PROFILE AND PATTERN OF PEOPLE DIAGNOSED WITH EARLY ONSET DEMENTIA ATTENDING A PSYCHOGERIATRIC CLINIC IN SOUTHWESTERN NIGERIA: A RETROSPECTIVE CASE SERIES

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ABSTRACT

Background: Accessing data on the profile and pattern of people diagnosed with early onset dementia (EOD) can be challenging, especially in Low-and-Middle-Income Countries. Research focused on the epidemiology of EOD will improve early detection and diagnosis, and the understanding of its impact on individuals and society.

Objective: The study seeks to describe the sociodemographic and clinical characteristics of people diagnosed with EOD in an outpatient memory clinic.

Method: A retrospective quantitative case series to investigate the pattern and characteristics of people diagnosed with EOD attending a Psychogeriatric Clinic in Southwestern Nigeria. Data were collected manually from the medical case records of people with dementia who attended the psychogeriatric clinic.

Results: The subjects' mean ± SD age was 60.2 ± 4.2 years and 50% were females. The most common medical comorbidity was hypertension (50.0%). Depression (15.8%) was the most common behavioral symptom. Alzheimer's dementia (50.0%) was the predominant dementia type. There was a significant difference in the age (p=0.001), Boston naming test (p=0.011), based on the educational status of the participants. The neuropsychological profile of the participants showed low scores in some specific domains like memory and language.

Conclusions: Depression and hypertension are major comorbid conditions affecting persons with EOD. Such persons are impaired in some specific domains such as memory and language skills. Early detection and management of both conditions could have a positive impact on the overall management of Early-Onset Dementia.

Keywords: Behavioral symptoms, Comorbidity, Dementia, Neuropsychological assessment, Older adults, Early onset dementia.

INTRODUCTION

Early-onset dementia (EOD) is a progressive and degenerative condition that predominantly affects adults before 65 years of age.[1] Notably, EOD affects a significant part of the population as about 3.9 million people live with the illness globally[2] and studies have suggested higher prevalence in Low-and-Middle-Income Countries (LMICs) based on lower life expectancy.[3] However, the rates and burdens of EOD in LMICs remain unclear as there exists a substantial literature gap in these regions[2] and a limited understanding of EOD in these regions despite the increasing body of studies on dementia in other regions. Although the diagnosis of dementia at any age is profound, diagnosis in younger persons poses a peculiar challenge with significant psychosocial impact, as they are often in the prime of their lives[4], and has a fast progression, usually associated with other metabolic co-morbidities and genetic predisposition.

Furthermore, the same diagnostic criteria are commonly used for both late-onset dementia and early-onset dementia despite the observable disparities in clinical features posing barriers to adequate management of the illness.[5] Additionally, early diagnosis of EOD can be challenging using some existing diagnostic criteria, which require cognitive impairment to be severe enough to impair social and occupational functioning.[6] However, this level of impairment may take a more extended period to manifest, despite ongoing cognitive decline, with an average delay of up to four years in some cases.[7,8] Moreover, persons diagnosed with EOD may not seek medical help until the symptoms significantly impact their daily functioning or quality of life.[9,10] The situation may be more daunting in developing countries like Nigeria, with limited availability of dementia specialists and EOD identification services.[11]

Examining the clinical features and presentation of patients diagnosed with EOD in our setting is crucial to obtaining information that can enhance early identification and diagnostic processes and contribute to developing post-diagnostic support and interventions for people diagnosed with EOD in Nigeria. Hence, this present study seeks to obtain relevant information on the characteristics and presentation of patients diagnosed with EOD in this region and its correlates.

MATERIALS AND METHODS
Study design
This was a retrospective quantitative case series to investigate the pattern and characteristics of Early Onset Dementia (EOD) in Nigeria. The data for this study were extracted manually from the medical registry.

Setting and participants
We performed a retrospective review of medical records of people with Early Onset Dementia (< 65 years) attending an outpatient clinic. All registered male and female participants diagnosed with dementia who had attended the outpatient clinic were recruited, however, only 38 were eligible. All recruited participants were younger than 65 years old at the onset of dementia symptoms with available records (Neuropsychological test and CT scan/MRI results) and had a diagnosis of dementia made by a specialist (Psychiatrist or Neurologist). Participants were excluded if they were 65 years and above.

Sampling strategy
A total sampling technique was used in recruiting the participants of this study.

Sample size calculation
According to a local registry at the outpatient clinic, the total number of participants diagnosed with dementia from 1st January 2004 to 31st December 2023 was 346. Of this population, 38 adults with early-onset dementia were identified from the clinic records and each participant served as a component of the case in this study (Fig I).

Variables
The variables in this study include age, gender, education, occupation, comorbidity, the type of dementia, behavioral symptoms, outcome of treatment, results of Neuropsychological test battery, and Neuroimaging.

Data collection and measurements
Data were collected retrospectively on participants diagnosed with dementia who were under 65 years of age as at their first diagnoses. Medical case records of all participants who were diagnosed with dementia from 1st January 2004 to 31st December 2023 were assessed. A total of 346 case files were available for review, out of which 38 participants were included. Details of the participants were obtained from the local registry. The records of 38 people diagnosed with EOD were examined for the socio-demographic characteristics of the participants and clinical characteristics which include the type of dementia, comorbidity, behavioral symptoms, results of investigations performed (Neuropsychological test battery and Neuroimaging) as well as the outcome of treatment (follow up or lost to follow-up) respectively were retrospectively extracted from their case records.

Consortium to Establish a Registry for Alzheimer's Disease-Neuropsychological Battery (CERAD)[12], Stick Design[13], and Geriatric Depression Scale.[14]
The Neuropsychological test battery was developed to assess domains; executive function, orientation, attention, language, memory, visuo-motor, reading, writing, and concentration of an individual; thereby, assessing the immediate and delayed recall of verbal and visual–nonverbal functioning of such an individual. The Neuropsychological test battery has also been used in the Indianapolis-Ibadan Dementia Project. This battery consists of Mini-Mental State Examination (MMSE), Animal Fluency, Boston Naming Test, Word Listing, Stick Design, Delayed Recall Word Listing, Delayed Recall Stick Design, Modified Token Test, Constructional Praxis, and Geriatric Depression Scale (GDS).[12]

Neuroimaging result
Imaging data in the form of both Computed Tomography (CT) scan or Magnetic Resonance Imaging (MRI) of the brain was analysed as per pre-designed proforma. Other details like family history were extracted from the participant's case files to determine if having EOD is associated with the family history.

Bias
There were no biases in this study.

Statistical Procedures
Data entering, cleaning, and analysis were carried out using SPSS (version 23, IBM Corp., Armonk, New York). Descriptive analysis was used to summarize the socio-demographic characteristics of the participants, the behavioral symptoms, the clinical characteristics, comorbidity, diagnosis, neuropsychological test, and neuroimaging. The degree of the cognitive impairment of each participant was determined by their scores in

the MMSE, Animal fluency, Boston naming, word listing, stick design, delayed recall, and modified token, and was measured using the Consortium to Establish a Registry for Alzheimer's Disease-Neuropsychological Battery (CERAD-NB). There exist CERAD norms with normative values determined from the Ibadan population of the Indianapolis Ibadan dementia Study. The normative values are used in evaluating scores on the battery for older people with suspected dementia which also have an education-stratified normative structure to determine if education influences test performance.[14] The CERAD-NB shows the rank of the result based on their educational status, that is, no education and any education (1+ years) and this was used in analyzing the results on the items in the test battery. Fisher's Exact T-test was used to determine the association between categorical variables and Student's t-test to test associations between continuous variables. All significance tests were measured using p< 0.05.

Ethical approval

This study was performed in accordance with the principles stated in the declaration of Helsinki and was approved by the University of Ibadan/University College Joint Ethical Committee (UI/EC/23/0015), Biode building, University College Hospital, Ibadan, Oyo State.

RESULTS
Participants' characteristics

Table 1 outlines the socio-demographic and clinical characteristics of the participants recruited in this study. The series comprised an equal gender proportion (50%) with a mean ± SD age of 60.2 ± 4.2 years and 63.2% of them having tertiary education. Among this cohort, 50.0% had hypertension and 18.4% had diabetes as medical co-morbidity. Depressive symptoms (15.8%) were the most common behavioral symptoms, and 55.3% were lost to follow-up. Based on the type of dementia, Alzheimer's dementia (50.0%) was highly predominant, followed by vascular dementia (31.6%). Table 2 shows the neuropsychological profile of the participants with a mean MMSE score of 14.5 ±7.5. In dichotomizing educational status, the mean age of those without any form of formal education was 58.5 years (±5.2) and those with at least one year of formal

Table 1: Characteristics of participants with early onset dementia N=38

Characteristics		N	%
Age	50-55	6	15.8
	56-60	10	26.3
	61-64	22	57.9
Gender	Male	19	50.0
	Female	19	50.0
Education	No formal education	4	10.5
	Elementary	4	10.5
	Secondary	6	15.8
	Tertiary	24	63.2
Current employment status	Employed	19	50.0
	Unemployed/Retired	19	50.0
Presence of comorbidity	Yes	24	63.2
	No	14	36.8
Type of comorbidity	Hypertension	19	50.0
	Diabetes	7	18.4
	Others*	6	15.8
Type of dementia	Vascular dementia	12	31.6
	Alzheimer's dementia	19	50.0
	Frontotemporal dementia	5	13.2
	Mixed dementia	1	2.6
	Lewy-body dementia	1	2.6
Behavioural symptoms	Depressive symptoms	6	15.8
	Talking out of context	5	13.2
	Hallucination	2	5.3
	Sleep disturbance	4	10.5
	Wandering	1	2.6
	Others**	3	7.9
Neuroimaging result	Yes	16	42.1
	No	22	57.9

*– asthma, stroke, ulcer, seizure

**- defecating on self and irrational behaviour
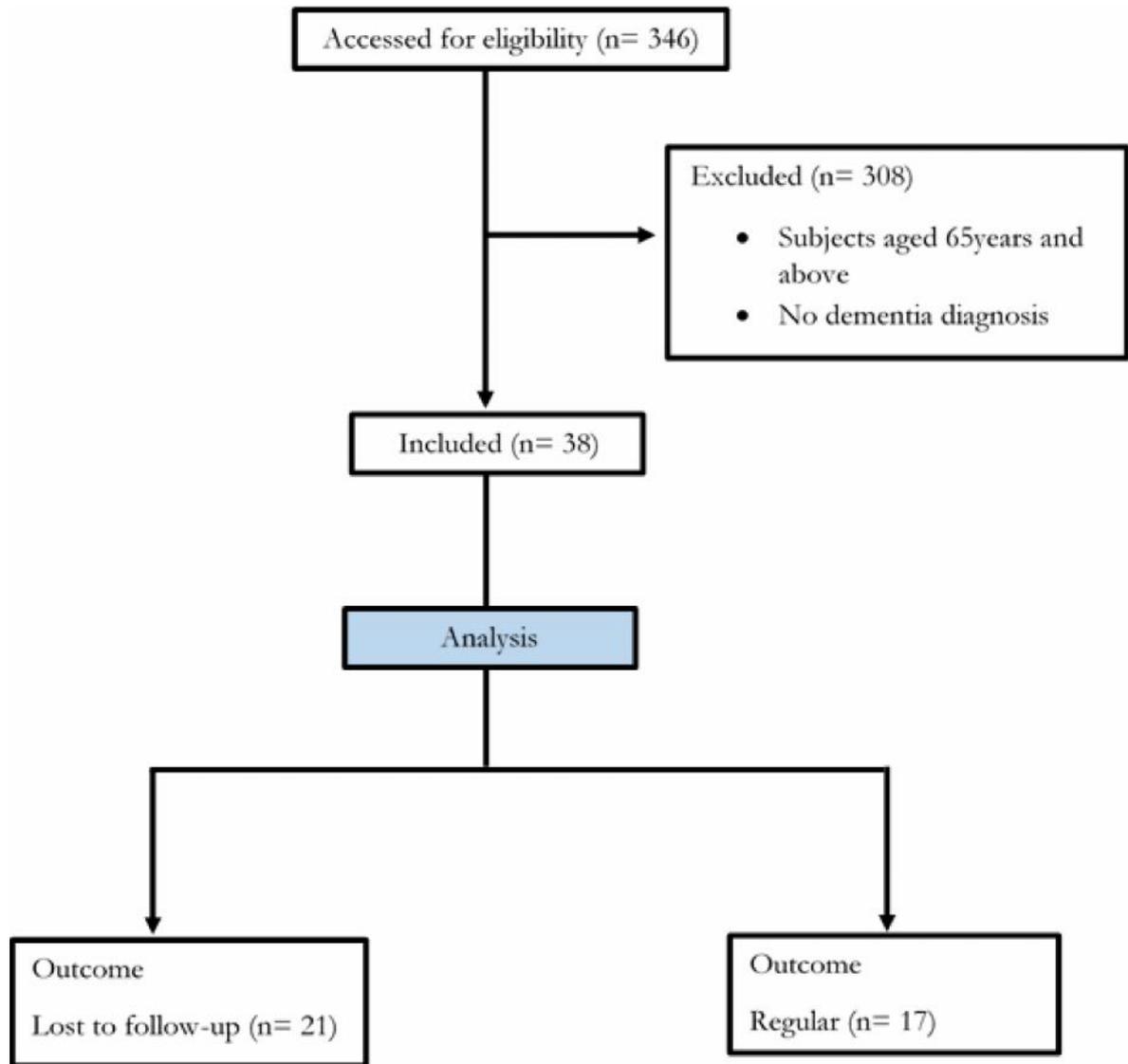
Figure 1: Consort flow chart

education was 60.4 ± 4.1 years. There was a significant difference in the age (p ≤0.001), and Boston naming test score based on the educational status of the participants (p = 0.011), with those educated having a higher mean score (6.06).

Table 2: Total mean score of participants' age and neuropsychological test subsets using the CERAD norm

Characteristic	Total Mean score ± SD	No formal education (n = 4)	Formal education (n = 34)	Mean difference	p-value
Age	60.2 ±4.2	58.5 ±5.2	60.4 ±4.1	89.221 [t]	<0.001
MMSE	14.47 ±7.52	9.0 ±7.53	15.1±7.36	-6.118	0.125
Animal fluency	4.03 ±3.72	3.75 ±2.75	4.06±3.85	-0.309	0.878
Boston naming	5.82 ±3.75	3.75 ±0.96	6.06±3.88	-2.309	0.011
Word listing	5.13 ±4.91	3.75 ±6.24	5.29±4.82	-1.544	0.559
Stick design	5.58 ±5.19	2.00 ±4.00	6.00±5.19	-4.000	0.147
Delayed recall word list	0.61±1.72	0.25 ±0.50	0.65±1.81	-0.397	0.688
Delayed recall stick design	3.92±3.50	0.50 ±1.00	1.18±1.77	-0.676	0.461
Modified token test	1.11±1.71	8.00 ±6.16	8.47±5.84	-0.471	0.880
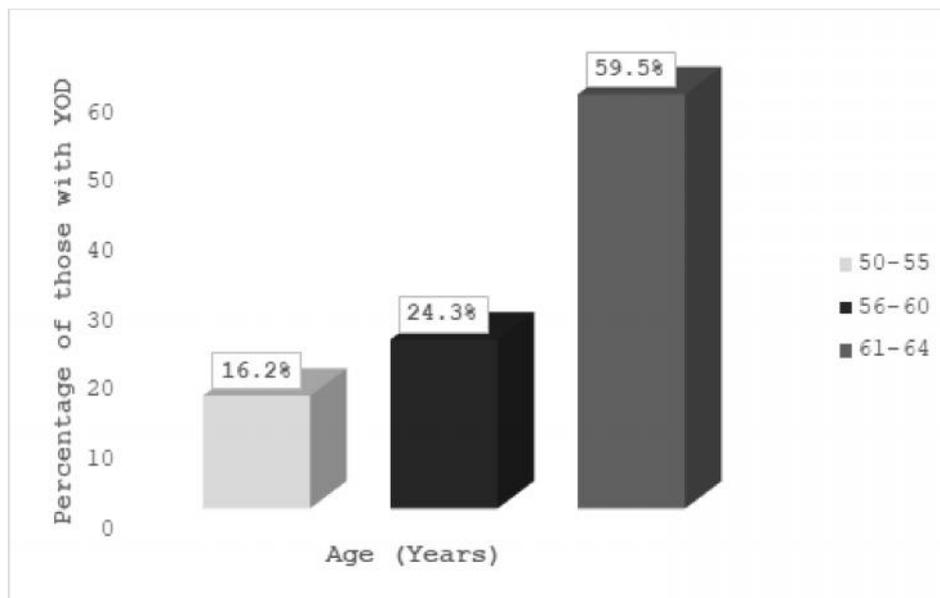
Figure 2: Prevalence of dementia by age
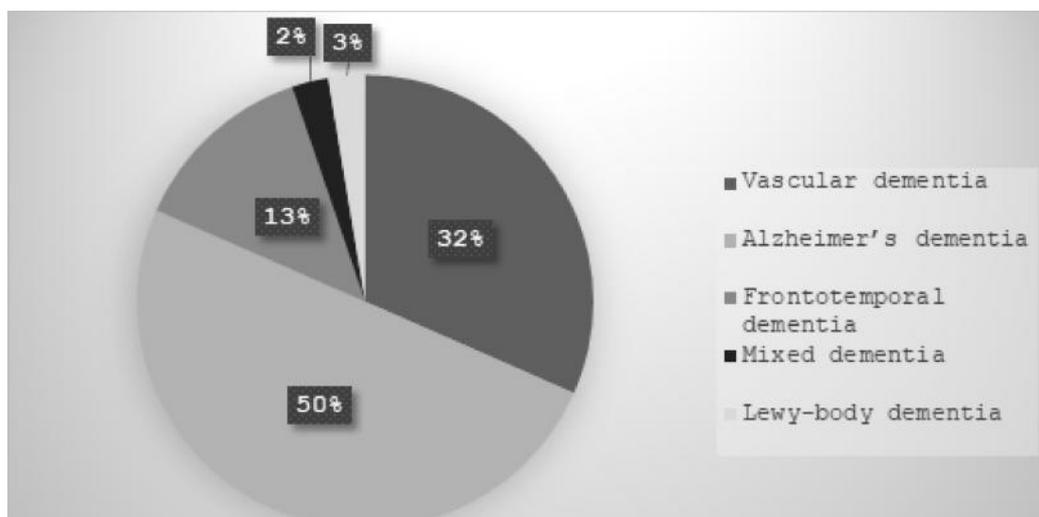
Figure 3: Distribution of early onset dementia

Figure 2 shows the prevalence of dementia by age with a higher proportion of the subjects being between ages 61 to 64 years.

A larger proportion of the participants have Alzheimer's dementia (50%) followed by Vascular dementia (32%) (Figure 3).

DISCUSSION
Our findings provide a demographical profile and clinical presentation of EOD in Nigeria. Apparently, a greater fraction of the subjects had Alzheimer's Dementia (AD), were educated, and notably, many of the subjects were still gainfully employed. Expectedly, the participants performed poorly in the memory test and, more significantly, among those with lower levels of education. Hypertension was the most prevalent comorbidity, and depressive symptoms was the most common behavioral symptom.

Demographic features of subjects
The demographic profile of this cohort is quite similar to that observed in a global report on the prevalence of EOD.[2] The equal prevalence of EOD across both genders as found in our study is similar to findings from other studies.[15–17] Although there have been studies that showed a higher prevalence of EOD in the male gender[15,18], other studies have also reported a higher prevalence in the female gender.[2,19] One possible reason for this gender difference is that women generally live longer than men. However, literature has postulated that the risk for developing EOD is less related to gender compared to age which is a major risk factor for dementia. Most subjects in this study were aged

60-64 years. At this age range, it has been observed that gradual degeneration of cognitive and physical features is not uncommon indicating early symptoms of dementia.[7,19,20] Our findings also showed that almost all the participants had a tertiary degree which corroborates with the findings of Wong *et al.* where a greater fraction of their cohort had a high level of formal education.[21] Our findings indicated cognitive abnormality as we observed poor performance in some specific domains of the cognitive assessment such as memory, language, and which is not surprising as these are cognitive markers for making a EOD diagnosis. However, we observed a significant disparity in the Boston naming test score based on the educational level of the subjects; those who were more educated performed better in their ability to retrieve words than those who were less educated. This is not surprising as previous studies have shown that neurocognitive performance is influenced by the level of education.[22] Increased intellectual capabilities owing to more exposure to formal education could explain for better performance of the group. Additionally, it has been reported that individuals with a higher cognitive reserve may be more resilient to the effects of neuro-degenerative diseases, such as EOD. Moreover, higher levels of education have been associated with increased cognitive reserve.[23] Apparently, subjects with more years of formal education may develop more efficient ways to cope with and manage the cognitive decline which is reflective of their neurocognitive performance and cognitive reserve.

Regarding age, we noted that age was a significant correlate of performance for specific domains in the neuropsychological test. This is consistent with previous studies that have indicated significant differences across age groups or significant correlations with age.[5,24]

Furthermore, the finding that most of our cohort are still working is in contrast with the findings of other studies.[25,26] Although persons diagnosed with EOD compared to those with late-onset dementia are more likely to still be employed as they are younger. EOD typically affects people under the age of 65, of which in some settings people are still working or progressing with their careers. Sixty-five years is also the standard retirement age in this setting, thus, a plausible reason for their current employment status. Also, the lack of social security schemes for older adults and adequate care for people diagnosed with dementia in this setting may have forced some participants, especially government workers, to continue working to cater to their needs, including their medical expenses. In our setting, people tend to retire late to compensate for the poor support for retirees and the financial hardship evident in this setting. Moreover, Nigeria has no post-diagnostic support scheme for people diagnosed with EOD, and many have to rely on their income for health care.[27]

Clinical presentation of EOD
As regards the clinical profile of the subjects, hypertension was the commonest comorbidity observed. According to a study conducted by Wysocki *et al.*, individuals with hypertension are more susceptible to cognitive decline than non-hypertensive individuals. Plausible explanations for this association include lifestyle and genetic factors.[28]

Alzheimer's dementia (AD) was the most prevalent subtype of dementia in this case series and our finding is in keeping with reports from several studies[16,19,29,30] that have identified AD as the most common type of EOD, followed by vascular and frontotemporal dementia, respectively.[2,30] Furthermore, depressive symptoms were the common behavioral symptom observed among those diagnosed with EOD in this study, similar to the findings in a study conducted by Wong *et al.* on the characteristics of EOD and Late Onset Dementia (LOD) at a memory clinic in Canada.[21] Notably, in their study, depression was the most common behavioral disorder among those diagnosed with EOD. This was attributed to the unexpected nature of illness, mental distress, financial burden, and strain on relationships, especially when children are involved. For many people diagnosed with EOD, their work and family life constitute an important part of their lives. Once these are affected, it may be difficult to meet the social, financial, and emotional needs.[21]

Continuity with hospital-based care
Our findings showed a high dropout rate. This pattern is consistent with the finding of Elugbadebo *et al.* in a study of access and discontinuity of care among older people in Southwestern Nigeria. In their study, majority of the participants dropped out of treatment after the initial consultation.[31] In this setting, dropout has been attributed to the long distance from the hospital, long waiting period, and financial constraints.[31] Moreover, patients and caregivers have an expectation of a cure for dementia when they approach health facilities, however, when they become aware of the prognosis, they may be discouraged from continuing with treatment.

Thus, it is expedient to develop post-diagnostic support services for persons living with EOD tailored to meet their needs. Several other issues must be addressed as well, including the development of formal diagnostic measures for early detection/diagnosis, treatment guidelines, and the creation of a

national plan for dementia inclusive of the particular needs of persons diagnosed with EOD in Nigeria.

Limitations
One limitation of this study is that people diagnosed with EOD are relatively few in this setting resulting in a small sample size which may limit the generalization of conclusions to a larger group. Due to the small sample size, the study did not investigate the effects of risk factors such as age, comorbidities, or EOD subtypes, to obtain more comprehensive results.

CONCLUSION
Persons with EOD in this setting have unique characteristics considering their high level of formal education and rate of employment which underscores the need for strategic post-diagnostic management and employee assistance programs. The findings of a high prevalence of AD type of EOD, medical comorbidity including depressive symptoms accentuate the need for a multidisciplinary approach to EOD which includes early detection and tailored interventions to address the cognitive, mental health and medical challenges. Further studies involving the exploration of the prevalence, incidence, and risk factors associated with young onset dementia in LMIC are needed to further facilitate early detection and diagnosis and develop tailored post-diagnostic support.

Author Roles
E.O: Conceptualization, Study administration, Data collection, Methodology and Writing- original draft preparation; O.T: Project execution, Data collection, Writing – Review & Editing; Okwudiri C: Data collection, Formal analysis, Writing- original draft preparation; A.L: Writing – Review & Editing; B.O: Conceptualization, organisation, Data collection, Methodology and Writing – Review & Editing

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