CAREGIVERS
EMPOWERMENT NETWORK AFRICA
(CENet)

Family Caregiving in Kenya

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

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Suruvi CARE FOR CAREGIVERS

LIGHT A CANDLE COUNSELLING SERVICES

Foreword

Caregiving is an act of love - but it is also labour. And like all labour, it deserves recognition, and rewarding. More importantly, the unpaid family caregivers need to be supported so that they do not suffer burn out or become sick themselves!

Across Kenya and the African continent in general, countless families quietly assume the responsibility of caring for loved ones living with non-communicable diseases, chronic illnesses, disabilities, or the frailties of old age. In the absence of adequate health and social services, they step into multiple roles of nursing, counselling, playing the role of breadwinner, and providing pillars of strength on a full-time basis. The duty of care is deeply human and essential to life and dignity, yet it is usually unpaid, and far too often invisible and mostly undertaken by women and girls.

This report, 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, brings the invisibility and unpaid work to light through the reported stories, data and deeply moving excerpts. Drawing on insights from 105 family caregivers across 11 counties in Kenya, the report fills a crucial gap and deepens our understanding of the labour of love involved in caring without training, material support, compensation and societal recognition.

The findings of this programmatic non-research determination are both sobering and illuminating. They confirm what caregiver advocates and researchers have been saying for years, that unpaid family caregiving is not just a private act of compassion. Caregiving is a foundational and often unrecognized pillar of healthcare and social protection systems.

Often, unpaid care-work and other family social reproductive roles are performed by women and girls. The majority (84%, n=88) of the respondents in this report were women who provide care to family members and bear the brunt of socio-economic exclusion, physical and mental health distress.

The experiences of caregivers are unique and diverse. This report presents a vivid picture of the multifaceted burden borne by caregivers, including:

- **Economic -** caregiving, apart from draining the caregivers' financial resources it also interrupts income-generation through job losses, reduced time to do business and generally less production thus exposing the caregivers and the household to poverty, thereby limiting the caregivers' (mainly women) economic empowerment.

- **Social -** depending on the severity of the condition, caregiving isolates caregivers from community life and religious practice, and deprives one of personal time since their lives revolve around the care-recipient.
- **Emotional and physical -** primary caregivers, depending on the condition of the care-recipient, can result in extreme burnout, round-the-clock exhaustion and deteriorating mental health.
- **Systemic -** there is a glaring gap in policies and programs. Few national policies recognize and or integrate family caregivers into health and other support systems.

The findings presented in this case study could not be more timely. Kenya's epidemiological profile, like several others in Africa, shows that non-communicable diseases account for more than half of all hospital admissions while life expectancy continues to drop. Health and well-being planning and urgent interventions are needed to contain this trend.

Call for Action: Even as we celebrate unpaid caregivers and the passage of the Kenya Persons with Disability Act 2025, which recognizes caregivers of persons with disabilities, we call upon African governments to firmly include family caregivers in national policies, health and safety net programmes.

I take this opportunity to thank the team and organizations involved in producing this report by documenting the dire situation of unpaid caregivers in Kenya. One of the key objectives of the Caregivers Empowerment Network-Africa (CENet) is to create a platform for advocacy for unpaid caregivers in Africa, build synergies and share learnings. I commend this milestone and first step.

Munya Saruchera (PhD Sociology)
Chairperson, Caregivers Empowerment Network-Africa (CENet)
11th July 2025

Voice of Caregivers

“I lost my dad suddenly in January 2017, and from that moment on, my life has felt like a never-ending struggle. Since then, my mum's health has been on a constant decline. One ailment after another.

In 2020, she broke her arm and had to undergo surgery. Not long after, she began suffering strokes. Then in April 2023, she suffered a major stroke. It affected her speech and memory; she spoke in a confused, almost gibberish language, but if you listened closely, you could understand her. Despite the challenges, she slowly began to recover. She remembered all of us, could write our names, and even started walking again. She was able to do basic chores, go to the toilet, feed herself, and interact with the kids.

But in February 2024, her condition worsened. Her neck begun swelling, and we struggled for weeks to get a proper diagnosis and treatment. We moved from one hospital to another. We took her into hospital while she was still walking, but she came out in a wheelchair. Since then, she has been mostly bedridden.

Now, she can’t speak. Her muscles have wasted away. We’ve tried occupational therapy, psychological therapy, nutritional support; nothing seems to be working. A counselor said mum is not yet ready for counseling. A speech therapist once assured us that mum’s vocal cords were intact, but we’ve never been able to return for follow-up due to her repeated hospitalizations. She’s been on an NG tube for feeding since January 2024.

This journey has drained me physically, mentally, spiritually, and financially. It’s taken a toll on every part of my being. And yet... I still have faith. I still believe she can get better with the right care and management. I haven’t lost hope.
I’m opening up here because I know I can’t do this alone anymore. I’m hoping that by sharing my story, I might find the help, guidance, or support needed for this incredibly difficult journey.”

(Message shared by a family caregiver on a caregivers support WhatsApp Wall. Name & dates changed for privacy)

Voice of Caregivers

“Dear Family, It is with a heavy heart that I share the news that my dear mum has been diagnosed with stomach cancer, and she is close to 100 years old. Over the past few days, she has stopped eating and has been unwilling to take her medication. She was admitted into hospital but has been discharged today, and now she is at home with us.

We are feeling lost and uncertain about the next steps, especially now that she is not eating or talking. Has anyone in your family experienced something similar or has experience with hospice care? We would greatly appreciate any advice or suggestions on how to provide the best care for her during this difficult time. Thank you all for your support and understanding. Any guidance would be invaluable to us right now.”

Catherine, Nairobi

(Message shared by a family caregiver on a caregivers support WhatsApp Wall. Name & dates changed for privacy)

DEDICATION

This report is dedicated to all unpaid family caregivers; the silent heroes who give their time, energy, and love without expectation of reward or recognition.

To the mothers, fathers, daughters, sons, siblings, extended family members and friends who wake up each day to care for their loved ones living with Non-Communicable Diseases(NCDs), Older persons, and Persons with Disability; your strength, resilience, and compassion are the heartbeat of our communities.

Though your sacrifices often go unseen and your voices unheard, this work stands as a testament to your unwavering commitment. May it bring greater awareness, recognition, and support for the critical role you play silently in our health systems and in the lives of those who need the most care.

May the efforts and advocacy of the past and current generations of family caregivers cause a revolution so that the next generations of family caregivers may enjoy more support and normalcy in their lives.

ACKNOWLEDGEMENT

This report would not have been possible without the generous and voluntary participation of the 105 unpaid family caregivers who shared their personal and often challenging caregiving journeys. Their willingness to provide candid insights into their lived experiences forms the foundation of this work. We extend our deepest gratitude and respect to each one of them.

We are especially indebted to Samuel Juma of Finestat Data Solutions for his invaluable contribution throughout this project; from the development of data collection tools to the analysis and final compilation of this report. His commitment, expertise, and countless hours of support were instrumental to the success of this initiative. We are sincerely grateful for his selflessness and unwavering dedication.

In a special way, we thank Global Affairs Canada and IDRC for the Scaling Care Innovations in Africa Project in which one of our members, Light A Candle Counselling Services is a partner.

This report also benefited from the tireless efforts of a dedicated team representing the Alzheimer's and Dementia Organization of Kenya (ADOK Kenya), Suruvi Care for Caregivers, ACK Canon Hesbon Parish of Thika Diocese, and Light a Candle Counselling Services - Family Caregivers Support Group, all operating under the umbrella of the Caregivers Empowerment Network (CENet). We thank each of these organizations and their members for their engagement in the validation process and their continued commitment to supporting caregivers.

The report's development involved evening meetings and long hours, often at the expense of personal and family time. We therefore wish to extend our heartfelt appreciation to our families; spouses, children, and even the care-receivers for their patience, understanding, and the sacrifices they made in supporting our involvement in this work.

Finally, to all those who contributed to this project in various ways but whose names may not appear here, please accept our sincere thanks. Your support is deeply appreciated.

Judy Chege-Ndung'u - Light A Candle Counselling Services, Family Caregivers Support Group & Caregivers Empowerment Network (CENet)

Renaldah Mboje - Family Caregivers Support Group, Silverstar Resources Africa Ltd & Caregivers Empowerment Network (CENet)

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Definition of Terms and Concepts

Family caregiver: A person who gives care to another member of the family or Community, a care-receiver, who needs help taking care of themselves. The support is usually required for a long period and continuously e.g. from six months up to a lifetime. The care receiver, who most of the time is suffering from Non-Communicable Diseases (NCDs), deteriorating conditions or disability depends fully or almost fully on the Caregiver. This situation poses a huge socio-economic, emotional, and psychosocial burden on the Family Caregiver since they are not paid or compensated in any way for providing the service. That burden is most of the time not acknowledged by the society. Family Caregivers need a lot of support.

NB: We recognize that there is a cadre of formally trained caregivers- who are formally employed to provide care. However, in this report, all reference to 'Caregivers' strictly refers to the family/unpaid caregivers.

Primary caregiver: The main person responsible for providing day-to-day care to a care receiver. In most cases, they live with the care receiver.

Secondary caregiver: A person who provides supplementary or occasional care to the care receiver, often supporting the primary caregiver.

Care receiver: The individual who depends on the caregiver for daily assistance, typically due to health challenges like chronic illnesses, disabilities, or aging-related conditions.

Non-Communicable Diseases (NCDs): Chronic illnesses that are not spread from person to person, such as diabetes, hypertension, and cancer.
Comorbidities: The presence of more than one medical condition in the same person at the same time, such as someone ailing from both diabetes and hypertension.

Neurological disorders: Medical conditions affecting the brain, spine, and nerves, including conditions like dementia, stroke, and epilepsy.

Burnout: A state of physical, emotional, and mental exhaustion caused by prolonged stress, often experienced by caregivers.

Respite care: Temporary care provided to care receivers to give their caregivers a break from their responsibilities. It can range from a few hours to days, depending on the arrangement. During this time, the caregiver can rest or undertake activities of personal care e.g. go to hospital or to the salon etc.

Social isolation: The experience of feeling disconnected from social networks or lacking meaningful relationships, common among caregivers.

Inua Jamii program: A Kenyan government initiative offering financial support to a section of vulnerable populations, including elderly and disabled persons (literal translation: "Lift the Community")

Emotional fatigue: A feeling of being emotionally drained and overwhelmed, often resulting from prolonged caregiving.

Social protection: Public policies and programs aimed at reducing poverty and vulnerability by providing financial and social support.

Acronyms and Abbreviations

ACK Anglican Church of Kenya
ADOK Alzheimer's and Dementia Organization of Kenya
ART Antiretroviral Therapy
ARUA African Research Universities Alliance
CENet Caregivers Empowerment Network-Africa
COPD Chronic Obstructive Pulmonary Disease
CT-OVC Cash Transfer for Orphans and Vulnerable Children
DESA Department of Economic and Social Affairs
FCs Family Caregivers
FCSG Family Caregivers Support Group
FKE Federation of Kenya Employers
HSNP Hunger Safety Net Programme
ILO International Labour Organization
KNBS Kenya National Bureau of Statistics
LACCS Light a Candle Counselling Services
LMI Low- and Middle-Income countries
NCDs Non-Communicable Diseases
OPCT Older Persons Cash Transfer
PrEP Pre-Exposure Prophylaxis
PWSD-CT Persons with Severe Disabilities Cash Transfer
SDG Sustainable Development Goals
SURUVI Suruvi Care for Caregivers
UN United Nations
UTIs Urinary Tract Infections
WHO World Health Organization

Executive Summary

Family caregiving in Kenya is a critical yet under-supported component of healthcare, particularly for individuals with non-communicable diseases, disabilities, and age-related deteriorating conditions. Caregiving responsibilities, often shouldered by women, are associated with significant socio-economic and emotional burdens.

Despite their essential role, family caregivers receive limited formal support, leading to financial instability, risk to mental health challenges, and inadequate access to necessary resources.

This compilation of self-reported information explores the experiences of family caregivers in Kenya as shared by members of ADOK; FCSG; Suruvi and ACK Canon Hesbon, Thika Parish with inputs from the Caregivers Empowerment Network - Africa.

It is important to note that the tool was limited to only members of the four institutions. The report highlights the economic, social, emotional, and physical challenges family caregivers face. It also identifies the key priorities and needs for both caregivers and care receivers.

The report is based on self-reported data from 105 family caregivers across 11 counties in Kenya. Participants were predominantly female at 84% (n=88), providing care to older family members, often with multiple chronic or neurological conditions. The analysis focused on family dynamics, economic status, disease burden, caregiving priorities, and the transformative effects of caregiving at the family level.

Key Findings

- **Family dynamics:** 84% (n=88) of the caregivers were women caring for immediate family members, particularly elderly parents, and 56% (n=59) live with their care receivers.
- **Economic impact:** 80% (n=84) of caregivers reported economic vulnerability due to caregiving responsibilities, with many experiencing income losses or struggling to balance caregiving with entrepreneurship or employment.
- **Disease burden:** Over half of caregiver's support people with neurological, mental health, or chronic diseases, with 56% (n=59) of care receivers managing multiple conditions.

- **Caregiving priorities:** Medical insurance, drug subsidies and counselling emerged as top priorities for caregivers, while mobility devices were given highest priority by caregivers whose care receivers had physical and mobility difficulties and persons with physical disabilities. These were proportionally smaller in these institutions.
- **Emotional and physical strain:** Caregiving leads to significant emotional and physical strain, with caregivers reporting burnout, health deterioration, and strained relationships, though some also reported to have developed healthcare skills.
- **Social and professional impact:** Social isolation and professional disruptions are common, with many caregivers reporting job loss or reduced working hours due to caregiving demands.
- **Inua Jamii:** Only 20% (n=21) of caregivers reported that their care-receivers were beneficiaries of the Inua Jamii program, most of whom said the support was inadequate to provide for caregiving responsibilities. Out of those who were not receiving the support, 75% (n=79) expressed interest to join the program.

Key Recommendations

- **Improve access to medical insurance:** Introduce and/ or expand affordable medical insurance programs which can address the needs of the care receivers, addressing the high medical costs associated with prolonged illnesses and conditions.
- **Subsidize cost of medicines and supportive devises:** medication costs: Provide subsidized or free medications for care receivers and family caregivers since managing NCDs places a significant financial burden on family caregivers. This includes essential drugs, assistive devices for those with mobility challenges as well as cost of regular materials such as adult diapers.
- **Strengthen social support programs:** Implement direct financial support or stipends for caregivers, especially those who have lost income or employment due to caregiving responsibilities.
- **Expand counselling and mental health services:** Put in place counselling services for caregivers to address burnout, depression, and emotional fatigue, which are prevalent among caregivers.
- **Create public Respite Care options:** Introduce respite care programs that allow caregivers to take regular breaks from their caregiving duties, reducing the risk of burning out and improving their overall well-being.
- **Promote caregiver education and training:** Offer training and resources to help caregivers acquire healthcare knowledge and caregiving strategies, enabling them to provide better care while reducing stress and physical strain.
- **Facilitate social and professional support:** Encourage workplace accommodation for caregivers, such as flexible hours or remote work, and promote sensitization among family members and employers to foster a supportive caregiving environment. Human Resource policies should accommodate caregiving to ensure caregivers remain both healthy and productive despite the burden of care.
- **Caregiver as part of the Health System Structure:** Caregivers can play an important role in being agents of change for better and healthier lifestyles. Through their caregiving activities, they have learnt many skills such as handling HBP machines and monitoring blood sugar etc. The government could harness their skills more effectively in the health system.

Section 1: Background

1.1 Introduction

'Care' is a group of activities that serve people for their well-being, provided by households, communities, the market and governments through a combination of paid and unpaid activities. Care work can be broadly divided into reproductive and productive. Reproductive care work is also associated with reproductive activities and sometimes cannot be delegated and must be carried out by female members of the household e.g. breastfeeding and nursing a young baby. However, some of the care work activities can be delegated to other people and yield the same results and are therefore productive in nature. These include cooking, cleaning and fetching water and fuel. These activities constitute production but are not included in the calculation of gross domestic product (KNBS, 2021). Yet, those activities too are work because they have cost implications – both time and energy (BEAM, 2016).

Unpaid care involves time and energy in supporting human well-being, arising out of social or contractual obligations, including marriage and parenting as well as less formal societal relationships. The main recipients of direct care are children (early childhood, school-aged children, adolescents), the sick and disabled members of the households, the elderly (UN Women, 2024). More often than not, it is women who end up doing both unpaid reproductive and productive care work, thus resulting in a huge socio-economic and psychological burden. That burden leaves girls with less time for education, leisure, political participation, paid work, and other economic activities.

The Beijing Declaration and Platform for Action emphasizes unpaid care and domestic work as a constraint for the realization of women's rights (UN, 2017).

1.2 Unpaid Care work in the Context of Health Challenges

Caregiving is an essential component of healthcare systems globally, especially for persons with chronic conditions, disabilities, or age-related degenerative illnesses. This role is becoming increasingly central to healthcare systems due to rising life expectancy and the prevalence of chronic diseases (Litzelman et al., 2016). Caregivers provide indispensable services, yet their contributions often go unrecognized, and the challenges they face are rarely addressed through formal policy structures. The growing demand for caregiving worldwide raises crucial questions about the well-being of caregivers and the adequacy of support systems available to them.

Providing care for persons with disabilities, those with long-term and chronic illnesses as well as those with age-related deteriorating conditions can be categorised mainly as productive work- because it can be delegated to someone else yet achieve similar results. In a best-case scenario, one can be employed to provide the services.

In resource-scarce settings, the work falls on unpaid women and girls, members of the care-receiver's family. Traditionally, caregiving was integrated into extended family systems. Studies show that most caregivers are middle-aged women, often balancing caregiving duties with paid employment and other family responsibilities (Pinquart & Sörensen, 2011). In low- and middle-income countries, the challenges of family caregiving are amplified by limited institutional support, weaker social security nets, and economic constraints. Additionally, rapidly changing socio-economic transitions characterized by urbanization, migration, and changing family structures impacts caregiving dynamics (Moore, 2023).

The role of caregivers is increasingly falling on women, many of whom have lower education levels and limited access to health services (Kanorio, 2019). Furthermore, the lack of formal employment protections for caregivers exacerbates their financial vulnerabilities.

Many family caregivers involuntarily give up paid employment to care for their relatives, and with limited government support, the economic strain is intensified, particularly for women in the informal sector.

According to the International Labour Organization (ILO), three-quarters of all unpaid care work globally is undertaken by women and girls (Oxfam, 2019). Though these tasks could theoretically be outsourced to paid workers, they are overwhelmingly performed by women and are often undervalued or seen as "women's work." This invisible labour places a burden on women, limiting their economic opportunities, autonomy, and participation in decision-making within households.

This burden can limit women's engagement in market activities and lead them to concentrate in low-paid, informal, or home-based work as a means of balancing unpaid care work and paid employment (Samman et al., 2016).

According to the ILO's report on the care economy (ILO, 2018), the most common profile of an unpaid carer in Africa is a woman aged between 15 and 54, with few economic resources, several children, a low level of education, often with health problems or disabilities, who simultaneously works for pay or profit, mostly in the informal economy, and receives little or no formal care support. In sub-Saharan Africa, 68% of community health workers are women. Most are young, and 59% of them have only primary education.

In high-income countries, caregiver demographics have been extensively studied, and efforts have been made to provide support through targeted interventions, such as respite care, financial compensation, and mental health services. For instance, the U.S. and several European nations have developed policies that provide tax breaks and financial assistance to caregivers, acknowledging the economic strain they face (Anderson et al., 2013). These interventions are based on the understanding that caregiving is not only emotionally and physically exhausting but also imposes a significant financial burden.

According to the Kenya 2019 census, women accounted for 50.2% (9.89 million) of the total working population, compared to 49.8 % (9.79 million) men. The majority of these women work in the informal sector; they are also heavily involved in care work at the household and community level (Oxfam, 2021). Nationally, the proportion of time spent on unpaid work by girls aged 15-17 years, is thrice as much (14.0%) as that of boys (4.1%) in the same age group. Among the youth (18-34 years), the proportion of time that women spend on similar activities per day is slightly over (21.6 %), about 6 times more than young men. Elderly women aged 60 years and above spend about three hours (13.0%) on unpaid domestic and care work, while their male counterparts spent about an hour (3.2%) at national level (KNBS, 2021).

The predominance of women respondents among members of the four institutions in this report aligns with global findings indicating that women disproportionately shoulder unpaid caregiving responsibilities. For instance, the International Labour Organization (ILO) reports that women perform 76.2% of total hours of unpaid care work globally, amounting to over three times the amount undertaken by men (ILO, 2020).

1.3 Problem Statement

Non-communicable diseases (NCDs) are a leading global health concern, accounting for an estimated 35 million deaths in 2005, representing 60% of all deaths worldwide. Of these, 80% occurred in low- and middle-income countries (LMICs), with 16 million involving individuals under 70 years old (WHO, 2020). These diseases, including cancers, diabetes, hypertension, chronic obstructive pulmonary diseases, injuries, and asthma, are projected to increase by 17% over the next decade. This trend underscores the need for caregivers to be adequately prepared and supported as they play a pivotal role in the care of NCD patients. Globally, caregiving responsibilities are disproportionately borne by women, who spend two to ten times more time on unpaid caregiving than men.

In Kenya, caregivers face immense challenges, particularly in the context of supporting individuals with disabilities, who constitute a significant segment of the population. According to the 2019 Kenya Population and Housing Census, approximately 2.2% of the population (900,000 people) live with some form of disability. Family and community caregivers have historically played a vital role in supporting people living with chronic illnesses, such as HIV/AIDS, particularly before the availability of antiretroviral therapy (ART). While ART and prevention measures like Pre-Exposure Prophylaxis (PrEP) have reduced new HIV infections, caregivers continue to provide essential support not only to HIV/AIDS patients, orphans, and vulnerable children but in the context of NCDs, it extends to the elderly and individuals with disabilities, emphasizing the critical yet undervalued role of caregivers in healthcare systems across Africa.

Despite its importance, family caregiving in Kenya remains an informal and largely unrecognized sector. Family Caregivers lack formal support systems, leaving them vulnerable to significant financial instability, mental health challenges, and physical strain. The absence of systemic structures to assist caregivers exacerbates their hardships, even as they shoulder responsibilities that are indispensable to the nation's healthcare system.

This report sought to explore the caregiving journeys of family caregivers in Kenya, drawing from insights shared by the Family Caregivers Support Group of the Light a Candle Counselling Services (LACCS), Caregivers Empowerment Network Africa, Alzheimer's and Dementia Organization of Kenya (ADOK Kenya), Suruvi-Care-for-me, and Canon Hesbon ACK Church, Thika Parish. By compiling critical empirical evidence, this report aims to inform advocacy efforts and policy development to provide essential support services for family caregivers, ensuring their well-being while enhancing the care they provide.

1.4 Key objectives

1. To analyse the demographic characteristics and socio-economic impacts of caregiving on family caregivers, members of the four institutions.
2. To assess the physical, emotional, and social well-being of family caregivers of the four institutions.
3. To identify main disease burdens and key areas of support as prioritised by the Family Caregivers of the four institutions
4. To make proposals to be considered for potential policy and Practice

Section 2: Methodology and Data Sources

2.1 Participants

This report is based on analysis of self-reported data from 105 caregivers (Female = 84.8% or 89 out of 105) from 11 counties in Kenya namely *Nairobi, Kiambu, Kajiado, Machakos, Kakamega, Kilifi, Uasin Gishu, Busia, Bomet, Mombasa and Murang'a*. See the following section for more details about demographic information.

2.2 Demographic information

Table 1

Caregivers' Demographic information

Demographic Information	Frequency	Percentage
Gender		
Female	89	84.8%
Male	16	15.2%
Education Level Attained		
Degree	33	31.4%
Diploma	24	22.9%
Masters	18	17.1%
Higher Diploma	15	14.3%
PhD	5	4.8%
Post-secondary certificate	5	4.8%
Secondary school level	5	4.8%
Age (year)		
18 - 28	5	4.8%
29 - 38	13	12.4%
39 - 48	33	31.4%
49 - 58	38	36.2%
59 - 68	14	13.3%
Above 69	2	1.9%
County of Residence		
Nairobi	47	44.8%
Kiambu	38	36.2%
Kajiado	7	6.7%
Machakos	3	2.9%
Kakamega	2	1.9%
Kilifi	2	1.9%
Uasin Gishu	2	1.9%
Busia	1	1.0%
Bomet	1	1.0%
Mombasa	1	1.0%
Murang'a	1	1.0%
Living Locality		
Urban	82	78.1%
Rural	23	21.9%

The sample consists predominantly of female caregivers (84.8%), therefore highlighting the gendered nature of caregiving in a patriarchal society. Most of the respondents were well-educated, with 31.4% holding degrees, 17.1% master's degrees, and 4.8% PhDs. This might point to the kind of clientele that the institutions that participated in this data collection serve and perhaps not necessarily the description of family caregivers.

The majority of respondents fall between 29 and 58 years of age (80%), an age range that is within what would be the most economically productive bracket. Geographically, Nairobi (44.8%) and Kiambu (36.2%) are the primary counties of residence, with 78.1% living in urban areas, in line with the fact that the headquarters of the four institutions are in urban areas.

Table 2 Care receivers' demographics information

Demographic Information	Frequency	Percentage
Gender		
Female	77	73.3%
Male	25	23.8%
Other	3	2.9%
Age (years)		
Below 18	2	1.9%
18 - 28	5	4.8%
29 - 38	5	4.8%
39 - 48	3	2.9%
49 - 58	3	2.9%
59 - 68	10	9.5%
69 - 78	27	25.7%
79 - 88	34	32.4%
89 - 98	15	14.3%
Above 99	1	1.0%
County of Residence		
Nairobi	48	45.7%
Kiambu	25	23.8%
Kajiado	5	4.8%
Kirinyaga	4	3.8%
Murang'a	4	3.8%
Nyeri	3	2.9%
Kilifi	2	1.9%
Machakos	2	1.9%
Uasin Gishu	2	1.9%
Bomet	1	1.0%
Busia	1	1.0%
Embu	1	1.0%
Kakamega	1	1.0%
Kisumu	1	1.0%
Kitui	1	1.0%
Laikipia	1	1.0%
Meru	1	1.0%
Mombasa	1	1.0%
Nakuru	1	1.0%
Living Locality		
Urban	77	73.3%
Rural	28	26.7%

The majority of care receivers are female (73.3%) and predominantly elderly, with 72.4% aged 69 and above. This indicates that caregiving largely focuses on older adults, many of whom are of advanced age and are likely dealing with age-related conditions. The data shows that a large portion of the care receivers lived in Nairobi (45.7%) and Kiambu (23.8%), which mirrors the caregivers' geographic distribution. The fact that 73.3% live in urban areas further highlights the membership of the four institutions.

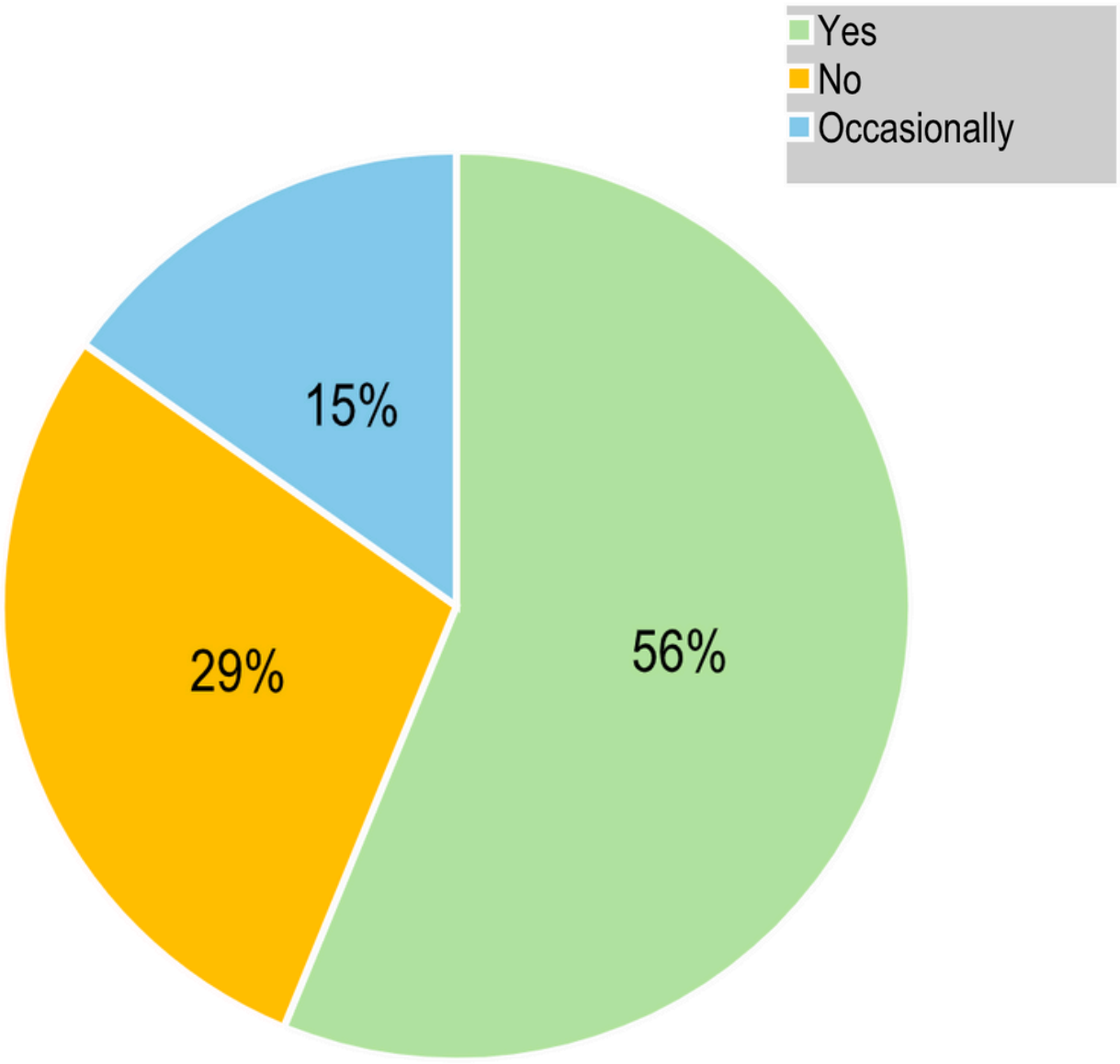
Section 3: Family Demographics and Socio-Economic Impact of Caregiving

This section begins with exploring how caregivers navigate their roles within family structures, including their residence status, relationships with care-receivers, and the time they dedicate to caregiving. The section proceeds by presenting an analysis of socio-economic impacts of caregiving on family caregivers.

3.1 Residence Status in Caregiving

We asked caregivers whether they lived with their care receivers in the same household and the results are presented in Figure 1.

Figure 1
Caregiver and Care-receiver Living Location

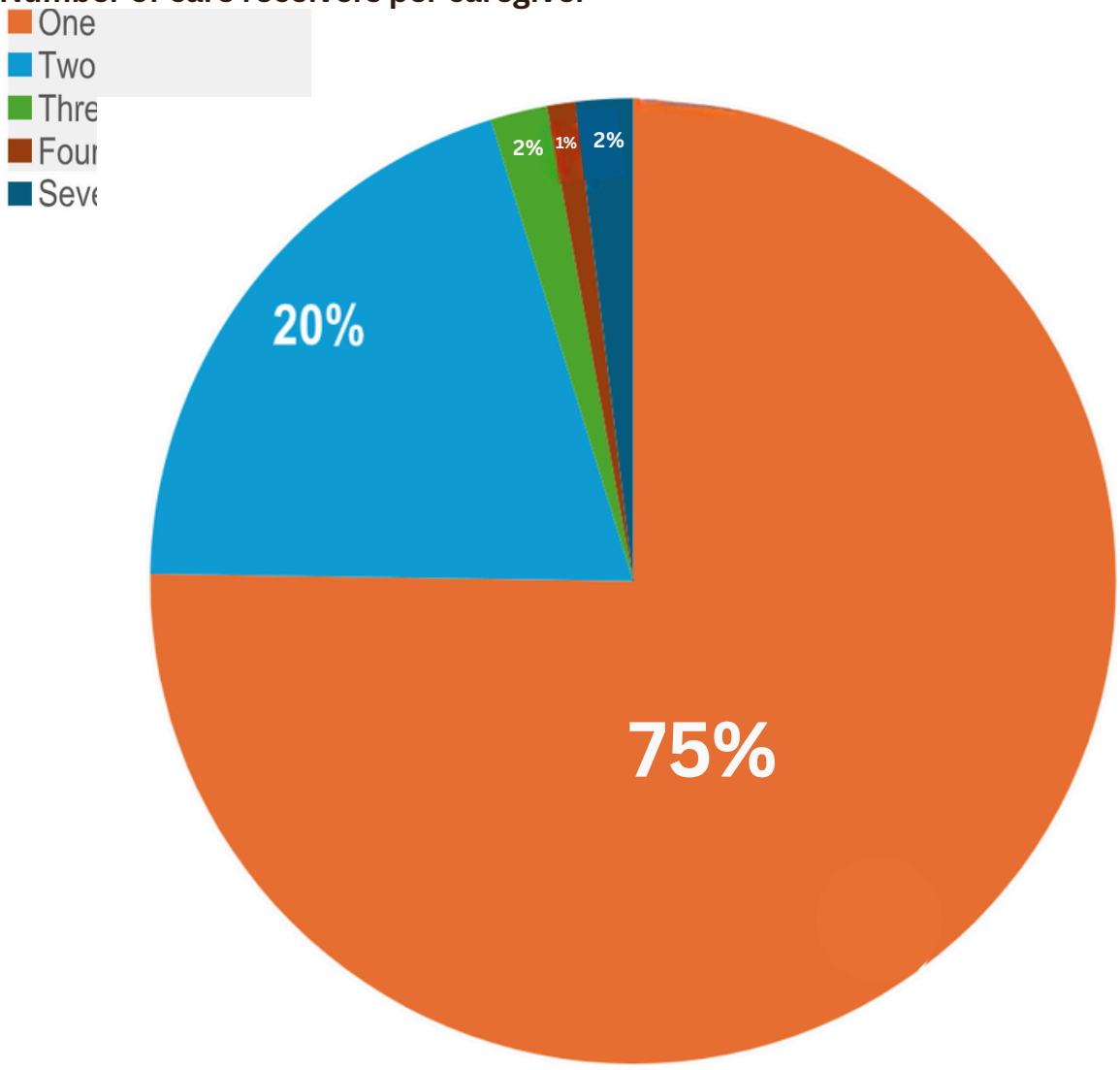


The results show that the majority of respondents 56% (n=59) lived in the same household as their care-receivers. This indicates that the majority of the respondents provided close and continuous caregiving arrangements. However, 29% (n=30) did not live with their care-receivers, and 15% (n=16) lived with them occasionally. We made a follow up with caregivers who did not stay with their care receivers to find out whether the care receiver lived in a facility such as old people's home or similar places. We found that only 17% (n=18) of caregivers who did not stay with their care receivers reported that they lived in a care home/old people's home.

3.2 Relationship between caregivers and care receivers

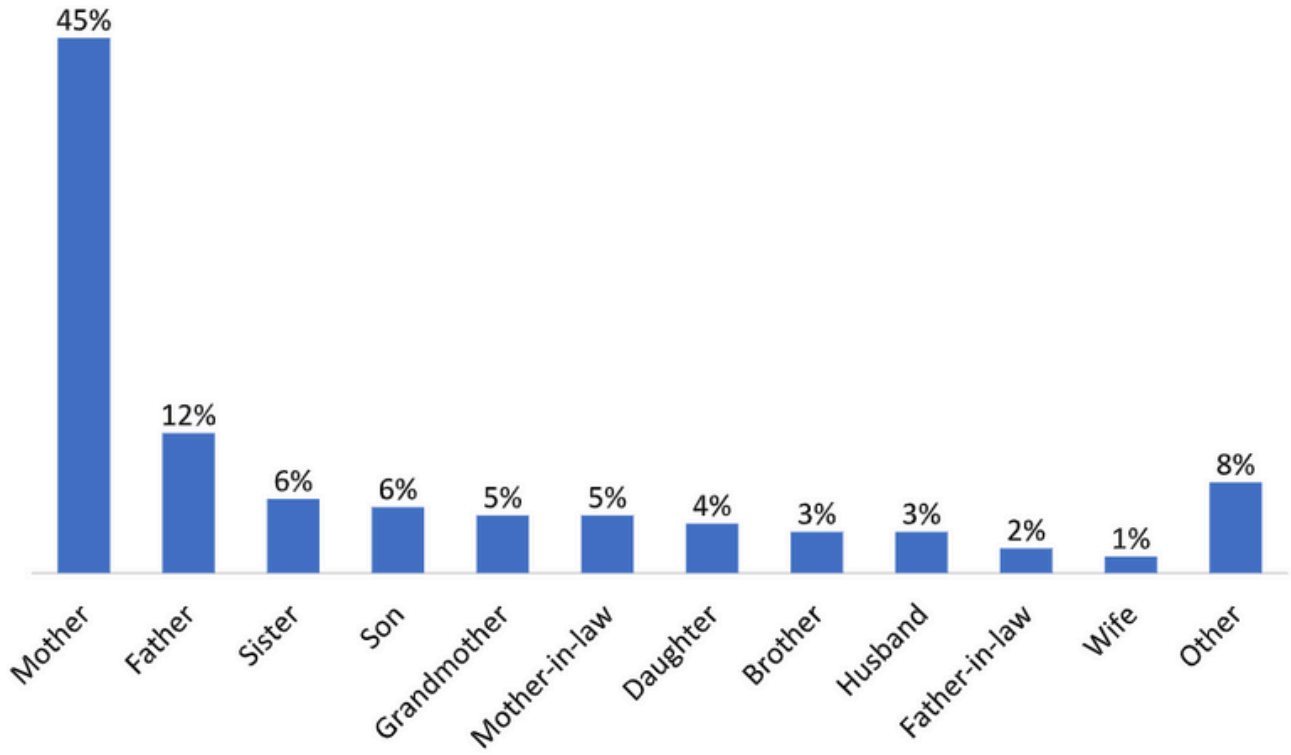
In the first part of this section, we asked caregivers to report the number of care receivers under their care and the results are presented in Figure 2.

Figure 2
Number of care receivers per caregiver



The results indicate that the majority of respondents 75% (n=77) were responsible for one care receiver each, while 20% (n=21)care for two individuals.

Figure 3
Relationship with care recipient

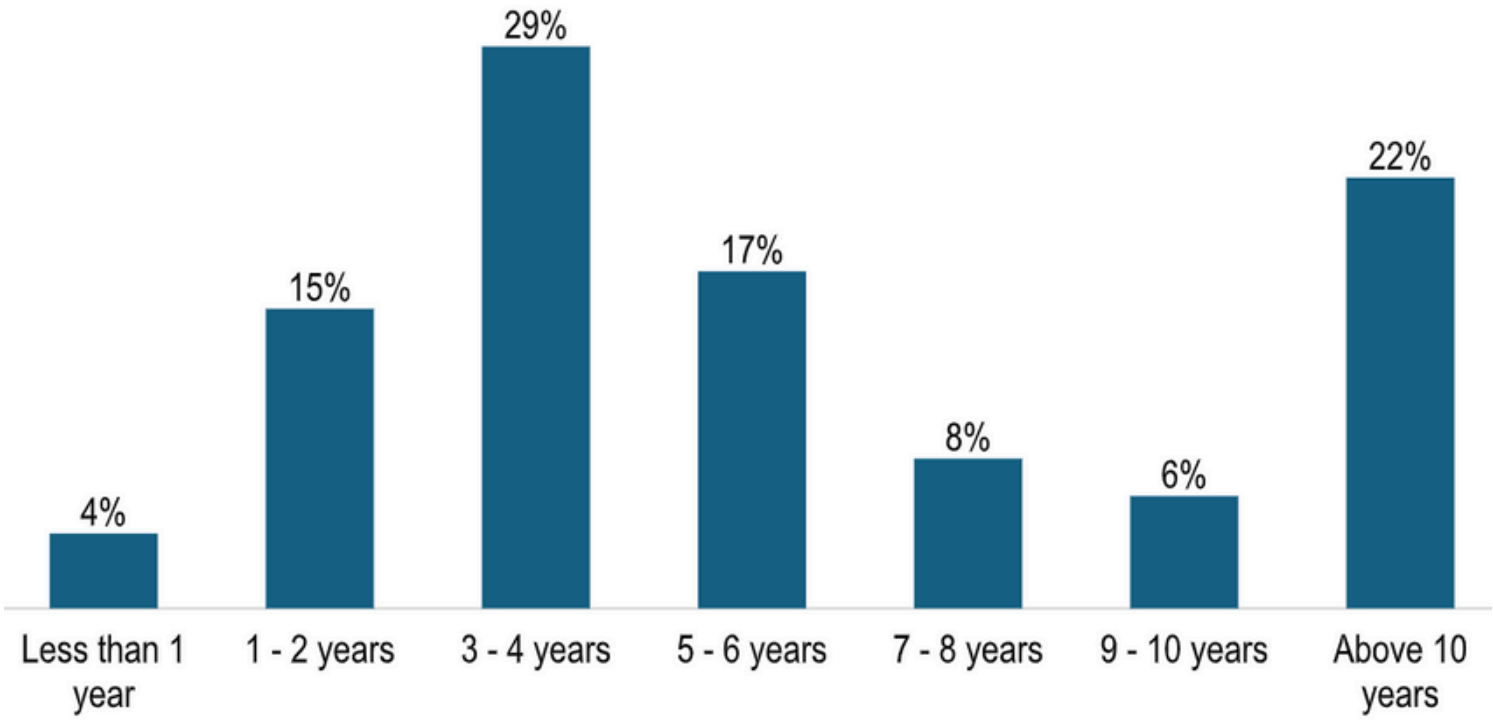


The results indicate that caregiving primarily occurs within the nuclear family, with 45% (n=47) of respondents providing care to their mothers and 12% (n=13) to their fathers. This suggests that majority of the respondents often assume responsibility for immediate family members, particularly elderly parents 57% (n=60), their children 10% (n=11) and therefore with a combined total of 67% (n=70). However, caregiving for extended family members is also big, with 5% (n=5) caring for their grandmothers and 5% (n=5) for their mothers-in-law, among other extended relations. The data reflects a blend of nuclear and extended family caregiving. Key observations: Majority of the care-receivers are women. This is an area that needs further research.

3.3 Time commitment in caregiving

We asked caregivers to state how long they had caregivers, and the results are presented in Figure 4.

Figure 4
Time Commitment of Caregivers



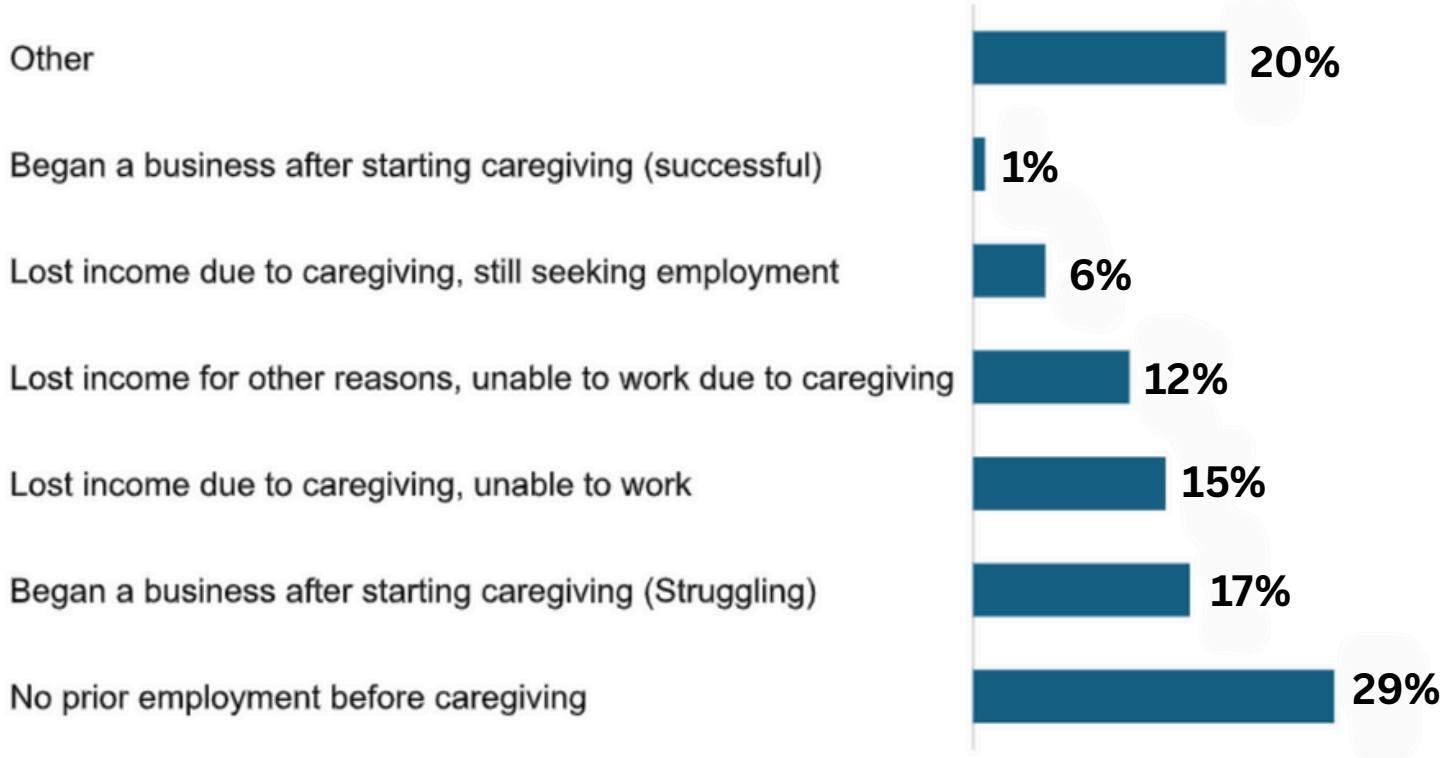
The results show that caregiving durations vary starting from below a year to over 10 years. Results show that there is a range of the duration from less than 1 year to above 10 years.

Extended caregiving duration has major implications on individual's productivity and career development in the context of the vulnerabilities reported regarding income situation. Caregivers in long-term roles (5 years or more) were more likely to face career disruptions, reduced working hours or complete withdrawal from the workforce. Additionally, the physical and emotional toll of long-term caregiving has the potential to increase the risk of socio-economic deterioration, burnout and exhaustion.

3.4 Income Dynamics of family caregivers

We asked caregivers to describe their current income situation, and the results are presented in Figure 5.

Figure 5
Self-reported Financial Situation



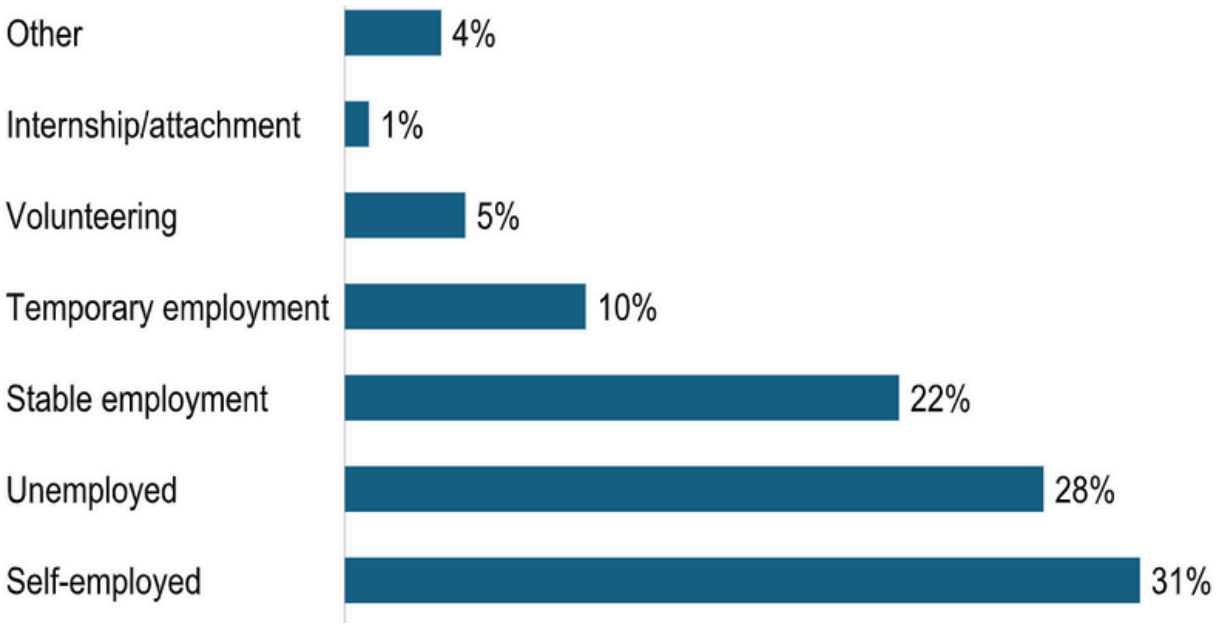
The results indicate that 29% (n=30) of caregivers were not engaged in any income-generating activities before assuming caregiving responsibilities. This suggests that many of these caregivers lacked stable sources of income, indicating that they were financially vulnerable even before assuming the responsibility of caregiving. Additionally, 17% (n=18) of caregivers who started a business after losing their jobs are struggling to keep the business afloat. They attribute the struggles to the demands of caregiving, which they reported consumes much of their time and attention. In contrast, only 1% (n=1) of caregivers reported to have successfully managed to start a thriving business after losing their income. The difference between struggling and successful businesses run by caregivers may suggest that while entrepreneurship may be a viable option, it is not always a practical solution to many caregivers. The challenges of balancing a struggling business and caregiving responsibilities can exacerbate stress and lead to further financial instability.

Moreover, 15% (n=16) of respondents reported having lost their jobs or businesses directly because of caregiving demands and are unable to engage in any income-generating activities. This underscores the strain caregiving places on individuals and can be a huge challenge on their ability to maintain employment and a stable livelihood.

An additional 12% (n=13) reported loss of income due to reasons unrelated to caregiving. However, they are now unable to re-enter the workforce due to caregiving demands. This emphasizes the barrier caregiving creates in re-entering the job market, regardless of the initial cause of job loss. Another 6% (n=6) of respondents indicated that they are actively seeking employment but have not yet succeeded in finding a job. This may be a demonstration of the possible long-lasting negative impact caregiving can have on one's ability to regain financial stability. At the same time, according to the Federation of Kenya Employers (FKE), unemployment in Kenya is at 12.7% (FKE, n.d).

There were 20% (n=21) of respondents who indicated different financial experiences , most being secondary caregivers. Most of the caregivers under this category were still either in employment or gainful business including flexible consultancies and online work. Some mentioned that they had already retired when they started providing care and hence rely on their pension. To further understand the income situation of caregivers, we asked about their current employment status and results and summarized it in Figure 6.

Figure 6
Employment Status of Caregivers



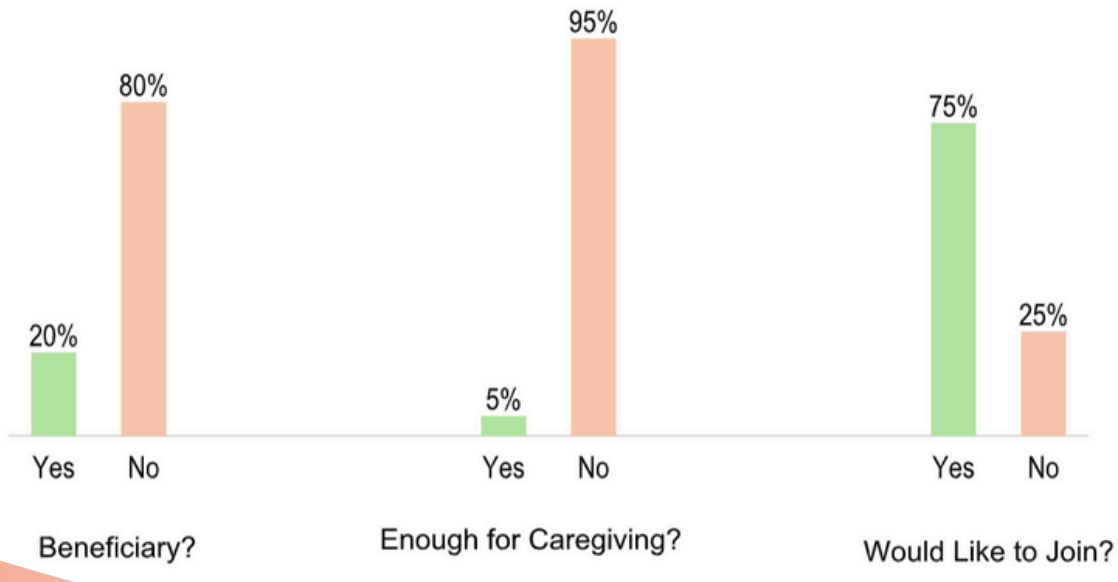
Results showed that majority of caregivers 31% (n=33) describe themselves as self-employed, which primarily includes those who have turned to entrepreneurship or freelance work regardless of success level. At least 28% (n=29) of caregivers are unemployed, 10% (n=11) reported being in temporary employment, 5% (n=5) in volunteering activities and 1% (n=1) in internship/attachment positions. These findings further highlight the economic vulnerabilities faced by many family caregivers.

On the other hand, roughly 1 in 5 (22%) of the respondents indicated that they had **stable employment**. It should be noted that, 52% (n=12) of those who reported as being in stable employment were secondary caregivers who could hire external help to take care of the care-receiver while they continue working. Nonetheless, one 1% (n=1) primary caregiver reported to have more flexibility or access to resources that allow them to maintain their job. The remaining 4% (n=4) were mainly those in the retirement bracket or in part-time jobs.

3.5 *Inua Jamii* Program in Caregiving

Inua Jamii program was launched in 2013 as Kenya's flagship National Safety Net Program aimed at providing financial support to vulnerable populations. The program consolidates four cash transfer initiatives: the Older Persons Cash Transfer (OPCT), Cash Transfer for Orphans and Vulnerable Children (CT-OVC), Persons with Severe Disabilities Cash Transfer (PWSD-CT), and the Hunger Safety Net Programme (HSNP). The program targets impoverished elderly individuals, orphans, vulnerable children, and persons with severe disabilities, offering them regular bi-monthly cash transfers to enhance their livelihoods and reduce poverty. We explored how many care-receivers were benefiting from the *Inua Jamii* program, and the level of awareness about the program among caregivers and results presented in Figure 7.

Figure 7
***Inua Jamii* Program in Caregiving**



Results showed that only 20% (n=21) of respondents indicated that their care-receivers were beneficiaries of the Inua Jamii program. However, 95% (n=100) of them reported that the amount received is not enough for caregiving requirements. We found that a majority of caregivers 80% (n=84) reported that their care-receivers were not beneficiaries of Inua Jamii program. We found that at least 75% (n=77) of those who were not beneficiary were willing to join the program while 25% (n=26) did not want to join. Among the reasons for not wanting to join included lack of awareness and long documentation process while others were not eligible because they did not meet the age requirement (they were not considered elderly). At the same time, one of the guidelines of *Inua Jamii* is that the beneficiaries should not be beneficiaries of any other government safety net scheme, including pension for former public servants. (NB: At this juncture, it is not possible to tell whether care receivers of caregivers who reported not being current beneficiaries, benefit from other schemes).

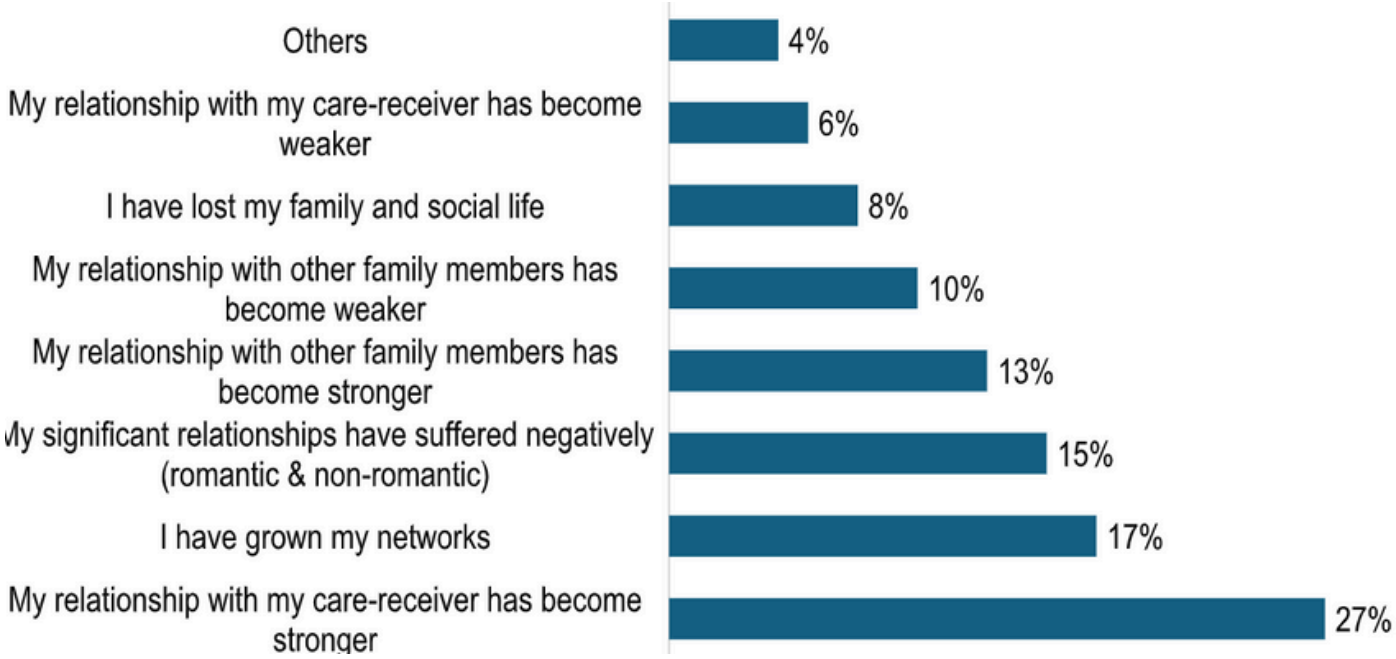
Section 4: Changes Experienced by Caregivers

This section assesses the physical, emotional, and social well-being of family caregivers. The section provides insight into both the growth and challenges they face as a result of their caregiving responsibilities.

4.1 Social changes

Figure 8 summarizes the reported social changes. These results highlight the complex social dynamics of caregiving.

Figure 8
Social changes reported by caregivers



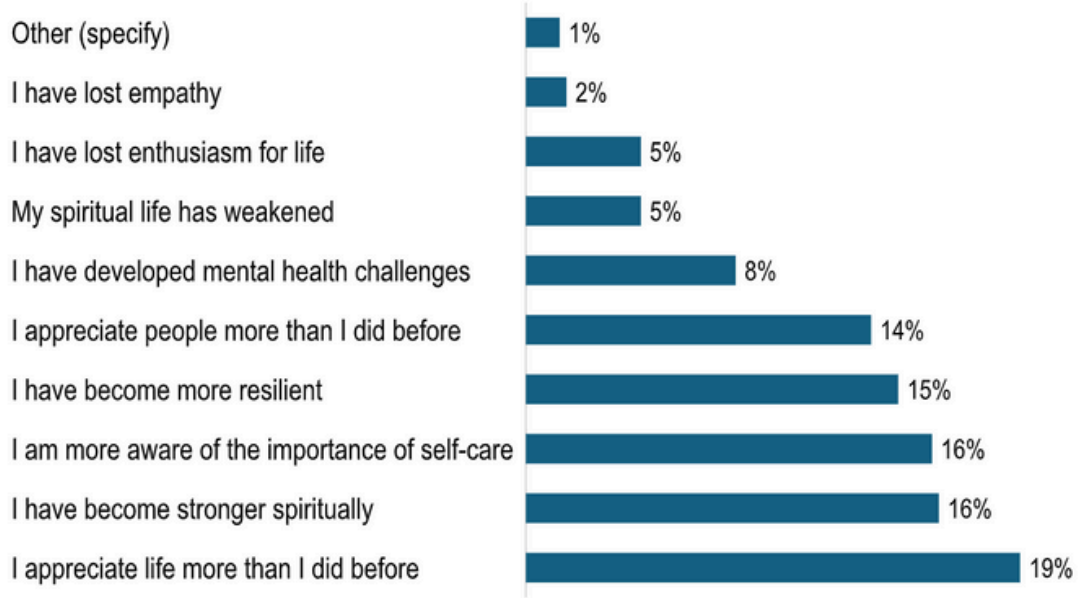
The results showed that 27% (n=28) of respondents stated that their relationship with their care-receiver became stronger. This may suggest that caregiving could promote closer emotional bonds, as caregivers spend time with their care-receivers and develop empathy toward their needs. On the other hand, the results also reflect the social sacrifices that many caregivers face. While 17% (n=18) reported that they have grown their networks, 15% (n=16) stated that their important relationships (both romantic and non-romantic) have suffered negatively. This underscores the strain that caregiving can place on personal relationships, particularly when the time and emotional energy required for caregiving leave little room for nurturing other connections. Additionally, 8% (n=8) of caregivers reported losing their family and social life altogether, which highlights the isolating nature of caregiving for some individuals.

Furthermore, the responses showed that caregiving had mixed effects on relationships with other family members. While 13% (n=14) of caregivers reported stronger relationships with family members, suggesting that caregiving may encourage family unity and shared responsibility, 10% (n=11) indicated that these relationships have weakened. This could point to conflicts or tensions within families regarding caregiving roles and responsibilities. Given that 6% (n=6) of caregivers noted that their relationship with the care-receiver has become weaker, it also suggests that caregiving can lead to emotional fatigue or resentment.

4.2 Spiritual and Emotional Changes

Figure 9 summarizes the reported spiritual and emotional changes because of caregiving experiences. These findings highlight the complexity, the interplay and nexus between spiritual, emotional/mental health and caregiving roles.

Figure 9
Spiritual and Emotional Changes among Caregivers



a) Spiritual changes

The results indicate that caregiving has had a spiritual impact on many caregivers, with 16% (n=17) reporting that they have become stronger spiritually and 19% (n=20) stating that they appreciate life more than before. These responses may suggest that caregiving, despite its challenges, has prompted some people to reflect more deeply on the value of life. This could have strengthened their spiritual beliefs and most likely as a coping mechanism. Caregiving often brings individuals closer to existential questions and the need for meaning in difficult circumstances and this drives spiritual growth. However, 5% (n=5) of respondents reported that their spiritual life has weakened. This could be an indication that caregiving can also lead to spiritual strain, possibly due to the overwhelming demands of the role or as a result of the emotional toll of witnessing a loved one's decline.

b)Emotional Changes

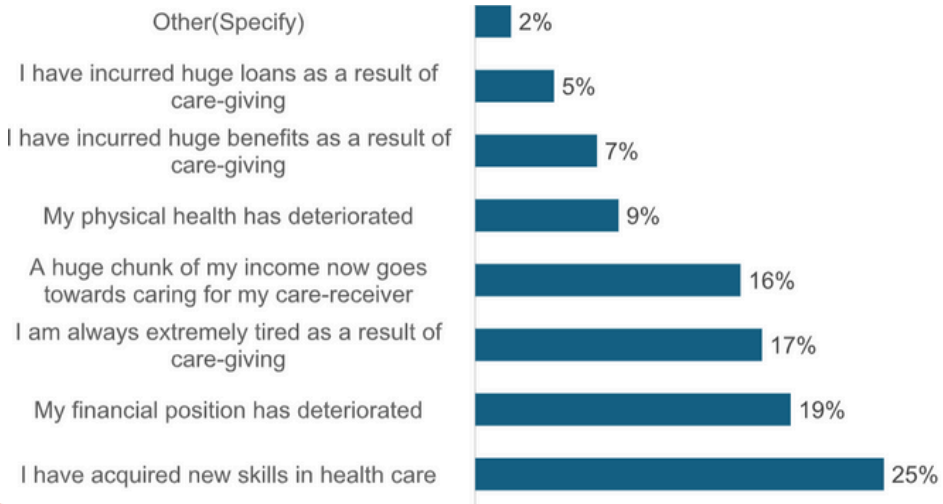
Results suggest that caregiving could have a dual impact. First, positive emotional changes as reflected in the 16% (n=17) of caregivers who became more aware of self-care, 15% (n=16) who became more resilient, and 14% (n=15) who now appreciate people more. These results suggest that caregiving can enhance personal growth, emotional resilience, and a heightened sense of empathy and self-awareness. However, the negative emotional toll is also reported, with 8% (n=8) of caregivers developing mental health challenges such as depression, compassion fatigue, or chronic stress. Additionally, 5% (n=5) have lost enthusiasm for life, and 2% (n=2)have lost empathy. This illustrates the emotional exhaustion that caregiving can cause to those who bear responsibility.

4.3 Physical and financial changes

Figure 10 summarizes the reported physical and financial changes as a result of caregiving experiences.

Figure 10

Caregivers Changes in physical and financial status



a) Physical Changes

The evidence of physical toll resulting from caregiving is clear as 17% (n=18)of caregivers reported that they are always extremely tired, and 9% (n=9) indicating that their physical health has deteriorated due to caregiving responsibilities. These numbers demonstrate the demanding nature of caregiving, which was reported to involve physically strenuous tasks such as assisting with mobility and maintaining a constant caregiving schedule. On a positive note, however, 25% (n=26) of caregivers reported acquiring new healthcare skills, such as taking readings for blood pressure or oxygen levels. While this demonstrates that caregivers could be adapting to the role by gaining practical skills, it underscores the complexity of their responsibilities, which can further contribute to physical exhaustion over time.

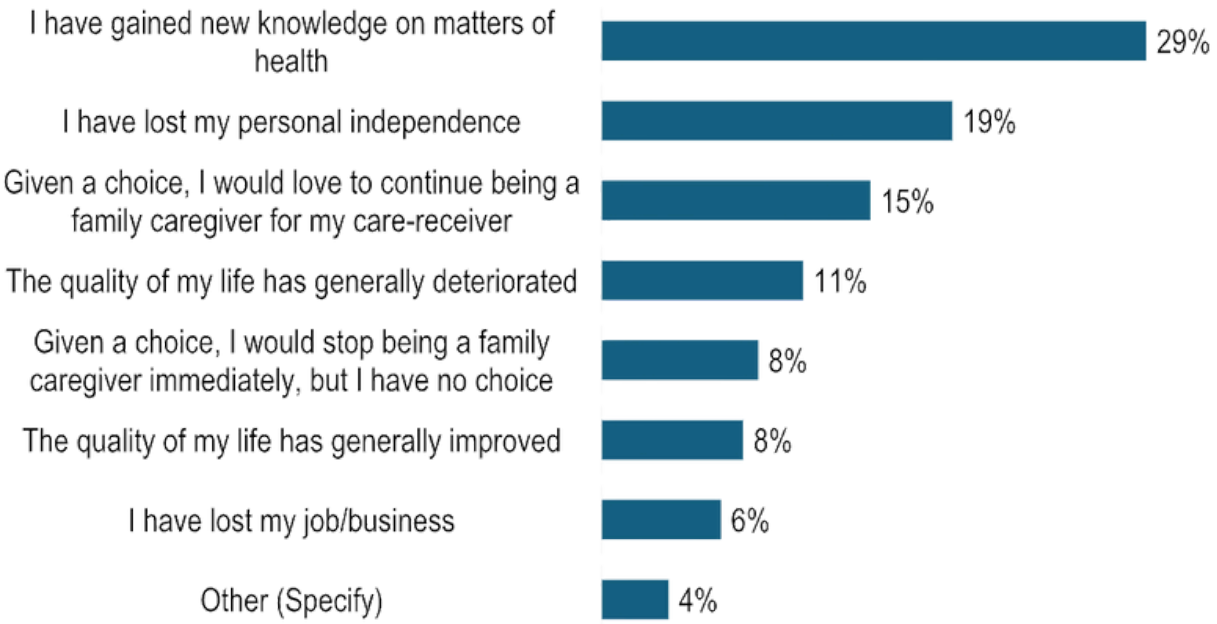
a) Financial Changes

Changes in financial status as a result of caregiving are also evident. For instance, 19% (n=20) of caregivers reported that their financial position has deteriorated, and 16% (n=17) reported that a large portion of their income is now spent on caregiving-related expenses. Additionally, 5% (n=5) of caregivers reported to have incurred loans due to caregiving. This financial strain reflects the possibility of long-term costs of medical care, supplies, and other caregiving needs, particularly in the absence of external financial support. This is perhaps the reason why most caregivers preferred medical insurance both for themselves and their care-receivers as previously discussed. On the positive side, however, 7% (n=7) of caregivers indicated that they have incurred financial benefits from caregiving. (This is an area that needs further research). Nevertheless, the overall financial stress underscores the need for greater economic support for caregivers.

4.4 Professional, intellectual and general life changes

Figure 11 summarizes the reported professional, intellectual and other general changes in life as a result of caregiving experiences.

Figure 11 Caregivers' changes in professional, intellectual and other changes



a) Professional Changes

The results show that caregiving had an impact on caregivers' professional lives, with 6% (n=6) of caregivers reporting that they have lost their job or business due to caregiving responsibilities. This indicates that the demands of caregiving, which often require full-time attention, can disrupt or end professional careers, leading to loss of income and career progression. Additionally, the inability to balance work and caregiving duties suggests that caregivers may lack access to flexible working arrangements, underscoring the need for workplace policies that accommodate caregiving roles to prevent further professional sacrifices.

b) Intellectual Changes

Despite the challenges, 29% (n=30) of respondents reported gaining new knowledge related to healthcare, which is a positive intellectual development. As caregivers take on more complex tasks, such as managing medical devices or administering treatments, they are expanding their skill sets and healthcare knowledge. This intellectual growth not only benefits the care-receiver but also equips caregivers with valuable competencies that may be useful in their personal and professional lives. However, this learning often comes at the cost of personal and professional independence, as caregiving responsibilities dominate much of the caregiver's time and mental capacity.

c) General Life Changes

Caregiving had a mixed impact on the overall quality of life for caregivers. While 8% (n=8) reported an improvement in their quality of life, 11% (n=12) stated that it has deteriorated. A further 19% (n=20) indicated that they have lost their personal independence, which reflects how caregiving can limit one's ability to plan and pursue individual goals. These results highlight the sacrifices caregivers make, with 8% (n=8) expressing that they would stop caregiving if they had a choice but feel they have no alternative. Conversely, 15% (n=16) would continue being caregivers to their loved ones, suggesting that despite the difficulties, some caregivers find meaning and fulfilment in the role.

Section 5: Disease Burden and Priority Support Areas

This section examines the prevalence of conditions among care-receivers as well as key resources and support services caregivers identify as most critical for both their care receivers as well as themselves.

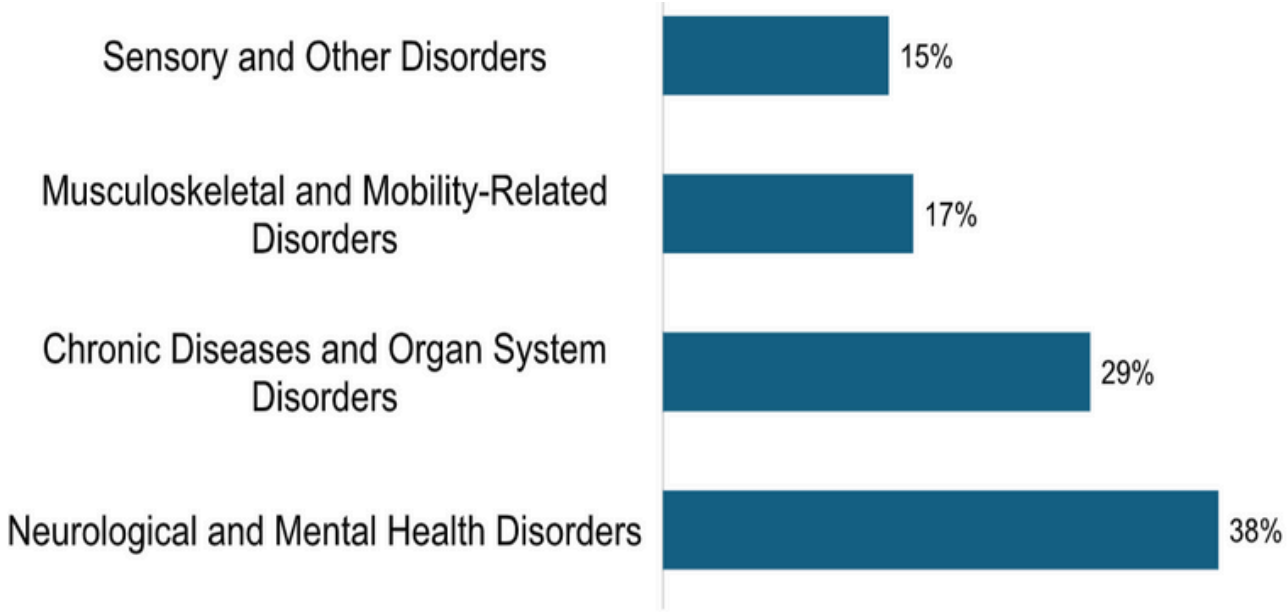
5.1 Prevalence of conditions

We sought to examine different conditions that necessitated caregiving responsibilities. Results found that there were more than 22 different conditions reported by caregivers.

These were: *Dementia & related conditions, Cancer, Depression, Hypertension, Lupus, Arthritis & related mobility challenges, Diabetes, Hearing Impairment, Epilepsy & other forms of convulsive conditions, Prostatic Hyperplasia & related (non-cancer) prostate conditions, Sight impairment including cataracts, Stroke & its after-effects, Parkinson's disease, Asthma, Chronic Obstructive Pulmonary Disorder (COPD), Hypoventilation, Nocturnal hypoxia & related breathing challenges, Chronic Urinary Tract Infections (UTIs), Cerebral Palsy, Attention Deficit Hyperactivity Disorder (ADHD)/Oppositional Defiant Disorder (ODD), Obstructive Sleep apnea & related sleep conditions, psychotic illnesses (Schizophrenia, Bipolar disorder, Severe depression), Chronic Kidney Disease, Hypothyroidism & related endocrine disorders and Hearing Impairment).*

These conditions were grouped into four major categories based on their manifestation as presented in Figure 12.

Figure 12
Prevalence of Different Conditions



a) Neurological and Mental Health Disorders

This category of conditions was the most prevalent of conditions at 38% as reported by the caregivers. The high prevalence could mean that majority of the respondents were providing care go care-receivers ailing from neurological and mental health challenges. The disorders those that affect the brain, nervous system, and mental well-being, leading to cognitive, motor, and emotional challenges. These conditions often require long-term care and can affect both the individual and their caregivers due to the complexities of managing cognitive and behavioural symptoms. More than two-thirds of neurological/mental health disorders reported were dementia & related conditions, stroke & its after-effects and depression. The other conditions reported under this category include psychotic illnesses (e.g. Schizophrenia, bipolar disorder), Parkinson's disease, epilepsy & other forms of convulsive conditions and Oppositional Defiant Disorder (ODD).

b) Chronic Diseases and Organ System Disorders

Chronic Diseases and Organ System Disorders were the second most prevalent conditions 29%, a category that includes chronic medical conditions that affect major organs or organ systems. These diseases are typically long-term and progressive, requiring ongoing medical management and lifestyle adaptations. Hypertension, cancer and diabetes account for over 80% of conditions reported under this category. Other conditions identified under this category include asthma, Chronic Obstructive Pulmonary Disorder (COPD), hypoventilation, nocturnal hypoxia & related breathing challenges, lupus, chronic kidney disease, Chronic Urinary Tract Infections (UTIs), hypothyroidism & related endocrine disorders and obstructive sleep apnea & related sleep conditions.

c) Musculoskeletal and Mobility-Related Disorders

This category involves conditions that impair the musculoskeletal system, which includes bones, joints, muscles, and related structures. These are the ones who are most commonly expected to use adult diapers and mobility devices. These conditions account for 17% of all conditions reported by the caregivers, and often lead to reduced mobility, chronic pain, and difficulty performing daily activities. These disorders typically require physical therapy, assistive devices (e.g., wheelchairs among others), and sometimes surgical interventions to improve mobility and manage pain. Arthritis and related mobility challenges accounted for over 80% of all conditions reported under this category. Other conditions include cerebral palsy and prostatic hyperplasia and related (non-cancer) prostrate conditions.

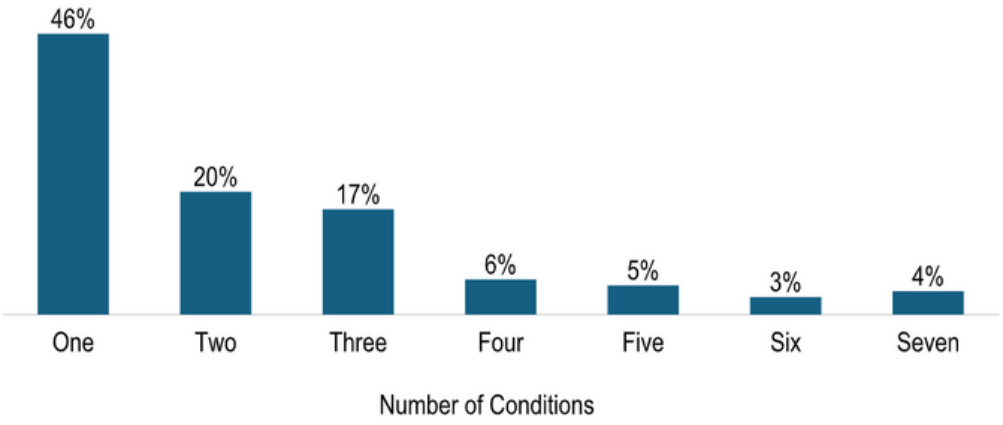
d) Sensory and Other Disorders

This category accounted for 15% of all conditions reported by caregivers. This category encompasses conditions that primarily affect sensory functions, such as sight and hearing, along with other disorders that don't neatly fit into the other categories. Sight impairment including cataracts made up 32% of all sensory impairments followed by hearing impairment at 27%. Other conditions reported include HIV/AIDS, endometriosis, idiopathic intra cranial hypertension, Addison's disease and other amorphous descriptions such as age-related challenges.

5.2 Comorbidities of conditions

We sought to examine the distribution of comorbidities/concurrent health conditions (the presence of more than one condition) among care-receivers as reported by caregivers and results presented in Figure 13.

Figure 13
Comorbidities of Health Conditions



Results showed that 46% (n=67) of care receivers had only one condition: Most care-receivers are managing a single health condition. This may include individuals with diseases like hypertension, diabetes, or dementia. We found that 20% (n=29) of care-receivers have two conditions 17% (n=25) of care-receivers have three conditions, 6% (n=9) of care-receivers have four conditions, 5% (n=7) have five conditions, 3% have six conditions, and 4% have seven conditions. These results show that at least 56% (n=81) of care-receivers are dealing with more than one concurrent condition. While these percentages represent smaller groups, they highlight the growing complexity of caregiving as care-receivers accumulate more conditions. It was particularly observed that older care-receivers above the 60 years of age formed 51% (n=61) of the population with more complex comorbidities.

NB: the prevalence of the diseases and their distribution does not in any way indicate the disease burden across the country- rather, it is solely the situation of the four institutions that participated in this exercise.

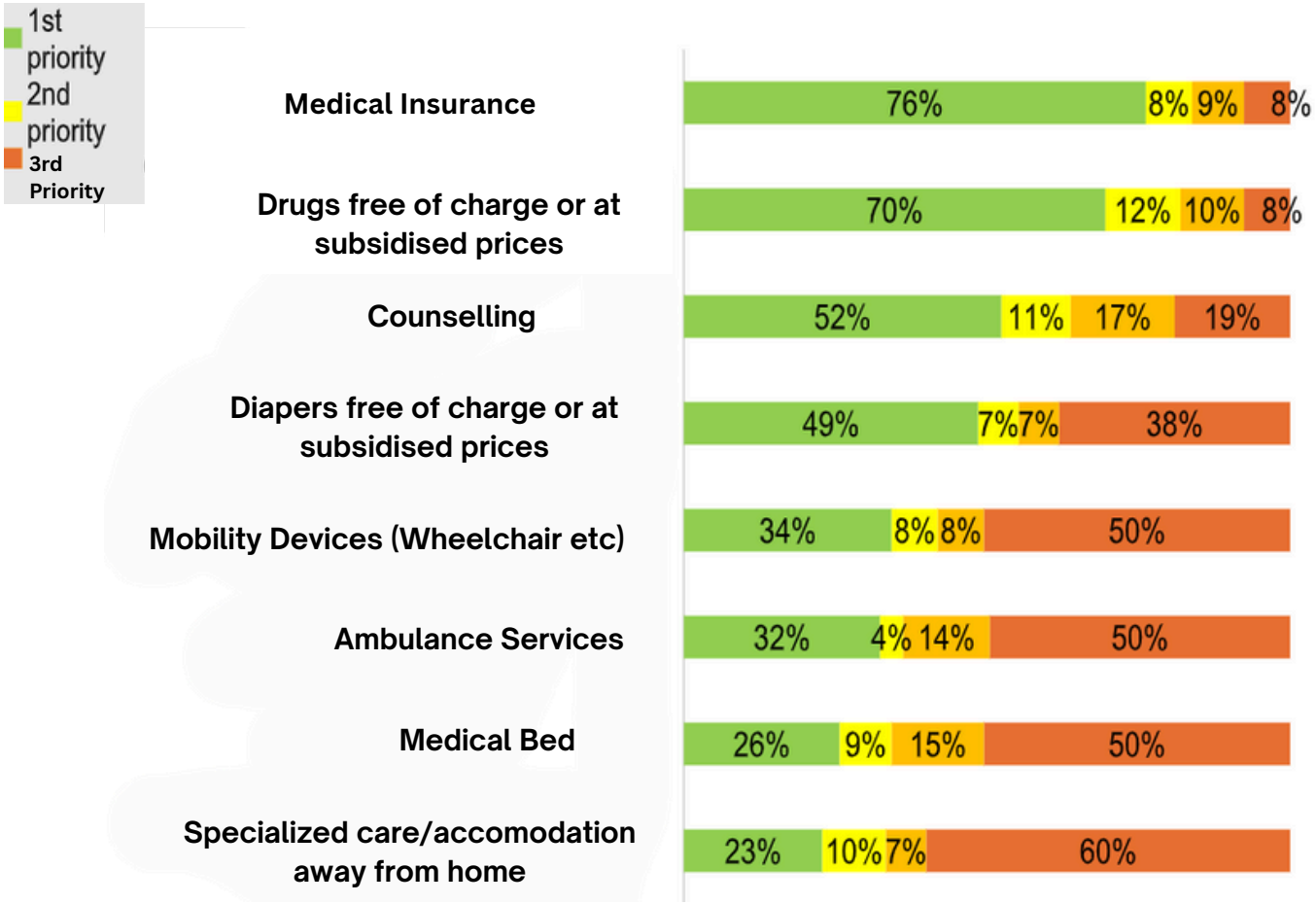
5.3 Priorities for the Care-recipient (According to the care giver)

We asked the caregivers to rank different resources and/or services in order of priority based on the current needs of their care-receivers. Results are as presented in Figure 14 i.e.

First priority - Medical Insurance.
Second Priority - Drugs being free of charge or at subsidized prices.
Third Priority - Counselling.
Fourth Priority - Diapers being free of charge or at subsidized prices.

Resources and/services that are not needed are reported as being less of a priority.

NB: It is important to note the fact that adult diapers were rated as first priority by only 49% of the respondents, potentially those whose care-receivers needed them, just as mobility devices were by only 34% does not mean they are not important.



5.4 Priorities for care-receivers' needs

In a similar manner, we asked caregivers to rank different resources and/or services in order of priority based on their current needs as caregivers/care providers and results presented in Figure15. 1st priority shows the most preferred resource/service needed followed by 2nd and 3rd priority respectively. Resources and/services that are not needed are reported as less of a priority.

The results reveal that medical insurance stands out as the top priority, with 76% (n=80) of caregivers ranking it as their first priority. This is closely followed by drugs free of charge or at subsidized prices was ranked as the first priority by 70% (n=74) of respondents. This finding is consistent with the economic pressures faced by caregivers discussed earlier. Many caregivers have either lost their income or struggled financially due to the demands of caregiving, making the cost of medical care a burden. Medical insurance offers a solution by reducing out-of-pocket expenses. Counselling services are also highly prioritized, with 52% (n=55) of respondents identifying it as their first priority. Counselling services could offer emotional support and help improve mental well-being.

On the other hand, mobility devices (wheelchairs, etc.) and ambulance services were identified as a first priority by 34% (n=36) and 32% (n=34) of respondents, respectively. These results reflect the physical caregiving demands associated with mobility challenges and emergency medical needs. Specialized care or accommodation away from home was ranked as a first priority by only 23% (n=24) of respondents, with 60% (n=63) viewing it as less of a priority.

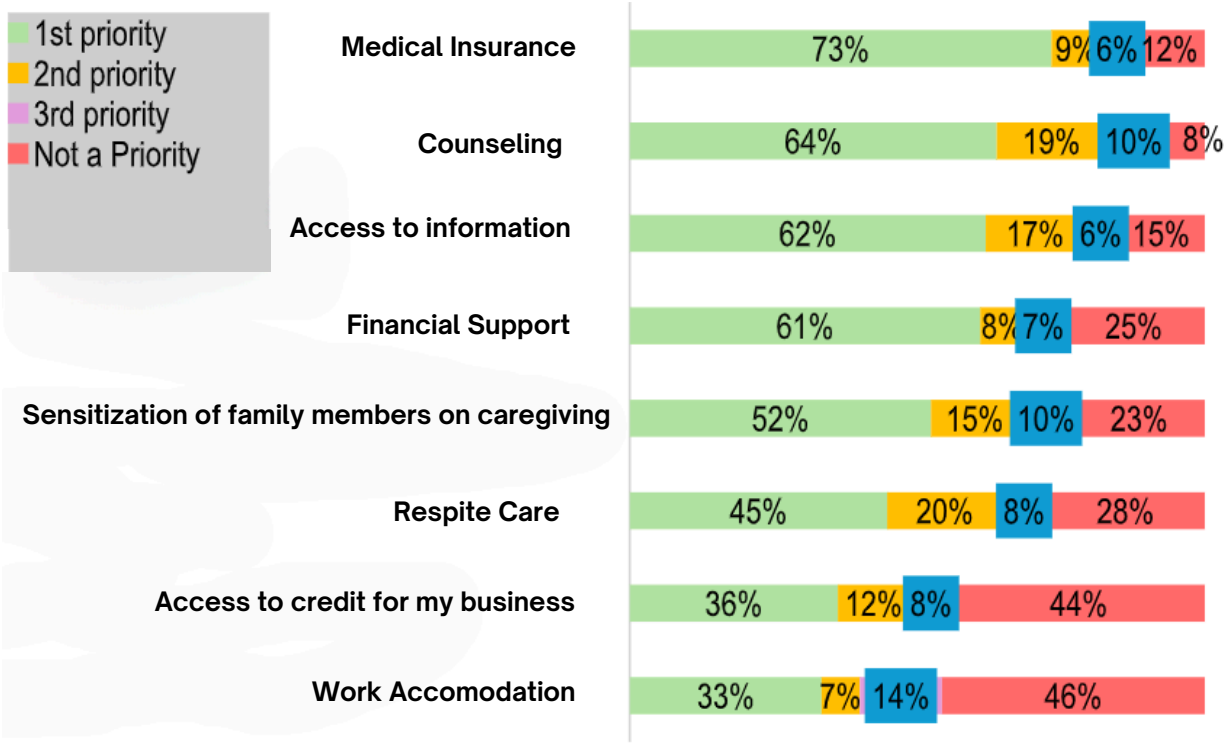
This suggests that, while specialized care can be important in certain severe or complex cases, many caregivers prefer to manage care at home, potentially pointing to the closely-knit family set up. However, the relatively low priority of this service could also reflect the economic constraints faced by caregivers, who may view home-based care as the most affordable and practical option despite its challenges.

Other services ranked as top priority by some care givers include physiotherapy (including reduction of charges), nutritional services, financial support, adaptation of home environment, school fees for care-receiver's children, special schools and teachers for home schooling.

Overall, the relationship between the reported disease burden and the priority profiles reported by caregivers shows a strong alignment between the most common health conditions and the services that caregivers prioritize.

Chronic conditions such as diabetes, hypertension, dementia, and arthritis, which require long-term medical management and consistent medication, are likely driving the high demand for medical insurance and subsidized drugs as top priorities. The prevalence of these chronic diseases increases the financial burden on caregivers, making affordable healthcare solutions essential for maintaining the well-being of care-receivers.

Figure 15
Priorities for caregivers' needs



Results showed the most important priority for caregivers is medical insurance, with 73% (n=77) ranking it as their first priority. Having medical insurance would not only alleviate financial strain but also ensure that both caregivers and care-receivers can access the necessary medical services without undue stress. It is a common practice in Kenya for employers to procure a private health insurance cover for their employees in addition to the mandatory contribution to the public health insurance scheme (currently Social Health Authority, changed from National Health Insurance Fund). For those not in employment, procuring a private health insurance cover can be very expensive. Accessing private medical services is a common practice in the country largely because of the unfavorable state of public health services across the country.

Counselling is the second highest priority, with 64% (n=67) of the respondents placing it as their top need. This underscores the emotional and psychological toll of caregiving, as caregivers often face stress, burnout, and emotional exhaustion. Counselling can provide essential mental health support to caregivers, enabling them to manage the challenges of caregiving more effectively.

Similarly, access to information ranks high, with 62% (n=65) of caregivers prioritizing it as essential. This indicates a need for better resources to educate caregivers on caregiving strategies, medical conditions, and how to navigate the healthcare system.

Financial support 61% (n=64) and Respite care 45% (n=47) also feature prominently. Financial support is particularly critical for caregivers who are not receiving any external assistance, such as those who are not beneficiaries of programs like *Inua Jamii*. Respite care, which would allow caregivers temporary relief from their duties, reflects the need for physical and mental breaks to prevent burnout. Both of these priorities are important in helping caregivers sustain their caregiving role over the long term.

Sensitization of family members 52% (n=55) and work accommodation 33% (n=35) show that caregivers also value collaborative support and workplace flexibility. Caregivers who receive understanding and practical assistance from family members, as well as accommodations from their employers, are better able to balance caregiving with other responsibilities, reducing their stress and improving their overall well-being. Most likely those who indicated that work accommodation is not a priority are those not in formal employment.

The need for access to credit for business 36% (n=38) also suggests that some caregivers are looking for ways to generate income while managing their caregiving duties.

Section 6: Limitations of the study

This study was conducted under the following limitations

(i) Self-Reported Data

The study relied heavily on self-reported data from caregivers, which may be subject to recall bias, social desirability bias, or inaccuracies in reporting due to emotional or cognitive fatigue. Future studies should incorporate triangulation methods such as combining self-reported data with caregiver diaries, direct observation, or healthcare records to improve the accuracy and reliability of responses.

(ii) Sampling Limitations

Although efforts were made to reach a diverse pool of respondents, the sample may not be fully representative of all caregivers in Kenya; particularly those in rural, nomadic, or marginalized communities who may lack access to digital platforms or networks through which data was collected. Future studies should employ a more comprehensive sampling framework that includes purposive and stratified sampling across different regions (urban, rural, and underserved areas). Additionally, collaborating with community-based organizations can help reach underrepresented caregiver groups.

(iii) Exclusion of Care-Receiver Perspectives

The study exclusively gathered data from caregivers and did not include perspectives from the care-receivers themselves, which could have enriched the understanding of care dynamics and needs. Future studies should include dual-perspective approaches in future research by gathering data from both caregivers and care-receivers. This can offer a more comprehensive understanding of care relationships, needs, and satisfaction.

Section 7: Recommendations for Policy, Practice and Further Research

7.1 Recommendations for Policy Considerations

(i) Expand access to medical insurance for caregivers and care receivers

The report highlights that caregivers rank medical insurance as their top priority due to the financial burden of chronic illnesses. Policymakers should introduce subsidized health insurance programs tailored to family caregivers and their dependents, ensuring affordability and comprehensive coverage, especially for chronic and neurological conditions.

(ii) Subsidize medical supplies and assistive devices

The findings show that mobility aids like wheelchairs and consumables such as diapers are expensive. A policy to subsidize these items through targeted funding or public-private partnerships could reduce financial strain on caregivers.

(iii) Introduce financial support programs for caregivers

According to the report, 80% (n=84) of the caregivers reported economic vulnerability. Establishing direct cash transfers or tax relief for caregivers would help mitigate income loss and enable caregivers to meet caregiving demands effectively.

(iv) Develop national guidelines on respite care services

At least 60% (n=67) of the caregivers experience burnout due to the lack of breaks. Policymakers should institutionalize respite care programs to provide temporary relief and support the mental health of caregivers.

(v) Promote workplace flexibility and employment policies

The report indicates job loss as a common consequence of caregiving. Policies mandating flexible work arrangements, paid leave, and caregiving allowances can enable caregivers to balance employment with their responsibilities.

7.2 Recommendations for practice of family caregivers

(i) Develop personalized care plans

Caregivers can use structured tools to assess care receivers' needs and create individualized care plans. This approach ensures more efficient management of daily tasks and health care.

(ii) Seek community and peer support
The report shows that caregiving can lead to social isolation. Caregivers should actively participate in local or online and other support groups to share experiences and access emotional support.

(iii). Enhance caregiving skills through training
The report highlights that caregivers often acquire health-related skills. Caregivers can proactively enroll in workshops or online courses to improve their skills in areas like first aid, mobility assistance, and mental health management.

(iv) Set boundaries and incorporate self-care
Caregivers experiencing burnout should learn to delegate tasks, accept help from family or friends, and engage in self-care routines to maintain physical and mental well-being.

(v) Leverage technology for support
Use digital tools such as medication reminders, health monitoring apps, or scheduling systems to reduce caregiving stress and manage time more effectively.

7.3 Recommendations for further Research
(i) Employer Attitudes Toward Workplace Accommodation for Caregivers.
To what extent do employers express concerns or reservations regarding the accommodation of employees who are also primary caregivers? Understanding potential workplace barriers can inform policy recommendations on caregiver support in formal employment settings.

(ii) Motivation for Continued Caregiving Despite Alternative Options
What are the underlying reasons why primary caregivers would still choose to remain in their caregiving roles, even when presented with alternative opportunities? This inquiry can shed light on the intrinsic, cultural, or systemic factors that influence caregiving decisions.

(iii) Financial Gains Associated with Caregiving Roles
As discussed in Section 4.3, it remains important to investigate how, if at all, family caregivers derive financial benefit from caregiving. This includes both direct compensation and indirect economic gains such as housing, food, or other forms of material support.

(iv) Gendered Nature of Care giving and Care-Receiving: Why Are Most Care-givers and Care-Receivers Women?

With up to 90% (n=95) of care-receivers being women (Figure 3) and up to 84% (n=89) of the respondents also being women, it is necessary to explore the structural, social, and health-related factors contributing to this disparity. Additionally, strategies should be examined for redistributing unpaid care work to promote greater male participation.

(v) Access to Government Safety Net Programmes Beyond *Inua Jamii*

What proportion of caregivers and care-receivers benefit from alternative social protection programmes apart from Inua Jamii, as highlighted in Section 3.5? A comprehensive mapping of available support mechanisms could reveal potential gaps and opportunities for more inclusive coverage.

(vi) Generalizability of Findings in a Larger, More Diverse Sample

Would the findings of this study be upheld if replicated with a more extensive and demographically representative sample? Conducting further research with broader scope would help validate and strengthen the conclusions drawn from this case study.

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