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The Lived Experiences of Informal Caregivers Assisting Individuals with Schizophrenia Diagnosis in Laguna

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Abstract

This study examines the experiences of informal caregivers supporting individuals with schizophrenia in Laguna, Philippines. Informal Caregivers, primarily family members, face emotional stress, physical exhaustion, financial strain, and social isolation while providing daily care, emotional support, and treatment assistance. Through in-depth interviews with five informal caregivers, key themes emerged: the emotional burden of caregiving, financial difficulties in managing treatment, and social isolation. Despite these challenges, informal caregivers rely on coping strategies such as faith, resilience, and self- care, finding fulfillment in their loved ones' progress. The study emphasizes the need for comprehensive support systems, including financial aid, psychoeducational programs, and accessible mental health resources, to alleviate informal caregivers' burdens. The findings call for proposed program to enhance informal caregivers' well-being and improve care quality, advocating for a holistic approach to supporting informal caregivers and strengthening community-based mental health care.

Keywords: Informal Caregivers, Schizophrenia, Emotional Burden, Financial Strain, Coping Mechanisms, Mental Health Support

1. Introduction

Informal caregivers are instrumental in supporting individuals with serious mental illnesses such as schizophrenia, providing essential assistance without financial compensation (Being a Caregiver, 2022).

The term 'informal caregivers' is consistent with the World Health Organization definitions of 'caregivers' and 'informal support' as stated by Hogan, Bingley, Morbey, and Walshe (2022). It refers to any person without formal health training who is not employed by the hospital and is present on-site as a 'carer' or 'guardian' of a person they know who has been admitted to the institution as a patient. Relying on informal caregivers in low- and middle-income countries to provide patient care that nurses would otherwise do may impact patient care quality and results.

Kamil and Velligan (2019) also emphasized that caregivers offer direct care, aid with everyday chores, and emotional, social, and financial support to people who have schizophrenia. Increased duration of disease and care, severe or chronic schizophrenic symptoms, criticism of the care recipient, financial load, and patient incapacity all add to the caregiver burden. Caregivers of people with persistent symptoms may report feeling overwhelmed, pressured, tired, burdened, frustrated, or furious. The financial consequences of caregiving include treatment expenditures for care users, providing financial support, and lost productivity and revenue. Formal support programs that increase caregiver stress management and coping skills, as well as informal forms of social support, help to lessen caregiver burden.

According to Chan (as cited in Mora-Castañeda, Márquez-González, Fernández-Liria, Huertas, Cabrera, Olmos, & O'Connell 2023), Family members who take on the role of informal caregivers are primarily responsible for providing care for patients with schizophrenia spectrum disorders. Adverse outcomes from this care may include reduced leisure activities, financial hardships, family and social issues, as well as psychological problems (such as depression).

Schizophrenia is a mental health disorder characterized by both positive and negative symptoms, which can significantly impact a person's overall well-being and daily functioning. Individuals experiencing severe symptoms or a significant risk of harm to themselves or others may require hospitalization. However, there is a growing emphasis on community-based care, which highlights the crucial role of family caregivers in the long-term management and rehabilitation of individuals with schizophrenia.

Schizophrenia is a condition that necessitates ongoing therapy and rehabilitation. As care shifts from hospital-based to community-based care, informal caregivers become increasingly essential in rehabilitation. These informal caregivers often face stigma, social isolation, and a lack of resources and support, all of which affect their mental health and well-being.

Understanding the unique needs and challenges of informal caregivers is vital. Mental health professionals and policymakers can develop more effective support services and programs by addressing these issues. This, in turn, helps informal caregivers manage their responsibilities better and improves the quality of life for both the caregiver and the individual with schizophrenia.

The researchers undertaking this study have a personal reason for looking into programs for informal caregivers: a close family member has schizophrenia. This personal connection prompted a strong desire to understand and support informal caregivers who experience similar issues. Witnessing their dedication and struggles has inspired the researchers to look into practical techniques for reducing their loads and improving their well-being.

By focusing on this area of research, the researchers want to provide vital information that will aid informal caregivers of individuals with schizophrenia diagnosis in similar situations. The goal is to develop realistic solutions and initiatives that can positively improve the lives of informal caregivers.

The researchers intend to shed light on informal caregivers' experiences with individuals with a schizophrenia diagnosis, highlighting the unseen problems they face daily. Understanding the informal caregivers' unique challenges and needs enables mental health professionals and policymakers to design better support services and programs to help informal caregivers cope with their responsibilities and improve the quality of life for both the caregiver and the person with schizophrenia.

Through interviews, this study will gather informal caregivers' insights to understand better their experiences, emotions, coping mechanisms, and support needs. The findings will inform the development of program and support services that address the specific challenges faced by informal caregivers of individuals with schizophrenia.

2. Methodology

A. Research Design

To explore the lived experiences of informal caregivers, this study was classified as qualitative research using phenomenology as an approach. Tenny *et al.* (2022) stated that qualitative research investigates and offers a more profound understanding of practical issues by compiling the participants' behaviors, perceptions, and experiences. Tenny *et al.* (2022) also noted that phenomenology examines experiences from the individual's viewpoint. It looks into the participants' "lived experiences" and seeks to understand, from their perspective, how and why they behaved in a particular way. This research employed a qualitative research design using a phenomenological approach to investigate the lived experiences of informal caregivers supporting individuals diagnosed with schizophrenia. The study aimed to gain a thorough examination and explanation of phenomena as they were consciously experienced.

B. Research Locale

The researchers selected Laguna Province as the study's locale. The research focused on understanding the perspectives and experiences of informal caregivers in order to improve the care and support provided to individuals with schizophrenia living in the community.

C. Population and Sampling

This study used a purposeful sampling technique, also known as purposive sampling, in which the researcher selected participants based on specific criteria or characteristics relevant to the research question or objectives and related to the phenomenon of interest. As stated by the Dovetail Editorial Team (2023), it enabled the researcher to focus on specific areas of interest and collect detailed information on those topics. It was also frequently used in small-scale studies with a limited sample size.

According to Shaheen, Pradhan, and Ranajee (2019), purposeful sampling involved choosing samples with a wealth of information to understand the phenomenon comprehensively.

D. Research Participants

Specifically, the study included 5 informal caregivers who were actively engaged in assisting individuals diagnosed with schizophrenia and had at least a year of experience. Participants were required to be 20 years old or above, and the individual with the schizophrenia diagnosis had to be residing within Laguna. The study excluded informal caregivers supporting more than one chronically ill individual within the family, informal caregivers who were stay- out caregivers, informal caregivers providing care in community or residential facilities, and informal caregivers who were being paid to assist individuals with a schizophrenia diagnosis.

According to Creswell (2013), as cited in Sarfo, Debrah, Obeng, & Jubey (2022), an appropriate sample size for a phenomenological investigation was between 5 and 25 people.

The study found and described the lived experience of 5 informal caregivers. Five (5) female informal caregivers that are qualified for the research participants criterion. Two (2) of them are the sisters of those diagnosed with schizophrenia and three (3) of them are the mothers of those diagnosed with schizophrenia. Two (2) of them are from Cabuyao and the others are from Los Banos, Sta. Rosa and Sta. Cruz. Three (3) of the informal caregivers has at least below 20 years of being an informal caregiver, while two (2) of them have 20 years and above of being an informal caregiver. This data highlights the long-term dedication and substantial experience of these informal caregivers, which likely contributes to their deep understanding of the challenges and coping strategies associated with caregiving.

E. Research Instrumentation

The researchers employed self-made questions, which were developed based on the experiences of informal caregivers of individuals with schizophrenia. These questions were specifically designed to elicit comprehensive insights into participants' attitudes, beliefs, behaviors, and other relevant aspects related to caregiving experiences.

A structured interview protocol was implemented to ensure consistency and rigor in data collection. This protocol provided clear guidelines for conducting interviews while allowing flexibility to delve deeply into specific issues as they arose during the conversations. By utilizing this approach, the study aimed to capture nuanced perspectives and enrich understanding of the challenges and dynamics within the caregiving context for schizophrenia.

F. Data Gathering Procedure

Before conducting the study, the researchers submitted a letter endorsed by their thesis adviser to the Dean of the College, outlining their intention to conduct personal interviews with selected participants.

After selecting participants using purposeful sampling, the interviews were scheduled for times that were convenient for the informal caregivers. Each interviewee was presented with a consent form before the interview. This document served as official approval for the researchers to proceed and included a study description, emphasizing the confidentiality of participants' identities during and after the interview session. Following consent, participants were informed about the interview process and the recording.

The study's descriptive nature was accommodated through a self-made interview format, which offered flexibility in question wording and facilitated detailed information gathering. Once all participants had been interviewed, recorded responses were transcribed into text for analysis.

H. Ethical Consideration

This study took four (4) ethical considerations into account: informed consent, confidentiality, anonymity in accordance with the Data Privacy Act of 2012, and the researcher's role and responsibilities. The researchers informed the participants about their rights to foster trust and confidence between the researchers and the participants.

Anonymity and Confidentiality

Participants provided informed consent for the use of their data. To ensure the privacy of their data, the anonymity and confidentiality of the informal caregivers were carefully maintained. Their names and identities were not disclosed during data collection or analysis of the study results. Furthermore, participants had the right to withdraw from the study at any point.

Data Privacy and Informed Consent

Consent was provided voluntarily, and participants understood what was required of them. Before the interview, the study and its objectives were explained, and participants had the freedom to choose whether to participate or decline. Given the ethical considerations of the research, participants were given adequate time throughout the interview process to ensure they could answer the research questions honestly and openly, based on their understanding of the study.

3. Results and Discussions

The comprehensive analysis of the caregiving experiences revealed ten core themes, each providing valuable insights into the various dimensions of the caregiving journey for informal caregivers supporting individuals with schizophrenia diagnosis. These themes highlight the multifaceted nature of caregiving, encompassing emotional, social, practical, and future-oriented aspects.

1. Personal and Social Impacts

Informal caregivers consistently reported experiencing significant personal restrictions that limit their freedom and social interactions. Many described feeling confined within their caregiving roles to the extent that engaging in leisure activities, pursuing personal hobbies, or traveling became difficult or impossible. They also shared feelings of social isolation, often resulting from the demanding nature of caregiving responsibilities that reduce their opportunities for socialization, leading to loneliness and a sense of disconnection from their community. Moreover, these responsibilities frequently caused shifts in social roles within families and communities, impacting their sense of identity and personal aspirations, as caregiving prioritized their loved ones' needs over their own personal growth or career development.

2. Daily Caregiving Responsibilities

The routine tasks involved in caring for individuals with schizophrenia were identified as physically demanding and emotionally draining. They took on roles that included managing medications, monitoring symptoms for potential relapses, providing emotional comfort, and ensuring general safety and well-being. These tasks required continuous vigilance and patience, often at the expense of their own health and leisure time. The repetitive nature of daily care led to feelings of fatigue, frustration, and sometimes hopelessness, especially when facing unpredictable illness episodes or behavioral challenges. The emotional toll of constant responsibility and the physical exertion associated with caregiving were underscored as major stressors.

3. Long-term Commitment to Caregiving Participants described their roles as enduring commitments that could last for decades, reflecting the chronic and lifelong nature of schizophrenia. Some shared experiences of caring for loved ones over more than 30 years, emphasizing the ongoing dedication despite increasing physical and emotional exhaustion. These long-term commitments often became deeply ingrained in their daily routines, shaping their lifestyles, aspirations, and personal narratives. The necessity to remain committed over such extended periods highlighted the resilience and steadfastness of caregivers, but also underscored the toll this relentless responsibility can impose.

4. Emotional Fulfillment in Caregiving Role

Despite the hardships, they expressed experiencing moments of emotional reward — a sense of purpose, joy, and fulfillment derived from supporting their loved ones. Witnessing small improvements, recovery, or moments of happiness in the person they care for served as motivators and sources of hope. These positive experiences reinforced their commitment and provided emotional sustenance, helping caregivers to manage feelings of fatigue and frustration. For some, the act of caregiving became a meaningful life pursuit that gave their lives a sense of importance and emotional richness.

5. Emotional and Financial Strains in Caregiving

Chronic stress and emotional exhaustion emerged as consistent themes, fueled by worries about relapses, the unpredictability of psychiatric symptoms, and the demanding nature of caregiving itself. Many caregivers also faced ongoing financial hardships, including high treatment costs, medication expenses, and related healthcare needs. For some, these financial burdens contributed to feelings of helplessness, especially when combined with limited income or lack of financial support. The cumulative effect of emotional distress and financial strain often led to feelings of burnout, anxiety, and despair, highlighting the urgent need for supportive interventions.

6. Coping Strategies to Relieve Caregiver Stress

To manage the emotional and physical burdens of caregiving, informal caregivers employed various coping mechanisms. Many relied on their faith or spiritual practices, such as prayer or attending religious activities, to foster resilience and find emotional comfort. Self-care practices, such as engaging in hobbies, taking walks, listening to music, and practicing mindfulness or relaxation techniques, provided essential mental breaks. Additionally, seeking social support from family, friends, or community groups became a crucial strategy to share their experiences, gain advice, and gain emotional relief. These coping mechanisms helped caregivers to sustain their well-being amid ongoing challenges.

7. Family and Institutional Support for Caregiving

The level of support from family members, community organizations, and healthcare institutions significantly influenced the caregiving experience. When strong support systems were present—such as family assistance, community-based programs, or accessible health services—caregivers expressed feeling more capable and less isolated. Conversely, lack of support or recognition often amplified their stress, feelings of loneliness, and perceived burden. Institutional assistance, such as counseling services, training, and financial aid, played a vital role in alleviating some of the hardships faced by caregivers, enabling them to perform their roles more effectively and with less emotional strain.

8. Learning Through Experience and Guidance

Over time, informal caregivers learned to better handle the demands of caregiving through experience, trial and error, and sometimes guidance from health professionals and peer support groups. They developed practical skills in managing medication schedules, recognizing early warning signs of relapse, and handling behavioral challenges. This experiential learning contributed to increased confidence and moderation in their caregiving approaches. Many caregivers acknowledged that gaining knowledge, whether through education sessions or personal observation, was essential to adapting to their evolving caregiving roles.

9. Future Planning and Time Management in Caregiving

Several caregivers actively engaged in planning for the long-term needs of their loved ones and themselves. This included organizing resources, considering financial sustainability, and making arrangements to ensure continuous care even if their own circumstances changed. Additionally, they practiced time management strategies such as creating schedules, preparing meals in advance, and balancing work responsibilities with caregiving duties. Such proactive planning was viewed as essential to maintaining stability, reducing future uncertainties, and ensuring ongoing support for the individuals with schizophrenia.

10. Hopes for Support and Improved Health Outcomes

The informal caregivers expressed strong hopes and aspirations for systemic improvements. They wished for better access to healthcare and social services, increased financial support, and more awareness campaigns to reduce societal stigma. Many believed that enhanced support systems could ease their burdens, improve the quality of care for the individuals with schizophrenia, and promote better health outcomes. They also hoped for innovations in treatment and community-based programs that could foster independence for their loved ones, and provide caregivers with the resources and understanding needed to sustain their caregiving roles over time.

4. Discussion

The comprehensive findings illustrate that informal caregivers of individuals with schizophrenia in Laguna face multifaceted challenges that significantly impact their emotional, social, and financial well- being. The prominent themes underscore the enduring and complex nature of caregiving, with many caregivers dedicating their lives to the sustained support of their loved ones. This long-term commitment, often extending over decades, reflects a deep sense of duty and love but also exposes caregivers to emotional exhaustion, social isolation, and financial hardship.

The social impacts, such as restricted social interactions and personal activities, highlight the need for community and institutional strategies that promote social engagement and respite. The emotional toll, characterized by fatigue, stress, and burnout, underscores the importance of accessible mental health services tailored for caregivers. Spiritual practices and social support emerged as vital coping mechanisms, aligning with existing literature that emphasizes cultural relevance in caregiving interventions.

Financial burdens, amplified by high treatment costs and limited income sources, exacerbate caregiver stress and threaten their capacity to provide sustained care. The absence of adequate financial aid and institutional support systems intensifies this burden, making it imperative for policymakers to prioritize resource allocation and support programs for caregivers.

Despite these hardships, caregivers' reports of emotional fulfillment and the adaptive strategies they develop reveal their resilience and capacity for growth. Their reliance on faith, community, and experiential learning demonstrates the importance of culturally sensitive, holistic approaches to caregiver support. These strategies, coupled with formal support services, could mitigate negative outcomes and enhance caregiver well-being.

The findings resonate with existing research emphasizing the critical role of social support, education, and healthcare infrastructure in caregiver sustainability. They also point to an urgent need for comprehensive health policies encompassing mental health services, caregiver training, financial assistance, and community outreach programs. Recognizing caregivers' pivotal role in the continuum of psychiatric care, interventions should be developed and implemented to foster their resilience, provide tangible support, and acknowledge their profound contribution to mental health management.

Limitations of this study, including its small sample size and regional focus, suggest that further research across diverse demographics and wider geographical settings is necessary. Broader studies could offer more generalized insights and inform national health strategies aimed at supporting informal caregivers.

In conclusion, the study underscores that supporting informal caregivers through multifaceted, culturally appropriate interventions is essential for improving their quality of life and ensuring sustainable care for individuals with schizophrenia. Addressing these issues holistically will contribute to a more effective, compassionate mental health care system.

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