Journal: Texila International Journal of Academic Research
Publisher: Texila International Journal
ISSN: 2520-3088
Volume 13 Issue 2, 2026
DOI: 10.21522/TIJAR.2014.13.02.Art004

Navigating Institutional Gaps: Lived Experiences of Family Caregivers Managing Chronic Psychosis in Zambia

Virginia Simasiku[1*], Catherine Mubita Ngoma[2], Rajesh Konnur[3]
[1]*Nursing, Eden University, Lusaka, Zambia*
[2]*Nursing, University of Zambia, Lusaka, Zambia*
[3]*Nursing, Texila American University, Guyana*

Abstract

Family caregivers bear the burdens of managing chronic psychosis as critical yet unrecognised partners in clinical decision making particularly in low resource settings where institutional support is inadequate. Their support exceeds beyond relational responsibility to include clinical decision making, medication management and crisis management. The objective of the study was to explore the experiences of caregivers on the roles, challenges and interactions with the formal mental health services. The study recruited 30 participants through purposive sampling and collected data using in-depth interviews. Data were analysed using the interpretive phenomenological design by Smith et.al (2009) criteria to identify superordinate and subordinate themes. Three overarching themes were identified: 1) primary managers of treatment decisions, 2) integrating biomedical and spiritual decision making, and 3) bearing clinical responsibility without adequate support. The experiences highlight the central role of caregivers in the management of psychosis within the limited mental health services. In conclusion, caregivers should be recognised as core stakeholders in clinical decision making rather than health seekers, as failure to integrate them may endanger their wellbeing. This risk of mismanagement could result from emotionally based decisions due to poor education on the illness. There is need to continuously engage caregivers in care planning, knowledge on adverse effects, provision of coping strategies and management of psychosis. These findings provide a basis for mental health policy to structure caregivers' frameworks that include mandatory crisis guidance and to nursing practice by incorporating routine assessments of caregiver wellbeing and support as standard psychiatric care.

Keywords: *Chronic Psychosis, Decision Making, Family Caregivers, Informal Caregivers, Institutional Gaps.*

Introduction

Psychosis is defined as a mental disorder characterised by sensory perceptual intrusions such as delusions and hallucinations which may involve periods of crisis or relapses [1]. Globally, Schzophrenia has been found to be a major contributor to the high burden of mental disordesrs, in which over 65 % of psychosis mangement is undertaken by family caregivers illustrating an over reliance on family support [2]. Family caregivers experience poor quality of life asociated with age, pschiatric symptoms and caregiving burden hence the need to improve community based mental health care [3]. Similarly, increasing caregivers' awareness through education on psychosis management and peer support has shown to improve quality of care and their ability to

Received: 01.02.2026 ***Accepted: 12.03.2026*** ***Published on: 30.04.2026***

****Corresponding Author: virginiasimasiku@gmail.com***

navigate shared decision making on therapy gaols [4, 5].

Caregivers take on the responsibility of managing medication in the community to ensure continuity of care hence require specific medivcation management skills to enhance their role [6]. However, caregivers perceive limited collaboration with health professionals as they recive inadequate to information on Antipsychotics [7]. Undoubtedly, ambivalence on reduction or continuation among caregivers has been observed due to the medication adverse effects that patients undergo hence the need to supoprt families to promote adherence [8]. In the same vain, caregivers' continue to express their unmet needs of lack of involvement in the management of adverse effects as they feel they are better at observing than health professionals [9].

Caring for patients with psychosis carries a risk of violence exposure, which ranges from verbal (35.5%) to physical (25.5%) associated to symptoms of illness at 57.3% and refusal to take medication at 49.1% [10]. Furthermore, significant levels of fear and anxities about relapses have observed and have been associated to unmet needs for relapse-focused education which could impact relapse prevention negatively [11]. In this vain, caregivers need to be trained with stress coping skills in order to cope with daily struggles of the caring process [12].

In Africa, Moral commitment conpounded by cultural expectations have significantly contributed to the caregivers' resileince and loyalty in the management of chronic psychosis [13]. Likewise, traditional beliefs contribute to poor help-seeking behaviours acting as a source of understanding accounting for poor perception on the causes of illness and increased stigma in the community [14]. Further, stigma associated with mental illness has impaired the need for help seeking behaviors leading to peole choosing traditional and spiritual healing methods over hospital based care [15]. Some of the challenges faced by caregivers in Zambia are disturbances in family function, financial difficulties, stigma and poor social suport in which acceptance of the illness and faith-based beliefs used as a means of coping [16]. It is worth noting that financial constraints have highly contributed to the preference of traditional healing methods compared to medical care due to acccompanied expenses like transport, hospital fees and purchase of medication [17].

Reduction of caregiver burdens have been associated with high levels of hope enhancing ability to continue caring and improving care recipient outcomes [18]. Additionally, family centered collaborative care is acceptable intervention that has suggested to have potential to improve caregiver and patient well being [19]. In the same way, psychoeducation improves confidence and autonomy by empowering caregivers' with adequate knowledge to manage psychosis [20]. However, integrating psychoeducation into mental health services and policies pose a challenge as implementation requires sustained support [21]. Although several interventions are being implemented, they fall short of caregiver inclusion into the mental health system to reduce the gap between in-patient and community services for continuity of care [22]. They require support and guidance as they navigate the uncertainties of caring by ensuring that they are engaged in shared decision making to promote participation in management [23].

The main objective of the study was to explore experiences of how family caregivers function as unrecognised and informal clinical decision makers in the management of individuals with psychosis, as well as how they navigate the challenges of inadequate institutional infrastructure. The novelty of the study is based on the reframing of caregivers as core stakeholders in the management of psychosis and not merely patient helpers. Furthermore, the study introduces decision making as a lived and contextual process experienced throughout the caring process. The application of interpretive phenomenological design reveals the interpretive and mean making process rather than challenging task. Also, the use of interpretive phenomenological analysis adds depth to the experiences making a significant methodological contribution to the body of knowledge to Zambia and globally.

Materials and Methods

Research Design

A qualitative research design rooted in interpretive phenomenology was adopted to explore and gain insights into how family caregivers experience and make sense of managing chronic psychosis within institutional gaps in Zambia. Interpretive phenomenology analysis (IPA) enabled the researcher to co-construct meaning with the participant while in-depth exploration of the phenomena highlighted both unique personal experiences and shared patterns [24, 25].

Study Setting and Sampling Procedures

Chainama Hills Hospital was the study site because it's a national referral facility that admits individuals from diverse geographical, social and cultural backgrounds providing diversity in the manner institutional gaps are navigated. Participants were selected using purposive sampling to include family caregivers who were directly involved in caring for the patient for a minimum period of 12 months. Through the application of the IPA principles on sample size determination, the study used 30 participants as there is no strict rule on the exact number [26, 27]. The choice was based on the context that the study needed to engage more participants considering that the phenomena required wider exploration for better insights [28, 29].

Data Collection Methods and Techniques

Interview guides were used to collect data from family caregivers who met the inclusion criteria. Through semi-structured, in-depth interviews, caregivers were enabled to share their experiences guided by open ended questions to facilitate free expression into rich contextual insights. The core research question was "Can *you describe your experience of caring for a family member with chronic psychosis at Chainama Hills Hospital*?". Also probes were used to elicit further clarifications and depth. English language was used for the interview guide and translated into Chichewa (Nyanja) one of the primary local languages for inclusivity and authenticity. Health professionals assisted in the recruitment process; all sessions were audio recorded while researcher took notes on nonverbal cues. Participants who presented with distress were emotionally supported through empathetic listening techniques, and were necessary additional support was sort from mental health professionals.

Data Management

Audio recordings from interviews were stored in password protected files and backed up for preservation. Researcher's notes were locked up in cabinets while identifying information was replaced with participant codes (e.g. *P002*) prior to transcription. Data access was restricted to researcher and academic supervisors and used only for academic purposes.

Rigour and trustworthiness were ensured using Lincoln and Guba's criteria (1985) [30]. Credibility was achieved through prolonged engagement with participants, in-depth interviews and verbatims transcription to accurately represent caregivers' experiences of navigating institutional gaps. Dependability was maintained through a clear audit trail documenting methodological decisions, coding processes and adherent to analytic steps with the IPA framework. While Conformability was ensured through reflexive journaling and grounding the interpretations in participants' direct quotes to minimise researcher bias. Researcher positionality as a mental health nurse was informed through prior knowledge and contextual familiarity enhancing interpretive depth while maintaining reflexive awareness. And transferability was supported by providing rich contextual descriptions of the caregivers' at Chainama Hills Hospital allowing readers to determine applicability to similar mental health settings.

Data Analysis

Data were analysed using IPA framework as guided by Smith et.al, 2009 [31]; grounded in phenomenology to explore caregivers' lived experiences, guided by the double hermeneutic in which the researcher co-constructed meaning with the participants on navigating institutional gaps, and informed by idiographic commitment to detailed case by case analysis before identifying shared patterns which were framed as superordinate and subordinate themes. The process was supported by the utilisation of NVivo version 11 to facilitate efficient organisation, coding and retrieval of data. Its visualization tools enabled the researcher to present patterns and provide baseline for interpretation of caregivers' experiences.

Participants

This section describes the methods followed and responds to the question of how the problem was studied. The order is as follows:

The study included 30 participants who were family caregivers comprising parents, siblings, children and spouses. To ensure rich and insightful accounts of the phenomenon, participants were required to have been first line caregivers for a minimum period of 12 months. Table 1 presents the participants' sociodemographic characteristics. The age ranged from 30 to 85 years showing representation across key life stages and rich diverse experiences. Females constituted the majority with 23 participants (76.7%) including mothers, sister, daughters and wives, while males had 7 participants (23.3%) comprising fathers, brothers, sons and husbands. The study achieved 90% national representation with participants drawn from nine provinces: Lusaka 10 (33.3%), Eastern 5 (16.7%), Central 4 (13.3%), Copperbelt and Western 3 each (10%), Southern 2 (6.6%), and Muchinga, Luapula and Northern 1 each (3.3%).

Most participants were married (16;53.3%), widowed (6;20%), single (5;16.7%), and divorced (3;10%). Educational attainment varied with 13 participants (43.3%), having completed secondary education, with primary education 8 (26.7%), with tertiary education (26.6%), no formal education 1(3.3%). Majority of caregivers were engaged in some form of employment, including formal employment 14 (46.7%), self employed 12 (40%) and retired 4 (13.3%).

Table 1. Sociodemographic Characteristics of Participants

Participant	Relationship to Patient	Age	Residence	Marital status	Education Level	Employment
P001	Wife	44	Mansa	Married	Secondary	Self employed
P002	Mother	60	Kabwe	Married	Secondary	Formal
P003	Sister	35	Lusaka	Married	Primary	Formal
P004	Sister	66	Lusaka	Single	Tertiary	Retired

P005	Brother	33	Ndola	Married	Tertiary	Formal
P006	Sister	64	Kitwe	Married	Secondary	Formal
P007	Mother	54	Kasama	Single	Secondary	Formal
P008	Sister	40	Chongwe	Widow	Secondary	Formal
P009	Mother	57	Kaoma	Divorced	Primary	Self-employed
P010	Husband	48	Monze	Married	Primary	Self-employed
P011	Mother	70	Mpika	Widow	No formal	Self-employed
P012	Sister	50	Kalomo	Divorced	Primary	Formal
P013	Mother	44	Lusaka	Married	Primary	Self-employed
P014	Sister	30	Kafue	Married	Secondary	Self-employed
P015	Sister	41	Lusaka	Married	Secondary	Self-employed
P016	Sister	38	Lusaka	Single	Secondary	Self-employed
P017	Mother	67	Chipata	Widow	Primary	Self-employed
P018	Sister	43	Luangwa	Divorced	Primary	Formal
P019	Mother	50	Chipata	Married	Secondary	Formal
P020	Father	74	Katete	Married	Tertiary	Formal
P021	Husband	49	Kabwe	Married	Tertiary	Self-employed
P022	Mother	59	Lusaka	Married	Secondary	Self-employed
P023	Daughter	34	Liteta	Single	Secondary	Self-employed
P024	Sister	39	Mumbwa	Single	Tertiary	Formal
P025	Mother	78	Mongu	Widow	Secondary	Retired
P026	Brother	51	Ndola	Married	Tertiary	Formal
P027	Mother	69	Mongu	Married	Primary	Formal
P028	Wife	44	Lusaka	Married	Tertiary	Formal
P029	Father	85	Chongwe	Widower	Tertiary	Retired
P030	Father	81	Lusaka	Widower	Secondary	Retired

Results

This section presents results from in-depth face to face interviews with family caregivers, demonstrating the existing gaps in the mental health care system and community mental health support placing them as unrecognised decision-makers in the care of patients with psychosis. The findings obtained were organised into themes across the participants and included three themes: 1) primary managers of treatment, 2) integrating biomedical and spiritual decision-making, and 3) bearing clinical responsibility without adequate support. Verbatims were included to show the caregivers' deep understanding of the phenomenon and aid to consolidate the interpretation of findings. Table 2 below illustrates both the superordinate and subordinate themes of the study.

Table 2. Superordinate and Subordinate Themes

Superordinate themes	Subordinate themes
Primary managers of treatment decisions	Control medication administration
	Decide the necessitate of hospital care
	Manage adverse effects without professional guidance
Integrating biomedical and	Assessing if medication works

spiritual decision-making	Balancing hospital care and prayer-based care
Bearing clinical responsibility without adequate support	Managing crises without training
	Carrying responsibility for every decision

Theme 1: Primary Managers of Treatment Decisions

Caregivers are attributed to practice as untrained clinicians as they manage their patients throughout the caring process. They have demonstrated that by the many acts and experiences that are encountered largely meant for professional clinicians. The impact of caregivers' commitment to care determines the health outcomes of the patient suffering from psychosis as they are decision makers outside the health institutions.

Control Medication Administration

> "*Administering medication can be difficult at times……i buy a drink then put the tablets……..that's how he agrees to drink" (P002).*

The caregiver must formulate ways of negotiating the when and how the medication is administered to the patient. The form of the drugs to be given is also determined by the caregiver based on the condition that is presenting at that point. Determining whether the drug should be melted or smashed even hidden in food just so the patient can drink it and its efficacy changed is unknown because the caregivers have no education on such aspects of information even from the professionals.

> "*Certain times I have to go to the hospital without her to collect the medication ……..just so I could give from home" (P020).*

The narration articulated that the commitment of the caregiver determines the patient's adherence to medication. The caregiver illustrates the importance of drug collection from the hospital even when they must defy professional instruction to present the patient for every visit. This was further demonstrated by P016 who highlights the struggles of engaging the patient to a hospital visit.

> "*You see……even when he refuses ……. I still must give the same haloperidol" (016).*

This suggests that caregivers' have the sole responsibility to decide to acquire medication even amidst the need for financial stability to sustain the patient on treatment. This interpreted that the professionals do not have to give such options as purchasing medication because of patient refusal, instead the caregiver oversees everything including the availability of medication against all odds.

Deciding the Necessity of Hospital Care

> "*I manage him from home……but when he is very bad, that is when I bring him to the hospital ………for medication or to be seen by the doctor" (009).*

The caregiver illustrates that it is within their ability to choose when the patient requires to be taken to the health facility for management. Their decision is based on their ability to recognise the difference between what is manageable and what is dangerous. This unrecognised empowerment indicates that the caregivers should have adequate information and education on the disease process for them to appropriately manage the patient's wellbeing.

> *"Sometimes I sign against medical advice and take him home……... I don't like the way they are kept…. how can my patient who's doing much better be harassed by other patients" (P019).*

Caregivers are faced with the choice of home management over hospital-based care considering the displeasures they observe at health facilities. They decide when it fits for the patients to be in a hospital environment, and how safe it is for them. When the safety of their patients is threatened, they withdraw them regardless of medical orders.

> *"If he feels better……. He refuses reviews, so I just come to get the drugs. These patients can be stressful...... but my duty is to help him get better" (P016).*

It is also observed that caregivers feel obligated to solely take care of the patients' desires. They interpret this obligation as part of patient's care than forcing them to be confined to the schedules of the hospitals. They act as mediators between the patient and health facilities especially when the feel better and regain their autonomy leading to the intervention by the caregivers.

Manage Adverse Effects Without Professional Guidance

> *"Despite him being difficult I still buy the same haloperidol and Artane ……I don't give him Artane daily but only when I see a change in his behaviour……. the way he is doing now, I see drooling" (007).*

The caregiver expresses the emotional toll of caring, in which they are expected to navigate difficult medication regimens, often requiring alterations to doses without regular expert guide. The mention of managing medications based on observed behavioural changes indicates a trial-and-error method, which could be risky if not managed overtime.

> *"Now look at the tongue, he is stiff and drooling……... I can't be happy and they are saying it's not the drugs ……... no! I told them that me I give the drugs at home and leave him...... and I give him every day, but he doesn't behave this way……. he doesn't look like that ……" (P013).*

This illustrates the distress the caregiver undergoes at the sight of the child seeming to be mismanaged by the professionals. There is a deeper cry insinuating that 'I know this behaviour; something is not right'. It demonstrates the importance of professionals paying attention to caregivers' observations as their insights about the patient could provide basis for better treatment plans. This level of concern for the significant other is further observed by P28 who says.

> "*The other problem is that some of these drugs like the other injection……. that they give him, it makes his leg to be numb so you find that we will be walking very slowly back home......until I chance a bus then that becomes easy" (P028).*

This shows how the caregiver deals with the practicality of managing side effects of medication which affects daily activities. This seems like they are experts in navigating the best care despite the varied challenges they are exposed to, while needing the health professionals to listen and adapt treatment plans accordingly.

Theme 2: Integrating Biomedical and Spiritual Decision-Making

This is a reflection on how caregivers combine hospital-based care with spiritual explanation of causes of psychosis especially when in the face of challenges and a sought for understanding of the disease process. They place themselves as key decision makers across intersecting belief systems as they avoid relying on one system of knowledge especially in the face of limited professional care. It is observed that they manage a complementary decision-making system that combines clinical judgement with faith-based interpretation.

Assessing If Medication Works

> *"You pray for one thing another thing comes up….so the problems continued and continued for some time and the hospital were not really helping because the drugs they were giving us were not working" (P030).*

This illustrates the frustration the caregiver feels between the expectation of the prayers being answered and the help the hospital should render, compared to the reality of the patient not responding to treatment. They express a feeling of helplessness and a disconnection that reality holds on the disease process and hoped for care. They suggest a sense of stagnation which keeps them cycling around a reality of suffering, breaking down the trust that the hospital has answers to their need.

> *"So, after I stopped going to the hospital, I kept the child home and we were just praying and praying for a long time and when he felt better again…. it started …. this time it was total confusion very aggressive, very restless and this time you could see that wasn't losing memory or looking very mad, but you can see that is a problem" (P022).*

Consistent with participant 030, the caregiver tuned to prayer after they felt let down at the hospital's inability to offer the expected treatment. This narration carries a sense of escalating distress to the realisation that even amid prayer they were losing control of the child's wellbeing, while also harbouring empathy and pain for the child's experience. They use prayer as a complementary path of coping with the illness, suggesting the complex ways people use to navigate between healthcare and spirituality in their search for answers.

> *"When he comes here (hospital), he looks pale ...... he looks hydrated and when I look at him, I feel bad and that's why I sometimes sign against medical advice. Sometimes I prefer I... I just go home because if I live him …. I feel like he's neglected …. sometimes beaten. And when I come back, I find this …this is very bad" (P018).*

The participant's narrative highlights the emotional turmoil they are facing at the reality of seeing their loved one entrusted into institutional care, leaving them to grapple with feelings of guilt and powerlessness. The decision to sign against medical advice can be seen as a sign desperation to regain their agency and therefore protect their child from the perceived harmful environment.

Balancing Hospital Care and Prayer-Based Care

> *"Continuing hospital with also prayers it helps … that's why some children get mismanaged because other parents just rely on drugs from the hospital, but something again is missing because some children need also to go for prayers" (P25).*

This experience implies that prayer can be a complement to hospital care, as it is regarded cardinal in addressing both the emotional and spiritual aspects of healing. It therefore acknowledges that hospital care isn't only about physical care but also nurturing the mind and spirit. It further shows that relying on one aspect either drugs or prayer may likely leave gaps in care. Therefore, it seems to suggest that the use of more integrated approaches is better in weaving together different threads of support through which the caregiver benefits too. This is in line with P17's belief as shown below.

> *"And I can't just say no its just prayers no…. but I should also take him for hospital where it needs hospital. I bring the boy, so when I see that something…. Something changes then again, I do it" (P17).*

This illustrates the caregivers' active role in the management of their patient's ever-changing condition. Instead of believing in one approach, the caregiver demonstrates her ongoing judgment as she critically observes changes in the condition of the patient and based on this, makes important decisions on when to intensify faith-based support or hospital care.

> *"So…. after they saw that I had gained strength in prayers, they casted a spirit of anger onto my son. That spirit of anger made him to refuse prayers. So, when a pastor shows up for prayers, they can't manage him because he could even beat him together with me. But it's like a phase, you pray over this, another spell is cast on him" (P004).*

The caregiver describes a spiritual and relational cycle that tries to explain how uncertainty is navigated. The behavioural fluctuations are interpreted as spiritual attacks that counteract the efforts of prayer on the illness, rather than medical relapses. Therefore, the experience shows how decisions are shaped and the need the alternative care and support.

Theme 3: Bearing Clinical Responsibility Without Adequate Support

This theme describes how caregivers bear the responsibility of caring without adequate training and empowerment to manage psychosis and its burdens. Caregivers learn to normalise emotional pain and tend to make decisions under distress rather than clinically based. They bear their suffering as moral duty through endurance and as a show of their affection for the loved ones. The narratives demonstrate that responsibility placed upon the caregivers is circumstantial as they find themselves filling in the various gaps the system imposes on them such as inadequate psychological support for caregivers, medication shortages, infrequent contacts with health professionals, as well as limited knowledge on diagnosis and medication adverse effects.

Managing Crises Without Training

> *"What even makes us feel very bad is that this was a very good man and now to see him remove his clothes defecate on himself, chase people around with knives…… it really makes us especially me feel very bad when the illness is at that stage" (P003).*

The narrative reveals the grief and distress being experienced as they recall the transformation their loved one has undergone. Yet again the observance of the aggression and self-neglect illustrates moments of crisis while also managing stigma and fear.

> *"So with my brother's condition when things are very bad, I take my children, lock them up and then I get my brother because he only listens to me than listen to other people…… I will leave him in that state until stable enough" (P006).*

This reveals caregivers as holders of dual roles in the management of risks in periods where the illness deteriorates. They act as protectors of other family members when they lock the children away from harm, and as clinical decision makers when they allow the patient to calm down before administering further interventions. It further positions caregivers as primary regulators of the situation, suggesting authority and experiential understanding that other people may not possess.

Carrying Responsibility for Every Decision

> *"I called the nurse saying he's got a side effect…… But she said no it's how the disease presents but ………. That is why I want to go home with him because the way I brought him …... he didn't have this behaviour" (P014).*

This shows the caregiver's dissatisfaction with the professional response and protective urge of possible mistrust and fear of the patient being exposed to harm. This disagreement illustrates the caregiver's active role of not passively accepting the health professional's opinions without drawing onto the experiential knowledge to question the explanation.

> *"This sickness she has even made me to separate from my husband, so my husband is now staying in another province…… because I have to continue managing my child" (P016).*

Caregiving experience in this narrative highlights another dimension that prolonged caregiving responsibility extend monitoring of symptoms and crisis management. Caregiving responsibility has the potential to reorganise and override family structure and marital relationships. Therefore, the caregiver conveys the message that the marital separation was not a voluntary breakdown, but a sacrifice made possible by the demands of the ongoing care.

> *"Where no one even helps me that's also telling you that don't trust people…… people will neglect you when you are alone just trust yourself. For me not even my friends, my neighbours…… my sister, none of them were available to help me in this situation" (P020).*

At another level, social isolation during the times of caregiving strain presents a switch from relational dependence to enforced self-reliance. This demonstrates how inadequate social support enhances the caregivers' role as a sole decision maker, emphasising the extent of the perceived absence. This suggests that trust in others could have been lost after repeated moments of abandonment, hence compelling them to use self-trust as a survival strategy.

Discussion

This study demonstrates that family caregivers of individuals with psychosis occupy a central and significant yet unrecognised role in the management of psychosis. The key findings of the study are represented into three themes: Primary managers of treatment decisions, integrating biomedical and spiritual decision-making, and bearing clinical responsibility without adequate support. This reveals that family caregiving exceeds beyond relational responsibilities to informal decision makers who buffer institutional gaps.

In particular, the study findings reveal that caregivers navigate three interconnected dimensions of informal clinical authority namely, managerial control, interpretive mediation and assumed responsibility. Consistent with several studies that frame caregivers as administrators of medication and observers of adverse effects of the medication with limited consultation from professionals, they have shown to be regulators of treatment from deciding when admission is needed to what medication should be given [32, 33]. Studies further indicate that caregivers face ambivalence when confronted with the choice of surrendering their loved ones for admission as they experience feelings of uncertainty of the management considering limited medical resources [34]. This is because caregivers are normally left out by professionals when planning for care and even rarely consulted as stakeholders who could offer alternative perspectives based on experiential knowledge of the illness [35].

Notably, caregivers apply a multiple belief system as they engage in decision making and deliver psychiatric care to their loved ones. They integrate hospital-based care with cultural or spiritual explanations of illness, without entirely privileging one approach as they function as interpretive mediators between two or more explanatory approaches. This aligns with studies suggesting the need for professionals to be aware of the individuality, spiritual and cultural factors that could influence caregivers' attitudes towards caregiving [36, 37]. Similarly, faith-based approach provides an alternative interpretation of illness by providing a coexistence with biomedical and other reasoning systems rather than a competition [38]. The study findings further propose that pluralism helps caregivers decide when to privilege one approach over the other as spiritual integration into mental health services improves quality of care for all stake holders [39].

Furthermore, the study findings reveal a significant burden upon caregivers’ who must make clinical decisions and bear the responsibility without support from professionals. This institutional gap is consistent with perspectives of mental health professionals on informal caregivers’ needs that proposed the need for social policy strategies and health programmes that promote their wellbeing [40]. Research further emphasises the need for informal caregivers to receive institutional attention as their role exposes them to mental instabilities [41].

Caregivers carry a huge responsibility of managing daily routines and crises for their patients, while longing for professional guidance throughout the caring process [42]. As a result, they report inadequate involvement in decision making as they are perceived as health seekers rather than core stakeholders [32, 43]. Moreover, caregivers have demonstrated their willingness to engage with professionals on more trainings and alternative therapies for their loved ones. Caring for individuals with psychosis has been found to be a stressful responsibility that requires the involvement of caregivers in care planning as well as professional support to promote their quality of life [44]. Therefore, the results reaffirm the call for caregivers to be recognised as stakeholders in the management of psychosis as they play a key role in the decision making, support and recovery of their loved ones [45-47].

Conclusion

The study explored the lived experiences of first-hand family caregivers on how they function as they navigate their role as unrecognised and informal clinical decision makers. The study places caregivers as central actors in the delivery of mental health care despite the limited institutional infrastructure the patients endure. Further, this advances the understanding on the need for consultative management within a broader mental health system comprising community structures, mental health services and faith-based beliefs. There’s emphasis on the need for provision of knowledge on the illness and side effects, coping strategies and management strategies of psychosis. The inability to support and integrate informal caregivers as core stakeholders into mental health services is likely to endanger health of care recipients as they are likely to be mismanaged and negatively impact the caregivers’ wellbeing.

The study’s strengths lie in the exploration of family caregivers lived experiences which provided rich insights into how they navigate institutional gaps while managing chronic psychosis. Conducting the study at Chainama Hills Hospital gave allowance for contextually grounded findings, while the inclusion of caregivers across genders, ages, provinces and family roles enriched the diversity of perspectives. The methodological rigour was strengthened through reflexivity, audit trails and verbatims to ensure credibility and conformability.

However, the qualitative approach used presents several limitations. The idiographic inquiry of 30 participants from a single hospital makes findings ungeneralisable to all caregivers in Zambia or other contexts. The data relied on self-reports which may be affected by research bias and social desirability and the researcher’s clinical background could have influenced the interpretation despite reflexive practices.

To maximise the impact of the findings, there is need to formally recognise family caregivers as core stakeholders in psychosis care with the national mental health polices and develop structured caregiver frameworks that include mandatory crisis guidance. Nursing practice can be enhanced by routinely assessing caregiver wellbeing and support needs as part of standard psychiatric care. Future research should focus on longitudinal studies to examine mental health outcomes for caregivers' overtime and comparative studies of caregiver decision making across different settings in Zambia.

Ethical Approval

Ethical approval was obtained from ERES Converge IRB Ref no.2025-Mar-001 and approval to conduct the study from National Health Research Authority Ref no. NHRA-2080/27/03/2025.

Conflict of Interest

The author declares no conflict of interest, as no external funding or relationships influenced this study.

Acknowledgements

The author extends gratitude to all caregivers who generously shared their experiences and staff at Chainama Hills Hospital for their support. Gratitude is further extended to academic supervisors Professor Catherine Mubita Ngoma and Professor Rajesh Konnur for their guidance and all who provided encouragement throughout the research process.

Author Contribution

The leading and corresponding author of this paper was Virginia Simasiku, responsible for data collection, storage, analysis and writing. Professor Catherine Mubita Ngoma and Professor Rajesh Konnur were co-authors and responsible for supervision throughout the research process and manuscript writing.

Funding

The author didn't receive any form of financial support for this work.

Data Availability

The data used in this research is available upon request, though anonymised in order to protect the privacy of the participants.

References

[1]. Hardy, A., Keen, N., van den Berg, D., Varese, F., Longden, E., Ward, T., & Brand, R. M., 2023, Trauma therapies for psychosis: A state-of-the-art review. *Psychology and Psychotherapy: Theory, Research and Practice*, 96(4), 1234–1256, https://doi.org/10.1111/papt.12499

[2]. Solmi, M., Seitidis, G., Mavridis, D., Correll, C. U., Dragioti, E., Guimond, S., Tuominen, L., Dargél, A., et al., 2023, Incidence, prevalence, and global burden of schizophrenia—data, with critical appraisal, from the Global Burden of Disease (GBD) 2019. *Molecular Psychiatry*, 28, 5319–5327, https://doi.org/10.1038/s41380-023-02138-4

[3]. Deng, S., Wang, Y., Peng, M., Zhang, T., Li, M., Luo, W., & Ran, M., 2023, Quality of life among family caregivers of people with schizophrenia in rural China. *Quality of Life Research*, 32(6), 1759-1769. https://doi.org/10.1007/s11136-023-03349-6

[4]. Yoo, A., Kim, M., Ross, M. M., Vaughn-Lee, A., Butler, B., & dosReis, S., 2018, Engaging Caregivers in the Treatment of Youth with Complex Developmental and Mental Health Needs. *The Journal of Behavioral Health Services & Research*, 45(3), 440-453. https://doi.org/10.1007/s11414-018-9604-0

[5]. Isaacs, A. N., Lawn, S., Lambert, C., and Dyer, A., 2025, A qualitative study of the responsibilities and unmet needs of carers of persons with severe mental health challenges. *Journal of Mental Health*, 1–11. https://doi.org/10.1080/09638237.2025.2558501

[6]. Alasmee, N., 2020, Primary caregivers experience of anti-psychotic medication: A qualitative study. *Archives of Psychiatric Nursing*, 34(6), 520-528. https://doi.org/10.1016/j.apnu.2020.09.002

[7]. Stomski, N. J., & Morrison, P., 2018, Carers' involvement in decision making about antipsychotic medication: A qualitative study. *Health Expectations: An International Journal of Public Participation in Health Care and Health*

Policy, 21(1), 308–31. https://doi.org/10.1111/hex.12616

[8]. Lewins, A., Morant, N., Akther-Robertson, J., Crellin, N. E., Stansfeld, J. L., Smith, R., and Moncrieff, J., 2024, A qualitative exploration of family members' perspectives on reducing and discontinuing antipsychotic medication. *Journal of Mental Health*, 33(3), 333–340. https://doi.org/10.1080/09638237.2022.2069710

[9]. Orlando, S., Long, M., Akther-Robertson, J., Stansfeld, J., Haime, Z., Smith, R., Moncrieff, J., and Morant, N., 2025, Family and informal carers' views and experiences of antipsychotic reduction and discontinuation within a medication reduction research trial. *Journal of Mental Health*, 1–11. https://doi.org/10.1080/09638237.2025.2585195

[10]. Fekih-Romdhane, F., Saguem, B. N., Stambouli, M., Hallit, S., & Cheour, M., 2025, Violence victimization and perpetration within the caregiver-patient relationship in schizophrenia: A cross-sectional study in Tunisia. *PloS one*, 20(5), e0323312. https://doi.org/10.1371/journal.pone.0323312

[11]. Lal, S., Malla, A., Marandola, G., Thériault, J., Tibbo, P., Manchanda, R., Williams, R., Joober, R., and Banks, N., 2019, "Worried about relapse": Family members' experiences and perspectives of relapse in first-episode psychosis. *Early Intervention in Psychiatry*, 13(1), 24-29.https://doi.org/10.1111/eip.12440

[12]. Peng, M. M., Ma, Z., and Ran, M. S., 2022, Family caregiving and chronic illness management in schizophrenia: positive and negative aspects of caregiving. *BMC Psychol*, 10(83). https://doi.org/10.1186/s40359-022-00794-9

[13]. Simasiku, V., Ngoma, C. M., & Konnur, R., 2026, Family caregiving as a moral and spiritual commitment in Zambia's mental health care setting. *Texila International Journal of Academic Research*, 13(1). https://doi.org/10.21522/TIJAR.2014.13.01.Art007

[14]. Sichimba, F., Janlöv, A., and Khalaf, A., 2022, Family caregivers' perspectives of cultural beliefs and practices towards mental illness in Zambia: An interview-based qualitative study. *Scientific Reports*, 12, 21388. https://doi.org/10.1038/s41598-022-25985-7

[15]. Agyemang Duah, E. K., and Wilson, R. L., 2025, The Experiences of Sub-Saharan African Migrant Carers and Families of Young People with Emerging Psychosis. *International Journal of Mental Health Nursing*, 34(6), e70162. https://doi.org/10.1111/inm.70162

[16]. Iseselo, M. K., Kajula, L. and Yahya-Malima, K. I., 2016, The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: a qualitative urban based study in Dar es Salaam, Tanzania. *BMC Psychiatry*, 16, 146. https://doi.org/10.1186/s12888-016-0857-y

[17]. Verity, F., Turiho, A., Mutamba, B. B., & Cappo, D., 2021, Family care for persons with severe mental illness: Experiences and perspectives of caregivers in Uganda. *International Journal of Mental Health Systems*, 15, 48. https://doi.org/10.1186/s13033-021-00470-2

[18]. Clari, R., Headley, J., Egger, J., Swai, P., Lawala, P., Minja, A., Kaaya, S., and Baumgartner, J. N., 2022, Perceived burden and family functioning among informal caregivers of individuals living with schizophrenia in Tanzania: a cross-sectional study. *BMC Psychiatry*, 2210). https://doi.org/10.1186/s12888-021-03560-0

[19]. Dehbozorgi, R., Shahriari, M., Fereidooni-Moghadam, M., and Moghimi-Sarani, E., 2023, Family-centered collaborative care for patients with chronic mental illness: A systematic review. *Journal of Research in Medical Sciences*, 28(1), 6. https://doi.org/10.4103/jrms.jrms_410_22

[20]. Cochrane, C., Moran, N., and Newton, E., 2021, Exploring the impacts of a carers' psycho-education group: personal insights from the family of people with early psychosis. *Psychosis*, 13(3), 253–264. https://doi.org/10.1080/17522439.2020.1861073

[21]. Chow, J. Y. A., Yeo, Y. T. T., and Goh, Y. S., 2024, Effects of Psychoeducation on Caregivers of Individuals Experiencing Schizophrenia: A Systematic Review and Meta-Analysis. *International Journal of Mental Health Nursing*, 33(6), 1962-1987. https://doi.org/10.1111/inm.13421

[22]. Abou Seif, N., Wood, L., and Morant, N., 2022, Invisible experts: A systematic review and thematic synthesis of informal carer experiences of inpatient mental health care. *BMC Psychiatry*, 22, 347. https://doi.org/10.1186/s12888-022-03872-9

[23]. Chen, Y. C., Sun, F. K., Huang, X. Y., Chien, C. H., and Kuo, Y. J., 2025, 'Did I Make the Right Choice': A Qualitative Exploration of Decision Regret Among Family Caregivers After Hospitalising a Patient with Schizophrenia. *International Journal of Mental Health Nursing*, 34(1), e70012. https://doi.org/10.1111/inm.70012

[24]. Wertz, F. J., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., and McSpadden, E., 2011, Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry. *New York: Guilford Press*.

[25]. Creswell, J. W., 2009, Research design: Qualitative, quantitative, and mixed methods approaches. 3rd ed. Thousand Oaks, *CA: Sage Publications*

[26]. Pietkiewicz, I., and Smith, J. A., 2012, A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 18(2), 361–369.

[27]. . Smith, J. A., and Osborn, M., 2008, Interpretative phenomenological analysis. In: J. A. Smith (ed.), Qualitative psychology: A practical guide to research methods, 2nd ed. (*London: Sage Publications*), pp. 53–80.

[28]. Muvwimi, T. S., Ngoma, C. M., and Salgado, A. B., 2025, Cultivating self-motivation, lifestyle modification and emotional resilience in elderly patients with multimorbidity: A path to successful self-management. *Texila Advanced Journal of Multidisciplinary Health Research*, 5(1), Article 018. doi:10.21522/TAJMHR.2016.05.01.Art018.

[29]. Smith, J. A., Flowers, P., and Larkin, M., 2009, Interpretative phenomenological analysis: Theory, *method and research (London: Sage Publications Ltd)*.

[30]. Lincoln, Y. S., & Guba, E. G., 1985, Naturalistic inquiry. Thousand Oaks, *CA: Sage*.

[31]. Smith, J. A., Flowers, P., and Larkin, M., 2009, Interpretative phenomenological analysis: Theory, *method and research (London: Sage Publications Ltd)*.

[32]. Huang, C., Lam, L., Plummer, V., Cross, W. M., 2021, Feeling responsible: Family caregivers' attitudes and experiences of shared decision-making regarding people diagnosed with schizophrenia: A qualitative study. *Patient Educ Couns*. 104(7):1553–1556. https://doi.org/10.1016/j.pec.2020.10.032

[33]. Zhou, H., Ma, F., Zhang, Y., Tan, Y., Bai, Y., Hu, Q., Wei, W., and Wang, Y., 2022, Perceptions of Family Caregivers of Patients with Schizophrenia Towards Antipsychotics Associated Side-Effects in China: A Qualitative Study. *Patient Preference and Adherence*, 16, 2171–2179. https://doi.org/10.2147/PPA.S372487

[34]. Akintobi, T., 2023, Caregiver Perspective in a Mental Diagnosis of Hyperreligiosity. *Research Square*. https://doi.org/10.21203/rs.3.rs-3152640/v1

[35]. Freeman, A., Swartz, L., and Asmal, L., 2026, Between relief and estrangement: Family experiences of involuntary treatment for psychosis in South Africa. *Social Science & Medicine*, 390, 118871.
https://doi.org/10.1016/j.socscimed.2025.118871

[36]. Subu, M. A., Holmes, D., Arumugam, A., Al-Yateem, N., Maria Dias, J., Rahman, S. A., Waluyo, I., Ahmed, F. R., and Abraham, M. S., 2022, Traditional, religious, and cultural perspectives on mental illness: A qualitative study on causal beliefs and treatment use. *International Journal of Qualitative Studies on Health and Well-Being*, 17(1). https://doi.org/10.1080/17482631.2022.2123090

[37]. Irawati, K., Indarwati, F., Haris, F., Lu, J. Y., and Shih, Y. H., 2023., Religious Practices and Spiritual Well-Being of Schizophrenia: Muslim Perspective. *Psychology Research and Behaviour Management*, 16, 739–748. https://doi.org/10.2147/PRBM.S402582

[38]. Benyah, F. E. K., 2023, Healing and mental illness in Ghana: Why prayer camps in Ghana are sometimes alternatives to psychiatric hospitals.

Temenos-Nordic Journal for the Study of Religion, 59(1), 101-123. https://doi.org/10.33356/temenos.109270

[39]. Rastogi, S., Pandey, P., Maurya, K., Kumar, S., Varma, A., and Singh, G., 2023, Self reported benefits of participating in group prayer in a hospital outpatient setting: A cross-sectional observational study. *Journal of Ayurveda and Integrative Medicine*, 14(5), p.100738. https://doi.org/10.1016/j.jaim.2023.100738

[40]. Moudatsou, M., Koukouli, S., Palioka, E., Pattakou, G., Teleme, P., Fasoi, G., Kaba, E., and Stavropoulou, A., 2021, Caring for Patients with Psychosis: Mental Health Professionals' Views on Informal Caregivers' Needs. *International Journal of Environmental Research and Public Health*, 18(6), 2964. https://doi.org/10.3390/ijerph18062964

[41]. Sin, J., Elkes, J., Batchelor, R., Henderson, C., Gillard, S., Woodham, L. A., & Cornelius, V., 2021, Mental health and caregiving experiences of family carers supporting people with psychosis. *Epidemiology and Psychiatric Sciences*, *30*, e3. https://doi.org/10.1017/S2045796020001067

[42]. Jimena, A. V., Morales-Asencio, J. M., Quemada, C., and Hurtado, M. M., 2025, A qualitative study on care roles and health support for family caregivers of people with psychotic disorders in Spain. *Archives of Psychiatric Nursing*. https://doi.org/10.1016/j.apnu.2025.152027

[43]. Citrome, L., Belcher, E., Stacy, S., Suett, M., Mychaskiw, M., & Salinas, G. D., 2022, Perceived Burdens and Educational Needs of Caregivers of People with Schizophrenia: Results of a National Survey Study. *Patient Preference and Adherence*, 16, 159–168. https://doi.org/10.2147/PPA.S326290

[44]. Cruz, E., Paré, M. A., Stan, C., Voth, J., Ward, L., & Taboun, M., 2024, Caring for the caregiver: an exploration of the experiences of caregivers of adults with mental illness. *SSM-Qualitative Research in Health*, 5, 100406. https://doi.org/10.1016/j.ssmqr.2024.100406

[45]. Estradé, A., Onwumere, J., Venables, J., Gilardi, L., Cabrera, A., Rico, J., Hoque, A., Otaiku, J., Hunter, N., Kéri, P., and Kpodo, L., 2023, The lived experiences of family members and carers of people with psychosis: a bottom-up review co-written by experts by experience and academics. *Psychopathology*, 56(5), 371-382. https://doi.org/10.1159/000528513

[46]. Schuster, F., Holzhüter, F., Heres, S., and Hamann, J., 2021, 'Triadic'shared decision making in mental health: Experiences and expectations of service users, caregivers and clinicians in Germany. *Health Expectations*, 24(2), 507-515. https://doi.org/10.1111/hex.13192

[47]. Kraun, L., De Vliegher, K., Vandamme, M., Holtzheimer, E., Ellen, M., and van Achterberg, T., 2022, Older peoples' and informal caregivers' experiences, views, and needs in transitional care decision-making: a systematic review. *International Journal of Nursing Studies*, 134, 104303. https://doi.org/10.1016/j.ijnurstu.2022.104303