Compounding Marginalization: Family-Sponsored Immigrant Older Adults' Access to Dementia Care in Canada

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Abstract

This paper was originally written for Dr. Sharon Koehn's Gerontology 410 course *Aging Immigrants*. The assignment asked students to write a critical research paper between 2,000 – 2,500 words exploring an area of interest related to the course topic. The paper uses APA 7th edition citation style.

Family-sponsored immigrant older adults are an extremely vulnerable group that experience multiple, compounding forms of marginalization in Canadian society. Stigma and shame, language and cultural incongruence, as well as economic policy related to both immigration and long-term care delivery impede family-sponsored immigrant older adult's access to dementia care. Additionally, flawed narratives framing dementia as a part of the normal ageing process, ill-informed criticisms of immigrant older adults failure to integrate into Canadian society, and the erroneous assumption that family-sponsored immigrant older adults do not contribute to the Canadian economy must be challenged. Overall, it is essential that we work to better understand the reasons why family-sponsored immigrant older adults struggle to access appropriate dementia care. Learning from the challenges faced by family-sponsored immigrant older adults can help us to reform our nation's elder care system to best support the social, emotional, mental, and physical health of Canada's aging and increasingly diverse population.

Introduction

Dementia is a terminal degenerative neurological disease with no cure. Therefore, treatments and therapies that help to manage symptoms are essential to preserve the health and quality of life of older adults living with dementia (Arvanitakis et al., 2019). However, access to this vital care is neither equitable nor guaranteed. As Canada's population continues to age, the prevalence of dementia is also expected to increase – placing additional strain on our nation's inadequate elder care system (Manuel et al., 2016). At the same time, the composition of the older adult population in Canada is shifting. Approximately 30% of people over the age of 65 years old in Canada are foreign-born and this proportion is only expected to increase in the coming years (Johnson et al., 2021). Among aging immigrants in Canada, family-sponsored immigrant older adults are an especially vulnerable – and often overlooked – group. Family-sponsored immigrant older adults with dementia do not receive appropriate dementia care in Canada because they may face stigma and shame related to dementia in their communities, language and cultural incongruence can impede their interactions with healthcare providers and care services, and they are negatively impacted by economic policy related to healthcare delivery for both older adults and immigrants.

Discussion

Stigma & Shame

Stigma and shame related to dementia can delay family-sponsored immigrant older adults' diagnosis and engagement with necessary care while contributing to social isolation and family dysfunction. This stigma and shame can act on multiple levels, for instance, family-sponsored immigrant older adults with dementia may experience internalized stigma and shame, leading them to attempt to conceal or normalize their symptoms (Chui & Gatz, 2005). The source of dementia-related stigma can often be traced back to different cultural understandings of dementia etiology and fear of judgement. In many cultures, dementia is believed to be a sign of weakness or a punishment for past wrongdoings or amorality (Mackenzie, 2016; Nielsen et al., 2020). As a result, family-sponsored immigrant older adults may change their behaviour in order to conceal dementia symptoms. For example, they may avoid healthcare interactions or stop participating in activities and socially withdraw to avoid detection (Husband, 2000). However, lack of medical care and social isolation can have serious negative impacts on the health and well-being of family-sponsored immigrant older adults with dementia.

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Stigma and shame related to dementia can also produce tension and dysfunction within a family-sponsored immigrant older adults' family leading to unmet care needs and strained relationships. In many immigrant communities, there is shame associated with placing family members with dementia in long-term care (LTC) facilities or accessing formal dementia care services (Bowes & Wilkinson, 2003). Additionally, since dementia is a highly stigmatized and taboo topic, caregivers may be hesitant to even enquire about available supports – and disagreements within families about accessing support are common (Nielsen et al., 2020). As a result, the burden of care often comes to rest solely on a family-sponsored immigrant older adults' family carers. Caregivers of immigrant older adults with dementia report deterioration of their relationship with the older adults they are caring for and significant distress (Bowes & Wilkinson, 2003). This can lead to elder abuse and neglect as well as a reduced capacity to care for other dependent family members like children (Nielsen et al., 2020). Overall, the damaging effect of stigma is not isolated to the older adult with dementia, it has the potential to lead to significant dysfunction and reduced health and well-being of all family members.

Outside of the family unit, significant stigma surrounding dementia in some immigrant communities can result in social isolation of family-sponsored immigrant older adults with dementia. Beliefs that someone with dementia is crazy or that dementia may be contagious or hereditary can cause alienation of the individual and their family from the community, at a time when they are most in need of support (Nielsen et al., 2020). Additionally, in an effort to avoid stigma and familial shame, family-sponsored immigrant older adults with dementia may be confined to their homes by caregivers and intentionally socially isolated due to fear of public displays of abnormal behaviour that could bring embarrassment to the family (Mackenzie, 2016). While social isolation carries many negative health effects, it is especially harmful for individuals with dementia. With recent brain-imaging research suggesting that social isolation is actually associated with faster dementia progression and deterioration of cognitive function (Muntsant & Giménez-Llort, 2020).

In response to the substantial stigma and shame associated with dementia and LTC in some immigrant communities, it may be argued that is better to frame dementia as a part of normal aging and care for elders in their home and community instead of labelling them with a medical diagnosis and "abandoning" them in a LTC facility (Mackenzie, 2016). While aging in place has been proven to benefit some people living with dementia, it requires significant and increasing support and is not feasible in all situations – especially as dementia progresses to later stages (Thoma-

Lürken et al., 2018). Considering dementia to be a normal part of aging is a maladaptive coping mechanism that can result in significant harm. Normalizing dementia often results in isolation of family-sponsored immigrant older adults, unmet physical and mental health needs, and families trying to cope until a crisis point where caregivers are exhausted and the situation is no longer safe (Nielsen et al., 2020). Instead, dementia diagnoses need to be acknowledged and properly understood so an individual and their family can access support.

Language & Cultural Incongruence

Language and cultural incongruence in healthcare settings, community programs, and the LTC system result in marginalization and unmet needs of family-sponsored immigrant older adults. Language and cultural incongruence between family-sponsored immigrant older adults with dementia and healthcare providers can result in problems with diagnosis, and management of dementia and overall health. For example, different cultural understandings of dementia etiology and a lack of common medical vocabulary between family-sponsored immigrant older adults and physicians can lead to delayed dementia diagnosis and problems assessing progression (Gove et al., 2021). Additionally, dementia diagnostic tests are usually delivered in English with questions and scenarios derived from a Western paradigm (Sagbakken et al., 2018). The issue of incongruence persists and is intensified in the context of LTC facilities. Language incongruity is associated with inadequate care provision and reduced health and quality of life for LTC residents (Martin et al., 2019). For example, LTC residents with dementia who do not speak English have significantly higher levels of agitation due to inability to express needs and discomfort to staff (Cooper et al., 2018). Overall, language and cultural incongruence can lead to intensifying health disparities for family-sponsored immigrant older adults across the course of dementia.

Language and cultural incongruence can also prevent family-sponsored immigrant older adults with dementia and their carers from engaging with community-based dementia support programs. While immigrant older adults have been found to have considerable unmet care needs in the community, they are also less likely than Canadian-born older adults to engage with homecare services. This is believed to be a result of language barriers, lack of awareness of available services, and differing cultural values related to care provision for elders (Um & Lightman, 2016). For example, family caregivers of immigrant older adults with dementia may not identify with the term "caregiver" so can miss opportunities to access education and respite services intended for them (Moriarty et al., 2011). Additionally, family-

sponsored immigrant older adults who do not speak English may not feel comfortable or be able to fully participate and benefit from community programs that are only offered in English. Overall, language and cultural incongruence can impede family-sponsored immigrant older adults with dementia and their family carers from being aware of, accessing, and actually being able to participate in community-based dementia care and social support – placing the burden of care solely on families.

Further, the majority of LTC facilities in Canada are designed around Western cultural ideals which are often incongruent with the cultural values of family-sponsored immigrant older adults living with dementia and this results in marginalization. Family-sponsored immigrant older adults with dementia do not have access to familiar cultural foods in most LTC facilities and may stop eating, putting their health and lives at risk (Bowden, 2021). Additionally, recreational activities and entertainment provided in LTC facilities are often Eurocentric and only offered in English (Badger & Koehn, n.d.). Also, the schedules and physical spaces in LTC facilities are designed for efficiency and are influenced by Western cultural ideals – so could contribute to discomfort experienced by some family-sponsored immigrant older adults with dementia. Further, family-sponsored immigrant older adults may not be provided with opportunities and support to engage in celebrations and rituals that provide them with comfort and identity (Cadieux et al., 2013). Overall, this incongruence can contribute to social isolation and produce additional – and arguably preventable – discomfort for individuals who are already struggling with anxiety and disorientation as a result of dementia.

A common criticism of calls to accommodate the needs of immigrant older adults in healthcare settings like LTC facilities is the notion that if people decide to immigrate to Canada they should be prepared to adapt to and integrate with Canadian society, learn English, and adopt Canadian cultural practices (Zhang et al., 2021). Therefore, immigrant older adults should not receive special treatment for failing to assimilate. However, this argument lacks perspective and compassion. Firstly, deteriorating cognitive function associated with dementia can cause people to revert back to their first-language and earlier memories, so even if family-sponsored immigrant older adults did take steps to integrate with Canadian society those skills and knowledge could be lost (Bowden, 2021; Martin et al., 2019). Secondly, an LTC system that is able to accommodate the needs of family-sponsored immigrants would be a system that is more aligned with person-centered care, which is a model that our LTC system should strive for to better meet the needs of all residents (Fazio et al., 2018).

Economic Policy

Family-sponsored immigrant older adults are disadvantaged by the compounding effects of economic policies related to provision of healthcare to immigrants and provision of LTC for people living with dementia. Family-sponsored immigrants are financially dependent on their sponsors for 20 years (Government of Canada, 2019). This means that family-sponsored immigrant older adults with dementia do not qualify for publicly-funded healthcare, homecare, or LTC within 20 years of their arrival in Canada (Meadus, 2009). Instead, the cost of this care falls solely on their sponsors who must pay out-of-pocket to access healthcare and dementia related services. These healthcare-related costs often also include transportation and translation expenses, or family members' lost wages if they need to accompany an older adult with dementia to their medical appointments (Ahmed et al., 2016). As a result of this policy, family-sponsored immigrant older adults with dementia and their families may be hesitant or unable to engage with healthcare and LTC services, even if they are desperately needed, because of the significant financial burden this care entails.

Concurrently, Canada's LTC system is not designed to meet the social and holistic health needs of people living with dementia. Understaffing means nurses and care aides in LTC facilities do not have enough time to socialize and build relationships with residents outside of ensuring basic standards of care are met (Canadian Health Coalition, 2018). Also, despite living with many other people and sometimes even having roommates, residents of LTC facilities experience high levels of social isolation (Boamah et al., 2021). The institutional model of LTC facilities also contributes to decreased autonomy, loss of identity and purpose, and an overall reduced quality of life for residents with dementia (Cadieux et al., 2013). Additionally, excessive wait times for admission to LTC facilities lead to "first-bed-available" policies where people living with dementia are pressured to accept the first available spot, even if it is not a good fit for their specific needs (Canadian Health Coalition, 2018). Overall, LTC facilities can provide a higher and more intensive level of dementia care than is available in community – but this often comes at the expense of individuals' social, emotional, and mental health and quality of life.

Culturally and linguistically specific LTC facilities are an increasingly popular solution to improve care for immigrant older adults with complex health issues like dementia; however, these facilities are scarce and challenging to gain admission to. A recent Canadian cohort study found that both being a new immigrant and applying to a culturally specific LTC facility are associated with

significantly increased wait times for admission (Qureshi et al., 2021). For example, Chinese language and culture LTC facilities in Ontario have a median 2-4 year wait time (Bowden, 2021). In addition to temporal barriers associated with accessing culturally specific LTC facilities, there are also geographic barriers. Culturally and linguistically specific LTC facilities are often clustered in metropolitan regions of Canada where there is a large enough immigrant community to economically justify and support them. Therefore, immigrant older adults with dementia living in rural areas are less likely to have access to these options (Canadian Health Coalition, 2018). While culturally and linguistically specific LTC facilities can address issues of language and cultural incongruence and may improve residents' health and quality of life, they are not barrier-free and are unfortunately not an option for all family-sponsored immigrant older adults with dementia.

There is a pervasive belief that family-sponsored immigrant older adults who come to Canada should be prepared to pay out-of-pocket for healthcare services since they have not been working in Canada and contributing to the economy. Therefore, they should not expect to be able to take advantage of free healthcare (Schuster, 2019). This attitude is reflected in Canada's current immigration policy and is often defended with assertions of "fairness." However, the claim that family-sponsored immigrant older adults do not contribute to the economy is flawed. Family-sponsored immigrant older adults actually make significant contributions to the economy through informal childcare, domestic work, and community volunteer service (Zou & Fang, 2017). This unrecognized work is arguably essential to allow their sponsoring family members to fully participate in the Canadian economy. Instead of being "fair," current Canadian immigration policies do not acknowledge immigrant older adults' contributions and put their health and safety at risk – undermining Canada's promise of welcoming immigrants.

Conclusion

Lack of access to appropriate dementia care and social support for family-sponsored immigrant older adults with dementia in Canada is a complex problem. Family-sponsored immigrant older adults with dementia face compounding marginalization, on multiple levels, from stigma to language and cultural incongruence to discriminatory economic policy. There is not a single cause, so there will not be a single solution to improve family-sponsored immigrant older adults' access to dementia care and social support. However, we can learn from the significant challenges this group faces. When it comes to reforming Canada's elder

care system, a daunting process that is long overdue, we must consider the needs of family-sponsored immigrant older adults. We must shift towards socialization instead of institutionalization, person-centered care, building meaningful relationships, and preserving and honouring individuals' identity because a system that is designed to best support the most vulnerable, will benefit everyone.

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