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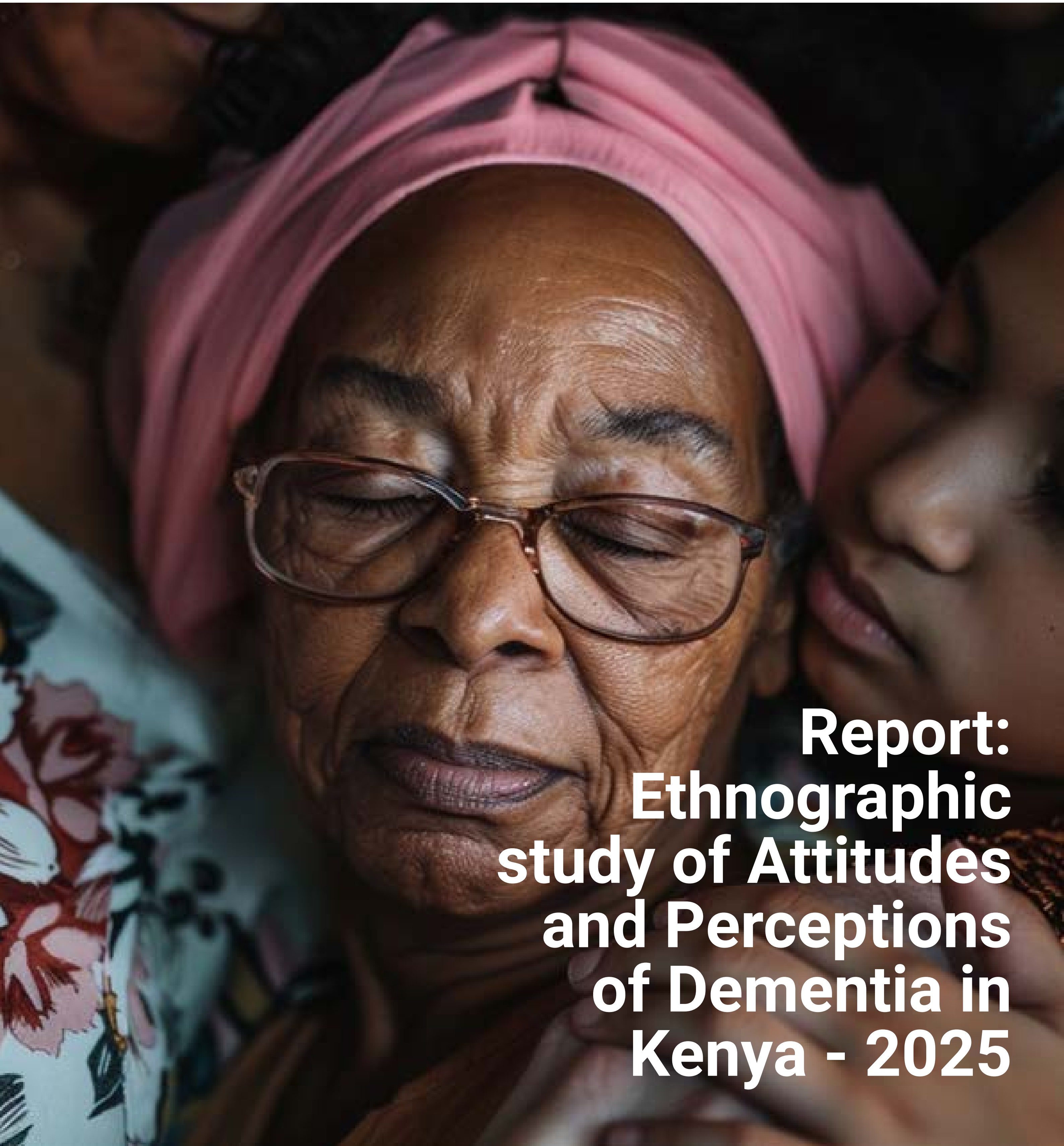

Report: Ethnographic study of Attitudes and Perceptions of Dementia in Kenya - 2025

Ethical approval

This study was approved by the Aga Khan University's Institutional Scientific and Ethics Review Committee (ISERC) (2023/ISERC-11 (v3)). We also received permissions from the National Commission for Science, technology and Innovation (NACOSTI/P/23/25757)

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Davos
Alzheimer's
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Ethnographic Study of Attitudes and Perceptions of Dementia in Kenya

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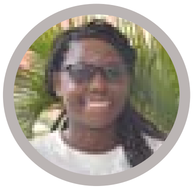

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Executive summary

Dementia, including Alzheimer's disease, is becoming increasingly common in sub-Saharan Africa, yet knowledge about the condition remains limited, particularly in East Africa. Misconceptions often lead people to attribute dementia symptoms, such as memory loss, to aging or cultural beliefs like being bewitched or cursed.

This study explored attitudes and perceptions of dementia among different individuals (patients, caregivers and healthcare providers) at Aga Khan University Hospital in Nairobi; as well as assessed community understanding of dementia in Nairobi's informal settlements. Findings revealed that lack of understanding and stigma towards dementia, limited access to healthcare providers and the high cost of care impacted patients and their caregivers including delayed diagnosis and management. In this case, most patients presented at the hospital when their conditions had advanced. Women bear the majority of caregiving responsibilities, often without adequate support or resources.

Meanwhile, healthcare providers face challenges such as a lack of specialized training, limited diagnostic tools, and unclear care pathways in public health systems. Community members expressed mixed feelings about participating in dementia research, influenced by cultural beliefs, lack of awareness, and trust issues. They recommended a need for dementia sensitization at community level to address lack of knowledge and stigma. These findings highlight the urgent need for awareness campaigns, caregiver support, and culturally sensitive approaches to dementia care and research in Kenya.

This study explored attitudes and perceptions of dementia among different individuals (patients, caregivers and healthcare providers) at Aga Khan University Hospital in Nairobi; as well as assessed community understanding of dementia in Nairobi's informal settlements.

Background

Among the challenges associated with the ageing population, dementia presents an increasingly pressing societal issue. Being one of the most prevalent neurodegenerative diseases with no cure currently available, dementia ranks at the top among the leading causes of disability and dependency among older people worldwide [1]. Alzheimer's disease (AD) is the most common type of dementia and accounts for fifth leading cause of death and the second leading contributor to death from neurological diseases [1]. More than 50 million people around the globe are living with AD and there is an estimated annual increase of 10 million new cases [2]. Yet, more than half of these cases (60%) are living in low- and middle-income countries [2,3]. The recent World Health Organization (WHO) estimates indicate that by 2050, if growth in the older population continues, and there are no changes in mortality or burden reduction by preventive measures, 150 million persons, representing a 204% increase from 2017, will be living with AD [4]. Majority of these increases will be found in low- and middle-income countries (LMIC) including Africa [5].

Sub-Saharan Africa (SSA) is experiencing a sharp rise in the size of the older population; consequently, the incidence and prevalence of ADs and other related dementias is also expected to rise [1,4]. Yet, there is limited evidence about ADs and other dementias in SSA. The *Dementia in Sub-Saharan Africa: Challenges and Opportunities* report by Alzheimer's Disease International identified only 12 studies conducted in sub-Saharan Africa; of these, six were conducted in West Africa, and only one study from East Africa (Tanzania). Indeed, other studies have established that highest dementia prevalence is mostly reported from Western, Central and Northern Africa region; with most of the data on incidence coming from Nigeria [6].

In Kenya, we do not know the actual numbers of dementia cases; it is estimated that dementia prevalence will increase from 600 cases per 100,000 in 2020, to 660 per 100,000 cases in 2050, translating to 316% percentage change in the number of people living with dementia [10]. While there is no national prevalence data on dementia in Kenya [11], a regional study conducted in 20 health facilities in Makueni County showed that the rate of cognitive impairment using Mini-Mental State Exam (MMSE) was 1%, ranking second after depression among mental health problems [12]. Lack of standardised or defined measures to assess dementia in Kenya has led to limited evidence on diagnosis rates in the country. In addition, the public health care system in Kenya is characterised by severe shortage of mental health care specialists, with a few trained psychiatrists and neurologists serving a population of 44 million [13]. Further, access to mental and neurological health services- especially amongst the poor populations is limited due to lack of standardized diagnostic tools, high cost of diagnosis and lack of equipment – forcing many people to seek mental healthcare services from informal caregivers such as traditional and faith healers [14].

This ethnographic study aimed to assess attitudes and perceptions of dementia in Kenya- engaging different stakeholders such as patients, their caregivers, healthcare providers and the general public in Nairobi. We assessed how health care is organized at the Aga Khan University Hospital (AKUH) in Nairobi and the barriers and opportunities in service provision. We also explored how day-to-day care is performed in domestic settings, and how family caregivers responded to patients' needs, as well as engage with different forms of medicine and modern technology to navigate care for the patients.

Methodology

i. Study design and sites

This study used ethnographic methods, including interviews and observations, to explore how people experience and understand dementia in Kenya. We conducted our research at the Neurology Clinic of Aga Khan University Hospital in Nairobi (AKUHN), focusing on the role of culture, social dynamics, and economic contexts in dementia care. By examining patient, caregiver, and healthcare provider experiences, the study aimed to address knowledge gaps and identify barriers to effective care.

ii. Sample size and sampling procedure

The study was conducted for 8 months, from August 2023 to March 2024.

Month 1 - 2: Over two days a week, researchers observed activities at the Neurology clinic at AKUHN, including patient consultations, caregiver roles during appointments, and overall patient-provider interactions. Field notes captured these observations to help contextualize findings.

Month 3: We purposively identified, recruited and interviewed 21 healthcare providers at AKUHN, including neurologists, psychiatrists, nurses, primary care physicians and speech therapists, to understand their experiences managing dementia care. Each interview lasted 45–60 minutes and focused on understanding their experiences managing patients, treatment and care, existing opportunities as well as challenges they experienced managing the patients.

Month 4 - 6: We purposively recruited and interviewed 26 patients (aged 45 and older) diagnosed with early-stage dementia and 36 caregivers. Patients were identified with the help of neurologists based on diagnostic criteria such as the Montreal Cognitive Assessment (MoCA) and imaging results. Patients with moderate-to-severe dementia were excluded. Interviews were conducted in private hospital spaces or offices. Caregivers, primarily family members, were included based on their close caregiving roles and those who consented to be part of the study.

After all interviews, we conducted 10 home visits. This was based on 10 participants (patient-caregiver dyad) who accepted to be visited at home. Home visits included informal conversations, observations on care and management away from clinical spaces.

Month 7 - 8: We conducted eight FGDs with 81 participants from informal settlements in Mathare and Kibera. Each group has about 8-10 people. These groups were organized by age and gender to explore general awareness of dementia, cultural attitudes, and interest in participating in dementia research. Community organizations helped recruit participants, and discussions lasted about two hours.

iii. Inclusion and exclusion criteria for patients & caregivers

Patients: Included individuals aged 45+ diagnosed with Alzheimer's or related dementia who consented to participate. Excluded were individuals too ill or those actively using substances and those who refused consent to be part of the study.

Caregivers: Included primary caregivers aged 18+ providing significant care and willing to participate. Excluded were caregivers with inconsistent involvement in patient care and those who refused consent to be part of the study.

All interviews for the patients were conducted in a private space within the hospital. Interviews with the caregivers were either conducted at the hospital or at the Brain and Mind Institute offices at Aga Khan University.

4.

Month 7 - 8

Conduct 8 focus group discussions (FDGs) (n=81)

Participating in research studies e.g. clinical trials

3.

Month 4 - 6

Patient interviews amd recruitment at AKUHN (n=26),Caregivers (n=36), Home visits (n=10)

2.

Month 3

Recruit and interview 21 healthcare providers.

1.

Month 1 - 2

Observations at the Neurology Clinic.

Informal conversations with different actors in the clinic.

4 phases of data collection

Key findings

i. Patients’ experiences and challenges

Our aim was to explore the lived experiences of patients with dementia, focusing on the resources they had, challenges they faced and how their social environments influenced their quality of life.

Understanding dementia and access to care

- Most patients were aged between 70 and 80 years and came from diverse socioeconomic backgrounds. While some accessed care at AKUHN with financial support from family members, others, particularly those without medical insurance, struggled significantly with the high costs of care.
- Patients were typically referred to AKUHN by friends, family, or primary healthcare providers.
- A general lack of understanding about dementia was evident. Many patients viewed symptoms such as forgetfulness as a normal part of aging, delaying care-seeking behavior.

Health and financial challenges

- Many patients faced additional health conditions, including diabetes, hypertension, and arthritis, which compounded the complexity and cost of managing dementia.
- Language and communication challenges were common as some patients reverted to their first vernacular language or struggled to follow conversations as the disease progressed.
- Most patients lacked health insurance, requiring them to pay out-of-pocket for diagnostics and treatment. The high costs posed a significant financial burden on patients and their caregivers.

Impact of the disease on daily life

- During home visits, we observed that care for patients primarily occurred in home settings.
- Some patients demonstrated functional decline – where they could no longer perform basic activities like going to work, running a business, managing medication, cooking, personal hygiene e.g., bathing, decision making e.g., dressing; eating- forget to eat or overeating. We observed severe cases where some patients could not wake up or use the toilet independently.
- Loss of self-identity was a recurring issue. Some patients could not recall personal details, such as their birthplace or family members' names. Others appeared withdrawn and emotionally disconnected, as noted by their caregivers.

Social and emotional impacts

- Stigma surrounding dementia negatively impacted patients' well-being. Discrimination and isolation were common, excluding patients from social activities and community participation.
- Stigma also extended to caregivers, affecting the broader social support network available to patients.

Positive observations from supportive environments

- Social engagement and interaction were found to enhance memory and improve patients' moods. Positive relationships with caregivers and family members reduced agitation and facilitated better communication.
- Caregivers using simple tools, such as diaries, helped patients manage their routines and remember essential tasks, demonstrating the importance of practical support strategies.

ii. Caregivers' findings and characteristics

Family members especially women were the primary caregivers for dementia patients, taking on significant responsibilities that began well before a formal diagnosis. Their involvement ranged from recognizing early symptoms to providing continuous care, often without adequate support or resources.

Caregivers came from varied educational backgrounds, from local schooling in Kenya to higher education abroad. Family structures varied, from small nuclear units to large extended families, influencing the availability of support networks.

Most patients lacked health insurance, requiring them to pay out-of-pocket for diagnostics and treatment. The high costs posed a significant financial burden on patients and their caregivers.

Our findings show that caregiving took four phases - from pre-diagnosis to post diagnosis as described below:

The four phases of caregiving

1. Symptoms manifestation

Caregivers often noticed behavioral changes like memory loss, mood swings, or agitation before seeking medical help.

Many mis-attributed these symptoms to normal aging, stress, or cultural beliefs like witchcraft or curses.

Stigma and lack of knowledge led to delays in seeking care, with some caregivers isolating patients to avoid community judgment.

2. Help-seeking behavior

Caregivers frequently turned to the internet for answers due to limited knowledge about dementia and a lack of clear care pathways.

Initial attempts to seek help from primary healthcare providers often resulted in misdiagnoses or inappropriate treatments, adding to frustration and delays.

On average, it took three years for most patients to receive a proper diagnosis from a neurologist.

> We started with just a general hospital that dad worked at. I think they misdiagnosed her. They said it was depression and she was put on antidepressants. I think they were just mixed up with the diagnosis.
>
> *CG 34*

3. Pathways to diagnosis

Once referred to a neurologist, patients underwent thorough assessments, including history taking, imaging (MRIs and CT scans), lab tests and cognitive evaluations.

Diagnostic procedures were described as expensive, even for those with insurance. Financial strain was a recurring challenge for caregivers.

4. Post diagnosis

Caregivers managed a range of tasks, from administering medication to providing emotional and physical support. Patients' dependency on caregivers was profound, often requiring round-the-clock vigilance to prevent harm or ensure well-being.

The caregiving burden included financial stress, emotional struggles, and sacrifices in personal and professional life.

In addition, caregivers described their experience to encompass a feeling of loss or worry. This was especially when caregivers' lives and identities were impacted by the patient's condition. Some were unable to work, go to school or get married due to caregiving roles.

> As I have said, it is draining, it drains you so much because, actually I would say I stopped living my life, and then I became a part of him, so I no longer live my life.
>
> *CG32*

Others struggled with deep emotional struggles due to overwhelming responsibilities caring for their loved ones, something that made them feel helplessness.

> It is not easy because he does not remember. You plan things this way and you turn around something else has happened. So you have to go and undo all that and do it all again. That's the difficult part.
>
> *CG 15*

Sometimes, caregivers reported that they felt embarrassed because of the observed symptoms some which were said to be shameful; others talked about discomfort in assuming intimate care tasks such as bathing or dressing their loved ones, but over time, they develop acceptance and normalized these responsibilities as part of their daily routine.

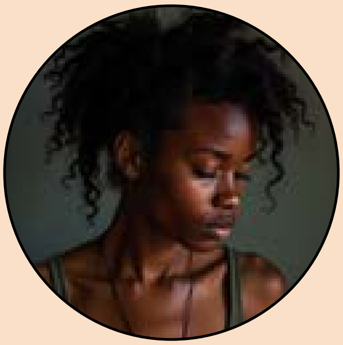
Easily flustered or frustrated

Uninterested in things they used to enjoy

Loss or worry

Quick to anger

Stressed, anxious, depressed



Hopeless or helpless

Forgetful or foggy

Common signs of caregiver burden

Coping mechanisms

Caregivers relied on various strategies, including faith, prayer, social support, and acceptance, to manage the emotional toll of caregiving. Support from family members and friends often made the caregiving journey less isolating.

Growth and fulfillment

Despite challenges, many caregivers found purpose and satisfaction in helping their loved ones. Caregiving was seen as a journey of resilience, acceptance, and empathy.

> I am very happy because, currently he is more open to getting assistance. Before that, he was very aloof. I remember us having the conversation of how we can help because we don't want to see him suffer, be it in his business or whatever. This is opening up new ways of living with the disease."
>
> *CG 28*

iii. Healthcare providers' perspectives: Diagnosis, treatment gaps and systemic challenges

This section summarizes the insights of healthcare providers at Aga Khan University Hospital Nairobi (AKUH-N) regarding the treatment and management of dementia patients.

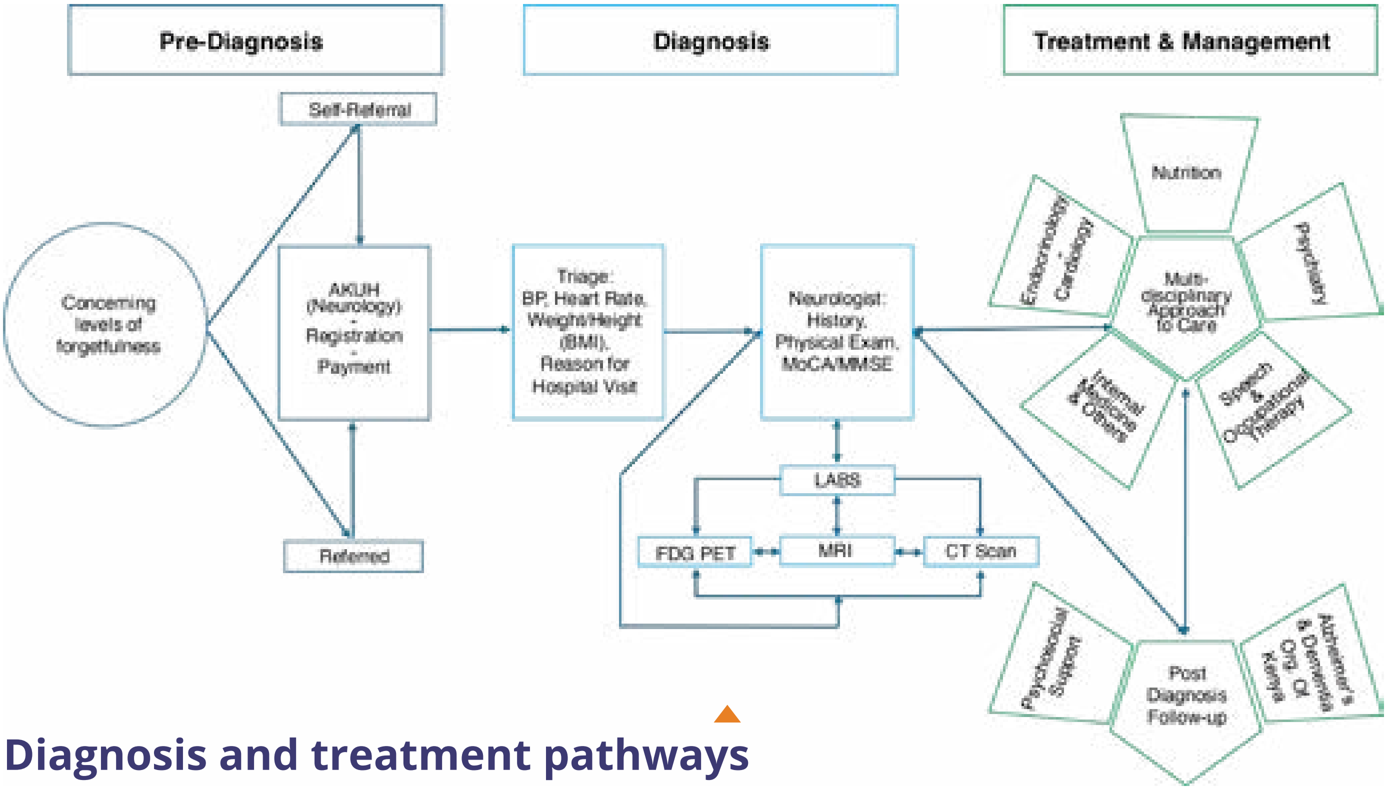
Pathways to care for dementia patients

We learnt that there is no clear pathway for dementia care and treatment. Most patients accessed AKUHN's neurology clinic through self-referrals, either on their own or via relatives who noticed concerning symptoms. In some cases, referrals came from healthcare providers within or outside AKUHN, especially when memory-related problems such as forgetfulness were observed. Patients with comorbidities were often referred across different hospital departments for integrated care.

Dementia characterization, diagnosis & evaluation

The diagnostic process at AKUHN follows a detailed and stepwise approach aimed at ruling out other conditions that may mimic dementia. Providers highlighted the following key steps:

1. **History taking:** Providers emphasized that history taking was crucial in identifying risk factors, the type of dementia, the patient's functional abilities, and their home environment. The process was described as a collaborative effort involving family members or caregivers, who provided detailed information about the patient's past illnesses, previous medications or treatments, and the family's general health history, including any hereditary conditions.
2. **Physical examination:** Healthcare providers conducted thorough physical exams to identify potential contributors to the patient's cognitive issues.
3. **Cognitive assessments:** Tools such as the Montreal Cognitive Assessment (MoCA) and Mini-Mental State Examination (MMSE) were frequently used to assess cognitive function. The Addenbrooke's Cognitive Examination was sometimes employed, though providers noted it required more time to administer. Psychiatrists relied on DSM-V criteria for diagnosis.
4. **Laboratory tests and imaging:** Advanced diagnostic tools, including CT scans, MRIs, and FDG PET scans (available only at AKUHN), were used to confirm dementia diagnosis, determine its type, and guide treatment. However, some advanced tests, like amyloid scans, were not readily available in Kenya.



Diagnosis and treatment pathways

In summary, access to cutting-edge diagnostic procedures and equipment at AKUHN was a significant enabler of quality dementia care in the region.

Challenges of care provision to dementia patients

The challenges described by healthcare providers can be broken down into health system related challenges and patient related challenges.

Health system related challenges

1. There is a significant **shortage of trained professionals**, such as neurologists and neuropsychologists, particularly in rural areas, which limits timely diagnosis and care for dementia patients.
2. Lack of national **dementia care protocols** to guide diagnosis, treatment, and access to care impede management of patients.
3. Many public hospitals lack **essential equipment** for diagnosing dementia, making it difficult for patients to receive timely care.
4. The absence of formal **support systems** for dementia patients and caregivers exacerbates the caregiving burden.

Patient-caregiver related challenges

Financial burden

Dementia care was described as prohibitively expensive. Most patients lacked medical insurance or had policies that did not cover degenerative conditions like dementia. Even for insured patients, coverage often ran out due to the high cost of diagnostic procedures.

Providers frequently had to prioritize tests based on patients' financial capabilities, which could compromise comprehensive diagnosis and care.

Lack of awareness and cultural beliefs

- Low awareness among the public about dementia delayed care-seeking. Symptoms were often misinterpreted as a normal part of aging or attributed to cultural beliefs such as witchcraft.
- Stigma surrounding dementia led to patients being hidden at home or seeking care from informal providers.
- Social dynamics also contributed to access challenges, as elderly individuals were often relocated to rural areas after retirement, where specialized care is less accessible.

In summary, while AKUHN provides advanced diagnostic tools and expertise, the public healthcare system in Kenya faces significant challenges in managing dementia. These include gaps in policies, infrastructure, and trained personnel, compounded by financial barriers and cultural misconceptions about the condition.

iv. Community knowledge and research perceptions: Awareness of dementia and willingness to participate in research

We conducted eight focus group discussions (FGDs), stratified by age and gender, with a total of 81 participants (approximately 10 per group). The study took place in two informal settlements in Nairobi: Kibera and Mathare.

Data collection

All FGDs were conducted in Swahili, with each session lasting around 90 minutes. The discussions were held in safe and accessible spaces within NGOs or community halls in the respective settlements.

Using an open-ended FGD guide, participants were encouraged to share their understanding of dementia and its perceived causes, their prior experiences with research participation, and their views on the collection of various biospecimens for dementia research. The biospecimens discussed included stool, saliva, blood, tears, hair, cerebrospinal fluid (CSF), and brain tissue samples. Participants also explored factors that motivated or hindered their willingness to donate these samples, with in-depth discussions focusing on the cultural, social, and practical considerations influencing their decisions.

v. Perceptions of providing biospecimen for dementia research

Participants were asked to identify which biospecimens they would find easiest to provide and were prompted to rank their preferences. Across all age and gender groups, blood and fecal samples were the most preferred, as participants were already familiar with providing these for routine medical diagnoses in Kenya. Saliva was also viewed favorably due to the simplicity of its collection. However, there was notable hesitation regarding hair, tear, and cerebrospinal fluid (CSF) samples.

Below is a detailed summary of participants' preferences, the reasons behind their willingness or reluctance, and illustrative quotes:

Blood sample

Most participants expressed a willingness to donate blood, citing their familiarity with blood collection for medical testing and the potential to help others or advance research.

> I can volunteer because I now know it is a disease. I didn't know that. If all I have to do is give a small blood sample for a treatment to be found that will help people, then I will do it.
>
> *FGD with women aged 45+ years, Mathare*

Some participants were hesitant due to health-related concerns, fear of side effects, or uncertainty about the amount of blood required.

Across all age and gender groups, blood and fecal samples were the most preferred, as participants were already familiar with providing these for routine medical diagnoses in Kenya. Saliva was also viewed favorably due to the simplicity of its collection. However, there was notable hesitation regarding hair, tear, and cerebrospinal fluid samples.

Additionally, socio-cultural factors influenced reluctance among certain groups, such as younger women, who raised concerns about taboos and cultural beliefs associating blood with covenants or spiritual significance.

> This whole situation has a scientific and cultural side. You may not know what I associate with my blood, so if I come and donate, you may not know what comes with it.
> *FGD with women aged 25–45 years, Mathare*

Participants also expressed concerns about not being informed beforehand about the volume of blood needed. However, they agreed that education and transparency could alleviate such worries.

> I can give my blood sample, and then I don't know the amount needed. So, after knowing that, I can decide whether to donate.
> *FGD with women aged 25–45 years, Kibera*

Fecal samples

Participants expressed a general willingness to provide fecal samples, citing familiarity with such procedures during medical consultations. In one discussion with men aged 45 and above in Mathare, participants responded positively in unison when asked if they would donate stool samples.

Participants were motivated by the potential benefits of their contribution, particularly the development of innovative medicines to help others.

> I will give so that novel medication can be found to help others.
> *FGD with men aged 45+ years, Mathare*

This willingness, tempered by practical considerations, highlights the need for flexibility and clear instructions when collecting fecal samples for research.

Saliva samples

Saliva as a biospecimen sparked significant debate among participants. Many were surprised, stating they did not consider saliva to be a legitimate sample for research.

Older participants echoed this sentiment, with some perceiving the idea as trivial or even humorous.

> Is saliva a biospecimen? Well, the young people can agree to give, but I think others (older generation) may think it's *sarakasi* (joke).
> *FGD with women aged 45+ years, Mathare*

Some participants argued that saliva seemed unimportant for research because it is often discarded carelessly.

> We always spit carelessly, and anytime. I did not know that saliva could be used in research.
> *FGD with women aged 45+ years, Mathare*

Despite these initial perceptions, participants expressed willingness to provide saliva samples due to the simplicity of the collection process. Many described it as easy and straightforward, requiring little effort.

Participants emphasized the need for education and awareness campaigns to highlight the importance of saliva as a biospecimen. They believed that sensitization would help address misconceptions and encourage people to contribute samples.

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Tear samples

Tear samples sparked curiosity and surprise among participants, as many were unaware that tears could be used in scientific research.

> It is today that I am actually getting to hear that tears can also be used as a sample. You find that people are used to blood, stool, etc.
> *FGD with men aged 45+ years, Mathare*

Some participants found the idea amusing, with one participant laughing and asking,

> Did you say that tears are also used to do research?
> *FGD with men aged 25–45 years, Kibera*

Participants raised practical concerns about the difficulty of producing tears on demand, especially in a clinical setting. Many noted that tears typically arise in response to emotional triggers such as sadness or distress, making them less feasible for immediate collection.

In addition, socio-cultural beliefs played a role in participants' reluctance to donate tears. Some associated tears with witchcraft, fearing that donated tears might be used for harmful purposes.

While the concept of using tears for research was intriguing to some, these practical and cultural concerns would need to be addressed to encourage participation in tear sample donation.

Hair samples

Hair samples were met with significant skepticism and resistance by participants, largely due to cultural fears of witchcraft. Many participants expressed outright refusal to provide hair samples, with some bluntly stating:

> Hair, no.
> *FGD with women aged 45+ years, Mathare*

Similar to the discussions around saliva and tears, participants questioned the scientific value of hair in research, with some asking:

> What research would be done on someone's hair?
> *FGD with men aged 45+ years, Kibera*

Participants highlighted the cultural context of hair in Kenyan societies, where it is often associated with witchcraft or harmful practices. Hair was described as a key material used by those with ill intentions to harm others, reinforcing fears of misuse.

> They will say you are going to bewitch them.
> *FGD with women aged 45+ years, Mathare*

> Now that is where they will associate it with witchcraft.
> *FGD with women aged 45+ years, Mathare*

When asked how these fears could be addressed, participants emphasized the importance of community education, sensitization, and

Socio-cultural beliefs played a role in participants' reluctance to donate tears and hair samples. Some associated these samples with witchcraft, fearing that they might be used for harmful purposes.

awareness campaigns to dispel misconceptions and build trust.

Overall, participants noted that targeted education efforts could help alleviate cultural fears and encourage participation in hair donation for research.

Cerebral spinal fluid (Tap)

Cerebrospinal fluid (CSF) collection, commonly referred to as a spinal tap, was met with significant fear and reluctance among participants. Concerns centered around pain, potential long-term health effects, and the perceived risks associated with the procedure.

Fear of pain was a dominant theme across focus groups, with participants sharing personal experiences or stories they had heard.

Some participants who had previously undergone a spinal tap described it as an extremely uncomfortable experience, often accompanied by side effects like headaches or back pain.

> I have had that fluid taken out, but it is painful. You find that you have a lot of headaches.
>
> *FGD with women aged 45+ years, Kibera*

> I will have fear. I have gone through a CS (Cesarean section), and the first complication I got after was that I could not bend, so I don't want to joke with the spinal cord again.
>
> *FGD with women aged 25–45 years, Mathare*

Female participants, in particular, voiced apprehension about the potential long-term impacts of the procedure on their ability to perform daily activities. Many believed that interference with the spinal cord could lead to disability, affecting their livelihoods and independence.

> When the sample is removed, I won't be able to do my normal activities. So, they need to pay me what will sustain me before I recover.
>
> *FGD with women aged 45+ years, Kibera*

> You won't be able to go to work in the 'jua kali' [informal] sector.
>
> *FGD with women aged 45+ years, Kibera*

Younger participants expressed concerns about the qualifications and expertise of those performing the procedure. They feared that unskilled practitioners could cause harm.

Participants suggested that strategies to alleviate concerns should focus on:

1. Reducing pain during CSF collection.
2. Ensuring that only qualified and experienced professionals perform the procedure.

These measures, along with community education about the purpose and safety of the procedure, could help build trust and address fears related to CSF sample donation.

Brain donation

Brain donation for research evoked mixed reactions among participants, with views influenced by cultural, religious, and family considerations.

Many participants emphasized the importance of family consent, noting that once they passed away, control over their body would rest with their family.

> Once I die, I do not have control over my body, but my family has.
>
> *FGD with men aged 45+ years, Kibera*

Some participants were curious about whether their families would benefit financially from the donation.

> If I die and then they take the brain, is there something that the people I have left behind will benefit from, or the brain is just removed and that's it?
>
> *FGD with men aged 45+ years, Kibera*

Cultural and religious beliefs strongly influenced participants' decisions about brain donation. Religious restrictions were a significant barrier, with some participants opposing postmortem procedures altogether.

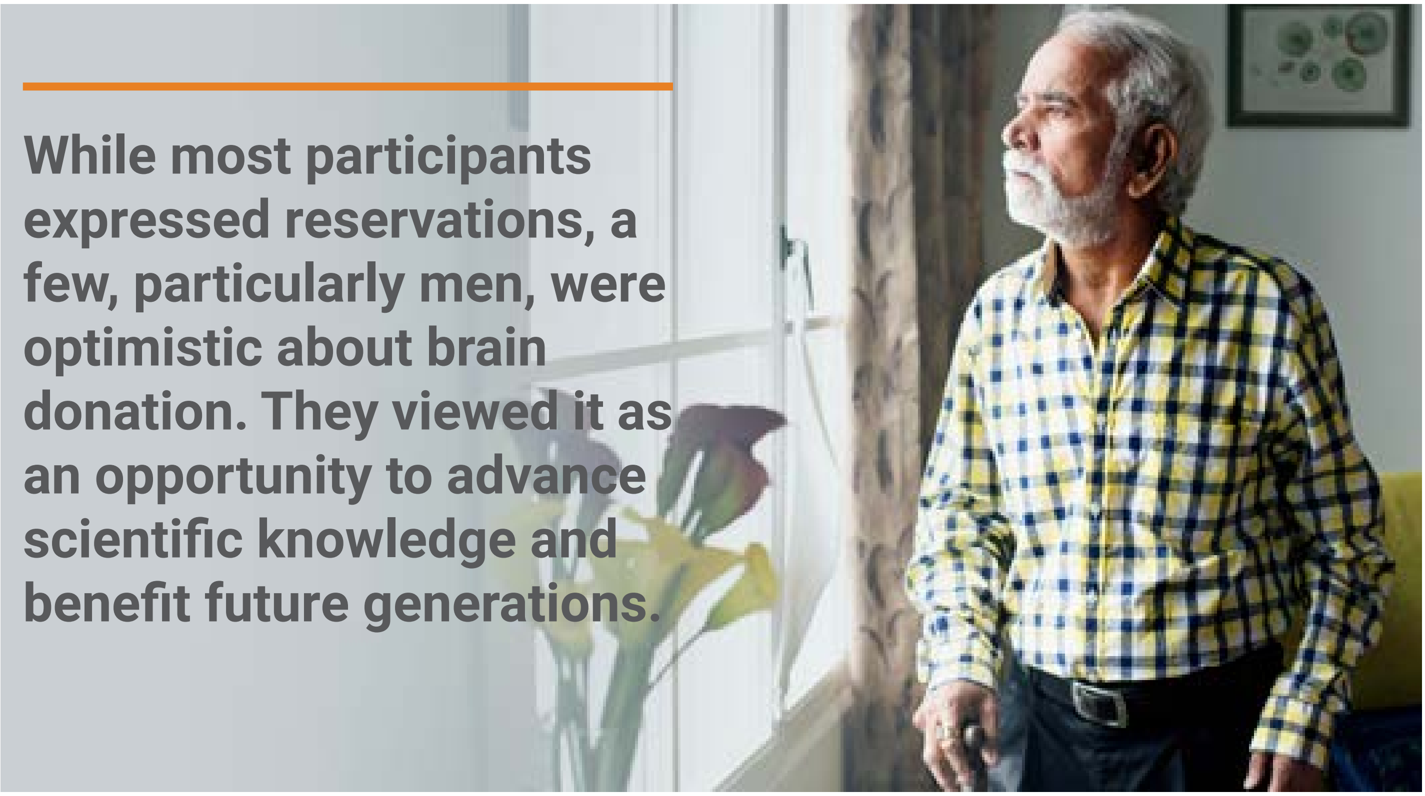
> For me, even when it comes to my religion, I am not allowed. I even tell my children that even if I die abruptly, I don't want anything to do with the postmortem.
>
> *FGD with women aged 45+ years, Kibera*

Other participants cited fears of spiritual disturbances, believing that burial without a brain could haunt the deceased's family or future generations.

While most participants expressed reservations, a few, particularly men, were optimistic about brain donation. They viewed it as an opportunity to advance scientific knowledge and benefit future generations.

> For me, I think there is no need for me to die with an organ that can help someone.
>
> *(FGD with men aged 25–45 years, Mathare)*

Participants' willingness to donate their brains for research was shaped by a mix of personal beliefs, family dynamics, and cultural influences. Addressing these concerns through education, community engagement, and discussions about the potential societal benefits of brain donation may help increase acceptance in the future.



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Understanding and perceptions of clinical trials

Participants shared their understanding of clinical trials, their willingness to participate, and the role of family involvement. Discussions revealed varied levels of knowledge, mixed feelings about participation, and a strong sense of responsibility toward family members.

Most participants, particularly younger groups, demonstrated a basic understanding of clinical trials, recognizing them as a method to test new medications before public release. Many associated clinical trials with the rapid development of COVID-19 treatments, noting that some individuals participated as test subjects.

Willingness to participate in clinical trials

Participants expressed a range of responses when asked about their willingness to engage in clinical trials.

Some were open to participating, motivated by the desire to help others or contribute to medical advancements.

Others expressed fear of the unknown, side effects, and the risks associated with being a test subject.

Motivations for future participation

Participants highlighted several motivations for future participation, including personal benefit, helping others, and scientific curiosity. Many participants were driven by a desire to contribute to advancements that could benefit others.

Some participants expressed reluctance to participate, prioritizing their health.

Cultural and religious beliefs also emerged as barriers, influencing decisions about participation.

Family involvement in clinical trials

Participants emphasized the importance of involving family in decisions about clinical trials. Younger participants highlighted the need to inform parents and siblings, while older participants prioritized consulting spouses and children.

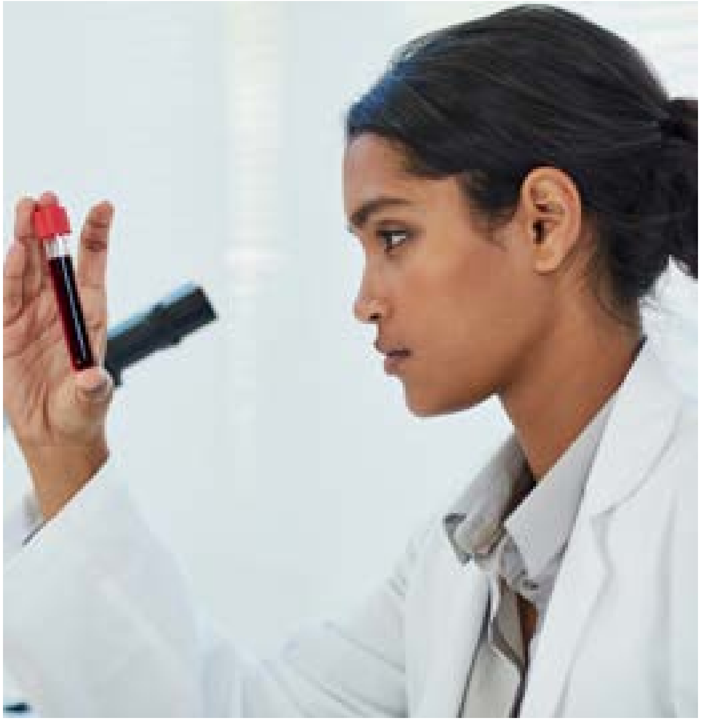
Some participants were open to encouraging family members to participate in clinical trials, particularly when they believed it could benefit their health.

However, concerns about potential harm to family members were a recurring theme.

Benefits of participation

Participants identified several potential benefits of clinical trials:

1. **Access to treatment:** Many saw participation as an opportunity to receive treatment that might otherwise be unavailable.
2. **Advancing medical research:** Participants recognized the broader value of clinical trials in scientific discovery.



Summary of findings

Objective 1

Our findings demonstrate that dementia awareness is low in Kenya, particularly among patients and their caregivers. This is also true for healthcare providers working in primary healthcare settings, who lack the knowledge, skills, and training necessary for timely screening and diagnosis. The absence of diagnostic equipment, especially in public healthcare facilities, further hinders many patients from accessing care in a timely manner, with some potentially dying in the community without engaging with the healthcare system.

Dementia is often regarded as an “aging disease,” and many people consider it a normal part of aging. This perception, coupled with the stigma associated with dementia, delays timely access to care.

Caregivers often begin providing care before a clear diagnosis is made. Living closely with patients, caregivers are quick to notice unusual behaviors. However, their lack of knowledge about dementia results in delayed help-seeking behavior.

Many patients end up being cared for at home by their relatives, mostly immediate family members who are women. However, most caregivers lack the necessary skills and experience to manage the patients effectively. Additionally, the emotional, physical, financial, and social burdens of caregiving led some caregivers to experience mental and physical breakdowns. The demanding and time-consuming nature of caregiving often prevents caregivers from pursuing their regular life routines, such as going to work or continuing their education. Despite these challenges, caregivers cope through various mechanisms, such as prayers, belief in God, family and social support, acceptance, and maintaining a positive outlook.

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Objective 2

Healthcare providers at AKUHN reported a variety of experiences in managing patients with dementia. They practiced multidisciplinary care, as patients often presented with comorbid conditions. Neurologists worked closely with psychiatrists to address mental health issues such as depression and anxiety.

Many patients presented with advanced disease, reflecting delays in help-seeking behavior, misdiagnosis, lack of knowledge on management at primary healthcare facilities, stigma, and limited resources at these facilities to enhance early screening.

For the few patients who had the opportunity to engage with the healthcare system, the cost of dementia care—particularly for MRI and FDG PET scans—was prohibitively expensive at private hospitals.

Objective 3

Participants were generally more receptive to donating non-invasive samples, such as saliva and fecal samples, compared to more invasive samples like cerebrospinal fluid (CSF) or brain tissue. Participants showed a high willingness to provide saliva samples, as the procedure was perceived to be simple.

In contrast, culturally sensitive samples, such as hair, were met with notable hesitancy due to socio-cultural beliefs, including concerns about witchcraft and general mistrust. Participants also expressed significant reservations about brain donation, primarily due to the need for family consent and religious considerations. Additionally, concerns about cultural implications or supernatural beliefs regarding the removal of body parts after death affected participants' willingness to donate their brains for research. This perspective aligns with attitudes in many African communities, where preserving body integrity after death is considered sacred and culturally significant.

These findings highlight the importance of awareness-building and clear communication about the safety and scientific purpose of blood and brain tissue samples in dementia research, as well as the need for culturally sensitive approaches and active community engagement to address these deeply rooted concerns.

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Objective 4

Participants demonstrated varied understandings of clinical trials, with some fully grasping the concept, while others harbored misconceptions or fears. Willingness to participate in clinical trials varied across age and gender groups, influenced by both individual and collective perceptions.

Many participants expressed a willingness to participate if they believed the research would contribute to the greater good, such as helping others or improving healthcare. However, hesitation was also evident, driven by concerns about potential side effects, the integrity of the research process, and religious or cultural beliefs.

Despite these concerns, many participants recognized the potential benefits of clinical trials, both for themselves and for advancing medical science. These findings underscore the need for clear communication, education, and reassurance to encourage broader participation in clinical trials, especially in communities where skepticism and fear are prevalent.

Additionally, trust emerged as a significant barrier. Historical exploitation in medical research in Africa, coupled with concerns about the misuse of biospecimens, contributed to reluctance in participating in clinical trials.

Findings underscore the need for clear communication, education, and reassurance to encourage broader participation in clinical trials, especially in communities where skepticism and fear are prevalent.

Project recommendations

1. There is a need to establish a clear vision and mission for dementia care in Kenya, as such a framework is currently lacking.

2. Dementia care and treatment in Kenya are expensive. There is a need to develop affordable care packages for dementia patients, such as including them under the Social Health Authority (SHA) package and offering subsidized services, including for diagnosis.

3. Public hospitals should be equipped with the necessary diagnostic tools to improve early screening and detection of dementia.

4. More healthcare providers should be trained in neurology to address the growing demand for expertise in brain health.

5. Many caregivers lack knowledge and experience, leading to caregiver burden. Therefore, it is essential to train and empower caregivers to manage dementia care effectively.

6. Raising awareness about dementia at the community level is crucial to improving dementia friendliness, increasing access to services, and enhancing overall public understanding.

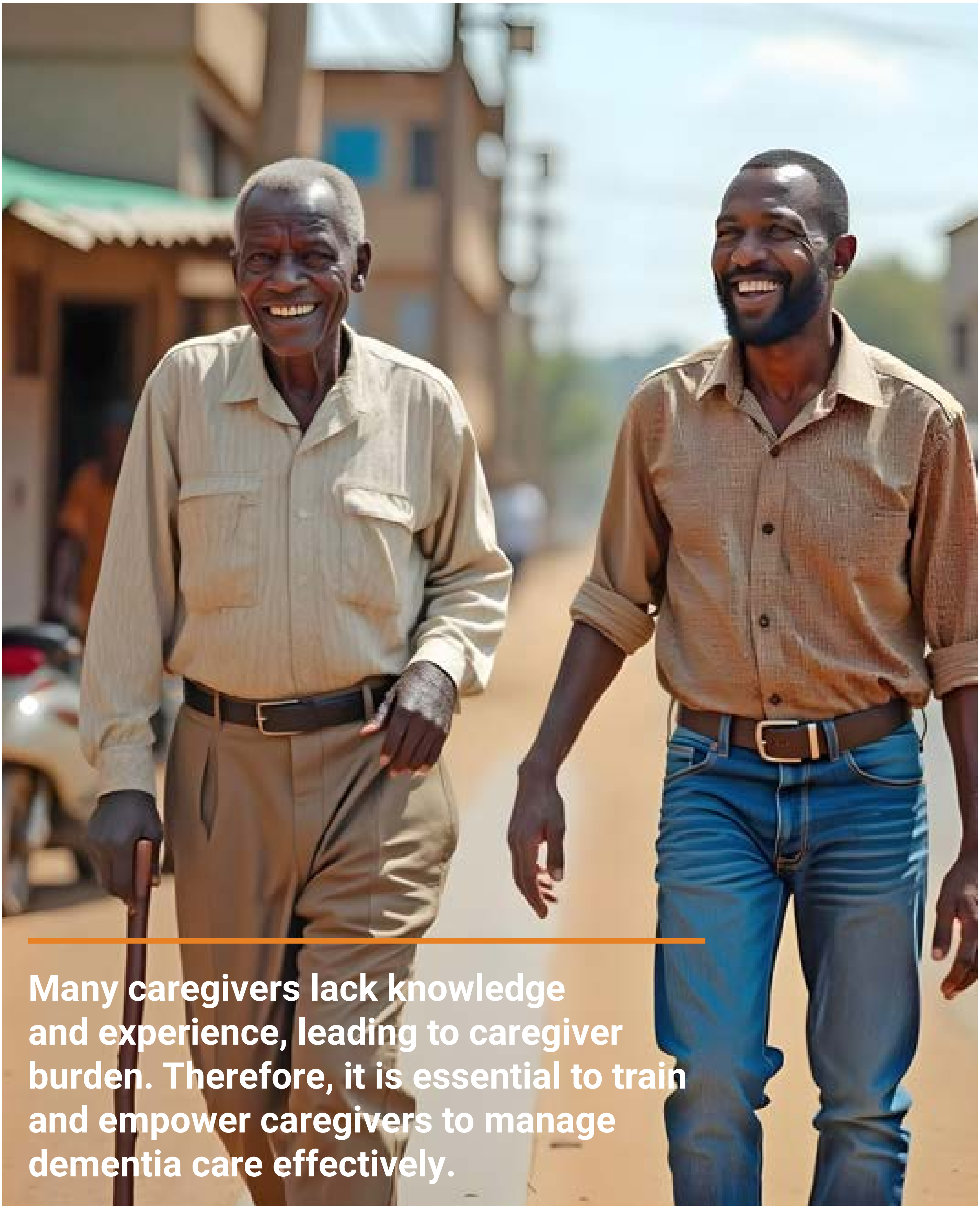
7. Currently, there are no policies in Kenya to protect individuals with dementia. It is important to develop policies that recognize, respect, and protect the rights of patients, caregivers, and family members.

8. More research is needed to understand the prevalence of dementia in Kenya, including studies on risk factors specific to our region.

9. The Kenyan government should collaborate with institutions, non-governmental organizations, and civil society groups focusing on the elderly to mobilize resources for patient care, treatment, and strengthening the healthcare system.

10. There is a need to create community awareness about the importance of biospecimen donation for dementia research in order to improve willingness to participate in such initiatives.

11. Ensuring transparency in research processes, where participants fully understand the goals and methods of clinical trials, is crucial for building trust and increasing participation rates.



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Caregiver’s lived experience

Maria’s changing world: A personal journey with Alzheimer’s

The morning sun casts a golden hue over the bustling streets of Nakuru. Maria, a seasoned 60-year-old shopkeeper, methodically arranges sacks of grains at her busy cereal shop. Her hands move with the practiced rhythm of decades in the trade, but her furrowed brow tells another story. Customers come and go, their chatter filling the air, but Maria seems momentarily lost in thought. A young boy asks her for change, and she hesitates, unsure of the amount. The boy waits patiently as she fumbles with the notes and coins, muttering softly, “I used to be so quick with numbers.”

Maria has lived in Nakuru County, Kenya for years, running her shop with pride. Sundays are her cherished respite; days for church and visiting her sister. Yet, lately, even these routines have become tinged with unease. Maria often finds herself retracing her steps, wondering why she entered a room or where she placed her keys. She brushes it off with a nervous laugh, but deep down, she knows something is amiss.

Her niece, Farida, first noticed the changes two years ago. Maria, once the life of family gatherings, began repeating stories, sometimes ten or fifteen times in a single day. At first, everyone laughed it off, chalking it up to aging. But the laughter faded as Maria’s forgetfulness grew more pronounced. She began misplacing shop records, forgetting customers’ names and even getting lost on her way to familiar places like her home.

“It started with headaches,” Farida recalls. A recent graduate in journalism, she had always looked up to her aunt as a beacon of strength. “In 2020, she complained of recurring headaches, and not long after, her memory started slipping.” Visits to the local hospital provided little clarity. Doctors dismissed her forgetfulness as a natural part of aging, with some attributing it to diabetes and hypertension, conditions Maria had managed for over a decade.

But the signs were undeniable. In early 2022, Maria’s behavior took a troubling turn. She often refused to stay at home, insisting on visiting Farida and then refusing to leave. Her moods became unpredictable, irritability replacing the warmth Farida had always known. Alarmed, Farida moved in with her aunt to provide consistent care.

Determined to find answers, Farida delved into online research and stumbled upon a term that resonated deeply: dementia. The possibility struck a chord of fear and urgency. Farida’s mother - Maria’s sister - believed her condition was a result of poor diet or complications from diabetes, but Farida suspected something more.

In February 2022, a visit to Rift Valley Provincial Hospital led to a referral to a specialist in Nairobi. By the time Maria was finally seen at Aga Khan University Hospital, her symptoms had progressed significantly. Tests confirmed what Farida had feared; Maria was living with early-onset Alzheimer’s disease.

The diagnosis brought clarity but also a heavy burden. Maria’s world began to shrink in ways that frightened her. She relied heavily on Farida, who became her primary caregiver. The young woman took it upon herself to ensure her aunt’s medications for Alzheimer’s, diabetes and hypertension were taken on time, and she encouraged Maria to stay active and engaged despite the challenges.

Farida speaks candidly about the obstacles they face. “The long trips to Nairobi every six months to see the neurologist are exhausting. And managing her mood swings is tough,” she admits. Yet, she finds solace in the quality-of-care Maria receives. “If it wasn’t good, trust me, we wouldn’t keep going back.”

Maria’s children, though living far away, contribute financially, easing the strain on Farida. Despite the challenges, Maria finds moments of joy in her routine. Sundays with her sister remain her anchor, even if she occasionally forgets the details of their conversations.

In the quiet of her home, Maria sometimes reflects on her journey. “I know I am forgetting things,” she says softly, her voice tinged with both acceptance and sadness. But with Farida by her side, she continues to face each day with resilience, her spirit unyielding even as her memories fade.

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