



# Investigating the Mechanisms through which Racialization Impacts Dementia Prevalence and Burden in Ethnic Minorities

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## Abstract

Ethnic minorities experience numerous adverse health consequences through their interactions with the healthcare system, but recently, their harmful experiences with dementia are of note. As dementia is among the fastest growing neurodegenerative diseases in the world, its consequences are vast, its clinical experiences bitter and its cost insurmountable. Unfortunately, even though most dementia growth and adverse consequences are in developing nations, ethnic minorities, are still prone to elevated risks of dementia even in North American society. Through the impacts of racialization, they are often treated unjustly by socioeconomic and healthcare systems, which put them at risk of dementia. This paper seeks to examine the mechanisms through which dementia prevalence and severity rates are high in ethnic minorities, while deriving evidence based clinical and healthcare policy suggestions to mitigate risk factors. Utilizing a three-fold approach, this paper leverages the impacts that healthcare systems, socioeconomic status, and social hierarchies play in creating exceptionally exacerbating environments that put ethnic minorities at inflated dementia risk.

**Keywords:** Dementia; Social policy; Clinical policy; Social determinants of health; Dementia prevention; Ethnic minorities in dementia

## Introduction

The modern geriatric healthcare problem lies within the increasing rates of dementia. In fact, groups of older adults that are 80 years or older, dementia is just as prevalent as heart failure, leading to a national average of 6.8% across Canada. To further fuel the fire, in the next 13 years, the prevalence of dementia in Canada is expected to increase by 104%.

Despite the national Canadian average, it is surprising to note that dementia prevalence rates are higher in areas with greater ethnic heterogeneity as compared to areas with more homogenous communities. Within these culturally diverse societies, it is ethnic minorities that bear the brunt of high dementia prevalence [1].

Putting biological and genetic factors aside in both Canada and the United States, it's important to note that both countries stem from racially abusive backgrounds, particularly towards ethnic minorities [1]. While older racial attitudes have been subsidized, the prevalence of systemic racism remains present, especially at the heart of healthcare services [1]. This pattern is consistent with dementia prevalence rates as well across North American society.

While systemic racism and the racialization of ethnic minorities impacts dementia prevalence rates, there is a clear gap in understanding the mechanisms through which these results are observed. This review article seeks to identify the means through which racialization increases dementia prevalence and burden amongst ethnic minorities in North American societies, and derive evidence based public policy, medical practice, and healthcare system solutions to mitigate these impacts.

To accomplish this task, this paper will utilize the following evaluating framework to look at research studies through the three perspectives shown below:

1. Access to Care and Healthcare Systems Experiences

2. Income and Socioeconomic Status
3. Systemic Oppression and Social Hierarchies

## Methods

This review was conducted using the PubMed Public Health Database. A 2 step screening process was utilized, the title and the abstract of papers. In the searches within the database, the results per page setting were set to 10 results per page. Only the first two pages of every search were examined to ensure the utmost relevance to the terms inputted.

Inclusion Criteria	Exclusion Criteria
Written in English	Other language
Study must be newer than 2000	Study is older than 2000
Discusses dementia and racialization with respect to the evaluating framework.	Does not discuss the topic with respect to the framework.
1. Access to Care and Healthcare Systems Experiences	
2. Income and Wealth	
3. Mental Health, Cognitive & Suppression impacts – Systemic Oppression and social hierarchies	

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Research should be limited to North American societies (Canada and the United States)	Research is outside Canada or United States
Racialized Groups include people of African descent (African-Americans/Canadians), Asian	Racialized groups do not belong to the aforementioned categories
Minorities (Chinese, Japanese, Korean, Vietnamese), and South East Asians	

**Table 1:** Inclusion and exclusion criteria

The inclusion and exclusion criteria, shown in (Table 1), were developed to determine eligible literature sources.

## Discussion

### Access to care and healthcare systems experiences

**Diagnostic criteria:** There is a gross misdiagnosis of dementia in ethnic minorities because the frameworks used to diagnose dementia are not structured to accommodate the ethnic diversities present within dementia symptomology [1]. For example, in dementia patients, people of Caucasian descent are more likely to display neuropsychological symptoms, whereas South East Asians are more likely to be co-morbid with Parkinson’s and Lewy Body’s Disease. In fact, analysis of clinical vignettes supports significant differences between the manifestation dementia symptoms between races. As racialization is a social concept as opposed to a biological one, the cultural and social practices of individuals across ethnicities have been found to result in different symptomologies of dementia. However, the diagnosis criteria in dementia that’s commonly utilized by practitioners, fails to account for this cultural diversity, resulting in higher rates of misdiagnosis among ethnic minorities, such as African or Asian Americans. To overcome this barrier, it is critical for health management, health informatics and health data organizations such as the Canadian Institute for Health Information or the Canadian Institute of Health Research to amplify health data collection endeavours on the dementia symptomatic diversity amongst ethnic minorities. This would require a greater level of funding and research endeavours into data collection for the diagnosis of dementia in ethnic minorities across an array of providers, particularly including primary care practitioners as well as geriatricians. Furthermore, a policy level research analysis is much required from provincial governments to better enable practitioners to understand, and medical curriculum to include the diversity of dementia symptoms to reduce misdiagnosis.

**Mistrust and medical racism:** Aside from a change in diagnostic criteria, a paradigm shift is also required to shift biases that practitioners have towards ethnic minorities [2]. For example, dementia is more likely to be dubbed as part of the normal aging process with ethnic minorities but is diagnosed correctly or even in the form of mild cognitive impairment when Caucasians are concerned [2]. This has led ethnic minorities to feeling foreign to the healthcare system as the bias’s donned by practitioners makes them feel unheard [2]. Fortunately, these experiences can certainly be mitigated through more inclusive health promotion efforts [2]. For example, in a systematic review of 11 countries, researchers found that establishing dementia oriented cultural events in community health centers helped people of different cultures understand and interpret dementia as a secondary aging phenomenon [3]. This, in turn, found that more culturally oriented community members were willing to consult more

open mindedly and freely with their healthcare practitioners [3]. As borne out by the evidence in this systematic review, developing culture specific dementia programs is an effective methodology to clear up misconceptions [3].

**Physicians and culturally sensitive care:** To further help alleviate medical racism, two fold service level interventions must be considered by policy makers; those that focus on communities, and those that focus on practitioners [2]. Some evidence based best practice interventions for both community and healthcare practitioners can be seen in (Figure 1). In literature, while these interventions are relatively new, they are showing some promising examples, such as the PRO DEM intervention in the United States, where physicians and community members were given culture specific, and dementia specific trainings alike, helping to bridge the divide between ethnic minorities and physicians [4]. This resulted in better physician and patient satisfaction, reduced dementia progression in patients with advanced stages of the disease, as well as lower at home or in community medical accidents [4].

The importance of having physicians that stems from ethnic minorities and can provide more culturally sensitive care is crucial [5]. A common complaint and barrier that many ethnic minority patients in older age face is communication and comfort ability with their provider [5]. Often, this is motivated by a lack of cultural understanding as



**Figure 1:** Community Intervention

well as shared language [5]. This further fuels the fears and traumas that many older adults have with interacting with providers outside of their ethnicity [5]. As a result, they are less likely to seek medical consultations [5]. To overcome these barriers, the incorporation of general practitioners, geriatricians, and neurologists that stem from ethnic minorities backgrounds, has proved to be successful in bridging the cultural gap within the healthcare continuum [6]. As a result, when interacting with practitioners of their own ethnicity, patients diagnosed with dementia, reported greater feelings of trust, more healthcare access, as well as enhanced engagement [6]. Ironically, culturally sensitive care, thought to deviate from medical norms, was found to have an increase in the deployment of evidence based treatments for patients with dementia [6]. While this analysis is emphasized largely on patients with dementia, it can further be applied in outer boundaries to include ethnic minorities that are at risk of dementia [6]. For example, in the African American demographic in the United States, most patients represent high

levels of LDL cholesterol and hypertension, which also makes them the leading ethnic cohort in the diagnosis of vascular dementia [7]. Unfortunately, many African American communities lack access to healthcare due to fiscal reasons, but also social ones such as medical racism [7]. This has a compounding effect on the increased risk of a dementia diagnosis, as these untreated conditions result in a severely higher prevalence [7]. In light of this, it's important for dementia prevention strategists to include specialists of ethnic minorities such as cardiologists, endocrinologists, nephrologists etc. that can mitigate the risk of dementia for patients in middle age with chronic diseases [7]. Having a more heterogeneous system in dementia care, as well as other forms of acute or specialist care is critical to ensuring healthcare access [7].

**Community level operations:** When it comes to evaluating the accessibility, and outcomes that the healthcare system has with respect to dementia in ethnic minorities, the sociocultural health belief model is an effective illustrator into the various community dynamics that affect outcomes [8]. As per the sociocultural health belief models, ethnic minorities are significantly more likely to adhere to cultural and religious leaders' interpretations of dementia [8]. Therefore, they are less likely to access healthcare services, resulting in a late dementia diagnosis as well as increased susceptibility [8]. This is also problematic because ethnic minorities, in general, have a significantly higher belief in the de-medicalization of diseases as they attach cultural and religious interpretations to it as opposed to medical ones [8]. Therefore, they are also less likely to seek treatment for critical risk factors of dementia such as hypercholesterolemia, hypertension, mental health concerns etc [8]. For instance, though the African American community has among the highest LDL cholesterol levels in the United States, it is also the community that least actively seeks treatment for it [5]. Rather, many attributions to this physical disease are explained through cultural and religious arguments [5]. As religious silos continue to grow, it's important for policy makers to leverage this information to develop community oriented dementia medicalization endeavors [5]. In literature, strong evidence supports the formation of community oriented health promotion efforts that employ degenerative disease information awareness by educating community leaders and religious scholars [9]. This has had the effect of embedding medical narratives of dementia into community programming and encouraging at-risk populations to access preventative care [9]. In Canada, it is recommended for policy makers to identify large community groups, as well as their representative community centers, prominent figures and large gatherings to educate them on dementia prevention techniques as well as symptomologies that may require a doctor's visit [9]. This top down management approach can help empower community members from their trusted community leaders to seek relevant and timely dementia care [9].

### Income and socioeconomic status

**Lower socioeconomic class:** Ethnic minorities are more likely to occupy lower tiers of socioeconomic cohorts at any given time. As these folks are often living at the poverty line, under the poverty line or pay cheque to pay cheque, they are more probable to experience a worse transition from work life to retirement a critical risk factor for dementia development in middle aged and older adult groups. With increasing financial worries in retirement, a lack of leisure and recreation, increased isolation, reduced mobility as well as social and political marginalization, the mental health repercussions are profoundly visible through anxiety, depression and loneliness. This, in turn, has impacts on blood flow into the brain and helps

formulate the development of plaques that are risk factors for dementia. Unfortunately, clinical policies for socioeconomically marginalized ethnic minorities do not exist because health data and reporting agencies don't collect such information. Literature urges federal government bodies, which in Canada include CIHI or CIHR to conduct research regarding ethnic minorities as to how social elements such as income, lifestyle, occupation etc. play a role in dementia risk. Similar to the Japanese National Dementia Strategy, where socioeconomic status was studied with respect to dementia risk across provinces, and multiple risk factors such as blue collar occupation, drinking and recreational drugs in low socioeconomic groups were identified, the Canadian National Dementia Strategy should broaden to incorporate some of the multi-factorial risk factors in middle age that remain exclusive to ethnic minorities and their likelihood of developing dementia [10].

**Poor health literacy/behaviour:** Beyond the level of income that ethnic minorities have, it's also critical to evaluate the environments in which they live, the actions they take, and behaviour they adopt [11]. Due to insufficient income, many ethnic minorities, in particular, African Americans in the United States are forced into poor food habits [11]. For example, McDonalds and KFC like fast food chains are most often utilized by these ethnic groups and also flourish most in these communities [11]. In fact, these communities also have among the lowest rates of physical activity, highest rates of obesity, hypertension and hypercholesterolemia [11]. As a result, policy level restructuring is crucial within these communities, and further interventions such as physical exercise platforms or healthy eating initiatives are more important to be developed [12]. However, a keynote here as noted in the literature is that many of the programs in these communities are youth centric, and in dementia, the most significant preventative time period is during middle age [12].

Therefore, it is recommended for policy makers to develop and implement new physical exercise, mental health support and social circles that promote dementia education and prevention practices for folks in middle age ethnic minorities [12]. It is these folks who respond best to treatment as well, particularly when the initiative is community led [12].

**Factoring socioeconomic resources into care planning:** As ethnic minorities are more likely to have fewer financial means of seeking specialist support, it poses a great problem for dementia practitioners [13]. For example, a lack of access to mental healthcare due to insufficient insurance coverage or funds results in a staunch under-utilization of mental health services by ethnic minorities [13]. As mental health concerns such as anxiety or depression are risk factors for dementia, when specialists seek to refer patients, it becomes a financial disaster [13]. Furthermore, other specialist forms of care such as geriatricians, cardiologists, neurologists and more specialties are also heavily time intensive [13]. They require an extensive amount of testing, potentially long travel times, wait times as well as appointments. Many ethnic minorities who work on the clock or are unable to take off time and have transportation barriers remain unable to fulfill these demands [13]. In light of this information, it is recommended for practitioners in the geriatric space to utilize virtual care to help reduce the cost of time that takes place for patients in ethnic minorities [13]. Furthermore, this can have the added effect of reducing the cost for healthcare providers as they will not have to worry of the overheads of running a physical facility [13]. Moreover, subsidizing specialist care for older adults at risk of dementia is also another policy that if implemented, can have significant cost reduction

effects for long term dementia care [13].

### Systemic Oppression and Social Hierarchies

**Social Suppression and Hierarchies:** While common medical evidence illustrates that cognitive decline initiates around the age of 25, ethnic minorities are at a relative disadvantage even in the uterus [14]. Social hierarchies, perpetuated by racist and capitalist beliefs lead ethnic minorities who are often immigrants and socioeconomically “lower” than their counterparts to feel inferior [14]. The result of these manifests even in pregnancy where the behaviours and feelings of parents can have epigenetic consequences that increase the size of the amygdala and cortisol levels [14]. This is highly apparent in African American populations born in the Southern states of America, where those whose families lived in the racist regions for longer were found to have a greater level of fear, stress and social inadequacy, further coupled with higher rates of mild cognitive decline in middle age, as well as inferior cognitive performance from childhood [14]. It’s of the utmost importance, therefore, for health policy makers to incorporate social data such as ethnicity, lived experiences, socioeconomic status and ancestral social conditions in geriatric care planning [14]. Embedding social network supports as a gateway to mitigating the impacts of these social hierarches is an illustratively powerful tool to slow down the cognitive aging process and empower ethnic minority groups to improve mental health conditions [14].

**Lack of access to mental healthcare:** There is a lack of access particularly towards mental healthcare [15]. This is partially because of cultural norms and stigmas associated with mental health, as well as an insufficient diagnostic criteria that fails to acknowledge the diverse symptomology of mental health in ethnic minorities [15]. In fact, 33% of practitioners report feelings of ambiguity when determining a diagnosis for an ethnic minority member with a mental health disorder [15]. As a result, ethnic minorities often experience unaddressed mental health disorders, which continue to compound and worsen [7]. These conditions are often exacerbated by poor socioeconomic conditions, familial concerns as well as social hierarches that trigger feelings of inferiority [7]. Subsequently, the presence of these conditions increases the rate of cognitive decline, and helps damage synaptic connections, increasing the likelihood and severity of dementia [7]. To alleviate these risk factors, policy makers are encouraged to conduct ethnicity based research on the prevalence and types of mental health diseases in each ethnic population to collect ethnicity specific data on mental health needs [7]. This information can be leveraged to develop accurate diagnostic criteria that can aid practitioners (particularly general practitioners) in identifying at risk patients [7]. As borne out by the experiences of mental health clinics in First Nations reserves in Alaska, enhancing research on ethnicity specific mental health needs, as well as evidence based treatment practices can aid practitioners in delivering timely mental healthcare to minimize dementia growth [7].

**Impacts of immigration:** Many of the mental health impacts faced by ethnic minorities are caused by immigration, effects of which can still be prevalent in first and second generations. In particular, the loss of language, traditions, cultural practices as well as norms due to assimilation into a new society is shown to break down emotional connections, having harmful impacts on the brain’s emotional domain.

This has the effect of resulting in higher rates of anxiety, depression, obsessive compulsive disorders, and other protein plaque based neurological conditions that can serve as precursors to the

development of dementia. It is important for community level practitioners to leverage social supports such as social support workers, community health centers as well as religious mediums to help at risk patients maintain emotional connections to their heritage [16]. On a broader scale, research encourages the development of new community health centres targeted towards middle aged and older adults that include ethnicity based programming to help preserve cognitive function [16].

### Conclusion

While all older adults are increasingly likely to suffer from dementia, ethnic minorities are not only more likely to get the disease, but also experience advanced and more debilitating versions of it. The range of healthcare in access, medical inequity and medical racism, coupled with deteriorating socioeconomic environments as well as social hierarches further worsens the conditions for ethnic minorities as they age. Policy reforms through more medical education, culturally sensitive care, more broadened data collection, as well as ethnicity and community led dementia prevention/treatment initiatives can help combat many risk factors faced by ethnic minorities.

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