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## **Dementia in sub-Saharan Africa: Challenges and opportunities.**

Maëlen Guechet, Rosie Mayston, Peter Lloyd-Sherlock, Martin Prince, Rufus Akinyemi, Stella-Maria Paddick, Anders Wimo, Mary Amoakoh-Coleman, Richard Uwakwe, Peter Ezeah, et al.

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**Alzheimer's Disease  
International**

*The global voice on dementia*

# **Dementia in sub-Saharan Africa** **Challenges and opportunities**



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## Chapter 1

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## Chapter 2

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## Chapter 3

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## Chapter 4

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This report was independently researched and authored by Dr Maëlenn Guerchet, Dr Rosie Mayston, Prof Peter Lloyd-Sherlock, Prof Martin Prince, Dr Isabella Aboderin, Dr Rufus Akinyemi, Dr Stella-Maria Paddick, Prof Anders Wimo, Dr Mary Amoakoh-Coleman, Dr Richard Uwakwe, Dr Peter Ezeah, with contributions from others as listed. The evidence reported and the inferences drawn are the responsibility of the authors alone.

## Personal stories

Stories included in boxes throughout the report were provided by Alzheimer's associations (members of ADI) in sub-Saharan Africa. They are to illustrate how living with dementia in different parts of the African continent can be, including the journey to diagnosis and care. We have specifically chosen stories highlighting how associations have been supporting the people with dementia and their carers. These are raw reports of personal experiences and are in no way generalizable to the population of either the country they are coming from or the region.

# Foreword

Sub-Saharan Africa represents today one of the biggest challenges for Alzheimer's Disease International (ADI). To understand the scale of this challenge it is sufficient to say that after 37 years of incessant work to build capacity in the civil society sector globally, we only have seven member nations out of a possible 49 in the region.

My discussions in the last few months with both our members and high level officials have brought to the fore a number of stark facts.

The scale of stigma in sub-Saharan Africa is huge. It was very difficult to find people with dementia willing to speak at our conference this September and, by doing that, to admit that they have the condition. There is talk of older people with mental illness being branded witches and being restrained forcefully, or worse. This report reassesses the scale of this problem, but we should not underestimate it, as few are willing to speak up.

At policymaking level, it is clear to me that mother and child health issues and infectious diseases are the top priority in this region and that non-communicable diseases (NCDs) and older people's issues are not really on the radar of many sub-Saharan countries.

This report is therefore extremely timely. It not only provides new quantitative and qualitative evidence and adjusts upwards most of our previous estimates – thereby confirming the scale of the epidemic is worse than previously suggested – but it examines many more issues. From risk prevention and reduction, to social and health care, health insurance and pensions, the report pragmatically raises possible solutions to an impending crisis.

The report also quantifies the obvious. The patterns of care in sub-Saharan Africa are changing; ageing population, lower fertility, more women working, rural-urban migration and migration more generally are all contributing factors to a change in the way care is delivered traditionally – within the family. With extended families increasingly losing this role, the potential for a crisis is evident. Yet, older people are seen as not contributing to economies, and their voices and rights are routinely excluded or ignored. Inequality is also a huge issue.

We obviously need more data and more research in virtually every area described in this report. There are large gaps in our knowledge and we need more evidence coming from countries in the region.

We must act now. Whereas in other regions we need more awareness of dementia as a disease, not a normal part of ageing, in sub-Saharan Africa we need to go deeper and challenge the prejudices faced by those who have the disease. Governments also need to tackle this from the viewpoint of risk reduction and prevention and in the context of NCDs more broadly. There is a pressing need to educate about dementia and this needs to be taken on by the public health functions of all countries.

The approval of the World Health Organisation (WHO) Global Action Plan on Dementia in May 2017 allows us to put greater pressure on governments to take the issue with the seriousness it deserves and act. The African Union adopted in January 2016 a 'Protocol on the Rights of Older Persons in Africa' which is legally binding. African states agreed on the Sustainable Development Goals framework, which includes older people, and recently all African countries approved the WHO's Global Action Plan. This includes the monitoring systems set up by the Global Dementia Observatory and the understanding that data should begin to arrive soon.

ADI and its members will continue in their work, challenging governments, proposing solutions, strengthening civil society, representing the voices of those most at risk and tackling inequality. If you are reading this report and think action should be taken, join us.



A handwritten signature in black ink, appearing to read 'Paola Barbarino'.

**Paola Barbarino**, Chief Executive Officer

Alzheimer's Disease International

# Dementia in sub-Saharan Africa

## Challenges and opportunities

### The Global Observatory for Ageing and Dementia Care

The Global Observatory for Ageing and Dementia Care, hosted at the Health Service and Population Research Department, King's College London, was founded in 2013.

Supported by Alzheimer's Disease International, and King's College London, the Observatory has a tripartite mission:

1. To build upon ADI's 10/66 Dementia Research Group program of population-based and intervention research in low and middle income countries, maximising the impact that research findings from our data can have upon policy and practice.
2. To develop, evaluate, and promote primary care and community interventions for people with dementia.
3. To synthesise global evidence for policymakers and public, in particular, continuing and developing our role in the preparation of high impact evidence-based reports for Alzheimer's Disease International (World Alzheimer Reports 2009, 2010, 2011, 2013, 2014, 2015, 2016 and Nutrition and dementia), the World Health Organization (Dementia: a public health priority, 2012) and other relevant intergovernmental organisations.

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# Summary

## CHAPTER 1

### Introduction – Ageing in sub-Saharan Africa

1. We have updated our estimates of the prevalence of dementia and numbers living with the condition in the sub-Saharan Africa (SSA) region, the incidence of dementia, and the economic impact of dementia, supplemented by new reviews of the evidence on the mortality risk for people with dementia and of risk factors in SSA. We have also systematically reviewed qualitative evidence on the experience of living with dementia in SSA, providing important insights into the everyday reality in this region. Finally, we examined briefly the development of social protection schemes in SSA and assessed their effects on the health of older people.
2. The phenomenon known as population ageing or 'demographic transition' is occurring globally – much more rapidly in some developing middle income countries. Despite having the youngest populations in the world, sub-Saharan African countries also have the fastest growing rates of older people in the world. The population of older people aged 60+ is projected to reach 161 million by 2050. However, there are clear sub-regional differences in ageing profiles.
3. Societal implications of population ageing and the effects of social change on experiences of old age in SSA remain poorly understood while being varied and complex. Families are a key social group, particularly in the absence of comprehensive public welfare systems and provision. Major concerns exist about changes in SSA family structures driven by urbanization, migration, global agendas and persistent economic strain.
4. As people live longer and changes in lifestyles and behaviours predisposing towards certain risk factors occur, chronic diseases become more common. Sub-Saharan Africa is not spared by this epidemiologic transition, and a rise in non-communicable diseases (NCDs) has been described, causing a triple burden of disease in SSA which could have a devastating impact on a region already facing significant resource constraints.
5. Health inequalities among SSA's older adults emerge along several axes, including gender, socio-economic position and age, but also place of residence and type of health condition.
6. The policy architecture on ageing and health in SSA has been consolidated in recent years, with an emergence of regional and national frameworks as well as African countries' commitments to global agendas (including the United Nations' Sustainable Development Goals and the WHO Global Strategy on Ageing and Health). Despite such policy advances, comprehensive programmatic actions on older people's health remain sparse. There is an urgent need for a concerted research effort to help promote and inform consideration of dementia in national and regional health agendas.

## CHAPTER 2

### The epidemiological evidence: prevalence, costs, incidence, mortality and risk factors

1. We provide an overview of the epidemiology and impact of dementia in SSA, using essentially the same methods as previously used in the World Alzheimer Reports, conducting new reviews of the studies regarding dementia prevalence, incidence and mortality. We present updated estimates of the numbers of people living with dementia in SSA, as well as costs, and evidence on risk factors of dementia, with a specific note on HIV-associated neurocognitive disorders.
2. Our regional estimate of age-specific dementia prevalence in people aged 60 years and over is now 6.38%, doubling with every 7.2 year increment in age. This prevalence is slightly higher than that presented in the World Alzheimer Report 2015, due to the inclusion of three additional studies in the meta-analysis.

3. We estimate that 2.13 million people were living with dementia in SSA in 2015. This number will reach 3.48 million by 2030, and 7.62 million in 2050, with the most important increases in Eastern and Central SSA. The increase in these new estimates compared to the World Alzheimer Report 2015 is driven by both population ageing and the slightly higher estimate of prevalence of dementia in SSA.
4. The total costs of dementia in sub-Saharan Africa were an estimated US\$ 6.2 billion in 2015. The pattern of distribution of costs between the three major sub-categories (direct medical, social care and informal care) has not changed, with two-thirds to three-quarters of the total costs attributed to informal care.
5. We estimated over 367,000 new cases of dementia in 2015 in SSA, a slightly lower estimate than that in the World Alzheimer Report 2015. However, previous estimates were generated by using the evidence on the incidence of dementia estimated in all low and middle countries (including one study in Nigeria) while we have now been able to rely on the evidence on incidence of dementia in SSA only.
6. A two-fold increased mortality risk for people living with dementia in SSA was estimated. Relatively similar mortality hazards have been reported in other low and middle countries.
7. Studies of risk factors of dementia in SSA have shown consistent association of age and female sex with dementia. The evidence around other risk factors is more patchy, and this needs to be more thoroughly investigated. Education and the APOE  $\epsilon$ 4 allele showed very mixed effects. The strongest evidence on modifiable risk factors is the association of dementia with vascular risk factors, while the evidence on early-life, psychological, psychosocial and lifestyle factors remains tentative.
8. An important gap in the evidence has been identified regarding HIV-associated dementia (prevalence or risk factors) among older people in SSA. Existing, albeit limited, data relate almost exclusively to young adults.
9. The evidence on dementia prevalence, incidence and mortality has considerably expanded since the World Alzheimer Report 2009. We are therefore slowly moving away from single estimates for the whole sub-Saharan region for most of the epidemiological indicators. However, the evidence on risk factors of dementia in the region is still not very strong, mainly relying on cross-sectional studies rather than longitudinal ones.
10. Although the overall quality of dementia studies in SSA is high, strengthened by the systematic use of multi-domain cognitive batteries and informant interviews during dementia assessment, there is still room for improvement on the correct implementation of multistage designs and their analysis, and adequate description of the studies when disseminating results.
11. A major current limitation regarding our estimates of costs of dementia in sub-Saharan Africa is that they are mainly based on imputations, as no original data has been published yet on resource use and costs of dementia in SSA. Descriptions of care systems and amounts of informal care provided for at least one country in each of the sub-regions would contribute to more reliable estimates.

## CHAPTER 3

### **Living with dementia in sub-Saharan Africa**

1. Understanding beliefs, perceptions and experiences relating to illness, care, help-seeking and treatment is critical to understanding the nature of the problem and designing interventions and services that are person-centred and which meet locally defined needs. We carried out a systematic review of the scientific qualitative evidence on the experience of living with dementia in SSA.
2. Four over-arching themes emerged from the data: beliefs (understandings of dementia and beliefs about causality), experiences (symptoms, stigma, impact of caring for a person living with dementia), responses (care arrangements, help-seeking) and unmet needs (emotional support, knowledge, economic support and services).
3. No equivalent term for dementia was identified in any local languages, while there was a general lack of awareness of dementia among the community. The most prominent belief regarding underlying cause of dementia was that although not experienced by everyone, dementia-like symptoms were part of “normal ageing”.

4. Participants most frequently reported problems with memory and communication, but problems with overall functioning were also reported, as well as problems typically associated with co-morbidities. When people with dementia were perceived to be witches, fear inevitably resulted in discrimination, isolation and instances of violence. Where participants stated that there was no stigma, as dementia-like symptoms were accepted as a “normal part of old age”, people with dementia were routinely referred to as childlike.
5. Care, mainly delivered by families, was shaped by a need to show gratitude for the care provided to the current carers by people with dementia earlier in their lives. Women tended to be the hands-on carers while men often played a role in decision-making about care. Caring was often a collective responsibility with different components assigned to different family members. When used, hired help was perceived as a difficult but necessary component of the care strategy.
6. Families were pluralistic in their approaches to treatment, using both biomedical and traditional or faith healing to treat the problems of older people. The condition was always recognised as incurable if the acknowledged cause was ageing. The proportion of people with dementia who seek help from non-biomedical healers in SSA was significant.
7. Emotional support for carers was felt to be essential to enable them to continue to deliver care. Education was also deemed to be essential, both to counteract beliefs related to witchcraft and to improve the level of support for carers in their role.
8. People living with dementia and carers were dependent upon families and communities to support the costs of care, with costs of transportation to clinics felt to be particularly problematic. Care was managed by families with no involvement or support from government sources.
9. The evidence identified covered only five countries, with all sub-regions but Southern SSA represented by only one or two studies. Given the heterogeneity and diversity of cultures, languages and beliefs within SSA, the generalisability of those results to other countries or settings than those where they originated is debatable.

## CHAPTER 4

### **Social protection and the health of older people in sub-Saharan Africa**

1. Social protection, which seeks to reduce individuals' vulnerability, is a necessity for older people across SSA, especially for people living with dementia. We examined the development of social protection in SSA, mainly based on cash-transfers and health insurance, and assessed its effects on the health of older people by looking at South Africa and Ghana, for which data were available.
2. A number of countries, mainly located in southern SSA, have relatively extensive and generous social pension schemes, usually combined with separate contributory arrangements. In the rest of the region, the coverage of pension schemes and the value of benefits is considerably more limited. Some countries have developed pilot social pension schemes, usually with the support of external funding. Social protection in SSA is highly inequitable and crowds out public expenditure for more vulnerable groups of older people.
3. South Africa has an established system of non-contributory pensions, disability benefits and “Grant-in-Aid” benefit for older people aged over 60-65, adults with chronic conditions or who “require regular care”. However, the geographical distribution of the benefits remains uneven. A system of non-contributory cash transfers also exists and has been put forward as an example of “best practice” for other developing countries. It has been claimed that it does not just benefit older people, but the entire households, which may increase the authority of older people and hence the potential willingness of family members to care for frail older relatives.
4. In SSA, only a small number of health insurance schemes have achieved good coverage of their populations. Coverage is usually highly concentrated on more affluent social groups. In this context, Ghana's national health insurance scheme, free for people aged over 69 years, is unique and has been presented as a potential model for other resource-constrained countries.

5. The availability of and access to health services across most of sub-Saharan Africa being extremely limited, the capacity of social pensions to have a significant impact on the health status of older people will remain very limited unless substantial improvements are made to the suitability, quality and accessibility of these services.
6. The direct effect of health insurance and pensions on enhancing health outcomes for older people is contingent on the generosity of the scheme, health awareness and the availability of suitable services. Simply being enrolled in health insurance or utilising health services should not in themselves be considered positive outcomes.

## CHAPTER 5

### Conclusions and recommendations

1. We estimate that 2.13 million people were living with dementia in sub-Saharan Africa in 2015, with numbers projected to nearly double every 20 years, increasing to 3.48 million by 2030 and 7.62 million by 2050. There were over 367,000 new cases of dementia in 2015, while people with dementia had a two-fold increased mortality risk compared to people not affected by the condition. The total costs of dementia in SSA are now estimated at US\$ 6.2 billion in 2015, with two-thirds to three-quarters of the total costs and cost per person attributed to informal care costs.
2. In May 2017, the World Health Organization's (WHO's) Global Plan of Action on Dementia was unanimously adopted at the 70th session of the World Health Assembly in Geneva. As yet, no dementia plans or strategies have been established by countries in SSA. The WHO Global Plan, which includes specific actions for Member States, international, regional and national level partners, provides indicators and targets to evaluate levels of implementation, progress and impact. For the first time, governments can be held accountable on the advancements of dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research in their countries.
3. Improving dementia awareness and friendliness, access to services (through Universal Health Coverage) and dementia risk reduction are challenges that countries in sub-Saharan Africa must tackle. Considering the evident lack of ethical, social and legal protection of people with dementia in SSA, it is essential that rights are recognized, respected and protected to empower people living with dementia, those who support them and the community as a whole. The gap in evidence for almost all domains of the dementia field in SSA is striking. The Global Plan must be used to support the development of dementia research globally and guide nations to define adequate research agendas, supporting national and regional health agendas.
4. ADI and its focused, energetic and committed member associations are committed to finding solutions to a very real and tangible problem. Associations are forging ahead, creating hope and activity where there was little, mobilizing goodwill and resources, and trying to sensitise their governments. Governments in the region have a real opportunity right now – thanks to the excellence of these grassroots organisations – to join forces with them and by adopting and implementing the seven key areas of the WHO Global Plan, to show the rest of Africa the way.

## CHAPTER 1

# Introduction – Ageing in sub-Saharan Africa



## Introduction

This report comprises an overview of current knowledge about the evolution, spread and patterns of dementia in sub-Saharan Africa (SSA). To offer a complete description of the epidemiology of the condition in the region, we provide updated estimates of the prevalence and incidence of dementia, the numbers of people living with the condition, and its economic impact. We additionally review evidence on key risk factors for, and the mortality risk of, people living with dementia in SSA. In order to provide insights on lived realities of the condition in the region we offer a systematic review of qualitative evidence of the experiences and perspectives of people with dementia, their families and those offering services to them in SSA contexts. Finally, we discuss key developments in the expansion of health- or old age-focused social protection schemes in SSA and their effects on the health status of older adults. Social protection measures are an increasingly salient element in countries' efforts to ensure the well-being of vulnerable populations. As such, such schemes are particularly relevant to meeting the growing care and service needs associated with a rising dementia burden.

As with previous reports, our focus is on older people aged 60 years and over. This is notwithstanding the possibly elevated proportion of early onset dementia in SSA (higher than the global estimate of 2-8% of all cases) due to the high seroprevalence of HIV infection<sup>1</sup>. Evidence on HIV-associated dementia in the region will be assessed separately.

The geographical focus of this report is on the region of sub-Saharan Africa, as commonly defined by key international organizations such as the United Nations or World Bank. SSA comprises 49 countries and four sub-regions with highly diverse social, economic, physical and cultural profiles. Nonetheless, certain features and challenges of SSA's demography and health context cut across nations. Key among these aspects are (i) an expected sharp rise in the absolute size of the older population, (ii) a triple burden of disease driven by persistent communicable- and emergent non-communicable conditions as well as injury and trauma and, (iii) weak or poorly developed health and social care systems.

We therefore begin this report – in the remainder of this chapter – with a brief description of broad demographic and epidemiological trends in SSA, key challenges of ageing, health and dementia that arise within this context, and the policy frames that presently exist to respond to them. We conclude with a reflection on emerging implications for research.

## 1.1 Demographic ageing in sub-Saharan Africa

The phenomenon known as population ageing – a last stage in the so called ‘demographic transition’ marked by a rise in the proportion of older people in the total population – is occurring globally. It results from shifts from high fertility / high mortality states to low fertility / low mortality states driven by improvements in public health, economic and social development. Such advances typically lead, first, to declines in child mortality, giving rise to high rates of population growth. Subsequent declines in fertility rates (people having fewer children) often to ‘replacement level’ (two births per woman) then slow population growth. Parallel improvements in adult health lead to decreased mortality in later life. This further increases life expectancy and, together with reduced fertility rates, causes a steady rise in the total population share of older adults.

The pace of such population ageing is much more rapid in some low and middle income countries (LMIC) than was the case in the ‘old’, now industrialised world. While, for example, it took between 45 and 115 years for some high income countries (HIC) to double their total population aged 65 years and over (from 7% to 14%), it is estimated that many LMIC will accomplish the transition in less than 25 years<sup>2</sup>.

Figure 1.1

**Projected trends in percentage of population over 60 years: SSA and other world regions**

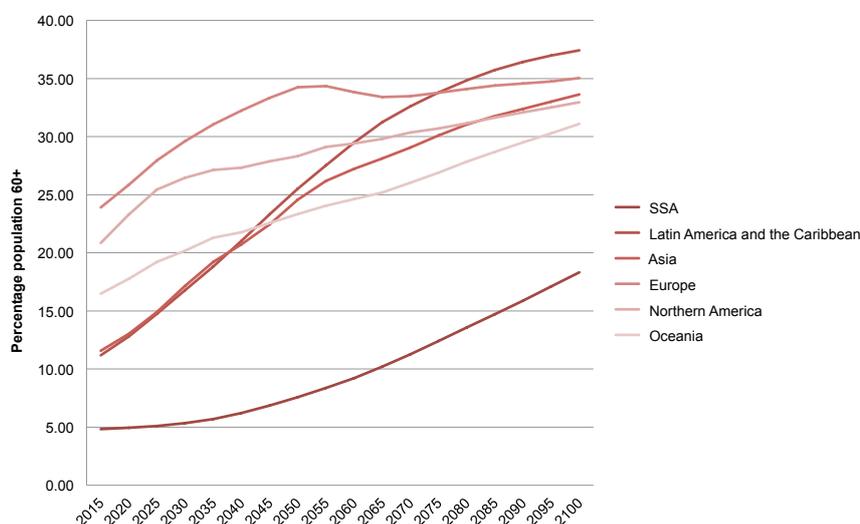


Table 1.1

**Projected trends in absolute numbers (in thousands) of older people (60+): SSA and other world regions**

	2015	2020	2025	2030	2035	2040	2045	2050
Sub-Saharan Africa	46,455	54,072	63,293	74,504	89,098	108,085	132,347	161,077
Latin America and the Caribbean	70,922	85,353	102,650	120,959	139,693	159,785	180,447	200,031
Asia	507,954	599,433	711,622	844,487	969,231	1,066,635	1,170,148	1,293,710
Europe	176,513	191,371	206,338	217,220	226,010	232,527	238,084	242,001
Northern America	74,589	86,537	97,743	104,799	110,403	113,741	118,442	122,679
Oceania	6,481	7,493	8,610	9,553	10,608	11,347	12,274	13,204

Within this overall picture there are clear sub-regional differences in ageing profiles. Central and eastern Africa, as Table 1.2 shows, will see the largest increases in the population of older people while Southern Africa will see the smallest. The highest rise in life expectancy at birth will take place in Central Africa (from 55.6 years in 2010–2015 to 67.7 years in 2045–2050). Life expectancy at 65, presently highest in Eastern Africa, will grow by the largest margin in this sub-region as well as in Southern Africa. Southern Africa also has the highest proportion of older adults in the population and, together with Eastern Africa, will see the highest rise - a doubling - in this share by mid-century. Much lower increases in the population proportion of older people are expected in Western and Central Africa.

Table 1.2

**Demographic profiles of ageing in SSA sub-regions between 2015 and 2050<sup>3</sup>**

	60+ (thousands)		Proportionate increase (%)	Percentage of population over 60 (%)		Life expectancy at birth		Life expectancy at 65	
	2015	2050	2015-2050	2015	2050	2010-2015	2045-2050	2010-2015	2045-2050
West Africa	16,006	52,752	230	4.53	6.61	55.0	65.5	11.3	12.9
Central Africa	6,901	24,411	254	4.54	6.61	55.6	67.7	13.2	15.0
East Africa	18,868	72,436	284	4.78	8.25	60.5	72.1	14.2	16.4
Southern Africa	4,680	11,477	145	7.47	14.71	57.1	68.2	13.2	15.5

The societal implications of population ageing and the effects of social change on experiences of old age in SSA remain poorly understood and are undoubtedly varied and complex. A critical factor in both, however, is families. Families are understood as the key social group in which the lives of, and support for, older people in SSA are embedded. The relevance of families is arguably particularly pronounced within contexts, as in most SSA countries, marked by a broad absence of comprehensive public welfare systems and provision<sup>4-6</sup>.

Major concerns exist about changes in SSA family structures and bonds driven by urbanization, migration, global agendas and persistent economic strain - and the impacts of such shifts on the roles of, security for, and attitudes toward older adults. Additional concerns focus on gaps in available care for older adults, as well as an expansion of new care responsibilities on them - as a result of the HIV/AIDS epidemic particularly in Southern and Eastern Africa<sup>6</sup>.

There remains considerable debate about the ways in which major social trends are shaping experiences of families and later life, and the extent to which a commonly assumed erosion of customary family care systems and values for elders is, indeed, occurring<sup>6</sup>.

However, there is little doubt that for many older adults in SSA, later life is marked by a vulnerability to poverty, social exclusion, ill-health and disability. At the same time, there is growing recognition that older adults continue to play a range of key roles and that they wield relevant influences whether positive or negative, active or latent, at family, community or societal levels<sup>7</sup>.

## **1.2 The rise of non-communicable diseases: epidemiological transition and triple burden**

To a large extent the burden of ill-health and disability faced by SSA's older adults results from chronic, non-communicable diseases (NCD), which are expanding in SSA as a function of a so-called 'epidemiological transition'. As people live longer and lifestyles and behaviours change, such conditions become more prevalent with bigger impacts on the health of a population. Such a transition involves specific processes in which:

- i) Infectious diseases, including malaria, tuberculosis, and polio are brought under control, and childhood and maternal health improves as a result of economic and social development. Together, such shifts reduce mortality at young ages, as well as preventable childhood or lifelong disability.
- ii) Simultaneously, changes in behaviour and lifestyles occur in tandem with urbanization, globalization and industrialisation – towards a 'western' pattern of sedentarism, high dietary consumption of salt, fat and sugars, smoking and alcohol use. Such risk factors drive an increase in the incidence of certain chronic diseases, specifically cardiovascular diseases, cancers, diabetes and obesity. They are also linked to dementia, however, suggesting likely rises in the condition in populations undergoing this transition.

A clear sign of an ongoing epidemiological transition in sub-Saharan Africa is the rise in morbidity and mortality caused by NCD over the last decade<sup>8-10</sup>. In 2015, over 2.7 million deaths due to NCDs occurred in SSA, a 63% increase from 1990<sup>11</sup>. Findings of the latest Global Burden of Disease

(GBD) Study estimate the number of Disability Adjusted Life Years (DALYs) caused by NCD in SSA at over 153 million, representing almost 30% of the burden caused by all diseases. Among the older population (aged 70 years and over), this proportion rises to 72%, with over 15 million DALYs<sup>11</sup>. The contribution of NCDs to the burden of disability in SSA is even higher. They account for 63% of all Years Lived with Disability (YLD) in the total population and 83% of YLD in the older<sup>11</sup>.

The most prominent NCDs in SSA at present are cardio-vascular diseases (CVDs) and neoplasms as the first causes of both death and disability in the overall population. This pattern remains the same for the older population, where neurological disorders rank as the 5th cause of deaths and 8th cause of DALYs<sup>11</sup>.

Dementia emerged globally as one of the 15 leading causes of DALYs among older people in 2010<sup>12</sup> and in the oldest age groups (75 and over), Alzheimer's and other dementias now rank as one of the top ten leading causes of disability in 2015<sup>13</sup>. In SSA, dementias such as Alzheimer's are still less prominent. Nonetheless they pose a considerable disease burden on the region's older population that is possibly underestimated in present GBD analysis. In 2010 in all of SSA, Alzheimer's disease (AD) was described as the 33rd leading cause of death in people aged 70 and older<sup>14</sup>. However, authors acknowledged that the GBD mortality estimates for AD had to be viewed with caution given a lack of data from brain autopsy, non-invasive diagnostic and imaging methods used and a lack of expert diagnosticians. Revised estimates for 2015 draw on updated reviews and computations but remain hampered by minimal evidence on dementia in SSA<sup>15</sup>. They identify AD as causing 2.4% of DALYs and 3% of deaths in the region's population aged 70 years and older<sup>11</sup>.

Concomitant with expanding NCD, SSA continues to face a major burden of communicable diseases, including HIV/AIDS, as well as injury and trauma. This triple burden of disease implies a critical challenge for SSA's already under-resourced health systems<sup>16, 17</sup>. Given the constrained health sector capacities in the region, services and responses for the prevention and management of NCD remain highly circumscribed<sup>18</sup>. The lack of requisite health care may be particularly pronounced among older adults who face a number of supply- but also demand-side barriers to service use<sup>19, 20</sup>. Thus, for example, awareness of hypertension in the older population was found to be extremely low in Ghana, South Africa and Central Africa, with rates of treatment and control even lower<sup>21-23</sup>.

A crucial, yet often overlooked, factor in assessing older adults' health and access to requisite care in SSA is the major disparities that exist in this regard – and that reflect a wider heterogeneity in the region's older population. Research suggests that health inequalities among SSA's older adults emerge along several axes, including gender, socio-economic position and age, but also the place of residence and the type of health condition. Studies such as the WHO Study on Global Ageing and Adult Health (SAGE) in collaboration with the INDEPTH network of Health and Demographic Surveillance sites (HDSS)<sup>24</sup> or the HAALSI study (Health and Aging in Africa: longitudinal studies of INDEPTH communities) point to a number of patterns in this regard. For example, in rural South Africa older adults with chronic communicable disease and non-communicable disease were found to report higher health care use than those with acute conditions<sup>25</sup>. In Ghana, higher wealth and multimorbidity were significant predictors of public and private outpatient healthcare utilization among older adults, with health insurance coverage a predictor only for the use of public facilities<sup>26</sup>. Older Ghanaians with higher levels of functional limitations were more likely to rate their health as being poorer, while wealthier individuals were more likely to rate their health as good<sup>27</sup>. In rural South Africa, higher mortality among older adults was associated with lower socio-economic status (assessed by household assets scores) as well as lower age (with greater death rates among those aged 50-69 as compared with those aged 70-79 years)<sup>28</sup>. The HAALSI study reported worse physical performance among older adults living in South Africa compared to those in the US, Mexico and China, as well as a high cardiometabolic risk in this South African population<sup>29, 30</sup>.

Over the longer term, the progressing epidemiological transition in SSA combined with thus far deficient health systems' responses to it portend a mounting burden of NCD, including dementia, in the region's expanding older population.

At the same time, social and economic change will likely entrench or modify patterns of health inequality among older adults and will shape the regional, national, and local contexts within which responses to unfolding health care and service needs must be forged.

### 1.3 Policy context and implications for research

The policy architecture on ageing and health in SSA has seen a remarkable consolidation in recent years, with an emergence of relevant regional and national frameworks as well as African countries' commitments to a number of overarching global agendas.

Chief among the global frames embraced by SSA governments are (i) the United Nations Sustainable Development Goals (SDG), including SDG 3 to 'ensure healthy lives for all at all ages'<sup>31</sup>, and (ii) the recently adopted World Health Organization (WHO) Global Strategy on Ageing and Health<sup>32</sup>. Grounded in the SDG, the Strategy commits Member States to action, among others, to align health systems to the needs of older persons and to forge sustainable and equitable systems for providing long-term care<sup>33</sup>.

Key Africa-regional instruments, which uphold the rights of older adults to health and access to care include the African Union (AU) Protocol to the African Charter on Human and People's Rights on the Rights of Older Persons<sup>34</sup> as well as the broader AU Agenda 2063<sup>35</sup>, which sets out an overall vision of development in the continent. Broad recommendations on action toward enhancing the health and care of older adults are incorporated in the AU Policy Framework and Plan of Action on Ageing (2002)<sup>36</sup> as well as in the more recently adopted Common Africa Position on Long-Term Care Systems (2017).

At country level such recommendations are broadly echoed in national policies or policy frameworks on ageing that have been adopted in a growing number of SSA States. A few countries, moreover, have enshrined key rights or entitlements of older citizens (including to health and care) in their Constitutions or in dedicated legislation. Some States, finally, have included varying provisions regarding older persons in sectoral plans or strategies on health or other areas<sup>37, 38</sup>.

Despite such policy advances, comprehensive programmatic action on older people's health has remained sparse. Where they exist, interventions have centred on measures – such as fee exemption schemes or social health insurance – intended to reduce financial barriers to older adults' service access. In some countries, community-based care schemes to address older people's health needs are being explored, often in conjunction with civil society-led initiatives.

A key impediment to the forging of more robust responses on older people's health, and dementia specifically, is the lack of consideration of such issues in priority agendas for health at both regional and national levels. A case in point is the virtual absence of any reference to ageing or older populations in the AU Africa Health Strategy 2016-2030.

In line with such gaps, SSA's health systems remain oriented toward serving children or reproductive age adults with little capacity to address old age-related health needs. Crucially, such orientation extends to emerging NCD agendas in the region. These centre on primary, lifestyle-focused prevention earlier in life of the 'big four' diseases (CVD, neoplasms, diabetes and chronic obstructive lung disease), with little focus on the management of established conditions in later life, and virtually no consideration of other diseases, such as dementia, that are of key concern to older populations<sup>20, 39</sup>.

The present policy context suggests an urgent need for a concerted research effort to help promote and inform a fuller consideration of dementia and other ageing and health challenges in mainstream national and regional health agendas.

Two principal kinds of evidence are required to this end. First, evidence that helps to 'clarify the case' on why SSA countries ought to address the health of older people, including dementia, as part of their core health and development interests. Second, evidence to 'clarify the specific directions' - in terms of target groups and settings, approaches or practice models that any such responses should take. Specific areas and questions for research are highlighted in this report.

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## CHAPTER 2

# The epidemiological evidence: prevalence, costs, incidence, mortality and risk factors



### 2.1 Introduction

In 2005, ADI convened a group of international experts to generate up-to-date evidence-based estimates for the prevalence and numbers of people living with dementia in all regions of the world<sup>1</sup>. Those figures have provided a good foundation for global policymaking and assisted national Alzheimer's associations in raising awareness of the upcoming challenge that would be faced by current and future generations.

At that time, the evidence on dementia was incomplete and scanty in many regions of the world, especially in low-and-middle income countries (LMIC). Only three epidemiological studies were identified for the entire African continent. As a result, the prevalence estimate for the African region was influenced by the one good quality study, performed in Nigeria, which reported a strikingly low prevalence of dementia<sup>2</sup>. The consensus therefore estimated the prevalence of dementia for the WHO AFRO (D/E) region to be 1.6% at age over 60 years, representing 0.5 million people living with dementia in this region in 2001. The projected increase over time was however important: 234% between 2001 and 2040, leading to an estimated 1.6 million people living with dementia in Africa in 2040. Africa was thus, as many other LMIC, starting from a low base but expected to experience a rapid increase in numbers. The rate of increase was generally 3-4 times higher in developing compared to developed regions<sup>1</sup>.

Hypotheses have been generated to explain these low prevalences (and the gap between developing/developed regions), including a low survival with dementia, low incidence (i.e. the rate at which new cases develop), a lower level of exposure to environmental risk factors (particularly cardiovascular risk and hyperlipidaemia), and a higher mortality in early life (conferring a 'survival advantage', potentially protecting against neurodegeneration or delaying the onset of clinical manifestations). Given the lack of evidence, the need for more research in Africa was obvious.

A few years later, the 2009 World Alzheimer Report<sup>3</sup> gave a further overview and analysis of the situation, based on the research data available at that time. Systematic reviews of the evidence were performed and global estimates for dementia prevalence and numbers were generated and updated. The evidence available on dementia prevalence in sub-Saharan Africa (SSA) had not changed much; coverage was still sparse and prevalence estimates were still primarily relying on the consensus estimates from 2005. However, despite relatively low standardised prevalence, higher estimates of the number of people living with dementia in SSA were provided (0.71 million in 2010, increasing to 2.54 million in 2050)<sup>3</sup>, mainly driven by the demographic ageing of the population. The WHO report ('Dementia: a public health priority') which followed in 2012 completed the picture by reviewing the evidence on the incidence of dementia. At that time, a single incidence study was identified, conducted in Nigeria<sup>4</sup>. It was then estimated that 525,818 new cases of dementia were arising each year in Africa, with more than half of them (293,191) living in SSA<sup>5</sup>.

In 2013, in preparation for the G8 Dementia Summit held in London, the Global Observatory for Ageing and Dementia Care and ADI worked in a joint effort on a policy brief reassessing and updating the evidence on the scale and the distribution of the global dementia epidemic<sup>6</sup>. The evidence from the sub-Saharan regions had significantly increased and prevalence estimates were higher than previously reported, with an age-standardised prevalence in SSA regions from 2.07 - 4.00% to 4.67%. Hence, it was estimated that in 2013, 1.3 million older people were living with dementia in SSA, reaching 5.05 million in 2050<sup>6</sup>.

Pursuing their efforts, a complete update of the global impact of dementia was published in the 2015 World Alzheimer Report<sup>7</sup>. The significant improvement in evidence coverage on dementia prevalence in African regions since 2009 was highlighted, as was the high quality of the new evidence generated. Prevalence and numbers of people living with dementia in Africa did not vary much between 2013 and 2015 as most of the new data on dementia prevalence were published between 2009 and 2013. However, accounting for the revised population estimates, the numbers of people living with dementia in SSA were estimated at 1.69 million in 2015, increasing to 2.64 million in 2030 and 5.72 million in 2050 (representing a 145 to 300% proportionate increase between 2015-2050).

The coverage regarding the incidence of dementia was not different from the previous WHO review, with still a single study representing SSA. However, considering revised population estimates, the estimated number of incident cases of dementia in SSA was 446,568 in 2015, representing 4.5% of the global number of incident cases<sup>7</sup>.

Although several reviews on the prevalence and epidemiology of dementia in SSA have been published<sup>8-11</sup>, their methods and inclusion/exclusion criteria were not always consistent, hence providing varying estimates. In this chapter, we therefore provide an overview of the epidemiology and impact of dementia in SSA, using essentially the same methods as previously used in the World Alzheimer Reports, conducting new reviews of the studies regarding dementia prevalence, incidence and mortality. We will also present updated estimates of the numbers of people living with dementia in this region, as well as costs. The evidence on risk factors of dementia will also be reviewed, with a specific note on the HIV-associated neurocognitive disorders.

## 2.2 Prevalence

### 2.2.1 Methods

We conducted a systematic review of the literature on the prevalence of dementia in different databases following the strategy below.

- Search date: May 2017
- Databases: Embase, Global Health, Ovid MEDLINE® In-Process & Other Non-Indexed Citations and Ovid MEDLINE®, PsycARTICLES Full Text & PsycINFO
- Search terms: (Africa OR individual countries of Africa) AND (epidemiolog\* or prevalence) AND (dement\* or alzheim\*)

**Inclusion criteria:** population-based studies of the prevalence of dementia among people aged 60 years and over (according to DSM-IV or ICD-10 criteria, or similar clinical criteria), for which the fieldwork started on or after 1st January 1980.

**Exclusion criteria** (related to sampling, case ascertainment procedures, and outcome definitions):

A. Sampling design

- Studies of prevalence from the follow-up phase (rather than the inception phase) of a population cohort
- Studies sampling from an out-of-date population register (prepared more than three years prior to the survey)
- Studies of nursing home or residential care populations, primary care attendees or other unrepresentative service-user populations

B. Ascertainment/outcome definition

- Studies in which the ascertainment of dementia depended upon help-seeking and/or receipt of dementia care services
- Studies in which 'dementia' was diagnosed purely on the basis of cognitive impairment, for example according to a cut point on the MMSE
- Two phase studies, in which screening procedures were clearly inadequate, especially all large-scale screening studies of people of all ages for all neurological disorders
- Studies of the prevalence of Alzheimer's disease or other subtypes of dementia, or restricted to young onset dementia
- Procedures

Two independent reviewers (MG and AMP) read the abstracts of all publications identified on the electronic databases, excluding only those that clearly did not meet the above criteria. In the next stage, printed copies of the remaining publications were read, and a consensus was made on those that met all criteria. We read studies published in English and French. All eligible studies were systematically coded for their study design and quality according to the following criteria:

1. Country
2. WHO/Global Burden of Disease World Region (see Appendix A for list of countries and regions)
3. Inclusion of residents of long term care institutions
4. Start and finish dates for fieldwork, and census dates if provided
5. Lower and upper age limits
6. Sampling (simple random, stratified random, whole population, other)
7. Design (one phase/two phase/three phase)
8. Overall sample size (first phase)
9. Numbers interviewed (first phase) and proportion responding
10. For two-phase surveys only
  - a. Numbers selected for the second phase (for two phase surveys)
  - b. Numbers interviewed (second phase) and proportion responding
  - c. Screen negatives sampled for the second phase (yes/no)
  - d. Screen negatives given same assessment as screen positives (yes/no)
  - e. Weighting back carried out (no weighting back/ appropriate weighting back/ no weighting back, but no false positives)
  - f. Time interval between first and second phase
  - g. Screening instrument/s
11. Diagnostic criteria (not specified, ICD, DSM, GMS/AGECAT, CAMDEX, other clinical criteria)
12. Use of multidomain cognitive assessment, informant interview, disability assessment, neuroimaging

An overall quality score was derived by summing scores for the following elements:

Sample size – <500, 0.5 points; 500-1499, 1 point; 1500-2999, 1.5 points; ≥3000 2 points

Design – Two-phase study with no sampling of screen negatives, 0 points; two-phase study with sampling of screen negatives but no weighting back, 1 point; one-phase study or two-phase study with appropriate sampling and weighting, 2 points

Response proportion – <60%, 1 point; 60-79%, 2 points; ≥80%, 3 points

Diagnostic assessment – one point each for multidomain cognitive test battery, formal disability assessment, informant interview and clinical interview

### Data extraction

For studies reporting unweighted prevalence, we extracted either numerator and denominator, or prevalence and denominator, or prevalence and standard error, or prevalence and 95% confidence intervals. Numerator and denominator could then be calculated from any of these combinations.

For studies reporting weighted prevalence we extracted either weighted prevalence and weighted standard error or weighted 95% confidence intervals. Effective numerators and denominators (taking account of the design effect) could then be calculated.

Prevalence estimates were stratified differently in different publications. Age-specific prevalence data could generally be calculated from age- and sex-specific estimates. If studies provided age-specific estimates not stratified by sex, sex-specific estimates not stratified by age or an overall prevalence stratified neither by age nor sex, we contacted the authors to request age- and sex-specific estimates. We could therefore model the effect of age on dementia prevalence for all included studies, and the effects of age and sex for the subset of studies that had provided age- and sex-specific estimates.

### Meta-analytical methods for estimating dementia prevalence

We used a random effect exponential (Poisson) model to assess the effects of age and sex on the prevalence of dementia in SSA. Random effects are assumed to have a gamma distribution – the alpha coefficient is an estimate of overdispersion and an index of between study heterogeneity. Age was coded as the mean for each age group reported, this was calculated from the mean observed in 4 population-based studies in West and Central Africa for which individual data was available<sup>12-14</sup>. We ran two models, one for the effect of age, and one for the main effects of age and sex, and an interaction between age and sex. We then applied the relevant mean ages and sex codings to the coefficients estimated from the models, to estimate prevalence in five year age-bands from 65-84 years, and for those aged 85 and over, for both sexes combined.

To facilitate comparison between regions, we have calculated overall age-specific and age- and sex-specific standardised prevalence for all those aged 60 and over, using Western Europe as the standard population.

### Estimation of the numbers of people with dementia

As described earlier, we generated both age-specific and age- and sex-specific meta-analysed dementia prevalence estimates for sub-Saharan Africa (including West, East, Central and Southern regions). Numbers of people living with dementia were estimated by applying the age- and sex-specific prevalence of dementia for each region to the UN population estimates for 2015 and the population projections until 2050<sup>15</sup>.

## 2.2.2 Results

The initial search yielded abstracts for 1007 publications, of which 328 were discarded as duplicates leaving 678 abstracts for review. After reading the abstracts, 653 publications were excluded as clearly ineligible (not carried out in SSA and/or before 1980, reviews, case or hospital-based studies, studies on other neurological or psychiatric disorders), leaving 21 publications for further review. We obtained copies of the full published version of each paper, which were then carefully assessed against inclusion/exclusion criteria and the citation of other relevant studies in SSA.

A further 10 publications were excluded at this stage (8 were already reported elsewhere, 1 was not matching the criteria, and 1 was a conference abstract only), leaving 8 publications (describing 10 studies) that were eligible for inclusion in the review. Two further studies were identified through conference abstracts and/or personal contacts with the 10/66 Dementia Research Group.

For 1 of these publications, we requested more information from the authors in order to be able to use the data in the meta-analysis in another form than in which it was provided in the publication.

Finally, 12 studies were fully eligible for inclusion.

## Coverage

Reasonable to good coverage was identified for West SSA (6 studies) and Central Africa (4 studies). Sparse coverage was achieved for East and Southern SSA, still represented by a single study each (Tanzania and South Africa) (Table 2.1).

Although improvements in coverage have been seen since the 2009 World Alzheimer Report for West SSA and Central SSA, Eastern and Southern SSA are still lacking research relative to their population size.

Table 2.1

### Coverage, by region, with respect to size of the older population

Region	Over 60 year old population (millions)	Number of eligible dementia prevalence studies	Number of studies/ 10 million population	Total population studied	Total population studied/ million population
SSA, Central	5.21	4	7.7	3020	580
SSA, East	20.08	1	0.5	1198	60
SSA, Southern	5.36	1	1.9	206	38
SSA, West	17.70	6	3.4	5925	335

## Quality

The principal characteristics of the included studies are given in Table 2.3, by region.

Most of the studies carried out in SSA have used a multistage design (2-3 stages). If multiphase surveys are reputed to be more cost- and time-efficient in epidemiological research, it can be a threat to quality when not implemented appropriately. The common error is to fail to submit a random sample of participants who have scored above the cutpoint during the screening assessment ('screen-negatives') to the same diagnostic assessment as those who scored below the cutpoint ('screen-positives'). The correct procedure, estimating the false positive rate before 'weighting back', allows the overall prevalence to be calculated accounting for the different sampling proportions of screen positive and screen negatives. Unfortunately, in half of the multiphase studies identified for the region, investigators have failed to apply the correct procedure including the assessment of screen negatives. In those studies, the results will tend towards an under-estimation of true dementia prevalence and an over-estimation of precision.

Multiphase designs can also generally be affected by participant loss to follow-up between the different stages of the study (screening and diagnostic assessment). This would tend to over- or under- estimate the true prevalence. Such bias can be avoided by the use of a single stage design where dementia diagnosis is performed through a computerized algorithm, like the one developed by the 10/66 Dementia Research Group. Although specifically developed for low- and middle-income countries where low levels of education are common and specialists able to diagnose dementia are lacking, this one-phase design has been little used so far in SSA.

Evidence of cognitive impairment (and decline compared to previous level of functioning) in memory and other domains of cognitive function, as well as consequent social or occupational impairment, are key in establishing a dementia diagnosis. Other potential causes of social and cognitive impairment, such as psychological comorbidities (depression, psychosis, or delirium) have to be excluded. Including multi-domain cognitive testing, disability assessment, and clinical as well as informant interviews is therefore necessary in a thorough dementia diagnostic assessment. All the studies included have done so, using a range of different instruments and scales. Although the effect of applying such diagnostic assessments on dementia prevalence is not known, the general quality of the studies is improved.

Most of the eligible studies (n=8) had a sample size of between 500-1499, with Central Africa being the region where the sample size was consistently around 500 participants. Sample sizes tended to be larger in West Africa. Although sample size should not bias prevalence estimates in a systematic way, larger studies will estimate prevalence with a better precision, and are therefore preferable.

Studies with higher proportions of participants responding provide more accurate prevalence estimates. Participants included in a survey might differ from those who could not be contacted

or did not consent to take part in the survey. High response proportions may avoid two different situations where bias would affect the estimation of dementia prevalence. People with dementia could be under-represented in the sample if relatives are reluctant for them to participate or because they find it more difficult to complete the interview / assessment. On the other hand, people with dementia could be over-represented due to an increased availability at the time of the survey (less likely to be out of the house working or carrying out other activities). Participation rates in the included studies are very high, mostly over 90%, exceeding that achieved in other world regions<sup>7</sup>.

As already highlighted in the 2015 World Alzheimer Report, overall study quality was especially high in sub-Saharan Africa, despite the lack of appropriate use of multiphase design and the somewhat small sample size in some regions.

### Prevalence

We considered the evidence-base to be sufficient and generalizable to conduct a meta-analysis for the sub-Saharan African region combining the central, southern, eastern, and western sub-regions.

The prevalence of dementia increased exponentially with age, doubling with every 7.2 year increment in age. For both sexes combined, it increased from 1.74% at 60-64 years to 23.31% at 85+ in SSA (Table 2.2). Prevalence of dementia tended to be lower for men in SSA, however this effect wasn't significant. Significant heterogeneity in age-specific and age- and sex-specific prevalence between studies within SSA was found (alpha=0.43/0.31).

Table 2.2

**Estimates of dementia prevalence (%) in sub-Saharan Africa**

Sub-Saharan Africa		60-64	65-69	70-74	75-79	80-84	85+	Age-standardised prevalence for all those aged 60 years and over
		All studies (n=12)	Male	1.34	2.02	3.09	5.05	
	Female	2.43	3.68	5.66	9.30	14.35	32.07	
	All	1.74	2.64	4.07	6.71	10.38	23.31	6.38
DSM criteria only (n=10)	Male	1.16	1.70	2.51	3.95	5.86	12.20	5.50*
	Female	1.74	2.66	4.16	6.94	10.86	24.90	
	All	1.23	1.89	2.94	4.91	7.68	17.60	

\*2 studies were not included in the meta-analysis because they did not provide age- and sex- specific prevalence

Both the age- and the age- and sex-specific dementia prevalences generated were slightly higher than the ones presented in 2015. Standardised prevalence for those aged 60 and over was also higher than previously described, 6.38% instead of 4.63% for the age-specific and 7.23% instead of 5.47% for the age and sex-specific prevalence.

The meta-analysis of dementia prevalence included three additional studies compared to the one realised in 2015, two from Nigeria and one from South Africa. The cross-culturally validated 10/66 dementia criteria were used in two of those additional studies, while all the other studies used the DSM (III or IV) criteria. A higher prevalence of dementia was recorded in studies using the 10/66 dementia criteria compared to the DSM-IV diagnostic criteria. When considering only the studies which diagnosed dementia according to the DSM (III or IV) criteria, the age- and age- and sex-specific prevalence of dementia were slightly lower, closer to those estimated in 2015 (Table 2.2). Heterogeneity in age-specific and age- and sex-specific prevalence between studies was reduced (alpha=0.26/0.18). The standardised prevalence of dementia was similar to our previous estimates (5.47%)<sup>7</sup>.

### Estimation of the number of people with dementia

Applying the age- and sex-specific prevalence generated earlier (which should provide the most precise overall prediction of regional prevalence) to the UN population projections<sup>15</sup>, we estimate that 2.13 million people were living with dementia in 2015 (Table 2.4). This number will reach 3.48 million by 2030, and 7.62 million in 2050. Between 2015 and 2050, numbers in the SSA region will increase by 257%, with the most important increases in East and Central SSA.

Table 2.3  
Study characteristics and quality, by region

Reference, by GBD region	Country, region/city	Rural / urban area	Design	Sampling	Residents of institutions	Lower & upper age limits	Dates of fieldwork	Sample size	Numbers interviewed (proportion responding)	Screening instruments	Diagnostic criteria	Second phase					Multidomain cognitive assessment? Disability? Neuroimaging?	
												Time interval	Numbers selected	Number interviewed	Screen negatives	Screen negatives Assessment		Weighting back
<b>SSA West</b>																		
Hendrie et al., 1995 <sup>2</sup>	Nigeria, Ibadan	urban	2 stage	Door-to-door	No	≥ 65	01/05/92-31/03/94	2535	2494 (98.4%)	CSI-D	DSM III-R/ICD10	10 months	279 (423)	214	Yes	Same	Yes	Clinical assessment / ADL / CT scans
Uwakwe and 10/66 Dementia Research Group**	Nigeria, Anambra	rural	1	Catchment area*	No	≥ 65	2003-2007	1238	538 (43.4% of complete interviews)	CSI-D, GMS, 10 words	10/66	n/a	n/a	n/a	n/a	n/a	n/a	WHO-DAS
Guerchet et al., 2009 <sup>12</sup>	Benin, Djidja	rural	2 stage	Catchment area*	No	≥ 65	03/07-04/07	514	502 (97.6%)	CSI-D	DSM-IV	1 month	52	47	Yes	Same	No	Clinical assessment / Psychometric tests / ADL / CDR
Yusuf et al., 2011 <sup>16</sup>	Nigeria, Zaria	urban	1 stage	Systematic random sampling	No	≥ 65	03/07-10/07	322	322 (100%)	CSI-D, CERAD, BDS	DSM-IV / ICD10	n/a	n/a	n/a	n/a	n/a	n/a	CERAD / Stick Design Test
Paraiso et al., 2011 <sup>14</sup>	Benin, Cotonou	urban	2 stage	Random sampling (Proportional)	No	≥ 65	05/08-09/08	1162	1139 (98.0%)	CSI-D	DSM-IV	2 months	154	147	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / CDR
Ogunniyi et al., 2016 <sup>17</sup>	Nigeria, Lalupon	rural	2 stage	Catchment area*	No	≥ 65	05/13-02/14	642	642 (100%)	IDEA	DSM-IV	2-8 months	175	146	Yes	Same	No	Clinical assessment / CHIF
<b>SSA Central</b>																		
Guerchet et al., 2010 <sup>13</sup>	CAR, Bangui	urban	2 stage	Catchment area*	No	≥ 65	10/09-12/09	509	496 (97.4%)	CSI-D / Five-word test	DSM-IV	1 month	188	165	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
	Congo, Brazzaville	urban	2 stage	Catchment area*	No	≥ 65	01/10-03/10	546	520 (95.2%)	CSI-D / Five-word test	DSM-IV	1 month	148	133	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
Guerchet et al., 2013 <sup>18</sup>	CAR, Nola	rural	2 stage	Catchment area*	No	≥ 65	11/11-03/12	501	473 (94.4%)	CSI-D	DSM-IV	2 months	182	117	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
	CAR, Bangui	urban	2 stage	Random sampling (Proportional)	No	≥ 65	01/12-03/12	514	500 (97.3%)	CSI-D	DSM-IV	1 month	161	115	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
Guerchet et al., 2013 <sup>18</sup>	Congo, Gamboma	rural	2 stage	Catchment area*	No	≥ 65	08/12-12/12	529	520 (94.3%)	CSI-D	DSM-IV	1.5 months	284	193	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
	Congo, Brazzaville	urban	2 stage	Random sampling (Proportional)	No	≥ 65	09/12-12/12	537	500 (93.1%)	CSI-D	DSM-IV	3 months	148	131	No	n/a	n/a	Clinical assessment / Psychometric tests / ADL / NPI / CDR
<b>SSA East</b>																		
Longdon et al., 2013 <sup>19</sup>	Tanzania, Hai	rural	2 stage	Catchment area*	No	≥ 70	Not stated	1260	1198 (95.1%)	CSI-D	DSM-IV	Not stated	312	296	Yes	Same	Yes	CERAD
<b>SSA South</b>																		
Vanderpoel et al., 2013 <sup>20</sup>	South Africa, Muangang	urban	1	Catchment area*	No	≥ 65	2003-2007	230	206 (89.6%)	CSI-D, GMS, 10 words	10/66	n/a	n/a	n/a	n/a	n/a	n/a	WHO-DAS

\* Door-to-door, \*\* Unpublished, 2004 – 2006

MMSE = Mini Mental State Examination (-il for the illiterate version)

CSI-D = Community Screening Interview for Dementia

GMS = Geriatric Mental State

DEA = Identification and Intervention for Dementia in Elderly Africans

CERAD = Consortium to Establish a Registry for Alzheimer's Disease

BDS = Blessed Dementia Scale

CHIF = Clinician home-based assessment of impairment in functioning

ADL = Activities of Daily Living

NPI = Neuropsychiatric Inventory

WHO-DAS = WHO Disability Assessment Scale

CDR = Clinical Dementia Rating scale

BOMC = Blessed Orientation-Memory-Concentration Test

BDRS-CERAD = Blessed Dementia Rating Scale - Consortium for the

Establishment of a Registry of Alzheimer's Disease version

ADAS = Alzheimer's Disease Assessment Scale

Psychometric tests = Free and Cued Reminding Test, Zazzo's cancellation

Task, Isaac's Set Test of verbal fluency

These new estimates are slightly higher than those reported in the 2015 World Alzheimer Report (1.63 million in 2015, 2.65 million in 2030 and 5.66 million in 2050)<sup>7</sup>. This increase is driven by both population ageing and the slightly higher prevalence of dementia estimated for SSA. The African region started from a low base but will continue to experience a rapid increase in numbers.

Table 2.4

**Total population over 60, crude estimated prevalence of dementia (2015), estimated number of people with dementia (2015, 2030, 2050) and proportionate increases (2015-2030, 2015-2050)**

GBD Region	Over 60 population (millions, 2015)	Crude estimated prevalence (% 2015)	Number of people with dementia (millions)			Proportionate increases (%)	
			2015	2030	2050	2015-2030	2015-2050
SSA, Central	5.21	4.41	0.23	0.39	0.85	70	269
SSA, East	20.08	4.53	0.91	1.57	3.62	72	298
SSA, Southern	5.36	5.41	0.29	0.41	0.76	41	162
SSA, West	17.70	3.95	0.70	1.11	2.39	59	241
<b>Sub-Saharan Africa</b>	<b>48.35</b>	<b>4.40</b>	<b>2.13</b>	<b>3.48</b>	<b>7.62</b>	<b>63</b>	<b>257</b>

## 2.3 Costs

The global cost of dementia, estimated at US\$ 818 billion in 2015, is unevenly distributed with 87% incurred in high income countries while 58% of people with dementia were living in low and middle income countries<sup>7</sup>. The increase of the global societal costs of dementia reported between 2010 and 2015 was given multiple plausible explanations, including the increases in numbers of people with dementia and/or increases in per person costs.

As estimated costs of dementia depend on the estimated numbers of people living with dementia in each region, we revised the estimation of the costs of dementia in sub-Saharan Africa in 2015.

### 2.3.1 Methods

The estimates of the societal economic cost of dementia provided in this report have been generated using the same general approach as for the 2010 and 2015 World Alzheimer Reports. Costs are estimated at the country level and then aggregated in various combinations to summarise cost by Global Burden of Disease region. For each country, there is a cost per person (per capita) estimate which is then multiplied by the number of people estimated to be living with dementia in that country. The per capita costs are divided into three cost sub-categories: direct medical costs, direct social care costs (paid and professional home care, and residential and nursing home care) and costs of informal (unpaid) care. The base option for costing informal care is an opportunity cost approach, valuing hours of informal care by the average wage for each country.

As in 2015, for countries with no cost data, cost estimations are derived by imputation. The assumption for the imputation is that there is a relationship between a country's per capita GDP and annual per capita direct costs of dementia. For low and middle income countries (LMIC), the partitioning of the imputed total direct costs into direct medical and social care sector costs was derived from a relevant study from China<sup>21</sup> and more information available from the 10/66 Cost of Illness (COI) studies (China, India, Cuba, Peru, Venezuela, Dominican Republic and Mexico)<sup>22</sup>, where two-thirds of the direct costs were medical and one-third derived from the social care sector. These proportions were used as a basis for imputation in many African countries. Data from SSA are still lacking. Compared to the estimates provided in 2015, the update of the costs of dementia in SSA is therefore purely based on the new prevalence figures presented earlier.

To make a forecast on future trends in the societal cost of dementia, we need to estimate trends in the numbers of people living with dementia and trends in the per person costs. Considering the lack of empirical data from SSA regarding resources use and costs, providing forecasts of costs of dementia in the future would only rely on imputations, which is why no projections have been made for this report.

## 2.3.2 Results

The total costs of dementia in sub-Saharan Africa were estimated at **US\$ 6.2 billion** in 2015 (Table 2.5). Our previous estimation was slightly lower (US\$ 4.9 billion) - the difference is only explained by the revision of the numbers of people living with dementia in SSA.

The pattern of distribution of costs between the three major sub-categories (direct medical, social care and informal care) has not changed. As often reported for low or lower-middle income countries, the proportional contribution of direct medical care is modest (19.7% overall) and the contribution of social care costs is low (9.7%). The major contribution to the total costs is attributed to informal care costs (two-thirds to three-quarters). Some of the greatest contributions of informal care were already reported in the African region in the 2010 and 2015 World Alzheimer Reports<sup>3, 7</sup>.

Table 2.5

**Sub-category costs of dementia in 2015 (billion US\$, and percent of total costs), by GBD region**

	Direct medical costs		Direct social sector costs		Informal care costs		Total costs
	US\$ (billions)	Per cent	US\$ (billions)	Per cent	US\$ (billions)	Per cent	US\$ (billions)
SSA, Central	0.1	28.5%	0.1	14.2%	0.2	57.3%	0.4
SSA, East	0.4	20.8%	0.2	10.3%	1.3	68.9%	1.9
SSA, Southern	0.5	16.4%	0.2	8.0%	2.1	75.6%	2.8
SSA, West	0.2	22.8%	0.1	11.2%	0.7	66.0%	1.0
<b>Sub-Saharan Africa</b>	<b>1.2</b>	<b>19.7%</b>	<b>0.6</b>	<b>9.7%</b>	<b>4.3</b>	<b>70.6%</b>	<b>6.2</b>

Per person costs of dementia did not change compared to those presented in the 2015 World Alzheimer Report, as they do not relate directly to the update of the numbers of people living with dementia.

As for societal costs of dementia, the greater contributions to the per person costs were those of informal care costs (more than half for all SSA regions).

Table 2.6

**Costs of dementia per person, in categories, in 2015 (billion US\$, and percent of total costs), by GBD region**

	Direct medical costs		Direct social sector costs		Informal care costs		Total costs
	US\$	Per cent	US\$	Per cent	US\$	Per cent	US\$
SSA, Central	536	28.5%	266	14.1%	1078	57.4%	1880
SSA, East	442	20.8%	219	10.3%	1460	68.9%	2120
SSA, Southern	1552	16.4%	768	8.1%	7170	75.5%	9490
SSA, West	338	22.8%	167	11.2%	978	66.0%	1480

Although the costs of dementia (by sub-category and per person) seem higher in Southern Africa than other regions, those figures need to be interpreted with caution as they are driven by a higher GDP per capita (which is used for imputations) in South Africa. However, income and wealth in South Africa are very inequitably distributed.

## 2.4 Incidence

### 2.4.1 Methods

We recently updated the systematic review of the world literature conducted for the 2015 World Alzheimer Report<sup>7</sup>, identifying population-based studies of the incidence of dementia (defined according to DSM-IV, ICD-10 or similar clinical criteria), including people aged 60 years and over, and for which the field work for the baseline phase started on or after 1st January 1980. The search followed the strategy below:

- Search date: February 2017

- Databases: EMBASE, Global Health, MEDLINE, PsychExtra and PsychInfo
- Search terms: dementia AND (incidence OR epidemiology)

Again, all stages of the search were completed by two independent reviewers (MG and AMP). Papers were excluded at this stage only when the abstract clearly demonstrated that the paper did not meet the above criteria. After a consensus was made on studies that met all criteria, publications from sub-Saharan Africa were selected for inclusion in this report.

### Data extraction

All eligible studies were systematically coded for their study design and characteristics according to the following criteria:

1. Country
2. WHO / Global Burden of Disease World Region (see Appendix A for list of countries and regions)
3. Inclusion of urban or rural areas
4. Start and finish dates for fieldwork
5. Lower and upper age limits
6. Sampling strategy (whole population, catchment area, random sampling, stratified random sampling)
7. Overall sample size
8. Response rate
9. Case ascertainment (community survey only or community + institution survey)
10. Diagnostic criteria (not specified, ICD, DSM, GMS/AGECAT, CAMDEX, other clinical criteria)
11. Presence of clinical diagnosis
12. Diagnostic Instruments (GMS/AGECAT, CAMDEX, MMSE, Dementia Differential Scale, Hachinski Ischemic Index, consensus panel, physical/neurological examination, standardized questionnaire, clinical evaluation, other).

Incidence data was extracted from the studies as follows. According to the data presented in the paper, we extracted numerator (case) and denominator (person-years), incidence and standard error, or incidence and 95% confidence intervals.

Incidence estimates were stratified differently in different publications. To maximise the precision of our meta-analysis, we required incidence estimates in five-year age-bands. If this was not available in the publication, we wrote to the authors to request age-specific incidence data. We could therefore model the effect of age on dementia incidence for all included studies.

### Meta-analytical methods for estimating dementia incidence

As for the meta-analysis of prevalence data, we used a random effect exponential (Poisson) model to assess the effect of age on the incidence of dementia. The alpha coefficient is an estimate of over-dispersion and an index of between study heterogeneity. Age was coded as the mean for each age group reported.

### 2.4.2 Results

While the 2015 World Alzheimer Report included only two studies from a single SSA country: Nigeria<sup>4,23</sup>, three new potentially eligible incidence studies were identified. Two were published between 2015 and 2017 and another study was identified through a conference abstract. Overall, 5 studies (representing 6 cohorts) from two countries, Nigeria and Congo (Republic of) were fully eligible. The characteristics of those studies are given in Table 2.7.

SSA West was the best represented sub-region, with 4 studies, while there was still no evidence regarding dementia incidence for the SSA Eastern and Southern regions.

After data extraction, only four of those studies<sup>24,25,27</sup> could be included in the meta-analysis, case (numerator) and person-years (denominator) could not be extracted for the remaining two<sup>4,26</sup>.

Collectively, the meta-analysed studies included 7,035 older people 'at risk' representing over 20,214 person-years of follow-up. Cohort size and length of follow-up were both higher in Nigerian

Table 2.7  
**Characteristics of the incidence studies in sub-Saharan Africa**

Study, reference	Country, region/ city	Rural / urban	Dates of fieldwork	Lower age limit	Sampling strategy	Case ascertainment	Diagnostic Criterion	Clinical diagnosis	Diagnostic instruments	Mid-year of baseline survey	Follow-up time (mean or *median)	Cohort at risk	Person-years
Indianapolis-Ibadan Dementia Project <sup>4</sup>	Nigeria, Ibadan	Urban	1992 onwards	65	Door-to-door	Community survey	DSM-III/ ICD10	Yes	CSI-D, CERAD, CAMDEX, clinical exam	1994	5.1	2459	Not stated
Indianapolis-Ibadan Dementia Project <sup>24</sup>	Nigeria, Ibadan	Urban	1992 onwards	70	Door-to-door	Community survey	DSM-III/ ICD10	Yes	CSI-D, CERAD, CAMDEX, clinical exam	1992	NS	1174	6158
			2001 onwards							2001	NS	1895	8712
Ibadan Study of Aging <sup>25</sup>	Nigeria, Ibadan	Urban	11/03-08/04	65	Cluster random sample	Community survey	§	Yes	10-WDRT, CHIF §	2004	3.3	1225	3888
Ibadan Study of Aging <sup>26</sup>	Nigeria, Ibadan	Urban	11/03-08/04	65	Cluster random sample	Community survey	§	Yes	10-WDRT, CHIF §	2003	NS	1894	6502
EPIDEMCA-FU** <sup>27</sup>	Congo, Gamboma and Brazzaville	Rural & urban	07/12 – 09/15	65	Catchment area / random sampling	Community survey	DSM-IV	Yes	Free and Cued Reminding Test, Zazzo's cancellation Task, Isaac's Set Test of verbal fluency, Geriatric Depression Scale	2012	2	847	1456

\* NS = not stated. \*\* EPIDEMCA-FU = Epidemiology of Dementia In Central Africa – Follow-up

§ Diagnostic relied on logistic regression models (drawing on data derived from the Ibadan Indianapolis Dementia Project, using the DSM-III / ICD10 criteria) to classify subjects with dementia from those without based on the performance on the 10-WDRT after adjusting for sex and age.

studies than in Congo. For one study, the research diagnostic criteria were not clearly specified; all the others had applied the DSM- III or IV criteria (combined with ICD-10 in one study).

### Estimation of the incidence of dementia

The incidence of dementia increases exponentially with increasing age. For all studies combined, the incidence of dementia doubles with every 7.7 year increase in age, from 4.1/ 1000 person years (pyr) at age 60-64 to 59.8/1000 pyr at age 90+ (see Table 2.8).

Based on the current evidence available, the incidence of dementia in SSA appears to be relatively similar to the incidence estimated for low and middle income countries in the 2015 World Alzheimer Report (according to DSM criteria). Those figures are lower than the dementia incidence estimated in countries with high incomes<sup>7</sup>.

There was significant heterogeneity in the incidence estimates of those four studies combined (alpha = 0.16, 95%CI: 0.00-0.19).

Table 2.8

#### Meta-analysed estimates of dementia incidence, generated from Poisson random effects models

Region	Number of studies included in meta-analysis	Age group							Age- and sex-standardised incidence, for those aged 60+ (using Western Europe as the standard population)
		60-64	65-69	70-74	75-79	80-84	85-89	90+	
Sub-Saharan Africa	4	4.1	6.1	9.2	14.4	22.6	34.4	59.8	13.26

### Estimation of the number of incident cases of dementia per year

The number of annual incident cases of dementia that occurred in SSA was generated by estimating first the numbers of older people at risk (total population in each age group, minus numbers with prevalent dementia), and then applying the incidence rates estimated earlier.

The numbers of new cases increases and then declines with increasing age in each region. In SSA peak incidence is among those aged 70-74 years, while it is for 75-79 in Southern SSA and among those aged 65-69 in West SSA (Table 2.9). We estimated about 367,698 new cases of dementia each year in SSA. These new estimates are slightly lower than annual numbers of new cases estimated in the 2015 World Alzheimer Report. However, the previous estimates were generated by using the age-specific incidence of dementia estimated in all LMIC (including one study in Nigeria) whilst we have now been able to use the age-specific incidence of dementia in SSA (including only studies in SSA).

Table 2.9

#### Estimated annual numbers of incident cases of dementia, by age group and region

Region	60-64	65-69	70-74	75-79	80-84	85-89	90+	Total
SSA Central	9,907	10,860	11,272	10,339	7,546	3,381	1,510	54,815
SSA East	26,238	29,574	30,486	28,669	23,336	11,243	5,406	154,955
SSA Southern	6,567	6,693	6,824	7,516	6,524	5,002	1,681	40,807
SSA West	24,523	26,561	26,180	21,350	12,928	4,394	1,185	117,121
<b>Sub-Saharan Africa</b>	<b>67,234</b>	<b>73,688</b>	<b>74,762</b>	<b>67,875</b>	<b>50,334</b>	<b>24,020</b>	<b>9,785</b>	<b>367,698</b>

## 2.5 Mortality associated with dementia

People developing dementia see their lives shortened by the condition. Although median survival times have been estimated at 7.1 years for people with Alzheimer's disease and 3.9 years for those with vascular dementia<sup>28</sup>, survival times with dementia can vary significantly across individuals. The independent contribution of dementia to mortality is difficult to assess. Dementia is rarely considered as a direct or underlying cause of death, making death certificates unreliable. People with dementia are also likely to have comorbid health conditions that may or not be related to the

dementia process and may precipitate death. Therefore, death of people with dementia cannot be attributed automatically to dementia.

### 2.5.1 Methods

We aimed at reviewing the evidence on mortality risk for people with dementia in sub-Saharan African populations.

We identified studies estimating mortality risk among older people with dementia in longitudinal cohort studies carried out in SSA, through the results of the systematic reviews conducted for the purpose of this report (prevalence and incidence) and by conducting a scoping review of the literature using the search terms ‘dementia AND mortality AND sub-Saharan Africa’.

We extracted estimates for each eligible study, provided as hazard ratios and their 95% confidence interval. A random effect meta-analysis was used to pool estimates. Heterogeneity was examined using Chi<sup>2</sup> test and quantified using Higgins I<sup>2</sup>.

### 2.5.2 Results

We identified 4 studies estimating the risk of death among people with dementia, two from Nigeria<sup>26, 29</sup>, one from Tanzania<sup>30</sup>, and one from the Republic of Congo<sup>31</sup>. All were based on cohort studies previously described in the incidence section (see Table 2.7).

Among all of them, an increased mortality risk was reported for people with dementia (from HR=1.5 (95%CI: 1.2-1.8) in the Ibadan Study of Ageing<sup>26</sup> to HR=6.3 (95%CI: 3.2-12.6) in Tanzania<sup>30</sup>). Overall, a two-fold increased mortality risk for people with dementia (HR=2.3, 95%CI: 1.0-3.5) was estimated in the meta-analysis (Figure 2.1). Relatively similar mortality hazards have been reported in other low and middle countries, with a pooled HR at 2.8 (95%CI: 2.5-3.1) in the 10/66 Dementia Research Group studies in Latin America and China<sup>32</sup>.

In two studies, the effect of dementia severity was investigated. For the Yorubas in Nigeria, the risk for low severity (CDR ≤1) was lower (HR=2.1, 95%CI: 0.7-6.3) than for the high severity group (CDR ≥2) (HR=4.5, 95%CI: 0.8-25.1)<sup>29</sup>. In Congo, greater dementia severity (CDR ≤1 vs. CDR ≥2) was also strongly associated with increased mortality risk (HR=1.9, 95%CI: 1.2-3.0)<sup>31</sup>.

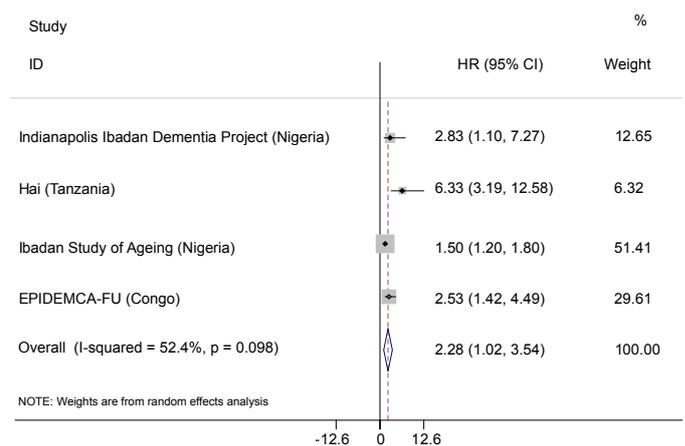
The role of the most common genetic risk factor for dementia, the APOE ε4 allele, was also examined in the Indianapolis Ibadan Dementia Project in Nigeria. Having APOE ε4 alleles was not significantly associated with mortality in Ibadan participants under 75 (HR=1.0, 95%CI: 0.8-1.4) or over 75 (HR=1.2, 95%CI: 0.8-1.7)<sup>33</sup>.

### 2.6 Risk factors

A large number of potential risk and protective factors for dementia and cognitive impairment have been investigated in epidemiological studies worldwide<sup>34</sup>. Research findings suggest that dementia has a lifelong trajectory, with risk clustering around specific periods and often accumulating, sometimes even decades before the onset of the first clinical symptoms<sup>35</sup>. Some risk factors may have an effect in early-life, other may have an influence later in life and interact with the environment over the life course.

In the following section, we will review the evidence on the association of several potential risk factors with the onset of dementia among sub-Saharan populations. Studies were identified through both systematic reviews for prevalence and incidence presented earlier, as well as a scoping review using the search terms ‘risk factor AND dementia AND sub-Saharan Africa’. We principally focused this review on population-based studies, where the participants were living in the community.

Figure 2.1  
Forest plot for studies estimating the mortality risk for people with dementia in SSA



### 2.6.1 Genetic factors

The Apolipoprotein E (APOE) gene appears to have been studied more than other dementia-related genes/loci in Africa<sup>36</sup>. Existing in 3 allelic forms (APOE  $\epsilon$ 2, APOE  $\epsilon$ 3, APOE  $\epsilon$ 4), APOE  $\epsilon$ 2 is protective whereas APOE  $\epsilon$ 4 is associated with age-at-onset and increases the risk of Alzheimer's Disease in a dose-dependent manner among Caucasians. Frequencies of APOE  $\epsilon$ 4 vary widely in sub-Saharan Africa: 19.8% (Yoruba Nigerians), 32% (Kikuyu Kenyans) and 40% (in the Pygmies of Central African Republic)<sup>37</sup>. Nevertheless, APOE  $\epsilon$ 4 showed a lack of association with Alzheimer's Disease (AD) among Yoruba Nigerians<sup>38</sup> and Kikuyus of East Africa<sup>39</sup> or with cognitive impairment in Benin<sup>12</sup>. More recent longitudinal data from an enriched cohort of the Yoruba subjects demonstrated a significant association between APOE  $\epsilon$ 4 homozygosity and AD and a weak association between one allele  $\epsilon$ 4 and incident AD and cognitive decline<sup>40</sup>. The possibility of gene - gene and/or gene-environment interactions which have varied over time offers plausible explanations for this observed trend.

While other mutations have been reported in the Amyloid Precursor Protein (APP), Presenilin 1 (PSEN1) and Presenilin 2 (PSEN2) gene among North African populations<sup>41</sup>, a study of a large South African Xhosa family with early onset AD (affecting 12 individuals across 4 generations) yielded a novel mutation in the PSEN1 gene and novel CHMP2B polymorphisms have been described in another South African family with Frontotemporal dementia (FTD)<sup>42</sup>.

### 2.6.2 Age and sex

Increasing age is the most consistent risk factor for dementia worldwide. It was also the most consistent across studies undertaken in SSA where an increased risk of dementia with advancing age was also described<sup>2, 12, 14, 16, 19, 43-47</sup>. While prenatal stress, early life exposure to infectious diseases of poverty, malnutrition and violence might cause early death or influence the ageing process and reduce longevity for people in developing countries, life expectancy has been rising in SSA in addition to exponential population growth, impacting the future burden of dementia in the region.

Dementia and AD were also significantly associated with the female sex in several SSA studies. The female sex is associated with a 2- to 8-fold increased risk<sup>14, 25, 43, 46</sup>, largely due to their longer lifespan. It conforms to nearly all studies in LMIC confirming that women are marginally more likely to develop dementia and AD, particularly in very old age, on the basis of the greater longevity in women<sup>48</sup>.

### 2.6.3 Vascular disease risk factors

Eighty-five percent of the global burden of non-communicable diseases (NCDs) occurs in LMICs including those of SSA<sup>49</sup> and cardiovascular diseases (CVDs) account for most of this burden. The current epidemiologic transition from infectious diseases to non-communicable but modifiable chronic disorders has resulted from gradual adoption of a Western lifestyle that includes excessive caloric intake, unhealthy diet, and decreased physical activity. Hypertension, one of the major NCDs, has the highest global burden in Africa with a prevalence of 46% according to the WHO<sup>50</sup>. The burdens of type 2 diabetes, obesity, hyperinsulinemia and dyslipidaemia are also rising in SSA with attendant increasing rates of stroke, a major outcome of vascular brain injury.

Accumulating evidence suggests that stroke injury and vascular factors increase risk for AD and other dementias<sup>51</sup>. Hypertension, hypercholesterolemia and peripheral arterial disease in particular have demonstrated significant associations with dementia and AD in SSA studies<sup>43, 52-54</sup>, with increased odds between 1.5 and 2.5 to develop dementia (Table 2.10).

### 2.6.4 Literacy and education

Robust evidence has accrued from prospective cohort studies, systematic reviews and meta-analyses demonstrating illiteracy or low educational achievement to be a robust risk factor for dementia worldwide<sup>34</sup>. Although more education does not necessarily protect individuals from developing neurodegenerative and vascular neuropathology, it does mitigate the impact of pathology on the clinical expression of cognitive decline and dementia<sup>55</sup>. This explains the 'Cognitive Reserve' hypothesis as a metric of educational attainment.

The findings from studies on the association between education and dementia are mixed in SSA. While several studies demonstrate an inverse association<sup>56-58</sup>, some show a lack of

## Box 1

**HIV-associated neurocognitive impairment in sub-Saharan Africa**

Worldwide, over 35 million individuals are infected with HIV, of whom over 24 million live in sub-Saharan Africa<sup>71</sup>. In high-income countries (HICs), combination antiretroviral therapy (cART) has greatly reduced opportunistic infections and near-normalised life expectancy, but long term complications including cognitive impairment and dementia are becoming increasingly prevalent<sup>72</sup>.

HIV-associated neurocognitive disorders (HAND) are defined by American Academy of Neurology (AAN) criteria reflecting the range of cognitive impairments currently seen in people with HIV<sup>73</sup>. These are:

- HIV-associated dementia (HAD),
- HIV-associated minor neurocognitive disorder (MND),
- Asymptomatic Neurocognitive Impairment (ANI).

Mechanisms are complex and include opportunistic infections of the central nervous system (CNS), direct neurotoxic effect of the HIV virus, long term inflammatory processes in the CNS and neurotoxic effect of cART<sup>74, 75</sup>. Access to cART reduces the prevalence and severity of HAND, but does not prevent it<sup>76-78</sup>.

In HIC, with widespread access to cART incidence of HAND is decreasing but prevalence increasing due to near-normalised life expectancy. HAD is becoming uncommon, and less severe HAND (ANI and MND) predominate<sup>72</sup>. This ageing of populations living with HIV has resulted in new challenges. Both HIV infection and long term cART treatment are associated with premature ageing, including accelerated Alzheimer's disease and vascular disease<sup>79, 80</sup>. Older individuals with HIV are therefore likely to be at increased risk of these dementias as well as HAND.

As the population of SSA continues to age, it is likely that greater numbers of older adults will be affected by HIV. The scale-up of cART in SSA has led to an increase in HIV prevalence due to increasing life expectancy in treated individuals<sup>81</sup>. The proportion of HIV positive individuals aged 50 and over in SSA is predicted to triple by 2040, and to increase from one in seven, to one in four by 2040<sup>82, 83</sup>.

Epidemiological studies of neurodegenerative dementia amongst the growing population of older adults in SSA, have not generally screened for HIV or HAND<sup>84</sup>. All existing published data on HAND relate to younger adults (mean age ranging from 29.5 to 42.7)<sup>85-87</sup> and many studies specifically exclude older adults.

Few studies of HAND in Africa report prevalence using AAN criteria. Early studies of HAD (previously known as the AIDS dementia complex) describe a subcortical dementia occurring in the context of advanced HIV infection, opportunistic infections and low CD4 count prior to the availability of cART and associated with poor prognosis. These hospital-based clinical prevalence studies, conducted during the original AIDS epidemic, report prevalence of between 11.4% and 41% in young adult inpatients, reflecting differing clinical diagnostic criteria<sup>88-90</sup>. The international WHO study reported prevalence of 19% in Zaire (now Democratic Republic of Congo) during this epidemic<sup>91</sup> using detailed neuropsychological assessment. More recent clinic-based studies using AAN criteria report high, but varying HAND prevalence across different SSA settings (see Table 2.A)<sup>92-96, 100</sup>. One retrospective hospital-based study of 175 HIV+ individuals aged 55 and over in Congo (Republic of) reported a high prevalence of neuropsychiatric disorder (49.7%) but did not assess for cognitive impairment or confusion<sup>99</sup>.

Most studies report HAND using the International HIV Dementia Scale (IHDS), a brief screening tool originally developed and validated in Uganda<sup>100</sup>. Reported prevalence of HAND using the IHDS is generally higher than that using standard diagnostic criteria but varies markedly between studies, ranging from 14% to 85% in studies completed in Uganda<sup>101, 102</sup>, Central African Republic (CAR)<sup>87</sup>, Ethiopia<sup>103</sup>, Malawi<sup>104</sup>, Botswana<sup>105</sup> and Cameroon<sup>106</sup>. The IHDS was validated in a relatively well-educated sample<sup>100</sup> unlikely to be typical of other areas of SSA. A recent meta-analysis reported the diagnostic accuracy of the IHDS for HAND to be limited (sensitivity 64.3%, specificity 49.6%)<sup>107</sup>.

Existing SSA studies consistently report cognitive impairment in individuals with HIV compared with HIV negative controls, especially in cognitive domains known to be most affected in HIV (executive function, processing and motor speed and verbal learning)<sup>93, 98, 108-110</sup>. As in HICs, there is evidence that cART improves but may not normalise cognitive function<sup>111</sup>.

Some initial evidence suggests that HAND prevalence may be affected by HIV clade<sup>112</sup> and that cardiovascular disease increases risk. Increasing age and lower educational level are relatively consistently associated with HAND<sup>92, 105, 106</sup>. HIV-related factors such as disease stage, CD4 count and viral load are associated with HAND in some studies<sup>92, 97, 113-115</sup> but not others<sup>92, 104, 114</sup>.

Generally, existing SSA studies (of prevalence or risk factors for HAND) are difficult to compare. The cohorts studied differ markedly in the diagnostic criteria used, proportion of individuals on cART, HIV disease stage and educational background<sup>85, 86</sup>. These existing, albeit limited data relate almost exclusively to young adults. Our current knowledge of prevalence and risk factors for HAND in older adults is limited to data from settings outside SSA. Studies of HAND in older people in SSA have not yet taken place and this is a current and urgent knowledge gap.

Table 2.A

**Studies of HAND by AAN (2007) criteria in SSA**

Author, Year	Location	Population	Age	HAND prevalence	Other/risk factors
Kelly et al., 2014	Blantyre, Malawi	HIV+ adults on cART	Med 39(18-71)	3% HAD 12% MND 55% ANI	Symptomatic HAND not associated with symptom score
Joska et al., 2011	South Africa, (primary care)	170 HIV + adults not on cART (commencing treatment)	Mn 29.5 (3.65) Range 18-35	42.4% MND 25.4% HAD	Significant association of older age and low education with HIV dementia. Trend towards lower CD4
Yusuf et al., 2017	Nigeria	418 HIV+ adults on cART for at least one year	Mn age 37.2 SD 9.3	21.5% 9.6% MND/HAD	
Sacktor et al., 2015	Uganda (rural)	299 HIV+ not on cART	Mn age 36 (SD 9)	27% HAD	D and A clades. No difference in dementia prevalence between HIV +/- groups, only MND/ANI
Oshinaike et al., 2012	Nigeria, (hospital)	208 HIV+	Mn age 36.8	42.3% HAND	
Yakasai et al., 2015	Nigeria (teaching hospital)	80 HIV + (50% on cART) 40 HIV -		HAD 23% off -cART (5% on cART) Symptomatic HAND 40% in cART - and 30% in cART +	Comprehensive neuropsych. battery and functional assessment (but possibly no clinical interview) used for AAN HAND diagnosis

association<sup>19, 43, 46, 59</sup>. Low literacy is often linked to poverty or lower socioeconomic status, which is also associated with poorer health, lower access to health care, and increased risk of dementia. However in African communities where formal education systems may be less developed, informal and traditional systems of instruction ensure that individuals are well trained to understand and cope with the environmental and socioculturally determined demands that life brings their way. This may explain the lack of association between literacy / 'formal' educational attainment and dementia in some studies. Formal education may not be a good indicator of cognitive ability in this context<sup>43</sup>.

### 2.6.5 Early-life factors

Early-life risk factors including factors related to perinatal circumstances (such as birth weight and intrauterine environment) as well as factors affecting the growth and development of the brain or body, such as nutrition, have been shown to influence the risk of dementia in later life. Although well-researched risk factors in longitudinal studies in HIC, early-life risk factors have been understudied for now in the SSA region. As early-life events can easily be subjects to recall bias, the establishment of a causal link between those and the onset of dementia in late-life can be challenging.

For now, only cross-sectional studies in Central Africa have investigated the association between early-parental death and dementia. In the EDAC (Epidemiology of Dementia in Central Africa) study, Guerchet and colleagues found a significant association between the death of one parent during childhood and dementia in late life<sup>43</sup> (Table 2.10). No stressful life event occurring during childhood was associated with dementia in the same countries a few years later<sup>60</sup>.

### 2.6.6 Lifestyle factors

Lifestyles including dietary habits, physical activity, smoking and alcohol use are often interrelated and are usual targets for optimal cardiovascular and brain health as well as dementia prevention.

The relationship of alcohol with dementia has been described as a 'J-' or 'U-' shaped relationship with abstainers and heavy drinkers having higher risk<sup>61</sup>. The findings from African studies on the relationship between alcohol and dementia are mixed with Pilleron et al. showing protective effect<sup>62</sup> while Gureje et al. demonstrated a deleterious effect<sup>44</sup> (Table 2.10).

Undernutrition is a major problem among older people in SSA with up to 96 % of participants demonstrating nutritional vulnerability and 18% undernourished in a Nigerian study on nutritional assessment in elderly Yorubas<sup>63</sup>. Nutritional factors associated with dementia in African populations include reduced body mass index – as an index of undernutrition<sup>64, 65</sup> and lower consumption of oleaginous foods<sup>62</sup> while pre-stroke daily fish intake was found to be protective against early cognitive impairment among stroke survivors<sup>56</sup>. The low incidence of dementia in the Yoruba Nigerians was consistent with their traditional low calorie and low fat diet consisting of grains, yam tubers (*Dioscorea rotundata*), vegetables, and some fish<sup>48</sup>.

### 2.6.7 Psychosocial and psychological factors

There is a weight of evidence from previous studies linking depression and subsequent onset of dementia, even though it remains to be disentangled whether the depression is a prodromal syndrome which comes before the full blown disease (dementia) or whether depression is an independent risk factor for dementia<sup>66</sup>.

The EDAC study in Central Africa found a significant cross-sectional association between depressive symptoms at time of diagnosis and dementia (OR=3.50, 95%CI: 1.56-7.82)<sup>43</sup>. There is also a body of evidence suggesting that personality types that demonstrate proneness to psychological distress may be more at risk of dementia. It was found in the Indianapolis – Ibadan Dementia Project that personality changes could predict future dementia irrespective of changes in cognition or functional status<sup>67</sup>. An association between Dependent Personality Disorders was described among older people in Congo but not in Central African Republic<sup>68</sup> (Table 2.10).

Investigating social network in the older populations, living with others was found protective against dementia<sup>69</sup> in Nigeria while social isolation or a poor social network were risk factors of prevalent or incident dementia in SSA<sup>25, 26, 70</sup>.

### 2.6.8 Summary

Overall, studies of risk factors of dementia have a similar coverage to that of prevalence and incidence studies, with the bulk of the evidence coming from West SSA (especially Nigeria) and Central SSA. Although age and sex seem to be consistently associated with dementia in SSA studies, the evidence around other risk factors is more patchy, and this needs to be more thoroughly investigated. Education and the APOE  $\epsilon 4$  allele, strong risk factors of dementia in HIC, showed very mixed effects in SSA populations, which might be explained by several hypotheses (gene-gene and/or gene-environment interactions, lack of power, cultural factors). The strongest evidence on modifiable risk factors is probably the association of dementia with vascular risk factors, while the evidence on early-life, psychological, psychosocial and lifestyle factors remains tentative. Most importantly, this evidence relies mainly on studies with a cross-sectional design, which cannot establish any causal relationship between dementia and those potential risk factors.

## 2.7 Conclusion and recommendations

This chapter assembles, for the first time, evidence on the incidence as well as the prevalence of dementia, the societal economic cost of dementia, mortality risk, and the potential for prevention in sub-Saharan Africa. This work has benefited from the recent expansion of the evidence base on the epidemiology of dementia in the region. Considering the direct evidence of the accumulated data, the earlier impression that the prevalence of dementia is much lower in sub-Saharan Africa compared to high income countries is now fading. The current evidence base, and the detailed estimates provided, while still provisional, constitute the best currently available basis for policy-making, planning and allocation of health, welfare and population prevention resources.

Thoroughly reviewing the research carried out up to now on dementia epidemiology in population surveys, we have identified a new set of studies for the sub-Saharan region. While the evidence on dementia prevalence has considerably expanded since the 2009 World Alzheimer Report, the evidence on dementia incidence and mortality have also improved. We are therefore slowly moving away from single estimates for the whole sub-Saharan region for most of the epidemiological indicators. However, the evidence on risk factors of dementia in the region is not very strong for now, remaining tentative for most of the modifiable risk factors and mainly relying on cross-sectional studies rather than longitudinal ones.

These updated reviews suggest that our previous estimates certainly underestimated the scale of the dementia epidemic in sub-Saharan countries. The upward revision of both prevalence of dementia and numbers of people living with dementia does not imply that prevalence has changed recently. Rather, improvements in the extent and quality of the available evidence have improved the precision of our estimates.

Overall, our reviews suggest:

- A modest increase in dementia prevalence, from 5.5% to 7.2% for the age- and sex-standardised dementia prevalence for all four sub-Saharan regions, coming closer to the prevalence reported for high income countries,
- A consequently modest increase in costs of dementia in SSA, with a great contribution to informal care costs for all regions,
- An incidence of dementia for all 4 SSA regions slightly lower than was estimated for all LMIC in 2015,
- A 2-fold mortality risk for people with dementia in SSA, relatively similar to other LMIC.

However, our reviews highlight continued deficiencies in research evidence. It is therefore important to underline the main limitations.

### Coverage

Despite a modest improvement in coverage for the West and Central SSA regions over the last decade, Southern and East SSA are still represented by single studies which cannot provide an accurate description of the epidemic compared to their population size. SSA is expected to experience rapid population ageing. Prevalence, incidence and mortality risk are almost, if not entirely, unknown for some regions and they may change over time considering the simultaneous rise in non-communicable diseases in the region. Studies of risk factors of dementia have a similar coverage to that of prevalence and incidence studies; consequently almost no evidence is available for the East and Southern SSA.

The need for descriptive studies is still huge. It may seem elementary but such studies are necessary to increase awareness among policy makers and stakeholders, and to improve the accuracy and recency of figures for planning and allocation of resources.

### Quality

Although the overall quality is high in dementia studies in SSA, the misapplication of the multiphase study design was seen in 50% of the studies, with no screen negatives included at the second stage and/or no weighting back to estimate the correct prevalence. Therefore, previous recommendations can be reiterated. Research funders, ethics committees and journals should encourage the application of the correct procedure by not funding or approving faulty designs or not publishing findings if the analyses are not correctly performed or limitations not clearly acknowledged. The effect of incorrect application of two-stage designs on dementia prevalence is difficult to quantify here although it should lead to an under-estimation of true dementia prevalence. When multistage designs are implemented, measures should also be taken to prevent the loss of follow-up between screening and diagnostic stages, the main one being to minimise the delay between the two stages.

The proportion of studies that had to be excluded from the meta-analyses for dementia prevalence or incidence because numerators (cases) and denominators (total population or person-years) were not reported was lower than in other regions. However, characteristics of the studies (sampling, diagnostic criterion, follow-up time) were also not always clearly reported. Despite the existence of reporting guidelines (like the STROBE<sup>116</sup>) to help increase the quality of published health research, it appears that authors, peer-reviewers and journal editors are not yet all following those. Some recent incidence studies have included sensitivity analyses to examine the robustness of their estimates taking into account the changes in cohort composition, length of follow-up or loss of follow-up<sup>24,27</sup>. Conducting verbal autopsies during follow-up to assess whether the older people have developed memory problems / dementia-like symptoms before death is useful for estimating the impact of attrition and the number of possible incident cases of dementia who died before diagnosis can therefore be estimated, and can be modelled to provide an alternative incidence estimate. Considering the high mortality rates observed among older populations in low and middle income countries, we would recommend the use of sensitivity analyses when possible in future studies.

Altogether, study quality was strengthened by the systematic use of multi-domain cognitive batteries and informant interviews during dementia assessment but there is still room for improvement on the correct implementation of multistage designs and their analysis, and adequate description of the studies when the time to disseminate the results comes.

### Heterogeneity

Considering the limited evidence available, modelling prevalence and incidence in this review assumed that both indicators were uniform within the sub-Saharan region. However, significant heterogeneity was found in both prevalence and incidence estimates across sub-Saharan Africa. Given the diversity of cultures, languages, levels of development, health and risk profiles, lifestyles, as well as genetic background existing in the SSA region, this is not surprising. Beyond the statistical heterogeneity, the level of similarity of methods and instruments to assess dementia used in these studies is certainly high compared to other GBD regions. The Community Screening Interview for Dementia (CSI-D) was a consistent screening instrument in prevalence studies while the majority of prevalence and incidence studies followed the DSM-IV criteria for dementia diagnosis. Standardisation of study procedures, which would reduce methodological variability, seems like an achievable goal in this region. The new DSM-V criteria and the use of one-phase designs might have to be considered but cross-cultural adaptations might still be necessary and validity of both in this context has to be established. The study of temporal trends in the coming decades will require maintaining a constant methodology over time. As research on dementia in SSA is actively developing, it might be timely to reach a consensus regarding standardisation of study methods.

### Risk factors and potential for prevention

Despite growing evidence on HIV-associated dementia (HAND) in Southern SSA, only younger populations have been included and a current and urgent knowledge gap has been identified for older populations in SSA. When feasible, including HIV screening in the future generations of population-based studies of dementia would help in filling this gap.

Table 2.10  
Characteristics of the epidemiological studies on the modifiable risk factors of dementia in SSA

	Reference	Country, region	Design	Population, sample size	Exposure	Outcome Measurement	Effect size (95% CI)
Vascular Factors	Hall et al., 2006 <sup>53</sup>	Nigeria, Ibadan	Longitudinal	≥ 70 yrs, n=1075	Cholesterol levels and LDL	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	Increasing levels of cholesterol levels and LDL associated with increasing risk of AD in individuals without the APOE-ε4 allele (respectively OR=1.015, p=0.025 and OR=1.017, p=0.023) but not in those with APOE-ε4 in Yoruba subjects
	Ogunniyi et al., 2011 <sup>54</sup>	Nigeria, Ibadan	Longitudinal	≥ 65 yrs, n=2494	Hypertension	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	aOR=1.52 (95%CI: 1.01-2.30)
	Guerchet et al., 2012 <sup>43</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	Hypertension	Dementia: DSM-IV	aOR=1.72 (95%CI: 1.03-2.85)
	Guerchet et al., 2013 <sup>52</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	Peripheral artery disease (measured by Ankle Brachial Index)	Dementia: DSM-IV	aOR=2.37 (95%CI: 1.31-4.26)
Education	Ochayi et al., 2006 <sup>59</sup>	Nigeria, Central	Cross-sectional	≥ 65 yrs, n=280	Education (none vs primary)	Dementia: Community Screening Interview for Dementia (cutpoint)	Lack of association between level of education and dementia (OR not shown)
	Ogunniyi et al., 2006 <sup>46</sup>	Nigeria, Ibadan	Longitudinal	≥ 65 yrs, n=1255	Education (in years)	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	aOR=0.81 (95%CI: 0.53-1.07)
	Chen et al., 2010 <sup>39</sup>	Kenya, Nyeri	Case-control	≥ 70 yrs, n=184 (84 cases and 100 controls)	Education (in years)	Dementia : DSM IV and ICD-10	No association between years of education and dementia status.
	Paraíso et al., 2011 <sup>14</sup>	Benin, Cotonou	Cross-sectional	≥ 65 yrs, n=1137	Primary school vs. none	Dementia Diagnosis: DSM-IV, NINCDS-ADRDA	Differences in level of education did not affect dementia prevalence
	Guerchet et al., 2012 <sup>43</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	No education (vs primary)	Dementia: DSM-IV	For men: aOR=0.52 (95%CI: 0.14-1.93); for women: aOR=2.41 (95%CI: 0.99-5.85)
	Toure et al., 2012 <sup>47</sup>	Senegal, Dakar	Cross-sectional	≥ 65 yrs, n=507	Illiteracy	Dementia: Aging in Senegal test (cutpoint)	aOR=2.76 (95%CI: 1.23-6.20)
	Longdon et al., 2013 <sup>19</sup>	Tanzania, Hai	Cross-sectional	≥ 70 yrs, n=1198	Education (none vs primary)	Dementia: DSM-IV	aOR=0.69 (95%CI: 0.40-1.20)
	Paddick et al., 2013 <sup>58</sup>	Tanzania, Hai	Cross-sectional	≥ 70 yrs, n=1198	Education (none vs primary)	Dementia: 10/66 criteria	aOR=2.76 (95%CI: 1.23-6.10)
	Akinyemi et al., 2014 <sup>56</sup>	Nigeria, Ibadan	Cross-sectional	Stroke survivors: ≥ 45 yrs, n=143	Low education	Post -stroke cognitive impairment: ASA/AHA and DSM IV criteria	aOR=5.09 (95%CI: 2.17-11.95)
Early - life factors	Guerchet et al., 2012 <sup>43</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	Death of one parent during childhood	Dementia: DSM-IV	aOR=1.72 (95%CI: 1.01-2.93)
	Lifestyle factors						
	Ochayi et al., 2006 <sup>59</sup>	Nigeria, Central	Cross-sectional	≥ 65 yrs, n=280	Undernutrition: BMI < 18.5 kg/m <sup>2</sup>	Dementia: Community Screening Interview for Dementia (cutpoint)	aOR=3.5 (95%CI: 1.2-9.9)
	Gureje et al., 2006 <sup>44</sup>	Nigeria, Southwest	Cross-sectional	≥ 65 yrs, n=2152	Lifetime history of alcohol	Dementia: 10-word delayed recall test and CHIF	aOR=1.92 (95%CI: 1.38-2.79)
	Ogunniyi et al., 2011 <sup>54</sup>	Nigeria, Ibadan	Longitudinal	≥ 65 yrs, n=2494	Body Mass Index	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	Subjects with incident dementia declined 0.19 kg/m <sup>2</sup> per year more than the normal
	Guerchet et al., 2012 <sup>43</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	Body Mass Index <18.5 (undernutrition)	Dementia: DSM-IV	aOR=1.77 (95%CI: 1.02-3.06)
	Pilleron et al., 2015 <sup>62</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=2002	Lower consumption of oleaginous food	Dementia: DSM-IV; MCI: Petersen's criteria	MCI: aOR=3.7 (95%CI: 1.4-9.9) & dementia: aOR=2.8 (95%CI: 1.0-7.7)
					Alcohol Consumption		aOR=0.3 (95%CI: 0.1-0.8)
	Akinyemi et al., 2014 <sup>56</sup>	Nigeria, Ibadan	Cross-sectional	Stroke survivors: ≥ 45 yrs, n=143	Fish intake	Post -stroke cognitive impairment: ASA/AHA and DSM IV criteria	Pre-stroke daily fish intake was protective: aOR=0.39 (95%CI: 0.15-0.89)
Psychosocial factors	Pilleron et al., 2015 <sup>65</sup>	CAR	Cross-sectional	≥ 65 yrs, n=2002	Undernutrition: mid-upper arm circumference (MUAC) <24 cm, BMI<18.5, or arm muscular circumference (AMC) < 5th percentile	Dementia: DSM-IV; MCI: Petersen's criteria	CAR: MUAC - aOR=1.8 (95%CI: 1.4-2.4), BMI - aOR=2.3 (95%CI: 1.6-3.1), AMC - aOR=2.3 (95%CI: 1.1-4.6)
		Congo					Congo: MUAC - aOR=1.8 (95%CI: 0.9-3.7), BMI - aOR=2.2 (95%CI: 0.9-5.8), AMC - aOR=2.6 (95%CI: 0.8-9.0)
	Ogunniyi et al., 2000 <sup>69</sup>	Nigeria, Ibadan	Cross-sectional	≥ 65 yrs, n=2494	Living with others	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	aOR=0.06 (95%CI: 0.01-0.49)
	Smith-Gamble et al., 2002 <sup>67</sup>	Nigeria, Ibadan	Longitudinal	≥ 65 yrs, n=2494	Personality change	Dementia: DSM-III-R/ICD-10; AD: NINCDS-ADRDA	OR=2.0
	Gureje et al., 2011 <sup>25</sup>	Nigeria, Southwest	Longitudinal	≥ 65 yrs, n=2149	Poor social engagement (no participation in family or communities activities)	Dementia: 10-word delayed recall test and CHIF	aOR=2.0 (95%CI: 0.8-5.1)
	Guerchet et al., 2012 <sup>43</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=977	Depressive symptoms (Goldberg's scale)	Dementia: DSM-IV	aOR=3.50 (95%CI: 1.56-7.82)
	Toure et al., 2012 <sup>47</sup>	Senegal, Dakar	Cross-sectional	≥ 65 yrs, n=507	Low social network (3 or less contacts with family per week)	Dementia: Aging in Senegal test (cutpoint)	aOR=4.37 (95%CI: 1.80-10.61)
	Pilleron et al., 2014 <sup>68</sup>	Congo	Cross-sectional	≥ 65 yrs, n=2002	Dependent personality disorder (PDQ-4+)	Dementia: DSM-IV; MCI: Petersen's criteria	Congo: aOR=4.8 (95%CI: 2.0-11.7)
		CAR					No association in CAR
Pilleron et al., 2015 <sup>60</sup>	Central Africa (CAR / Congo)	Cross-sectional	≥ 65 yrs, n=2002	Stressful life events	Dementia: DSM-IV; MCI: Petersen's criteria	Associations with MCI: total number of SLEs (OR = 1.1, 95%CI: 1.0-1.2), number of SLEs from the age of 65 (OR = 1.2, 95%CI: 1.0-1.3), and serious illness in a child when the participant was aged 65 or more (OR = 2.8, 95%CI: 1.6-4.6). No association with dementia	
Ojagbemi et al., 2016 <sup>26</sup>	Nigeria, Ibadan	Longitudinal	≥ 65 yrs, n=2149	Low occupational status	Dementia: 10-word delayed recall test and CHIF	HR=3.2 (95%CI: 1.3-8.0)	

Longitudinal studies of dementia in the United States, Rotterdam (Netherlands), Stockholm (Sweden) and Britain (CFAS) have reported recent decreases in prevalence and incidence rates<sup>117</sup>. The reasons adduced for the observations include better prevention/control of vascular diseases and decline in stroke incidence, higher educational attainment and healthier lifestyles. Given the fact that the profile of vascular risk factors for dementia in Africa might largely be similar to those reported from these high income countries, and in absence of stronger evidence in SSA, African countries as other LMIC regions might benefit from adopting measures aiming at controlling vascular factors as well as improving education and nutrition in order to stem the looming dementia epidemic predicted for these regions.

### Absence of evidence on costs

The main limitation regarding the estimation of costs of dementia in sub-Saharan Africa is that those are mainly based on imputations (see methods), as no original data has been published yet on resource use and costs of dementia in sub-Saharan Africa. Descriptions of care systems and amounts of informal care provided for at least one country in each of the regions would greatly contribute to having more reliable estimates, on which stakeholders and policymakers could confidently rely.

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## Personal story

# South Africa – Mr C



**M**rs C and her husband live in a house in Umlazi, a township outside Durban. They have two sons and a daughter. Around two years ago, Mr C's behaviour started to change. He was repeating himself and kept telling stories of his youth, and on many occasions he would get lost. On one such occasion, he was travelling with a friend to Durban. When his friend was busy, he slipped away, asking a stranger for a lift to Inchanga - the area where he grew up. When they arrived in Inchanga, the man who gave him a lift soon realised that Mr C was confused and did not recognise the area. He took him to Pietermaritzburg Police station.

In the meantime, the friend whom Mr C had travelled with realised he had disappeared, and alerted Mrs C. That whole day and night, she and her children searched for Mr C, stopping at various hospitals, the railway station, and the morgue – frantically trying to find him. The following day, the Pietermaritzburg Police contact the Umlazi Police station informing them of Mr C's whereabouts. The family were extremely relieved, but knew they had to take measures to ensure his safety. They had a family meeting, and it was decided that Mrs C would quit her job to become a full-time carer for her husband.

Around this time, in 2015, she contacted Alzheimer's South Africa for information and assistance. She attended a 'Caring for the person with dementia' course at the Alzheimer's South Africa office in Pinetown. The family employed three carers to assist Mrs C, and to take care of Mr C's daily and nightly needs. Mr C spends much of his time in bed and needs assistance to eat, but he goes out into the yard, with assistance, to exercise his legs and retain as much mobility as possible. The family follows a holistic approach to his care, with support from a neurologist, minister of religion, physiotherapist, nurse, community development worker, as well as family and friends.

Having realised that other families in the area are facing similar challenges, Mrs C has opened her home to allow a community development worker from Alzheimer's South Africa to run a support group for carers and family members of people affected by Alzheimer's disease, which meets on a monthly basis. Mr C's experience shows how a loving and caring family, with support, can ensure that a loved one affected by Alzheimer's disease can live a higher quality life, retaining their dignity and self-respect.

## CHAPTER 3

# Living with dementia in sub-Saharan Africa: systematic review of qualitative evidence



### 3.1 Methodology

The value of qualitative evidence alongside findings from quantitative methodologies is increasingly recognised in health sciences. Qualitative methods offer the opportunity to put flesh on the bones of statistics by foregrounding individual real-life experiences of people living with illness and their caregivers. Understanding beliefs, perceptions and experiences relating to illness, care, help-seeking and treatment are critical to understanding the nature of the problem and designing interventions and services that are person-centred and which meet locally defined needs. Qualitative evidence about dementia in SSA is therefore an essential complement to quantitative understanding of the scale of the problem.

We carried out a systematic review of the scientific qualitative evidence on the experience of living with dementia in SSA. We were interested in all kinds of qualitative research: findings based on studies using any kind of qualitative methodologies. This included: open-ended in-depth interviews, focus-group discussions and ethnographic methods. These methodologies differ from quantitative research in that they aim to capture the voices, perceptions and experiences of participants through more open-ended interactions with researchers, which are often more naturalistic in tone. Research participants were: people living with dementia (PLWD), family caregivers of PLWD, paid caregivers (delivering treatment or care in the homes of PLWD or at public or private day care or residential facilities), healthcare workers, traditional and faith healers with experience of treating PLWD, community members.

We used the following search strategy to identify relevant articles. We used the search terms “(dementia OR Alzheimers)” AND “(qualitative OR anthrop\* OR ethnog\* OR cultural OR understand\* OR belie\* OR experien\* OR phenomenol\*)” AND “(Africa OR sub-Saharan Africa OR {list of countries included in SSA according to World Bank definition})”. We searched four databases: Embase, MEDLINE, Global Health and PsychInfo. Following this, we checked the reference lists of all selected articles. Chapter authors, experts in ageing in SSA/qualitative methodologies, reviewed the list of selected articles and made additional suggestions for possible inclusions.

#### **Inclusion criteria:**

- Studies reporting results of primary qualitative research, carried out in SSA countries
- Studies published in peer-reviewed scientific journals
- Studies focussed upon dementia, i.e. with participants who: have a diagnosis of dementia or have symptoms consistent with this diagnosis; carers of these people; healthcare workers/healers involved in the care of this group; community members talking about this group
- English language publications

#### **Exclusion criteria:**

- Editorials and opinion pieces, letters where no primary data is presented
- Studies carried out among samples not resident in sub-Saharan African countries
- Quantitative studies
- Studies focussed more generally upon older people or older people with other chronic conditions

In order to combine and summarise the results of the different studies identified, we used a “thematic synthesis” approach<sup>1</sup> to our analysis. This is a recognised approach widely used by qualitative researchers to examine consistencies and contradictions across different studies, with the aim of achieving insights which go beyond simple description of individual study results. This approach required the extraction of the results sections of included articles, which were then entered into a qualitative software programme (OpenCode 4.0<sup>2</sup>), in which format they were then coded. This involved free coding of excerpts of text which were organised into ‘descriptive’ themes; this was followed by further interpretation and development of higher level ‘analytical’ themes.

### **3.2 Search results and characteristics of selected studies**

The search retrieved 1129 abstracts. On the basis of an initial screening, we removed 295 records due to duplication. One article not identified in the database search (accepted for publication by a peer reviewed journal but not yet published) was added to the screening list. Eight hundred and thirty-five titles and abstracts were screened by RM for relevance and 28 full-texts were assessed for eligibility. Articles were excluded for the following reasons: 475 because they were not clearly focussed on dementia; 309 did not appear to report the results of primary qualitative research; 37 were duplicates not previously identified as such; 3 studies were not published in peer reviewed publications (1 x dissertation; 2 x conference abstracts). One study was not carried out in SSA. Ten articles were ultimately selected for inclusion in the synthesis.

The selected studies were carried out in South Africa (n=5), Tanzania (n=2), Nigeria (n=1), Ghana (n=1) and Congo (n=1). Family caregivers of PLWD were the most common participant group included (n=8)<sup>3-10</sup>, followed by PLWD (n=4)<sup>3, 5, 8, 10</sup> (see Table 3.1). Three out of four studies carried out among paid caregivers were conducted among residential facility staff, mostly nurses, in South Africa<sup>7, 9, 11</sup>. The final study was carried out with hospital workers in the Republic of Congo<sup>5</sup>. A study carried out in Tanzania included traditional and faith healer participants, whilst the only Nigerian study was carried out with community members<sup>8</sup>. In-depth interviews were the most common methodology, used in all but the Nigerian study, which was based on data from focus-group discussions<sup>12</sup>. Authors’ research questions focussed on experiences of symptoms, understandings of dementia and causality, caregiving arrangements and management strategies.

### 3.3 Results

Four over-arching themes encompassing ten sub-themes emerged from the data:

1. **Beliefs**
  - Understandings of dementia
  - Beliefs about causality
2. **Experiences**
  - Symptoms
  - Stigma
  - Impact of caring for a person living with dementia
3. **Responses**
  - Care arrangements
  - Help-seeking
4. **Unmet needs**
  - Emotional support
  - Knowledge
  - Economic support and services

#### **Beliefs**

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##### **Understandings of “dementia”**

*“I have never heard of [dementia]. Nevertheless, I know that when you get older, you become like a small child. You have problems, worries, and memory loss.”*

##### **Relative of PLWD, Republic of Congo<sup>5</sup>**

When prompted by interviewers, no equivalent term for dementia was identified in any local languages<sup>3, 5, 8, 10</sup>. In general, there was felt to be a lack of awareness of dementia among the community<sup>10</sup>, a nurse in South Africa described how, before she started working in residential care, she perceived dementia as a “white person’s disease”<sup>9</sup>. Health problems of older people were rather characterised as problems associated with having “grown very old... ‘hangyena’” in Ghana<sup>3</sup> or “ugonjwa wa wazee” disease of old people in Tanzania<sup>10</sup>. Often these general descriptors encompassed dementia-like symptoms as well as symptoms of other chronic health problems<sup>3, 5</sup>. However, in Tanzania, in some cases, participants highlighted specific symptoms “ugonjwa wa kusahau” (memory loss disease/disease of forgetting)<sup>10</sup> within this syndrome. In Ghana, participants recognised the specific role of the deterioration of the brain as a component of overall bodily decline<sup>3</sup>.

##### **Beliefs about causality**

*“You know when you buy something new and you use it for a long time it becomes old, it does not remain like you bought it. That is how the human brain is: when you are young it works well, but when you grow old it does not work well – so when someone becomes old then every part of the body too becomes old”*

##### **Grandson of PLWD, Ghana<sup>3</sup>**

Five papers reported results related to the underlying cause of dementia-like symptoms. The most prominent belief regarding underlying cause of dementia was that although not experienced by everyone, dementia-like symptoms were part of “normal ageing”. Metaphors from nature and from material objects were used to describe decline in functionality over time<sup>3, 8, 12</sup>. Both stress<sup>5, 8</sup> and grief<sup>3</sup> were perceived to be associated with dementia-like symptoms. Witchcraft was understood to be a cause for a minority of participants in the studies carried out in Ghana and Tanzania<sup>3, 10</sup>. In Tanzania, one faith healer ascribed dementia to punishment by God<sup>8</sup>. A minority of participants in the Mushi et al study were unsure as to the cause of dementia<sup>10</sup>.

## Experiences

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### Symptoms

*“At first she was able to go to the farm and gather firewood. Even when you tried to stop her, she would not mind you- she was very strong. She would fetch all the firewood a tractor could bring, as if three young men went to fetch that firewood. Now she cannot even come out of her room, not even to talk of going to the farm to gather firewood. When you ask her, she complains of joint pains and that she cannot walk, that is how I got to know that she has changed. Then I already mentioned to you that when I tell her something immediately I come back to ask again she has forgotten about it. So, that too I have seen that she has changed”*

#### Daughter of PLWD, Ghana<sup>3</sup>

Participants most frequently reported problems with memory and communication, e.g. forgetting appointments, forgetting where they put things, repeating themselves<sup>3, 5, 8, 10</sup>. Problems with overall functionality were also reported, as well as problems typically associated with co-morbidities (pain, sight/hearing problems) in Ghana and Tanzania<sup>3, 8</sup>. Caregivers in Congo reported behavioural problems such as irritability and suspicion<sup>5</sup>.

### Stigma

*“When persons act in strange ways the talk starts in villages and townships: they say ‘that one has been bewitched’...they go to these old people, vandalise their houses, burn their houses... they accuse them of being witches”*

#### Residential facility nurse, South Africa<sup>9</sup>

Symptoms of dementia meant that PLWD were the subject of teasing within their communities in Ghana, South Africa and Nigeria<sup>3, 4, 12</sup>. The meaning of this was interpreted differently by participants. In Ghana, this was not perceived to transgress the boundaries of respect for older people<sup>3</sup>, however, in South Africa, the fact that a PWD was perceived as a joke by the community was interpreted as an indirect threat to the older person as this meant that their safety and wellbeing were not taken seriously<sup>4</sup>. When PLWD were perceived to be witches, as reported in Nigeria, fear inevitably resulted in discrimination, isolation and instances of violence<sup>4</sup>. In Ghana, Congo and Tanzania, where participants stated that there was no stigma as dementia-like symptoms were accepted as a “normal part of old age”<sup>3, 5, 10</sup>, symptoms were associated with a much-changed role. In Ghana and Congo, PLWD were routinely referred to as childlike<sup>3, 5</sup>, whilst in Nigeria, symptoms (forgetfulness) were associated with a loss of authority<sup>12</sup>.

### Impact

*“Since he is sick, everything is done by me, he cannot do anything. That is why there are changes in my life, and I feel like a person who is also sick”*

#### Wife of PLWD, South Africa<sup>6</sup>

The strongest theme related to the impact of the condition was the effect that the need for supervision had upon the activities of the caregiver, limiting their ability to do other things as they used to, namely, income generating activities (in Ghana and South Africa)<sup>3, 6, 10</sup> as well as social activities<sup>6</sup> (in South Africa). Participants in Ghana and South Africa who presented caregiving as a collective responsibility shared among family members<sup>3, 4</sup> sounded more positive about the burden of caregiving as the impact upon any one individual was felt to be minimised. In South Africa, the positive impact of the work of caregiving was highlighted by one family caregiver<sup>6</sup> and one residential care-worker<sup>11</sup>. However, residential care-workers highlighted the difficulties associated with aggressive behaviour, passivity and racism from residents. Costs of care - transportation,

food, medication - were mentioned as an additional burden that was often difficult to manage in Ghana, Congo and South Africa<sup>3,5,6</sup>, particularly in the context of other economic burdens within the family<sup>3</sup>. In Ghana, although most older people had health insurance and this was perceived to be helpful, it was perceived to cover only a small proportion of the costs associated with chronic illness<sup>3</sup>.

## Responses

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### Care arrangements

*"Each one has a role to play. During the day, I am not there. My dad's niece actually comes in to help my wife look after him. And as far as his medication is concerned - that is where my sister comes in; she will take care of the medical side of things. I am on the financial side of everything"*

#### Male caregiver of PLWD, South Africa<sup>4</sup>

Care, mainly delivered by families, was shaped by a need to show gratitude for the caregiving provided to the current carers by PLWD earlier in their lives- findings from South Africa indicate a typology of reciprocity<sup>4</sup> and a notion of collectivity and responsibilities associated with that kinship<sup>6</sup>. Results from Ghana, South Africa and Tanzania suggest that women tend to be the hands-on caregivers for PLWD<sup>3,4,10</sup>, with men often playing a role in decision-making about care<sup>3</sup>, particularly related to finances<sup>4</sup>. There was evidence that caregiving was often a collective responsibility with different components assigned to different family members in Ghana<sup>3</sup>, commonly children of the PLWD but in Tanzania also involving grand-children<sup>10</sup>. Two studies from South Africa provided insight into the role of paid care (respite and residential) from the perspective of family caregivers and residential facility staff. Hired help was perceived as a difficult but necessary component of the caregiving strategy for PLWD, in order to give family members a break so that they were able to regain energy to continue in their role<sup>4</sup>. Residential staff outlined strategies for managing often challenging symptoms of PLWD: these centred around communicating in such a way as to encourage trust and respect - using touch, verbal and non-verbal ways to communicate<sup>11</sup>. In another study carried out in South Africa, nurses reported the positive impact of serving patients traditional foods which was felt to trigger reminiscence and joy, resulting in a calming effect<sup>7</sup>. Approaches were felt to be rendered ineffective when PLWD were over-medicated, resulting in passivity, which consequently care workers found difficult to manage<sup>11</sup>.

### Help-seeking

*"Yes I will bring them to you [allopathic services] and I see the collaboration will be good... because you will treat them, sometimes they get treated in hospital and sometimes they come to us and we treat them. So it won't be a problem because you can't do everything by yourself!"*

#### Traditional healer, Tanzania<sup>8</sup>

The most salient overall theme regarding help-seeking was one of pluralism: in Ghana and Tanzania, participants used both biomedical, traditional and faith healing to treat the problems of older people<sup>3,10</sup>. This was often experimental, with participants trying out one type of treatment, monitoring the response and then switching to a different one as necessary<sup>3,10</sup>. However, there was some evidence that explanatory models influenced patterns of help-seeking/attitudes to treatment. In Tanzania, traditional healers believed that they could cure cases where the cause was supernatural but not if the only cause was ageing<sup>8</sup>. Older participants shared this view in Congo<sup>5</sup>. Some older people and their family members shared this view that modern medicine could not help problems that were deemed to be "beyond human control"<sup>10</sup>. Similarly, in seeking help from biomedical services in Ghana and Tanzania, participants sought help from biomedical services for problems other than dementia-like symptoms, aiming to improve the overall comfort of older people, rather than cure problems entirely<sup>3,10</sup>. In Tanzania, faith healers and prayers (their modus operandi) were perceived to be helpful but not curative and were seen as a "safe" treatment<sup>8,10</sup>, as compared to traditional healers whom participants in Tanzania and South Africa perceived to be

potentially dangerous<sup>5, 8</sup>. In Tanzania, faith and traditional healers were positive regarding potential collaboration with biomedical services in the management of PLWD, and requested ongoing involvement in case management of patients they referred, in addition to training and education about dementia<sup>8</sup>.

## **Unmet needs**

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### **Emotional support**

*“Emotionally it’s a strain and there’s no way you can do it alone. You need someone. My advice to anyone would be to use whatever help you can get. Don’t push anyone away, the more hands the better”*

#### **Family caregiver of PLWD, South Africa<sup>4</sup>**

The need for emotional support for caregivers was a strong theme in two South African studies<sup>4, 6</sup>. This took the form of having someone to talk to and good communication between family members involved in the care of the older person<sup>4</sup>. A lack of emotional support was perceived to manifest as feelings of depression and strain<sup>4</sup>. This was felt to be essential to enable the caregiver to continue to deliver the work of caregiving. Costs of transportation to clinics, namely, hiring transport, were perceived as burdensome<sup>6</sup>.

### **Knowledge**

*“Doctors should educate us more because we don’t know much about this problem”*

#### **Family caregiver of PLWD, Tanzania<sup>10</sup>**

Education, in order to improve knowledge and understanding of dementia, among caregivers and local communities was deemed to be essential: both to counteract beliefs related to witchcraft which in South Africa, were perceived to put older people living with dementia at risk<sup>9</sup> and in South Africa and Tanzania were education was felt to be necessary to improve the level of support for caregivers in their role<sup>4, 10</sup>. Non-Governmental Organisations (NGOs) (Dementia South Africa and Alzheimer’s South Africa) were identified as useful sources for information<sup>4</sup>. In fact, the potential for NGOs and civil society to take the lead in terms of educating communities and caregivers was recognised by participants in South Africa and Tanzania<sup>9, 10</sup>.

### **Economic support and services**

*“I wish they could give us soup. She can no longer swallow even nutritional porridge... She can’t swallow at all... and wound care medicines, because when taking her to the clinic one needs to hire transport and pay for all those things”*

#### **Family caregiver of PLWD, South Africa<sup>6</sup>**

In South Africa and Tanzania, people living with dementia and their caregivers were dependent upon families and communities in to support the costs of care<sup>4, 6, 10</sup>. Costs of transportation to clinics were felt to be particularly problematic<sup>6</sup>. One nurse participant in South Africa suggested that government provision of local, township-based geriatric facilities would not only provide a much-needed service for PLWD but could also play an important role in improving community understandings of the condition<sup>9</sup>. In Tanzania, it was suggested that churches and NGOs “should actively be involved in this problem like in other social problems” and that one way in which they might do this could be through provision of day centres.

## **3.4 Discussion**

Our systematic review reveals a small but useful evidence base which offers important insights into the everyday reality of living with dementia in SSA. Experiences of living with dementia and the responses of families, health services and communities take place in the context of cultural understandings of dementia and beliefs about the causality of the condition. The biomedical label

of dementia was absent from participant narratives in all but studies carried out in residential care facilities in South Africa. As has been found elsewhere, although not perceived to be an inevitable component of the ageing process, dementia was generally seen as a part of the overarching condition of growing old which afflicted some but not all older people<sup>13-15</sup>. This perceived normality helped to differentiate dementia from "madness" that is perceived to affect younger people, despite the overlap of some symptoms. Our findings suggest that belief in witchcraft or other sorcery as a cause of dementia was a minority view, albeit one that was associated with negative consequences: stigma and discrimination, violence and threat of violence. It is important to note that this finding emerged alongside a strong appetite for information and knowledge about dementia among caregivers, care-workers, healers and community, in recognition of the fact that a lack of understanding of the condition fuelled fear and discrimination and perpetuated negative beliefs to those affected by the disease.

Although most participants reported that PLWD were not subjected to stigma or discrimination, there is evidence to suggest that their symptoms were perceived as a regression to a childlike state, which inevitably led to infantilisation, loss of authority and discontinuity of role. In HIC, both maintaining a sense of continuity and participating in life have been identified as important factors in determining quality of life of PLWD<sup>16</sup>. The voices of people living with dementia were largely absent from findings, even when study authors reported that they were included as interviewees. In HIC where there are large numbers of older people and dementia is recognised as a public health priority, the importance of knowledge derived from first-hand experience of dementia is recognised as a key contributor to comprehensive understanding of the disease and its impact<sup>16</sup>.

As has been found elsewhere, in relation to help-seeking for mental disorders, explanatory models also influenced patterns of help-seeking and attitudes to treatment of dementia<sup>17</sup>. PLWD and their caregivers as well as healers, generally believed that if the cause of symptoms was supernatural, traditional or faith healing was likely to be more efficacious than biomedical treatments. That said; families were also experimental and pluralistic in their approach to treatment of any kind, monitoring responses and switching or stopping a particular approach if it was perceived to be having no positive effect. There was consensus that if the cause was ageing, the condition was incurable. Families and healers alike focussed upon addressing remediable co-morbidities and providing holistic treatments to improve the comfort and wellbeing of the older person.

Despite the fact that rapid demographic ageing means across the region means that a failure to address the health of older people will inhibit attainment of development goals, health systems in SSA remain focussed upon services for infectious diseases, child health and adults of reproductive age and are not equipped to deal with chronic health problems associated with older age<sup>18</sup>. Healers outside the biomedical system are arguably further ahead of biomedical health services in providing holistic, community-based care which meets the needs of older people. It is therefore unsurprising, that although unclear, the proportion of PLWD in SSA who seek help from non-biomedical healers is likely to be significant. Mushi et al. found that 41% of participants in the qualitative study had visited Christian faith healers and 19% had visited traditional healers<sup>10</sup>. Hindley et al. found that traditional and faith healers were positive about the idea of collaboration with biomedical services in the treatment and management of problems associated with older age<sup>8</sup>. Indeed, the potential advantages of collaboration between different models of healing have been recognised but not yet fully implemented in the context of increasing access mental healthcare in low and middle income country settings<sup>19</sup>. Likely benefits include: cultural acceptability, accessibility, and a person-centred approach<sup>19</sup>.

Consistent with demographic ageing and changing epidemiological profile, quantitative evidence points to a growing prevalence of functional impairment among older people in SSA and a growing need for support from others to carry out essential everyday tasks<sup>20</sup>. Caregiving is managed by families with no involvement or support from government sources. The sustainability of this approach is highly questionable. It is notable that many of the symptoms reported by caregivers as the most difficult to manage at home (such as aggression and incontinence) are largely absent from narratives identified in our review. This may be an artefact of the focus of topic guides used in the studies included in this review, which tend not to focus on obtaining detailed symptomology of the condition. In any case, these symptoms are common features of mid-stage dementia, which will only become more common as SSA populations rapidly age. It is of note that the only evidence related to caregiving outside of the household comes from South Africa. The call for more training about dementia and narratives relating to the challenges of managing difficult behaviour associated with dementia are illustrative of the challenges accompanying the necessary provision

of long-term care around the world. In some middle income countries, societal changes (such as greater participation in the labour market, urbanisation, higher levels of divorce, later marriage), are leading the established role of female family members as unpaid caregivers to become contested<sup>21</sup>. Findings illustrate the additional financial pressure that caring for a PLWD can bring to often already stretched household budgets. A lack of formal governmental provision to support the economic impacts of older age and disability means that the family are the sole source of social security for older people<sup>22</sup>. It remains to be seen to what extent traditional notions of filial duty and reciprocity will hold fast in the face of societal change and “modernisation”<sup>22, 23</sup>.

### 3.5 Recommendations

#### Provision of culturally sensitive education about dementia

Findings suggest that there is a desire across different stakeholder groups to gain a better understanding of dementia, in order to both counteract stigma and to enhance management of the condition. Although associations between beliefs in the supernatural as the cause of dementia and stigma should be addressed, it is important to do this using a culturally sensitive approach. In the absence of effective biomedical treatments for dementia, the medicalisation of dementia should be approached with caution. There is little evidence that replacing existing local understandings of dementia with Western diagnostic categories will lead to improvements in outcomes for PLWD and their families. Rather, a culturally sensitive but common-sense approach is required. Utilisation of existing conceptualisations of dementia as a normal part of old age in combination with feasible practical advice for caregivers and PLWD regarding the management of symptoms would seem to be the best pathway to provision of education that offers the best opportunity of being effective whilst remaining culturally acceptable and supportive of the norm of familial reciprocity. Some research participants suggested that NGOs, civil society and religious institutions might be best-placed to deliver this kind of training within community and healthcare settings. This possibility should be explored.

#### Advocacy to strengthen the voices of people living with dementia

The design of policies and services which successfully meet the needs of PLWD and their carers will be impossible without the input derived from lived experience of the disease. Evidence from research carried out in Ethiopia suggested that societal stigma severely limited the ability of people living with severe mental illness to participate in research related to the design of mental health services<sup>24</sup>. Therefore, it is important that governments, non-governmental organisations and researchers make efforts to address this disparity and find innovative ways to ensure that the voices of PLWD are heard. Lessons in how to achieve this may be learnt from elsewhere: both from other successful global advocacy movements for disadvantaged and stigmatised groups (e.g. people living with HIV) as well as from the empowerment of PLWD in HIC settings.

#### Development and scale-up of integrated health services for older people

Although policy frameworks directed at ageing populations are beginning to emerge, these have yet to effect change in policy and practice<sup>25</sup>. Design and implementation of services designed to meet the needs of older people in SSA lags behind that of mental health, itself a marginalised area of public health in the region. The urgent need to build capacity within primary care to manage chronic conditions and co-morbidities associated with old age has however been recognised by WHO. ICOPE is a WHO-led programme to develop evidence-based guidelines for the prevention and management of dependence by non-specialist healthcare workers, focussing on problems (such as nutrition, mobility, falls, cognition, mood and behaviour, sensory impairment and incontinence) rather than specific conditions<sup>26, 27</sup>. The potential for integration of healers from outside the biomedical system into the implementation and scale-up of ICOPE should be explored. Working with existing pluralist approaches to healthcare for older people is likely to enhance acceptability and healthcare workers may have much to learn from traditional and faith healers experiences of managing the health problems of older patients.

#### Development of policies related to long-term care and economic security of older people

Evidence from elsewhere suggests that in the face of changing societal norms and ageing populations, family systems of social security struggle to cope with increased numbers of older people living with chronic health problems, leading to indebtedness, family strain and conflict and household rationing of healthcare and food<sup>21</sup>. The generalisability of these findings to the SSA

Table 3.1  
Description of selected studies

	Authors/Country	Participants	Research questions/aims	Themes identified by authors
1	Adebisi et al 2016 Nigeria <sup>12</sup>	Community members (n=36): older people, middle-aged, youth	To investigate the occurrence of implied/enacted stigma	Implied stigma Enacted stigma
2	Agyeman et al 2017 Ghana <sup>3</sup>	Caregivers and PLWD (n=28)	To explore sociocultural beliefs, understandings, perceptions and behaviours related to dementia To explore beliefs about causality and stigma and help-seeking behaviours To explore care arrangements and the impacts of caregiving	Symptoms Understandings of cognitive symptoms Help-seeking Course of cognitive illness Care arrangements Economic impacts of care Stigma
3	Deist and Greef 2017 South Africa <sup>4</sup>	Children of older PLWD who are caregivers (n=21)	To identify, explore and describe resilience factors that are present in families caring for a PWD	Social support Financial stability Religion and spirituality Optimism Positive communication patterns Family closeness Acceptance Managing the illness
4	Faure-Delage et al 2012 Republic of Congo <sup>5</sup>	PLWD (n=27); their family members (n=31); cognitively impaired older people (n=90); their family members (n=92); hospital workers (n=33)	To describe the sociocultural representations of dementia in Brazzaville	Knowledge about the phenomenon called 'dementia' Recognition of dementia Patterns of distress Perceived causes Help-seeking
5	Gurayah et al 2015 South Africa <sup>6</sup>	Caregivers of PLWD (n=5)	To explore experiences of being a carer for a PLWD	Views and responsibilities of the caregiver Impact of caregiving Services to assist the caregiver
6	Hanssen and Kuven 2015 South Africa <sup>7</sup>	Nurses in geriatric facilities (n=4); family members of PLWD (n=1)	What does it mean to institutionalised patients with dementia to be served dishes they recognise from childhood and youth	Belonging and joy Improved appetite Food and reminiscence
7	Hindley et al 2016 Tanzania <sup>8</sup>	Traditional healers (n=11)/faith healers (n=10) PLWD (n=18) (and their carers, n=17)	How do traditional and faith healers understand and manage people with dementia? Why do PLWD present to traditional and faith healers	Conceptualisation of dementia by healers: normal part of ageing process People with dementia and carer reasons for seeking help and experiences of treatment: prayers, plants and witchcraft Collaboration with allopathic healthcare services
8	Mkhonto et al 2017 South Africa <sup>9</sup>	Nurses in residential care facilities (n=7) Family member of PLWD (n=1)	To explore and describe the link between culture and dementia care, focussed on the belief in dementia as witchcraft and PLWD as witches	Belief in witchcraft causing fear of PLWD Need of knowledge and education
9	Mushi et al 2014 Tanzania <sup>10</sup>	People living with dementia (PLWD) (n=21) Carers (n=16)	What are the perceived causes and symptoms of dementia? What are the experiences of PLWD and their carers and what meaning is attached to these? What are the health seeking behaviours of PLWD and their carers?	Knowledge and perception of dementia Symptoms of dementia Stigma against dementia Health seeking behaviour Source of social support Views on how to address the problem
10	Van Wyk et al 2016 South Africa <sup>11</sup>	Staff in residential care facilities (n=17)	Explore unmet needs of staff working with residents with dementia in long-term care facilities Explore which behaviours of PLWD staff found challenging and how they managed these Hear from staff how they learn to deal with distressing/challenging behaviour	Attitudes toward PLWD Distressed behaviour Management techniques Training and education Managing distressing behaviour more effectively

region requires further research<sup>23</sup>. With the numbers of older people living with dementia projected to rise in SSA more rapidly than elsewhere and an almost total lack of governmental support for older people, there is an urgent demand for governments to begin to develop and implement policies related to both economic security of older people and long-term care for chronic conditions associated with older age.

### 3.6 Strengths and limitations of our approach

We believe this is the first synthesis of qualitative research evidence on dementia from the SSA region. This is timely. As quantitative evidence relating to the prevalence, incidence and overall burden of disease advances, it is equally important to develop the knowledge base around lived experience of the disease. Both of these will be important in terms of shaping the next steps of the research and policy agenda. There are a number of limitations to our approach. Chosen search terms were pragmatic, chosen to limit the number of results in order to identify highly relevant records. However, results will only include studies using the category of “dementia”. It is possible that we have missed studies which have samples of people with dementia-like symptoms who were not identified as such. Some authors may have used the broad term of cognitive decline or cognitive impairment as synonymous with dementia, but we restricted our search to dementia. We note that, while unlikely, the modern American DSM 5 recommending the non-use of “dementia” where possible (but instead using major neurocognitive disorder) may have prompted some researchers in SSA after 2013 to have studied but not used the term “dementia”. We searched titles and abstracts published in English only. It is possible that we may have missed some relevant articles published in other languages. We included articles published in peer reviewed journals only. Although this acted as a mechanism for quality control, it means that we have excluded all grey literature. It is plausible that reasonable quality, relevant evidence exists in the form of reports and student dissertations.

Given the heterogeneity of cultures, languages and beliefs within the region, selection of SSA as an area of interest is potentially misleading. The extent to which findings from particular settings are generalizable to other countries, cultures and communities within the region is debatable. This is perhaps most striking when considering the likely relevance of findings from South Africa, an upper middle income country with an epidemiological and sociodemographic profile unlike that found elsewhere in SSA, to experiences of people living in communities elsewhere in the region. For example, South African studies included a minority of white participants, whose experiences, due to historical, political, social and economic conditions are highly unlikely to be representative of the majority of South Africans affected by dementia, let alone people living elsewhere in SSA. That said, there are some common threads which support the relevance of SSA as a region in the context of dementia and ageing research and advocacy<sup>18</sup>. These include: rapid demographic ageing, under-resourced and over-stretched health systems, and a lack of prioritisation of the health and social security of older people on public health and policy agendas.

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## CHAPTER 4

# Social protection and the health of older people in sub-Saharan Africa



### 4.1 Introduction

Conceptually, social protection refers to any intervention that seeks to reduce individuals' vulnerability to adverse outcomes as a consequence of specific risks<sup>1</sup>. Among policy-makers, this is usually limited to two broad areas of intervention: regular cash payments and insurance against potential healthcare costs. Across international development networks increased attention has been given to social protection over the past 15 years, particularly cash transfers for mothers and pensions for older people<sup>2</sup>. This chapter examines the development of social protection in sub-Saharan Africa and assesses effects on the health status of older people. It is not possible to do justice to the diversity of regional experience, so the chapter mainly focusses on Ghana and South Africa. Country selection reflects data availability and the presence of social protection schemes of particular interest. The chapter starts by briefly reviewing the development of pension provision across the region, followed by a similar review of health insurance. The final part includes discussion and analysis of the effects of these interventions on health outcomes, followed by some policy recommendations.

### 4.2 Pensions for older people

As in other regions, it is helpful to distinguish between non-contributory "social" pensions, and separate contributory schemes providing retirement benefits for specific sets of workers. It is possible to establish a broad categorisation of pension provision in sub-Saharan Africa. A number of countries have relatively extensive and generous social pension schemes, usually combined with separate contributory arrangements. These countries are mainly located in southern Africa and include South Africa, Botswana, Namibia and Mauritius. In the rest of the region, the coverage of pension schemes and the value of benefits are considerably more limited, although all countries have generous provision for the military, police and civil service. The coverage of contributory

schemes is limited by the small number of people employed in the formal sector of the labour force and by low wages, which reduce capacity for making monthly contributions. The coverage of social pension schemes is limited by state fiscal capacity and competing priorities in public expenditure. A number of countries have developed pilot social pension schemes, usually with the support of external funding. In many cases, such as Ghana, these provide only a small number of low value benefits. In other cases, such as Kenya, more progress has been made to scale-up social pension provision, although benefits remain much lower than schemes in southern Africa.

Across sub-Saharan Africa the focus of academic research and policy debate is almost entirely on social pensions. Despite this, far larger amounts of public funds are usually devoted to contributory schemes for relatively privileged social groups. For example, in Uganda 0.4 percent of GDP is spent on civil service pensions, but these cover only 2.5 per cent of the older population<sup>3</sup>. In some countries in the region civil servants are permitted to retire at 45 or even younger, and in some cases pensions are worth the full amount of final salaries<sup>3</sup>. This neglected aspect of social protection in Africa is highly inequitable and crowds out public expenditure for more vulnerable groups of older people.

#### 4.2.1 South Africa: an example of extensive pension provision

In South Africa non-contributory pensions (known as old age grants) are well-established, dating back to the Apartheid era. Old age grants are notionally means-tested and available for men aged 65 and over and women aged 60 and over. It is estimated that around 80 per cent of eligible older people received an old age grant<sup>4</sup>. The basic grant value is about US\$110 a month (US\$112 for people aged 70 and over). In 2017, 3.3 million old age grants are being paid out. The scheme is funded through general taxation, and costs around 1.5 per cent of GDP. Additionally, the government pays out around 1.1 million non-contributory disability benefits to adults aged under 60, including chronic conditions such as Alzheimer's disease.

In recognition of the costs of paid care at home, the Department of Social Development offers a "Grant-in-Aid" benefit to older people who "require regular care". Eligibility requires a medical report or assessment report (less than three months old) that shows the applicant needs full-time care. In theory, medical eligibility for the grant should be reviewed every year. In 2012, 68,000 benefits worth around £17 a month were being paid out, at a total cost of £14 million. In its Strategic Plan for 2012-15, the Department observed that there was a need to generate greater awareness of these grants<sup>5</sup>. Progress seems to have been made: in 2016, the number of benefits being awarded had risen to 152,000. However, the geographical distribution of the benefits remains uneven. In 2015, 18 per cent of South Africans aged 70 or over lived in the province of Kwazulu Natal, but the province accounted for 33 per cent of Grant-in-Aid benefits.

South Africa's current system of non-contributory cash transfers has been a focus of international interest for both researchers and policy-makers working in ageing and development. The scheme has been put forward as an example of "best practice" for other developing countries to emulate<sup>6</sup>. It has been claimed that the social pension does not just benefit older people, but is pooled across entire households<sup>7</sup>. Indeed, in settings of high unemployment, it may represent the only reliable source of household income. It is sometimes claimed that household dependence on the old age grant increases the authority of older people and hence the potential willingness of family members to care for frail older relatives<sup>8</sup>. However, a separate issue is whether older people share their pension income willingly or are coerced or bullied into doing so<sup>9</sup>. Frail older people, including those with cognitive impairments, may be particularly vulnerable to financial exploitation.

South Africa also has several large contributory pension schemes, although these receive little attention from academics or policy-makers outside the country. These cover people with lifetime employment in the formal sector of the labour market, mainly focussing on more affluent groups. For example, in 2000 over 60 per cent of white men and 40 per cent of white women aged over 60 received an employer-provided private pension; for black Africans coverage was under 10 per cent<sup>10</sup>. By 2004 contributory pension funds were paying out around 1.1 million benefits: roughly half the number of old age grants<sup>11</sup>. South Africa has a separate set of pension provisions for civil servants, providing around 230,000 retirement benefits a year<sup>12</sup>.

## 4.2.2 Ghana: a more limited pension provision

Ghana can be taken as broadly representative of most other countries outside southern Africa, where coverage mainly consists of contributory schemes for relatively affluent occupations and where social pensions are largely non-existent.

Ghana's main contributory fund, the Social Security and National Insurance Trust (SSNIT), provides retirement pensions mainly for civil servants and formal sector workers. Coverage of the labour force is estimated at around 10 per cent and in 2001 the scheme paid out 50,000 pensions, representing less than 5 per cent of Ghana's population aged 60 and over. Some efforts have been made to extend protection to informal sector workers with a dedicated voluntary scheme, but uptake has been low due to high rates of cash poverty. Despite high administration costs, SSNIT pension claims typically take around four months to process. In 2008 the government approved a bill to combine different contributory funds into a single three pillar system, but this makes no specific provision for non-contributory social pensions.

The Livelihood Empowerment Against Poverty Program (LEAP) has been extended across Ghana since March, 2008 and reaches over 35,000 households<sup>13</sup>. LEAP benefits are worth between US\$8 and US\$15 per month, depending on the number of qualifying individuals in the household. The scheme targets a range of different vulnerable population groups, of which one is people aged 65 and over. Specific data on the number of older people receiving LEAP payments are unavailable, but since there were 934,000 people aged 65 and over in 2015, only a small minority of them are likely to be covered by the scheme. As such, the large majority of older Ghanaians receive no pension: either from the contributory system or from LEAP.

## 4.2.3 New universal social pension schemes

Since the 1990s, often with the support of overseas agencies, a number of sub-Saharan African countries established pilot social pension programmes. However, typically these schemes have been small-scale, means-tested and pay small pensions. For example, in 2011 Uganda's Senior Citizens Grant paid a monthly pension of US\$7 to around 4 per cent of its population aged 60 and over. In some cases, these pilot schemes were discontinued after international funding stopped.

One sub-Saharan African country conformed to neither the more embracing southern African model nor the minimalist model found in elsewhere. In 2004 Lesotho established a universal pension for all people aged 70 and over worth around US\$37 a month. More recently, a number of other sub-Saharan African countries have established similar schemes. For example, in 2016 Zanzibar established a universal pension worth US\$9 a month for people aged 70 and over, with Kenya proposing to set up a similar scheme from 2018.

## 4.3 Health insurance: does Ghana show the way forward?

In sub-Saharan Africa, only a small number of health insurance schemes have attained more than 30 per cent coverage of their populations. In most countries, low rates of enrolment and high rates of drop out mean coverage struggles to exceed 10 per cent. Coverage is highly concentrated on more affluent social groups. In Nigeria, for example, only 4 per cent of the population, mainly federal government workers, are covered by public health insurance schemes<sup>14</sup>. In contrast to its generous pension coverage, South Africa does not yet have a universal health insurance system, with coverage concentrated among civil servants and formal sector workers. The South African ministry of health does not aspire to achieve universal coverage until 2026 at the soonest<sup>15</sup>.

Ghana represents an exceptional case, with a national health insurance scheme that has received much international attention and is sometimes framed as a potential model for other resource-constrained countries. Around 66 per cent of the population are enrolled in the scheme<sup>16</sup>. Membership requires payment of an annual registration fee, ranging from around US\$3 to US\$30, depending on the socio-economic profile of the registration district. People over the age of 69 with contributory pensions and/or enrolled in LEAP are exempt from making payments. This explains why rates of enrolment are higher among over 70s (63 per cent in 2011) than for adults aged 18 to 49 (32 per cent)<sup>17</sup>. In theory, the scheme offers a minimum package that covers 95 per cent of diseases reported in health facilities in Ghana and requires no co-payment. In practice, most NCDs, such as most forms of cancer, are not covered<sup>18</sup>. More generally, questions have been raised about the capacity of the national health insurance scheme to deliver improved health outcomes without substantial upgrading of Ghana's limited health service infrastructure<sup>19</sup>.

## 4.4 The effects of social protection on the health status of older people

Increasing attention is being given to the potential of pensions and other cash transfers to improve health outcomes of older people. A recent study focussed on Ethiopia, Mozambique, Tanzania and Zimbabwe observed a:

*“positive impact of cash transfers on access to health services, but this impact is limited by the fact that many vulnerable older people are excluded, and benefit levels are low”.*<sup>20</sup>

It also noted:

*“Cash transfers cannot compensate for major weaknesses in health systems”*<sup>20</sup>.

Likewise, a more general review of cash transfers and health in low and middle-income countries concludes:

*“There are good reasons to be somewhat sceptical about the promise of these programmes...”*<sup>21</sup>

The availability of and access to health services (including preventive services) across most of sub-Saharan Africa is extremely limited, particularly for NCDs and for poorer groups living in rural areas. As such, the capacity of social pensions to have significant impacts on the health status of older people will remain very limited unless substantial improvements are made to the suitability, quality and accessibility of these services. In other words, cash transfers should not be viewed as a stand-alone intervention.

The challenges of translating pension coverage into improved health for older people are evident in South Africa. Here, despite the generosity of the old age grant and other pension schemes, older people experience one of the highest rates of uncontrolled hypertension reported worldwide<sup>22</sup>. Key contributing factors include low levels of health awareness among older people and the generally poor quality of health services, especially in rural areas. The most important risk factor for hypertension (and several other common NCDs) is obesity. A national survey conducted in 2008 found that 72 per cent of people aged 50 or over were either overweight or obese<sup>22</sup>. Consequently, addressing high rates of disease among older people in South Africa will require a combined strategy of awareness-raising, health promotion and investment in key health services.

It might be expected that health insurance would have a more direct effect on enhancing health outcomes for older people. Just as with pensions, however, any effect is contingent on the generosity of the scheme, health awareness and the availability of suitable services. Simply being enrolled in health insurance or utilising health services should not in itself be considered positive outcomes, unless it can be shown that these lead to improved health status. This is particularly true where the quality of services is uneven, as is the case in most of sub-Saharan Africa. Despite the many studies of Ghana’s national health insurance scheme, robust evidence of enhanced health outcomes for older people is relatively scant. It has been shown that rates of awareness of hypertension are higher among older people with insurance (31 per cent) than those without (18 per cent)<sup>23</sup>. Likewise, rates of hypertension control are higher for those with insurance (6 per cent) than those without (4 per cent). Thus, while insurance does improve outcomes to some degree, 94 per cent of insured older people with hypertension were still not effectively managing the condition. Robust data for other NCDs, such as diabetes and heart disease, are not available, but patterns are likely to be similar.

## 4.5 Conclusion

Overall, the effects of social protection on the health status of older people in sub-Saharan Africa remain limited by a range of different factors. Most critically, there is an urgent need to bolster the “supply-side” of health service infrastructure. There is also a need to re-orientate services away from a near-exclusive focus on infectious disease and mother and child health towards NCDs and conditions associated with later life<sup>20, 24</sup>. Social pensions have considerable potential to enhance the wellbeing of older people, especially in those countries where nutritional intake is widely inadequate. The real benefits of health insurance for older people will remain marginal and notional, unless entitlement to services is translated into genuine access.

Consequently, the most effective approach to enhance the well-being of older people in much of sub-Saharan Africa would be to combine a general reorientation and upgrading of basic health services with extended provision of cash transfers. It is often argued that limited fiscal resources

represent an insurmountable barrier to such interventions. However, this chapter shows that many countries in the region already devote considerable resources to contributory pension and health schemes, which only include small, more affluent sectors of their population. With specific reference to dementia, there may be particular scope to enhance health worker knowledge of the condition and of simple interventions, such as cognitive stimulation. This should come to be seen as a core component of sub-Saharan African primary health care systems, rather than an unaffordable luxury.

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## Personal story

# Mauritius – Mrs C

**M**rs C is 85 years old, and lives at home with her unmarried son and daughter. Around eight years ago, they began to notice that their mother was becoming forgetful, but she was still very socially active – visiting friends, and taking the bus daily into the city of Port Louis to visit a friend's shop. Mrs C's forgetfulness amplified, as she started forgetting to pay bills and to take her antihypertensive medications, and misplacing small things. However, she still enjoyed her independence and was going out alone undeterred.

Things changed three years ago when the family built a new house, and Mrs C became disorientated by the change and had difficulty with daily activities. Her children did not want her to take the bus alone, but she resisted and this became difficult for them to handle. On one occasion, she decided to go to hospital on her own and did not come back until late. When asked where she had gone, she said she was unwell. Her family contacted a doctor and she was diagnosed with dementia.

Since her diagnosis, Mrs C is not on any medications, but has attended the Alzheimer Centre organised by Alzheimer Association Mauritius. She started attending twice a week, and spending the rest of the week with a neighbour, but has since started attending daily during the week. In the evening she stays at home with the supervision of her daughter, and at the weekend is supported by her children, who repeat the activities they have learned with her at the Centre. Mrs C is active and still likes to go to malls and to the sea side. She sometimes repeats herself, but her children are tolerant and patient with her. Thankfully, she has good familial support and she receives social support from the Centre. She is benefitting a lot and is now calmer, having received a lot of love and human warmth.

## CHAPTER 5

# Conclusions and recommendations



## 5.1 Summary

### 5.1.1 Prevalence and numbers affected, costs, incidence, and mortality

We estimate now that 2.13 million people were living with dementia in sub-Saharan Africa in 2015, with numbers projected to nearly double every 20 years, increasing to 3.48 million by 2030 and 7.62 million by 2050. These estimates are slightly higher than those for the 2015 World Alzheimer Report<sup>1</sup>. The increases are accounted for by two factors. First, the 2015 UN population estimates include larger numbers of older people than the 2012 estimates which had been used previously. Second, the evidence base regarding the prevalence of dementia has slightly expanded, including data from three additional studies. This resulted in a slight increase in age-standardised prevalence of dementia in SSA than had been estimated previously, but it does not mean that prevalence has increased since.

These estimates are now closer to the estimates for other high income or low and middle income regions, and suggest that previous estimates may have underestimated the scale of the dementia epidemic in the region.

Based on these latest estimates of numbers of people living with dementia in SSA, the total costs of dementia are now estimated at US\$ 6.2 billion in 2015. The upward revision of the costs compared to the previous estimates is only explained by the larger numbers of people with dementia estimated in this report. Distributions of the costs were not different from previous estimates, with two-thirds to three-quarters of the total costs and cost per person attributed to informal care costs. Contribution of formal social care to overall costs remains low in the region. However, one important limitation is the absence of relevant published research on resource use and costs of dementia in the region. Our cost estimates are therefore mainly relying on imputations.

From our review and meta-analysis of incidence rates in SSA, we estimate that there were over 367,000 new cases of dementia in 2015, most of them arising in Eastern and Western SSA. Although this number is lower than our previous estimate, for the first time we have been able to

provide an estimate relying on evidence of dementia incidence from SSA countries only, rather than relying on evidence from all LMIC.

We reviewed for the first time the evidence on mortality risk for people with dementia living in SSA. Pooling the results from four studies carried out in Western and Central Africa, we estimated that people with dementia had a two-fold increased mortality risk compared to people not affected by this condition. This risk is similar to the hazards reported in other low and middle income countries. Furthermore, the evidence was indicating a higher mortality risk for people with more severe dementia compared to the ones with lower severity.

### 5.1.2 Risk factors

In the course of this review, we have examined the evidence existing on factors associated with dementia in sub-Saharan Africa. The evidence covers non-modifiable (age, sex, genetics) as well as modifiable risk factors (education, vascular disease risk factors, early-life, lifestyle, psychosocial and psychological risk factors).

While both older age and female sex show strong associations with higher dementia prevalence and incidence as it is the case more globally, the evidence on genetic risk factors (mainly focused on the APOE gene) remains limited and contradictory. When investigated, the APOE  $\epsilon 4$  allele, which is the allele with the greatest known effect on the risk of developing dementia, does not seem to be systematically associated with dementia despite a high frequency within sub-Saharan populations. The possibility of gene-environment or gene-gene interactions that would explain those negative or weak associations with dementia needs to be explored further.

Most of the evidence regarding modifiable risk factors is provided by cross-sectional rather than longitudinal cohort studies, which would demonstrate aetiological pathways more clearly. The strongest evidence on modifiable risk factors is probably the association of vascular disease risk factors (hypertension, hypercholesterolemia and peripheral artery disease) with dementia. Evidence on early-life, psychological, psychosocial and lifestyle risk factors remains very tentative. Considering the scale of the HIV/AIDS epidemic in sub-Saharan Africa and the ageing of the population, including of those treated by antiretroviral therapy, HIV infection seems a relevant potential risk factor to investigate in the region. Our review on HIV-associated dementia (HAND) revealed that the evidence in older adults is completely lacking, either because older people were excluded from most of the studies on HAND or because population-based studies on dementia among older people did not screen for HIV or HAND. This is an important knowledge gap that needs to be addressed in future studies.

### 5.1.3 The experience of people living with dementia

Understanding beliefs, perceptions and experiences relating to illness, care, help-seeking and treatment are critical to understanding the nature of the problem, and are therefore an essential complement to quantitative understanding of the scale of the epidemic of dementia in SSA. A small but useful evidence base was revealed in our systematic review, offering valuable insights into how people live with dementia in this region.

The biomedical label of dementia was absent from narratives in almost all studies. The only exception was found in residential care settings in South Africa – in other studies dementia was generally seen as a part of the ageing process, which affected some but not all older people. Beliefs in witchcraft or other sorcery were found to be a minority view, although one that was associated with stigma and discrimination, violence and threat of violence. It was recognised that the lack of awareness and understanding of dementia could contribute to fear and discrimination, and negative beliefs relating to those affected by the condition. On the other hand, perceptions of symptoms shown by people living with dementia as a regression to a childlike state were not generally linked to stigma or discrimination. However, despite their contribution to the research, the voices of people with dementia were largely absent from reported narratives and findings.

There was a general belief that if the cause of symptoms was supernatural, traditional or faith healing would be more efficient than biomedical treatments. But families were also pluralistic in their approaches to treatment. The condition was always recognised as incurable if the acknowledged cause was ageing. The proportion of people with dementia who seek help from non-biomedical healers in SSA was significant.

For now, the only evidence related to caregiving outside of the household comes from South Africa. When care was delivered by families, women tended to be the hands-on carers whilst caring was also a collective responsibility in some settings. Education was felt to be necessary to improve the level of support for carers in their role. The potential for non-governmental associations (including Alzheimer associations) and civil society to lead education initiatives towards communities and carers was recognised.

Yet the evidence identified covered only five countries, with all sub-regions other than Southern SSA represented by only one or two studies. Given the heterogeneity and diversity of cultures, languages and beliefs within SSA, the generalisability of those results to countries or settings other than those where they originated is debatable.

#### **5.1.4 Social protection for older people**

With the rapidly growing number of older people living in SSA, who are more likely to develop chronic diseases such as dementia, increasing needs in support and health and social services are forecasted. Social protection, which seeks to reduce individuals' vulnerability, is therefore a necessity for older people across SSA. This is even more true for people living with dementia. In that perspective, we examined the development of social protection programs in SSA, mainly based on cash transfers and health insurance, and assessed their effects on the health of older people by looking in particular at two countries for which data was available (South Africa and Ghana).

A number of countries, mainly in Southern SSA, have social pension schemes mostly combined with contributory arrangements. Some countries have developed pilot social pension schemes with the support of external funding while others have dedicated larger amounts of public funds to develop contributory schemes for relatively privileged social groups (civil servants). Overall social protection in SSA is highly inequitable and most often excludes the most vulnerable groups of older people.

In SSA, only a small number of health insurance schemes have reached more than 30% coverage of their populations. Coverage is usually highly concentrated on more affluent social groups. However, Ghana's national health insurance scheme, free for people aged over 69 years, is quite unique and has been presented as a potential model for other resource-constrained countries. For now, the capacity of this scheme to improve health outcomes in the context of limited health services is debatable.

The availability of and access to health services across most of SSA is very limited, including for older people. There are significant challenges of translating pension coverage and health insurance into improved health and social outcomes. For now, the effects of social protection on the health status of older people in SSA remain limited by several factors, including weak health infrastructures and services still focussed on infectious diseases and child and maternal health. Social pensions have potential to enhance the wellbeing of older people. Health insurance for older people will improve older people's health only if entitlement to services ensures access to services that meet their needs.

## **5.2 Global Action Plan on Dementia**

In May 2017, the World Health Organization's Global Plan of Action on Dementia was unanimously adopted at the 70th session of the World Health Assembly in Geneva. The plan follows ten years of advocacy by ADI for a global response to the growing impact of dementia worldwide, and includes targets for the advancement of dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research (see Box 2). The Global Plan of Action on the Public Health Response to Dementia 2017-2025<sup>2</sup> commits Member States to take practical steps by 2025 to encourage progress in those different domains.

## Box 2

**The global plan on dementia: actions and targets****Action 1. Dementia as Public Health Policy**

*Target* 75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies, by 2025.

**Action 2. Dementia Awareness and Friendliness**

*Target* 100% of countries will have at least one functioning public-awareness campaign on dementia to foster a dementia-inclusive society by 2025. 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

**Action 3. Dementia Risk Reduction**

*Target* The relevant global targets defined in the Global Action Plan for prevention and control of non-communicable disease (NCDs) 2013–2020 and any future revisions are achieved for risk reduction and reported. (The risk factors for dementia are the same as other NCDs such as cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. The following measures can reduce the risk of cognitive decline and dementia: increase physical activity, prevent and reduce obesity, promote balanced and healthy diets, stop smoking and harmful use of alcohol, promote social engagement, cognitive stimulating activities and learning, and prevent and manage diabetes and hypertension – especially in midlife – and depression.)

**Action 4. Diagnosis, Treatment, and Care**

*Target* In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.

**Action 5. Support for Dementia Care**

*Target* 75% of countries provide support and training programs for carers and families of people with dementia.

**Action 6. Information systems for Dementia**

*Target* 50% routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.

**Action 7. Dementia Research and Innovation**

*Target* The output of global research on dementia doubles between 2017 and 2025.

From Rees G., Australian Journal of Dementia Care 2017; 6(4):7-9.

### 5.2.1 What does the plan mean for sub-Saharan Africa?

While it is estimated that 58% of all people with dementia live in low and middle income countries<sup>1</sup>, we have estimated in this report that 2.13 million people with dementia were living in sub-Saharan Africa, a number that is expected to almost double every 20 years. Increasing and emerging needs will therefore arise in this region as more dementia awareness might be induced by the increasing numbers of people affected.

Health and care systems will be increasingly challenged. Specialist services, already under-resourced, will not have the capacity to deal with the levels of demand, which will likely increase faster than the development of the specialist workforce<sup>3</sup>. Primary care services, potentially better suited to facilitate care coordination for people with complex multimorbidities (including dementia), are currently not designed and not trained to assume such a responsibility. As highlighted previously, the focus on infectious diseases and maternal and child health rather than non-communicable and chronic diseases is still very strong in SSA. Besides the weakness of healthcare services, the erosion of customary family care systems and old-age support (reputed to be an asset for African populations) will certainly continue given the context of social, demographic and economic changes within the region. The implications of these considerable changes and increasing needs must be considered urgently by countries and the African Union.

For now, no dementia plans or strategies have been established by countries in SSA. The issue of dementia is often within the remit of Ministries of Health and Social Affairs; sometimes included in national plans for Non-Communicable Diseases or Mental Health. The World Health Organization (WHO) has a role in monitoring health trends, disseminating information, and providing leadership, policy guidance and technical assistance to governments. After almost a decade of efforts and energy deployed towards the dementia field, with the inclusion of dementia in the 10 'priority neurological and mental disorders' for the WHO Mental Health Gap Action Plan (mhGAP)<sup>4</sup>, the WHO/ADI joint report 'Dementia: a public health priority'<sup>5</sup> and the conference on Global Action Against Dementia, the Global Action Plan on Dementia<sup>2</sup> has now been adopted. This plan includes specific actions for Member States, international, regional and national level partners. Indicators and targets, which can be used to evaluate levels of implementation, progress and impact, have been set. For the first time, governments can now be held accountable on the advancements of dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research in their countries.

### 5.2.2 Awareness

Raising awareness is the foundation of the public health approach to addressing the dementia epidemic. The core message is that dementia is a disease causing disability and not an inevitable consequence of ageing<sup>5</sup>. Awareness-raising and understanding are essential to counter the fatalism and stigma that can often be associated with dementia, and may also help family members and carers to access support and cope better with their caregiving role. Awareness often needs to be raised at different levels: the broader community, people with dementia and their families, and those who provide health and social services to them.

Dementia awareness and friendliness are one of the seven action areas listed in the WHO Global Plan. It is believed that increasing public awareness, acceptance and understanding of dementia and making the social environment dementia friendly will enable people with dementia to participate in the community and develop their autonomy<sup>2</sup>. We have seen in the past that 'Dementia Friendly Communities' were popular among the governments that had developed policies and plans. Dementia Friends initiatives are aiming at transforming the way the nation thinks, acts and talks about dementia. It seeks a change in attitudes and behaviour towards dementia, for people with dementia and their carers to be treated with respect and dignity, and for communities to be able to support people with dementia so they can 'live well with dementia'. One of the proposed actions for the WHO Secretariat is to build upon the WHO Global Network of Age-friendly Cities and Communities<sup>A</sup> to integrate and link dementia friendly initiatives, learning from previous experiences of what works in different contexts. The current limitation is that the network does not include any members (city or community) in the whole African continent, where experiences could be more efficiently shared.

A [http://www.who.int/ageing/projects/age\\_friendly\\_cities\\_network/en/](http://www.who.int/ageing/projects/age_friendly_cities_network/en/)

However, Dementia Friends initiatives have already been introduced in the sub-Saharan region. A Dementia Friends programme was launched in Nigeria in early 2016 by Dementia Nigeria with the support and guidance of the Alzheimer's Society (UK), using outline and materials adapted from the UK programme<sup>B</sup>. Within a few months, over 21 Dementia Friends Champions (trained volunteers who encourage others to learn a little bit about dementia) were spread in 19 of the 36 Nigerian states. Information sessions were held in schools, hospitals, places of worship and other places within villages and towns. Over 80,000 people in Nigeria have now become Dementia Friends and positive changes within communities are described by Dementia Nigeria. The strength of their programme was to get individual village chiefs and elders involved, who would then cascade the learning to the lower chiefs and then to individual households within their communities. Having key respected members of the community engaged in the programme helped to give the Dementia Friends messages some weight. The role of associations in dementia education and awareness is often key and has been recognised. Currently, only seven Alzheimer's associations are members of the ADI network, from countries spread over the sub-Saharan region. The Nigerian experience regarding the implementation of the Dementia Friends initiative is a good opportunity for all those associations and beyond to learn how this challenging task can be successfully approached.

### 5.2.3 Access to services

With the new United Nations Sustainable Development Goals, all UN Member States have agreed to try to achieve Universal Health Coverage by 2030. This includes financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all. A challenge will have to be faced by many low and middle income countries, especially in SSA where the availability of and access to health services can be very limited, particularly for NCDs, populations from rural areas and for older people.

Problems of access to services are numerous, including limited help-seeking due to low awareness and financial barriers (especially in case of a continuous need for care, when there is limited or no reimbursement for health and social care, when people have insufficient outcomes to cover out-of-pocket payments)<sup>1</sup>.

For countries in SSA, like many low and middle income countries, one of the main issues is the lack of coverage of services. Specialists caring for people with dementia (neurologists, psychiatrists, geriatricians, psychologists, occupational and physical therapists, specialist nurses) are too few (if available at all) to provide services to a significant number of people with dementia, and they are mostly based in the main urban areas. This problem is not exclusive to dementia and has been identified for other non-communicable diseases or mental health domains<sup>1</sup>. However, the increase in demand for services related to dementia will be particularly acute and will add strain on already under-resourced specialist services.

'Task-shifting' or 'task-sharing' approaches have been presented as potential solutions in this context, whereby much of the delivery of care is contributed by non-specialist primary care and community services, which would be supported and trained by more experienced specialists. Rationale for a move towards a more task-shifted model of care for dementia can be based on two arguments<sup>3</sup>. First, mobilising the non-specialist primary care workforce can relieve resource constraints and therefore facilitate scaling up of the model. This is particularly relevant for low and middle countries including SSA. Secondly, this approach will likely help to reach productive efficiency, when more healthcare services are provided at a given quality and cost or when the same healthcare services are provided at a given quality but lower cost<sup>3</sup>. The cost of care per person with dementia is then assumed to decrease. When considering the task-shifted model of dementia care pathways for South Africa in the World Alzheimer Report 2016, the main challenges identified remained the competing claims to limited resources, aggravated by inequities in access to care, stigma, and lack of professional training and awareness<sup>3</sup>.

Although the task-shifted approach for dementia care is attractive, such a transition will not be achieved overnight and assumes a complex process, including changes of roles and responsibilities, additional resources and new models for the delivery of care. Non-specialists will need to be trained to take on new and unfamiliar tasks, with the support and supervision of specialists. Specialists will therefore become more focused on service delivery management rather than delivery of frontline care (reserved for complex cases), and will need to ensure the coverage of services and the quality of care provided.

<sup>B</sup> <https://blog.alzheimers.org.uk/campaigns/dementia-friends-nigeria-tackling-a-global-health-epidemic/>

For sub-Saharan African countries, like other low and middle income countries, the implementation of task-shifted approaches will most likely rely on the WHO mhGAP guideline for dementia diagnosis and management<sup>4</sup>. In summary, dementia healthcare would be provided by community healthcare workers providing outreach in the community (hence boosting detection), a case manager and the primary care physician, screening for those presenting with subjective memory impairment. Only a small proportion of patients (5%) would be referred to the specialist because of unusual presentations or young onset for example. In complement of the mhGAP guidelines, the assessment and management of physical comorbidity to optimise physical health can be provided by the community healthcare worker, through the WHO Integrated Care for Older People (ICOPE) programme<sup>6</sup>. Post-diagnostic support and care would be provided by community healthcare workers and primary care physicians.

The readiness of primary care services to assume such roles will vary among countries, depending on existing levels of population coverage, workforce resources and competencies, and capacity to provide continuous care for chronic diseases.

In the Global Action Plan, the WHO secretariat proposed to develop and implement guidelines, tools and materials such as model training covering core competencies relating to dementia for health and social care workers, as well as to provide guidance on strengthening the implementation of the dementia component of the mhGAP programme to enhance capabilities of existing human resources and train more staff, and the ability to provide quality care through primary care<sup>2</sup>.

### 5.2.4 Prevention

One of the key areas of the Global Action Plan is dementia risk reduction. While the strongest evidence for possible causal associations with dementia identified in the 2014 World Alzheimer Report reviews were those with low education in early life, hypertension in midlife, and smoking and diabetes across the life course<sup>7</sup>, the evidence from studies in SSA is not consistent. More research needs to be dedicated to identifying potential risk factors in SSA, some of which might be specific to the region, before we can even assess the likely impact of dementia risk reduction on the incidence of dementia.

Considering that cardiovascular health is becoming increasingly compromised in many SSA countries, actions to promote good health need to be supported without waiting for more robust research to be carried out. Health promotion activities, publicising risk associations to achieve change through aggregated modification of lifestyles and behaviours, have been effective in the past improving cardiovascular health<sup>8</sup>. The focus on control of detection and treatment of diabetes and hypertension, reduction of levels of obesity, smoking cessation, increased physical activity and better education are public health priorities in many countries worldwide. This certainly needs to be reinforced in SSA countries where non-communicable diseases are still competing for attention with communicable diseases and where levels of education can still be low, especially in rural areas. Yet, tackling NCD prevention and management in SSA countries, including the assessment of risk factors, identification and active management of high risk status, early disease detection and long-term follow-up with regular monitoring and promotion of adherence to treatment, means there is a need for primary health care to be substantially strengthened<sup>9</sup>.

The WHO recommends linking dementia with other programmes, policies and campaigns on non-communicable disease risk reduction, and raising awareness of the links between dementia and other non-communicable diseases. The message that dementia, alongside heart disease, stroke and cancer, may be prevented through increased adoption and implementation of public health strategies needs to be heard by the public as well as policymakers.

The potential for dementia risk reduction has been modelled multiple times, mostly based on data from high-income countries<sup>10-12</sup> where age-specific dementia incidence has been reported to decline<sup>13-16</sup>. However, even with urgent action to address this problem in LMIC and SSA, it is unlikely that trends in dementia incidence and prevalence will follow the same patterns, at least short- to medium-term.

### 5.2.5 Rights

People with dementia and their carers have the same human rights as every other citizen. It is widely recognized that people with dementia are frequently denied their basic rights in both the community and care homes. The lack of ethical, social and legal protection of people with dementia in sub-Saharan countries is evident. People with dementia are not always involved in decision-

making processes and their wishes and preferences for care are not often respected. As mentioned in this report, the voices of those affected by dementia are often forgotten or not sought, when they might have a lot to tell us about their experience of living with dementia and how they would wish their rights to be respected. It is essential that rights are recognized, respected and protected to empower people with dementia, those who support them and the community as a whole.

The Global Action Plan for Dementia is grounded on cross-cutting principles, including respect for the Human Rights of people with dementia and universal health and social care coverage for dementia<sup>2</sup>. More recently, the World Health Organization's newly elected director-general, Dr Tedros Adhanom Ghebreyesus, reiterated that universal health coverage would be a priority during his mandate, which would address the issue of health as a human right.

Within that framework, the basic principle of equity (the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically) is therefore important. It means that all people affected by dementia should be acknowledged as having equal status and value, and should be accorded equal access to diagnosis, treatment, care and support, regardless of age, sex, socioeconomic status, ethnicity or country of residence. With the perspective of a disease-course modifying treatment for dementia by 2025, one of the impressive commitments of the G7 Global Action on Dementia, it is essential that issues of equity are addressed. The WHO Global Action Plan indicates that:

*'designing and implementing health programmes for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers'<sup>2</sup>*

As highlighted in the World Alzheimer Report 2015 and the present report, this objective will take time and commitment to achieve in sub-Saharan Africa.

### 5.2.6 Research prioritisation

Dementia research is globally underfunded with respect to the burden of the disease and the societal economic cost. While ADI and several international and national organisations have called for nation states to dedicate 1% of their respective societal economic cost to dementia research, investment in dementia research remains uneven globally.

The WHO Global Action Plan on Dementia proposed actions regarding dementia research and innovation, stating that implementation of research aligned with identified priorities and social and technological innovations can increase the likelihood of effective progress towards better prevention, diagnosis, treatment and care for people with dementia. Actions for Member states include:

- the development, implementation and monitoring of national research agendas on prevention, diagnosis, treatment and care which would fill the gaps in evidence to support policy and practice;
- the increase in investment in dementia research and innovative health technologies; and
- supporting the development of technological innovations that respond to the physical, psychological and social needs of people with dementia, their carers, or people at risk of developing dementia<sup>2</sup>.

Although this Action Plan will support the development of dementia research globally and guide nations to define adequate research agendas, the results of this report show the gap in evidence for almost all domains of the dementia field in the sub-Saharan region. Estimating the prevalence and incidence of the disease in this region is still a task that needs to be prioritised, and new studies need to be ideally designed to be able to monitor any secular trends in incidence and mortality when feasible. Those studies should as much as possible be conducted in nationally representative samples, and could potentially be nested within national surveys of health and ageing. An alternative would be to build upon the existing networks of Health and Demographic Surveillance Sites across sub-Saharan Africa to develop dementia studies, as has already been done on ageing and health with the SAGE and HAALSI studies.

Future studies should also consider investigating a diverse range of areas using multiple methodologies to help filling gaps of evidence highlighted in this report on:

- the experience of people with dementia and their carers, the understanding of the condition and how it can lead to stigma, discrimination and help-seeking behaviours, that would support adequate education, counteract stigma and enhance the management of dementia;
- the use of services, the description of care systems and care arrangements, especially informal care, which would allow a better estimation of the costs of dementia;
- the potential effect of genetic and modifiable risk factors of dementia and how they relate to geographic variations and changes in dementia prevalence and incidence, which would support the relevant implementation of programmes, policies and campaigns on non-communicable disease and dementia risk reduction;
- the impact of the HIV/AIDS epidemic on both the dementia epidemiology and the changes in social and economic context for older people in SSA;
- the impact of social protection and health insurance on the access to services for people with dementia and their carers.

Despite the striking gaps in evidence for the dementia field in SSA, we must acknowledge the overall challenge brought by the epidemiologic and demographic transitions in a region where most health systems are not equipped to provide the comprehensive care needed to manage complex health states and where there may already be difficulties dealing with individual conditions, especially among older people. The World Health Organization in its report on Ageing and Health<sup>17</sup> recently recognised that meeting the needs of ageing populations would require significant changes in the way health systems are structured and health care is delivered. Many existing services were designed to cure acute conditions or symptoms, often resulting in disconnected and fragmented disease management as well as a lack of coordination across care providers, settings and time.

Moving away from disease-based curative models towards the provision of older-person-centred and integrated care is one way health systems could be transformed<sup>17</sup>, which would likely benefit older populations in SSA. The development of generalizable models of community healthcare for frail and dependent older people, who are likely to develop dementia, is therefore fundamental. The WHO has initiated the development of evidence-based guidelines on integrated care for older people (ICOPE) with a focus on less resourced settings. Targeted at non-specialist health workers, they will guide home-based interventions for older people that can prevent, reverse or slow declines in intrinsic capacity. Those guidelines, to be published by the WHO by the end of 2017, will cover issues such as malnutrition, mobility loss, urinary incontinence, falls, hearing and visual impairments, depression, and cognitive, behavioural and psychological problems<sup>6</sup>.

### 5.3 Concluding remarks and call to action

This report tries as far as possible to give a faithful snapshot of the situation today. The lack of available data continues to make it difficult to create a baseline which future publications of this type can use to ascertain whether there have been changes and, more crucially, any progress. Lack of data will not deter ADI and its focused, energetic and committed members from working to find solutions to a very real and tangible problem. But the solutions for Africa can only come from Africa. Alzheimer associations in Ghana, Kenya, Namibia, Nigeria, South Africa, Zambia and Zimbabwe – our members at the date of publication – cannot be alone in their fight, we need more to join them. They are forging ahead, creating hope and activity where there was little, mobilizing goodwill and resources to find solutions, and trying to sensitise their governments.

Governments in the region have a real opportunity right now – thanks to the excellence of these grassroots organisations – to join forces with them and by adopting and implementing the seven key areas of the WHO Global Action Plan and the recommendations in this report, show the rest of Africa the way. At the same time, we need the African Union to listen to the important truths about the scale and cost of dementia today and in the future. Now is the time to protect those in society who are most vulnerable.

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## Appendix A: Global Burden of Disease (GBD) Regions

Table A.1

### GBD regions and countries

GBD Region	Countries	Relationship to WHO regions used for ADI/ Lancet estimates
Sub-Saharan Africa, Central	Angola, Central African Republic, Congo, Democratic Republic of the Congo, Equatorial Guinea, Gabon	A mixture of AFRO D and AFRO E
Sub-Saharan Africa, East	Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mauritius, Mozambique, Rwanda, Seychelles, Somalia, South Sudan, Sudan, Uganda, United Republic of Tanzania, Zambia	AFRO E except for Comoros (AFRO D) and Somalia and Sudan (EMRO D)
Sub-Saharan Africa, Southern	Botswana, Lesotho, Namibia, South Africa, Swaziland, Zimbabwe	AFRO E
Sub-Saharan Africa, West	Benin, Burkina Faso, Cameroon, Cape Verde, Chad, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Sao Tome and Principe, Senegal, Sierra Leone, Togo	AFRO D

## Personal story



# Zimbabwe – Mrs Z

**M**rs Z is 94 years old, and lives on the farm where she and her husband raised their eight children. After retirement, they both stayed at the farm, and Mrs Z remained active, as Chairwoman at the local church, and as both Secretary and Treasurer of the Women Fellowship. Her grandchildren came to the farm, and enjoyed spending time with them.

Her husband and four of her children sadly passed away. After the death of her youngest daughter in 2013, she began to wake up during the night and start praying continuously, mentioning the name of her dead daughter. Her children attributed this to the mourning process. By 2014, they started to notice changes in her behaviour: she would forget things and wanted to stay at her maternal farm although her in-laws were no longer there. Mrs Z started leaving the family home to go to neighbouring houses without informing anyone where she was going. Her children became worried for her safety as she was travelling 25km to reach the Women Fellowship, and the farm is surrounded by tall grass, which is home to pythons. She was increasingly spending time alone in her room, and packing clothes to visit relatives who had passed away.

In December 2016, Mrs Z was admitted to hospital and was diagnosed with congested cardiac failure. When her daughter described to the physician the changes in Mrs Z's behaviour, he initially said it was just old age. However, after speaking to her further, he explained that she was going through the early stages of dementia. A month later, Mrs Z started becoming more confused and had trouble sleeping.

At this point the family got in contact with Zimbabwe Alzheimer's and Related Disorders Association (ZARDA), who have been a great help to Mrs Z and her family. They have done much to raise awareness and train carers in communities across Zimbabwe – a country in which there is still a pervasive stigma surrounding dementia.

Her daughter continues to care for her, and has support from a maid. She ensures her mother's safety by locking the gates, but she freely walks around the garden, and enjoys getting some fresh air and exercise. Her daughter does some basic occupational therapy by giving her tasks to exercise her brain. The local community, particularly members of the church, neighbours, and extended family, remain supportive of Mrs Z, and often visit her. Having seen ZARDA's work and interventions, Mrs Z's daughter says: "It is my hope and wish to research this condition in different cultures and tribes. A big thank you to ZARDA".



**Alzheimer's Disease  
International**

## **About ADI**

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our 90 members is a non-profit Alzheimer association supporting people with dementia and their families. ADI's mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

## **What we do**

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families on international platforms at the UN and WHO.

## **Key activities**

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Supporting the 10/66 Dementia Research Group's work on the prevalence and impact of dementia in developing countries.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organisation in the USA. ADI was founded in 1984, has been in official relations with the World Health Organization since 1996 and has had consultative status with the United Nations since 2012. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy and support in the fight for individual autonomy for people with dementia.

You can find out more about ADI at [www.alz.co.uk/adi](http://www.alz.co.uk/adi)

Alzheimer's Disease International:  
The International Federation  
of Alzheimer's Disease and  
Related Disorders Societies, Inc.  
is incorporated in Illinois, USA,  
and is a 501(c)(3) not-for-profit  
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