OPEN ACCESS

Early-onset dementia: key issues using a relationship-centred care approach

Martin Nwadiugwu ^{1,2}

¹Health and Sport, University of Stirling, Stirling, UK
²Biomedical Informatics, University of Nebraska Omaha, Omaha, Nebraska, USA

Correspondence to

Martin Nwadiugwu, Faculty of Health and Sports, University of Stirling, Stirling FK9 4LA, UK; mcn00003@students.stir.ac.uk

Received 22 June 2020

Revised 29 July 2020

ABSTRACT

People with early-onset dementia have a potential risk of being marginalised with respect to care and social support as a result of the blame and stigma associated with their condition, and because they have reduced access to treatment options and postdiagnostic care. The limited use of community services and the resulting psychological implications are two key issues facing the group and their caregivers. Early diagnosis, behavioural therapies such as talking therapy, meaningful Montessori activities and friendly community services tailored to meet the needs of people with early-onset dementia are relationship-centred care approaches that could be implemented in practice, using the 'Senses Framework' to promote an enriched supportive environment of care with zero tolerance for marginalisation and discriminatory tendencies. Support for caregivers is invaluable in controlling behavioural changes in people with early-onset dementia. A combined approach involving pharmacological and behavioural interventions could be used in severe mood and behavioural changes.

INTRODUCTION

Dementia is a cognitive disability characterised by a decline in mental ability and globally occurs every 3 s.¹ It is degenerative, has no current cure and often associated with the process of ageing.¹ In the absence of dementia, the human brain can retain its cognitive ability for about a hundred years.² Dementia can be caused by Alzheimer's disease, appearance of Lewy bodies, vascular defects in the brain, head injury and excessive alcohol consumption.³ Alzheimer's disease is the most common dementia type followed by vascular dementia, and although possible pharmacological interventions such as donepezil hydrochloride have been suggested, there are no popular therapies that decelerate or terminate its progression.^{4 5}

The incidence of dementia is rising in both developed and developing countries and is more prevalent among older adults compared to younger population⁴; however, a 20-year study comparing dementia in individuals (>65 years) in England by Matthews *et al*⁶ reported a decrease in incidence for the oldest old adults. According to Ferri *et al*⁷, dementia rapidly decreases from 20% to 25% among persons (>85 years) to about 2–3% among people aged between 70 and 75 years. Accessing the epidemiology across countries, WHO projections⁸ forecast that in 2025, developing countries will have a higher number of dementia patients. Currently, the incidence of dementia in developed countries is probably at the top of the pyramid as a study comparing the incidence of dementia in Nigeria and the

USA revealed a 2.3% incidence rate in Ibadan (Nigeria) and 8.3% rate in Indianapolis (USA).⁹ In estimating a standardised age-prevalence rate for dementia, WHO in 2012 reported a rate of 5–7% in people above 59 years, and Prince *et al*¹⁰ suggested that the age-prevalence rate of dementia will not change despite an increase in the ageing population. Evidence from these studies suggests that the prevalence of dementia varies relatively among countries. Although in many developed countries there has been more awareness on reduction in risk factors such as smoking, alcohol consumption and increased awareness to participate in physical activities, trends in developing countries are different leading to increased disease burden.^{11–13}

Early-onset dementia is typically dementia in people younger than 65 years old.^{14 15} It can occur before the age of 65¹⁵ or even under the age of 45 where it is known as young-onset dementia (YOD).^{16 17} Populations with early-onset dementia have a high risk of being potentially marginalised and discriminated with respect to dementia diagnosis and care because of the challenges early-onset detection poses to patients, caregivers and the fact that healthcare providers do not always look for the signs at an early age.¹⁸ Moreover, dementia may be confused with symptoms from other conditions and may remain undetected for a long period of time due to its long and highly variable latency period.¹⁰

An important concern for people with early-onset dementia is the negative stereotype and fear attached with it, which presents a barrier to unhindered access to support services available to them. This stigma associated with positive diagnosis of the condition comes from the opinion of others who believe people with the condition are to blame as they did not live a healthy, mental and socially active life.¹⁹ This shaming and blaming leads to initial denial of the condition by those affected, and even by doctors and the patient caregivers, further limiting opportunities that could provide helpful and beneficial information on available support groups and services.¹⁹ The negative stereotypes, stigma, shaming and blaming associated with dementia are often as a result of misinformation¹⁹ and lead to marginalisation. There is a need to provide an articulate information that increases knowledge on the consequences of marginalisation among people with early-onset dementia, specifically by examining barriers limiting the use of formal community services, the psychosocial implications of this condition and approaches to reducing it.

This review focuses on people with early-onset dementia as a group experiencing marginalisation resulting from lack of understanding, shame and

© Author(s) (or their employer(s)) 2020. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Nwadiugwu M. *Postgrad Med J* Epub ahead of print: [please include Day Month Year]. doi:10.1136/postgradmedj-2020-138517

blame leading to adverse psychosocial outcomes and unwillingness to use formal community services. These two key issues will be discussed using the Senses Framework, a relationship-centred approach focused on genuine reciprocal care relationship affecting the health, emotions and personhood of the parties involved, proposing that 'interaction among people is the foundation of any therapeutic or healing activity'.²⁰ The 'Senses Framework' originally described by Nolan²¹ in 1997 and further developed by Nolan *et al*^{20–22} seeks to promote an enriched environment of care where the paid caregivers (the organisation), the patients (individuals) and their supporters experience the six senses of security, belonging, continuity, purpose, achievement and significance.²⁰ The justification for the Senses Framework is that it seeks to support an all-round relationship, given that dementia often results in social isolation and cessation of active life leading to social death.²³ Moreover, although the patient is the focus of a relationship-centred care, other members involved in the care are not neglected.²⁴ Pharmacological interventions and therapeutic strategies for behavioural support using talking therapy, Montessori activities or a combination of both were explored as a means to improve well-being among people with early-onset dementia.

The remaining sections of this paper will discuss people with early-onset dementia as a group experiencing marginalisation. Next, two key issues, namely, limited use of community services and psychosocial implications of dementia diagnosis for the patient and their family will be explored incorporating possible preventative recommendations and adopting the Senses Framework using a relationship-centred care approach. The review will conclude with a summary of the key recommendation.

EARLY-ONSET DEMENTIA PATIENTS: A GROUP EXPERIENCING MARGINALISATION

The progression of early-onset dementia is estimated to be between 8.3 and 22.8 per 100 000 population,²⁵ and the incidence of YOD is 11–13.4% per 100 000 persons.²⁶ The prevalence of early-onset dementia doubles every 5 years and rises from 42 to 54 per 100 000 for people between the age of 30 and 64 years to a range of 78–98 years per 100 000 for those aged between 45 and 64 years.^{14–25} It is more prevalent in men than in women between age 50 and 65 years, unlike late-onset dementia which is slightly more prevalent in women than men.²⁷ The World Alzheimer's Report puts the prevalence rate for early-onset dementia to be between 2% and 10%.²⁸

The signs for early-onset diagnosis of dementia are hampered by hidden symptoms, being part of a minority ethnic group and especially misdiagnosis, which is reported in 30–50% of people in this group.²⁹ Challenges faced by people with early-onset dementia include loss of employment and job-related income after diagnosis, difficulty getting accurate diagnosis, difficulty obtaining disability payments, lack of appropriate medical care, high out-of-pocket expenditures for medical care and lack of health insurance, residential care and community services.³⁰ These challenges are often engrained in the delivery and design of the support services leaving them feeling isolated, ignored and invincible and making them unlikely to get postdiagnosis support.³¹

Complicating matters even further, about 60% of younger patients with mild dementia type are not diagnosed, and the 40% who are diagnosed have reduced access to treatment options and postdiagnostic care.³² It has been suggested that early detection in specialist units with mandatory neuro-imaging requirement may completely or partly reverse dementia in 1% of young people with early-onset dementia.²⁹ In addition, drugs such as

cholinesterase inhibitors have been suggested to considerably improve daily activities after early diagnosis, while evidence from non-drug therapies such as a brief programme of support for caregivers and in-home support for patients after early diagnosis are said to reduce admission to care homes by 28% and reduce the risk of institutionalisation by 22%, respectively.^{18–33}

Nevertheless, not everyone would like to know their dementia status, especially at a young age because they want to keep their jobs, maintain their social status and avoid depression arising from the stigma, labelling, lack of affection and the overall fear of what knowledge of this may bring.¹⁰ For those seeking accurate diagnosis, reports of the diagnostic process spanning a couple of years, misdiagnosis, lack of knowledgeable clinicians, doctors thinking they were too young, failure to listen to patient and/or caregivers, and timely notification of the diagnosis highlight the uncertainties associated with dementia diagnosis. More so, the focus of surveillance medicine (the medical observation of healthy populations) on targeting older adults as the categories with possible risk of dementia has further worsened the situation.^{10–18} The strong association of the incidence of dementia with older adults (>65 years) has meant that clinical practitioners and younger adults do not always look for signs of dementia at a young age.

The number of people with early-onset dementia in the USA according to estimates from the Health and Retirement Study is between 220 000 and 640 000,³⁰ and loss of employment after diagnosis is one of the discriminatory tendencies this group faces. In a survey on job loss among Americans with early-onset dementia conducted by Alzheimer's Association, half of the respondents said they were fired or forced to retire as a result of early diagnosis³⁰; while people with late-onset dementia have access to a retirement package, this is not always the case for those with early-onset dementia who probably will voluntarily retire or be fired without benefits.

Another more worrying concern is the fact that caregiving in formal community settings is more concentrated among older persons despite the funding generated.³⁴ About 109 billion dollars have been spent on paid services in community care support services, and between \$159 and \$215 billion is estimated in unpaid primary caregiving in the USA.³⁵ However, the lack of awareness and differentiation in precise measures of care and residential settings for early-onset and late-onset patients have presented a barrier to understanding dementia care and management in community settings.³⁴

The need to address the issues faced by people with early-onset dementia in primary care is hampered by variation in screening methods given the fact that few people with dementia are clinically diagnosed, and too much priority focus of early support service intervention is on older dementia patients,¹⁸ leaving individuals with early-onset dementia increasingly at risk of being undetected and uncared for. Understanding the key challenges facing people with early-onset dementia from an approach that pays attention to the needs of all members to promote an enriched environment of care will be paramount to raise awareness for public health education and to investigate corrective strategies and practices for engagement.

Key issues

Some of the key challenges faced by people with the onset of early dementia require a collective effort to improve quality of life. A relationship-centred care approach rather than a person-centred model has been suggested by Nolan *et al*²⁰ as a more effective approach to achieve the six senses for enriched care, because it provides better service for relationships and support needed for all including primary caregivers. The Senses

Framework is a relationship-centred approach that promotes zero tolerance for poor care through a supportive culture and prioritises knowing the patient for optimum outcome.²⁰ The limited use of community services and psychosocial implications of early-onset dementia to the patients and their family were two key issues evaluated using this approach.

LIMITED USE OF COMMUNITY SERVICES

It is repeatedly assumed that people with dementia cannot benefit from physical rehabilitation services because they cannot learn new behaviours or relearn old ones.³⁶ The assumption that people with dementia cannot benefit from these services can result in a denial of care that would help maintain or improve the person's functioning. It is not clear, however, whether people with early-onset dementia are more likely than those with late-onset dementia to need physical rehabilitation services or to be denied these services because of the assumption that they cannot benefit or for any other reasons that stereotype dementia as merely getting old.³⁰

Early diagnosis of dementia in younger adults impacts negatively on their social lives, and interventions that would allow these people to maintain social connectedness and participate in meaningful activities have been recommended.¹⁷ Community support services have been suggested as a way to reduce social isolation, but young patients and their caregivers reported that the structure of the service falls short of their psychosocial needs.^{17 37} In a mixed-method study conducted by Australian researchers involving 86 YOD participants and their caregivers aimed at understanding the barriers limiting them from using community services, findings showed that two out of three (66.3%) declined to use at least one or more of these services due to lack of perceived need specific to them.³⁷ The psychological impact of using a service not specific to them because the initial design was meant for and dominated by older users, and other barriers such as feeling insecure to participate and cost were also mentioned despite the fact that knowledge of at least one recommended community support service available to them was high.³⁷

The underlining concern for the limited usage of formal community services by people with early-onset dementia and their primary caregivers is eligibility due to age and its failure to meet peculiar experiences associated with dementia occurring at an early age. This dissatisfaction with the service did not only create a mismatch, but made patients physically agile to abscond while others only use the service in extreme circumstances.³⁷ Information overload, no information, lack of information and meaningful engagement to alleviate social isolation, security and suitability of facilities were other concerns. Accessing whether limited use of community services was clinically motivated, Cations *et al*³⁷ noted that few clinical factors were associated with the reason to limit the use of formal community services, as lack of automatic referral to specialised services was strongly acknowledged as a limiting factor. Recognising that the structure of formal community services to prioritise older patients may frighten people with early-onset dementia and could make them feel insecure is a forward-thinking way of using the Senses Framework to achieve a sense of security in care management.

It is important to note international differences in formal community service delivery for people with dementia and that there has been a growing awareness of the need to provide support for people with early-onset dementia. For example, the National Disability Insurance Scheme in Australia provides support for those with dementia below age 65.³⁸ The RHAPSODY study, a European Union initiative that leverage e-learning to support carers for people with dementia (<65 years) is now available

for testing.³⁹ Moreover, in the Netherlands, there is the national YOD care service that is supported by the government and provides age-specific dementia care units.⁴⁰ This is probably not the case in some other European countries and even in parts of Africa where, for example, in Nigeria, specialised care is limited by lack of health facilities and inconsistent health policies.^{40 41} This universal problem requires careful planning such as those undertaken by the Young Dementia Steering group in the UK which provides guidance to commissioners of care in local services, as well as expectations for the patients receiving care.⁴⁰

Furthermore, understanding the job caregivers in community support service do and their work ethics is a paramount starting point for supporting primary caregivers because socially isolated caregivers are less likely to use formal community services. Acknowledging the need for authentic human encounters using the Senses Framework would spur formal services to engage with primary caregivers meaningfully with flexibility and affordability, uniquely tailored to dementia experiences. This evidence is supported by Millenaar *et al*⁴² who reported that people with YOD and their caregivers are dissatisfied using services tailored for older persons, recommending further research on the design and suitability of the service. Another strategy to support people with early occurrence of dementia and to encourage the use of formal community services is for the needs of all groups irrespective of age to be accorded equal value, status and significance. The Senses Framework recognises that an interdependent relationship is necessary to create an enriched environment of care to foster a welcoming environment where all members are respected.²⁰ How practitioners in formal community services see their own role in supporting younger people with dementia matters a lot to build an enriched relationship-centred environment of care, since people with early-onset dementia and their supporters want to have a sense of belonging to the community for dementia support.^{17 37 42}

Accordingly, involving the local community in developing formal services and recruiting qualified practitioners who have a passion for community support may be another solution that could optimise the gains from a relationship-centred care model.²⁰ It is even more important to consider the support available for paid carers after a patient has been diagnosed with dementia. Ongoing training and support are vital for providing optimal care as it has been reported that healthcare practitioners in Norway received less training on drug use for older patients, while in the UK, Community Psychiatric Nurses were previously reported to have limited understanding in implementing memory aids and strategies.^{43 44} Apart from specialised training, paid carers should be mindful of the influential drivers of dementia prevalence and its changing landscape such as demography, policy and economy if they are looking to deliver evidence-based services that incorporate these changes into service delivery, since it has been suggested that knowledge of these combined drivers are effective in promoting productive ways of dealing with the complexities of dementia.⁴⁵

A non-pharmacological strategy that could help people with early-onset dementia adapt formal community services is by introducing meaningful Montessori activities such as games, puzzles, exercise, music singing and listening, which are inexpensive, in order to improve mood and self-esteem for a group at risk of relapsing into depression.⁴⁶ These activities help them to be active and motivated⁴⁷ and could be part of a friendly, informal setting where dementia support groups (organisation), caregivers and the patients meet to gather personal history and share information and experiences.⁴⁶ According to the Senses Framework, events like these will foster a sense of achievement at the organisational level by recognising that practical work is a key aspect to caring for the whole person.²⁴

The social relationship from these activities helps ensure that the opinion of the patients and difficulties encountered by caregivers are brought to the forefront through effective communication. According to the Senses Framework, communication promotes therapeutic activity and enables practitioners to keep in contact with their patients and vice versa to ensure that all factors that could potentially impact on a patient's well-being are limited.²⁰ Measuring the satisfaction of patients and their caregivers could be a way to access the performance of formal community services for people with early onset or late onset of dementia.²⁴

The six senses of the Senses Framework incorporated in the above discussion will help enhance the experience of people with early-onset dementia in formal community services, and build an interactive relationship with community service practitioners, which according to Nolan *et al*²⁰ is the foundation of any therapeutic or healing activity. This underlines how vital the Senses Framework can be incorporated as a practical guide for the patients, caregivers and healthcare practitioners to benefit all parties involved in the relationship. The strategies discussed and suggested implication for practice can be seen in [table 1](#).

PSYCHOSOCIAL IMPLICATIONS FOR THE PATIENT AND THEIR FAMILY

A diagnosis of dementia can be associated with low self-esteem, loneliness and the feeling of being a liability to family and colleagues at workplaces, among other psychosocial risks.^{18 48} It could lead to depression⁴⁹ because true knowledge of one's dementia status may separate them from their social ties.⁵⁰ The adverse psychological

events are especially worrisome for young people with early diagnosis of dementia because of the lack of support facilities and the feeling of being deserted by the system after diagnosis.⁵¹

Psychological evidence has suggested that the mental and social potential of people with early-onset of dementia is still intact, including knowledge of memory problems which afterwards is lost.^{51 52} People with early stage of dementia appear capable of having insight and contributing to decisions relating to their care⁵³ and could cope with the implications to maintain their quality of life.⁵⁴ Evidence suggests that more cases of early-onset dementia could be of a corrective type than late-onset dementia,⁵⁵ making the argument for early detection of dementia in people less than 65 years of age to preserve their abilities, which is vital to maintain a sense of utility, esteem and dignity.⁵⁶

While evidence for early diagnosis is appealing, there has been a disparity in dementia prevalence rate and actual numbers for both people with early-onset dementia and late-onset dementia in the UK, which has led to committed efforts to improve immediate postdiagnostic support.⁴⁵ A study by Chrisp *et al*⁵⁷ reported that it took about 3 years for one to get a formal diagnosis after early symptoms of dementia and people of minority ethnic communities rely on help-seeking at a later stage leading to recommendations for telemedicine, and further research in the use of ICT technologies as non-pharmacological interventions that could be implemented to provide night-time care, encourage early detection in rural communities, support stay-at-home care and reduce home-based care and carer burden.⁴⁵

The imminence of dementia for adults under 65 years of age elicits fear than any other illness; about 39% of adults (>55 years) are frightened about getting Alzheimer's of dementia type compared to 25% that worry about cancer.²⁶ People with early-onset dementia are likely to be in the working-class age group, which makes it difficult for them to accept the illness and to possibly resist further diagnosis.³⁶ Evidence from a quantitative study collated from Japan Medical database found that 14% of early-onset dementia patients (<59 years) left their jobs after a year of initial diagnosis, recommending employment support for patients initially diagnosed.⁵⁸ A relationship-centred approach where employers match job tasks to employee abilities to enhance job outcome could be the needed support that would give an employee with early-onset dementia a sense of continuity.²⁰ Thus, while patients with early-onset dementia are likely to leave their jobs after initial diagnosis, they can be supported to continue active work, which could reduce depression and other psychosocial risks.

Another psychosocial implication for people with dementia is delirium which tends to occur within hours or days after diagnosis due to the associated emotional stress.^{46 59} Delirium is common in about 20% of people hospitalised with dementia, and the signs could be alertness and agitation, tiredness and withdrawal, or a mixture of both.⁶⁰ The cognitive-behavioural therapy or talking therapy could be used after initial diagnosis of dementia to reduce the extent of anxiety, depression and delirium in the person and family supporters by providing activities that reduce boredom.³⁶ It involves interaction between the therapist, patients and their supporters and to develop a better way of thinking for the patient to promote a sense of security and a sense of significance for the supporters at the organisational level by involving them in care planning, invariably promoting a sense of achievement among therapists who embark to provide the best possible care.²⁰

In severe cases of delirium involving agitation and repeated questioning, the talking therapy could be combined with pharmacological intervention (eg, antidepressants and cholinesterase inhibitors) to control life-threatening situations.⁶¹ Although the

Table 1 Implication for early-onset dementia practice using Senses Framework

S/N	Senses	Implication
1	Sense of security—to not feel unsafe	At organisation and individual levels: recognising that the structure of formal community services to prioritise older patients may frighten young people with dementia and make them insecure At individual level: understanding that young people with dementia may not communicate their insecurity
2	Sense of belonging—to feel included	Organisation level: creating opportunities for social encounters Individual level: to acknowledge that young people with dementia are open to socio-connectedness
3	Sense of continuity—an experience of affinity and relation	Organisation level: acknowledging the identity of the person Individual level: acknowledging biography of the person
4	Sense of purpose—having essential personal goals to aspire to	Organisation level: focusing on the recognition that dementia at young age is not abnormal Individual level: recognise clear independence of the young person in everyday decision-making
5	Sense of achievement—to make progress towards attaining set goals	Organisation and individual levels: to confidently acknowledge that people with early-onset dementia can go unnoticed but can also have human encounters.
6	Sense of significance—feeling of self-worth	Organisation level: acknowledging that relationship matters; interconnecting the feelings of all stakeholders involved in the care Individual level: recognising and attending to one with early-onset dementia and taking them very seriously

therapy may be unsuitable or unsuccessful with some persons, or become less effective at advanced stage of the illness,¹⁸ it helps the individual to behave positively, cope with the reality and change negative patterns of thought.⁶² It is important that there is effective communication in the relationship between caregivers and healthcare providers to determine when drug intervention is necessary.

Consequently, support from family members is invaluable in the relationship-centred care plan because they can help in detailing mood changes, unusual mistakes, repeated questioning and other sudden behavioural changes by keeping and recording events in a diary.⁶³ Evidence from a randomised controlled study assessing behavioural and psychological symptoms in people with dementia suggest that family caregiver training targeting sudden behavioural changes could improve outcome.⁶⁴ Although the study was targeted at older people with dementia, it highlights the need to consider family caregivers as an important member in a relationship-centred care. This can be a helpful guide to create a sense of achievement and for the therapist and clinicians in deciding other possible care options.

Primary caregivers of persons with early-onset dementia also deserve to be attended to and cared for otherwise they may become disoriented from the daily routine and dependence on them, creating a feeling that their future life plans have been put to an abrupt stop.⁵⁸ This is especially demanding if there is a reversal of roles at a young age, where children of the affected adult become the primary caregiver, and worse still if the parent has been forcefully retired. A sense of purpose arising from social experience could offer continuing emotional support to the caregiver, convincing them to unlearn previously held perceptions but to see essential personal goals to aspire to. This may include recommending communities of support where caregivers can receive advice and support to reduce the devastating impact of everyday routine on their self-esteem and self-worth, as it has been previously reported that people with early-onset dementia and their caregivers desire to be in community with like-minded people, rather than agencies focused on older persons.⁵⁸ While this study focuses on people with early-onset dementia, the recommendations such as early diagnosis, talking therapy, meaningful Montessori activities and other strategies associated with improving psychosocial risk and limited use of formal community services are key issues that could also be considered in context and applied in caring and planning for people with late-onset dementia.

CONCLUSION

The incidence of dementia is more common among older adults than in young individuals. It relatively varies among countries due to level of awareness of the risk factors and also varies in men and women at different age categories. Dementia among younger age groups (<65 years) could remain hidden due to misdiagnosis resulting from lack of thorough investigation and the fact that healthcare providers do not always look for the signs at an early age.

Early detection of dementia in young people could elicit changes in mood and behaviour due to loss of societal status and the associated stigma. Many young people with dementia feel that they receive less postdiagnostic attention in formal community services compared to people with late-onset dementia, and attention is gradually being drawn to the plight of these people. An enriched environment of care where the importance of all members involved are valued, to promote an interactive relationship-centred care, has been suggested as a way of making formal community services more dementia-friendly for younger people. Introducing Montessori activities and encouraging positive thoughts using talking therapy to improve the mood of young people with dementia faced with psychosocial challenges such as delirium, agitation and depression

are non-pharmacological solutions. A combinatorial approach involving drugs (antidepressants and cholinesterase inhibitors) and behavioural therapies could be used in severe forms.

Supporting healthcare providers and caregivers as important members in the relationship-centred care plan geared towards improving the plight of people with early-onset dementia can be done in practice by adopting the Senses Framework to promote a supportive culture and zero tolerance for poor care. Support from caregivers is invaluable in controlling behavioural changes in younger people with dementia, while support for healthcare providers is needed to maintain a high standard of care and achieve the needed goals.

Self-assessment questions

1. A key issue among people with early-onset dementia include.
 - a. Limited use of community services
 - b. Limited use of public arenas
 - c. Hiking
2. How can the Senses Framework foster preventative approaches for patients with early-onset dementia?
 - a. Recognising that relationship-centred care is vital and the need to create an enriched care environment that fosters warmth and respect
 - b. By making law enforcement readily involved
 - c. By ensuring patients do not argue with healthcare practitioners
3. Why should we care about limited use of community services among people with early-onset dementia?
 - a. We should instead treat all age groups without discrimination
 - b. It fails to meet their peculiar needs as they are dissatisfied using services tailored for older persons
 - c. It is a problem for the government
4. What are the implications for Question 3?
 - a. They have reduced access to treatment options and postdiagnostic care
 - b. Leads to more hospital visits
 - c. Leads to care home admissions
5. Why are primary caregivers invaluable in their relationship-centred care plan?
 - a. They help in detailing mood changes, unusual mistakes and repeated questioning
 - b. They assist in cooking meals
 - c. They provide financial support

Key references

1. Clare L. Managing threats to self: awareness in early stage Alzheimer's disease. *Soc Sci Med* 2003;57(1):1017–29.
2. Clare L, Roth I, Pratt R. Perceptions of change over time in early stage Alzheimer's disease: implications for understanding awareness and coping style. *Dementia* 2005;4(4):487–20.
3. Cations M, Withall A, Horsfall R, et al. Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLoS One* 2017;12(7). doi:10.1371/journal.pone.0180935
4. Nolan M, Brown J, Davies S, et al. *The senses framework: improving care for older people through a relationship-centred approach*. Sheffield Hallam University, 2006. Available https://shura.shu.ac.uk/280/1/PDF_Senses accessed 7 Feb 2019.
5. Vieira RT, Caixeta L, Carta MG. Epidemiology of early-onset dementia: a review of the literature. *Clin Pract Epidemiol Ment Health* 2013. doi:10.2174/1745017901309010088.

Acknowledgements I would like to acknowledge the University of Stirling and the Association of Commonwealth Universities (ACU) for the scholarship.

Contributors MN: developed the study question, undertook the study and typed the manuscript.

Funding The author has not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Martin Nwadiugwu <http://orcid.org/0000-0001-6788-8305>

REFERENCES

- Alzheimer's Disease International. About dementia. Global voice on dementia. 2018. Available <https://www.alz.co.uk/about-dementia>
- Rodgers AB. Alzheimer's disease: unraveling the mystery. *Alzheimer Dis Educ Res Centre* 2003. Available <http://www.alzheimers.org>
- Dening T, Sandilyan MB. Dementia: definition and types. *Nurs Stand* 2015;29:37–42.
- Rizzi L, Rosset I, Roriz-Cruz M. Global epidemiology of dementia: Alzheimer's and vascular types. *Biomed Res Int* 2014;2014:1–8.
- Yiannopoulou K, Sokratis P. Current and future treatments for Alzheimer's disease. *Ther Adv Neurol Disord* 2013;6:19–33.
- Matthews FE, Arthur A, Barnes LE, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the cognitive function and ageing study I and II. *Lancet* 2013;382:1405–12.
- Ferri CP, Prince M, Brayne C. Global prevalence of dementia: a Delphi consensus study. *Lancet* 2005;366:2112–7.
- WHO. *World healthy report: reducing risks, promoting healthy life*. World Health Organization, 2002. Available <https://www.who.int/whr/2002/en/>
- Hendrie HC, Ogunniyi A, Hall KS. Incidence of dementia and Alzheimer disease in 2 communities: Yoruba residing in Ibadan, Nigeria, and African Americans residing in Indianapolis, Indiana. *J Am Med Assoc* 2001;285:739–47.
- Prince M, Gemma-Claire A, Maelenn G, et al. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's Res Ther* 2016;8.
- Feigin VL, Lawes CM, Bennett DA, et al. Worldwide stroke incidence and early case fatality reported in 56 population-based studies: a systematic review. *Lancet Neurol* 2009;8:355–69.
- Gao S, Ogunniyi A, Hall KS, et al. Dementia incidence declined in African-Americans but not in Yoruba. *Alzheimer's & dementia. J Alzheimer's Assoc* 2016;12:244–51.
- Alladi S, Hachinski V. World dementia. *Neurology* 2018;91:264–70.
- Harvey RJ, Skelton-Robinson M, Rossor MN. The prevalence and causes of dementia in people under the age of 65 years. *J Neurol Neurosurg Psychiatry* 2003;74:1206–9.
- Kelley B, Bradley B, Keith J. Young-onset dementia: demographic and etiologic characteristics of 235 patients. *Arch Neurol* 2008;65:1502–8.
- Masellis M, Sherborn K, Neto PR, et al. Early-onset dementias: diagnostic and etiological considerations. *Alzheimer's Res Ther* 2013;5:1–7.
- Greenwood N, Raymond S. The experiences of people with young-onset dementia: a meta-ethnographic review of the qualitative literature. *Maturitas* 2016;92:102–9.
- Milne A. Dementia screening and early diagnosis: the case for and against. *Health Risk Soc* 2010;12:65–76.
- Alzheimer's Australia NSW. Addressing the stigma associated with dementia. 2010. Available <https://www.dementia.org.au/sites/default/files/2010NSWAddressingStigmaDiscussionPaper2.pdf>
- Nolan M, Jayne B, Sue D, et al. *The senses framework: improving care for older people through a relationship-centered approach*. Sheffield Hallam University, 2006. Available https://shura.shu.ac.uk/2801/1/PDF_Senses
- Nolan M. Health and social care: what the future holds for nursing. Keynote address at the Third Royal College of Nursing Older Person European Conference and Exhibition. Harrogate, 1997. Available https://www.sheffield.ac.uk/polopoly_fs/1.1456781/file/issues8.pdf
- Nolan M, Sue D, Janet B, et al. Beyond 'person-centered care': a new vision for gerontological nursing. *Int J Older People Nurs* 2004;13:45–53. 10.1111/j.1365-2702.2004.00926.x
- Watson J. Developing the senses framework to support relationship-centered care for people with advanced dementia until the end of life in care homes. *Dementia* 2019;18:545–66.
- Beach M, Inui T, Frankel R, et al. Relationship-centered care: a constructive reframing. *J Gen Intern Med* 2006;21:53–58.
- Vieira RT, Caixeta L, Carta MG. Epidemiology of early-onset dementia: a review of the literature. *Clin Pract Epidemiol Ment Health* 2013;9:88–95.
- Devineni B, Onyike CU. Young-onset dementia epidemiology applied to neuropsychiatry practice. *Psychiatr Clin North Am* 2015;38:233–48.
- Department of Health. Dementia: a state of the nation report on dementia care and support in England. Department of Health, 2013. Available https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf
- Prince M, Knapp M, Guerchet M, et al. *Dementia UK: update*. UK: Alzheimer's Society, 2014.
- Bentham P, Fontaine LJ. Services for younger people with dementia. *Psychiatry* 2008;7:84–7.
- Alzheimer's Association. Early-onset dementia. A national challenge, a future crisis. 2006. Available https://www.alz.org/national/documents/report_earlyonset_full.pdf
- Macdonald G, Mears J. *Dementia as social experience: valuing life and care*. Taylor & Francis, 2008. Available <https://books.google.com/books?id=Kc1mDwAAQBAJ>
- National Health Insurance (NHS) Scotland. *The pharmaceutical care of people with dementia*. Scotland: NHS, 2014. Available <https://www.nhs.uk/scotland/media/4104909/pharmaceutical-care-of-people-with-dementia-2014.pdf>
- Gaugler JE. Early community based service utilization and its effects on institutionalization in dementia caregiving. *Gerontologist* 2005;45:177–85.
- Kasper JD, Freedman VA, Spillman BC. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff* 2015;34:1642–9.
- Hurd MD, Martorell P, Delavande A. Monetary costs of dementia in the United States. *N Engl J Med* 2013;368:1326–34.
- Alzheimer's Society. Particular issues faced by younger people with dementia. Alzheimer's Society, 2019. Available <https://www.alzheimers.org.uk/about-dementia/types-dementia/particular-issues-faced-younger-people-dementia>
- Cations M, Adrienne W, Ruth H, et al. Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLoS ONE* 2017;12:e0180935.
- Dementia Australia. Young onset dementia and the NDIS. 2018. Available <http://www.dementia.org.au/sites/default/files/resources/yod-and-ndis-booklet.pdf>
- Join Dementia Research. Rhapsody project. 2019. Available <https://news.joindementiaresearch.nihr.ac.uk/the-rhapsody-project/>
- Carter JE, Oyebode JR, Koopmans RTCM. Young-onset dementia and the need for specialist care: a national and international perspective. *Aging Ment Health* 2018;22:468–73.
- Ogunniyi A, Hall KS, Baiyewu O. Caring for individuals with dementia: the Nigerian experience. *West Afr J Med* 2005;24:259–62.
- Millenaar JK, Bakker C, Koopmans RT, et al. The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *Int J Geriatr Psychiatry* 2016;31:1261–76.
- Forsetlund L, Eike MC, Gjerberg E, et al. Effect of interventions to reduce potentially inappropriate use of drugs in nursing homes: a systematic review of randomised controlled trials. *BMC Geriatr* 2011;11:1–18.
- Cross SMB, Broomfield NM, Davies R, et al. Awareness, knowledge and application of memory rehabilitation among community psychiatric nurses working with dementia. *Int J Social Res Pract* 2008;7:383–95. 10.1177/1471301208093290
- Dawson A, Bowes A, Kelly F. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatr* 2015;15:59.
- Fitzpatrick L. Practical strategies to help develop dementia-friendly hospital wards. *Nurs Older People* 2018;30:30–4.
- NHS Choices. *Activities for dementia*. UK: NHS, 2015. Available www.nhs.uk/Conditions/dementiaguide/Pages/dementia-activities.aspx
- Hayo H. Diagnosis and support for younger people with dementia. *Nurs Stand* 2015;29:36–40.
- Carpenter BD, Xiong C, Porensky EK, et al. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *J Am Geriatr Soc* 2008;56:405–12.
- Lindesay J. Memory clinics. In: Jacoby R, Oppenheimer C, eds. *The Oxford textbook of old age psychiatry*. Oxford: Oxford University Press, 2008.
- Clare L, Roth I, Pratt R. Perceptions of change over time in early stage Alzheimer's disease: implications for understanding awareness and coping style. *Dementia* 2005;4:487–520.
- Clare L. Managing threats to self: awareness in early stage Alzheimer's disease. *Soc Sci Med* 2003;57:1017–29.
- Trigg R, Jones RW, Skevington SM. Can people with mild to moderate dementia provide reliable answers about their quality of life? *Age Ageing* 2007;34:663–9.
- Cabrera E, Caroline S, Verbeek H, et al. Non-pharmacological interventions as a best practice strategy in people with dementia living in nursing homes. A systematic review. *Eur Geriatr Med* 2016;6:34–150. 10.1016/j.eurger.2014.06.003
- Rossor MN, Fox NC, Mummery CJ, et al. The diagnosis of young-onset dementia. *Lancet Neurol* 2010;9:793–806.
- Kimura NRS, Maffioletti VLR, Santos RL, et al. Psychosocial impact of early onset dementia among caregivers. *Trends Psychiatry Psychotherapy* 2015;37:213–9.

- 57 Chrisp T, Thomas B, Goddard W, *et al.* Dementia timeline: journeys, delays and decisions on the pathway to an early diagnosis. *Dementia* 2011;10:555–70.
- 58 Sakata N, Okumura Y. Job loss after diagnosis of early-onset dementia: a matched cohort study. *J Alzheimers Dis* 2017;60:1231–5.
- 59 Fick DM, Kolanowski A, Beattie E. Delirium in early-stage Alzheimer's disease. *J Gerontol Nurs* 2010;35:30.
- 60 Alzheimer's Society. Delirium. Alzheimer's Society, 2017. Available www.alzheimers.org.uk/info/20029/daily_living/370/delirium.
- 61 NIH. Behavioral management therapy for autism, 2019. Available <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/behavioral-management>
- 62 NHS. *Cognitive behavioral therapy*. UK: NHS, 2019. Available <https://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/>
- 63 Jayalath D, Ashaye K, Kvavilashvili L. Carer's diaries in dementia: is there a role in clinical practice? *Alzheimers Dement* 2016.
- 64 Trivedi PD, Braun A, Dickinson A. Managing behavioural and psychological symptoms in community dwelling older people with dementia: a systematic review of the effectiveness of interventions. *Dementia* 2018.

Answers

1. a
2. a
3. b
4. a
5. a