

Family Caregiving for Individuals with Mental Disorders in Zambia: Implications for Health Systems Strengthening in a Resource-Constrained Setting

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Abstract

Mental disorders are a leading cause of disability globally, and the transition toward community-based mental health care has increased reliance on family caregivers, particularly in low- and middle-income countries. In these settings, limited institutional support has shifted substantial caregiving responsibilities onto households, raising critical public health concerns. This study explored the multidimensional burden experienced by family caregivers of individuals with mental disorders and examined its implications for health systems strengthening in Zambia.

A descriptive qualitative design was employed at a national psychiatric referral hospital, where twenty caregivers were purposively selected. Data were collected through semi-structured interviews and analyzed using thematic analysis. The findings revealed that caregiver burden is multifaceted, encompassing psychological distress characterized by anxiety, stigma, and emotional exhaustion; physical strain including fatigue, sleep disruption, and neglect of personal health; and socio-economic challenges such as financial hardship, employment disruption, and barriers to accessing care. These burdens were exacerbated by systemic gaps, including limited mental health infrastructure, inadequate community-based services, and the absence of formal caregiver support mechanisms.

The study concludes that family caregiving represents a critical yet under-recognized component of mental health systems. Addressing caregiver burden requires integrating caregiver support into national mental health strategies, strengthening community-based care, and implementing policies that recognize and support informal caregivers as part of the health workforce.

Keywords: Caregivers, Family Caregivers, Challenges, Effects, Mental Illness, Mental Disorders

1. Introduction

Mental disorders constitute a major public health challenge, contributing significantly to global morbidity, disability, and reduced quality of life [1]. The global transition from institutionalized psychiatric care to community-based models has redefined the structure of mental health systems, shifting the responsibility for long-term care from formal institutions to families and communities. While this transition aligns with human rights principles and promotes social inclusion, it has also resulted in increased reliance on informal caregivers, particularly in low- and middle-income countries (LMICs) where health systems are

often under-resourced.

In many LMICs, including Zambia, mental health services are characterized by limited funding, workforce shortages, and centralized care delivery. As a result, family caregivers play a central role in supporting individuals with mental disorders, often without adequate training, financial support, or access to healthcare services. This reliance on informal caregiving effectively shifts part of the health system burden to households, raising important questions about equity, sustainability, and health system resilience [2].

Caregiver burden is increasingly recognized as a multidimensional construct encompassing psychological, physical, and socio-economic challenges [3]. Recent evidence from Africa indicates that caregiver burden is highly prevalent, with a substantial proportion of caregivers experiencing significant levels of distress [4]. These challenges not only affect caregiver well-being but also have broader implications for patient outcomes and the effectiveness of mental health systems.

Despite the growing recognition of caregiver burden, there is limited context-specific evidence from Zambia examining caregiving within a health systems framework. Most existing studies focus on individual experiences without adequately linking these to broader public health and policy implications. This study addresses this gap by exploring caregiver experiences through a health systems lens, with a focus on understanding how caregiver burden reflects and reinforces systemic weaknesses in mental health service delivery.

2. Conceptual Framework

This study is informed by the integration of the Social Determinants of Health framework and the Stress–Coping Model, providing a comprehensive lens through which caregiver burden can be understood. The Social Determinants of Health framework emphasizes the role of socio-economic factors, including income, employment, education, and access to healthcare, in shaping health outcomes [1]. These determinants are particularly relevant in caregiving contexts, where financial constraints and limited access to services exacerbate the burden experienced by caregivers.

The Stress–Coping Model complements this perspective by conceptualizing caregiving as a dynamic process in which stress arises from the interaction between caregiving demands and available coping resources. Primary stressors include patient-related factors such as symptom severity and behavioural unpredictability, while secondary stressors involve role strain, financial pressures, and social expectations. The ability of caregivers to cope with these stressors is influenced by the availability of social support, coping strategies, and access to resources.

By integrating these frameworks, caregiver burden is conceptualized not only as an individual experience but also as a manifestation of broader social and health system dynamics. This perspective underscores the importance of addressing caregiver needs as part of comprehensive public health and health systems strengthening strategies.

3. Methods

A descriptive qualitative design was employed to explore the lived experiences of family caregivers in depth. The study was conducted at Chainama Hills Hospital, Zambia's national psychiatric referral facility. Participants were purposively selected based on their role as primary caregivers of individuals with mental disorders and their caregiving experience of at least six months. Twenty caregivers participated in the study, with recruitment continuing until data saturation was achieved.

Data were collected through semi-structured interviews, which provided participants with the opportunity to describe their experiences in their own words. Interviews were conducted in English and local languages to ensure inclusivity and clarity. All interviews were audio-recorded with participant consent and transcribed verbatim.

Data analysis was conducted using thematic analysis, involving a systematic process of familiarization, coding, theme development, and interpretation. Ethical approval was obtained from Cavendish University Ethical Research Board and Ministry of Health. All participants provided informed consent. Measures were taken to ensure confidentiality and voluntary participation throughout the study.

4. Results

The findings of this study reveal that caregiver burden is multidimensional and shaped by the interaction of psychological, physical, and socio-economic factors within a constrained health system context.

Caregivers reported significant psychological distress, characterized by persistent anxiety, emotional exhaustion, and feelings of helplessness.

4.1. Theme 1: Psychological Challenges Experienced by Family Caregivers

The findings from the interviews revealed that family caregivers experienced significant psychological and emotional challenges while caring for their relatives with mental illness. Participants described feelings of helplessness, fear, emotional pain, stigma, loneliness, frustration, and mental exhaustion. Their responses showed that caregiving affected not only their daily routines but also their emotional well-being. The following subthemes emerged from the participants' narratives.

4.1.1. Feelings of Helplessness

Many participants described a strong sense of helplessness when dealing with their relative's condition. They explained that despite their efforts to provide care, they often felt unable to change or control the situation.

Participant 03 stated, *"Sometimes I just sit down and look at him and I feel empty inside. I ask myself, what else can I do? I talk, I advise, I even beg him to take his medicine, but he refuses. At that moment I feel like I have failed."* This response reflected deep emotional pain and a feeling of personal inadequacy.

Similarly, **Participant 15** explained, *"When he starts behaving strangely, I try to calm him down, but he pushes me away. I feel useless because nothing I do seems to help."* She further added, *"There are days I cry quietly at night because I do not know what tomorrow will bring."*

Participant 01 also expressed dependence on external support, stating, *"I rely on God and the mental hospital because alone I*

cannot manage.” These statements showed that caregivers often felt powerless and emotionally overwhelmed.

4.1.2. Fear and Constant Anxiety

Fear was another common psychological challenge reported by participants. Many caregivers described living in constant worry due to unpredictable and sometimes aggressive behavior.

Participant 12 shared, “*When he starts shouting and breaking things, my heart beats fast. I fear he might hurt someone or even hurt himself.*” He added that even during calm moments, he remained anxious because he did not know when another episode might occur.

Participant 18 stated, “*He throws plates and sometimes stones outside. I worry the neighbors will complain or that someone will get injured.*” This response showed that caregivers feared both physical harm and possible community conflict.

Participant 07 explained, “*If he leaves the house without telling anyone, I cannot rest. My mind keeps thinking about what might happen.*” These responses demonstrated that caregivers lived in a state of ongoing tension and alertness.

4.1.3. Emotional Pain Due to Stigma

Stigma and negative attitudes from the community caused deep emotional distress among caregivers. Several participants reported feeling ashamed and hurt by the comments made by neighbors.

Participant 02 said, “*Some neighbors say we are cursed. Those words hurt me deeply.*” She further explained that although she tried to ignore such remarks, they affected her emotionally.

Participant 07 stated, “*People point at our house and whisper. It makes me feel ashamed.*”

Participant 20 added, “*I stopped attending some gatherings because I feel people are talking about us.*” These responses showed that stigma led to embarrassment, reduced self-confidence, and withdrawal from social activities.

4.1.4. Loneliness and Social Isolation

Many caregivers described feeling isolated and unsupported. They explained that friends and even extended family members distanced themselves after learning about the mental illness in their household.

Participant 05 stated, “*Before the illness, we had visitors often. Now nobody comes. It feels like people are afraid of us.*”

Participant 11 shared, “*Even our relatives stopped calling. It feels like we are alone in this situation.*”

These responses highlighted the emotional burden caused by lack of social support. The absence of encouragement and understanding made caregiving more stressful.

4.1.5. Frustration and Emotional Exhaustion

Participants also reported frustration due to the unpredictable nature of mental illness. They explained that sudden mood changes made it difficult to plan daily activities.

Participant 01 said, “*It is very hard to plan anything because his mood changes anytime.*”

Participant 12 explained, “*You have to watch him closely every day. Even when you are tired, you cannot relax.*”

Participant 17 expressed emotional exhaustion by saying, “*Sometimes I feel tired in my mind more than in my body. I keep asking myself how long this will continue.*”

These statements showed that continuous monitoring and uncertainty caused mental fatigue and stress.

4.2. Theme 2: Physical Challenges Faced by Family Caregivers

The study revealed that family caregivers faced multiple physical challenges due to the constant demands of caring for their relatives with mental disorders. These challenges included exhaustion, lack of sleep, body pains, and neglect of their own health. The participants’ own words highlighted the intensity of these experiences.

Many participants reported feeling physically drained.

Participant 08 said, “*I am always tired. Even when I sit down to rest, I feel like my body is giving up. I have to watch him all the time; I cannot leave him alone.*”

Participant 12 also shared, “*I sleep very little because I am always worried. I wake up several times at night to check if he is okay or if he has done something wrong.*” This demonstrates that sleep deprivation was a major concern, as caregivers had to remain alert almost around the clock.

Some participants reported chronic body pains.

Participant 14 explained, “*My knees hurt, and my eyes feel sore from watching him all the time. Sometimes I take medicine to manage the pain, but it does not go away completely.*”

Similarly, **Participant 16** added, “*My back and shoulders are always aching because I lift him or help him with daily tasks. I barely have time to care for my own health.*” These statements reflect how the physical effort of caregiving directly affected the caregivers’ health.

Neglect of personal health was common and the participants expressed the following sentiments:

Participant 16 admitted, “*I have not gone to the doctor in months. Everything I do is for him. I cannot leave him alone even for a short time. My own health is suffering, but I have no choice.*”

Participant 14 echoed this, saying, “*I feel weak sometimes, but I cannot take a break. I have to make sure he eats and takes his*

medicine. There is no one else to do it.”

The participants also reported that caregiving responsibilities disrupted their social and personal lives.

Participant 14 said, “I cannot go to weddings, funerals, or even visit friends. There is no one to stay with him, so I have to stay home.”

Participant 16 expressed a similar concern, “I used to be able to go out and do my own things, but now I spend all my time at home. My life has completely changed because of him.”

Several participants described altered daily priorities due to caregiving.

Participant 05 stated, “Everything in my life now revolves around him. I cannot plan anything else because his care comes first. I even skip meals sometimes because I am too busy with him.”

Participant 03 shared, “He used to take care of himself, but now I have to remind him to eat, bathe, and take his medicine. I even help him dress sometimes. It takes all my energy.”

Aggressive or unpredictable behavior of their relatives made caregiving even more physically demanding.

Participant 08 said, “Sometimes he breaks things in the house or throws objects. I have to stop him, calm him down, and make sure nobody gets hurt. By the end of the day, I feel completely worn out.”

Participant 19 added, “He shouts and acts violently, and I have to be on guard all the time. I cannot rest because I do not know what will happen next.”

Some caregivers reported high blood pressure, heart problems, and other chronic conditions. **Participant 05** explained, “I get sick often, and my blood pressure rises when I think about his future. The stress and worry do not leave me. I lose my appetite, and I feel weak.”

Participant 12 said, “My heart races sometimes just thinking about what might happen if I am not around to take care of him. It is very stressful physically and emotionally.”

Overall, the participants’ words showed that caregiving placed a heavy physical burden on family members. Exhaustion, sleep loss, body pains, and neglect of personal health were common. The unpredictability and occasional violence of the mentally ill relative made caregiving even more challenging. Social life restrictions and altered priorities further compounded their physical strain. These experiences highlight how caregiving affects not only the mental but also the physical well-being of family caregivers.

4.3. Theme 3: Family Caregivers’ Social-Economic Challenges

The study revealed that family caregivers faced significant social and economic challenges while caring for their relatives with

mental disorders. These challenges mainly revolved around financial strain, difficulties in accessing healthcare, and balancing caregiving responsibilities with personal and family needs. The participants’ own words highlighted the real impact of these challenges on their daily lives.

Several participants reported that ensuring their relative took their medication correctly was a constant struggle that also affected their finances.

Participant 03 said, “I always have to remind him and sometimes beg him to take his medicine. If I don’t, he refuses, and then he becomes very agitated.”

Similarly, **Participant 09** shared, “I spend a lot of money on transport every month to bring him to the hospital for his free medication. Sometimes it feels like I am buying the medicine because the fare is so high. It is really hard on my wallet because I live far from the hospital.”

Participant 17 added, “It is very tiring and expensive. I have to come here every month, and the transport costs are a real problem for me. I have to choose between food and transport sometimes.” These statements show that even when medication is provided free, caregivers still face financial burdens just in trying to access services.

Other participants reported missing hospital reviews or appointments for their relatives because of lack of money for transport.

Participant 02 said, “Sometimes I cannot bring him to the hospital because I do not have money for transport. I feel bad because I want him to get better, but there is nothing I can do.”

Participant 13 expressed a similar struggle, “I have missed many reviews for him because I cannot afford to come. I just hope he takes his medicine at home, but I worry a lot.”

Participant 20 added, “It is really frustrating. I want to help him, but I do not have enough money to provide even the basic things he needs. Sometimes I feel helpless.” These experiences highlight how financial limitations can directly affect the care that family members are able to provide, leading to stress and worry.

The study also found that caregiving affected participants’ work and ability to earn a living. Many participants reported that caregiving responsibilities took up most of their time, leaving little opportunity for employment or business activities.

Participant 03 said, “I cannot go to work like I used to because I have to stay home and watch him. If I leave him alone, he can hurt himself or destroy things.”

Participant 09 explained, “I used to run a small business, but now I have to stop it because I have to be here every day. I am losing

money and I cannot provide for the family like before.” This shows that caregiving not only imposed a direct financial burden but also reduced opportunities for income generation. Moreover, participants described the emotional impact of financial strain.

Participant 17 shared, “I feel stressed and worried all the time because I do not know how I will get money for transport, food, or other needs. It is like a constant weight on my shoulders.”

Participant 13 added, “I cannot sleep at night thinking about how I will manage everything. It affects my health and my ability to take care of him properly.” These words show that social and economic challenges were closely linked to psychological stress, creating a cycle of worry, financial strain, and physical exhaustion.

Physical burden was also a prominent feature of caregiving experiences. Participants described chronic fatigue, sleep deprivation, and neglect of their own health needs because of continuous caregiving responsibilities. The absence of formal support services, such as respite care, further intensified physical strain, highlighting gaps in service provision within the health system. Socio-economic challenges were pervasive, with caregivers experiencing financial strain due to the costs associated with caregiving, including transportation, medication, and daily living expenses. Caregiving responsibilities often interfered with employment, leading to reduced income and financial insecurity. These challenges reflect broader structural inequalities and underscore the role of socio-economic determinants in shaping caregiver experiences.

5. Discussion

This study highlights the critical role of family caregivers as an informal extension of the mental health workforce in resource-constrained settings. From a health systems perspective, caregivers provide essential services that would otherwise require formal institutional support. However, this reliance on informal caregiving is not matched by corresponding investments in caregiver support, resulting in significant burden and vulnerability.

The unpredictable nature of mental illness contributed to chronic stress, while stigma associated with mental disorders led to social isolation and reduced community support. These findings are consistent with existing evidence indicating that caregivers are at increased risk of mental health problems due to prolonged exposure to caregiving stressors [4].

The psychological distress experienced by caregivers reflects the emotional demands of managing chronic mental illness, compounded by stigma and limited social support. These findings suggest that caregiver mental health should be recognized as a public health priority, given its implications for both caregivers and patients.

Physical strain observed among caregivers highlights the need for health systems to incorporate support mechanisms that address

caregiver well-being. The absence of respite care and structured support services indicates a gap in service delivery that requires urgent attention.

Socio-economic challenges further illustrate the intersection between health and social determinants. Financial strain and employment disruption not only affect caregiver well-being but also undermine the sustainability of caregiving arrangements. This has implications for health system resilience, as caregiver burnout may lead to increased demand for institutional care.

Overall, the findings suggest that caregiver burden is not merely an individual issue but a reflection of systemic weaknesses in mental health service delivery. Addressing these challenges requires a shift toward integrated, multi-sectoral approaches that recognize caregivers as key stakeholders in health systems.

5.1. Public Health and Health Systems Implications

The findings of this study underscore the need to integrate caregiver support into national mental health strategies as part of broader health systems strengthening efforts. Recognizing caregivers as an essential component of the mental health workforce is critical for improving service delivery and patient outcomes. This recognition should be accompanied by the development of policies that provide financial support, access to healthcare, and social protection for caregivers.

Strengthening community-based mental health services is also essential for reducing the burden on caregivers. Expanding access to decentralized services can improve continuity of care and reduce reliance on informal caregiving. Additionally, the implementation of caregiver education and support programs can enhance caregiving capacity and reduce psychological distress.

Efforts to address stigma are equally important, as stigma remains a significant barrier to social support and service utilization. Public health interventions aimed at increasing awareness and promoting mental health literacy can contribute to more supportive environments for caregivers and patients.

6. Conclusion

Family caregiving is a central yet under-recognized pillar of mental health systems in resource-constrained settings. The multidimensional burden experienced by caregivers reflects broader health system gaps and social inequalities. Addressing caregiver needs requires a comprehensive public health approach that integrates caregiver support into policy, practice, and service delivery. Strengthening support for caregivers is essential for improving population mental health outcomes and enhancing the resilience of health systems.

Availability of data and materials

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Clinical Trial Number: not applicable.

Human Ethics Declaration

This research study titled, “**Family Caregiving for Individuals with Mental Disorders at Chainama Hills Hospital, Zambia: Implications for Health Systems Strengthening in a Resource-Constrained Setting**”, this study followed the ethical principles of Helsinki [5].

Informed Consent Declaration

This study was conducted in accordance with ethical principles governing research involving human participants and received approval from the Cavendish University Ethics Committee [CU REC], Lusaka, Zambia. Participation in the study was voluntary. Participants were provided with detailed participant information sheets explaining the purpose, procedures, potential risks and benefits of the study. Written informed consent was obtained from participants prior to their inclusion in the study. All participants were assured of confidentiality; anonymity and the protection of personal information. They were informed of their right to decline participation or to withdraw from the study at any stage without any penalty or loss of benefits.

Informed Consent for Publication

Informed consent for publication was obtained from the participants at the point of recruitment to the study.

Conflict of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Author Contributions

V.N and B.C.M wrote the main manuscript text, T.K.structured the manuscript and K.T.M proofread the manuscript. All authors reviewed the manuscript.

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