

## Research Article

## Dementia research needs in Ghana: a perspective

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## **Background**

Estimates suggest that about 50 million individuals are living with dementia globally. Thus, dementia remains a public health concern at all levels. Although there are several factors that offer conditions for the provision of empirical evidence for an intervention, little is known about dementia within the Ghanaian population. This write-up aims to describe Ghana's dementia research needs.

## Methods

Based on results from a study conducted in the Kintampo area of Ghana, the study team strategized to identify dementia research needs in Ghana. Additionally, a literature search was used to identify and outline the dementia research needs.

## Results

The study identified three main thematic areas: diagnosis and prevalence; studies on the prevention of dementia; and other interventions to improve the quality of life of older persons. For diagnosis and prevalence; epidemiological studies should be conducted using a nationally representative sample to determine the prevalence of dementia. In terms of studies on the prevention of dementia, it is important to conduct studies that will highlight ways of preventing or delaying the onset of dementia in Ghana. There are other approaches to combat the burden of dementia such as building the capacity of primary care health care workers to address this challenge among other population and their families.

## **Conclusions**

There is paucity of epidemiological data on dementia in Ghana. Thus, the research needs identified will be useful in dealing with the challenges that dementia presents to the Ghanaian population.

Dementia is a syndrome usually of a chronic or progressive nature in which there is deterioration in memory, thinking, behaviour and an individual's ability to undertake everyday activities. Although evidence suggests that dementia mainly affects older people, it is not a normal part of ageing as it is portrayed. Globally, 35.6 million people have dementia and there are about 8 million new cases every year. Alzheimer's disease is the most common cause of dementia and accounts for 60-70% of the cases. Dementia is one of the major causes of disability and dependency among older people worldwide. It is overwhelming, not only for the people who have it but also for their caregivers and families.

There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. The impact of dementia on caregivers, families, and societies can be physical, psychological, social and economic. Estimates suggest that there will be about

50 million individuals globally who will be living with dementia and this has associated estimated economic cost of about \$1 Trillion.<sup>3,4</sup> This therefore remains a public health concern at the global, national and regional levels.<sup>3,4</sup> According to the Alzheimer's Disease International report, approximately 2.54 million people will be living with dementia in Africa by 2050.<sup>5</sup> However, with the considerable increases noted in current estimates, sub-Saharan Africa (SSA) will be having one of the largest increases of 7.62 million people living with dementia (PLWD) by 2050.<sup>4,6</sup>

Globally, the population aged 60 years and above is increasing at 3.2% per annum and will continue at this rate for the next few years.<sup>7,8</sup> In Africa, ageing is more rapid, with SSA having the fastest growing older population of the world.<sup>7</sup> This suggests that it is time to pay attention to the needs and especially, the health of the older persons including, dementia prevention and intervention programmes. The ageing of Ghana's population has been rapid over the

Table 1. Description of key search terms and databases used

PubMed (Medline and PubMed Central), African Index Medicus EMBASE, PsycINFO, Google Scholar		
Key search term	Alternative search term	
Dementia	Dement*, Alzheimer*, Aging, Elderly, Neurodegenerative	
Research Needs	Research priorities	
Ghana	Ghana*	
Scope	Ghana, Africa	

past two decades and will continue into the future with an increasing number of Ghanaians surviving to 60 years and beyond.<sup>8,9</sup> This is as a result of declining fertility rates and increasing life expectancy.<sup>7</sup>

Ghana has a population policy that seeks to address the physical and health needs of the elderly and strategies for implementing is targeted at the specific subgroups of the population. 10 Like other sub-Saharan African countries, Ghana has other competing health needs that affect the will to implement the policy and thereby affect the wellbeing of the elderly. Ageing is taking place in an era in which the traditional systems that support elderly care have been transformed by the processes of modernization and globalization and in the absence of good public welfare systems.<sup>11</sup> Consequently, SSA countries have not made enough economic progress before population ageing sets in. This is a cause for concern since ageing is associated with decline not only in physical and health status of an individual but also mental health issues like dementia and depression among older people, resulting in poor functioning, affecting the perception of health, healthcare utilization and health-care costs.12

In this regard, it is important to have more high-quality research and studies from low and middle-income countries (LMIC) and in Ghana, in particular, to achieve reliable estimates of prevalence dementia and accurate projections. <sup>13</sup> Access to such data would assist in raising awareness among stakeholders on the extent of the burden of dementia, its impact and looming health challenges in the coming decades. What is more, the data will be useful for designing an effective healthcare delivery system to mitigate the burden of dementia.

So far, only one dementia study has been conducted in Ghana despite the projected rapid increase in the aged population. Studies on older persons have been confined to experiences of caregiving and health care needs assessment. Other studies on the aged were on self-reported health particularly in the area of chronic conditions. 14 According to Mba, 2010, Ghana has one of the region's largest aged populations (7.2% of 60 + years). The 2010 national policy on ageing and its strategy on 'improving health, nutrition, and wellbeing of older persons has been established. 15 However, there was no mention of how to handle the burden of dementia in the policy document. Coupled with an impetus for mental health in Ghana<sup>16</sup> a commentary on dementia is a timely contribution to the emerging area in SSA. This commentary is useful by highlighting the dementia research needs in Ghana. It also provides the basis for the conduct

of other studies that will improve awareness and dementia care in Ghana.

## **METHODS**

Based on the prevalence reported by the Kintampo Dementia Initiative (KDI), the study team strategized to identify the dementia research needs in Ghana. Literature searches was done to identify and outline the dementia research needs. The research needs were identified using various search engines such as PubMed (Medline and PubMed Central), African Index Medicus and Google Scholar databases. This enabled the team to capture as many relevant articles as possible.

## SEARCH STRATEGY

We conducted a systematic search over a period of one-month 1 October, 2018 to 1 November, 2018 and the process was repeated in the month of February, 2019 to update the search results, with no restrictions on article publication date. Table 1 shows a breakdown of the terms and databases used in the search.

# ARTICLE SELECTION, DATA EXTRACTION AND SYNTHESIS

Two authors (SN and KAA) reviewed and selected eligible articles based on the selection criteria described below. Articles were deemed relevant for inclusion by initially scanning the titles and abstracts. If the criteria were not easily identifiable from the titles, the abstracts were then examined; if the author was still unsure, the article was included and a full article review was then conducted to confirm eligibility. The second round of screening comprised a more in-depth evaluation of each article. We downloaded the full-text articles and reviewed them for eligibility. Eligible studies were examined for indicators such as the diagnosis and prevalence of dementia; prevention of dementia and other studies on dementia. After selection, the following information was extracted from each article; author(s), title of study, population/sample size, average age of participants, theme, and key findings. We extracted all data using a spreadsheet which was designed based on eligibility criteria. This effort resulted in 435 citations from which relevant studies were selected for this commentary. These were examined (reviewing the titles and abstracts), and 368 citations were excluded as irrelevant. The full papers of the remaining 67 citations were assessed to select those primary studies that reflects the objective of this commentary. These criteria excluded 35 studies and left 32 for this write up.

## KINTAMPO DEMENTIA INITIATIVE

The KDI sought to identify the burden of dementia and design interventions to address them. Between November 2014 and August 2015, collaborative research between Kintampo Health Research Centre, Ghana and the 10/66 Dementia Research Consortium based at Kings College London, UK was conducted in the Kintampo area. A one-phase population-based cross-sectional study, embedded with qualitative method was conducted. Participants aged 70+ years were sampled from the Kintampo Health and Demographic Surveillance System's database. The 10/66 short dementia diagnostic schedule (comprising of a household questionnaire, Euro-D, a background sociodemographic and risk factor interview, a cognitive test battery, and an informant interview)<sup>17,18</sup> was administered to participants in their homes. A total of 761 participants agreed to participate and were interviewed for the first part of the aim (quantitative component). For the second part of the aim (qualitative component), 10 households were selected for in-depth interviews.

## RESULTS

Results from the KDI showed an overall prevalence of 5.0% (95% confidence interval, CI=3.6–6.8) and a standardised prevalence of 6.6% (95% CI=3.6–6.8), for all ages.<sup>19</sup> In addition, the kinsfolk in the study area ascribed the symptoms of dementia to normal aging and linked them to other comorbidities of aging.<sup>19</sup> Table 2 shows a breakdown and the characteristics of the publications found in our search, highlighting the research needs, which can be grouped into three main thematic areas: diagnosis and prevalence; studies on the prevention of dementia; and other interventions to improve the quality of life of older persons (Box 1).

## **Box 1: Research questions**

- What are the dementia research priorities in Ghana?
- What is the national prevalence and correlates for dementia in Ghana?
- What are the culturally acceptable strategies for preventing dementia in Ghana?
- What are the strategies available for delivering care to the older persons in general and to people living with dementia at the community level?

## DIAGNOSIS AND PREVALENCE

Currently, there is a gap regarding data on the prevalence of dementia in Ghana. Thus, there is a strong need for the conduct of more studies on the prevalence of dementia using a nationally representative sample. This reliable data will document the risk factors of dementia and how they change over time. In high-income countries, the use of artificial intelligence to diagnose dementia and its associated risk factors has become prominent. <sup>29</sup> In addition, research on genetic and environmental factors associated with dementia should be included. These studies are needed in Ghana to estimate the actual prevalence of dementia.

## PREVENTION OF DEMENTIA

When the burden and the risk factors are estimated, it is essential that studies that will highlight ways of preventing or delaying the onset of dementia as evidenced in a plethora of studies conducted within other settings. <sup>30–32</sup> Within the Ghanaian context, it is important that studies which identify culturally acceptable packages at preventing as well as delaying the onset of dementia are conducted. This will lead to an eventual reduction of the burden of dementia amidst the ageing population in Ghana.

## OTHER RESEARCH NEEDS

TASK SHARING APPROACHES FOR DELIVERING CARE TO THE OLDER PERSONS AT THE COMMUNITY LEVEL

In Ghana, health care delivery approaches have adopted the task shifting or task sharing approach at the primary care level as in other countries. 33,34 Task shifting is a rational distribution of tasks from physicians to non-physician health workers.<sup>35</sup> This approach is useful in delivering healthcare to the doorstep of individuals at the community level. Such studies relied on the Community Health Planning Services (CHPS) set up to deliver healthcare. CHPS is a concept within the health system of Ghana that aims at providing accessible primary health care to all communities within Ghana. A key element of CHPS is a community-based healthcare service delivery, focusing on collaboration with key community members. The health worker within the CHPS involves each community within a zone (catchment area) in micro health planning activities. The composition of a CHPS zone is a defined healthcare catchment area of up to three-unit committees (a population of 3000 to 4500) within a sub-district. Some of these catchment areas have buildings that host the activities of the health workers. 36,37 These buildings are called CHPS compounds. With regards to the care of older persons, this community-based approach has not been explored in Ghana. Studies can be conducted to explore the feasibility of adopting this approach to improve the quality of life for older persons, including care for people living with dementia. There is also an urgent need to create awareness about dementia and improve the capacity of primary health care workers to identify and refer patients with dementia using the WHO ICOPE guidelines. 38 These guidelines were developed to provide evidence-based guidelines for non-specialized

Table 2. Characteristics of studies included in this write-up

Author(s)	Title	Population/ Sample Size	Average age of participants	Theme	Key Findings
de Jager et al., 2017 <sup>20</sup>	Dementia prevalence in a rural region of South Africa: a cross-sectional community study	A total of 1,394 Xhosa- speaking community dwellers	Mean age ±SD 71.3 ± 8.3 y	Diagnosis and prevalence	Using a published CSID sensitivity/specificity values the prevalence estimate was 0.8 (95% CI=0.06-0.09). Using CSID cut-off scores the estimated prevalence was 0.12 (95% CI=0.10-0.13), with 161 screen-positives.
Dewhurst et al., 2013 <sup>21</sup>	The prevalence of neurological disorders in older people in Tanzania	A total of 2232 individuals from rural Hai district	70 years and above	Diagnosis and prevalence	Results show that the age- adjusted prevalence of people with neurological diagnoses was 154.1 per 1000 (95% CI=139.2-169.1). The age- adjusted prevalence per 1000 of the most common neurological disorders were tremor (48.2), headache (41.8), stroke (23.0), peripheral polyneuropathy (18.6), upper limb mononeuropathy (6.5) and parkinsonism (5.9).
Guerchet et al., 2013 <sup>22</sup>	Comparison of rural and urban dementia prevalence in two countries of Central Africa: The EPIDEMCA	A total of 2004 elderly were interviewed in Central African Republic (CAR) and Republic of Congo	Participants aged ≥65 years old	Diagnosis and Prevalence	Preliminary analysis showed a DSM-IV dementia prevalence at 8.8% (95% CI=6.4-11.8) in Nola and at 6.0% (95% CI: 4.1-8.4) in Bangui.
Longdon et al., 2013 <sup>23</sup>	The prevalence of dementia in rural Tanzania: a cross-sectional community-based study.	A total of 1198 People from rural Hai district	Participants were 70 years and older	Diagnosis and Prevalence	Analysis of the data showed that 184 screened positive for probable dementia, and 104 screened positive for possible dementia using the Community Screening Instrument for Dementia. Following clinical assessment, 78 cases of dementia were identified according to the DSM-IV criteria. The agestandardised prevalence of dementia was 6.4% (95% CI=4.9-7.9). Prevalence rates increased significantly with increasing age.
Pellegrini et al., 2018 <sup>24</sup>	Machine learning of neuroimaging for assisted diagnosis of cognitive impairment and dementia: A systematic review.	Not applicable (NA)	NA	Diagnosis and Prevalence	Systematic analysis of the data showed that accuracy was highest for differentiating Alzheimer's disease from healthy controls and not good for differentiating healthy controls versus mild cognitive impairment
Ngandu et al., 2015 <sup>25</sup>	A 2-year multidomain	A total 2654 individuals	Participants were 60-77	Prevention of dementia	Findings from this large, long-term, randomised

Author(s)	Title	Population/ Sample Size	Average age of participants	Theme	Key Findings
	intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in atrisk elderly people (FINGER): a randomised controlled trial		years		controlled trial suggest that a multidomain intervention could improve or maintain cognitive functioning in at-risk elderly people from the general population
Mangialasche et al., 2012 <sup>26</sup>	Dementia prevention: current epidemiological evidence and future perspective	NA	NA	Prevention of dementia	Evidence suggest that prevention of dementia is moving from observational to interventional studies to verify hypotheses and define tools that can be applied in the general population. Since a cure for dementia is not yet available, finding effective preventive strategies is essential for a sustainable society in an aging world.
Andrade and Radhakrishnan, 2009 <sup>27</sup>	The prevention and treatment of cognitive decline and dementia: An overview of recent research on experimental treatments	NA	NA	Prevention of dementia	Analysis of epidemiological studies suggest that dietary measures, physical exercise, and mental activity may reduce the risk of cognitive impairment and Alzheimer's disease in elderly subjects. Statins may protect against incident dementia.
Clarke and Bailey, 2016 <sup>28</sup>	Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places	Families living at home with dementia and interviews with service providers and commissioners (a total of 57 diaries, 69 interviews with people living with dementia and 6 interviews with service providers and commissioners)	NA	Advocacy – understanding of living with dementia	Familiarity with people and place was seen to be supportive of inclusion and feeling on the inside.

CAR - Central African Republic, CSID - The Community Screening Instrument for Dementia, DSM - Diagnostic and Statistical Manual of Mental Disorders, NA - not available

health workforce to implement at both the primary care and the community levels. The health workforce can work with the family caregivers to ensure adherence to the interventions implemented.

## ADVOCACY

Advocacy could be a useful tool to help raise awareness about dementia; push for change; and build actions towards alleviating the burden of dementia to the individual, family and society. These advocacy tools could also be useful in providing public sensitization aimed at reducing the stigma associated with living with dementia. In Ghana, the promi-

nent non-governmental organizations (NGOs) currently undertaking most of the advocacy roles in terms of dementia and welfare of older persons include Alzheimer's Ghana,<sup>39</sup> Help Age International,<sup>40</sup> and Aged Help Foundation.<sup>41</sup> The NGOs advocate for activities to improve care for older persons, awareness and sensitization of the Ghanaian society on the care for older persons, including those living with dementia. There is an urgent need to foster collaboration between the various stakeholders to ensure that their activities are aimed at achieving a common goal in creating awareness and sensitization within the Ghanaian society. An evaluation using a uniform framework such as the one recommended by Roche (1999) for impact assessment; 'project out' and 'context in'. The first approach, the 'project out' approach, starts with the aim of the project or programme and then finds ways of measuring the outcomes of the aim or objective from a variety of perspectives. The other approach, the 'context in' approach, measures the changes happening in people's lives, the significance about these changes, and then assesses the usefulness or effect of any intervention in relation to these changes. 42 Such advocacy activities can include the promotion for building a dementia-friendly community suggested by Clarke et al and Lin et al. $^{28,43}$ 

## DISCUSSION

The estimated demographic shift toward an older age group in Ghana suggests that there is a burgeoning need for ageing research particularly, on dementia in Ghana. The results of the ground-breaking epidemiological study conducted within the Kintampo North and Kintampo South Districts revealed dementia is prevalent. <sup>19</sup>

There is, therefore, an urgent need to replicate more of such epidemiological studies nationally. An example of such large studies is one conducted by the 10/66 Dementia Research Group (DRG), across 11 LMIC in 2003. In this multi-centre cross-sectional survey, dementia diagnosis was done using a culturally and educationally sensitive 10/ 66 dementia diagnostic algorithm and prevalidated in 25 Centres in India, China and southeast Asia, Latin America and the Caribbean, and Africa, and by computerized application of the dementia criterion from the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).44 The study found that dementia varied from 0.3% (95% CI=0.1-0.5) in rural India to 6.3% (95% CI=5.0-7.7) in Cuba. Such a study should be replicated in all the 16 Regions in Ghana to highlight the actual burden of dementia and create a dementia database in Ghana. This data will assist in the planning of useful interventions to mitigate the strain associated with caring for older persons and those living with dementia.

Also, studies on the prevention and or delay of the onset of dementia in Ghana are critical. A study conducted by Reiman, Langbaum, and Tariot proposed a prevention initiative for evaluating the most promising pre-symptomatic Alzheimer's disease treatments, and help develop a regulatory pathway for its approval. Furthermore, a review conducted by Wilson et al. concluded there are numerous risk factors that may lead to a greater likelihood of developing dementia, yet there is no simple intervention to mod-

ify these risks. As well, the study concluded that avoiding high blood pressure, controlling cholesterol and diabetes and maintaining a healthy diet and lifestyle may lower the risk of developing dementia. With such an initiative, stakeholder engagement will be key in identifying culturally acceptable ways of preventing and delaying the onset of dementia in Ghana. This can be done from the national level through the primary care level to ensure that the approaches adopted will be effective and bought-in.

Other research needs identified include, building the capacity of non-specialist health workforce using the WHO ICOPE guideline and for advocacy. The focus of this policy and plan was to use community health workers (CHW) to perform assessments of older persons' household health needs and provide the CHWs with training on healthy ageing issues and protocols on ageing and health. When this is done, frontline health workers within the community will be empowered to give the needed support to family caregivers to alleviate the strain they experience when caring for older persons. Strong advocacy will ensure community members are sensitized to adequately address issues of stigma. Fostering collaboration among the various agencies currently working to improve the conditions of older persons in the Ghanaian society is needed.

The research needs were identified using various search engines such as PubMed and Google Scholar databases. However, there are systematic ways of identifying and setting research priorities on particular health topics such as the Child Health and Nutrition Research Initiative (CHNRI) method and Group Concept Mapping (GCM). 47–50 There is a pressing need to conduct the research needs assessment (setting research priority) using a systematic approach like the CHNRI method to further explore the identified research needs.

## CONCLUSION

There is a paucity of epidemiological data on dementia in Ghana, however, the study conducted within a predominantly rural setting has shown that dementia was prevalent in the Kintampo districts with more females living with dementia than males. Thus, the research needs identified will be useful in dealing with the challenges that dementia presents to the Ghanaian population in the near future.

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## COMPETING INTERESTS

The authors completed the Unified Competing Interest form, and declare no conflicts of interest.

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