

Global dialogue on LMICs: Reflections

The dementia landscape project

Essays from international leaders in dementia



Organized in partnership with



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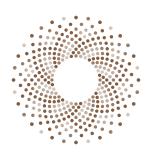


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1. Introductions





Giving a platform to the challenges faced by people living with dementia and their caregivers in LMICs



Paola Barbarino

CEO, Alzheimer's Disease International (ADI) and member, World Dementia Council

The low- and middle-income countries (LMICs) global dialogue of the World Dementia Council held on 11 March 2021, aimed to give a platform to the challenges faced by people living with dementia and their caregivers in these countries. People in LMICs have complex barriers to overcome when faced with implementing the WHO's Global Action Plan on the Public Health Response to dementia and these need to be clearly defined, so that we can be best placed to help address them. The dialogue focused on how the international community can help to accelerate progress towards overcoming these obstacles. Alzheimer's Disease International is a federation of over 105 Alzheimer's and dementia associations from around the world, with just over 26% of these associations originating from LMiCs. As such, this topic is at the forefront of ADIs and our members minds and thus was reflected by their representation and participation in the dialogue, with Meera Pattabiraman (Chair of the Alzheimer's and Related Disorders Society of India) as co-chair, speakers such as Dr Paul Kiwanuka-Mukiibi (Executive Director of the Uganda Alzheimer Association) and interventions from Petra Du Toit (Executive Director, Alzheimer's South Africa) and Professor Huali Wang (Alzheimer's Disease China).

During the dialogue the subject of low rates of diagnosis was raised on a number of occasions and with good reason; there are over 55 million people living with dementia around the world, a number projected to rise to 139 million by 2050. More people are now living with dementia in LMiCs than in high income countries (HIC). Despite this, diagnosis is still a major challenge globally, with those who seek a diagnosis often experiencing long wait times, if they are able to receive a diagnosis at all. Societal stigma, self-stigma and clinician related stigma also exacerbate what is already a difficult journey.

Most recently, during World Alzheimer's Month we released our 2021 World Alzheimer Report 'Journey through the diagnosis of dementia' which explores the diagnosis journey through the lens of those living with dementia, carers, clinicians, researchers, academics and Alzheimer and dementia associations. The report focused on what can and must be improved to make the lives of those living with dementia and their cares better. To

achieve this, the report features over 50 expert essays; survey data from 1,111 clinicians from 108 countries, 205 people living with dementia and 2,122 carers from 83 countries and 101 Alzheimers and dementia associations from across the world. I will focus on this report in the context of what was discussed at the WDC dialogue, as in many ways it delves deeper into some of the issues that were raised during the meeting.



The report confirmed what many of us already expected, that the diagnosis process for those living with dementia can and must be improved. Despite the majority of those living with dementia originating from LMiCs, up to 90% of those living with dementia from these countries do not receive a diagnosis. Expert essays from the report also highlighted that these low diagnosis rates are frequently linked with the absence of, or a limited a healthcare system, inadequately designed to address the needs of those living with dementia and their family/carers. One example is through the requirement to use CT or MRI scanners for a confirmatory diagnosis of dementia. In our survey of clinicians, those representing LMiCs frequently cited accessibility issues and the cost, as barriers to utilising these techniques, a trend also identified for other techniques such as for CSF testing, genetic testing and blood biomarker tests. Excluding all other financial and accessibility issues, this is likely to have knock on effects to the availability of new treatments, if and when they come to market as the requirement by the Federal Drug Administration (FDA) of a confirmatory diagnosis may be mirrored elsewhere around the world.

Further essays demonstrated that stigma and lack of awareness remain a major barrier to diagnosis globally, including from healthcare practitioners themselves, with 33% of clinicians who were surveyed believing nothing can be done so why bother. Insights from rural China also illustrated that cultural values of hardiness and independence can delay diagnosis by up to two years, and essays from other areas such as Africa, talked about how in some instances dementia is believed to be a curse or witchcraft or other supernatural phenomena. In the Arabic speaking world, there are efforts to change the use of the word kharaf, which means 'the one who has lost his mind'.

A greater understanding of how dementia impacts LMiCs and how people living with dementia and their family and carers can be supported is required if we are to have a lasting impact. We, as a body of advocates, carers and Alzheimers and dementia associations must work with governments in LMiCs and other multilateral bodies to ensure provisions are in place to improve all aspects of dementia care and strategy. Most importantly, we must listen to representatives from LMiCs to ensure that our work is culturally relevant, beneficial and meaningful to those who are living with dementia and their carers in LMiCs.



A perspective of dementia health care delivery in the LMIC context





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Background

Low and middle income countries (LMICs) face the challenge of disproportionate high burden of health issues, life-style disorders, and limited health care resources at their disposal to handle the high demand due to their large populations. In the context of dementia, the care burden both at personal, community and institutional level are unassumingly large especially in LMICs. The problem gets compounded because of the low per capita income and lack of facilities. Poor resources, lack of skills among medical fraternity and low awareness about the disease results in delayed diagnosis. By the time, a proper diagnosis could be made, the affected person cross the early intervention stage, disallowing the scope to stall disease progression and lose the opportunity of quality living post dementia diagnosis. The health seeking behaviour by the general public, specifically elders, in LMICs, differs according to socio-economic status across the population and their capacity to afford health care and facilities accessible in their vicinity. It is, therefore, essential to understand the patient perspective and their health care seeking patterns, care pathways followed and models of health delivery systems available.

In India, we have three-tiered health delivery system to respond to the health care needs of people living in remote areas to people living in urban areas. There are primary, secondary, and tertiary health care systems. However, due to poor awareness, dementia is yet to be part of primary and second health care systems. Tertiary levels do have some facilities, but access and efficiency of services do not cater to specialised dementia care. However, no residential care facilities are run by union government except a very few by local governments. India at present has a 5.91 million people affected with Dementia and only 10% of the people able to get right diagnosis. In India, community care and home-based care are largely in vogue, institutional care is a distant option, when situation gets unmanageable. Support services and mechanisms are necessary for care givers to be able to address their needs and enable them to handle the health needs of persons living with Dementia. Similarly, strategies for prevention/risk reduction should be in vogue for people to follow. This should start in early life, which can help them to lead healthy life styles with reduced risks of developing dementia in later life.

Need for Responsive Health care System

An effective and responsive health care system in LMICs should essentially understand the public health care seeking patterns. Appropriate care models to address necessary care needs of persons with dementia by enhancing facilities closer to their living area and ensuring they are accessible and affordable. To design such a responsive health care system, a situational analysis of present health care delivery (which is invariably health care mapping process) must be done. Then a plan to augment facilities with assessment of the capacity to deliver with the resource availability within a time frame. The common points would be to explore the aspects of awareness, access to facility, trained health care professionals to ensure diagnosis, treatment, and adherence to protocol, with hand holding to ensure continued health care pathway both at community and institutional level. Engaging the patient early with correct care path is essential aspect of a responsive health care delivery system.



Health care system compliant to Global action Plan on Dementia – Call for Action of WHO

For LMICs there is no need for re-inventing the wheel. All we need to understand the gaps from situational analysis and juxtapose the same in terms of the seven action areas of the WHO's Global Action Pan. LMICs need a clear idea about their prevalence. If prevalence is not possible, the whole geriatric population living above the age of 60 should be extrapolated where 4-5% of them to have some form of dementia. This would help them to figure out the magnitude in which the health care system has to cater. The approach is given very well in the GAP-Dementia by WHO, based on which, India worked out the following action, targets and sought resource allocation accordingly:

- a. Dementia as a public health priority: 30% of States to have their own action plans by 2025.
- b. Dementia awareness and friendliness: 50% dementia friendliness and stakeholder specific sensitization guides/manuals and 80% increase in awareness among states having ARDSI chapters
- c. Dementia Risk Reduction: overarching component of NCD indicators already in place to see a significant change
- Dementia diagnosis, treatment, care and support: 40% diagnosis in 30% states, setting up of full-time care centers and capacity building of health professionals to for early diagnosis and treatment
- e. Support for dementia carers: 40% of states, by civil society organizations and other similar institutions
- f. Dementia research and innovation: the national and regional research are augmented, by 30% of current levels, for person centric care
- g. Information systems for dementia: standardized in 30% of states through setting up of a national registry

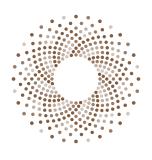
The above methodology can serve as a guide to all LMICs. Based on the prevalence and local prevailing conditions, these seven action areas can be addressed with country specific plans based on needs and requirements.

Conclusion

LMICs should have a proactive health care system which is inclusive of holistic dementia care, catering to culturally diverse population and different stages of the disease. The bottom line is creating awareness about the disease. Diagnosis of symptoms through accurate screening in their vicinity by trained professionals, treatment at secondary and tertiary levels following standard guidelines and patients adhering to treatment prognosis as suggested by physicians, therapists and social workers. A large care workforce must be created for handling the dementia health care beyond institutional care homes, which are scarce and not affordable. People should resort to healthy lifestyles to ensure risk reduction as this augurs well for LMICs.



2. International perspectives





Cognitive assessment: The challenges in lowand middle-income countries



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Background

Approximately 47 million people with dementia worldwide, most of whom (approximately two-thirds) live in low- and middle-income countries (LMICs).1

In the absence of a cure, reducing the future costs of dementia care may be best achieved by emphasising early detection of cases and avoiding risk factors. Early intervention to retain functional independence will be accelerated if "screening" is conducted in populations at high risk of developing dementia.

Dementia is a clinical definition based on an accurate history and examination of cognitive function. In clinical settings, a wide range of cognitive assessment instruments are currently available in LMICs. However, there are many challenges to its implementation, especially in the setting of LMICs.

The journey to cognitive assessment

The process towards a diagnosis of dementia starts with awareness about dementia. Data shows that 90% of caregivers still state that memory impairment is part of normal aging.² Self-stigma and societal stigma will be a barrier to the diagnosis pathway.^{1,3} Cognitive complaints often occur as an addition to other major symptoms that lead to hospitalization of the elderly (unless there is a behavioral disorder). As a result, detecting cognitive impairment is not a primary concern for the family or the doctor.

The limited-time for doctors to interact with patients and the need for time to conduct assessments and explain the examination results will be a barrier for conducting cognitive assessments when doctors assume that nothing can be done for further action. The belief that no treatment can be done will affect the need for an assessment of a disease. Data from the 2021 ADI report shows healthcare practitioner stigma, with 33% of clinicians surveyed believing nothing can be done. People with dementia and their caregivers frequently express frustration with the length of time it takes to receive a diagnosis, and a lack of information about specific varieties of dementia, progression, and available support at the time of diagnosis.



The most common method of cognitive assessment is to employ well-established tests and are familiar to physicians. However, these cognitive assessment tools are mostly adapted from tests used in high-income countries (HICs). These assessments were developed with English as the primary language and a minimum of a 7th-grade educational prerequisite, hence they frequently lack validation in LMICs, where the populations are often multicultured, multilingual, and have low levels of education.

Cognitive assessment and dementia registration in LMICs

There is a need for a cognitive assessment policy to become a standard for basic health screening services, especially for at-risk groups. A standardized tool should be used at all healthcare levels as differences will make it difficult to carry out further analysis at the national level.

Unlike cerebrovascular disorders such as stroke, for which the general public is more aware and is more willing to admit patients to hospitals, thereby facilitating national-level data gathering, most dementia patients are not hospitalized. Dementia management can occur in community private clinics which are often not recorded in the national data. In contrast to the diagnosis of diabetes based on standardized blood test results, the tools used to diagnose cognitive disorders and dementia vary, and their validity is strongly influenced by education level and a variety of other variables. Even though doctors are competent and cognitive assessment tools are valid, various conditions, such as depression (which mostly affects elderly patients in LMICs), influence the outcomes of cognitive assessments.

Strengthening in the future

There is a need to raise community awareness about dementia, including the importance of early detection. Healthcare providers require more knowledge and competence in dealing with cognitive disorders and dementia. Based on experiences gained from the COVID-19 pandemic, it is time to prepare for remote cognitive assessments in clinical practice, especially for older people and people living with dementia who cannot attend in-person consultations. This may help to alleviate geographical healthcare inequalities in LMIC rural communities. Research is urgently needed to develop cognitive assessment tools as a part of a diagnostic approach that is appropriate and feasible in LMIC settings. National policies must support this, ensuring that cognitive assessment is included in basic health services for all citizens, particularly those at high risk of dementia.

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Latin American Dementia Network: An urgent regional need





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Latin America constitutes a large region united by a common culture and a shared history while at the same time evidencing significant differences in terms of demographic and geographical singularities. Uneven distribution of income and unequal access to resources may help explain the uniqueness of each community. Nevertheless, the different groups under study consist of relatively homogeneous populations regarding determinants of health and socioeconomic situation to justify a unified approach and guarantee valid scientific research.

Recent publications have called our attention to the increased burden of risk factors prevalent amongst the entire Latin American population contrasting with stable or declining rates in North America and Europe. Within Latin America, the reported population-attributable fractions (PAFs) account for different factors ranging from inadequate access to food, deficient eating habits, and unequal educational systems to health-related pathologies such as hypertension, obesity, and diabetes.

To date, dementia research in Latin American countries is scarce and insufficient. Existing studies do not encompass the whole region and present discrepancies in their results. We consider that the scarceness of data regarding dementia studies in Latin America is the consequence of several complex variables. One obvious factor is the uneven and low-level funding for research and public health interventions. This is in direct relationship to the region's political and social instability. Long-term healthcare policies and general support to scientific research are not viewed as priorities by governments that struggle to cover basic needs to tackle poverty and generate employment.

In this context, LatAm – FINGERS was created as a Latin American initiative to develop a joint regional intervention protocol for the prevention of cognitive deterioration and to share, compare, and harmonize data across the region. The aforementioned inadequacy of data sharing, together with deficient public health policies, highlight LatAm FINGERS substantial potential as a crucial agent of change.

This multicultural and inclusive initiative gathers at the moment twelve Latin American countries and is open to new incorporations. Participating centers differ in the characteristics of their population in terms of language, race and ethnicity, educational level and socioeconomic condition. The project attempts to implement a multidomain lifestyle intervention and develop tools that will contribute to bringing Latin America under a unified database.

Significant assets of the project are the information platforms, the tools for data collection, and the policies regarding data sharing. These can be aligned in four fundamental data collection pillars: demographic information, clinical and cognitive information, an MRI database, and the creation of a biobank. All the data to be reported would be part of a novel data-sharing experience. The platforms are designed to have the same variables with Spanish, English, and Portuguese labels, providing a harmonized structure that will facilitate the unrestricted use of information.



The main challenge is to build and sustain a collaborative project where each country can contribute towards a common harmonization initiative. For this purpose, the process of variable and intervention harmonization has been a critical experience that led us to discover many gaps in the research methods for the diagnosis of dementia across the region. A good example is the absence, in most countries, of age and education stratified norms in essential diagnostic screening tools such as the MMSE. Being Latin America a region where educational level, a major risk factor for dementia, can be very low, the absence of norms is quite alarming. Analogous issues arose with various aspects of dementia diagnosis in the biobank and the MRI area.

The LatAm Fingers initiative is to build a clinical, cognitive MRI and Biobank structure for data harmonization and data sharing. In order to organize collaboration, demographic, clinical and cognitive information is stored in a common database and MRI data. Building the database structure has been a fruitful learning process as every country has had to contribute and comply with numerous requirements. The harmonization of MRI and Biobank is the result of meticulous work that included surveying the available equipment, technologies, and human resources in the different centers.

This biobank is designed so that each center collects blood and DNA samples and performs basic laboratory work. However, as technology for APOE genotyping and biomarker quantification is not available in every center, these specific procedures are performed at selected sites (Argentina, Brazil, Colombia, and México) where samples are delivered according to geographical convenience.

Shared collaborative research results on subjects at-risk of dementia, together with the impact of non-pharmacological interventions, will encourage consistent public health policies in the region and bring a meaningful and necessary change. The relevance of this data-sharing initiative exceeds the collection of data, and it constitutes the first attempt to centralize and coordinate data on high chance.



Understanding dementia and its prevention in the African context





Dr Christine Musvimi Community Researcher (STRiDE), Africa Mental Health Research and Training Foundation

with Levi Muyela, Elizabeth Mutunga, and Dr David Ndetei

More than 60% of people living with dementia reside in Low and Middle Income Countries (LMICs) and the number (50 Million globally) is expected to drastically triple over the next three decades. Dementia is known to affect the brain of an individual and is marked by decline in memory, cognitive and behavioral functionality resulting in diminished interest or energy to effectively and comprehensively perform activities of daily living among other tasks.^{2,3} The effects of the condition are also seen on the whole family of the individual particularly the primary carers.4

In LMICs, capacity has not been built to sustain the pressure that may come with the increase of dementia cases. ⁵ In most African settings, the human resource in the healthcare sector is ill-equipped with limited knowledge on dementia attribution, diagnosis and care among health care workers, carers and members of the general public, resulting in neglect, abuse and uncoordinated pathways to care.⁶⁻⁸ In particular, some interpretations of dementia-like symptoms have been linked to normal ageing, witchcraft, being cursed and other skewed perspectives affecting access to care.⁶ One of the local communities in Kenya has interpreted the term 'dementia' to mean 'thing'ai' relatable to thinking high. Community members imply that people living with dementia were once respectable people perhaps in positions of authority "thinking high" of themselves. 6 As the saying goes, what goes up must come down, they must have been reduced to behaving like children, totally dependent on others for day-today functioning. These interpretations have led to individuals experiencing stigma and discrimination contributing to delayed health-seeking behavior in African settings. Lack of policies to address the needs of people living with dementia such as improving access to care or easing their diagnostic pathway has also contributed to the overall burden of disease.9

It is therefore important to reduce stigma from the person living with dementia (selfstigma), carer (associative stigma) and health care system levels. This will in turn help avoid overutilization of resources on otherwise preventable circumstances. The creation of awareness is also paramount as a preventive measure such as; ensuring appropriate cognitive and physical activity, a well-balanced diet as well as addressing risk factors that are important when it comes to dementia prevention¹⁰ since 50% of Alzheimer's disease cases are attributable to modifiable risk factors.¹¹

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Although reducing stigma could improve care quality and treatment seeking and lead to better quality of life for people with dementia and their carers, we know little about how this works in relation to dementia in Africa. In an attempt to address this gap, the Strengthening Responses to dementia in Developing Countries (STRiDE) team aims to contribute in improving dementia care, treatment and support systems in seven countries (Kenya, South Africa, India, Indonesia, Brazil, Jamaica and Mexico).



Specifically, the STRiDE Kenya team led by Africa Mental Health Research and Training Foundation and Alzheimer's and Dementia Organization Kenya in collaboration with health care workers, carers of people living with dementia and members of the general public have developed a dementia anti-stigma intervention to create awareness, reduce stigma towards people with dementia and increase help-seeking and access to care. The intervention uses a train-the-trainer approach with community health workers (CHWs) trained on how to deliver the intervention to members of the general public in four 1-2 hour weekly or biweekly group sessions. Each session includes learning objectives and key messages that need to be covered to ensure CHWS are within these parameters even when participants deviate through story telling. A key component of the intervention is a video-based social contact element of individual experiences of living with and caring for persons living with dementia and how human rights of persons living with dementia are violated and can be addressed. The manual is simple, detailed and can be used by other lay workers in low resource settings. For adaptation in other dissimilar settings or where CHWs have higher literacy levels, researchers/intervention implementers can opt to cut down specific details.

Figure 1: Dementia anti-stigma intervention sessions

Session 1

 Understanding dementia

Session 2

 Addressing common myths and misconceptions

Session 3

 Indirect contact (video-based) to amplify voices of persons with dementia and their carers

Session 4

 Social inclusion for people with dementia and their carers using a case vignette



The burden of vascular cognitive impairment in low- and middle-income countries





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Population ageing is happening at a much faster pace in low- and middle-income countries (LMIC) than in high-income countries (HIC). As an example, France had almost 150 years to adapt to changes related to an increase from 10% to 20% in the number of individuals who were 60 years or older, while Brazil, China, and India will face the same challenge in slightly more than 20 years. This rapid demographic change has led to health system constrictions in LMIC due to the large burden of chronic degenerative diseases. Alzheimer's disease (AD) and other dementias are already the most important cause of healthy life lost due to disability among chronic degenerative diseases in HIC.1 Although dementia is the 10th health condition associated with disability in LMIC, the accelerated ageing process will rapidly increase the dementia burden in these countries. Dementia prevalence in Latin America is estimated to be 8%,² the highest in the world. Moreover, dementia may occur 10 years earlier in LMIC than in HIC, probably because of low education and the high prevalence of untreated vascular risk factors in poor settings.³

AD is still the most common cause of dementia worldwide. However, vascular cognitive impairment (VCI) is the second cause of dementia and may be of particular importance in LMIC, where VCI frequency seems to be higher than in HIC. 4 In a large Brazilian autopsy study, VCI accounted for 35% of neuropathologic lesions, suggesting a high burden of cerebrovascular disease.⁵ Moreover, cerebrovascular disease is very common in LMIC, where 63% and 80% of ischemic and hemorrhagic strokes currently occur.6 VCI can be caused by a variety of cerebrovascular lesions, including macro and microinfarcts, cortical and subcortical lesions, ischemic and hemorrhagic lesions. Because of this heterogeneity, the clinical and neuropathologic criteria for VCI are not universally accepted, and they show better specificity than sensibility. Moreover, pure VCI is uncommon. Frequently, VCI coexists with other neurodegenerative diseases as mixed dementia. Despite the challenges to VCI diagnosis, the high prevalence in LMIC and the fact that VCI can be preventable makes the detection and management of vascular risk factors a priority in these settings to decrease the dementia burden. Indeed, 40%, 41%, and 56% of dementia cases in India, China, and Latin America, respectively, were attributable to nine modifiable risk factors: low education, hearing loss, hypertension, obesity, smoking, depression, physical inactivity, low social contact, and diabetes.8 The population attributable fractions (PAF) of these risk factors suggest that the potential for dementia prevention in LMIC is larger than in HIC, where the calculated PAF for the same risk factors was 35%.9 The larger frequency of low early-life education, smoking,

hypertension, obesity, and diabetes in LMIC explained these differences in PAF between poor and rich countries.

The effect of low education on dementia risk may happen through different mechanisms. Education is a proxy of cognitive reserve, which is related to greater resilience to cerebrovascular and neurodegenerative diseases. In addition, more years of education are associated with better socioeconomic status later in life secondary to access to more cognitively complex occupations with higher salaries later in life. Finally, better education can facilitate access to health care and better management skills for the control of chronic diseases, leading to better overall health and greater life expectancy. The literacy rate in Latin America among individuals 15 years or older is currently 94%, and 81% among older adults aged 65 years or older. Despite great progress in education coverage in the last 30 years, the average education is still lower than in HIC. For example, 23% of children do not complete upper secondary school in Latin America.¹⁰ In addition, education access is unequally distributed among different socioeconomic levels with near half of low-income children and those living in rural areas failing to complete nine years of education.¹⁰ Therefore, improving education quality and assuring children can stay longer in schools are important to prevent dementia, particularly in LMIC, where 11% of dementia cases are attributable to low education.8

In addition, vascular risk factors, as hypertension, obesity, smoking, physical inactivity, and diabetes, showed higher PAFs for dementia in LMIC due to higher prevalence of these factors than in HIC.8 Overweight and obesity prevalence has increased in the last years probably due to unhealthy diets and physical inactivity. For example, obesity prevalence in adults is 20% in Brazil with a 72% increase in the last 13 years. 11 The same trend of increase in prevalence has been observed for hypertension and diabetes. Unfortunately, most cases of hypertension and diabetes are not diagnosed, and among those that were detected, few are adequately treated.¹² Early detection of vascular risk factors and adequate treatment will reduce cerebrovascular lesions and consequent VCI. Investing in controlling upstream lifestyle variables will have an even greater impact on vascular risk factors. Physical activity and healthy diets are important to reducing obesity, hypertension, and diabetes incidence.

It is important to promote population awareness about the key elements to prevent VCI through public policies that focus on improving population education and managing upstream lifestyle factors, as physical activity and a healthy diet that will reduce the incidence of obesity, diabetes, and hypertension through the life course. Moreover, early detection and management of vascular risk factors will greatly reduce the burden of VCI, preventing many dementia cases and reducing disability later in life.



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The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

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