

Title: The Uncompensated Workforce: A Critical Analysis of the Experiences and Challenges of Informal Caregivers in Zambia



Research Article

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Abstract

Introduction: The growing burden of Alzheimer's disease and related dementias in low- and middle-income countries (LMICs) has significant implications for health systems, household economies and social protection frameworks. In Zambia, long-term care is largely delivered through community- and home-based models, resulting in a heavy reliance on informal caregivers. Despite their central role in sustaining care provision, informal caregivers remain economically invisible and largely uncompensated in national health and labour systems.

Methodology: This article analyses the experiences and challenges faced by caregivers of individuals living with Alzheimer's disease in Zambia. Using a qualitative descriptive approach based on secondary data analysis, this study synthesises evidence from peer-reviewed literature, policy documents, and regional caregiving research to situate caregiving within the broader Sub-Saharan African care burden context.

Results: The findings indicate that the caregiver burden is multidimensional. Physically, caregivers often operate under conditions of infrastructural deprivation, including limited access to water, sanitation, and assistive care technology. Economically, caregiving contributes to financial strain

through direct medical costs, income loss, and depletion of household assets. Caregivers experience stigma, isolation, and chronic stress.

Conclusion: The study concludes that informal caregiving represents essential but unpaid health labour in Zambia. Greater policy recognition, financial protection mechanisms, and integration of caregivers into health system planning are required to ensure the sustainability of long-term care.

Keywords: Informal caregiving; Alzheimer's disease; unpaid labour; financial toxicity; health systems; Zambia; development policy.

1.0 Introduction

1.1 Global and Regional Context

Alzheimer's disease is a progressive neurodegenerative condition characterised by cognitive decline, behavioural changes, and loss of functional independence. Globally, more than 55 million people live with dementia, and the numbers are expected to rise significantly, particularly in LMICs, due to demographic transition and increased life expectancy. These trends place increasing pressure on health systems, especially in settings where long-term care infrastructure is limited.

Sub-Saharan Africa is undergoing an epidemiological transition marked by the coexistence of infectious and rising non-communicable diseases,

including dementia. However, many health systems remain primarily oriented toward acute and infectious disease management, resulting in limited institutional capacity for long-term chronic care provision.

1.2 The Zambian Caregiving Context

In Zambia, limitations in the formal health system have reinforced the reliance on informal caregivers. The expansion of home-based care during the HIV epidemic strengthened dependence on family labour as a cost containment strategy. While this improved treatment access, it also shifted long-term care responsibilities to households without providing adequate financial protection, training or labour recognition.

Caregiving is also shaped by socio-cultural norms that emphasise family responsibility and collective identity. In many communities, caregiving is viewed as a social obligation rather than a formal or compensated role. While these norms provide social legitimacy to caregiving, they may also discourage seeking external support.

Evidence suggests that the caregiver burden extends beyond emotional strain. Physical demands include patient handling and sanitation management, often under limited water access. Economically, caregivers frequently experience reduced labour participation, income loss, and long-term economic insecurity, particularly among women who constitute the majority of caregivers.

1.3 Problem Statement

Although informal caregivers play a central role in sustaining healthcare delivery, they remain largely absent from formal health workforce planning, labour policy, and social protection frameworks. This structural

gap exposes caregivers to economic vulnerability and health risks.

While existing research documents caregiver burden globally and regionally, limited scholarship conceptualises informal caregivers as part of a functional health labour system within national development and economic structures, particularly in Zambia.

1.4 Contribution of the Study

This study contributes to development and health policy scholarship by moving beyond the traditional conceptualisation of caregiver burden as an individual or family concern and instead framing informal caregiving as an essential but unpaid component of Zambia's health system and national development. While previous studies have largely documented the psychological, physical, and economic burdens experienced by caregivers, they have paid limited attention to the structural role of unpaid caregivers in sustaining health service delivery in resource-constrained settings. By synthesising evidence through the combined

lenses of the Stress Process Model, Social Solidarity Theory, and the Feminist Political Economy of Care, this study demonstrates how caregiving functions as hidden health labour that subsidises public health systems while reinforcing gender and socioeconomic inequalities. The study therefore addresses an important theoretical gap by integrating health systems, development, and care economy perspectives, and a policy gap by providing evidence

1.5 Objective

This study aimed to analyse the experiences and challenges faced by caregivers providing care to individuals living with Alzheimer's disease in Zambia.

2. Literature Review

2.1 Nature of Caregiving and Financial Compensation

2.1.1 Informal Caregiving as Essential but Structurally Unpaid Health Labour

Informal caregiving is a foundational but largely invisible component of

global health system functioning. Informal caregivers, typically family members, friends, or community actors, provide the majority of long-term care for individuals living with chronic illnesses, disabilities, and age-related dependency. Despite its centrality to health system sustainability, caregiving labour remains largely unpaid and structurally unrecognised within formal economic accounting systems (Arno et al., 1999; WHO, 2023).

Global demographic aging and the epidemiological transition toward chronic non-communicable diseases (NCDs), including dementia, have intensified reliance on household-based care provision. In low- and middle-income countries (LMICs), this reliance is amplified by constrained public health financing, weak long-term care systems, and limited social protection coverage (Prince et al., 2015). In Zambia, historical policy reliance on home-based care during the HIV epidemic institutionalized dependence on family labour, effectively transferring long-term care responsibilities from the state to households (Banda et al., 2017)

This structural arrangement positions informal caregivers as a de facto, unpaid workforce. From a policy perspective, unpaid caregiving represents a hidden subsidy that sustains health system functionality

while transferring economic and health risks to the households.

Although informal caregivers provide most long-term care for individuals living with Alzheimer's disease in Zambia, formal care systems remain an essential component of comprehensive dementia care. Formal care refers to services provided by trained healthcare professionals, social workers, community health workers, hospitals, residential care facilities, and government-supported services. In many high-income countries, these services complement family caregiving through respite care, home-based nursing, counselling, memory clinics and long-term care programmes. However, in Zambia, specialised dementia services remain limited, resulting in families assuming most caregiving responsibilities with minimal institutional support. Therefore, strengthening collaboration between formal health services and informal caregivers is critical for improving the quality and sustainability of dementia care.

2.1.2 Financial Compensation and Financial Toxicity

The economic consequences of caregiving are increasingly conceptualised through the framework of financial toxicity, which captures both direct medical expenditures and indirect economic losses associated with caregiving

responsibilities (Chong et al. 2022). These include transportation costs, medical supplies, lost wages, disrupted employment trajectories, and long-term income penalties.

In LMIC settings, caregiving costs frequently drive households into medical poverty traps, where families liquidate productive assets or withdraw from income-generating activities to finance care (Whitehead et al., 2001). In Zambia, even where public healthcare services are nominally free, indirect costs such as transport and consumables create substantial financial barriers to treatment access (World Bank, 2021)

Opportunity costs are particularly severe for women in the informal economy, where caregiving often results in permanent income loss due to absence from markets or trading networks (Mukosiku and Zulu, 2020)

2.1.3 Gendered Distribution of Unpaid Care Labour

Caregiving labour is globally gendered, with women performing the majority of physically and emotionally intensive care tasks (Sharma et al., 2016). In Sub-Saharan Africa and Zambia specifically, women frequently experience a triple burden of domestic labour, income generation, and caregiving (women frequently experience a triple burden of domestic labour, income generation,

and caregiving (Musonda et al., 2021; Mfidi, 2023).")

This distribution reflects structural social expectations rather than individual choices. The persistent feminisation of care labour reinforces structural inequality by limiting women's labour force participation and long-term economic security (Tronto, 2013; Folbre, 2001).

2.2 Empirical Evidence

Global research consistently demonstrates that caregiving is associated with a multidimensional burden encompassing psychological, physical, social, and economic strain (Zarit et al., 1980; Pearlin et al., 1990). Caregivers experience higher rates of depression, anxiety, chronic stress, and immune dysfunction than non-caregivers (Pinquart and Sörensen, 2003; Choi, 2024).

Evidence suggests that care intensity, particularly in dementia care, is the primary determinant of caregiver health decline (Adelman et al., 2014). These findings establish caregiving as a public health issue rather than purely a private family responsibility.

Caregiving in Sub-Saharan Africa occurs within what has been described as a crisis of care, driven by the convergence of the infectious disease burden, rising NCD prevalence, and weak health system infrastructure (Ogwumike and Aboderin, 2005).

The regional phenomenon of grandmother caregiving reflects structural demographic shifts, wherein older women provide care for both adult children and grandchildren (Schatz, 2007). This pattern accelerates health decline among elderly caregivers and redistributes limited social protection resources across entire households

In Zambia, older women frequently assume caregiving responsibilities for spouses, adult children, and other family members living with Alzheimer's disease while simultaneously managing their own age-related health conditions and limited financial resources. Many grandmothers rely on small pensions, subsistence farming, or family support to sustain caregiving, which increases their vulnerability to physical exhaustion and economic hardship. Despite their significant contribution to household and community well-being, older caregivers remain largely overlooked in health policy and social protection programs, highlighting the need for targeted interventions that recognise their unique caregiving role.

Empirical studies demonstrate that caregiving in Zambia occurs within a resource-constrained environment characterised by infrastructure limitations, high poverty levels, and weak, long-term care policy frameworks (Iliffe et al., 2019). Caregivers frequently provide care

without access to assistive devices, sanitation infrastructure, or protective equipment, which increases physical strain and infection risk (Phiri et al., 2024). The economic burden is severe. Households frequently engage in distress coping strategies including asset depletion, food rationing, and withdrawal from employment to sustain caregiving responsibilities (Seshamani and Kaela, 2019)

Despite these challenges, Zambia has introduced several policy initiatives that indirectly support older persons and community-based healthcare, including the National Health Strategic Plan (2022–2026), National Ageing Policy (2023), and broader social protection programmes implemented through the Ministry of Community Development and Social Services. These policies promote healthy aging, strengthen primary healthcare, and support vulnerable households. However, they provide limited guidance on Alzheimer's disease and dementia-specific care. Consequently, informal caregivers continue to provide most long-term care with limited training, financial assistance and psychosocial support. This highlights the need for a dedicated national dementia strategy that explicitly recognises and supports informal caregivers within Zambia's health and social protection systems.

2.3 Theoretical Framework

This study is informed by four complementary theoretical perspectives: the Stress Process Model, Social Solidarity Theory, the Feminist Political Economy of Care, and the Health Belief Model. Together, these frameworks provide a multidimensional understanding of informal caregiving in Zambia by explaining the health, social, cultural, behavioural and economic dimensions of caregiving.

Two key concepts underpinned the analysis. The first is health labour, which refers to the unpaid physical, emotional, and organizational work undertaken by informal caregivers to sustain the health and well-being of individuals living with chronic illness. Although this labour contributes substantially to the functioning of health systems, it is rarely recognised in labour markets or public policy. The second concept is financial toxicity, which describes the cumulative financial hardship experienced by households as a result of chronic illness, including direct medical expenses, transportation costs, lost income, and depletion of household assets (Chong et al., 2022). These concepts provide a foundation for interpreting caregiving as both a health system issue and a developmental challenge.

2.3.1 Stress Process Model

The Stress Process Model (Pearlin et al., 1990) explains the caregiving burden as a dynamic interaction between primary stressors, secondary stressors, and available coping resources. Primary stressors include the direct demands of caregiving, such as assisting with activities of daily living, managing behavioural symptoms, and providing continuous supervision. Secondary stressors arise from the broader consequences of caregiving, including financial strain, social isolation, and employment disruption.

Within the Zambian context, caregivers frequently experience both categories of stressors simultaneously because long-term care is delivered in settings characterised by limited health infrastructure, inadequate social protection and widespread poverty (Grant et al., 2013; Kamocha & Banda, 2017). Therefore, the model provides a useful framework for understanding how structural conditions influence caregiver well-being.

2.3.2 Social Solidarity Theory

Social Solidarity Theory explains caregiving as a socially embedded responsibility shaped by shared cultural values, collective identity, and family obligations. In many African societies, caregiving is closely associated with Ubuntu and

communal reciprocity, where caring for older family members is regarded as a moral obligation rather than an economic activity (Muga, 2014).

These cultural values strengthen family support networks and encourage a sense of community responsibility. However, they may also discourage caregivers from seeking external assistance or demanding policy recognition because caregiving is often perceived as a private family duty rather than a public responsibility (Musonda et al., 2021)

2.3.3 Feminist Political Economy of Care

The Feminist Political Economy of Care provides the principal analytical lens for this study. Modern economies depend heavily on unpaid reproductive labour, particularly the care work undertaken by women, to sustain labour markets and health systems (Folbre, 2001; Fraser, 2016; Tronto, 2013).

In Zambia, informal caregiving serves as a hidden subsidy for the health system, as families absorb much of the cost of long-term care that the state would otherwise bear. While this arrangement reduces public expenditure, it also transfers financial risk to households and reinforces gender inequalities, as women perform most unpaid caregiving responsibilities (Banda et al. 2017).

2.3.4 Health Belief Model

The Health Belief Model complements the preceding theories by explaining caregivers' health-related decisions and care-seeking behaviours. The model proposes that individuals' actions are influenced by their perceptions of illness severity, susceptibility, perceived benefits, perceived barriers, and confidence in their ability to perform the required health behaviours.

In this study, the Health Belief Model helps explain why caregivers may delay seeking formal support despite experiencing a significant burden. Cultural expectations, financial constraints, stigma surrounding dementia, and limited access to specialised services all influence caregivers' perceptions of the benefits and feasibility of obtaining external assistance.

2.3.5 Integration of the Theoretical Framework

The four theoretical perspectives are complementary but also reveal important tensions between them. The Stress Process Model explains how caregiving generates physical, psychological, and economic strain. Social Solidarity Theory explains why caregivers continue to provide care despite these burdens, emphasising family obligations and communal responsibilities. In contrast, the Feminist Political Economy of Care critically questions these social

expectations, arguing that cultural norms may unintentionally legitimise the unequal distribution of unpaid care work, particularly among women. The Health Belief Model adds a behavioural dimension by explaining how caregivers interpret illness, evaluate available support, and decide to seek formal healthcare services.

Collectively, these frameworks provide a comprehensive understanding of informal caregiving in Zambia. They demonstrated that caregiving is simultaneously a cultural practice, behavioural response, source of psychosocial stress, and form of unpaid health labour that has significant implications for health systems, gender equality, and national development.

3.0 Research Methodology

3.1 Research Design

This study employed a qualitative descriptive research design based on a secondary data analysis. The design was selected because it allows for an in-depth synthesis and interpretation of existing evidence relating to informal caregiving for individuals living with Alzheimer's disease in Zambia's health and development context. Rather than

generating primary empirical data, this study critically analysed published academic literature, government policy documents, institutional reports, and international development publications to examine how informal caregiving is conceptualised, experienced, and addressed within existing scholarship.

A qualitative descriptive approach was considered appropriate because this study sought to provide a comprehensive understanding of caregiving experiences, structural challenges, and policy implications, rather than test causal relationships. The design also enabled the integration of multidisciplinary evidence from public health, development studies, sociology, economics and social policy.

3.2 Literature Search Strategy

Relevant literature was identified from peer-reviewed journal articles, books, policy documents, government publications, and reports from recognised international organisations, including the World Health Organization (WHO), World

Bank, Alzheimer's Disease International (ADI), Ministry of Health Zambia, and Zambia Statistics Agency (ZamStats). The literature covered key themes related to Alzheimer's disease, dementia, informal caregiving, community-based care, caregiver burden, health systems and social protection.

Additional relevant sources were identified by examining the reference lists of key publications to ensure that seminal and contextually relevant studies were included in the review. This approach enabled the inclusion of both international and Zambian literature relevant to this study.

3.3 Population and Source Selection

The study population consisted of published scholarly literature, policy documents, institutional reports, and development publications relevant to informal caregiving, Alzheimer's disease, dementia, community-based care, and long-term care. Sources were selected based on their relevance to the study objectives.

Sources were included if they met the following criteria:

- addressed Alzheimer's disease, dementia, or informal caregiving.
- focused on community-based care, long-term care, or caregiver experiences.
- were published in English.
- were peer-reviewed articles or publications from recognised organisations or government institutions.

Sources were excluded if they met the following criteria:

- focused solely on clinical or biomedical treatment without discussing caregiving.

- were opinion articles lacking empirical or policy evidence.
- duplicated information available in high-quality publications.

3.4 Validity and Reliability

Validity was strengthened through triangulation of the academic literature, development agency reports, and national policy documents. Reliability was enhanced through the consistent application of source inclusion criteria and the use of established theoretical frameworks to guide interpretation.

3.5 Ethical Considerations

This study relied exclusively on secondary data and did not involve direct human participant interactions. Consequently, formal institutional ethical clearance was not required for this study. All data were obtained from publicly accessible academic publications, institutional reports and government policy documents. Academic integrity was maintained through the accurate representation of source material and consistent citation of all referenced works. This study adhered to the principles of responsible scholarship by avoiding selective reporting and ensuring a balanced interpretation of the available evidence.

3.6 Data Analysis Procedure

Data were analysed using thematic synthesis. Relevant literature and policy findings were systematically reviewed and interpreted through the lens of the stress process and health belief models. The Stress Process Model enabled the classification of caregiving stressors into primary and secondary categories, allowing an analysis of how structural socioeconomic and infrastructural factors translate into caregivers' health, economic, and psychosocial outcomes. The Health Belief Model supported the interpretation of caregiving decision-making behaviour, particularly in relation to cultural norms, perceived caregiving obligations, and barriers to accessing formal support services.

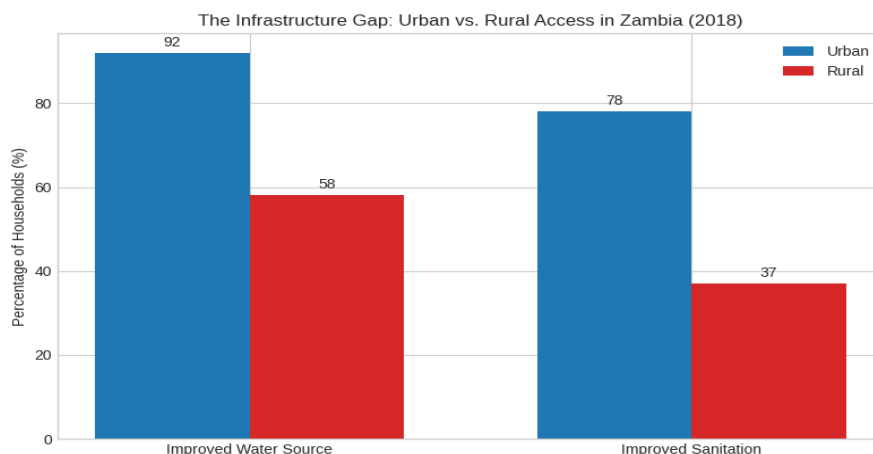
Following theoretical coding, the findings were synthesised into three dominant domains of caregiver

burden: physical, economic, and psychosocial. These domains reflect recurring patterns documented across global and sub-Saharan African caregiving literature and provide a coherent structure for analysing caregiving experiences within Zambia's development and health system context.

4.0 Results and Findings

The analysis indicates that caregiving challenges in Zambia are closely linked to broader socioeconomic and infrastructure conditions. Rather than existing as isolated individual experiences, caregiver burden is shaped by structural access to services, income stability, and social support systems. The findings are grouped into physical, economic, and psychosocial domains to reflect the dominant patterns identified in the literature, although these dimensions frequently overlap in practice.

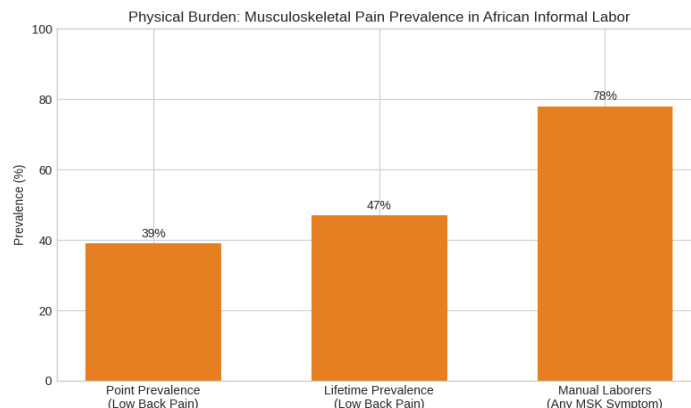
4.1 Physical Challenges: Infrastructure and Labour Intensity



This chart illustrates the marked disparity in access to basic water, sanitation, and hygiene (WASH) infrastructure between urban and rural households in the country. In urban areas, 92% of households have access to improved water sources, compared to only 58% in rural settings. Similarly, access to improved sanitation was substantially higher in urban areas (78%) than in rural areas (37%).

The findings demonstrate that caregiving in Zambia occurs under conditions of significant infrastructural inequality, particularly in access to water, sanitation, and hygiene

services. The WASH disparity graph illustrates the structural gap between urban and rural service access. Urban households have significantly higher access to improved water and sanitation infrastructure than rural households. This disparity directly increases the daily labour demands placed on caregivers, particularly in households caring for individuals with chronic neurological conditions, such as Alzheimer's disease. Limited infrastructure increases the physical workload, infection risk, and time burden, effectively transforming caregiving into physically hazardous labour.



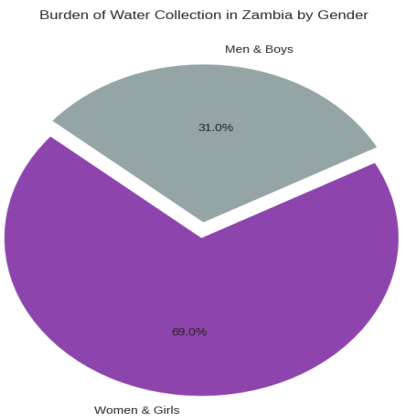
The chart presents the prevalence of musculoskeletal pain in the African informal and manual labour populations, serving as a proxy indicator for the physical strain experienced by caregivers. The data show a point prevalence of low back pain of 39% and a lifetime prevalence of 47%, whereas as many as 78% of manual labourers reported

experiencing at least one musculoskeletal symptom.

Musculoskeletal strain data further support this finding. High prevalence rates of back pain and musculoskeletal symptoms among manual labour populations provide a proxy indicator of the physical strain experienced by caregivers. Given the absence of assistive devices and safe

patient-handling infrastructure, caregivers frequently perform high-risk manual-lifting and mobility-assistance tasks. Over time, this

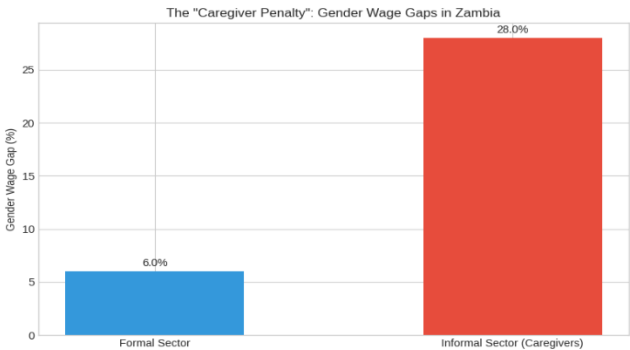
contributes to declining caregiver health and reduced capacity for long-term caregiving.



The third chart highlights the gendered nature of water collection responsibilities in Zambia, showing that women and girls account for 69% of water-fetching activities compared to 31% for men and boys. This unequal distribution underscores the disproportionate caregiving and domestic workload placed on women, particularly in rural and peri-urban areas, where water sources may be distant.

The water collection gender distribution graph further demonstrates the gendered nature of the physical caregiving burden. Women and girls perform the majority of water collection labour, compounding existing caregiving and domestic workloads. This layered burden reinforces structural gender inequality and limits women’s ability to engage in income-generating work.

4.2 Economic Challenges: Financial Toxicity and Caregiver Penalty



The chart illustrates the gender wage gap in Zambia, comparing the formal and informal sectors, where caregiving work is predominantly situated. While the gender wage gap in the formal sector is relatively low at 6%, it widens dramatically to 28% in the informal sector, which includes many unpaid or underpaid caregivers. The gender wage gap graph highlights the structural income inequality between the formal and informal sectors. While the formal sector shows relatively smaller wage disparities, the informal sector demonstrates significantly larger gender-based income gaps than the formal sector. Given that caregiving labour is predominantly situated within informal and unpaid labour structures, women caregivers experience what can be conceptualised as a “caregiver penalty”, characterised by lower lifetime earnings and reduced financial resilience.

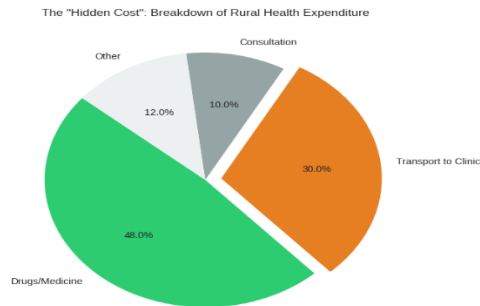
The rural health expenditure graph demonstrates the hidden costs of caregiving, despite nominally free public healthcare services. A high

proportion of household health expenditure is allocated to medicines and transportation. Transport costs are particularly significant owing to centralised healthcare service delivery models. For families caring for individuals with Alzheimer’s disease, repeated transport costs create a cumulative financial burden.

The household coping strategy graph demonstrates low financial resilience in households. While most households rely on current income or savings to meet medical costs, a significant minority relies on asset depletion or borrowing. In the context of chronic disease management, repeated expenditure shocks gradually erode household’s financial stability.

The caregiver impoverishment cycle model demonstrates how caregiving transitions households through stages of economic decline, beginning with income shocks and progressing through expenditure spikes, asset liquidation, and intergenerational economic effects, such as school withdrawal.

4.3 Psychosocial Challenges: Stigma, Isolation and Emotional Burden

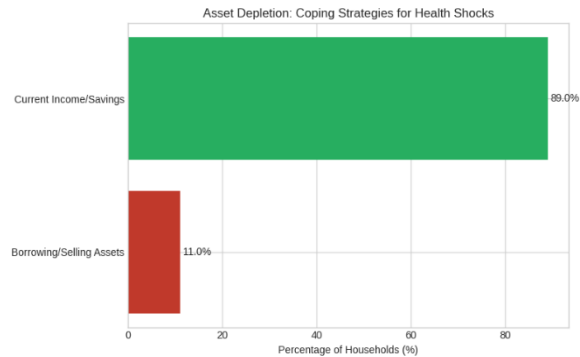


This chart presents a breakdown of the out-of-pocket health expenditures of rural households in Zambia. Nearly half of the total health spending (48%) is allocated to drugs and medicines, followed by transport to health facilities (30%), consultation fees (10%), and other miscellaneous costs (12%). The findings indicate that the psychosocial burden is intensified by cultural and social dynamics. Caregivers often experience courtesy stigma, where the social stigma associated with chronic illness extends to the caregivers themselves. This results in social isolation and reduced participation in the community.

Spiritual distress also emerged as a recurring theme. Caregivers frequently experience moral and

emotional strain when they are unable to provide adequate symptom relief due to limited access to palliative care resources. The chronic nature of Alzheimer's disease contributes to prolonged psychological strain, resulting in compassion fatigue and chronic anxiety rather than acute grief responses

The substantial proportion spent on transportation underscores the geographical and infrastructural barriers to accessing healthcare services in rural areas. For households caring for individuals with Alzheimer's disease, these recurring expenses represent hidden costs that intensify financial strain, particularly in contexts where household income is already constrained.



This chart depicts household coping strategies in response to medical expenses, highlighting the economic vulnerability associated with health emergencies. Most households (89%) rely on current income or savings to meet medical costs, while 11% resort to borrowing or selling assets. Although reliance on income and savings appears to be dominant, the need for asset depletion among a

subset of households indicates limited financial resilience. In the context of chronic conditions such as Alzheimer’s disease, repeated health expenditures may progressively erode household resources, pushing caregivers into long-term economic insecurity and undermining the sustainability of community-based care.

Table Set for Section 4.2 – Economic Challenges: Financial Toxicity

Table 1. Labor Structure and Caregiving Opportunity Cost Risk in Zambia

Indicator	Statistic	Interpretation for Caregiving	Source
Informal employment (ILO / OECD estimates)	~71.8% of total employment	Majority of caregivers likely drawn from income-unstable informal sector	(TheGlobalEconomy.com)
Informal employment (OECD deep estimate)	88.7% of employed population	Indicates extreme vulnerability to income shocks from caregiving	(OECD)

Informal economy share (Labour Force Survey 2024)	68.3% informal vs 31.7% formal	Confirms structural dominance of informal livelihoods	(mlss.gov.zm)
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The data presented in Table 1 demonstrate that Zambia’s labour structure is heavily dominated by informal employment, with estimates ranging between approximately 68% and nearly 90%, depending on the measurement approach. This structural characteristic significantly amplifies the economic consequences of caregiving in the region. In informal labour systems, income is typically daily and directly linked to physical presence in the market or the workplace. Consequently, when caregivers withdraw from economic activities to provide full-time care, income loss is

immediate and total, rather than partial or temporary.

This finding supports the argument that caregiving in Zambia generates severe opportunity costs because it removes caregivers from the primary economic sector, which sustains household survival. Unlike formal sector workers who may access leave benefits or income protection, informal workers experience a direct income collapse. Therefore, the data reinforce the interpretation of caregiving as a structural labour displacement mechanism rather than simply a time burden.

Table 2. Household Poverty and Vulnerability Context for Caregiving

Indicator	Statistic	Implication for Caregiving Households	Source
Population living below poverty line	~60% (2022 estimate)	High baseline vulnerability increases risk of caregiving poverty traps	Zambia Living Conditions Monitoring Survey (LCMS) World Bank Poverty & Equity Database (World Bank)

Population below poverty line (older estimate cited in chapter)	~54%	Confirms chronic poverty context for caregiving	World Bank historical poverty trend series (World Bank)
Self-employment share	~73.8%	Indicates dependence on daily income streams vulnerable to care disruption	ILOSTAT labour force structure data Zambia Labour Force Survey World Bank employment structure datasets (TheGlobalEconomy.com)

Table 2 illustrates that caregiving occurs within the context of widespread baseline economic vulnerability. With over half of the population living below the poverty line, households have limited financial buffers to absorb health-related economic shock. The high prevalence of self-employment further compounds vulnerability because self-employment income is highly variable and sensitive to labour availability in the region.

These conditions imply that caregiving-related income loss does not occur in isolation but instead compounds pre-existing economic fragility. This reinforces the concept of caregiving as a poverty multiplier, rather than a standalone financial stressor. In this context, even small increases in healthcare expenditure or temporary labour withdrawal can trigger a long-term household economic decline.

Table 3. Health Financing Structure and Financial Toxicity Risk

Indicator	Statistic	Caregiving Relevance	Source
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Out-of-pocket spending as % of total health expenditure	~10.3%	Even low national averages can mask high household catastrophe	(P4H Network)
Historical OOP spending (2000)	~44.9%	Shows long-term structural burden of household financing	(P4H Network)
Household medical spending share (terminal care global comparator)	~30% of household income	Demonstrates catastrophic expenditure potential in chronic care	

Table 3 highlights the structural limitations of health financing in Zambia. Although national out-of-pocket expenditure appears moderate at the aggregate level, micro-level evidence indicates that households managing chronic illnesses frequently experience catastrophic expenditure levels. This disparity reflects the difference between the national averages and disease-specific household experiences.

The data support the argument that financial toxicity in caregiving is driven not only by direct medical costs but also by cumulative indirect costs. Chronic illness management requires repeated health facility visits, transport payments, and supply purchases, creating continuous financial leakage from already resource-constrained households. This reinforces the poverty–illness cycle identified in the Sub-Saharan African health financing literature.

Table 4. Household Health Expenditure Composition (Rural Zambia Evidence)

Category	Health Spending	Caregiving Impact
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Medicines and drugs	48%	Chronic disease d cost pressure
Transport to health facilities	30%	Key driver of catastrophic expenditure
Consultation fees	10%	Lower relative but still cumulative

The expenditure structure shown in Table 4 highlights the disproportionate financial burden of medicine and transport costs in rural health spending. The high share of transport expenditure demonstrates that geographic barriers function as economic barriers to healthcare. This finding is particularly significant for chronic disease caregiving, where travel costs accumulate over time.

The high share of medicine expenditure further reflects supply chain limitations in public health systems. Together, these findings demonstrate that chronic caregiving generates predictable and recurring expenditure streams that progressively erode the financial resilience of households.

Table 5. Cycle of Care article
Evidence-Based Statistical Mapping

Stage	Observable Indicator	Evidence
Income shock	om informal economy	Women forced out of trade or farming
Expenditure spike	Transport + medicine purchase	Centralised healthcare increases costs
Asset liquidation	Sale of livestock, land, equipment	Long-term

Intergenerational poverty	School withdrawal / pension divert cycle	
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This table provides an empirical grounding for the conceptual Cycle of Caregiver Impoverishment model. The staged progression from income shock to intergenerational poverty demonstrates that caregiving-related financial decline is both cumulative and self-reinforcing. Evidence shows that households do not experience single financial shocks but rather repeated and compounding economic stress events.

This model is particularly important because it shifts the interpretation of caregiving from a short-term crisis event to a long-term structural poverty driver. The intergenerational dimension further highlights the broader developmental implications of the informal caregiving burden.

5.0 Discussion

The findings suggest that caregiving experiences in Zambia differ from those typically described in the

literature on high-income countries. While studies from high-income contexts often emphasise psychological stress and emotional burden, caregiving in Zambia is strongly shaped by material and structural constraints, including infrastructure access, income stability, and health system design.

Caregiver health risks are closely linked to broader developmental conditions. Physical strain is often associated with limited access to water, sanitation infrastructure, assistive technologies and consistent medical supplies. In this context, a decline in caregiver health reflects systemic developmental challenges rather than purely individual-level risks.

Economic findings highlight the gendered nature of caregiving responsibilities in the family. A heavy reliance on unpaid female labour effectively shifts long-term care costs from public systems to households. This limits women’s long-term

economic participation and reinforces the structural gender inequality.

The findings also highlight the gaps in long-term care governance. In many cases, older women assume multigenerational caregiving roles while using limited pensions or social protection resources to support entire households. Existing social protection systems are not designed to address caregiving realities, particularly in the context of informal labour.

responses should prioritise caregiver financial protection, the expansion of social protection coverage, investment in long-term care infrastructure, and the expansion of caregiver training and support programmes.

Strengthening caregiver-inclusive policy frameworks is essential for long-term health system resilience, poverty reduction, and gender equity outcomes.

Author Contributions: The author acknowledges sole ownership, conceptualisation of the study,

6.0 Conclusion

This study demonstrates that informal caregiving in Zambia operates within a system characterised by unpaid labour, health-system dependence on household care provision, and limited policy recognition. Caregiver burden is multidimensional, spanning physical workload, economic strain and psychosocial stress.

Addressing informal caregiving requires recognition of caregivers as part of the broader health system ecosystem. Policy

design, data collection, analysis, interpretation, results, and manuscript preparation.

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7.0 References

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