Chapter 20
Sex, gender and cultural factors

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Key points

- Evidence suggests that minority groups and women are not diagnosed with dementia in as timely a manner as others.

- There is insufficient awareness of how sex and gender influence the diagnostic journey.

- Precision medicine with the inclusion of sex and gender factors will optimise not only the diagnostic pathway, but also patient experience.

- For effective and culturally optimal diagnosis and care, health and social care providers must comprehend, and be responsive to, the specific characteristics and needs of Indigenous Peoples with dementia.

Background for clinicians

Diagnosing dementia is a complex procedure that necessitates healthcare professionals to process a large volume of information. Our own personal and cultural biases inform us as people, though when considering scientific evidence, it is our imperative to be as objective, accurate and efficient as possible. Anything less, and the health and well-being of those who trust and rely on our expertise will be impacted. Among the many potential biases that can influence us as clinicians, there exist those inherent or underlying ones we carry that may significantly impact our diagnosis and treatment, namely our attitude towards such factors as sex, gender and ethnocultural differences.

The essays below will address timely issues such as racial and ethnic disparities when diagnosing dementia as well as equity, diversity, and inclusion from a Canadian perspective. Considerations on sex and gender in the diagnosis of dementia are also addressed. Differences to be aware of when diagnosing dementia in Arabic countries and in Indigenous populations worldwide are discussed.

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Expert essay

Racial and ethnic disparities in the diagnosis of dementia

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With rising life expectancy, the global burden of dementia is expected to increase exponentially. Whereas high-income countries (HICs) are projected to experience an approximately 56% rise in older adult populations in the next 30 years, this growth is anticipated to exceed 150% in low-and middle-income countries (LMICs) (1). Moreover, in many high-income countries, including the United States and several European Union nations, the number of racially and ethnically diverse older adults is expected to increase dramatically in the coming decades (2,3). With age being the main risk factor for dementia, these rapid demographic changes require a prompt and effective response from healthcare systems to address the needs of diverse older adults.

Most experts agree that early diagnosis of dementia is a healthcare priority (4), and its benefits are numerous. These include opportunities to identify aetiological causes, inform and coordinate medical care, enable planning for the future, address possible safety issues, and connect families to interventions. It also allows for the identification of appropriate candidates for clinical trials of potentially disease-modifying therapies that are anticipated to benefit people in early stages (5). In turn, missed or late diagnosis may result in devastating outcomes for individuals and their families, including lost opportunities for treatment, complications of comorbid medical conditions, increased healthcare expenditures, adverse effects on patient safety, and increased carer burden (4).

Evidence and consequences of diagnostic disparities

Diagnostic practice recommendations for early diagnosis of dementia and its prodromal phase, mild cognitive impairment, underline the importance of a comprehensive work-up. This can vary by setting and needs of each person but typically includes evaluation by a dementia specialist, cognitive examination, and laboratory and neuroimaging studies to help identify underlying aetiology including potential non-neurodegenerative causes (6). For most people with dementia, their evaluation does not approximate this standard (5), and commonly, no diagnosis is made. The rates of underdiagnosis are inversely related to income of countries, from around 60% in high-income countries to above 90% in low- and middle-income countries (7). Furthermore, older adults in LMICs frequently experience substantial disability and poor general health due to unaddressed modifiable risk factors and unmanaged chronic disease (8). In high-income countries, racial and ethnic minorities are at higher risk of underdiagnosis than the majority (frequently White/Caucasian) population, as documented by studies from Denmark, Norway, the United Kingdom, and the United States (3,5). Moreover, even when racially and ethnically diverse older adults do receive a diagnosis, they are more likely to be diagnosed at a later stage and receive a less comprehensive diagnostic evaluation than the ethnic majority group (3,5), making them more vulnerable to adverse outcomes associated with late or inaccurate diagnosis.

Diagnostic disparities in dementia have wide-ranging consequences for individuals and their families including, perhaps most critically, access to support and treatment that are most effective in earlier stages (5). Indeed, racial and ethnic minorities have been reported to be less likely to be prescribed cholinesterase inhibitors and to access fewer services (9), which is possibly directly related to upstream diagnostic disparities early in the disease process. Moreover, later or missed diagnosis of dementia among racially and ethnically diverse older adults may indirectly result in inaccurate representation of these communities in epidemiological studies on prevalence and incidence rates of dementia that are critical sources of information for public health policy (5). Finally, diagnostic disparities likely play a crucial role in underrepresentation and often exclusion of diverse older adults in clinical trials, which in turn puts these individuals at risk for future treatment disparities, particularly if a disease-modifying agent is approved.

What is driving diagnostic disparities?

Much more research is needed to elucidate the patient-level and system-level factors that underlie racial and ethnic disparities in the diagnosis of dementia (3). Patient-level factors include low awareness of dementia, limited health literacy, language and communication barriers, cultural and familial perceptions of dementia and ageing, stigma of mental illness, and distrust of healthcare services (3,5). System-level factors, in turn, are comprised of the historical and structural inequities and include lack of culturally appropriate services and tools, shortage of dementia specialists particularly in low resource areas, inadequate training of general healthcare professionals in the recognition of dementia, bias in referral practices to specialists, and time- and cost-related barriers to access quality care that may disproportionally affect underrepresented groups (3). Furthermore, these patient- and system-level factors must be understood in the context of the structural racism that is experienced by many racial and ethnic groups, which has resulted in the accumulation of disadvantage and higher risk of poor health outcomes in general (3). The combination of these factors drives racial and ethnic diagnostic disparities and represent a critical area for research and intervention to reduce inequities in the timely and accurate diagnosis of dementia amongst racially and ethnically diverse older adults.

Future directions

Racial and ethnic disparities in the diagnosis of dementia are a major research and public health priority. We urgently need to better understand the causes of these disparities, develop targeted interventions that are amenable to scale, and implement the interventions with attention to what works and what can be sustained in diverse communities. We propose a multi-pronged approach that includes culturally tailored campaigns to increase public awareness about brain health and reduce stigma, policies to increase the diversity of the general practitioner and dementia specialty healthcare workforce, better education and training for general practitioners on dementia recognition and care, outreach by dementia specialist providers to facilitate referral of underserved patient groups, adequate reimbursement and time for providers to diagnose and manage dementia, and improved access to effective dementia care models that provide critical support for individuals, carers, and general practitioners following diagnosis. We emphasise this last point, that improved diagnosis must always be linked to quality care (10), because without this link, the providers will not be motivated to diagnose, and the benefits of diagnosis will not be realised. Collaborative efforts among researchers, clinicians, community partners, and policymakers are essential to achieve equity in dementia diagnosis.

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Expert essay

Equity, diversity, and inclusion in dementia diagnosis: a Canadian perspective

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Canada, like other western nations, has experienced unprecedented demographic changes in its age-based population. Since 2016, the number of adults over the age of 65 has outnumbered those 0–14 years of age (1). Moreover, there has been an increase in both the rate of immigration and differences in countries of origin for newcomers, resulting in 1 in every 5 Canadians now identifying as foreign born, and 1 in every 5 Canadians also identifying as a visible minority (2). As dementia is poised to impact almost a million Canadians by 2030 (3) focused attention is crucial to understand the needs and experience of these racially diverse communities when accessing dementia care services and programmes.

Unlike other western nations, there is little Canadian data or resources available for the needs and experiences of people living with dementia and their carers from racially diverse communities, particularly from a population-level perspective (4,5). Specific studies found that racially diverse communities have a higher prevalence of dementia and face disproportionate challenges due to a lack of culturally safe carer and community support, and poor system-level awareness of their education needs and health-seeking behaviours (4,6). These gaps in knowledge can further exacerbate the burden of care felt in these communities, including increased isolation, stigma and delays in seeking a diagnosis.

Receiving a timely dementia diagnosis has been shown to help decrease the progression of the condition, yet the decision-making process to seek a diagnosis for people experiencing dementia complaints from racialised backgrounds is complex. It operates on cultural and structural levels. Cultural barriers are both knowledge- and society-related. Knowledge-related barriers include misidentification of the causes of dementia to spiritual, psychological, and other physical health or social origins (7,8), beliefs that dementia is part of normal ageing, misinterpreting changes in behaviour and personality, and not perceiving a need to seek a diagnosis or support (9). Society-related cultural barriers can include fear of shame, ostracisation, and stigma within families and communities (8,10). Cultural expectations about

family carers can create barriers to seeking a diagnosis; they can place a large onus on the family to provide for the needs of elders, thus contributing to delays in seeking a diagnosis (11).

Importantly, cultural barriers do not occur in isolation. They can be strongly influenced by structural barriers that are part of broader social contexts that inform access to healthcare services. Specifically, structural barriers can cause hesitancy engaging with the healthcare system due to systemic discrimination, difficulty navigating health services that are not culturally appropriate, and lack of resources in the language of choice (7,9).

While these studies highlight some barriers experienced by racially diverse communities, more in-depth analysis needs to take place to understand the experiences and barriers faced by physicians providing care to these communities. In Canada, primary care physicians are gatekeepers for those seeking a dementia diagnosis, making this information particularly relevant to physicians' provision of care. Primary care physicians have been shown to have difficulty with accurately diagnosing dementia when their patients do not speak English or French, or have potential low literacy and education (12). Moreover, many of the widely used assessment tools for the diagnosis of dementia are not culturally

appropriate. Education, language, ethnocultural factors can affect performance on neuropsychological testing, leading to false-positives and false-negatives (13,14). Lastly, primary care physicians may have their own biases about dementia. They may have been reluctant to confirm a diagnosis based on assumptions that people do not want to receive a diagnosis due to associated stigma or their own views that a diagnosis was not useful.

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The following recommendations can enable a planned and systematic pathway to seeking a diagnosis and accessing supports. Community level recommendations include implementing and encouraging anti-stigma campaigns that are culturally safe and appropriate, along with psychoeducation, vigilant screening, culturally-friendly dementia services, and awareness building (15). For example, community agencies can provide tailored information and support to immigrants and at-risk communities. Interventions targeted at building knowledge and awareness can be customised to the needs of racially diverse groups. These could include multilingual informational pamphlets about dementia and culturally-appropriate services (11).

Clinicians should also be attentive to the subtle signs of possible dementia, including missed appointments or mismanaged chronic conditions (12). To prevent false-positive and false-negative dementia misclassification by the brief

cognitive assessments in ethnically diverse groups, clinicians should also consider encouraging older adults to bring a companion or carer to the appointment. They may be in a position to inform the clinician of culturally relevant issues (12), participate in informant-rated cognition and potential test specific biases (13). Informant reports from cultural perspectives can also complement cognitive testing to improve the accuracy of a dementia diagnosis (14).

Incorporating these recommendations into dementia-friendly communities can help to normalise dementia so that individuals and their carers from these communities can be confident in obtaining a timely dementia diagnosis.

As the primary national organisation that provides education and support for people living with dementia, the Alzheimer Society of Canada continues to play a crucial role in implementing these recommendations and has taken a more active approach to relationship building and understanding the experiences of ethnically diverse communities is essential. In partnership with the College of Family Physicians of Canada, the Alzheimer Society of Canada launched the first national survey focused on understanding the needs of racially diverse people living with dementia, and a companion survey to family physicians providing care to these communities. Concurrent with the survey, targeted community outreach and awareness raising is occurring within racially diverse communities. Data from the survey will be shared back with the communities to support their own decision-making and advocacy, a step rarely taken but crucial for building those communities' capacity. Phase two will involve leveraging existing relationships and supports as a starting point, while recognising the need for co-creation of culture-first (instead of language-first) resources.

As the population of people living with dementia continues to grow and diversify, more data and research will be essential to develop better resources and supports that focus on building knowledge and confidence in communities that have long experienced structural barriers in the healthcare system. This must be the first step in a long-term, multi-year, multimedia strategy to provide dementia care programmes and services.

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Expert essay

Optimal Alzheimer's disease detection and diagnosis under the sex and gender lens: a crucial step towards precision neurology

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Alzheimer's disease pathophysiology emerges decades before the first clinical signs and symptoms appear. The clinical continuum of the disease is therefore characterised by a long asymptomatic, preclinical stage and a complex trajectory. It is important to detect the first biological indicators and diagnose affected individuals as early as possible, to effectively implement secondary preventative strategies, to provide access to potential (pharmacological and non-pharmacological) disease-modifying treatments, and to allow individuals and their families to plan for the future.

Sex (biological) and gender (socio-cultural) differences in Alzheimer's disease are particularly relevant in the individual's diagnostic pathway and medical journey.

Definition of sex and gender

Sex: genetically determined differences resulting from the expression of sex chromosomes (XX/XY)

Gender: socio-cultural construct determining feminine and masculine expected behaviours and norms in a particular society

In this essay, we highlight gaps that could be addressed by specific advocacy and policy actions to enable accurate, reliable and precise diagnosis and treatment for both sexes, a crucial step towards precision neurology.

Lifetime risk and need for personalised prevention

Datasets consistently show that approximately two-thirds of people with Alzheimer's disease are women (2). Although differences in indicators of Alzheimer's disease risk by sex are controversial and vary by country, the lifetime risk of dementia is higher in women (2). This highlights the importance of a timely diagnosis as well as of understanding and managing risk factors early in women.

Of the 12 modifiable risk factors identified by the Lancet Commission in 2020 (3), several are more common in women, including low level of education and depression. Also, sex- and gender-specific risk factors have been proposed for both men and women (see Table 1) and might be leveraged for personalised prevention.

Access to healthcare and gender considerations

The diagnostic process is directly related to health awareness and healthcare access. Differences between men and women in interpreting symptoms, as well as accessing and receiving healthcare, include:

Socio-economic factors: Examples of these include lower level of education, lower income, poverty, less health coverage, old age, and multimorbidity. These represent barriers to healthcare access and a timely diagnosis, where women are typically overrepresented (4).

Table 1. Modifiable risk factors of Alzheimer's disease under the sex and gender lens

Modifiable risk factors identified by The Lancet Commission (in **bold**, factors which were shown to be different in men and women)	Potential female-specific risk factors	Potential male-specific risk factors
• **Lower level of education** • **Hypertension** • **Obesity** • Hearing loss • **Smoking** • **Depression** • Physical inactivity • Social isolation • **Diabetes** • **Excessive alcohol consumption** • **Traumatic Brain Injury** • Air pollution	• Age-related decline in female sex hormones • Early menopause • Pregnancies and pregnancy complications • Shorter reproductive period • Migraine • Traumatic Brain Injury by domestic violence	• Androgen depleting treatments for prostate cancer • Age-related decline in male sex hormones (andropause)

Stigma: Women living with Alzheimer's disease face a 'triple jeopardy' (5) of barriers from stigma related to old age, cognitive decline, and gender stereotypes and bias, which can create a hurdle to acknowledge and talk about their symptoms and seek professional help.

Carer role: Approximately two-thirds of informal carers are women, often juggling their carer role with other family and professional responsibilities. On the one hand, because women tend to be more engaged in household and other managing tasks, it may be easier for family members to identify behavioural changes in women rather than men. However, as the Alzheimer's disease diagnostic journey can take years, necessitating a significant investment in terms of time and personal resources, this can generate a specific problem for women carers who lack the required time and family support (6).

Help-seeking behaviour: Men engage in healthcare-seeking behaviour less than women and only when symptoms are severe; the World Health Organization reports that women tend to talk about mental health issues with their general practitioner (GP) while men are more likely to seek specialist help. This difference in help-seeking behaviour could also have an impact on delayed diagnosis or misdiagnosis (7).

Not only do these gender factors affect access to healthcare and early diagnosis, they also have an impact on clinical trial access., (8,9).

Sex and gender considerations in the clinical diagnosis of Alzheimer's disease

According to published studies, mild cognitive impairment (MCI) is more common in men (2); its diagnosis however is often missed in women or occurs at an advanced pathological stage. This is partly due to sex differences in neuropsychological tests, which rely heavily on verbal memory, and where women perform on average better than men, despite equal amounts of Alzheimer's disease pathology. Adjusting cut-offs based on sex-specific considerations can detect approximately 20% more women who missed out an MCI diagnosis (10).

In addition to biological differences, MCI is often overlooked in women as gender stereotypes tend to steer diagnosis towards depression rather than MCI due to Alzheimer's disease. When treating mental health problems, doctors were more likely to diagnose depression in older women than men presenting the same symptoms (5).

Sex differences in biomarkers for Alzheimer's disease diagnosis

Biomarker-aided (fluid, imaging, and digital) diagnosis is increasingly used to diagnose Alzheimer's disease. The use of biomarkers has the potential to overcome gender biases and leverage sex differences for a more precise diagnosis.

There is growing evidence that the levels of several currently used biomarkers differ between men and women (11). Cerebrospinal fluid (CSF) concentration of neurofilament light chain, a biomarker for neurodegeneration, has been shown to be higher in men, while tau, another biomarker for neurodegeneration, was higher in women. In addition, several PET-imaging studies show that tau levels in the brain accumulate at higher levels and faster in women. This suggests that sex-specific cut-offs, for both diagnostic and prognostic value, should be carefully examined.

> **Several PET-imaging studies show that tau levels in the brain accumulate at higher levels and faster in women. This suggests that sex-specific cut-offs, for both diagnostic and prognostic value, should be carefully examined.**

Several digital biomarkers, tools, smart technology, wearables and apps are under development and validation for early detection of cognitive impairment and signs of decline. Their use could help accelerate early diagnosis and follow-up of Alzheimer's disease. Initial evidence suggests even digital biomarkers differ significantly between men and women. Therefore, considering sex and gender differences will also be crucial in the development of digital solutions.

Finally, in the near future, improved validation of blood-based biomarkers will allow for inexpensive, regular and timely screening and early detection of at-risk individuals, even in primary care. It will therefore be important to also consider sex-related aspects in the application of such biomarkers.

To enable precision medicine, multidimensional data needs to be analysed and interpreted via predictive algorithms. In this context, sex and gender are crucial factors affecting the overall predictive power of clinical models. Indeed, it has been shown that including sex in predictive algorithms improves their efficiency (12).

Both sex (biological) and gender (socio-economic) factors can influence access to healthcare and accurate diagnosis of Alzheimer's disease. However, there is insufficient awareness of sex and gender influence on the diagnostic journey by the medical community and society overall.

Considering sex- and gender-specific factors is a key step to improve access to and precision of diagnosis of Alzheimer's disease, especially during early stages. A paradigm shift towards precision neurology will optimise the diagnostic pathway and the individual's medical journey.

Recommendations

- Promote awareness campaigns to address 'triple jeopardy' barriers older adult women face and reduce stigma.

- Determine evidence-based sex-specific cut-offs for cognitive/clinical/biomarker testing, using both standard and digital solutions.

- Increase awareness of sex and gender differences at societal and professional levels.

- Healthcare providers from primary care physicians to academia, from generalists to specialists, need to be educated and informed.

- Make gender equity in medicine a priority for governments, regulators, and policymakers.

- Implement multi-stage, sex-specific brain health screening and diagnostic process for people at risk over the age of 50.

- Promote sex- and gender-specific prevention campaigns such as cognitive training for women with lower education or early menopause.

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Expert essay

Access to diagnostic evaluations in people with symptoms suggesting dementia in the Arab world

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The Arab world is made up of 22 countries distributed between the Atlantic coast of Northern Africa to the Arabian Gulf, with a total population of approximately 280 million. A report by the World Health Organization (WHO) estimated that the prevalence of people with dementia in the Arab world would increase 125% by 2050 (Dementia: A public health priority, WHO 2012).

Like other parts of the globe, the number of older adults in the Arab world has been increasing gradually and the number of people living with dementia in these countries is expected to reach 4.4 million by the year 2030 (1).

This means that such countries would need to consider dementia as a global health issue and start developing guidelines and policies to improve detection and management. It is worth noting that by 2021, out of the 22 countries, only three had a national plan.[i]

Despite a significant variation in income levels, Arab countries share common values, social customs, cultural and religious beliefs (Islam being the most widely practiced religion followed by Christianity and Judaism). In many Arab communities, the elders are considered a source of spiritual blessing, religious faith, wisdom, and love. Such values may influence help-seeking behaviour when a person develops cognitive impairment and becomes unable to fulfil social expectations (2). When an older person requires assistance, the family may hire a carer or a nurse at home; if the family is unable to afford to pay for a carer or nurse, a family member, usually a spouse or a daughter, becomes the main carer (3).

While Arabic is the formal language, different variations are spoken ranging from formal and literary to vernacular. This raises the question: how can psychological tests be written and understood by people from different countries? This will not only affect how the test is interpreted, but also its validity and its appropriateness to be used in another Arabic-speaking country (4).

The diagnostic process

In many Arab countries, the diagnosis of dementia is often not made or is delayed until it reaches the advanced stages. This is attributed to several factors such as stigma, lack of awareness, and access to dedicated services for diagnosis and treatment.

Stigma

Stigma towards people with dementia is a worldwide phenomenon and is not limited to the general public but also extends to healthcare workers. According to the 2019 World Alzheimer Report, both the public and some healthcare professionals in many countries consider dementia a normal part of ageing. Families will mostly consult a healthcare professional when someone starts exhibiting challenging behaviours.

In Arabic, the term *kharaf* is used to describe dementia and means 'the one who has lost his mind' (4). There has been a recent attempt to change that to a less stigmatising definition which translates to cognitive impairment. However, many people find this too academic, and some health workers have adopted the term 'Alzheimer's like' to describes other forms of dementia. Recent health education campaigns are gradually contributing toward a better awareness about dementia.

Clinical memory services

Clinical services that provide both assessment and management to people with dementia vary across Arab countries based on the availability of resources and the clinicians' training and background in each country. That said, as a general rule, neurologists, psychiatrists, and geriatrics specialists are consulted after initial assessment from primary care physicians. In some countries where clinicians have North American-based post-graduate training, behavioural neurologists with the combined expertise of neurology and psychiatry are also involved in the assessment and

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[i] For more information please see From Plan to Impact IV (ADI, 2021) https://www.alzint.org/resource/from-plan-to-impact-iv/

management of people with dementia. The number of experienced psychologists in neurocognitive assessment is incredibly limited and cognitive assessments scales that have been translated to Arabic and validated are equally scarce. Traditionally, the Mini-Mental Status Examination (MMSE) is used as the standard scale for assessment, however copyright issues restrict its use to specific centres. Albanna et al., conducted a study in Qatar on the validation of the Arabic versions of the MMSE and Mini-Cog screening tests when used together. Results found that the combination improved the balance between sensitivity and specificity rather than using either measure alone (5). In Egypt, a validation study of the Addenbrooke's Cognitive Examination III (ACE III) was conducted by Qaseem et al., and a cut-off score for mild cognitive impairment was established (6). Chayya et al., from Lebanon validated the Arabic version of the Rowland Universal Dementia Assessment Scale (RUDAS) and concluded that it is a reliable short screening test with good psychometric properties among different types of older adults, regardless of their demographic characteristics and depressed states. This finding is of particular interest when assessing people with limited educational backgrounds (7).

When it comes to neuroimaging, most centres that assess people with dementia follow international guidelines such as those from National Institute for Health and Care Excellence (NICE). However, the lack of widespread neuroimaging technology restricts its use to tertiary care centres (8).

Post diagnosis services vary across the region; some countries provide psycho-education and support groups for carers, others conduct formal training for carers covering topics related to physical and psychological care, improving communication and dealing with different behavioural problems.

Dementia care in the era of COVID-19

The COVID-19 pandemic had a significant worldwide impact on the services available to people with dementia. Measures such as physical distancing and lockdown restrictions were introduced as ways to reduce the risk of spreading the infection and of protecting older adults. This led to fewer available medical appointments for people with dementia. Eventually, this situation incurred additional delays in providing diagnostic and follow-up assessments. People with dementia experienced significant deterioration of cognitive abilities while they and their carers also endured increased loneliness and isolation. Pandemic conditions also contributed to carer burnout because of regulated social interaction with others. Other factors, including a lack of internet literacy coupled with limited accessibility to high-speed internet servers, hindered the use of virtual clinics in many countries. At a governmental level, the economic impact of COVID-19, as well as the focus on physical care and well-being, have likely diverted attention from developing appropriate dementia plans.

The way forward

Despite the significant growth of available dementia services in some Arab countries, further improvement in terms of ongoing health education campaigns, early diagnosis advocacy, clinical research focused on validating cognitive assessment scales and developing post diagnosis services that are practical, affordable, and culturally appropriate to improve the quality of care of people with dementia and their carers (9) are still lacking. Providing home care for the person with dementia can be exhausting and several studies from the Arab world reported high levels of carer burnout. This points to the need for a more structured carer support system to improve their quality of life as well as that of the person with dementia.

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Expert essay

Understanding diagnosis of dementia in Indigenous populations

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The emergence of dementia is a significant concern for Indigenous populations worldwide. The limited available research points to higher rates of dementia compared with non-Indigenous populations (1). These higher rates are rooted in colonial disruption and collective trauma that affect diverse Indigenous nations worldwide. However, despite observed higher rates, underdiagnosis and misdiagnosis are serious concerns due to notable structural barriers and healthcare systems that are under-resourced and ill-equipped for the needs of Indigenous populations. Existing diagnostic guidelines and approaches must be evaluated for how well they attend to Indigenous cultural knowledges, Indigenous experiences with colonisation, and determinants of Indigenous Peoples' health.

Indigenous communities and populations often have limited access to dementia care resources (2). This is particularly true for Indigenous People living in rural and remote communities who often need to travel long distances to visit a physician (2). In addition, many older Indigenous People speak an Indigenous language as their first language, which has implications for diagnosis and care. With a widespread lack of health services offered in these languages, older Indigenous adults often struggle to communicate with physicians, making it increasingly difficult to recognise the signs and symptoms of dementia (2). Additional healthcare resources for Indigenous populations will facilitate improved access to diagnosis, but it is equally critical that systemic barriers arising from racism and discrimination be addressed. For urban Indigenous populations, although there may be a greater availability of formalised healthcare services, systemic racism rooted in healthcare systems create a significant barrier to accessing healthcare (3), therefore preventing or delaying a diagnosis of dementia. Fears of experiencing racism or discrimination in healthcare service settings can prevent individuals from seeking medical help for symptoms of dementia. Indigenous families may avoid accessing healthcare due to a lack of trust in colonial institutions, and a lack of culturally-relevant, or culturally-appropriate care (3).

> " **For urban Indigenous populations, although there may be a greater availability of formalised healthcare services, systemic racism rooted in healthcare systems create a significant barrier to accessing healthcare, therefore preventing or delaying a diagnosis of dementia.**

Disparate access to primary healthcare and neuroimaging services among Indigenous populations, accompanied by restrictive diagnostic criteria (4), have contributed to the underdiagnosis of dementia in Indigenous populations. Emerging clinical guidelines and diagnostic resources offer the opportunity to address the health and healthcare disparity that Indigenous Peoples with dementia experience. Recommendations from the Fifth Canadian Consensus Conference on the diagnosis and treatment of dementia (CCCDTD); highlight the importance of targeted case-finding by primary healthcare professionals who should be 'vigilant for potential symptoms' and subsequent anatomical neuroimaging in most situations (4). Current recommendations in Canada also propose using an 'objective assessment' such as the Montreal Cognitive Assessment (MoCA) or the Mini-Mental State Examination (MMSE) to aid in the diagnosis of dementia (4). However, research findings from Indigenous-engaged dementia research projects raise concerns that standard Western biomedical assessments do not accurately detect dementia in Indigenous populations (5,6). In response to these concerns, culturally-relevant cognitive assessment tools have been developed to aid in accurate case-finding of dementia in Indigenous communities and populations. These include the Kimberley Indigenous Cognitive Assessment (KICA) in Australia (7), the Māori

Assessment of Neuropsychological Abilities (MANA) in New Zealand (8), and the Canadian Indigenous Cognitive Assessment (CICA) (6) in Canada. While these resources are promising, any success will require strategic engagement with Indigenous communities, healthcare providers and health system policymakers to enable effective uptake and implementation.

It is critical for healthcare providers to comprehend that dementia is influenced by intergenerational social traumas experienced as pervasive poverty, accumulative psychosocial adversities, racism, cultural genocide and social exclusion. Key knowledge includes how historical and ongoing colonisation and discrimination towards Indigenous People in Canada has a lasting impact on the health of Indigenous populations, resulting in higher rates of chronic illness and comorbidities within Indigenous populations compared to non-Indigenous populations (9). Further, chronic illnesses also influenced by colonisation, such as diabetes and hypertension, have been identified as risk factors for the development of dementia (10). This increases the complexity of medical needs in a population that is already underserved by the healthcare system. As a result, the presence of multiple chronic illnesses not only increases the complexity of disease but may confound potential dementia diagnoses. For effective and culturally safe diagnosis and care, healthcare providers must fully comprehend and be responsive to the very complex social and cultural realities of Indigenous Peoples that influence dementia. Ignoring this reality is not only a missed opportunity for diagnostic clarity and appropriate critical management approaches, but it is also an erasure revealing complicity in perpetuating colonial violence towards Indigenous Peoples.

In alignment with equity-oriented care, a potential model to inform a framework for addressing diagnostic barriers for Indigenous populations may emerge from the Educating for Equity Care Framework that was developed with a focus on diabetes in Indigenous populations but has generalisable principles for other conditions. According to Crowshoe et

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al., (11), the principles offered by this framework emphasise that: 'colonisation is the predominant cause of health inequity for Indigenous People.' Furthermore, 'healthcare equity is providing appropriate resources according to need and addressing differential treatment arising from system and individual factors' while 'empowerment is building capacity within individuals to address social determinants influencing health outcomes,' and that 'culture, by respecting its diverse perspectives and experiences, is a facilitator of the clinical relationship and patient capacity.'

By understanding the key structural challenges and enablers for Indigenous populations, we can develop better responses to the unique needs of Indigenous adults with dementia, as well as the needs of their carers. The standardised approaches used in non-Indigenous populations have limitations that render them ineffective for the accurate diagnosis and monitoring of dementia in Indigenous populations. The uptake of culturally-safe cognitive assessment tools and equity-oriented approaches will aid in more accurate case-finding, thus improving detection and diagnosis of dementia in Indigenous populations. With an improved understanding of dementia prevalence, appropriate and accessible infrastructure can be developed alongside policies and community-level healthcare services appropriate for Indigenous People around the world.

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Conclusions

The scientific and medical communities are not immune to long-standing personal and cultural biases. At the heart of this Chapter is how such bias may hinder an accurate and timely diagnosis of dementia. Across the globe, this collection of essays points to the racial, ethnic, demographic, language, gender, education and socioeconomic factors that influence this diagnostic disparity, while also acknowledging that early diagnosis is a healthcare priority that must be addressed. Providing medical access to individuals with dementia and services for their families is essential as are solutions to develop targeted interventions to improve care provided and quality of life. As worldwide life expectancy increases, these are critical factors to consider today and for the future.

That is why there is such a rallying cry for change and recommendations that include campaigns to increase public awareness about brain health and reduce its associated stigma as well as outreach to underserved groups, all to help overcome systemic barriers in place. This includes adapting standardised assessment tests to account for educational and cultural differences. Under- or late diagnosis adds a tremendous burden on individuals with dementia, their carers and the healthcare system in general. An improved understanding of dementia is needed to reform infrastructure in a meaningful and necessary way, as well as integrate consequential policy changes.