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Protecting Older Adults: Designing Right-Based Dementia Policies that Address Cultural Stigma, Social Exclusion, Safeguarding, and Person-Centered Care in Africa

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Abstract

The number of dementia cases in Africa is increasing rapidly, with a notable increase of about 300% over just a few decades. This increase aligns with the growth in the number of older people, particularly in low- and middle-income countries, especially on the African continent. But that's not all. The increase in dementia cases in Africa has also been linked to modifiable lifestyle risks such as poor nutrition, sedentary lifestyle, and smoking, as well as the burden of infections in Africa.

Despite the increased incidence and prevalence of dementia in Africa over the past years, many Africans do not understand the scope of dementia as a neurological disease condition. This is evidence in the stigmatization and exclusion of people, particularly older adults, living with dementia in many African communities. These negative practices are usually rooted in cultural and traditional beliefs and in extreme cases, can manifest as neglect, abuse, and persistent infringement on the human rights of people living with dementia.

This study will examine the role of human rights-based policies on dementia and the components required in their design to address stigma and exclusion in African communities and to promote safeguarding mechanisms and person-centered care, thereby achieving the goal of protecting individuals living with dementia in Africa. With global human rights principles, medical ethics, and African sociocultural contexts as foundations, this article contends the key features of effective dementia policies, the core strategies in their implementation, in tandem with cultural responsiveness, and their overall implication in ensuring a good quality of life for older adults living with dementia.

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Introduction

Dementia is a neurological condition that is marked by mental impairment and a significant, progressive deterioration of cognition, functioning, and the ability to live independently (Prince *et al.*, 2015) [25]. Currently, an estimated 55 million people are living with dementia is 55 million, with approximately 10 million new cases occurring annually (The Lancet Public, 2021) [28]. This current global burden is projected to nearly triple in 2050, reaching an estimated 139 million people living with dementia (The Lancet Public, 2021) [28].

Largely driven by population ageing, the incidence and prevalence rates of dementia in Africa's low-and middle-income countries (LMICs) are also projected to continue increasing over the coming decades (Prince, Guerchet and Prina, 2013; Prince *et al.*, 2015) [25]. Dementia in African populations has traditionally received limited attention in terms of health policies and research. When dementia care is available, particularly in underserved societies, it is constrained by the abandonment of informal care systems such as family caregivers which have been the long-standing backbone of dementia care in Africa, and factors such as globalization and socio-economic transitions (Ogunniyi and Akinyemi, 2003) [31].

Studies argue that the prevalence of dementia cases in Africa is also largely due to the high level of illiteracy and high rates of poorly managed hypertension and stroke which are worsened by nutritional deficiencies and infectious diseases which are quite prevalent in Africa (Ogunniyi and Farombi, 2024; Wakawa *et al.*, 2025; Ojagbemi, Okekunle, and Babatunde, 2021) [32, 35, 36]. This lack of formal education coupled with the lack of health infrastructure and prioritization of unhealthy cultural beliefs passed down through generations in underserved communities in Africa, leads to stigmas, myths, and misconceptions about dementia

Of particular concern is also the dearth of national dementia policies in several African countries, particularly countries in Sub-Saharan Africa, despite the existence of the World Health Organization's Global Action Plan on the Public Health Response to Dementia (Alzheimer's Dementia International,). This vacuum in policies regarding dementia which is attributable to inefficiencies in governmental structures, national and state-based health organizations worsens the exposure and vulnerability of older adults living with dementia to social exclusion, abuse, and mistreatment, further perpetuating the misconceptions that thrive in some African communities that dementia symptoms are manifestations of witchcraft (Adebisi and Salawu, 2023) [4].

A dementia policy in Africa and for Africans should protect the human rights of people living with dementia, and emphasize principles such as inclusion and participation of people living with dementia, accountability non-discrimination, autonomy, legality, and empowerment, discarding social exclusion, and including human rights standards in the planning and implementation processes (Diaz-Gil *et al.*, 2023) [40]. This corresponds with set standards in international policies such as the Universal Declaration of Human Rights and the Convention for the Rights of Persons with Disabilities (Harden *et al.*, 2025) [3].

This study seeks to examine the processes comprehensively and required components in designing a human rights-based dementia policy that addresses social exclusion, cultural stigma, safeguarding, and person-centered care specifically in African communities.

Dementia in African Contexts

Epidemiology and Burden

Most studies on the incidence and prevalence rates of dementia in the Sub-Saharan region of Africa only focus on Nigeria due to poor research culture on dementia in other countries in Sub-Saharan Africa (Akinyemi *et al.*, 2023) [9]. The incidence rate of dementia in this region is 13/1000 person-years which corresponds with the incidence rate of dementia in other low-and middle-income countries. This implies that in Sub-Saharan Africa, there are roughly 368,000 known dementia cases every year (Guerchet *et al.*, 2017) [10]. Using Egypt as a case study over 20 years, Bhalla *et al.* (2018) estimate the incidence of dementia cases in North Africa to be about 27/1000. The notion of increasing incidence rates of dementia cases in Africa compared to other continents is buttressed by comparative studies carried out using two cohorts, Yorubas in Nigeria and African Americans which show a sharp decline in dementia cases among the African-American cohort as opposed to the steady rise among the Yoruba cohort (Gao *et al.*, 2016) [15].

Contrary to the incidence rates of dementia in Africa, the current and accurate estimates of the prevalence rate of dementia in Africa remain scarce largely due to limited coverage of most African regions, poor health-seeking behaviours, and lack of health infrastructure leading to underdiagnosis and underreporting, and poor surveillance systems in African communities (Ojagbemi and Bello, 2020) [37].

However, existing reports on the prevalence of dementia in Africa highlight that countries in West Africa have lower rates of around 3%, lower than the intermediate rates in North Africa which ranges from around 3 to 5%, and that of Central, East and Southern Africa which hits a peak above 6% (Yusuf *et al.*, 2011: Guerchet *et al.*, 2010; El Tallawy, 2012) [45, 16].

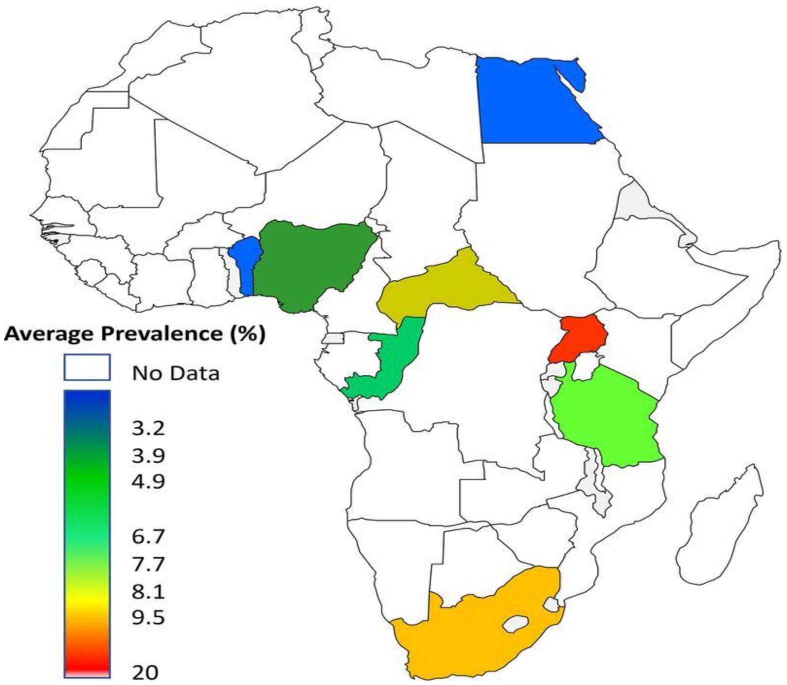

Fig 1: Prevalence of Dementia in Africa (Akinyemi *et al*., 2023) [9]

Despite the high expectations of higher mortality rates in Africa due to the increasing incidence and prevalence rates of dementia in Africa, studies show that the risk of people dying due to dementia in Africa is significantly lower than in other continents of the world (Ojagbemi, Bello, and Gureje, 2016) [38]. Using Nigeria as a case study being the country with the largest population in Africa, including older adults above 60 years of age, there are notably no national dementia policies despite its ever-growing dementia prevalence.

The negative effects of dementia are not limited to the individual living with dementia alone, as it can also extend, affecting the lives of their family members and even communities. This is quite common in African communities, where support care for older adults living with dementia is usually provided by unpaid family members, especially women, who in turn, have to cope with the physical and emotional stress associated with caregiving (Nankinga *et al.*, 2020).

These family-based caregivers have neither the professional training nor the resources to support their relatives living with dementia, and when coupled with the paucity of health infrastructures in many African communities, it worsens the prognosis and burden of dementia cases in these communities (Duodu *et al.*, 2024, Hailu *et al.*, 2025).

Cultural Definitions and Interpretations of Dementia in Africa

In many African societies, developed and developing alike, culture and tradition shape how people view dementia within their families and from a communal perspective (Jacobs *et al.*, 2022). Some communities view dementia as witchcraft, an ancestral curse, or divine punishment for moral misdeeds while others view it as a normal occurrence that comes with ageing (Mwendwa *et al.*, 2022).

These beliefs are harmful, often influencing health-seeking behaviours, and manifesting as stigmatization of individuals living with dementia and their families, fear, neglect and abandonment, social exclusion, all forms of abuse, harm, denial and rejection of dementia-related healthcare services, and even death of older adults living with dementia (Jacobs *et al.*, 2022).

Human Rights-Based Framework for Dementia Policies in Africa

The foundation of any effective dementia policy for Africa and in Africa is a human rights-based framework rooted in the proper comprehension and recognition that all individuals irrespective of cognition and functional ability, in this context, people living with dementia, should be treated with dignity and possess equal rights (Cohen-Mansfield, 2021). This rights-based framework incorporates human rights principles such as autonomy, participation, non-discrimination, legality, inclusion empowerment, and accountability (Diaz-Gil *et al.*, 2023) [40].

This allows for older adults living with dementia to be seen not just in the context of their disability or the symptomatology of the disease condition, but as people with human rights, who deserve to be treated with dignity and respect by their families, communities, and even health care workers. For these right-based approaches to dementia policy to thrive and achieve the desired outcomes in African communities, they must also integrate and align with African cultural values such as communal care, collective responsibility, and interdependence, which are core hallmarks of the Ubuntu philosophy useful in health policy planning and implementation for dementia (Mutanga, 2023) [33].

Dementia policies that incorporate cultural values as well as standards of human rights have a higher potential to be effective and deemed to be culturally appropriate in many African communities. In addition to this, it is germane that these dementia policies designed for African societies align with international and continental human rights policies and frameworks. The Universal Declaration of Human Rights (UDHR) and the Convention on the Rights of Persons with Disabilities (CRPD) are global rights-based frameworks that emphasize equality, non-discrimination based on disability, freedom to access healthcare, freedom to participate fully in society, and freedom from abuse and harm (De Sabbata, 2020; Diaz-Gil *et al.*, 2023) [10, 40].

For the African continent, the African Charter on Human and Peoples’ Rights and the Protocol on the Rights of Older Persons in Africa are frameworks that can be utilized in the design of smaller scale rights-based dementia policies for African communities, even though the impact and implementation of these frameworks are below expectations (Doron, Spanier, Lazar, 2016; Anya, Iroh and Richards, 2025) [5].

Addressing Cultural Stigma in African Communities

There are multiple ways the cultural stigmatization of older adults living with dementia in Africa manifests. Firstly, the cultural beliefs that dementia is witchcraft or madness from a curse or divine punishment due to moral misdeeds can translate into a loss of status, dignity, and identity in family and community (Mwendwa *et al.*, 2022).

Due to the stigma of people living with dementia, their families and family-based caregivers can experience shame, leading to a concealment of diagnosis and symptoms and avoidance of contact with the community, further exacerbating social exclusion, late presentation to health care facilities, and early diagnosis (Lopez *et al.*, 2020) [23]. Older adults with dementia in African communities, where dementia is strongly believed to be witchcraft are susceptible to physical, psychological, and/or emotional abuse, abandonment, physical harm, and/or violence (Brooke *et al.*, 2020) [6].

Addressing cultural stigma is of utmost importance in these African societies as it is necessary in the protection of the rights and health status of people living with dementia, especially adults aged 60 years and above. This can be achieved through rights-based dementia policies that prioritize culturally appropriate educational awareness campaigns and professional training that would help reframe dementia as a neurological disease condition, as opposed to beliefs of it being witchcraft or a normal ageing event (Stoner *et al.*, 2020) [11].

Also, just as important in addressing cultural stigma about dementia is community engagement which involves primarily engaging key community stakeholders such as community leaders, heads of community-based organizations, and religious leaders to achieve desired behavioural change and address negative cultural beliefs and norms about dementia (Shatnawi, Steiner-Lim, Karamacoska, 2023).

Combating Social Exclusion of People Living with Dementia in Africa

Due to shame of families and caregivers, and stigmatization, people living with dementia are usually excluded from social contact, community interaction, decision-making processes in the family, and at times, access to healthcare services (Low and Purwaningrum, 2020). Decline in cognition of people living with dementia is usually used to justify the infringements of rights to participation in social activities, legal capacity, and property rights (Filakovic *et al.*, 2011). For older women, social exclusion may be significantly worse due to general inequality typical of some African communities (Ekoh *et al.*, 2023).

Inclusion of older adults living with dementia in Africa should be prioritized in the design of rights-based dementia policies by instituting legal protection systems and ensuring older adults living with dementia can access community-based services (Mwendwa *et al.*, 2022). Financial risk protection frameworks such as pensions and monetary incentives for individuals living with dementia can also help to bear the overwhelming health expenditure associated with the management of dementia (Mostert *et al.*, 2025)

Safeguarding People Living with Dementia in African Societies

The susceptibility of people living with dementia to all forms of abuse e.g. physical, sexual, and emotional, is significantly higher. (Dong *et al.*, 2014) [44]. This is because initial cases of abuse of people living with dementia, especially older adults, are poorly reported due to fear of repercussions, and unavailability and poor accessibility of reporting channels (Adib *et al.*, 2019) [1]. In addition, the paucity of effective legal systems and health care institutions that can accommodate and monitor people living with dementia is another major contributing factor to the perpetuation of the abuse of people living with dementia.

To reduce this to the barest minimum in African communities, legal protection frameworks should be established and monitored, safeguarding should be emphasized, and active reporting and rapid, trained response teams should be integrated into the design of dementia policies (Lasrado *et al.*, 2025). Community health officers, community health extension workers, social workers and volunteers, caregivers, family members, and law enforcement personnel should also be trained to identify warning signs of abuse and how to properly respond to the abuse of older adults living with dementia in their communities. Informal community-based monitoring groups can serve as a complement to formal safeguarding systems, protecting the dignity and quality of life of older adults living with dementia in Africa (Nankinga *et al.*, 2020).

Promotion of Person-Centered Care for People Living with Dementia in Africa.

Principles and Standards of Person-Centered Care

Personal-centered care is the administration of essential, adequate, accessible, and affordable health care services in line with respect for a person's values, choices, preferences, and history. It is essential in the care of older adults living with dementia as it helps to preserve and protect their dignity, identity, autonomy, and quality of life, even with the deterioration and decline of their cognitive function (Kyung Hee Lee *et al.*, 2022).

Person-centered care in its entirety is a biopsychosocial model which contradicts other biomedical care models where the disease condition and symptoms of the disease are emphasized more than the individual (Wade *et al.*, 2017) [43]. It is built on the premise that individuals living with dementia are firstly persons with rights, feelings, duties, and relationships, rather than just receivers of care. It highlights dignity, respect, engagement in decision-making, and continuity of care.

Person-centered care in African societies must be structured in a way that corresponds with cultural beliefs, communal values, and communal comprehension of personhood. Many African cultures believe that a person's identity is entrenched in relationships whether it be familial or communal. As such, person-centered care in these cultural communities must take into consideration the environments that define the identities of older adults living with dementia (Kpanake *et al.*, 2018) [18].

These environments may be physical, family systems and structures, intergenerational belief systems, and/or communal networks. The incorporation of beliefs, preferences, spirituality, and life histories of older adults living with dementia can significantly improve the emotional and psychological domains of their well-being as well as reduce some behaviours, signs, and symptoms of dementia (Toivonen *et al.*, 2023).

Implementing Person-Centered Care in Africa

The implementation of person-centered care in communities in Africa requires adaptation to the existing cultural and social contexts in said communities. A great start in the implementation process is the promotion of community-based healthcare systems and models, the integration of dementia care services in the primary health centers as a basic minimum health care service, and support for families and caregivers (Linda Lee *et al.*, 2014).

The recommended integration of dementia care into primary healthcare systems is due to the scarcity of specialist dementia services in many African communities. This integration will serve as an essential entry point for improving the diagnosis, management, and referral of dementia cases. Education and training of community health officers and community health extension workers to accurately identify symptoms of dementia and offer culturally appropriate support can improve health outcomes of older adults living with dementia and reduce dementia-related stigma (Lee *et al.*, 2025).

Besides community health workers, family caregivers are usually the first contact and play a crucial role in dementia care in Africa, and often provide unpaid, informal care and support in the absence of resources to access formal care or the limited availability of formal long-term healthcare systems. Therefore, dementia policies that prioritize person-centered care must also focus on caregiver support, rather than on the individual living with dementia alone. Caregiver support includes education, communication techniques, behavioural management, and self-care.

Person-centered care can also involve psychological support groups, whether faith-based or community-led, crucial in providing emotional support, reducing social exclusion, and providing avenues for shared experiences and learning among caregivers who are going through the same challenges with care of people living with dementia (Nankinga *et al.*, 2020). Respite care offered in healthcare institutions isn't quite a popular phenomenon in Africa yet, however, it can help to reduce the strains of dementia care on caregivers and prevent neglect of people living with dementia due to caregivers' burnout.

Dementia Policy Implementation Challenges and Opportunities in Africa

The design and implementation of human rights-based policies for dementia in Africa is restricted by the lack of resources, both manpower and financial resources. This lack of financial resources is linked to poor health planning and prioritization by leaders and policymakers in African communities, leading to fragile health institutions and infrastructures, as well as a focus on less pressing health needs and diseases (Oyinlola, 2024).

In spite of these challenges, Africa is a fertile ground for health and health policy innovation in dementia care. With its ever growing working population, communal structures, and influx of technology and health startups, appropriate and adequate care of older adults living with dementia can spread through the African continent in no time. Collaboration with global health organizations and bilateral partnerships with other continents can further help to bolster the design and implementation of rights-based policies for dementia care.

Conclusion

The existence of human rights-based policies for the care of older adults living with dementia in Africa is necessary to improve the overall health status of African communities. These policies will not only achieve behavioural change from archaic, negative cultural practices to better, supportive ones but they will also institute a biopsychosocial approach to dementia care in Africa. It is imperative that policymakers make policies that promote human rights and their principles, and are functional not just in potential or writing, but can bring about real change in the health outcomes of people living with dementia when implemented.

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