CAREGIVERS
EMPOWERMENT NETWORK AFRICA
(CENet)

Evidence Brief

Silent Pillars of Care: A Case Study on the Burdens and Needs of Unpaid Family Caregivers for Patients with Non-Communicable Diseases, Older Persons and Persons With Disabilities in Kenya

PARTNERS:

Faraja CANCER SUPPORT TRUST
ACK Hesbon Thika Parish
Alzheimer's & Dementia Organisation Kenya
Suruvi CARE FOR CAREGIVERS
LIGHT A CANDLE COUNSELLING SERVICES

BACKGROUND

A family caregiver is an unpaid individual; often a relative or member of the community who provides essential support to a person (the care recipient) who is unable to care for themselves. This unpaid caregiving is typically long-term and continuous, often lasting from six months to a lifetime. Care recipients are frequently affected by non-communicable diseases (NCDs), progressive health conditions, or disabilities, and they depend fully or nearly fully on their family caregivers; most of whom are women. Due to multiple intersecting factors; including a strained health system, the chronic nature of NCDs, disability, and age-related health deterioration; an increasing number of people are being cared for within the home setting. The burden of unpaid caregiving can be overwhelming, leading some family caregivers to experience psychological distress or even develop NCDs themselves.

According to the World Health Organization (WHO,2012), NCDs disproportionately impact populations in low- and middle-income countries, accounting for 73% of global NCD-related deaths (32 million). In 2021, WHO estimated that 18 million people died prematurely (before the age of 70) due to NCDs, with 82% of these deaths occurring in low- and middle-income countries, including Kenya.

In Kenya, NCDs are estimated to account for over 50% of inpatient admissions and 40% of hospital deaths, with out-of-pocket health expenditure reaching up to 45% of total health costs. These conditions place a significant financial strain on the healthcare system, diverting resources from other critical development priorities. Globally, the International Labour Organization (ILO,2018) estimates that 708 million women are outside the labor force due to unpaid care responsibilities. The Kenya Time Use Survey (2021) further underscores this gender disparity, revealing that women and girls spend, on average, five times more time on unpaid domestic and caregiving work than men. This gendered dynamic underscores the need for the government to develop and/or review policies that reflect the lived realities and demands of family caregiving.

This evidence brief summarizes the experiences of 105 family and community family caregivers in Kenya, based on 2024 self-reported data. The data were collected from four groups under the umbrella of the Family caregivers Empowerment Network (CENet) namely:

- ACK Canon Hesbon Parish-Diocese of Thika
- Alzheimer's and Dementia Organization of Kenya (ADOK)
- Family caregivers Support Group of Light A Candle Counselling Services (LACCS)
- Suruvi Care – for- Caregivers

The report was compiled with the kind support of Finestat Data Solutions, and the family caregivers were drawn from 11 counties across Kenya.

This brief is a summary of a longer report and highlights the socio-economic, psychological, and physical burdens associated with unpaid care work, particularly in caring for individuals with NCDs, disabilities, and age-related conditions. It also outlines key priority needs for both family caregivers and care recipients, providing a basis for informing future policy and programmatic intervention.

Key Recommendations

1.Strengthen Social Support Programs

There is an urgent need to implement direct financial support and/or stipends for family caregivers, using a needs-based framework that assesses the vulnerability of both family caregivers and care recipients. While Kenya's *Inua Jamii* Programme is a commendable initiative, 80% of the respondents (84 family caregivers) reported that their care recipients were not beneficiaries of the program due to various eligibility and administrative barriers.

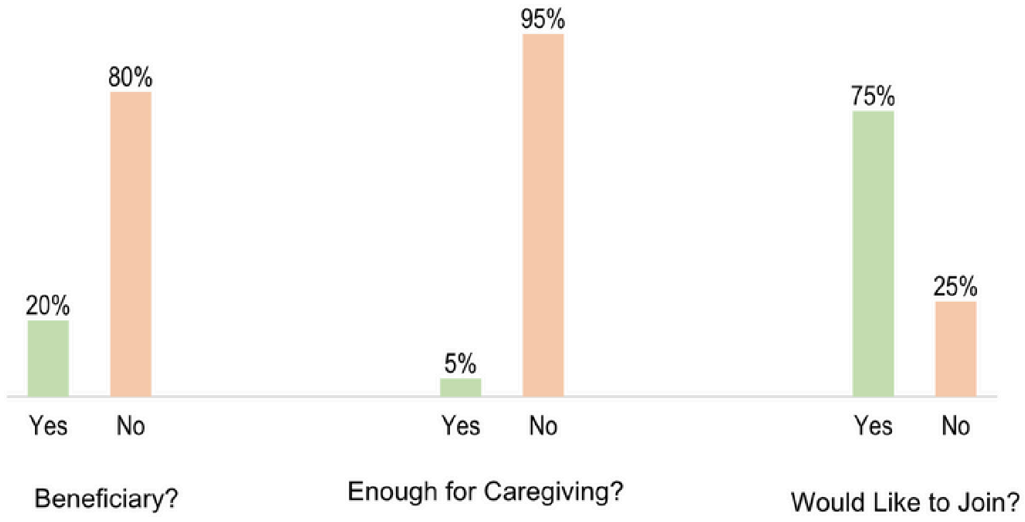
To address this gap, the *Inua Jamii* Programme and other related social protection schemes should be expanded and refined to include a broader segment of vulnerable individuals—particularly care recipients and their family caregivers. The inclusion of family caregivers in such programs is critical, given the intense financial, physical, emotional, and psychological strain they endure in fulfilling their caregiving roles.

2. Improve Access to Quality Health Care, Including Health Insurance

There is a critical need to expand access to affordable and inclusive health insurance schemes that reflect the realities of both family caregivers and their dependents in addition to the care recipients. Current out-of-pocket healthcare expenses impose a significant financial burden on family caregivers, who often bear the cost of medical care for themselves and their care recipients. Medical needs typically include consultations, prescription medications, counselling, assistive and mobility devices, diapers, and other essential supplies. Yet, even those with employer-provided private insurance face limitations such as exclusion of extended family members (including parents and dependents outside the nuclear family),age restrictions, lack of coverage for pre-existing conditions, which most non-communicable diseases fall under.

The case of family caregivers who are not engaged in wage or formal self-employment, purchasing individual health insurance is largely unaffordable, leaving them highly vulnerable to untreated health issues. It is imperative to ensure universal access to quality health care; including insurance for both care receivers and their family caregivers, particularly at the community and primary care levels.

Fig 1: Situation of Family Caregiving and Inua Jamii



80% of the care receivers and their caregivers were not beneficiaries of the Inua Jamii program.

3. Supportive Policies for Family Caregivers

Caregiving responsibilities often come at a significant cost to family caregivers; professional and economic well-being. Among respondents, 21% (n=22) reported losing their jobs, while 46% (n=48) experienced loss or reduction of income, either directly or indirectly due to their caregiving responsibilities.

There is an urgent need for supportive policy frameworks that formally recognize the role of family caregivers, particularly within workplace and labor regulations. Human Resource (HR) policies should accommodate caregiving needs by introducing flexible working hours, remote or hybrid work options and job protection measures. Sensitization within families, employers and institutions is also essential to foster supportive caregiving environments.

In practice, many employed family caregivers are compelled to dedicate portions of their regular working hours to caregiving, often leading to stress and conflict between job responsibilities and caregiving demands. Current human resource (HR) policies typically fail to acknowledge or accommodate this dual role, forcing family caregivers to operate under unsustainable pressures. A review of labor and HR policies is necessary to prevent punitive outcomes for employees who assume unpaid caregiving roles, and to promote equitable workplace inclusion.

4. Establishment of Respite Care Options

To reduce caregiver fatigue and improve long-term wellbeing, it is essential to introduce respite care programs accessible to family caregivers across Kenya. These services would enable family caregivers to take temporary breaks from their responsibilities; whether for rest, self-care or other personal needs without compromising the quality of care provided to the recipient. The wellbeing of care recipients is closely tied to the wellbeing of their family caregivers, making respite care not only a support mechanism for the caregiver but also a strategic investment in the overall healthcare outcome.

5.Caregiver Education and Training

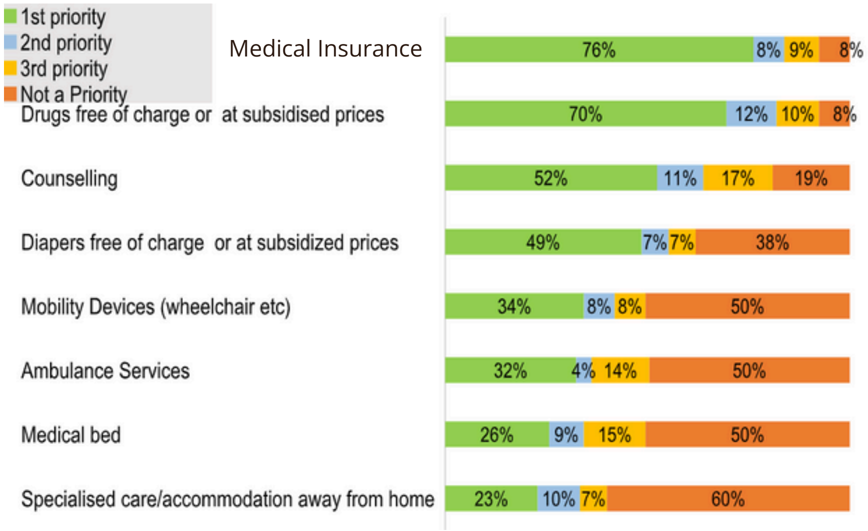
Family caregivers often lack formal training in caregiving, which can lead to both inadequate care on the case of the recipient and heightened caregiver stress. There is a clear need for structured caregiver education and training programs that equip family caregivers with knowledge of:

- Basic healthcare and first aid;
- Management of the NCDs and disabilities their recipients have;
- Use of assistive devices;
- Emotional and mental health support for them and their recipients;
- How to involve other family members in the caregiving roles.

Additionally, the provision of information kits including directories of relevant service providers (e.g., physiotherapists, ambulance services, registered homecare nurses, adult diaper suppliers, specialists etc.) would offer much-needed practical guidance. These resources can enhance family caregivers’ capacity, reduce anxiety, and support more effective and dignified care for the care recipients.

Wishes of Family Caregivers

Figure 2 Priorities of Caregivers



Medical Insurance as the Top Priority

Medical insurance emerged as the most urgent need among family caregivers, with 76% (n=80) ranking it as their highest priority. This finding aligns with the broader economic vulnerabilities identified earlier, where 46% of family caregivers reported either job loss or financial hardship due to the demands of caregiving. The burden of high out-of-pocket medical costs; both for themselves and their care recipients makes access to affordable medical insurance essential. In the Kenyan context, existing health insurance frameworks are often inadequate for family caregivers. Most insurance products are limited to nuclear family members and typically exclude elderly dependents. Moreover, private insurance options for older adults are not only scarce but also prohibitively expensive, forcing family caregivers to shoulder medical expenses directly. This financial strain compounds existing caregiving stressors and exacerbates the vulnerability of both family caregivers and care receivers.

Health Risks Among Family caregivers

Research shows that family caregivers are particularly susceptible to negative health outcomes (Schulz,2016). These include increased occurrences of acid reflux, chronic pain, headaches, and a weakened immune system, which heightens susceptibility to infections and chronic illnesses such as cancer. Studies indicate family caregivers have 23% (n=24) higher stress hormone levels and 15% (n=16) lower antibody responses, resulting in slower wound healing and a greater risk for cardiovascular diseases such as hypertension and heart disease. Additionally, family caregivers are more likely to:

- Miss medical appointments
- Forego preventive health practices,

- Neglect their own health due to time and financial constraints.

Access to medical insurance would not only alleviate financial burdens but also enable family caregivers to prioritize their health, thereby ensuring they remain physically and mentally able to provide care.

3. Cost of Drugs and Assistive Devices

Closely tied to health insurance is the cost of medications and assistive devices, which was also a top concern:

- 70% (n=74) of family caregivers prioritized access to free or subsidized drugs—a critical need given that many care receivers, particularly those with NCDs, require daily medication.
- 49% (n=51) identified subsidized adult diapers, and 39% (n=41) prioritized access to mobility aids like wheelchairs and walking frames.

Although not all care recipients require such items, for those who do, the financial burden is substantial. These essential supplies, often unavailable in public health facilities, become a recurring cost for family caregivers, especially in rural and underserved areas.

4. Counseling and Psychosocial Support

Counseling services were ranked as a top priority by 52% (n=55) of respondents. The emotional strain of caregiving, especially long-term, unpaid care often leads to burnout, anxiety, depression, and compassion fatigue. Empirical evidence supports the value of psychological interventions, showing that non-pharmacological treatment of depression can be more effective than medication alone (Linde et al., 2015). Research (Choy Qing Cham, 2022; Schulz,2008;) further confirms that:

- Family caregivers report significantly higher levels of mental health challenges than non-family caregivers.
- Female family caregivers, in particular, experience elevated symptoms of

depression and anxiety compared to their male counterparts. Counseling and mental health support are therefore, not optional add-ons but essential services for sustaining the well-being of family caregivers.

5. Access to Information and Resources

Access to reliable and timely information was ranked a key priority by 62% (n=65) of the respondents. Many family caregivers are tasked with managing multiple chronic or complex conditions among care receivers. As such, they need access to:

- Accurate medical information,
- Contacts of specialists and service providers (e.g. physiotherapists, home care

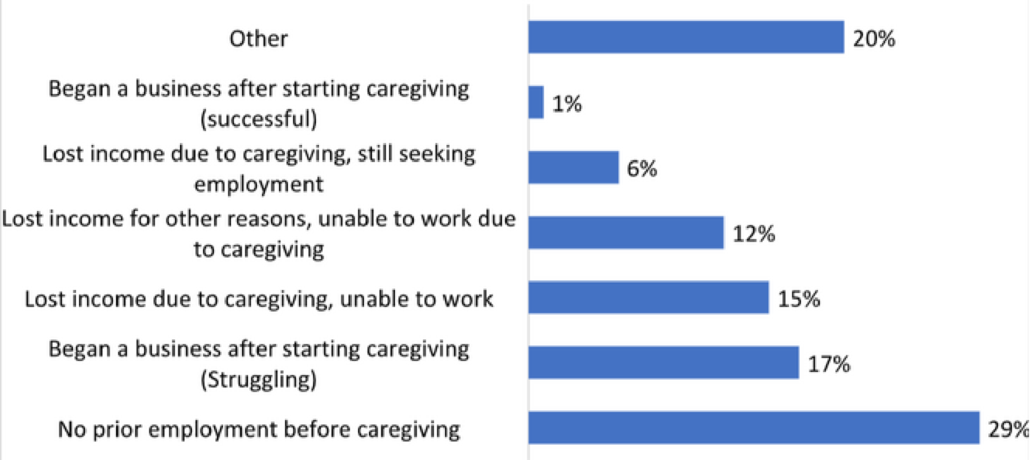
nurses),

- Sources of specific medications or medical equipment,
- Navigation support within Kenya's fragmented healthcare system.

This need is especially pressing for rural-based family caregivers, where availability of such services is limited, and distances to health facilities are greater. Providing user-friendly, accessible information platforms or care navigation tools would greatly enhance family caregivers' capacity to manage care effectively and reduce preventable health complications for both themselves and their care recipients.

Financial Situation

Figure 3 Self-reported Financial Situation of Caregivers



Financial Support and Respite Care

A significant 61% (n=64) of the respondents identified financial support as a top priority, particularly among those not receiving any formal assistance—such as family caregivers whose care recipients were not enrolled in government social protection schemes like *Inua Jamii*. This financial vulnerability reflects the hidden economic cost of unpaid caregiving, which often includes direct expenditures on medical care, mobility aids, and daily living support.

In addition, 45% (n=47) of the respondents emphasized the need for respite care, underscoring the need for regular breaks that can provide physical and psychological breaks. The identification of respite care as a priority illustrates the emotional toll of prolonged caregiving, which frequently leads to depression, burnout, and compassion fatigue. These two needs—financial support and access to respite care—are critical enablers that can help family caregivers sustain their role over time without compromising their own health and wellbeing.

Need for Family Sensitization and Support Networks

Over 52% (n=55) of the respondents reported that sensitization of family members was a priority. Many family caregivers operate in environments where family support is minimal or unevenly distributed, resulting in mainly the female members of the family bearing the heaviest burdens. Increased awareness and education within families about the demands and pressures of caregiving would help build more supportive home environments, reduce social isolation, and promote a culture of shared responsibility.

Career Stagnation and Economic Opportunity

The caregiving burden has significant implications for family caregivers; economic and professional development:

- 33% (n=35) of the respondents, primarily those employed or formerly employed, cited the need for workplace accommodations, such as flexible hours and remote work options where possible.
- 36% (n=39) of the respondents, most likely those self-employed or aspiring entrepreneurs, prioritized access to credit, highlighting the need to balance caregiving with income-generating activities.

These findings suggest that family caregivers are not only looking for financial relief, but also for opportunities to remain productive and economically engaged. Supportive employers, inclusive HR policies, and access to small business financing can significantly improve the economic resilience of family caregivers.

Additional Priorities Identified

Family caregivers also expressed interest in a wide range of supportive services, including:

- Self-care initiatives and wellness programs;
- Family caregivers; allowance or regular stipends;
- Legal services, especially for guardianship or care planning;
- Debriefing seminars and peer learning forums;
- Psycho-social support, including counselling and peer mentoring.

These priorities emphasize that caregiving is not only a practical and economic role, but also a deeply emotional experience that requires multidimensional support.

Synopsis

An analysis of data from 105 family caregivers revealed several important trends and challenges within the caregiving landscape in Kenya:

- **Gender Disparity:** The majority of family caregivers were women, accounting for 84.8% (89 out of 105) of respondents. Only 15.2% (16 family caregivers) were men, underscoring the gendered nature of unpaid care work.
- **Living Arrangements and Caregiving Role:** More than half of the family caregivers (56%) resided with their care recipients, identifying them as primary family caregivers.
- **Economic Vulnerability:** A significant proportion of family caregivers (80%) reported experiencing varying degrees of economic vulnerability directly linked to their caregiving responsibilities. Notably, 46% (48 respondents) indicated job loss, business disruptions, or financial instability resulting from the demands of caregiving. These financial challenges often led to social isolation, career disruption, and income loss, as many family caregivers struggled to balance employment or entrepreneurship with their caregiving roles.
- **Complexity of Conditions:** While the family caregivers supported individuals with disabilities, NCDs, chronic illnesses, and age-related conditions, 56% reported caring for individuals with multiple co-existing health conditions.
- **Health and Well-being of Family caregivers:** The physical and emotional toll of caregiving was evident. Family caregivers commonly reported burnout, compassion fatigue, and a decline in their own health. Those caring for individuals with musculoskeletal conditions faced additional physical strain, compounding the emotional and psychological burden of care.
- **Top Priority Needs:** Family caregivers identified medical insurance an subsidized access to medications for both care recipients and themselves as their most urgent needs. This was followed closely by the need for psychosocial support, such as counselling services, reflecting the significant emotional stress associated with caregiving.
- **Care for the Elderly:** The largest share of family caregivers (57%) was supporting elderly parents, primarily those suffering from age-related chronic and non-communicable diseases.
- **Extended Family Caregiving:** Caregiving extended beyond the nuclear family. Seven percent of respondents were caring for extended family members such as grandparents or in-laws; highlighting the continued relevance of extended family support structures within Kenya’s informal care network.

- **Peer Support:** Through their groups and networks, family caregivers also offer mutual support, including practical advice and psychosocial assistance. These peer-based support systems play a critical role in alleviating the emotional burden of caregiving and fostering a sense of community.
- **Duration:** The duration of caregiving further compounds the complexity of caregivers' experiences. 54% (n=57) of family caregivers reported providing care for extended periods ranging from 5 to over 10 years. This prolonged caregiving trajectory significantly affects family caregivers' personal lives, socio-economic stability, and mental well-being, highlighting the long-term nature of care responsibilities and the need for sustained support mechanisms.

These findings underscore the need for targeted policy interventions to support family caregivers, particularly women, and address the systemic socio-economic and health-related impacts of unpaid caregiving in Kenya.

Conclusion

Extended caregiving duration has major implications on an individual's productivity and career development in the context of the vulnerabilities reported. Depending on several factors, including but not limited to the degree of care and support required by the care receiver, the Caregivers are likely to face career disruptions, loss of income and/or livelihoods, reduced working hours or complete withdrawal from the workforce. Additionally, the socio-economic, physical and psychological toll of caregiving, if unchecked, has the potential to increase the risk of burnout and progressively making the caregiver a candidate of mental health challenges and NCDs themselves, and therefore creating a cycle of NCDs.

Majority of the caregivers are women. There is need to recognize this burden and its toll on women and girls and redistribute it across the society through the involvement of boys and men. This might require policy formulation and/or implementation to balance the burden of care across the board.

The national and devolved governments need to review existing policies or introduce new policies that take into account the circumstances of family caregivers with the aim of reducing their financial and health vulnerabilities which if unchecked, could affect the health of the care giver negatively, potentially exposing them to neurological and mental NCDs and thus perpetuating the cycle of NCDs in the country.

This evidence brief reveals that family caregiving significantly impacts the economic stability of caregivers, with 80% reporting financial vulnerability directly linked to their caregiving responsibilities. Many caregivers, especially those who were previously unemployed, face considerable economic challenges, and those who attempt to start businesses struggle to balance caregiving duties with entrepreneurship. Additionally, caregivers who have lost their jobs due to caregiving often encounter difficulties when attempting to reintegrate into the job market. Only 22% managed to maintain steady employment, and these are mostly secondary caregivers with external support. **The economic toll on caregivers is profound, underscoring the need for stronger financial support systems.** On a positive note, 27% caregivers (28) reported experiencing stronger bonds with care receivers but often at the expense of their broader social networks and personal relationships.

CONTACT INFORMATION

Caregivers Empowerment Network-Africa (CENet)
www.caregiversempowermentnetwork.co.ke
info@caregiversempowermentnetwork.co.ke
+254 108 070 496