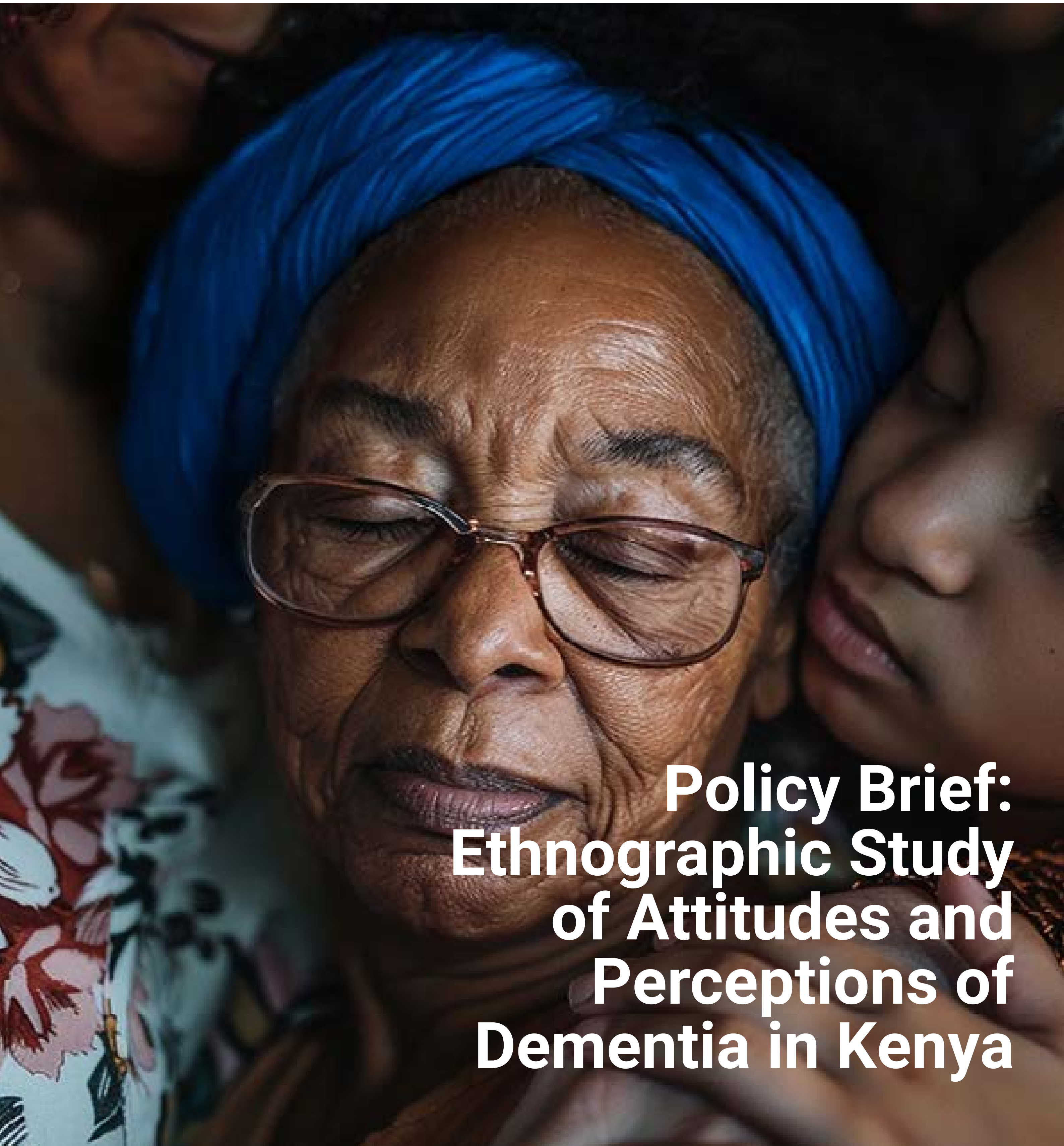
THE AGA KHAN UNIVERSITY

Brain & Mind Institute
from neuron to neighbourhood

Davos
Alzheimer's
Collaborative



Policy Brief: Ethnographic Study of Attitudes and Perceptions of Dementia in Kenya

Executive summary

Dementia, including Alzheimer's disease (AD), is becoming increasingly prevalent in sub-Saharan Africa. However, awareness and understanding of the condition remain critically low, particularly in East Africa. Misconceptions surrounding dementia often lead people to attribute symptoms such as memory loss to aging, spiritual causes, or supernatural beliefs. This study conducted by Aga Khan University's Brain and Mind Institute in Nairobi explored attitudes and perceptions of dementia among various stakeholders, including patients, caregivers, and healthcare providers at Aga Khan University Hospital in Nairobi. Additionally, it examined community-level knowledge of dementia, willingness to provide biospecimen and participation in dementia clinical trials.

Findings from this study indicate that widespread stigma and limited awareness of dementia contribute to delays in access to care and timely diagnosis. Many patients only seek medical attention when their condition has significantly worsened, often due to financial barriers and a lack of trained healthcare providers at primary health facilities.

Family members especially women disproportionately bear the burden of caregiving, often with little to no training and support. Additionally, healthcare professionals face challenges such as insufficient training, inadequate diagnostic tools, and unclear dementia protocols and management pathways within healthcare systems. Community members expressed scepticism about providing biospecimens, such as hair and brain donations, due to cultural beliefs, and cerebral spinal fluid (CSF) taps due to the invasive nature of the procedure. They also expressed reluctance in participating in dementia clinical trials, citing cultural beliefs, lack of awareness and trust issues. The findings emphasize the urgent need for a comprehensive dementia policy, dementia awareness campaigns, caregiver support programs, and culturally sensitive policies to improve dementia care and research participation in Kenya.

Introduction: What is at stake?

Dementia poses a growing public health crisis, particularly in low- and middle-income countries (LMICs) such as Kenya. Globally, over 50 million people live with Alzheimer's disease (AD) and related dementias, with an annual increase of approximately 10 million new cases. By 2050, projections estimate that 150 million people will be living with AD, with the majority of these cases occurring in LMICs.

Sub-Saharan Africa is experiencing an increase in the aging population, leading to a corresponding rise in the incidence of dementia. However, empirical research on dementia in the region remains limited. In East Africa, the number of people living with dementia is projected to increase by 357% from 2019 to 2050 - one of the highest rates among developing countries. The lack of national prevalence data and standardized diagnostic measures further complicates efforts to develop targeted interventions. In Kenya, public healthcare systems are already strained due to a severe shortage of mental and brain health specialists, inadequate diagnostic tools, and the high costs of diagnosis and care.

Given these circumstances, it is imperative to establish dementia-specific policies, improve community awareness, and enhance healthcare infrastructure to better manage dementia cases.

How we did it

This study employed ethnographic research methods including in-depth interviews, key informant interviews and observations to explore the lived experiences and perceptions of dementia among patients, caregivers and the general public, and dementia care and management amongst healthcare providers. Research was conducted at the Aga Khan University Hospital Neurology Clinic, with additional community engagement in informal settlements in Nairobi.

Study design and sites

Observational research at AKUH Neurology clinic: Field researchers observed patient consultations, provider-patient interactions, and overall health care access and navigation twice a week for an extended period.

Stakeholder interviews: Researchers conducted in-depth interviews with healthcare providers, patients, and caregivers to gather qualitative data on dementia lived experiences and care challenges.

Home visits: Selected patient-caregiver dyads were visited at home to gain insight into home-based dementia care and management.

Community focus group discussions (FGDs): FGDs were held in Mathare and Kibera informal settlements in Nairobi to assess general community knowledge of dementia, biospecimen collection and willingness to participate in dementia clinical trials.

Sample size

21 healthcare providers
(neurologists, psychiatrists, nurses, and speech therapists) were interviewed.

26 dementia patients
(aged 45 and older) were purposively recruited from the neurology clinic and interviewed.

36 caregivers
were purposively recruited from the neurology clinic and interviewed, with additional 10 home visits conducted.

8 focus group discussions
with 81 community members were organized based on age and gender to explore dementia awareness, willingness to provide biospecimen and participation in dementia clinical trials.

What we found out

Patient and caregiver experiences

- Dementia awareness remains critically low among patients and their caregivers. Many patients seek medical care only when symptoms have significantly worsened.
- Traditional beliefs and stigma surrounding dementia (e.g., normal part of aging, curses or witchcraft) contribute to delays in seeking medical care, with some individuals attributing symptoms to spiritual causes.
- Caregivers, primarily female family members, lack the knowledge/training and resources needed for effective dementia management.
- The financial, emotional, and physical burden of caregiving is immense, often leading to caregiver burnout.

Healthcare provider challenges

- Most primary healthcare providers lack training in dementia diagnosis and management, leading to missed or late diagnoses.
- Public hospitals are poorly equipped with diagnostic tools such as MRI and PET scans, limiting early detection.
- The high cost of dementia care, particularly in private hospitals, is a major barrier for many families.
- Healthcare providers noted a lack of coordinated dementia care pathways, leaving many patients and caregivers uncertain about the next steps.
- Lack of dementia policy guidelines is an impediment to dementia care and management in Kenya.

Community perceptions on dementia and research participation

- Awareness of dementia in informal settlements is minimal, leading to misinformation and stigma.
- Willingness to provide biospecimen for dementia research varied, with many people skeptical of donating biospecimens such as hair or cerebrospinal fluid due to cultural and religious beliefs as well as procedures involved in obtaining biospecimen.
- Blood, fecal matter and saliva were found to be familiar samples and there was more willingness to provide them.
- Participants were skeptical about participating in clinical trials for fear of their safety.
- Trust in medical research remains low, largely due to historical exploitation and lack of transparent community engagement.
- Despite concerns, many community members expressed interest in dementia research if ethical considerations and community benefits were emphasized.

What it means

Establish a national dementia policy framework

Kenya should develop a national dementia policy framework that provides clear guidelines for dementia care, diagnosis, and management within the country's healthcare system. Recognizing dementia as a public health priority is crucial, and appropriate resources should be allocated to ensure effective implementation.

Improve accessibility and affordability of dementia care

Kenya faces significant challenges in providing comprehensive care for individuals with brain health conditions like dementia, primarily due to a shortage of skilled healthcare professionals. Expanding training in neurology and geriatrics is crucial to improving the quality of care for those living with dementia. Additionally, integrating dementia care into Kenya's Social Health Authority (SHA) package would enhance access to essential services.

Strengthen healthcare infrastructure

Public hospitals must be equipped with standardized diagnostic tools to facilitate early and accurate detection of dementia. Furthermore, healthcare environments should be designed to be dementia-friendly, incorporating clear care pathways that enhance patient support and navigation within the system.

Community awareness and public education

Raising public awareness about dementia is essential to combating stigma and misinformation. Nationwide awareness campaigns should be launched to educate the public on the realities of the condition. Preventive policy strategies across the lifespan are emerging as vital tools for mitigating the impact of brain health conditions. Additionally, caregiver education programs should be developed to empower families with the necessary knowledge and skills to support individuals living with dementia.

Enhance research participation and transparency

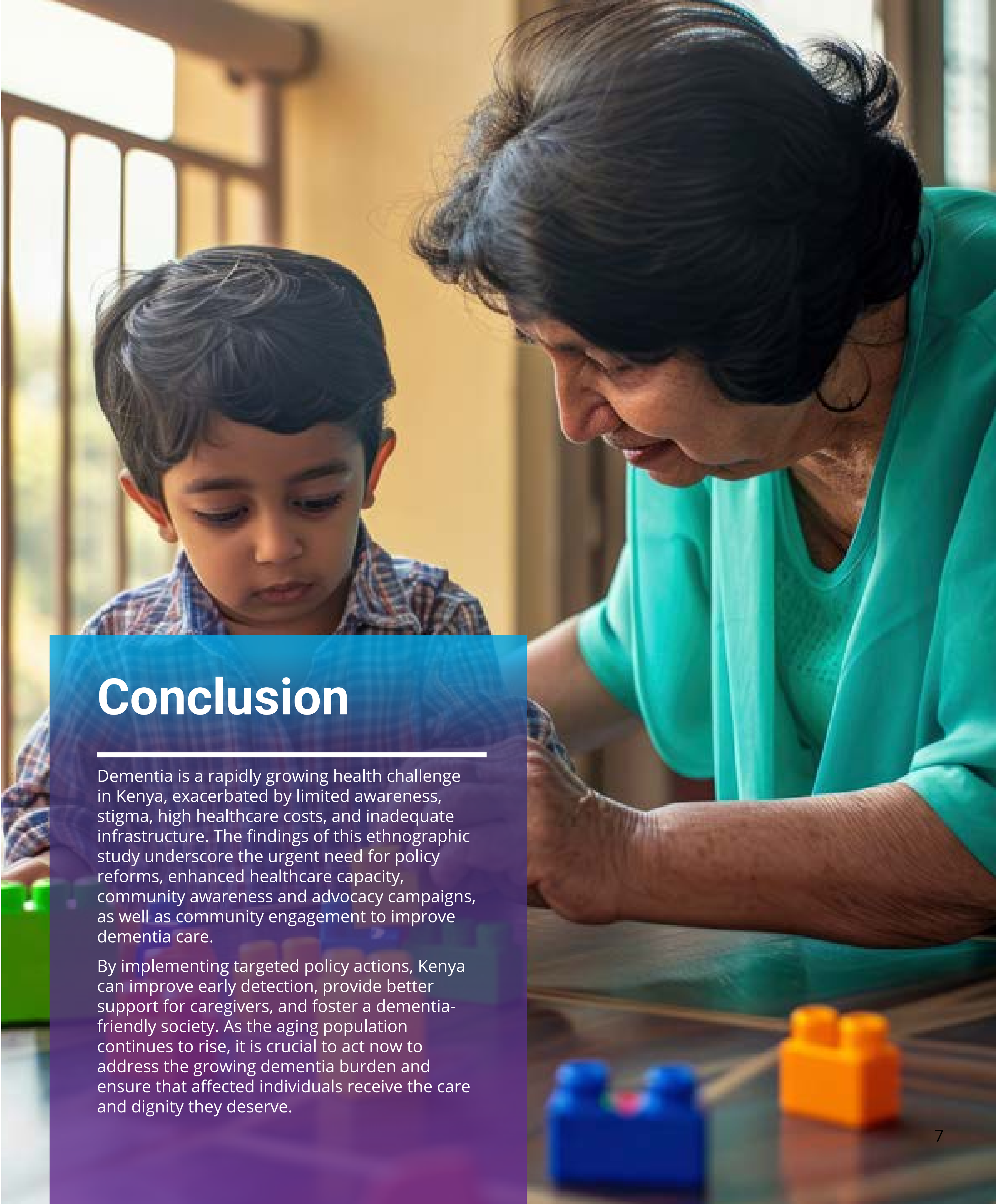
Communities should be engaged through culturally sensitive educational programs that highlight the benefits of dementia research and encourage participation. Research ethics must be upheld, ensuring that informed consent is prioritized and that community benefits from such research are clearly communicated.

Caregiver support initiatives

Structured support programs should be developed to assist caregivers in their role. These programs should include training, financial assistance, mental health support, and respite care options to alleviate caregiver stress and improve overall care quality.

Government and institutional collaboration

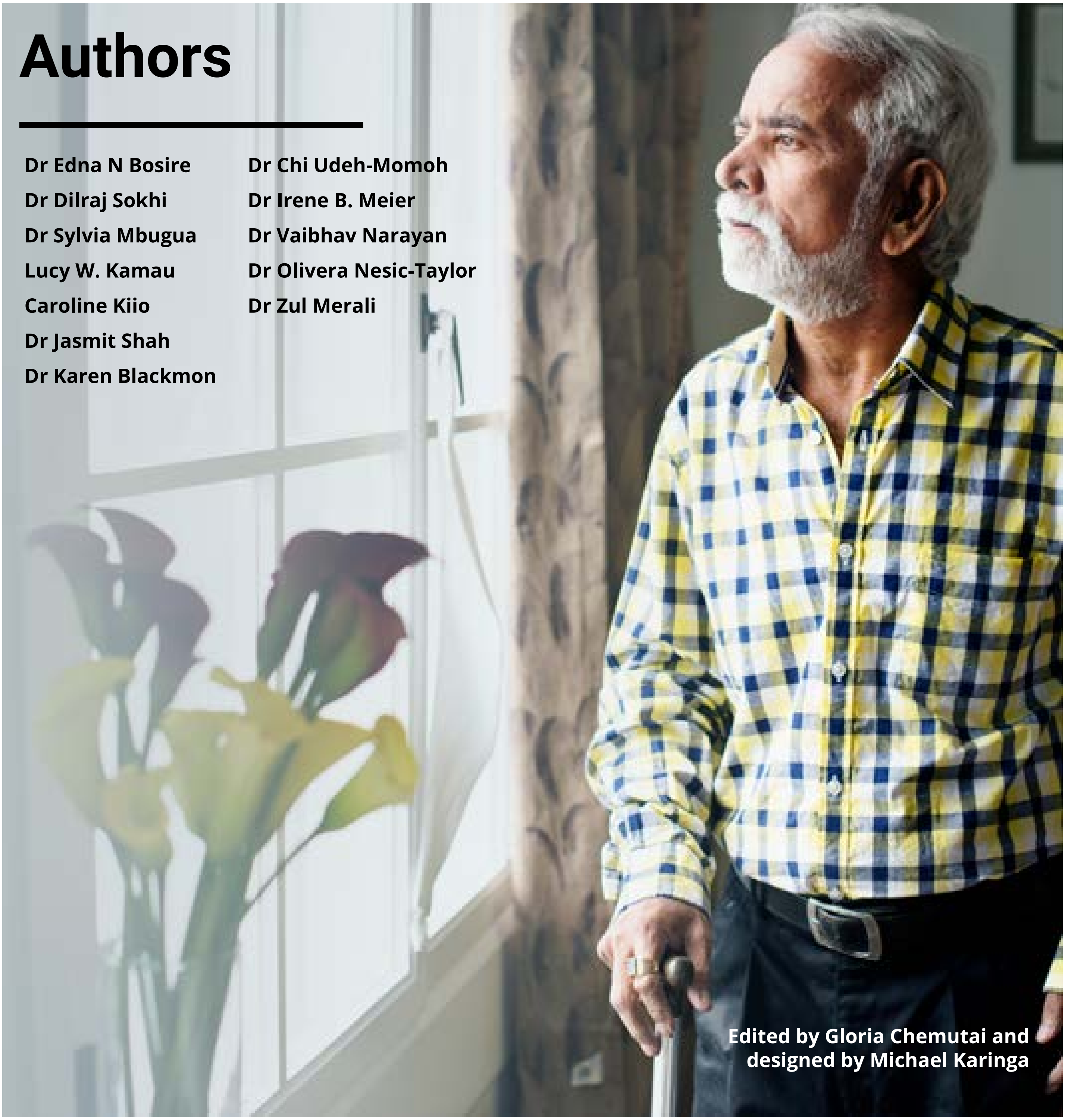
Collaboration between government agencies, non-governmental organizations, and civil society should be strengthened to mobilize resources for dementia care and advocacy efforts. A coordinated approach will enhance service delivery, policy implementation, and public engagement in addressing dementia-related challenges.



Conclusion

Dementia is a rapidly growing health challenge in Kenya, exacerbated by limited awareness, stigma, high healthcare costs, and inadequate infrastructure. The findings of this ethnographic study underscore the urgent need for policy reforms, enhanced healthcare capacity, community awareness and advocacy campaigns, as well as community engagement to improve dementia care.

By implementing targeted policy actions, Kenya can improve early detection, provide better support for caregivers, and foster a dementia-friendly society. As the aging population continues to rise, it is crucial to act now to address the growing dementia burden and ensure that affected individuals receive the care and dignity they deserve.



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