

# Examining the barriers of influenza vaccine hesitancy in persons with dementia: a literature review

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# Abstract

**Background/aims** Despite the proven benefits of vaccine prevention and the continuous development of this important public health measure, vaccine hesitancy is among the top ten threats to global health according to the World Health Organization in 2019. Those who contract the influenza virus will typically develop a mild illness. However, for populations at a higher risk, including those diagnosed with dementia, influenza is proven to be more detrimental. Persons with dementia (PWD) face a serious threat to influenza on an annual basis, and vaccine hesitancy may further potentiate this risk. The purpose of this paper is to explore and understand the barriers PWD face in receiving the influenza vaccine.

**Methods** A literature review was conducted to examine the barriers that prevent PWD from seeking out the annual influenza vaccine. A thematic analysis provided an understanding of the overarching relationships found among the influences between the identified themes.

**Results** Three main influences were identified: (1) intra-personal, (2) inter-personal, and (3) extra-personal, with each influence containing several subsequent sub-themes.

**Discussion/conclusion** The literature review found that there is a lack of research involving this high-risk population and the barriers they face, especially within the extra-personal influences. Further research is required to understand how each barrier relates and connects with each other. Understanding this connection will aid public health organizations in decreasing the threat of vaccine hesitancy, thus decreasing the incidents of preventable deaths.

Keywords Influenza vaccine · Vaccine uptake · Vaccine hesitancy · Dementia · Barriers · Public health

# Introduction

The Center for Disease Control and Prevention (CDC) describes that most individuals affected by influenza will have mild illness [1]. However, for a population that is considered high risk, influenza prevalence is higher, and complications are more detrimental. Cognitive impairment as result of dementia may present major barriers for the individual to fight against infection, thus resulting in an increased likelihood to develop serious complications [2]. In fact, dementia is an independent risk factor for influenza complications and can be especially dangerous as early symptoms of influenza are difficult to recognize in persons with dementia (PWD) [3]. As a result, PWD are hospitalized more frequently and

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The best influenza prevention strategy is receiving the annual vaccine. In Canada, during the 2017/2018 influenza season, the overall adult vaccine coverage was 38.3%, while coverage for the high-risk population of seniors over 65 years of age was 70.7%, which is below the national coverage goal of 80% [5]. Even more specifically, a Canadian study about influenza vaccine uptake showed that approximately 55% of the sample population living with dementia had received the flu vaccine [6]. It is an alarming result as close to half of the participating PWD population had not received the influenza vaccine, despite this population having a greater risk of contracting influenza and its deadly complications [6].

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A systematic review of influenza vaccine efficacy for older persons concluded that the influenza vaccine reduces the risk for pneumonia, hospitalization, and death in older persons if the strain of the vaccine is the same or similar to the influenza epidemic strain [7]. The review also discussed that all persons older than 65 should have the influenza vaccine as a part of their care plan, and this requires involvement from informal caregivers, physicians, and public health organizations. Despite these factors posing as motivations for PWD to receive influenza vaccine, uptake among this population is inferior.

# **Objectives**

The objection or rejection of vaccines, despite their availability, is known as vaccine hesitancy [8]. It is evident that PWD have an increased risk for influenza complications. This, coupled with the lack of vaccine uptake specifically in this population, makes the seemingly harmless annual influenza season a deadly threat to PWD. To combat this public health issue of vaccine hesitancy, it is essential to identify and understand the various barriers that this population faces when it comes to accessing the influenza vaccine. The purpose of this literature review is to explore the barriers PWD face in receiving the influenza vaccine.

# Methods

A literature review was conducted to examine the barriers PWD face in receiving the influenza vaccination. This included barriers that may be a result of care from informal caregivers (ICs) and health care providers (HCPs). The three concepts used for the initial search were (1) vaccines, (2) dementia, and (3) barriers. Within each concept, there were different keywords used. The vaccine concept used vaccine\*, immuniz\*, or immunis\*; the dementia concept used Alzheimer\* or dementia; and the barriers concept used access\*, barrier\*, or convenien\*. A variety of databases were accessed for the search, primarily PubMed, CINAHL, the Ontario Tech University database, and Google Scholar. Each database search consisted of using the same keywords and pairing either two or three of the concepts together. On CINAHL, for example, pairing all three concepts yielded only 22 results, so a broader search of pairing two concepts at the same time was used. Titles and abstracts were first screened for relevance to the research question, and only articles published in English were used. Reference pages from peer-reviewed articles were scanned for relevant resources. Overall, 24 resources were used to conduct a thematic analysis (See Table 1).

## Results

Altogether, we classified the themes among three major influences: (1) intra-personal, (2) inter-personal, and (3) extra-personal. A summary and relationship between these three themes and their sub-themes is presented in Fig. 1. Table 1 presents the details of the contributions from each study, while Table 2 presents a summary chart of each sub-theme.

Intra-personal influences include themes that directly relate to the PWD, including dementia-related symptoms, personal factors, and culture and race. Dementia-related symptoms relate to the cognitive and motor decline that PWD experience. As a result of this decline, PWD may have difficulty accessing, understanding, and adhering to the influenza vaccine [9–13]. Personal factors of PWD, specifically marital/relationship status, was a common theme found among the literature [14, 15]. Culture and ethnicity play a role in this public health crisis as cultural traditions, beliefs, and superstitions may influence decisions made by PWD, HCPs, and ICs [16–19]. Some sources discussed how past public health controversies involving minorities continue to create distrust, thus resulting in low influenza vaccine uptake in these specific minority populations [17, 18].

Inter-personal influences extend beyond the PWD, instead involving those who directly aid in their care, primarily IC and HCP. Literature suggests that caregiver distress may influence the decision to seek out a vaccination for the PWD in their care [20, 21]. In a similar way, the financial burden that some ICs experience can influence the accessibility aspect of vaccines [4]. HCP impact refers to all the factors a HCP may possess that can alter the likelihood of a PWD receiving the vaccine. Personal factors for HCPs refer to gender, lifestyle, and immunization status [22, 23]. Additionally, the level of trust between HCP, IC, and PWD was found to be a contributing factor. Finally, the beliefs of complementary and alternative medicine (CAM) providers play an important role in accessing vaccination as they often offer vaccine advice to patients and families [24].

The final major influence is extra-personal, which involves everything beyond those in direct care of the PWD. A common environmental influence was accommodation and accessibility of the vaccine based on living situations [25, 26]. Our research also indicated that media influence was one of the driving factors in vaccine hesitancy [27–31]. With online and social media usage being at an all-time high, finding misinformation and anti-vaccination movements can be easy, thus negatively changing the perception of influenza vaccinations.

References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[22]	Is performance of influenza vac- cination in the elderly related to treating physician's self-immu- nization and other physician characteristics?	Abramson and Levi 2008	To examine the association between physician characteris- tics including self-immunization status and patient immunization status	Data extraction and Questionnaire	Patients were more likely to get vaccinations if the physician was also vaccinated There were physician characteris- tics that impacted the likeliness of a patient being immunized: (1) If a physician was a female, (2) If a physician was trained in West Europe or America, (3) If a physician exercised regularly, (4) If physicians understood that the vaccine can't cause influenza
[23]	Seasonal influenza vaccination among homebound elderly receiving home-based primary care in New York City	Banach et al. 2012	To assess the factors associ- ated with flu shot refusal in community-dwelling elderly that were receiving care urban home- based primary care (HBPC)	Cross sectional	-For the participants that were eligi- ble for the flu shot, 84% accepted, and 16% denied -Flu shot denial was positively associated with female gender, black race, and living indepen- dently. It was negatively associ- ated with dementia
[4]	Immunology beliefs as a factors in vaccine opposition among complementary and alternative medical providers	Bean and Catania 2018	To examine the beliefs that complementary and alternative medical providers have about vaccinations to derive how this may impact parents deciding about vaccinations for their children	Semi-structured interview	-The beliefs discovered about CAM providers attitudes towards vaccines included "natural is best", "innate intelligence", and "the fragile immune system" -CAM providers that also accepted mainstream medicine were more likely to be vaccine supporters. These providers associated with the thermes "vaccines prevent ill-ness" and "herd immunity" -CAM providers do provide advice to their patients but often provide advice to their patients but often provide the parent should do for their children rather than what the CAM providers that were not vaccine supporters had come to their standpoints through post-

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Table 1 (co.	ntinued)				
References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[15]	Factors influencing influenza vaccination uptake in an elderly, community-based sample	Burns et al. 2005	To examine the factors involved in flu shot uptake in the elderly community-dwelling population	Cross sectional interview study	-The most common reasons given for vaccine refusal were fear and vaccine side effects Most participants that received the flu shot mentioned it was because of a reminder from a health care provider Participants that had a health care provider that explained the importance and side effects of the flu shot Participants that lived with others, had higher occupational status, and had a car or were able to walk to a doctor's office were the participants with higher rates of flu shot uptake
[4]	Dementia in Canada: Summary	Canadian Institute for Health Information 2019	To present a summary of informa- tion about dementia in Canada	Report	The number of PWD continues to increase in Canada, and this can be related to the overall increase in an aging population. The number of seniors in Canada is predicted to increase by 68% over the next 20 years Most seniors with dementia live in the community PWD over 65 years old are hospitalized more frequently and for longer durations. This makes them more susceptible to hospital acquired harm including UTIs, pneumonia, and falls. They also wait longer in emergency depart- ments Approximately 1 in 4 Canadians over 85 years old have been diag- nosed with dementia canadians with young-onset dementia are more likely to experience stigma related to the disease

Table 1 (cc	intinued)				
References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[14]	The effect of patient characteristic upon uptake of the influenza vaccination: A study comparing community-based older adults in two healthcare systems	Crawford et al. 2011	To examine the relationship between flu shot uptake and community-dwelling patient characteristics for two differ- ently structured healthcare systems	Interviews	-Uptake rates were higher than set community targets -Flu shot uptake is higher in older age, widowhood, greater func- tional impairment, and for those who have greater use of services such as chiropody, meals-on- wheels, social work, and occupa- tional therapy -Increased exposure to health care services may positively impact flu shot uptake rates
[29]	The overlooked dangers of anti- vaccination groups social media presence	Evrony and Caplan 2017	To draw attention to and provide information about well-devel- oped and highly visible antivac- cination websites that provide the public with information that is not scientifically supported	Research Article	-Outbreaks are becoming increas- ingly common due to lowered vaccination rates, and this is partially due to antivaccination online resources that have strong visibility in the online community -A Voice for Choice in an antivax website that claims to provide evidence-informed information for users to then make evidence- informed decisions, but it is actually an anti-vax website that does not support their claims with scientific research -A Voice for Choice provides infor- mation about vaccine ingredients and harms that are not backed with scientific rigour. This web- site promotes debunked myths and encourages individuals to hoor about vaccine advance effects

Table 1 (cc	ntinued)				
References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[2] [2]	Dementia diagnosis and influenza vaccination in French nursing home residents	Gallini et al. 2015	To investigate the impact demen- tia status has on flu shot uptake in nursing home residents	Cross-sectional study	-The nursing home that was included in this study exceeded the WHO goals for flu shot rates for seniors (>75%) and 89.9% of their residents were vaccinated Residents with dementia were more likely to have received a flu shot than those without dementia, and this is consistent with UK and US studies -Authors discussed the reasons for these findings as the recognition by nursing staff that dementia is an independent risk factor for influenza complications -Another reason for the increased rate in flu shot uptake in PWD was that PWD and associated family members were less likely to have been asked permission to get the vaccine. As a result, they were less likely to have had the
[71]	Under the shadow of Tuskegee	Gamble 1997	To provide social context to the Tuskegee Syphilis Study	Research paper	option to refuse -The Tuskegee Syphilis Study continues to impact African American's trust in western medi- cine practices -The Tuskegee Syphilis Study led to discussion about informed consent, communication of diag- nosis, and accurate reporting of test results -African American men were not told about the length of the study (told 6 months but actually lasted 40 years) or that they would not actually be treated after funding was lost

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References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[20]	Caregiver Distress Report—The Reality of Caring	Health Quality Ontario 2016	To report findings on caregiver distress associated with long- stay home care residents	Report	-In 2013/14, among the 97% of home-care residents that received care from informal caregivers (ICs), 33% of the ICs reported caregiver distress. This number doubled from the 2009/10 data There was more distress seen for ICs looking after residents with higher levels cognitive impair- ment, functional disablement, and frailty The amount Canada relies on ICs is increasing with the aging population
[26]	Rural Disparities in Alzheimer's Disease-Related Community Pharmacy Care in the United States	Henkel and Marvanova 2017	To examine the relationship between area population density and community pharmacy-based Alzheimer's Disease-related services including pharmacist's medication knowledge, immu- nizations, in-stock cognitive enhancers	Standardized interviews	-Pharmacists in more rural areas were 50% less likely to offer immunizations -Rural pharmacists were less likely to have cognitive enhancing drugs in stock and were also less likely to name as many adverse effects of medications compared to phar- macists in less rural areas
[13]	Evidence of bias in estimated of influenza vaccine effectiveness in seniors	Jackson et al. 2005	To assess the risk of death from any cause or hospitalization for pneumonia or influenza before, during, and after flu season	Observational	-Seniors that receive the flu shot are at lower risk of hospitalization and death during flu season -The greatest reductions in risk of death and pneumonia hospi- talization were in the time period before flu season when there is no real vaccine effect -Persons with chronic conditions had higher proportions of vac- cinated compared to unvaccinated persons. The only exception was dementia

References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
6	The assessment of language and communication in dementia: A synthesis of evidence	Krein et al. 2019	To review tools used for the lan- guage and communication for persons with dementia	Scoping review	-Language and communication impairment impact most of the population of persons with dementia -Three tools were identified as valid and were reviewed in depth: Ari- zona Battery of Communication Disorders in Dementia, Sydney Language Battery, and Adden- brooke's Cognitive examination
[61]	Do superstitions beliefs affect influenza vaccine uptake through shaping health beliefs?	Lu et al. 2019	To examine the relationship between superstitious beliefs and influenza vaccine uptake	Cross sectional survey	-Of the participants in Singapore, 60% had never received the flu shot -Superstitious beliefs showed mixed results for flu shot uptake -Superstitious beliefs predicted higher perceived barriers and lower perceived barriers and lower perceived benefits of the flu shot. Both of these factors predicted a lower intent to get the flu shot the next year. However, superstitious beliefs also pre- dicted higher perceived severity and susceptibility of the flu lead- ing to a higher intent to receive the flu shot
[18]	Why Blacks do not take part in HIV vaccine trials	Moutsiakis and Chin 2007	To examine why HIV vaccine tri- als have a low percent of Blacks	Interviews	-There were three reasons for HIV vaccine trial hesitancy: (1) misin-formation. (2) mistrust and fear, and (3) stigma -If a participant was homosexual or had a close friend with HIV, this increased the likelihood of par- ticipating in an HIV vaccine trial
[01]	Pneumonia and influenza hos- pitalizations in elderly people with dementia	Naumova et al. 2009	To examine the relationship between healthcare accessibility and pneumonia and influenza by looking at demographic and geographic patterns of PWD hospitalization in comparison to the US population	Observational study	-Rural and poorer areas had higher rates of pneumonia and influenza -PWD had a lower number of influ- enza diagnoses, shorter hospital stays, and 1.5 times as high a death rate when compared to the national average

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Table 1 (continued)

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References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[12]	Behavioral, psychological and physical symptoms in group homes for older adults with dementia	Onishi et al. 2006	To compare symptoms of persons with dementia living in group homes vs. nursing homes vs. long-term care homes	Questionnaires	-The most common symptoms in group homes were as follows: requests/desire to go home, UTIs, general complaints -Level of coping was worst in LTC homes -Anxiety, depression, and disorien- tation were frequently found in all three settings
[25]		Shah et al. 2011	To examine the relationship between dementia diagnosis and flu shot uptake in commu- nity and care home residents in England and Wales	Retrospective Analysis	-There is less uptake in residents that live at home compared to those living in home care facili- ties -The difference in uptake with home care vs. care home residents shows organizational barriers may be a factor with it being harder for home care residents to access all services at home -consent does not seem to be a fac- tor in accessibility of flu shot with care home residents
[27]	Why do parents decide against immunization? The effect of health beliefs and health profes- sionals	Smailbegovic et al. 2003	To examine vaccine and vaccine- preventable infection knowl- edge, attitudes, and concerns of parents whose children have not completed the recommended immunizations	Observational, case-control study (Questionnaire & Interviews)	-MMR and meningitis C were most frequently omitted vaccines with primary concern being vaccine safety -34% of parents expressed concern about the side effects of vaccines being more dangerous than the vaccine-preventable infection -Of the respondents that were inter- viewed, it was reported that the information provided by health professionals about vaccines is poor

References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
Ē	A systematic review of medica- tion non-adherence in persons with dementia or cognitive impairment	Smith et al. 2017	To compile research that exam- ined medication adherence in PWD and cognitive impairment	Systematic Review	-Individuals with cognitive impairment have adherence rates of 10.7–38% which is lower compared to individuals without cognitive impairment -The definition of medication adherence is broadly defined, and multiple factors were considered impactful in medication adher- ence
[16]	Cultural Perspectives on Vac- cination	The College of Physicians of Philadelphia 2018	To provide information about cul- tural perspectives on vaccines	Website article	-Cultural perspectives on vaccines often stem from religious stand- points, suspicion and mistrust, and rights surrounding vaccines -Religious standpoints can be based on ethical dilemmas with the products used in vaccines and/ or what should be put in to the sacred human body along with the belief that healing should come from God or natural means -Suspicion and mistrust of vaccines may stem from "Western plot" theories or the history of inequal- ity in healthcare and research

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Table 1 (co	ntinued)				
References	Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[]]	Caregiver psychological distress as a barrier to influenza vaccina- tion among community-dwelling elderly with dementia	Thorpe et al. 2006	To examine if informal caregiver distress decreased the likeliness of PWD receiving a flu-shot. The secondary aim was to examine how psychological distress affected other medical need variables or vaccines	Data retrieved from a National Longitudinal Survey and then multivariate variables were observed	-Caregiver distress was associ- ated with decreased likeliness of flu-shot -Out of 1406 care-recipients, 503 received flu shot -Du of 1406 care-recipients, 503 received flu shot -29.7% of caregivers were dis- tressed -Likelihood of having distressed caregiver was higher in unvacci- nated recipients were more likely to exhibit ADL and IADL limitations, higher level dementia- related behavioural problems -Unvaccinated recipients were more likely to have private insurance or Medicaid, live farther away from medical facilities, and have caregivers with lower perceived financial adequacy -Predicted probability of vaccina- tion for non-distress was 37.7%, distress was 29.4% Greater care-recipient behavioural problems and greater caregiver limitations from comorbidities decreased likelihood of vaccina- tion

Table 1 (c	sontinued)				
References	s Title	Author and date	Study purpose	Study or resource design	Summary of key findings
[31]	Content and Design Attributes of	Wolfe et al. 2002	To identify and delineate the	Metasearch review	-There were common content
	Antivaccination Web sites		claims and concerns on antivac-		claims on antivaccination
			cination websites		websites: (1) vaccines cause
					idiopathic illness; (2) vaccines
					destroy immunity; (3) vaccine
					adverse reactions are under-
					reported; and (4) profit drives
					vaccine policies
					-Antivaccination websites often
					included resources on how to get
					further anti-vax information as

cines. These websites also regularly used emotive appeals about

children that have been harmed

killed by vaccines

well as how to legally avoid vac-

## Discussion

This literature review revealed the over-arching three types of influences that affect persons with dementia's access to vaccination of influenza: (1) intra-personal influence (dementia-related symptoms; personal factors; culture and ethnicity); (2) inter-personal influence (informal caregiver distress; healthcare professional impact; and (3) extra-personal influence (environmental factors; media impact). The review of the existing evidence highlighted the gaps in the literature that examined the barriers of access to influenza vaccine and factors related to vaccine hesitancy among persons with dementia.

## Intra-personal influence

## **Dementia-related symptoms**

Given that language impairment is among the first cognitive functions to be affected by the onset of dementia, the lack of communication is widespread among PWD [9]. As a result, PWD are unable to access the medical support they require in a timely manner, putting them at an increased risk of hospitalization, complications, and death. One study illustrated that PWD who are hospitalized present more severe conditions and worse outcomes [10]. Another common cognitive deficit experienced by PWD is a decline in memory. Memory loss and difficulty learning contributes to an increase of non-adherence. Researchers found that participants who scored higher on memory tests had greater medication adherence [11] which has implications to PWD's compliance of receiving annual vaccination. PWD also experience motor decline and have limited access to specialized care and testing practices. Due to motor decline, including bradykinesia and walking disturbances [12], transporting PWD may present as a barrier to access influenza vaccination. Additionally, PWD are more likely to have poor oral hygiene and difficulty swallowing. One study found that these symptoms can increase the risk of developing influenza and consequently the difficulty of treating it [10]. These two factors of cognitive and motor decline together make it extremely difficult for a PWD to seek medical help and access influenza vaccination. Another study conducted in the US explored the percentage of vaccine uptake among seniors with a variety of diagnosed chronic conditions, including heart disease, diabetes, cancer, and dementia [13]. Interestingly, every population with the exception of PWD had a greater proportion of vaccinated than unvaccinated people [13]. As a whole, it is evident that the symptoms of a dementia diagnosis illustrate poor outcomes when it comes to influenza and its vaccine uptake.



Fig. 1 Summary and relationship between the three major influences identified, along with their sub-themes

 Table 2
 Summary of findings, including factors of each theme, as well as the negative outcomes that prevent PWD from actively seeking out an influenza vaccine

Summary of findings		
Themes	Factors	Outcomes
Dementia-related symptoms	Cognitive and motor decline Medical complications	Decreased accessibility Medication adherence
Personal factors	Relationship status	Decreased accessibility Potential misinformation Lack of motivation
Culture and ethnicity	Superstitions Cultural beliefs Past cultural or ethnic influences	Medication adherence Lack of trust in vaccine and healthcare providers
Healthcare professional (HCP) impact	Personal factors Relationship status with PWD and/or IC Alternative medicine beliefs	Lack of trust in HCP Lack of positive influence Misinformation
Informal caregiver (IC) distress	Stress Low financial income	Lack of motivation Decreased accessibility Misinformation
Environmental factors	Living accommodation	Decreased accessibility to healthcare services Potential misinformation
Media impact	Anti-vaccination sites Social media	Misinformation Lack of trust in vaccine and healthcare providers

Relationship status, specifically widowhood, was another factor found to have an influence on the likelihood of an older adult seeking out the influenza vaccination. Researchers theorized that due to the increased vulnerability of widows, this population may have an increased likelihood of vaccination [14]. On the other hand, it may be possible that due to the increased caregiving and monitoring of PWD, family caregivers often have the assumptions that PWD may not necessarily require to receive the influenza vaccine. Another study found that participants who lived with others were more likely to get the vaccine than those who were living alone [15]. A limitation of this study was that the participants included were recruited randomly from the general populations, which had different characteristics than persons with dementia. Due to these mixed results, it is essential to conduct further research to truly understand how relationship status may affect influenza vaccine uptake. Regardless, it is evident from the existing literature that personal factors play a role in influencing PWD's access to influenza vaccination.

#### **Culture and ethnicity**

Cultural beliefs may impact vaccine uptake. These cultural beliefs are typically based around the usage of human tissue cells in vaccines, with the belief that the body is sacred and should not receive chemicals, blood, or tissues from animals; as well as the idea that God or natural means will heal the body [16]. Further, the distrust of modern medicine can stem from historical and social inequality and mistrust. This is displayed by the African Americans' distrust in medical treatments, including vaccination, after being denied appropriate treatment during the Tuskegee Syphilis study [17]. Another study also indicated that Black populations were more likely to refuse the vaccine, expressing concerns about vaccine safety and efficacy [18].

Lu et al. [19] studied how superstitious beliefs may specifically impact influenza vaccine uptake in Singapore. It was found that superstitions do have an impact on flu vaccine uptake. However, the impacts were mixed. Superstitious beliefs led to a predicted lower uptake because of higher perceived barriers and lower perceived benefits of vaccines. In contrast, some superstitious beliefs led to a higher uptake because of higher perceived susceptibility and severity of influenza. The impact of intra-personal factors has implications about persons with dementia's vaccine uptake, and future health education about vaccination should take into considerations about factors related to personal beliefs, cultural background, and ethnicity.

#### Inter-personal influence

#### Informal caregiver distress

Health Quality Ontario reports an ongoing increase in caregiver distress [20], and this may impact vaccine uptake. Caregiver distress refers to the stress and exhaustion some ICs feel due to the responsibility of caring for a PWD. Thorpe et al. examined caregiver psychological distress as a barrier to influenza vaccination uptake in communitydwelling PWD [21]. From a sample of 1406 PWD who were male veterans, and their corresponding female IC, it was found that caregiver distress was associated with decreased likeliness of the PWD receiving the influenza vaccine. The likelihood of having a distressed caregiver was higher in unvaccinated care recipients. Unvaccinated recipients were more likely to exhibit limitations in their activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and had higher level dementia-related behavioural problems. Additionally, unvaccinated recipients were more likely to have private insurance or use Medicaid, suggesting that financial barrier play an important role in vaccine uptake. Unvaccinated recipients were more likely to have caregivers with lower perceived financial adequacy and who lived farther away from medical facilities [4].

#### Healthcare professional impact

Healthcare providers, especially family physicians, are typically the first link or connection to the healthcare system. Several different factors were found to influence influenza vaccine uptake, including HCP's personal characteristics and the relationship between the HCP and their patients. A study conducted in Israel found that patients were more likely to be immunized if their physician was also immunized [22]. Female doctors were more likely to be vaccinated than male doctors, which coincides with the finding that female doctors give stronger recommendations for vaccination than their male counterparts. In addition to physician's gender, their background and lifestyle also contributed to the findings [22]. Physicians who were educated in Western Europe or America, as well as physicians who exercised were more likely to be vaccinated. Furthermore, physicians who had greater knowledge about the complex risk factors associated with influenza, such as the high risk of lower respiratory infections and mortality rates among PWD, were more likely to make stronger recommendations to PWD for getting the vaccine, while being more reluctant to accept refusal [23].

Bean and Catania [24] examined CAM providers' beliefs regarding vaccinations since these providers may play an influential role in vaccine uptake for their clients. For the CAM providers that endorsed vaccinations, their reasoning was likely to fall within two themes: "vaccines prevent illness" and "herd immunity". In contrast, for the CAM providers that did not endorse vaccines, their reasoning was likely to fall within three themes: "natural is best", "innate intelligence", and "the fragile immune system". The nonendorsers focus was on providing health for the person rather than health for the population, and this emphasis has implications about the potential vaccine uptake among persons with dementia, who relied heavily on the advice from healthcare professionals to access vaccinations.

## **Extra-personal influence**

#### **Environmental factors**

One of the more common environmental factors contributing to vaccine uptake among PWD was living accommodation. PWD were less likely than their counterparts to get the vaccine if they lived alone in their community. Researchers suggested that this result can be attributed to poor access of preventative care by PWD living in their own homes [25]. For those living in rural neighbourhoods, PWD may face even greater difficulty in accessing care and vaccination. Henkel and Marvanova [26] found that pharmacies in more rural areas are about 50% less likely to offer immunizations compared to less rural areas. Furthermore, Shah et al. [25] found that dementia does have an impact on influenza vaccine uptake in PWD who live in their homes. There is less vaccine uptake among PWD who live at home compared to those living in congregate and institutionalized settings. On the other hand, PWD were more likely to get the vaccine while living in a nursing or residential home compared to those without dementia [25]. Research found that 89.6% of PWD living in French nursing homes had the influenza vaccine administered, which is higher than the recommendation made by the WHO for that year ( $\geq 75\%$  of older persons) [3]. One of the reasons the authors provided for this positive finding is that nursing home staff recognize that dementia is an independent risk factor for influenza complications.

#### Media impact

Media can impact an individual's belief as he/she seeks out information from a variety of external sources. It was proposed that the strongest predictor of immunization uptake for children was parental attitude [27], so it is essential to have evidence-informed information for those who make decisions about vaccination. A study examining MMR (Mumps, Measles, Rubella) vaccine uptake reported that parents that have confidence in vaccination effectiveness are more likely to have their children vaccinated. However, respondents felt that the information they received from HCPs about vaccinations was biased, and vaccination safety information was not forthcoming [27]. If individuals feel that the information they are receiving from HCPs is biased, they are more likely to seek information elsewhere. There are dangers associated with this approach. Specifically, not all internet resources are credible or reliable for an individual to use when making informed decisions, for example A Voice for Choice. A Voice for Choice is a non-profit website that has a strong online following, and it claims to be promotive of evidenceinformed decision-making. However, there is a clear intention of promoting anti-vaccination [28, 29]. Davies et al. [30] investigated the likelihood of finding anti-vaccination sites when people search "immunization" or "vaccination". They found that 43% of resultant websites were related to anti-vaccination, and this result shows that there is a high probability that individuals seeking information about vaccinations are likely to discover anti-vaccination information. These anti-vax websites most commonly use emotional appeal to display the idea that vaccines cause idiopathic illness and destroy immunity. They also commonly impact vaccine confidence by sharing those adverse reactions to vaccines are underreported and that vaccination policies are motivated by profit [31]. The analogy of MMR vaccination and parental attitudes has implications for understanding persons of dementia's vaccine hesitancy because they often rely on caregivers to make decisions on their behalf.

#### **Study limitations**

There is a lack of existing literature that examines the barriers PWD face in receiving the influenza vaccine. While this topic is under-studied, our current literature review was able to highlight some of the factors that may impact the vaccine uptake among dementia populations. However, this literature review has limitations that need to be acknowledged. Most evidently, some literature being examined may not related directly to the study topic, but rather it provides implications to enhance our understanding about the potential factors that impact PWD's influenza vaccine uptake. A systematic review may potentially offer a more comprehensive approach to understanding the phenomenon of interest, as well as providing an appraisal of the included literature to assess the strength and quality of the available evidence.

### Conclusion

Despite the categorization into the three over-arching themes, it is important to underscore that each theme, subtheme, and stakeholder group is interconnected, and altogether influencing access to influenza vaccination among PWD. Based on this literature review, certain sub-themes may need to be examined more closely to help advance our understanding and implement effective strategies to improve vaccine uptake among PWD. Today, social media and online sources play a major role in contributing to vaccine hesitancy. Future research needs to focus on examining the facilitating factors to overcome the challenges of this important public health issue.

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Availability of data and material The data supporting the findings of this literature review are available within the article and/or supplementary materials. Additional data are available on request from the corresponding author, [WS].

Code availability Not applicable.

# Declarations

**Conflict of interest** The authors declare that they have no conflict of interest.

Ethics approval Not required (not a human study).

Consent to participate Not applicable.

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