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# Caregivers' Strategies for Managing Medical Expenses for Children with Epilepsy in Ubungo Municipality, Tanzania

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**ABSTRACT** **Original Research Article**

Caring for a child with epilepsy may involve recurring medical expenses and additional costs that place pressure on household resources. These expenses may include medication, clinical consultations, transportation to health facilities, food during hospital visits, childcare assistance, and other daily needs associated with care. This article explores how caregivers of children with epilepsy cope with medical expenses in Ubungo Municipality, Dar es Salaam, Tanzania. Drawing on a qualitative study, the article examines caregivers' experiences of financial pressure and the strategies they use to maintain care while meeting competing household obligations. The findings are organised into five themes: medical expenses and household financial pressure; household budgeting and expenditure reduction; health insurance and external financial assistance; family and community support; and lost income and competing caregiving responsibilities. The findings show that caregivers use several interconnected strategies, including reallocating household resources, reducing non-essential expenditure, borrowing from trusted relatives, using health insurance, and seeking assistance from social networks. However, these strategies do not necessarily eliminate financial pressure because assistance may be unreliable and caregiving can reduce opportunities to earn income. The article highlights the importance of considering both direct healthcare costs and the wider financial circumstances of families caring for children with epilepsy.

**Keywords:** Medical Expenses, Childhood Epilepsy, Caregivers, Financial Coping Strategies, Household Expenditure, Tanzania.

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## Introduction

Epilepsy is a neurological condition that can affect children's health, everyday activities, and family life. When a child requires continuing treatment and support, caregivers may need to organise healthcare appointments, obtain medicines, arrange transport, and respond to the child's daily needs. These responsibilities can create financial demands that extend beyond the cost of clinical treatment. For families with limited or irregular income, medical expenses may compete with spending on food, housing, education, and other household necessities. Research on childhood epilepsy has also highlighted the importance of understanding the experiences of caregivers and the wider effects of the condition on families (Mushi et al., 2012; Puka et al., 2018a; Yu et al., 2022).

Medical expenses should therefore be understood in relation to the resources available to households and the practical demands of caregiving. The cost of attending a health facility, for example, may include transport and food in addition to the amount paid for treatment. Caregivers may also incur expenses related to childcare arrangements or the everyday needs of a child while managing their own domestic responsibilities. Evidence from studies of families caring for children with chronic conditions suggests that caregiving can involve both financial costs and time demands (Zan & Scharff, 2015). In epilepsy care, these demands may continue alongside the need to maintain household livelihoods and other family responsibilities.

The financial challenges associated with healthcare are particularly relevant in settings where households pay directly

for some healthcare services. Research in Tanzania has examined out-of-pocket payments and the possibility that healthcare expenditure can place substantial pressure on household finances (Brinda et al., 2014; Kagaigai et al., 2023). Such expenditure may affect families differently depending on income, insurance coverage, household composition, access to support, and the nature of healthcare needs. However, household responses to these costs cannot be understood only by identifying the amount spent. It is also important to examine how caregivers mobilise resources, adjust their budgets, seek assistance, and manage the consequences of spending on treatment.

Studies of caregiving in epilepsy have documented emotional, social, and practical challenges experienced by parents and other family caregivers (Hussain et al., 2020; Yang et al., 2023; Yu et al., 2022). Nevertheless, the ways caregivers manage medical expenses are shaped by their specific economic and social circumstances. Caregivers may reduce non-essential spending, redirect money from other household needs, rely on relatives, or use health insurance where available. These strategies can provide immediate assistance, but their effectiveness depends on whether caregivers have sufficient resources and whether support is accessible when needed.

In Tanzania, understanding these experiences requires attention to the circumstances of caregivers in particular local settings. Ubungo Municipality provides the context for examining how caregivers manage the financial demands of caring for children with epilepsy. The focus is not simply on whether medical expenses are high, but on how caregivers respond to these expenses within households where income, time, and other resources may be limited.

By examining caregivers' reported strategies and the challenges associated with them, the article contributes to understanding the relationship between healthcare costs, household financial management, and family caregiving.

# Literature Review

## Medical Expenses and the Financial Burden of Caregiving

Medical expenses may include direct costs associated with treatment and related expenses required to access healthcare. Direct costs can include payments for consultations, medicines, and other clinical services, while associated expenses may include transport and food during visits to health facilities. Families caring for children with long-term health conditions may also face costs related to everyday care and the time required to accompany or supervise a child. Research on the economic burden of caregiving in epilepsy has drawn attention to the financial and practical demands that may affect caregivers' lives (Hussain et al., 2020).

The financial consequences of healthcare spending are influenced by household income and the availability of financial protection. Studies in Tanzania have investigated out-of-pocket healthcare payments and catastrophic expenditure, demonstrating why healthcare costs must be considered in relation to households' ability to pay (Brinda et al., 2014; Kagaigai et al., 2023; Mwinuka & Mwemutsi, 2024). When treatment-related expenditure competes with basic household needs, caregivers may be required to make difficult choices about which expenses to prioritise. Consequently, the financial burden of childhood epilepsy may involve not only the money used for treatment but also the sacrifices households make to meet those costs.

## Household Budgeting and Financial Coping Strategies

Household budgeting is one possible response to medical expenses. Caregivers may plan spending, reduce purchases considered non-essential, and redirect available money towards treatment. These adjustments can help households manage immediate costs, although they do not necessarily increase the amount of money available. When the household budget is already limited, reducing expenditure on one item may create pressure in another area, such as food, rent, education, or small business activities.

Evidence from research on healthcare costs in low- and middle-income countries indicates that people may use multiple strategies to manage the financial consequences of illness, including drawing on household resources and seeking assistance from others (Murphy et al., 2019). However, coping strategies should not automatically be interpreted as evidence that families can comfortably afford healthcare. Some strategies may provide temporary relief while leaving households exposed to continuing expenses or future debt. It is therefore important to examine not only which strategies caregivers use but also the constraints under which they use them.

## Health Insurance and Social Support

Health insurance can help caregivers manage some healthcare expenses, depending on the services and costs covered. Nevertheless, insurance does not necessarily cover every expense associated with accessing treatment and providing daily care. Transportation, food, childcare, and other household needs may remain the responsibility of families. Studies of healthcare expenditure in Tanzania have highlighted the importance of financial protection in reducing the risk that healthcare payments will impose severe economic pressure on households (Brinda et al., 2014; Massito & Hinju, 2025).

Social support is another potential resource. Relatives, spouses, friends, and community members may contribute money, assist with transport, or help meet other caregiving needs. Such support can be important when caregivers cannot meet expenses from their own income. However, assistance may depend on the financial circumstances and willingness of potential supporters, and it may not be available whenever a

cost arises. The experiences of caregivers of children with epilepsy therefore need to be understood in relation to both formal resources, such as insurance, and informal support networks (Yang et al., 2023; Yu et al., 2022).

### Caregiving Responsibilities and Lost Income

The financial effects of caregiving are not limited to money spent on treatment. Caregivers may also lose income or have fewer opportunities to work because they must accompany a child to healthcare facilities, supervise the child, or organise daily care. These time demands can affect business activities and other income-generating responsibilities. Research on families caring for children with chronic conditions has identified financial and time-related demands as important aspects of the caregiving experience (Zan & Scharff, 2015).

This relationship creates a potential cycle of financial pressure: medical expenses increase household spending while caregiving responsibilities may reduce the time available to earn money. As a result, caregivers may find it difficult to maintain treatment expenses and meet other household needs simultaneously. This issue is relevant to understanding coping because a household's ability to respond to medical expenses depends not only on spending decisions but also on its capacity to generate income.

## Theoretical Orientation

This article draws on the Stress Process Theory developed by Pearlin et al. (1981). The theory explains how stressful experiences are shaped by the demands individuals face, the resources available to them, and the social circumstances in which stress occurs. In caregiving, stress may arise from the responsibilities of looking after a child, the practical demands of arranging care, and the financial pressures associated with treatment. The theory is relevant because medical expenses do not occur in isolation; they interact with income, family responsibilities, social support, and caregivers' opportunities to work.

The theory also helps explain why caregivers facing similar types of expenses may respond differently. A caregiver with a reliable income, health insurance, or supportive relatives may have more resources available than a caregiver whose income is irregular and whose support network cannot consistently contribute. Budgeting, borrowing, insurance, and assistance from relatives can be understood as resources used to respond to stressful financial demands. However, these strategies may have limitations when expenses continue or support is uncertain.

In this article, Stress Process Theory provides a framework for interpreting the relationship between medical expenses, household financial pressure, and coping strategies. It does not imply that all caregivers experience the same level of stress or use the same responses. Rather, it directs attention to how available resources and competing responsibilities shape caregivers' experiences.

## Methodology

### Research Approach and Study Context

The article draws on a qualitative descriptive phenomenological study conducted in Ubungo Municipality, Dar es Salaam, Tanzania. A qualitative approach was appropriate for examining caregivers' experiences and the meanings they attached to managing medical expenses while caring for children with epilepsy. Rather than measuring the prevalence of particular coping strategies, the study sought to understand how participants described their financial challenges and the responses they used in their everyday circumstances.

The dissertation informing this article reports interviews with 10 caregivers and two healthcare providers as key informants, alongside one focus group discussion involving eight community participants. These sources provided different perspectives on caregiving, financial challenges, and the social environment surrounding childhood epilepsy. The article focuses on the findings relevant to the objective concerning medical expenses. The participant numbers and procedures should remain consistent with the final approved dissertation when preparing the article for journal submission.

### Data Collection and Analysis

The study used qualitative data collection methods reported in the dissertation, including interviews and a focus group discussion. The interviews enabled caregivers to describe the expenses they encountered, the effects of those expenses on household budgets, and the ways they sought to meet financial demands. The healthcare providers and community participants contributed contextual perspectives on care and the social environment surrounding children with epilepsy.

The data relevant to the objective were organised thematically. The analysis focused on recurring patterns in participants' accounts and grouped the findings into five themes: medical expenses and household financial pressure; household budgeting and reduction of expenditure; health insurance and external financial assistance; family and community support; and lost income and competing caregiving responsibilities. These themes are presented as qualitative findings rather than as statistical estimates of how frequently each strategy was used.

Participant codes are used to protect confidentiality. Quotations included in the article are drawn from the supplied dissertation text and should be checked against the final approved transcripts before publication. The study's consent and ethical procedures should be reported in the final manuscript using the exact information from the approved dissertation and institutional documentation.

## Findings

### Medical Expenses and Household Financial Pressure

Caregivers described medical expenses as recurring demands that extended beyond medicines and clinical consultations.

Other reported expenses included transportation to health facilities, food, diapers, childcare assistance, and additional needs associated with caring for a child. These costs were particularly difficult to manage when household income was limited. Participants' accounts also indicated that caregiving could reduce the time available for business and other income-generating activities. Medical expenses therefore affected household finances both through direct spending and through limitations on earning opportunities.

One caregiver, CG01, described the range of expenses and their effect on her economic activities:

> *"Medication, clinic consultations, transport, food, Pampers, and payment for someone to assist with childcare. Hospital transport can reach about TZS 60,000 for a return trip. They force me to choose between my own needs and the child's needs. My business suffers because I spend time caring for the child." (CG01, personal communication, 2026).*

This account illustrates how the cost of accessing treatment could be connected to everyday household needs and lost working time. The reported transport amount reflects this participant's experience and should not be interpreted as an average for all caregivers. Nevertheless, the account shows that the financial challenge involved several related expenses rather than medication alone.

## Household Budgeting and Reduction of Expenditure

Caregivers reported reorganising household budgets to meet medical expenses. Money that would otherwise have been used for food, rent, school requirements, or other household priorities could be redirected towards treatment. Some caregivers responded by planning expenditure more carefully and reducing purchases they considered non-essential. Others borrowed from trusted relatives when available funds were insufficient. These strategies enabled caregivers to respond to immediate needs by redistributing the resources already available to them.

CG02 described how treatment expenses affected household spending and the strategies used to manage them:

> *"The household budget becomes tight. Money that could be used for food, rent or school needs is sometimes directed to treatment. I plan expenses, reduce non-essential spending, and borrow from trusted relatives when necessary. My husband and relatives help when they can." (CG02, personal communication, 2026).*

The account suggests that budgeting was a practical response to competing financial demands. However, reducing non-essential expenditure did not remove the need to pay for food, housing, and education. Similarly, borrowing could provide short-term assistance but might create an obligation to repay the money later. The usefulness of these strategies therefore depended on the flexibility of the household budget and the availability of relatives who could help.

## Health Insurance and External Financial Assistance

Some caregivers reported using health insurance alongside seeking financial assistance from people outside their immediate household. Insurance provided one means of managing healthcare needs, while trusted contacts and social media offered additional ways to request help when available resources were insufficient. These strategies indicate that caregivers did not necessarily depend on a single source of support; instead, they combined different resources to address expenses.

CG01 explained the use of insurance and external assistance:

> *"I use health insurance, ask trusted people for help, communicate my situation openly, and sometimes use social media to seek assistance. I have received help from individuals and sometimes use insurance. The assistance is useful, although it is not always available when I need it." (CG01, personal communication, 2026).*

The participant's account shows that assistance could be useful without being consistently available. Health insurance and external contributions helped the caregiver respond to some financial demands, but they did not guarantee that every expense would be covered at the time it arose. This finding highlights the difference between having a coping resource and having reliable financial protection. Caregivers could still experience uncertainty when medical or related expenses arose unexpectedly or when assistance was delayed.

## Family and Community Support

Family and community support formed another component of caregivers' responses to medical expenses. Spouses, relatives, and trusted people could help with money, transport, medication, or other needs associated with caregiving. Such contributions were important where caregivers could not meet all expenses using their own income. Support could also help caregivers manage the competing demands of treatment and household responsibilities.

However, the findings indicate that informal assistance was not always predictable. Relatives and friends had their own financial obligations, meaning that their ability to contribute could vary over time. Consequently, caregivers could not necessarily rely on the same level of assistance whenever a cost arose. This uncertainty meant that social support functioned as a useful but sometimes limited resource. Where contributions were unavailable, caregivers still had to reorganise household expenditure, use other resources, or find alternative ways to meet medical expenses.

The findings suggest that coping with medical expenses was partly relational: caregivers' options were influenced by the people around them and their capacity to offer assistance. At the same time, reliance on informal support did not remove

the wider financial responsibilities associated with caring for a child with epilepsy. Support networks helped caregivers respond to immediate needs, but their reliability depended on the circumstances of both the caregiver and the people providing assistance.

### Lost Income and Competing Caregiving Responsibilities

Caregivers' accounts also showed that caring for a child with epilepsy could affect their income-generating activities. Time spent accompanying a child to health facilities, providing care, and arranging everyday needs could reduce the time available for business or other work. This created an additional financial challenge because caregivers needed money to meet treatment expenses while caregiving responsibilities could restrict their opportunities to earn it.

CG01's account that her business suffered because she spent time caring for the child illustrates this connection. The issue was not simply the amount of money spent on healthcare; it was also the potential loss of income associated with caregiving. These two pressures could reinforce each other: medical expenses required resources, while reduced working time could limit the resources available to cover them.

The findings therefore suggest that caregivers' financial coping strategies must be understood in the context of their livelihoods and time commitments. Budgeting and assistance may help households manage particular expenses, but these strategies may be less effective when caregiving continually interferes with earning opportunities. Recognising the relationship between medical expenses and lost income is important when considering the financial circumstances of families caring for children with epilepsy.

## Discussion

The findings show that caregivers in Ubungo Municipality managed medical expenses through a combination of household budgeting, reductions in expenditure, health insurance, requests for external assistance, family and community support, and adjustments to work and caregiving responsibilities. These strategies were interconnected rather than independent. For example, a caregiver who redirected money from household needs towards treatment might also borrow from relatives or seek help from other trusted people. The findings suggest that coping involved coordinating several limited resources to meet continuing demands.

The reported expenses also demonstrate that the financial implications of childhood epilepsy extend beyond the immediate cost of treatment. Transportation, food, diapers, childcare assistance, and other practical requirements contributed to the demands experienced by caregivers. This is consistent with wider literature identifying economic and time-related pressures among families caring for children with chronic conditions (Hussain et al., 2020; Zan & Scharff, 2015). The findings underline the importance of examining the full range of expenses involved in accessing and sustaining care rather than treating medical expenditure as a single payment.

Household budgeting was a common practical response, but it had limitations. Redirecting money from food, rent, education, or other household needs could help meet treatment costs in the short term while increasing pressure elsewhere. Similarly, borrowing from relatives provided temporary resources but did not necessarily create a sustainable financial solution. These experiences are relevant to research on healthcare expenditure in Tanzania, which has examined the implications of out-of-pocket payments for households (Brinda et al., 2014; Kagaigai et al., 2023; Mwinuka & Mwemutsi, 2024). The present findings provide qualitative insight into how such pressures may be experienced within families caring for children with epilepsy.

Health insurance and social support were important resources, but their usefulness depended on availability and coverage. The participant account indicated that assistance was not always available when required. This suggests that caregivers may remain financially vulnerable even when they have some form of insurance or access to supportive relationships. Informal assistance can be valuable, but it may not offer predictable or sufficient protection against recurring expenses. Therefore, support for caregivers should consider both formal financial protection and the everyday costs that families must manage outside clinical treatment.

The relationship between caregiving and lost income is another important finding. Caregivers may face increased expenditure while having less time for business or paid work. This combination can limit their ability to recover financially from one episode of spending before further expenses arise. The finding is consistent with literature that recognises the time and economic demands associated with caring for children with chronic health conditions (Zan & Scharff, 2015). It also supports the relevance of Stress Process Theory: the pressure associated with caregiving is shaped not only by the demands themselves but also by the availability of resources that can help individuals manage them (Pearlin et al., 1981).

Overall, the findings indicate that caregivers' strategies should not be interpreted as proof that medical expenses are manageable. Rather, these strategies show how families attempt to maintain care under financial constraints. The ability to cope depends on income, access to insurance, the availability of relatives and community support, and the extent to which caregiving affects livelihood activities. Because this is a qualitative study in one municipality, the findings provide contextual understanding rather than statistical generalisation to all caregivers of children with epilepsy in Tanzania.

## Conclusion and Implications

This article explored how caregivers of children with epilepsy cope with medical expenses in Ubungo Municipality. The

findings identified five connected dimensions of coping: managing household financial pressure, adjusting household budgets, using health insurance and external assistance, relying on family and community support, and dealing with lost income associated with caregiving responsibilities. These strategies helped caregivers respond to expenses, but they did not necessarily eliminate financial vulnerability.

The study shows that medical expenses should be understood broadly. In addition to medication and clinical consultations, caregivers reported costs related to transportation, food, diapers, childcare assistance, and other everyday needs. Caregiving could also reduce time available for income-generating activities, creating pressure from both increased expenditure and constrained earnings. Budgeting, borrowing, insurance, and informal support were important, but their effectiveness depended on the resources available and whether assistance could be obtained when needed.

Several implications follow. Healthcare providers and relevant social support services should consider asking caregivers about transport and other practical expenses that may affect their ability to attend appointments and maintain care. Information about available health insurance and legitimate support services may help caregivers identify resources. Social protection and community support initiatives should also recognise that caregivers may require assistance with costs beyond clinical treatment. Finally, future research could examine how different income levels, household arrangements, insurance coverage, and access to support shape caregivers' experiences of medical expenses across different settings in Tanzania.

The findings should be interpreted in light of the study's qualitative design and local context. They provide an account of the coping strategies described by participants rather than estimates of the frequency or cost of medical expenses among all families. Nevertheless, they demonstrate why support for children with epilepsy should take account of the financial realities faced by those responsible for their care.

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