordinate theme, participants shared some profound understanding and wisdom that they developed as they navigated the complexities of schizophrenia and its impact on their lives. They empathize with others who may be facing similar challenges. Participants gain a non-judgmental perspective as they witness the complexity of schizophrenia and its impact on their family member's behavior and well-being. Makisig shared that:

> *"Maybe those who are sick are the ones who don't understand [mental illness] with empathy and compassion. That's a more severe illness than having schizophrenia. I pity those who place stigma on mental health; they're the ones who should know better. Those families who have loved ones suffering from a mental disorder, if possible, don't exhaust your patience; always have some left; always have reserves; if possible, increase it even more."*

Discussion

Guided by Culture: Embracing the Caregiving Journey With Filipino Values

Filipino culture, with its emphasis on strong family ties, religious faith, and community support, deeply shapes the experience of caring for individuals with schizophrenia. Family members feel an inherent cultural obligation to care for their loved ones (Ignacio et al., 2020). This responsibility often falls primarily on parents, who are motivated by unconditional love and a sense of duty (Liu & Zhang, 2020).

The Filipino concept of bahala na ("leave it to God") provides caregivers with a sense of humility and trust in a higher power (Jiolito, 2022). Rather than being a passive resignation, bahala na instills inner strength to face challenges (Magilan, 2019). This religious faith allows caregivers to accept their loved one's condition, find meaning in their caregiving journey (Casaleiro et al., 2022; Kamarulbahri et al., 2022), and cope with the associated burdens. Participants in this study seek help from medical professionals rather than traditional healers, which contrasts with findings from other studies that show a reliance on religious rituals for healing (Martinez et al., 2020).

The Filipino values of bayanihan (community support) and damayan (compassion) are crucial. These values encourage neighbors and community members to offer practical and emotional assistance to caregivers, helping to ease the burdens of caregiving (Aruta et al., 2022; Casaleiro et al., 2022). The kindness shown by those around the participants, combined with a lack of discrimination, has been instrumental in enabling these families to thrive (Redubla & Cuaton, 2019).

Emotions Unveiled: Mapping the Emotional Trajectory of Caring

Caregivers experience a wide range of emotions, including anger, frustration, fear, and worry. In the early stages, anger may be directed at others or the situation itself (Narayanan, 2021; Estradé et al., 2023). Worries about the patient's future—their well-being, employment, and relationships—are also common. The intensity of these fears can fluctuate depending on the patient's condition and the occurrence of acute episodes (Cleary et al., 2020). Over time, acceptance and adaptation emerge. Caregivers learn to manage their anger and adjust to a new normal (Imkome & Waraassawapati, 2018). Participants describe finding joy in small moments, such as when patients respond positively to treatment, gain insight into their condition, or show love and appreciation (Liu & Zhang, 2020; Redubla & Cuaton, 2019).

Unseen Warriors: Fighting Silent Battles and Overcoming Untold Struggles

Caregivers of individuals with schizophrenia face significant hidden challenges. Dealing with episodes involving aggression, delusions, hallucinations, and social withdrawal can be particularly difficult (Iswanti et al., 2022). These episodes place stress on both caregivers and patients, influencing quality of life for all involved. The emotional burden on caregivers is considerable, with feelings of helplessness and sadness being prevalent (Cleary et al., 2020; Kamil & Velligan, 2019; Rahmani et al., 2022; Liu & Zhang, 2020). These challenges are amplified for low-income families, where the financial costs of care can be overwhelming. Limited resources can lead to caregiver burnout and neglect of their own needs (Arun et al., 2018; Cleary et al., 2020; Siddiqui & Khalid, 2019; Manao & Pardede, 2019).

Boundless Devotion: Navigating the Altruistic World of the Primary Caregivers

This study highlights the sacrifices and profound transformation experienced by those who care for individuals with schizophrenia. Caregivers often feel isolated due to the all-consuming time and energy required by their role (Estradé et al., 2023; Liu & Zhang, 2020; Bademli & Lök, 2020). Despite these challenges, the journey leads to personal growth. Caregivers develop deep empathy, allowing them to provide compassionate mental health support. They may experience a shift in their own priorities and identities as their focus centers on their loved one (Dijkxhoorn et al., 2022). Caregivers utilize various coping strategies, such as seeking social support, engaging in self-care, and relying on their inner strength (Bademli & Lok, 2020; Liu & Zhang, 2020). Through their experiences, caregivers gain a broader perspective on life and its challenges, often developing a deeper appreciation for resilience and compassion.

5. Conclusion

The study contributed to the deep understanding of the lived experiences of the indigent primary caregivers of patients diagnosed with schizophrenia spectrum disorders, particularly those from indigent families in General Luna, Quezon Province, in the Philippines. The findings highlight the profound impact of Filipino cultural values on their caregiving journey, shaped by cultural factors such as strong family bonds, faith in God, and a sense of community care. Despite the emotional complexity inherent in caring for individuals with schizophrenia, these caregivers demonstrate remarkable resilience, adaptability, and the ability to find moments of happiness within their roles. They navigate through a spectrum of challenges, encompassing the management of schizophrenic episodes, the emotional toll of caregiving, and the financial strains linked to the condition. Serving as primary caregivers in such circumstances is an inherently altruistic endeavor, involving significant sacrifices, transformative self-discovery, and the application of coping mechanisms to surmount obstacles. The insights gleaned from these caregivers' experiences hold immense potential for the development of tailored support systems and interventions to address the unique needs of other individuals in similar caregiving roles. The study offers several recommendations, urging the recognition of cultural values in healthcare services, the incorporation of family caregivers in mental health policies, the integration of faith-based approaches, fostering community engagement, enhancing mental health services, and encouraging further research to strengthen local mental health policies.

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