

The Alzheimer's Dementia Patients' Observed Illness Course and Experience in Ghana and Care Lessons to Be Learnt: A Mental Health Professional's Perspective

Albert M. E. Coleman 

Centre for Bioethics, Medical Law and Patient Advocacy, Sekondi, Ghana

Email: albert.coleman@gmail.com

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Abstract

Alzheimer's disease (AD) and associated dementia patient numbers continue to increase globally with associated economic costs to healthcare systems. Of note is the increase in numbers in lower and middle-income countries (LMICs) including Sub-Saharan African (SSA) countries, which already face challenges with their health budgets from communicable and non-communicable diseases. Ghana, an SSA country, faces the problem of healthcare budgetary difficulties and the additional impact of AD as a consequence of increasing population strata of old aged persons (OAPs) due to the demographic transition effect. This article uses examples of known patients' illness courses to give a perspective on the lived experience of patients with dementia (PWD) in Ghana, living amongst a populace with a culture of stigmatization of PWD, and a relatively fragile public mental health system (PMHS) for those with mental illness, including AD. The lived experience of AD patients is characterised by stigmatisation, discrimination, non-inclusiveness, diminished dignity and human rights abuses in the face of their mental disability, and eventually death. This article is an advocacy article giving voice to the voiceless and all persons suffering from AD and other dementias in Ghana, whilst pleading for a call to action from healthcare professionals and responsible state agencies.

Keywords

Alzheimer's Dementia, Patients, Ghana, Stigmatization, Discrimination, Human Rights, Dignity

1. Introduction

Alzheimer's dementia (AD), a chronic progressive neurodegenerative disorder,

is a non-communicable disease that is on the rise globally [1]. This is a consequence of an ageing population, especially in the high-income countries (HICs), and increasingly so, in the lower and middle-income countries (LMICs) [1] [2]. Specifically for LMIC, more so Sub-Saharan African (SSA) countries, the population ageing increase is attributed to a relative improvement in the standard of living-induced longevity among a demographic segment of their population, a phenomenon described as “epidemiologic transition” [3] [4]. Ghana, a SSA country and a LMIC, has experienced its fair share of the demographic transition. As in 2010, the proportion of persons over the age of 60 years in Ghana constituted 7.2 percent of the population, considered then as among the highest proportion of the elderly population in SSA [5]. With the global increase in the proportion of the elderly population, comes an increase in the number of persons suffering from Alzheimer’s dementia and related dementias. As of 2019, the global number of AD patients was estimated to be 57.4 million, and this number is estimated to reach 152.8 million by 2050 [1]. For SSA countries, the estimated population of people living with dementia in 2015 was 1.69 million. This was estimated to increase to 2.64 million in 2030, and again to 5.05 million in 2050 [3]. The economic cost of AD and related dementias globally for 55.2 million persons living with dementia in 2019 was estimated at US\$1313 billion [6]. 74% (percent) of these costs are for persons in higher-income countries (HICs), even though 61% of persons living with dementia, live in LMICs.

Specifically, for SSA countries, the cost of dementia care in the region was estimated in 2015 to be US\$2.8 billion (when the global cost then was US\$818 billion) [3]. Using a “value of statistical life” (VSL) based economic burden projection, the global cost burden of Alzheimer’s and related dementias was projected at US\$2.8 trillion in 2019, rising to US\$11.3 - 27 trillion in 2050 [7].

The cause of AD is linked to many factors, the predominant one being age, which may be linked to apolipoprotein E (APOE) genetics, with the APOE $\epsilon 4$ conferring a higher relative risk of disease and the APOE $\epsilon 2$ gene conferring a strong protective factor against disease for late-onset AD [8]. Specifically, APOE $\epsilon 4$ gene allele is strongly linked to AD, which could be autosomal dominant, sporadic or non-sporadic. In the Caucasian population whereas the APOE $\epsilon 4$ gene allele increases the risk of AD, interestingly for Sub-Saharan Africa, this association is rather weak, leading some to speculate that the presence of the APOE $\epsilon 4$ allele in SSA populations confers relative neuroprotection against AD compared to caucasian populations [9]. This disparity in association may be attributed to the relatively low (<2%) reported genome-wide studies that involve African data [10]. Other risk factors for AD include diabetes, hypertension, lower education achievement, obesity, physical inactivity, depression, smoking, low socialization, hearing loss, excessive alcohol, air pollution, diet and brain damage [11]. The “five-finger” model for the prevention of cognitive decline (fbhi.se) is another preventative model that shows a strong relationship between preventable risk factors and AD [12]. The mechanism or pathogene-

sis of AD is multiple with the formation of β -amyloid combined with tau fibrils leading to amyloid plaque formation in the brain featuring prominently for years. Additional mechanisms include the role of brain chemicals, acetylcholine, gamma-aminobutyric acid (GABA), serotonin, etc., reduction in brain connectivity fibres and recently the rate of brain amyloid clearance featuring among others [13]. Of interest is a recent study indicating that it may not necessarily be the quantity of amyloid quantity in the brain in those with genetic risk for AD, but rather the level of highly soluble amyloid- β_{42} in the cerebrospinal fluid (CSF) that dictates a progression to cognitive impairment and subsequent dementia [14]. Increasingly, the mitochondrial cascade hypothesis based on brain cell mitochondrial destruction in addition to antioxidant depletion seems to be gaining traction as another plausible disease mechanism [15].

The diagnosis of AD usually starts with a clinical suspicion of a combination of signs and symptoms of gradual cognitive impairment (memory and/or language decline), and an associated decline in activities of daily living (ADL) together with a memory test. Diagnostic functional imaging including proton emission tomography plays an important role, especially in the case of atypical AD [16]. Increasingly the analysis of biomarkers like cerebrospinal fluid (CSF) is used [17], and very recently two much less invasive and quicker blood tests have been reported to be potentially useful in the diagnosis of AD [18] [19]. Overall the diagnosis of AD should meet the criteria of the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) or the National Institute of Aging Alzheimer's association workgroups guidelines for Alzheimer's disease (NIA-AA criteria) or the International Classification of Diseases 11th edition (ICD 11). Definite AD diagnosis is usually a post-mortem or anatomic-pathologic diagnosis.

AD has no cure to date, however, disease or symptom-modifying drug treatment is available in the form of acetylcholinesterase inhibitors (ACIs) specifically Donepezil, Rivastigmine and Galantamine, and the GABA-ergic drug (Memantine), specifically for moderate to severe AD Patients [20]. The Federal Drug Agency (FDA), of the United States of America in the year 2023 approved Aducanumab, an amyloid clearance injectable monoclonal treatment, of utility for pre-AD or mild cognitive impairment stage of the disease for use in patients [21]. Very recently the FDA again approved another amyloid clearance monoclonal sister drug Lecanemab [22], (albeit both with some untoward side effects in some persons) [21] [22]. This has led to the American Academy of Neurology coming up with recommended guidelines on the use of injectable monoclonal antibodies in the management of early AD [23]. On the therapeutic horizon in the case of AD is a prospective drug allopregnanolone (ALLO), an endogenous neurosteroid, considered a "first regenerative therapeutic agent", currently in stage 1a/2b of clinical trial cohorts. ALLO was found in earlier trials on mice models of AD and a batch of human subjects to clear brain amyloid and tau

protein, as well as restore hippocampal volume, and improve cognition in some APOE $\epsilon 4$ carriers [24]. Unfortunately attempts to find a preventative vaccine, have not met with success for now. Non-drug management features prominently in the overall management of AD, especially in the moderate to severe type, where person-centred care at home, day centres or in very severe cases nursing homes are indicated. These non-pharmacologic treatment modalities include psychologic therapies, occupational therapy, music therapy, reminiscence therapy, aromatherapy, massage and other complementary medicine therapies and dementia technology-assisted interventions [25]. AD does not only impact the patient but affects especially the close family carers of the patients resulting in some cases of depression and other emotional syndromes and carer fatigue in carers [3].

Of interest is a recent article that reported that mass spectrometry CSF proteomic analysis has identified five heterogeneous molecular types of AD clinical sub-types with “each subtype related to specific AD genetic subtypes”, with “different subtypes” having different “in clinic outcomes, survival times and anatomic patterns of brain atrophy” [26]. This has led the authors to suggest that “the molecular heterogeneity highlights the need for personalized medicine” in the management of persons suffering from AD.

2. Alzheimer’s Patients’ Lived Experience in Ghana

This section is approached from two viewpoints: 1) posthumous case narratives of personal illness courses I know of and 2) the known country-specific general situation/problems in providing care for PWD.

2.1. Case Narrative Vignettes

Case I: This is a case I know of from when I was circa 10 - 11 years old, there was an elderly neighbour who was usually left in the care of younger family adults and grandchildren relatives. I remember he had become “less capable” memory-wise with a gradual loss of language function and difficulty reasoning, a few years post-retirement. He was usually kept locked indoors, frequently when he got the chance, he would come out of his room, exit the house and venture on the streets. What intrigued us the neighbourhood children was observing the elderly man’s grandchildren shouting after him, to get him to return home. Often adult neighbours will race and catch up with him and sometimes struggle to get him back home. Not knowing any better this was a sort of “puzzle” for his neighbours, especially for the neighbourhood children. These incidents recurred until he eventually passed on in his late 70 s’ (obviously without any specialist help).

Case II: As a physician and psychiatrist, on one of my visits to Ghana from my overseas base, a friend in a casual conversation told me the sad story of his older sister. The lady in her early 60 s had been under psychiatric care off and on for 8 - 9 years and was diagnosed as “schizophrenic”. As is usual among local families,

my friend ascribed his sister's illness to "her husband having started an affair with another woman". At the request of her family, I volunteered to stop by their house and check on her before I left for my base. My friend meanwhile introduced me to an adult child of the sick sister who happened to be visiting him. When I inquired from the adult child about how everything started from the beginning with her sick mother, it became apparent that things did not add up compared to what my friend had told me. The patient's daughter said that the patient initially exhibited brief fleeting periods of confusion, ostensibly getting out on some days to go to her sewing shop, but ending up in nearby towns, yet saying at the end of the day that she "went to work". Because her work output was declining compared to her previous work standard, she started losing customers to her sister (who also was a seamstress), resulting in the family complaining that the sister was using "black magic/witch-craft to steal the patient's customers" from her. Gradually with the years, her cognitive function declined as well as her activities of daily living (ADL).

Before I saw her, I requested a computerised tomography (CT) examination of her brain based on my suspicion. The head CT results showed "pathologically enlarged lateral ventricles and cortical sulci with generalised atrophy of the brain". On a visit to see the then 64-year-old patient, I could not interact meaningfully with her due to her advanced loss of language and severe cognitive problems. Additionally, she suffered from severe tardive dyskinesia from the long-acting injectable (LAI) anti-psychotic she had been on for the past 5-plus years whilst being cared for at home by her children. I discussed her diagnosis with her family and discussed the non-drug care aspects of her management. Following a discussion with her local private physician and her family, she had a trial of Memantine under the supervision of her local physician to help with her frequent episodes of agitation. She tolerated the Memantine favourably. Unfortunately, she died at home two years later after I last visited her. Her case from the clinical history represented a case of young onset AD.

Case III: This was a case of a close family member that resulted in my frequent trips to Ghana to see to her welfare, and sometimes to discuss her management with her local doctor. This well-educated family member (now deceased) began to suffer from high blood pressure and type two diabetes in her early 60s and was fairly controlled under treatment from the local hospital.

Around her late 60 s, she started having episodes of "forgetfulness" which initially was not much of an issue to her children/carers. Around age 72 years old after an interaction with her I decided to administer a mini mental status examination (MMSE) on her. She scored 17/30 then, with challenges in short-term memory, recall of three words, writing and copying the overlapping pentagon. Her ADL capabilities had reduced moderately. I took the occasion of my visit to request a head CT for my family member because of her deteriorating memory (as well as having the existence of a recently commissioned local CT imaging facility in the local hospital). The head CT results showed "moderate brain atrophy

as well as moderately enlarged ventricles and cortical sulci with some white matter ischaemic changes". She developed ankylosis of her left knee around age 81, which made her housebound. Around age 87 she increasingly was cared for in bed due to her poor mobility coupled with weakness in the non-ankylosed lower limb. Around 88 years old she developed mild tremors of her fingers on movement (not at rest), with some mild cog wheeling. She was seen by a local internist at home and prescribed L-dopa (anti-parkinsonian medication). As was usual with any doctor's visit, family members discussed the L-dopa prescribed with me. Eventually, the family did not think it was in the best interest of the patient to have the medication. I agreed with the family members that considering her frailty and the degree of tremor, the L-dopa prescribed should be deferred, and the prescriber was informed accordingly. Her cognitive state along with ADLs continued to decline to the point where she could not even execute the "clock face test". She continued to be cared for at home but increasingly became frail and passed on at home, after her 90th birthday.

2.2. General and Specific Considerations of the AD Patient's Lived Experience in Ghana

The lived experience of AD patients in Ghana cannot be discussed without first reviewing the overall situation of the perception and care of mentally ill (psychiatric) patients in Ghana as a whole. Overall mental health care in the public sector for persons with mental illness (PWMI) has relatively made some strides in Ghana, granted the small number of psychiatrists in the public sector, and a relatively small number in the private sector. However, the signing into law of the Mental Health Act (MHA) 846 of 2012, and the accelerated training of clinical mental health officers/practitioners has increased the number of trained mid-level cadres to care for PWMI who engage with the country's public mental health service (PMHS). Despite these gains, the public mental health sector, which is the primary mental health services provider still struggles in the face of inadequate sector financing/resourcing, operational problems linked with the passed MHA law, and low speciality and sub-speciality medical professionals (psychiatrists) [27].

These problems were also articulated by the government's then-chief psychiatrist and then head of the state mental health authority, in some of his advocacy public pronouncements [28] [29]. Beyond the problems of public mental health services inadequacy is the larger problem of local cultural beliefs surrounding mental illness and PWMI [30] [31], resulting in stigmatisation of the mentally ill (including dementia patients). This results in carers of PWMI pursuing alternate pathways of care for PWMI, a common one being spiritual and prayer camps [32] [33]. In some of these spiritual/prayer camps, PWMI are subjected to abuse of human rights (including being chained) [32] [33] [34].

Patients with dementia (PWD) in Ghana apart from those with AD, include also those with HIV dementia [35] (due to the relatively high number of HIV pa-

tients) and post-cerebrovascular accident-related vascular dementia [36], among other causes. Unfortunately, persons with AD (and other related dementias) are not immune from the effects of the above challenges in the PMHS and prayer camps. A fair number of AD patients end up in some of these prayer camps under the guise of being branded “witches” out of ignorance of the populace, with the resultant abuse of their human rights and disregard for their dignity [37], whilst being socially excluded in a fair number of cases [38]. This situation involving PWMI, including AD patients and other PWD, has led to the human rights watch (HRW) organisation submitting their concern to the United Nations Committee on the rights of persons with disabilities, in this particular worrying country situation [39]. Interestingly, qualitative research by some staff working with the Ghana chapter of Alzheimer’s International documents the challenges facing AD patients in accessing/utilizing healthcare in Ghana [40].

In addition to the challenges facing the public the mental health system is the national or state preparedness towards an ageing population due to the demographic transition taking place in Ghana (and other SSA countries). The increasing number of old age persons (OAPs) with the associated increase of ageing-associated non-communicable diseases poses additional socio-economic challenges to their families and the state, due to the apparent unpreparedness of the state to manage the associated socioeconomic and health issues associated with the gradually increasing numbers of OAPs [41] [42] [43]. When one superimposes the problem of Alzheimer’s disease associated with the OAPs to that of an already challenged public mental health system, one is left facing a dire situation, especially for those OAPs suffering from AD and related dementia. To compound the situation of OAP’s plight and poor older persons in the PMHS is the seeming aversion of healthcare students/personnel to undergo specialised geriatric medicine training or psycho-geriatric training; hence the almost non-existence of specialists in these areas [44] [45]. This situation is not surprising considering that in informal discussions with medical students and pre-specialist doctors, gerontological medicine (and or psycho-geriatrics) is considered much down the specialities ladder compared to surgery, obstetrics and gynaecology, and paediatrics, etc. It is thus not surprising that the first locally trained gerontologist received media attention and praise after completion of training in 2022 [46]. The above-mentioned factors impact negatively the OAP healthcare service and OAP mental healthcare service delivery. Especially, AD service delivery is affected negatively in terms of the sparse structures (or non-existent service structures).

Such a situation ultimately impacts on the early diagnosis and or the utilisation of AD-specific disease-ameliorating drugs like ACIs, and or Memantine (not to mention the latest medications of the type of Aducanumab), and poor non-standardised non-pharmacological care and support services. This results in poor management of AD patients, coupled with carer stress/fatigue for the fam-

ily members caring for such patients without professional guidance [47]. Of interest is the situation where some of these PWD are so advanced with their illness and frail to the point, where family carers are not able to offer them much-needed appropriate care at home. Unfortunately, in such cases, there are no regulated specialised care homes or institutions to receive them and offer them the specialised appropriate care required [48] [49]. Hence, the end-of-life (EOL) care of AD patients (and other PWD) with severe illness and frail is nothing to write about, compared to the standard of care in the developed world or higher-income countries.

Of note in the observed illness experience of the three persons who were suffering from dementia were some common characteristics, namely, lack of appropriate local follow-up care by trained local psychiatrists in the care of patients with dementia, limited access to disease-modifying medications for dementia, care at home without the appropriate training of their carers/family members, (hence, their care was ad hoc and not necessarily evidence-based). Additionally, there was no access to specialist dementia care homes in case of care fatigue of carers, nor was there any specialised social care oversight of their care.

3. Discussion

Notwithstanding the issue of mental illness and or AD among the elderly in the population and the associated care issues, it may appear that the increasing urbanization in Ghana, the prevailing societal economic challenges and the associated demographic transition, coupled with the lack of a financially sustainable national programme for the elderly, has resulted in what one will term “elderly care fatigue” among some of the younger generation? This is an unfortunate sociological shift in the mindset of the younger populace, in a country, that years ago culturally looked up to the elderly and held them in high esteem [50] [51]. The challenges of OAPs in Ghana interestingly are even worse for the female elderly in some cases [52]. Such female elderly persons who additionally suffer from AD are seen as “witches”, in their communities, and often ostracised and placed in spiritual or prayer camps, their sins being that they are old and confused. This situation is seen as gender-based elderly abuse and in the context of their AD illness this specifically goes against the grain of the United Nations Convention on rights of persons with disability (CRPD) [53]. Specifically for elderly female patients with AD (or other forms of dementia), this particular gender-associated abuse should be taken seriously as a recent multi-country research of PWD indicates that in general female PWD end up outnumbering male PWD [54] due to females having more dementia-related risks. For a country where years ago the elderly were held in high esteem, the population’s superstitions and belief in the spiritual/witchcraft causation of mental illness, along with the migration transition of its youth, as well as hard economic times have brought about the changing negative attitudes towards the elderly in society (and by extension the elderly PWD) [55] [56] [57].

Healthcare services delivery wise, the Ghana government should accelerate its efforts to implement and fund appropriately the national ageing policy (NAP) [51] [55] as research indicates that despite the existence of NAP and other policies to alleviate the well-being of the elderly, these seem not to have achieved their aims [48] [52] [56]. The Ghana ministry of health on its part has to come up with policies to advance and protect elderly health and mental health services as current policies appear not to work as they should. Additionally, the Ghana Health Service and the Ghana Mental Health Authority need to operate needs-based elderly health and mental health services delivery that will serve the elderly PWD [42] [47]. Specifically for PWD, the Ghana chapter of Alzheimer's International has a strong role to play in terms of advocacy, education and topping up the community health services of the Ghana health service by organising day activity centres for community-based PWD, as is done in the developed world countries.

On the education of the general population and healthcare professionals (HCPs) about ageing, AD and related dementias, a recent relatively small study of HCPs in Ghana [58] concluded that there are knowledge gaps on AD and related dementias amongst HCPs and that more effort at educating HCPs as well as funding for education should be made available. This does not come as a surprise considering the aversion of medical and nursing personnel towards training in geriatric medicine/nursing and related sub-specialities [44] [45], coupled with a dearth of neuroscience research and especially dementia-specific research in Ghana [59]. In this situation, the medical schools' curricula need to be enhanced to reflect the pathologies related to the country's demographic transition [43]. Alzheimer's International Ghana has in the past engaged in dementia awareness education, media broadcasts, campaigns, etc. However, this has not gained enough traction to educate the population on the above issues to the extent as to demystify the illness and the unhealthy superstitions associated with it (witchcraft, evil spirits, etc. I would guess funding in such endeavours, as well as the shortage of appropriate specialised staff might be issues facing the organisation, as they tend to depend also on transient expatriate volunteers to do their local work, along with their core local staff. To this end, I think the organisation being a charitable one, should get involved heavily in fundraising activities on its behalf to facilitate its local activities, and not depend on funding from the global organisation. State institutions, churches, and other non-governmental organisations (NGOs') could be marshalled to help with this to rid society of the pervasive ideas of spirituality and witchcraft directed at the elderly, and especially the PWD. Of great importance not to be left out, is the issue of specialised care homes for PWD, especially when they can no longer be cared for by family members or when they are too ill and frail and/or require EOL care. As has been mentioned earlier this is a contentious issue on many fronts.

Firstly, there is the lack of such specialised care homes at this time, secondly, there is the issue of appropriate registration, governance regulation and care

quality body [48] [52] [55] [60], hence, the emergence of unregulated, sub-standard care homes, and lastly the population's attitude towards such outsourced care. These specialised homes become necessary, especially for respite care of AD patients to relieve carer stress and burden of the informal carers of PWD, while maintaining the dignity of the PWD as well as diminishing their suffering [61]. More importantly in cases of advanced or severe AD coupled with frailty, such specialised homes are the best settings for non-pharmacologic management of these patients.

4. Conclusions

Having experienced the care of PWD in the USA, UK, Belgium, Holland, Jamaica West Indies and my native Ghana, I can safely comment that the care of PWD including AD patients in Ghana has a lot of catching up to do in the spheres of policy, health and social care, education and legislation, this point has also been reiterated by others [60]. This is important as PWDs are vulnerable in so many ways that without the proper societal protective and treatment measures, as pertain to developed country systems, they will continue to be mishandled, stigmatised, discriminated against, abused and suffer. PWD in chains, secluded in prayer camps, and sometimes given traditional/allopathic medicines that they may not properly consent to, etc. [37] [38] [39], raise issues of care-related acts of malfeasance and serious matters of healthcare ethics where AD and PWD care (and research) matters are concerned [62].

For the above reasons, health and social care personnel in their care of PWDs should adopt the care ethics paradigm of care to ensure that patients suffering from AD and related dementias “do not fall through the web of vulnerability” [63]. Additionally, HCPs and social care professionals should be cognisant of their duty of care towards such patients and recognise and accept their responsibility to protect PWDs as a vulnerable group, as exemplified by the UN charter against victims of genocide [64]. All HCPs caring for the elderly and mentally impaired patients, including those with AD, should inculcate in their care planning and work on the notion of dignity-based mental health care for the elderly [65]. Without this, the lived experiences of AD and other PWDs in Ghana will remain on a trajectory of under-diagnosis, poor management, poor care, stigmatised, loss of dignity, human and disability rights abuse and eventual death. Bluntly put a life not worth living. This, unfortunately, was the situation in the case of the three persons in the narratives in the article, a situation replicated almost daily in the contemporary lives of PWD including AD, in Ghana.

Last but not least, considering the relative lack of accessibility to appropriate specialist psycho-geriatric or neurology dementia interest care and management services in Ghana, the public health sector primary and secondary care services should pay attention to the proven preventable risk factors for AD and other dementias [11] [12], as a relatively cost-effective way of preventing/delaying the onset of AD, considering the country's demographic shift towards a relatively

ageing population. This approach is articulated in the World Alzheimer Report of 2023 [66].

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Ethical Clearance/Consideration

The author sought and obtained permission from the families of the patients (all deceased), in order to utilise their “blinded” brief disease trajectory narratives, for this article.

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

References

- [1] GBD 2019 Dementia Forecasting Collaborators (2022) Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, **7**, e105-e125. <http://www.thelancet.com/public-health>
- [2] Kalaria, R.N., Maestre, G.E., Arizaga, R., Friedland, R., *et al.* (2008) Alzheimer’s Disease and Vascular Dementia in Developing Countries: Prevalence, Management and Risk Factors. *The Lancet Neurology*, **7**, 818-826. <http://www.thelancet.com/neurology> [https://doi.org/10.1016/S1474-4422\(08\)70169-8](https://doi.org/10.1016/S1474-4422(08)70169-8)
- [3] Guerchet, M.M., Mayston, R., Lloyd-Sherlock, P., Prince, M.J., Aboderin, I., Akinyemi, R., *et al.* (2017) Dementia in Sub-Saharan Africa: Challenges and Opportunities. Alzheimer’s Disease International. <https://unilim.hal.science/hal-03495416>
- [4] Akinyemi, R.O., Yaria, J., Ojagbemi, A., Guerchet, M., *et al.* (2022) Dementia in Africa: Current Evidence, Knowledge Gaps, and Future Directions. *Alzheimer’s & Dementia*, **18**, 790-809.
- [5] Mba, C.J. (2010) Population Ageing in Ghana: Research Gaps and the Way Forward. *Journal of Ageing Research*, **2010**, Article ID: 672157. <https://doi.org/10.4061/2010/672157>
- [6] Wimo, A., Seeher, K., Cataldi, R., Cyhlarova, E., Dielemann, J.L., Frisell, O., *et al.* (2023) The Worldwide Costs of Dementia in 2019. *Alzheimer’s and Dementia*, **19**, 2865-2873. <https://doi.org/10.1002/alz.12901>
- [7] Nandi, A., Counts, N., Chen, S., Seligman, B., Tortorice, D., *et al.* (2022) Global and Regional Projections of the Economic Burden of Alzheimer’s Dementia and Related Dementias from 2019 to 2050: A Value of Statistical Life Approach. *eClinicalMedicine*, **51**, Article 101580. <https://doi.org/10.1016/j.eclinm.2022.101580>
- [8] Belloy, M.E., Napolioni, V. and Greicius, M.D. (2019) A Quarter Century of APOE

- and Alzheimer's Disease: Progress to Date and the Path Forward. *Neuron*, **101**, 820-838. <https://doi.org/10.1016/j.eclinm.2022.101580>
- [9] Schlesinger, D., Grinberg, L., Alba, J., *et al.* (2013) African Ancestry Protects against Alzheimer's Disease-Related Neuropathology. *Molecular Psychiatry*, **18**, 79-85. <https://doi.org/10.1038/mp.2011.136>
- [10] Sirugo, G., Williams, S.M. and Tishkoff, S.A. (2019) The Missing Diversity in Human Genetic Studies. *Cell*, **177**, 1080. <https://doi.org/10.1016/j.cell.2019.04.032>
- [11] Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., *et al.* (2020) Dementia Prevention, Intervention and Care: 2020 Report of the Lancet Commission. *The Lancet*, **396**, 413-446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
- [12] Fingers Brain Health Institute (2023) Dementia Prevention, Research and Implementation. <https://fbhi.se/>
- [13] Ju, Y. and Tam, K.Y. (2021) Pathological Mechanisms and Therapeutic Strategies for Alzheimer's Disease. *Neural Regeneration Research*, **17**, 543-549. <https://doi.org/10.4103/1673-5374.320970>
- [14] Sturchio, A., Dwidevi, A.K., Malm, T., Wood, M.J.A., Cilia, R., *et al.* (2022) High Soluble Amyloid- β_{42} Predicts Normal Cognition in Amyloid-Positive Individuals with Alzheimer's Disease-Causing Mutations. *Journal of Alzheimer's Disease*, **90**, 333-348. <https://doi.org/10.3233/JAD-220808>
- [15] Swerdlow, R.H. (2023) The Alzheimer's Disease Mitochondrial Cascade Hypothesis: A Current Overview. *Journal of Alzheimer's Disease*, **92**, 751-768. <https://doi.org/10.3233/JAD-221286>
- [16] Atri, A. (2019) The Alzheimer's Disease Clinical Spectrum: Diagnosis and Management. *Medical Clinics of North America*, **103**, 263-293. <https://doi.org/10.1016/j.mcna.2018.10.009>
- [17] Pedroro-Prieto, C.M., Garcia-Carpintero, S., Frontinan-Rubio, J., Llanos-Gonzalez, E., Garcia, C.A., *et al.* (2020) A Comprehensive Systematic Review of CSF Proteins and Peptides that Define Alzheimer's Disease. *Clinical Proteomics*, **17**, Article No. 21. <https://doi.org/10.1186/s12014-020-09276-9>
- [18] Gonzalez-Ortiz, F., Turton, M., Przemyslaw, R.K., *et al.* (2023) Brain-Derived Tau: A Novel Blood-Based Biomarker for Alzheimer's Disease-Type Neurodegeneration. *Brain*, **146**, 1152-1165. <https://doi.org/10.1093/brain/awac407>
- [19] Ashton, N.J., Brum, W.S., Di Molfetta, G., Benedet, A.L., Arslan, B., *et al.* (2024) Diagnostic Accuracy of a Plasma Phosphorylated Tau 217 Immunoassay for Alzheimer Disease Pathology. *JAMA Neurology*, E1-E10. <https://doi.org/10.1001/jamaneurol.2023.5319>
- [20] Ju, C., Wong, I.C., Mann, K.K., Braur, R., Ma, T.T., *et al.* (2021) Global Trends in Symptomatic Medication against Dementia in 66 Countries/Regions from 2008 to 2016. *European Journal of Neurology*, **28**, 3979-3989. <https://doi.org/10.1111/ene.15053>
- [21] Alexander, G.C., Knopman, D.S., Emerson, S.S., Ovbiagele, B., Kryscio, R.J., *et al.* (2021) Revisiting FDA Approval of Aducanumab. *The New England Journal of Medicine*, **385**, 769-771. <https://doi.org/10.1056/NEJMp2110468>
- [22] Mahase, E. (2023) Alzheimer's Disease: FDA Approves Lecanemab Amid Cost and Safety Concerns. *The BMJ*, **380**, 73. <https://doi.org/10.1136/bmj.p73>
- [23] Ramanan, V.K., Armstrong, M.J., Choudhury, P., Coever, K., Hamilton, R.H., *et al.* (2023) Antiamyloid Monoclonal Antibody Therapy for Alzheimer's Disease: Emerging Issues in Neurology. *Neurology*, **101**, 842-852.

- <https://doi.org/10.1212/WNL.000000000207757>
- [24] Raikes, A.C., Hernandez, G.D., Mathews, D.C., Lukic, A.S., Law, M., *et al.* (2022) Exploratory Imaging Outcome of a Phase 1b/2a Clinical Trial Allopregnanolone as a Regenerative Therapeutic for Alzheimer's Disease: Structural Effects and Functional Connectivity Outcomes. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, **8**, e12258. <https://doi.org/10.1002/trc2.12258>
- [25] Zucchella, C., Sinforiani, E., Tamburin, S., Federico, A., Mantovani, E., *et al.* (2018) The Multidisciplinary Approach to Alzheimer's Disease and Dementia. A Narrative Review of Non-Pharmacological Treatment. *Frontiers in Neurology*, **9**, Article 1058. <https://doi.org/10.3389/fneur.2018.01058>
- [26] Tijms, B.M., Vromen, E.M., Mjaavatten, O., Holstege, H., Reus, L.M., *et al.* (2024) Cerebrospinal Fluid Proteomics in Patients with Alzheimer's Disease Reveals Five Molecular Subtypes with Distinct Genetic Risk Profiles. *Nature Aging*, **4**, 33-47. <https://doi.org/10.1038/s43587-023-00550-7>
- [27] Nyarko, C.A. (2022) Mental Healthcare in Ghana: A Time Bomb. GNA. <https://gna.org.gh/2022/08/mental-healthcare-in-ghana-a-time-bomb/>
- [28] Osei, A. (2018) The Mental Health Act 846, Six Years on. Graphic Online. <https://www.graphic.com.gh/news/health/the-mental-health-act-846-six-years-on.html>
- [29] Andoh, D. (2022) 10 Years after Passage of Law: Mental Health Care Still Unsatisfactory-Dr. Akwasi Osei Laments. Graphic Online. <https://www.adomonline.com/10-years-after-passage-of-law-mental-health-care-still-unsatisfactory/>
- [30] Opare-Henaku, A. and Utsey, S.O. (2017) Culturally Prescribed Beliefs about Mental Illness among the Akan of Ghana. *Transcultural Psychiatry*, **54**, 502-522. <https://doi.org/10.1177/1363461517708120>
- [31] Quin, N. (2007) Beliefs and Community Responses to Mental Health in Ghana: The Experiences of Family Carers. *International Journal of Social Psychiatry*, **53**, 175-188. <https://doi.org/10.1177/0020764006074527>
- [32] Ae-Ngibise, K., Cooper, S., Adiibokah, E., Akpalu, B., Lund, C., Mhapp Research Programme Consortium., *et al.* (2010) "Whether You Like It or Not People with Mental Problems Are Going to Go to Them": A Qualitative Exploration into the Widespread Use of Traditional and Faith Healers in the Provision of Mental Health Care in Ghana. *International Review of Psychiatry*, **22**, 558-567. <https://doi.org/10.3109/09540261.2010.536149>
- [33] Read, U.M., Adiibokah, E. and Nyame, S. (2009) Local Suffering and the Global Discourse of Mental Health and Human Rights: An Ethnographic Study of Response to Mental Illness in Rural Ghana. *Globalization and Health*, **5**, Article No. 13. <https://doi.org/10.1186/1744-8603-5-13>
- [34] Human Rights Watch (2017) #BreakTheChains: End Shackling in Ghana. <https://www.hrw.org/video-photos/video/2017/10/07/breakthechains-end-shackling-Ghana>
- [35] Sarfo, F.S., Kyem, G., Asibey, S.O., Tagge, R. and Ovbiagele, B. (2021) Contemporary Trends in HIV-Associated Neurocognitive Disorders in Ghana. *Clinical Neurology and Neurosurgery*, **210**, Article id: 107003. <https://doi.org/10.1016/j.clineuro.2021.107003>
- [36] Sarfo, F.S., Akassi, J., Adamu, S., Obese, V. and Ovbiagele, B. (2017) Burden and Predictors of Post-Stroke Cognitive Impairment in a Sample of Ghanaian Stroke Survivors. *The Journal of Stroke & Cerebrovascular Diseases*, **26**, 2553-2562.

- <https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.05.041>
- [37] Ofori-Atta, A., Attafuah, J., Jack, H., Banning, F., Rosenheck, R. and the Joining Forces Research Consortium (2018) Joining Psychiatric Care and Faith Healing in a Prayer Camp in Ghana: Randomised Trial. *The British Journal of Psychiatry*, **212**, 34-41. <https://doi.org/10.1192/bjp.2017.12>
- [38] Mfoafo-M'Carthy, M. and Grishow, J. (2022) Social Exclusion and Marginalization of Mental Illness in Ghana. In: Liamputtong, P., Ed., *Handbook of Social Inclusion*, Springer, Cham, 953-967. https://doi.org/10.1007/978-3-030-89594-5_53
- [39] 15th Pre-Sessional Working Group (2022) Ghana: Submission to the UN Committee on the Rights of Persons with Disabilities. Human Rights Watch (HRW). <https://www.hrw.org/news/2022/03/02/ghana-submission-un-committee-rights-persons-disabilities>
- [40] Spittel, S. and Wolf-Ostermann, K. (2013) P2-350: Challenges in Health Care for People with Dementia in Ghana. *Alzheimer's & Dementia*, **9**, 488. <https://doi.org/10.1016/j.jalz.2013.05.998>
- [41] Yirabo, E., Lulin, Z., Antwi, H.A., Marfo, E.O., Amoako, K.O. and Offin, D.K. (2014) A Qualitative Review of Ghana's Elderly Care Policy: A Grounded Theory Approach Using EU's "Carmen" Model. *International Journal of Academic Research in Public Policy and Governance*, **1**, 91-116.
- [42] Kwankye, S.O. (2013) Growing Old in Ghana: Health and Economic Implications. *Postgraduate Medical Journal of Ghana*, **2**, 88-89. <https://doi.org/10.60014/pmij.v2i2.42>
- [43] Kpessa-White, M. (2018) Aging and Demographic Transition in Ghana: State of the Elderly and Emerging Issues. *The Gerontologist*, **58**, 403-408. <https://doi.org/10.1093/geront/gnx205>
- [44] Karikari, G., Lohrmann, D.K., Huber, L., Adamek, M. and Omodior, O. (2022) Attitudes of Graduating Health Practitioners toward Older Persons in Ghana. Indigenous Health Faculty Publications. <https://commons.und.edu/ih-fac/1>
- [45] Atakro, C.A. (2022) Gerontological Nursing in Ghana: Preferences and Perceptions of Nursing Students. *Gerontology & Geriatrics Education*, **43**, 482-498. <https://doi.org/10.1080/02701960.2022.2060419>
- [46] Gyesei, K.Z. (2022) First Ghana Trained Geriatrician Demands Better Care for the Elderly. Graphic Online. <https://www.graphic.com.gh/news/general-news/ghana-s-first-locally-trained-geriatrician-graduates-demands-better-care-for-the-elderly.html>
- [47] Ayisi-Boateng, N.K., Opoku, D.A., Tawiah, P., Owusu-Antwi, R., Kunadu, E., *et al* (2022) Carers' Needs Assessment for Patients with Dementia in Ghana. *African Journal of Primary Health Care & Family Medicine*, **14**, a3595. <https://doi.org/10.4102/phcfm.v14i1.3595>
- [48] Dovie, D.A. (2019) The Status of Older Adult Care in Contemporary Ghana: A Profile of Some Emerging Issues. *Frontiers in Sociology*, **4**, Article 25. <https://doi.org/10.3389/fsoc.2019.00025>
- [49] Atakro, C.A., Atakro, A., Aboagye, J.S., Blay, A.A., Addo, S.B., Agyare, D.F., *et al* (2021) Older People's Challenges and Expectation of Healthcare in Ghana: A Qualitative Study. *PLOS ONE*, **16**, e0245451. <https://doi.org/10.1371/journal.pone.0245451>
- [50] Van der Geest, S. (2016) Will Families in Ghana Continue to Care for Older People? In: Hoffman, J. and Pype, K., Eds., *Ageing in Sub-Saharan Africa: Spaces and Practices of Care*, Policy Press, Bristol, 21-41.

- <https://doi.org/10.56687/9781447325277-006>
- [51] Essuman, A. and Mate-Kole, C.C. (2021) Ageing in Ghana. In: Selin, H., Ed., *Ageing across Cultures*, Vol. 10, Springer, Cham, 1-11.
https://doi.org/10.1007/978-3-030-76501-9_1
- [52] Sossou, M.A. and Yogtiba, J.A. (2015) Abuse, Neglect, and Violence against Elderly Women in Ghana: Implications for Social Justice and Human Rights. *Journal of Elder Abuse & Neglect*, **27**, 422-427. <https://doi.org/10.1080/08946566.2015.1091423>
- [53] United Nations (2006) Convention of the Rights of Persons with Disabilities and Optional Protocol.
<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- [54] Gong, J., Harris, K., Lipnicki, D.M., *et al.* (2023) Sex Differences in Dementia Risk and Risk Factors: Individual-Participant Data Analysis Using 21 Cohorts across Six Continents from the COSMIC Consortium. *Alzheimer's & Dementia*, **19**, 3365-3378.
<https://doi.org/10.1002/alz.12962>
- [55] Ashirifi, G.D., Karikari, G. and Adamek M.E. (2022) Prioritizing the National Aging Policy in Ghana: Critical Next Steps. *Journal of Aging & Social Policy*, **34**, 127-144.
<https://doi.org/10.1080/08959420.2021.1927621>
- [56] Kpessa-Whyte, M. and Tsekpo, K. (2020) Lived Experience of the Elderly in Ghana: Analysis of Ageing Policies and Options for Reform. *Journal of Cross-Cultural Gerontology*, **35**, 341-352. <https://doi.org/10.1007/s10823-020-09401-z>
- [57] Aboderin, I. (2009) Ageing in West Africa. In: Uhlenberg, P., Ed., *International Handbook of Population Ageing*, Springer, Dordrecht, 253-276.
https://doi.org/10.1007/978-1-4020-8356-3_12
- [58] Ayisi-Boateng, N.K., Sarfo, F.S., Opoku, D.A., *et al.* (2022) Educational Intervention to Enhance the Knowledge of Ghanaian Health Workers on Alzheimer's Disease and Related Dementias. *African Journal of Primary Health Care & Family Medicine*, **14**, a3448. <https://doi.org/10.4102/phcfm.v14i1.3448>
- [59] Quansah, E. and Karikari, T.K. (2016) Neuroscience-Related Research in Ghana: A Systemic Evaluation of Direction and Capacity. *Metabolic Brain Disease*, **31**, 11-24.
<https://doi.org/10.1007/s11011-015-9724-7>
- [60] Spittel, S., Kraus, E., Maier, A. and Wolf-Osterman, K. (2018) Healthcare Challenges of Older People with and without Dementia in Ghana: An Exploratory Pilot Study. *International Journal on Ageing in Developing Countries*, **3**, 116-131.
https://www.inia.org.mt/wp-content/uploads/2019/07/3.2-Full-Final_compressed-1.pdf#page=10
- [61] Aminoff, B.F. and Adunsky, A. (2004) Dying Dementia Patients: Too Much Suffering, Too Little Palliation. *American Journal of Alzheimer's Disease & Other Dementias*, **4**, 243-247. <https://doi.org/10.1177/153331750401900402>
- [62] Coleman, A.M.E. (2019) The Ethics of Psychiatric Care and Research in Resource Poor Settings: The Case of a Research Trial in a Prayer Camp in Ghana. *Indian Journal of Medical Ethics*, **4**, 139-143. <https://doi.org/10.20529/IJME.2019.004>
- [63] Tronto, J.C. (2001) An Ethics of Care. In: Holstein, M.B. and Mitzen, P., Eds., *Ethics in Community-Based Elder Care*, Springer, New York, 60-68.
- [64] Arbour L. (2008) The Responsibility to Protect as a Duty of Care in International Law and Practice. *Review of International Studies*, **34**, 445-458.
<https://doi.org/10.1017/S0260210508008115>
- [65] Banerjee, D., Rabheru, K., Ivbijaro, G. and Mendonca, L.C. (2021) Dignity of Older Persons with Mental Conditions: Why Should the Clinician Care? *Frontiers in Psy-*

chiatry, **12**, Article 774533. <https://doi.org/10.3389/fpsyt.2021.774533>

- [66] Alzheimer's Disease International (2023) World Alzheimer Report 2023. Reducing Dementia Risk: Never Too Early, Never Too Late. <https://www.alzint.org/resource/world-alzheimer-report-2023/>