Chapter 18
Limited access to healthcare resources

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Key points

- Low- and middle-income countries face a greater challenge making the diagnosis of dementia in a timely fashion due to human and technological restrictions.

- Well-structured virtual educational programmes may facilitate quick dissemination to the public about dementia risk factors and warning signs.

- Data gathering on the prevalence of dementia is a crucial step to inform stakeholders.

- Formulation of policies and national dementia strategies are needed to improve diagnostics and the living condition of people with dementia in all countries.

This is a chapter of the *World Alzheimer Report 2021, Journey to a Diagnosis of Dementia* which can be accessed in full at: https://www.alzint.org/resource/world-alzheimer-report-2021/

General background

From a global perspective, dementia has no boundaries, and it does not discriminate. It affects people of every gender, culture, ethnicity, religion, citizenship, sexual orientation and ability. It does not have any preference when it comes to geographical location, be it remote and uncrowded or urban and densely populated. It affects individuals from all levels of education, professional and work backgrounds as well as financial status.

When it comes to accessing healthcare resources for dementia, there are, however, many boundaries in place around the world: a lack of awareness about the signs and symptoms of the disease; resource-poor countries; transportation systems; language barriers; specialised healthcare experts and diagnostic tools; health insurance; access to free public healthcare and/or financial assistance, home care support services and residential long-term care. The recent COVID-19 pandemic has also highlighted the important role that modern day technology such as cellular phones, iPads and computers play in a restriction-bound environment. Unfortunately, millions of people around the world may not have the privilege to own such resources nor have access to them.

The ever-evolving progression of dementia demands that the person living with the illness, as well as their carers, have access to healthcare resources. By the time the disease has evolved to its full manifestation, the majority of

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people will require full-time care. There is currently no universal public healthcare system in the world that can provide all of the components needed to respond to this reality. As a result, care management and decision-making responsibilities fall squarely into the hands of the carers. Sadly, the numerous boundaries highlighted above can make a significant difference in a person's quality of life, the individual living with dementia as well as that of their carer. This is a direct outcome of whether they have access to essential healthcare resources.

Two of the essays below present the challenges that people from rural, low- and middle-income countries face when dealing with a dementia diagnosis while the third one is dedicated specifically to the diagnostic issues faced in Africa.

Expert essay

Dementia diagnosis in rural areas

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An estimated 55 million people worldwide have dementia, and this number is projected to increase with the growth of the ageing population. In contrast to the enormous number of people living with dementia, diagnostic coverage for dementia is estimated to be only 5–10% in low- and middle-income countries (1). The situation is even worse in rural areas (2). Globally, a large percentage of the population resides in rural areas. Delineating the sociocultural and biological barriers, and exploring the solutions for access to care, are essential steps to address the health disparity in the timely diagnosis of dementia in rural areas.

In rural communities, early dementia diagnosis may be impeded by numerous factors, including cultural obstacles, scarcity of professionals, inadequate access to memory clinics and support services, and geographic distancing.

In rural areas, families may attribute symptoms of dementia to the process of ageing. A multi-centre survey conducted in city-based memory clinics found that seeking diagnosis was delayed for an average of two years from the time families observed symptoms of dementia (3). The delay may be even longer than that, as symptoms may have been dismissed. Some families considered symptoms as something to be ashamed of (4). They would prefer to cover up the problems associated with dementia. Cultural values of resilience and independence can be barriers to seeking mental health services in these areas (5). The values of self-reliance and independence may contribute to health service underutilisation among rural carers of people living with dementia. Families tend to seek help when people living with dementia present prominent behavioural problems and cause difficulties in managing their personal lives. Another common belief that dementia cannot be cured may contribute to the nihilism among older adults and family carers in rural areas. The concerns of cognitive symptoms and the post diagnosis care may influence the actions of seeking a diagnosis (6).

Globally, the number of healthcare workers specialising in dementia is limited, especially within rural communities. Among the underrepresented population, 85% of dementia diagnosis was made by nondementia specialist physicians.

> **In rural communities, early dementia diagnosis may be impeded by numerous factors, including cultural obstacles, scarcity of professionals, inadequate access to memory clinics and support services, and geographic distancing.**

The use of dementia specialty care was low, particularly for Hispanics and Asians (7). Nurses may also play significant roles in the diagnostic periods for people with early-stage cognitive impairment (6). Most healthcare workers regarded memory loss as part of the normal ageing process in rural areas and reported that it does not need any specific treatment. Other healthcare workers could recognise signs and symptoms of dementia but focused on managing other medical problems at the expense of assessing cognitive decline and mental health (8).

In addition, healthcare workers in rural areas have not received specific training on assessing and diagnosing dementia. Lack of knowledge regarding appropriate diagnostic tools among these healthcare professionals may reinforce the challenges of dementia diagnosis. Healthcare workers with specialised training are more likely to use neuropsychological tests, blood tests, urine tests, and brain imaging to diagnose dementia. In contrast, healthcare workers without specific training assessed and diagnosed dementia based on history and physical examination alone (8), even though screening instruments, such as AD8, community screening instrument – dementia (CSI-D), Mini-cog, Rowland Universal Dementia Assessment Scale (RUDAS), have been validated to be applicable for people with different schooling levels (9–12). Compared with dementia specialists, nondementia specialists are more likely to use 'unspecified' dementia diagnoses (7). Sometimes, city-based clinicians who have limited experience with older immigrants may experience difficulties assessing

dementia due to language barriers and difficulties related to the involvement of the family or an interpreter (4). These factors may also impede the early detection and diagnosis of dementia and its aetiological subtype.

'Our village doctor is only responsible for minor physical problems. They never diagnose dementia in practice. If an older adult cannot manage his or her daily living, he or she has to be cared for by family members. We all know he or she has dementia. Very few of them are brought to city hospitals because there is no medicinal cure for the disease. Sometimes, when experts from big cities come and provide consultation in city hospitals, these patients might be brought to the clinic for further check-up and advice on medications.'

A retired 72-year-old woman with middle-school education, living in the village for ten years.

Memory clinics are considered the optimal setting for dementia diagnosis. Currently, most memory clinics are in urban areas (13). Access to memory clinics may be restricted by geographic distancing. Transportation challenges may become barriers to accessing dementia services. Also, when older adults are referred to memory clinics in cities, they may not be familiar with test situations of cognitive assessment. What's more, a lack of continuity and poor information exchange in the chain of care seem to reinforce the challenges of dementia diagnosis in rural areas (4).

Additionally, underserved populations are less likely to receive a timely diagnosis of mild cognitive impairment (14). One of the reasons is that the assay for Alzheimer's disease biomarkers is not well accepted. The situation is similar in rural areas where the infrastructure is lacking. MRI scanners are not available in rural health and often people referred for a scan must travel to city hospitals. People are also concerned with the idea of a lumbar puncture (15), especially those living in rural areas. Some even believe that cerebrospinal fluid is the essence of the mind, and extraction of it may make cognitive function worse. These misconceptions about biomarker examinations may further account for the underdiagnosis of dementia in rural areas, especially for mild cognitive impairment.

'Our hospital plans to set up a memory clinic. However, we find that there is a great shortage of professionals to provide service. We will send young doctors to a well-known memory centre for further training on assessment, diagnostic, and treatment algorithms. In our city, there are only two scanners installed in the general hospitals. Our hospital is a psychiatric hospital. Although we see a lot of elderly patients, MRI scanning is not a routine examination for diagnosis. Lumbar puncture is not routinely performed. We do not know that it could support dementia diagnosis. Another challenge is that family members of the patients may consider it harmful for the mind. We need more education on using biomarkers for dementia diagnosis'.

A psychiatric hospital director in a low-resource city, where older patients are usually referred.

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Expert essay

Estimating prevalence of dementia in low- and middle-income countries

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It is widely acknowledged that dementia is underdiagnosed in many low- and middle-income countries (1,2), and when diagnosis does take place, it is typically many years after its onset. This is due to many complex reasons, including lack of knowledge about the condition, fear of diagnosis, and nihilism. While these barriers are not country specific, within low- and middle-income countries, dementia diagnosis occurs in the context of having under-resourced healthcare systems, lack of trained healthcare professionals, and inequalities to access of care. The inability to receive a clinical diagnosis prevents people from receiving treatment and care, while denying them the recognition that there is a medical explanation to their impairment. Another consequence of underdiagnoses is our inability to rely on health service statistics of dementia to be an accurate reflection of those living with the condition in many low- and middle-income countries.

Researchers internationally have made great strides in developing our understanding of dementia prevalence in low- and middle-income countries, with previous iterations of the World Alzheimer Report contributing to the synthesis and interpretation of the literature (3–5). Such reviews highlight that there are still many low- and middle-income countries that have limited or no estimates of dementia prevalence, and therefore it is important to fill these gaps, even if incrementally. Importantly, we should recognise that countries (like the term 'low- and middle-income countries') are not homogeneous groups. Factors such as ethnicity, sex and education levels may all play a part in the risk of dementia, and hence recruiting participants from a single region may prevent us from making generalisations within and between countries. Brazil is a good example of this, where the majority of dementia prevalence estimates are derived from samples originating almost exclusively from the South East region (6).

Accurate estimates of dementia prevalence in individual country settings are essential, primarily because they can shine a light on the size of the problem, but also act as the foundation for other estimates of incidence, mortality, costs and care needs. In addition, there is an inherent value of being able to highlight local data to policymakers, maximising potential buy-in while minimising the potential disregard of evidence because it is not relevant. International cross-country initiatives such as the 10/66 Dementia Research Group project, the HCAP Network-Harmonized Cognitive Assessment Protocol and the STRiDE project – Strengthening responses to dementia in developing countries (STRiDE)[i] aims to generate meaningful data to inform a country's dementia policies.

STRiDE has developed a pragmatic approach to estimating the prevalence of dementia. One of the key strategies to achieve this is by adopting a diagnostic approach that is not reliant on clinicians. Instead, trained researchers would use a standardised set of cognitive and functional measures, and dementia prevalence estimates would be calculated using a validated algorithm. This should not be viewed as unreasonable, considering that dementia (and its subtypes) is regularly clinically diagnosed by symptoms alone. STRiDE has opted for the use of the brief 10/66 algorithm, which has identified potential cases of dementia in line with clinical diagnosis, across a range of settings with little evidence of cultural or education bias (7,8). However, STRiDE also goes far beyond just identifying how many people might have dementia, and instead seeks to understand how dementia impacts people's lives in low- and middle-income countries. This means that instead of being primarily focused on cognitive outcomes and factors that potentially have led to an increased risk of dementia, the project is interested in how people are living with dementia now. The merit of such an approach is that it adds value when engaging with policymakers about the need for support for people with dementia, demonstrating the profound impact of dementia within the context of a given country. This includes quality of life, general (or physical) health, elder abuse and experienced stigma, but also carer burden, financial impact and services accessed. STRiDE

i   For more information about STRiDE please visit www.stride-dementia.org

is due to collect prevalence data in Indonesia and South Africa (pandemic dependent), although the methodology and tools used within the project will be widely shared to enable other countries to replicate or adapt this model.

Despite fantastic initiatives already existing, it is important that countries continue to invest in the accurate monitoring and estimation of dementia prevalence to ensure resources are properly directed to meet the needs of those living with dementia and their carers.

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Expert essay

Early diagnosis of dementia: a complex problem requiring a multidimensional approach for India

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Early diagnosis of dementia is crucial for providing care to persons with dementia and their families. In diverse and low- and middle-income countries like India, the diagnostic journey is complex and often fraught with numerous challenges. From being a relatively unknown disease a few decades ago, dementia has now become a major source of disability. A rise in life expectancy has contributed to a high burden of dementia in India. This rise, however, has not been met with a proportionate increase in awareness or availability of healthcare services. The lack of awareness, stigmatising attitudes towards persons with dementia, and the absence of a coordinated system of care in India are major barriers to receiving a dementia diagnosis. This significantly impacts quality of life of persons with dementia and their families.

It is estimated that 5.29 million people are living with dementia in India currently (1). However, only 1 in 10 people with dementia receive any diagnosis, treatment, or care (2). In the majority of cases, families do not look for help, waiting until significant behavioural disturbances emerge in order to seek care. Even when support is sought, the type of healthcare service that families look for substantially influences the possibility of receiving an early diagnosis or a diagnosis at all. Health-seeking behaviours in India are highly heterogeneous, varying across geographic areas, socioeconomic groups and influenced significantly by the availability and accessibility of services within a given region. In rural India, families from lower-socioeconomic groups may communicate concerns to a community health worker or visit a traditional medical practitioner. In urban areas where there is a larger concentration of private hospitals, the well-educated are likely to visit their general physician, or directly consult a specialist for a diagnosis due to the absence of a structured referral system. This diversity in health seeking behaviours contributes to a large proportion of people with dementia falling through the gaps, continuing to remain undetected and undiagnosed. Therefore, there is a need to improve care coordination between modern and traditional health systems, strengthen referral networks within the existing public health infrastructure, create effective partnerships between private and public health sectors and develop a multi-level feedback loop that allows for tertiary level specialist centres to support service delivery for complex conditions like dementia.

Another significant concern that impacts dementia diagnosis in India is that only specialists like neurologists, psychiatrists or geriatricians are currently trained to diagnose and manage dementia. Dementia is not emphasised in the undergraduate medical degree curriculum. In addition, very few multidisciplinary memory clinics exist throughout the country (1). In this context, of considerable shortage of specialists and limited expertise, general physicians can play a crucial role in recognising dementia.

The process of making a dementia diagnosis in itself is multifaceted and requires a comprehensive understanding of cognitive, behavioural and functional deficits that involve the use of standardised tests. The majority of tests have been developed for use in predominantly English speaking and formally educated people. In countries like India that are characterised by linguistic diversity and educational heterogeneity, diagnosis requires availability of culturally appropriate tools. Screening tools to diagnose dementia have been adapted (3) and the Indian Council of Medical Research-Neuro Cognitive Tool Box (ICMR-NCTB) (4) has been developed in many Indian languages and for people who are illiterate/low literate. There are also efforts to implement physician training modules to diagnose and manage dementia. Training cadres of community/lay health workers to identify and/or screen for dementia can also be an effective way to address specialist shortages and reduce underdiagnosis, particularly in underserved areas. Such task-shifting strategies have been trialled for mental health conditions in India (5,6) and have demonstrated relative success. The accurate diagnosis of dementia also involves use of laboratory investigations and brain imaging to determine the subtype of dementia and detect reversible causes such as nutritional deficiencies, stroke and thyroid diseases

that are still common in India. Biomarker-based diagnosis of dementia is frequently advocated in developed countries but poses challenges for widespread implementation in India due to a lack of availability, costs and requirement of expertise for interpretation (7).

The costs involved in the diagnostic process are sizeable and present as another major obstacle to receiving a diagnosis, especially for low- and middle-income families. Substantial distances to facilities, long waiting times and overcrowding further deter an individual or their family members from seeking help. In addition, costs associated with diagnostics and indirect costs result in significant out-of-pocket payments.

Indeed, out-of-pocket payments is the major contributor of healthcare expenditure in India (8) and social protection mechanisms to cover costs encountered are therefore essential. The Ayushman Bharat scheme – a national government health insurance scheme to support the economically disadvantaged focuses significantly on hospitalisation. However, the government is working towards strengthening primary care services by transforming existing infrastructure into Health and Wellness centres. These centres will include provision of elder care services as well as cover costs for essential drugs and diagnostics. This is a step forward

towards universal health coverage, and the future of this scheme relies significantly on overcoming challenges that hamper effective implementation.

The COVID-19 pandemic has further complicated dementia diagnosis due to the implementation of widespread infection-prevention measures and a system overwhelmed with COVID-19 related care. While constant efforts were made by hospitals and NGOs like Alzheimer's and Related Disorders Society of India (ARDSI) to reach out to families both in-person and through telemedicine (9,10), there are substantial concerns on how to ensure people with dementia do not go undetected as the current pandemic continues, or in the event of future health emergencies.

Dementia diagnosis in India remains a complex problem, influenced by several factors ranging from low awareness, infrastructure gaps and costs associated with help-seeking. Concentrated efforts need to be taken to address these vulnerabilities in our health system, and placing people with dementia and their families at the centre of these efforts is crucial. Strategies that take into account the diverse and low-resource nature of such settings is a way forward to facilitate early and accurate diagnosis of dementia and ensuring they receive the care they need.

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Expert essay

The challenges of diagnosing dementia in Africa[i]

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Introduction

There is a huge gap between the current rate of diagnosis of dementia in Africa compared to the World Health Organization's Global action plan on dementia target of diagnosing at least 50% of those living with dementia in 50 countries at the minimum by 2025 (1). In fact, it is estimated that up to 75% of those living with dementia globally have not been diagnosed and no doubt most of these people live in low- and middle-income countries (2) including African countries. The rate of diagnosis of dementia in low- and middle-income countries is estimated to be less than 10%. This is especially worrisome as the elderly population is increasing in Africa. The reasons for this alarming underdiagnosis are many, and they include, little knowledge and understanding of symptoms and signs of dementia, odd beliefs and stigmatisation of those living with dementia, poor health-seeking behaviour, lack of diagnostic tools and services, language barriers, reluctance on the part of health workers to diagnose a disease with enormous burden that has no cure, poor access to neurology and geriatric specialists, poor awareness and insufficient support services post diagnosis (3–6).

Little knowledge of the symptoms of dementia

In a questionnaire survey from eastern Africa assessing the knowledge of undergraduate students (going through various health programmes) on dementia, it was reported that up to 53.4% believed that memory loss was only an ageing phenomenon (3). Furthermore, the study showed that 32% of the students had poor knowledge of dementia, 41% had moderate knowledge, leaving only 26.8% with good knowledge (3). Even among healthcare workers, some believe that 'memory loss' is part of the normal ageing process that

requires no specific treatment (6). The inadequate awareness of dementia in the general population is a barrier to a timely visit to the hospital for prompt and proper diagnosis of cognitive impairment and dementia.

Odd beliefs and stigmatisation of people with symptoms of dementia

A systematic review of contemporary views on dementia in sub-Saharan Africa revealed that some people believe that dementia is related to witchcraft; some believe it is a curse from God or ancestors, while others belief it is a curse from the devil (7). Another systematic review from sub-Saharan Africa demonstrated that these weird beliefs strongly influence people's perception of dementia and other mental health disorders (8). No doubt, these 'supernatural' concepts or beliefs fuel stigmatisation and discrimination against the people living with dementia. Although higher levels of education appear to reduce discrimination against people with dementia, other individuals, despite their educational attainment in healthcare, may still hold tenaciously to odd beliefs regarding dementias (8).

Reluctance of health workers to diagnose dementia

Healthcare workers are important in the diagnostic process of dementia but unfortunately, there is a high level of apathy and reluctance among many, either due to the level of their training, perception about the disease, ignorance of the modalities available to make a diagnosis, or the fact that there is no cure for dementia. In a study assessing the diagnostic practices with regards to dementia among healthcare workers, it was observed that only healthcare workers with specialised training could confidently make a clinical diagnosis of dementia using history-taking, neuropsychiatric

exam, and relevant investigations. Other healthcare workers may be able to recognise signs and symptoms of dementia, but focus instead on managing other medical problems and disregard the assessment of cognitive decline and mental health since they are not confident in making the diagnosis of dementia (6).

Poor health-seeking behaviour

The health-seeking behaviour of a population is determined by various factors which vary somewhat from one region to another in Africa. Very important among these factors are level of education, religious beliefs, socioeconomic status, gender, age, family size, and availability of healthcare services. Another important factor that perpetuates poor health-seeking behaviour is the inability to pay for healthcare services, since most people pay out-of-pocket due to low coverage of health insurance schemes (9). Generally, those with low level education, low economic status, large family sizes are less likely to seek medical care when ill. This low drive to seek medical care is worse when it has to do with a disease that is perceived to be age-related or alluded to spiritual attack, such as dementia.

Lack of culturally appropriate diagnostic tools and facilities, and trained personnel

In Africa, cognitive tools are often influenced by educational status, language differences and cultural beliefs. There is also a lack of diagnostic facilities, including neuroimaging which is sometimes needed for accurate phenotyping. Facilities dedicated to the care of people living with dementia are also inadequate when compared to the Western world where there are memory clinics and specialised diagnostic centres with diagnostic services and post diagnosis care (1).

This is so crucial among those who reside in rural settings who have to travel long distances to access healthcare. Few healthcare workers have acquired knowledge and skills to function as specialists in neurology, geriatrics, psychiatry and other important aspects of healthcare to cater to the needs of people living with dementia.

Poor awareness and insufficient support services post diagnosis

A good number of healthcare workers across Africa are not aware of any support services that people with dementia can be enrolled in to continue their care. This is due to the level of training acquired and information available to most healthcare workers who are not specialists, as the level of advocacy for those living with dementia in Africa is quite low compared to high-income countries. The support services available to people living with dementia are also quite insufficient. This might be the reason why most people living with dementia who initially accessed care at a hospital in Eastern Africa ended up in the religious and traditional homes after two encounters there, due to lack of skill to manage their condition and low improvement in quality of life (10).

Summary

There is a need for training and retraining of healthcare workers, development of simple diagnostic tools and tests that are resistant to the influence of language and education, advocacy in the society to support people living with dementia, and formulation of policies and national dementia strategies that will improve diagnostics and the living condition of those living with dementia across African countries.

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Conclusions

There are some great equalisers in life that make us realise that no matter who or where we are, we are more alike than we are different. Dementia is one of those equalisers. An estimated 55 million people worldwide have dementia, and that number continues to grow every day. It is a condition that does not care about gender, culture, ethnicity, religion, citizenship or sexual orientation. It pays no heed to education, achievements, contributions or how much money a person has. In essence, it is impervious to anything that makes you… you.

However, when delving a little deeper, you come to understand that things are not created equal after all. For people in low- and middle-income countries, and in rural areas, dementia falls prey to an often understaffed or underfunded healthcare system that does not provide enough access, nor adequate dementia training or dementia-centric care management and support. When coupled with people's lack of awareness of the signs; language barriers that impede critical testing; cultural biases that make one want to hide symptoms; reluctance to travel long distances for medical appointments; and a lack of facilitating modern technology, a person may be far advanced in their condition and consequently have a significantly diminished quality of life.

In Africa, in addition to the constraints listed above, cultural beliefs about dementia, stigmatisation, a reluctance by healthcare workers to diagnose dementia and a lack of tools to do so adequately remain key challenges. STRiDE – strengthening responses to dementia in developing countries – has developed a new pragmatic approach that does not rely on clinicians. Rather, trained researchers will use a standardised set of cognitive and functional measures to estimate dementia prevalence. It is a step in the right direction as countries need to invest in the development of resources to support dementia diagnosis and care.