

## **Beyond Private? Dementia, Family Caregiving and Public Health**

Monique Lanoix

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Article abstract

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

## Beyond Private? Dementia, Family Caregiving and Public Health

Monique Lanoix<sup>a</sup>

### Résumé

Le Forum économique mondial a qualifié la démence de l'une des plus grandes crises sanitaires mondiales du XXI<sup>e</sup> siècle. Dans cet article, je soutiens que les soins non rémunérés prodigués par la famille ou les proches des personnes atteintes de démence devraient être une question de santé publique. Shaji et Reddy l'ont proposé en 2012 dans le contexte des soins aux personnes atteintes de démence en Inde. Ils reconnaissent explicitement l'influence de l'article de Talley et Crews de 2007 sur la prestation de soins en tant que nouveau problème de santé publique. Cependant, ils limitent leur proposition aux soins prodigués aux personnes atteintes de la maladie d'Alzheimer et de démences apparentées (MADA), ce que je considère comme une première étape importante dans l'élaboration d'un argumentaire visant à inscrire plus fermement les soins dans un programme de santé publique. Pour étayer mon propos, j'établis tout d'abord que la prestation de soins est un déterminant social de la santé. Ensuite, je réfute les objections à l'ajout de la prestation de soins aux personnes atteintes de la MADA à un programme de santé publique, car cela entraînerait une dérive de la mission de la santé publique. Je soutiens ensuite qu'une compréhension large de la santé publique peut inclure ce type de prestation de soins et est préférable car elle met en évidence une question d'équité en matière de santé, la nature sexuée de la prestation de soins. Enfin, je soutiens qu'une définition de la santé publique incluant les déterminants sociaux de la santé et la prestation de soins est mieux adaptée pour faire face aux conséquences sanitaires de l'évolution actuelle des schémas démographiques. Mon argumentation renforce les écrits sur la migration qui appellent à l'élargissement du champ d'application de la santé publique.

### Mots-clés

démence, soins familiaux, santé publique, relationnel, déterminants sociaux de la santé, équité

### Abstract

The World Economic Forum has called dementia one of the biggest global health crises of the 21<sup>st</sup> century. In this paper, I make the case that unpaid caregiving by family or close others of persons living with dementia should be a matter of public health. Shaji and Reddy proposed this in 2012 in the context of dementia care in India. They explicitly acknowledge the influence of Talley and Crews' 2007 article on caregiving as an emerging public health concern. However, they narrow their proposal to caregiving for persons living with Alzheimer's disease and related dementias (ADRD), which I take to be an important first step in building an argument for putting caregiving more firmly on a public health agenda. In order to support my claim, first, I establish that caregiving is a social determinant of health. Second, I counter objections to the addition of caregiving for persons living with ADRD to a public health agenda, as it would lead to public health mission creep. I then argue that a broad understanding of public health can be inclusive of this type caregiving and is preferable as it highlights an issue of health equity, the gendered nature of caregiving. Finally, I make the case that a definition of public health inclusive of the social determinants of health and caregiving is more adequately suited to address the health consequences of the current changing demographic patterns. My argument adds support to writings on migration calling for broadening the scope of public health.

### Keywords

dementia, family caregiving, public health, relational, social determinants of health, equity

### Affiliations

<sup>a</sup> Faculty of Philosophy, Saint Paul University, Ottawa, Ontario, Canada

**Correspondance / Correspondence:** Monique Lanoix, [mlanoix@ustpaul.ca](mailto:mlanoix@ustpaul.ca)

## INTRODUCTION

The World Economic Forum has called dementia one of the biggest global health crises of the 21<sup>st</sup> century (1). Alzheimer's is the most prevalent disease that leads to dementia, but other diseases can cause this degenerative condition, and together they are labelled Alzheimer's disease and related dementias (ADRD), which is the term I will use (2). In this paper, I make the case that unpaid caregiving by family or close others of persons living with ADRD should be a matter of public health. This possibility first came to my attention through Shaji and Reddy's 2012 proposal in the context of dementia care in India (3). In India, most persons living with ADRD are cared for at home since institutional care is not readily accessible or affordable, and very often is not culturally acceptable (4). Shaji and Reddy argue that the best way to meet the needs of family caregivers as well as that of persons living with dementia is through an array of services, from education to support (3). They put forward that a public health framework would lead to exploring more fully the needs of populations and would result in better services not only for the persons living with ADRD but also their caregivers as the wellbeing of the former is tied to the latter (3).

Shaji and Reddy (3) explicitly acknowledge the influence of Talley and Crews' 2007 (5) article on caregiving as an emerging public health concern. However, they narrow their proposal to caregiving for persons living with ADRD, which I take to be an important first step in building an argument for putting caregiving more firmly on a public health agenda. My paper also owes much to Talley and Crews' proposal, which I regard as a call to delve more deeply into an analysis of caregiving and its potential ties to public health. It is certainly the case that caregiving for persons living with ADRD is more widely recognized in

all parts of the world, from high to low-income countries, as a complex, and demanding activity that often has a negative impact on caregivers' mental and physical health. If this supports a greater examination of the question, there is also another reason for my analysis, which is the definition of public health. The proposal to include caregiving within a public health framework prompts a critical examination of the definition of public health, more specifically whether public health should be narrowly or broadly defined. The chosen perspective, whether narrow or broad, will have a direct impact on the development of public health policies, which is why it is important to build consensus on this question.

I focus on policy and recommendations from Canada and the USA and I insist on referring to *caregiving* as opposed to *caregivers*. This may appear to be a trivial point since caregivers are already present in many of the Canadian and American public health recommendations. However, if current policies and initiatives refer to caregivers, the manner in which they are addressed is tangential to the greater concern of the social and health status of persons living with ADRD and the consequences for the health care systems. Explicitly referring to caregiving entrenches its recognition as a risk factor for harm that warrants prevention at the population level. It calls attention to the fact that caregiving is not an isolated practice as it is influenced by the caregiver's socioeconomic context. Finally, since women are most often the caregivers of persons living with ADRD, a focus on caregiving makes possible the explicit acknowledgement of the gendered nature of caregiving, which is an essential step in addressing this matter of health equity.

To build my case, I first establish that caregiving is a social determinant of health. Second, I counter objections to the addition of caregiving for persons living with ADRD to a public health agenda and argue that a broad understanding of public health can be inclusive of this type caregiving. Thirdly, I make the case that a broad definition of public health is more adequately suited to address the health consequences of the current changing demographic patterns, thus adding support to the writings on migration that call for a broadening the scope of public health. Finally, my paper makes clear that Talley and Crews' proposal remains relevant; however, "framing the public health of caregiving" as they propose requires developing initiatives and strategies that are suitable for the population requiring caregiving. My discussion demonstrates how this is possible for persons living with ADRD and their caregivers.

## CAREGIVING AS A SOCIAL DETERMINANT OF HEALTH

My analysis is directed at caregiving understood as the assistance typically provided to older adults who have difficulty carrying out the activities of daily living. Home health care aides and personal support staff working in nursing homes perform this type of work for remuneration. For the purposes of my paper, I limit my study to the assistance that is unpaid and provided by family or friends of persons diagnosed with ADRD who are living at home.<sup>1</sup> This type of assistance is classified as "informal care" even if it often has a positive impact on the care receiver's health. Given that this type of caregiving can involve complex tasks, I use the term "unpaid caregiving" to distinguish it from the paid care provided by nurses or care aides in the home.

The rehabilitation and the neuropsychological literature recognize two types of activities of daily living: those that are needed to survive, such as eating and personal hygiene (ADL); and the activities that are instrumental to life (IADL), such as managing a bank account (6). In the first instance, the assistance provided can range from cleaning someone's living space, to helping with meals and intimate tasks such as dressing or bathing. In the case of persons living with ADRD, the assistance needed initially may only be with the IADLs; however, as the disease progresses, individuals living with ADRD will increasingly need help with the ADLs and this assistance will likely become more complex.

The first step in determining whether this type of caregiving can be located under the umbrella of public health is to demonstrate that it is a social determinant of health. The World Health Organization defines the social determinants of health as "the non-medical factors that influence health outcomes. These are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems" (7).<sup>2</sup> Baker, Metzler and Galea observe "that certain conditions commonly referred to as social determinants – including access to affordable healthy food, potable water, safe housing, and supportive social networks – are linked to health outcomes is something on which most of us agree" (8). It is not immediately obvious that there would be general agreement that caregiving for persons living with ADRD can be included on the list of social determinants of health. In order to establish that it can be included, it must meet three criteria. First, that caregiving can have a significant negative impact on caregivers' health outcomes. Second, that it is a risk factor affecting a large segment of the population. Third, that these negative health outcomes are preventable or at least mitigated by adequate policies.

In the following paragraphs, I examine studies discussing caregiver burden. I do not present a systematic literature review as there is broad agreement that caregiving takes a toll on caregivers (9). For example, the World Health Organization explicitly acknowledges caregiver strain in their 2017 guidelines to assess the effectiveness of caregiver support (10). Rather, I draw attention to findings from specific studies to highlight how caregiving activities are complex and often involve multiple actors and systems. I begin my analysis by looking briefly at studies directed at caregiving for adults living with a chronic illness or a disability; then, I examine research focusing on caregiving for persons living with ADRD.

<sup>1</sup> I use the term 'family' in a broad sense to include family, spouses, partners, as well as close others.

<sup>2</sup> I draw attention to the mention of 'work' in the definition. Although caregiving is not paid, it is work, as many caregivers will attest.

In their proposed theoretical framework to understand caregiver burnout, G erain and Zech write that “[a]cross the literature and the media, it is widely accepted that being an informal caregiver puts a person at risk of poorer mental and physical health” (11, p.1). In interviews conducted by phone with over one thousand caregivers in the USA, Navaie-Waliser et al. determined that 36% were vulnerable caregivers (12), which they define as older, with health problems and as having less education. Vulnerable caregivers had more problems providing care and they reported that their health had suffered (12). In their study of older caregivers providing care for their spouses living with a chronic illness, Schulz and Beach observe that “being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers” (13, p.2215).

In the more limited case of caregiving for persons living with ADRD, Gitlin and Schultz report that caregiving activities can have a negative impact on the caregiver’s health (14). Studies comparing caregivers of persons living with ADRD to individuals who are not providing care reveal that caregivers faced more distress as well as negative health outcomes (15). In their scoping literature review of peer-reviewed articles pertaining to caregiver burden, Queluz et al. note that the personal health of caregivers as well as their emotional health was a key concern (16). The authors included data from various countries, published in English, with a focus on caregivers of persons living with ADRD. If these studies are limited by language, they nevertheless concur with international studies on the risk factors associated with caregiving for persons living with ADRD (17).

Unsurprisingly, the disease trajectory of the person receiving assistance will have an impact on caregiver burden. In addition, it will be influenced by the caregiver’s age, culture, sex, socioeconomic status and their attitude (18). If older caregivers confront the risk of negative health outcomes, younger caregivers often tackle challenges, albeit of a different sort. Nonetheless, these can also lead to negative health outcomes. As Brodaty and Donkin explain, “caregivers [of persons living with ADRD] face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships. They are at increased risk for burden, stress, depression, and a variety of other health complications” (19, p.218-19).

If the physical and emotional strain of caregiving is usually associated with the direct activities of care, other aspects of caregiving can increase caregiver stress. In their study of the structural burden of caregiving for persons with chronic illness and/or ADRD in the USA and Canada, Taylor et al. highlight an under explored area of caregiver burden, that of having to manage fragmented health care structures (20). They point out that in much of the literature, the stress of caregiving is assumed to come from an imbalance between caregiving demands and the caregiver’s time (20). Their analysis reveals the impact of having to negotiate and manage access to long-term care services. Not only are these caregivers dealing with the strain of direct care, but they also face a secondary stress of having to navigate various systems, from health to social services, in order to access adequate care and support (21). Although support services are put in place to be of use to those who provide care, they can increase time commitments and frustration. This added burden, although more frequent in high-income nations, highlights how caregiving for persons with either chronic diseases and/or ADRD is complex and requires commitment, time, effort as well as knowledge.

Although not exhaustive, the studies mentioned so far agree that caregiving for persons living with ADRD is a risk factor for negative mental and physical health outcomes. Moreover, they highlight the impact of other social determinants of health on the strain experienced by caregivers. These findings indicate that caregiving for persons living with ADRD satisfies the first criterion of its inclusion as a determinant of health. As for the second criterion, a 2022 study published in *Lancet Public Health*, estimated that the global number of people with dementia will nearly triple from 2019 to 2050 (22). If the number of persons who are living with dementia is on the rise, more family members and friends will become caregivers.<sup>3</sup> As large segments of the population undertake assisting individuals living with ADRD, I propose that the question becomes one of population health. Finally, if caregivers of persons living with ADRD often face diminished health outcomes, studies have shown that policies directed at caregivers, which include education and supportive care, helped mitigate some of the effects of caregiving (23). Because caregiving of persons living with ADRD fulfills all three criteria, it can be classified as a social determinant of health.

## PUBLIC HEALTH AND CAREGIVING

Granting that caregiving for persons living with ADRD is a social determinant of health, it remains to be shown that it can and should be part of a public health agenda. In this section, I counter possible objections to my proposal.

According to Faden et al. (24), there are four characteristics of public health. The first is that public health targets populations, not individuals; it is a public good. The second is a commitment to prevention of disease and injury. A requirement of government action constitutes the third feature and, fourth, public health is outcome oriented. It can be readily agreed that caregiving for persons living with ADRD meets criteria two, three and four. However, there are two possible objections related to the first criterion. Both objections pertain to the assumption that caregiving is a familial activity involving individuals, not populations. Although the two objections are conceptually linked, I consider them separately as they bring to light different problematic suppositions.

The first objection identifies governmental support for family caregivers of persons living with ADRD as unpaid care and not health care proper and thus not directly relevant to public health. The second objection is that caregiving for persons living

<sup>3</sup> The greater demand for caregiving as well as the increasingly complex nature of caregiving are two of the factors motivating Talley and Crews’ call for framing “caregiving as an emerging public health issue” (5, p.224).

with ADRD pertains to familial care. The reasoning behind the latter objection is that, regardless of how many people are caregivers, familial care involves close others in the private sphere. I turn to the first objection next, and then examine the second by mobilizing some of the recent literature on populations and migration.

It is generally agreed that public health can be defined from a narrow or a broad perspective (25). The classic version, which is the narrow version from Winslow (1920), which defines public health as “the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts...” (26, p.30). In their 2023 scoping review on public health, Azari and Borisch found Winslow’s definition to be the most cited (27). However, global, social and political transformations have incited the search for a more comprehensive definition of public health that would include attention to broader questions such as that of health equity. Powers and Faden’s proposal to view public health as a matter of social justice is an example of a broad understanding. In their 2006 book, *Social Justice: The Moral Foundations of Public Health and Public Health Policy*, Powers and Faden argue that “the foundational moral justification for the social institution of public health is social justice” (28, p.80). They view a close allegiance between public health and social justice as necessary to advance the goals of public health.

Labelling caregiving for persons living with ADRD as unpaid care, as opposed to health care, would not necessarily prevent its integration into a public health agenda. A broad definition of public health could easily include family caregiving for persons living with ADRD as caregiving touches upon matters of social justice. To explain, first, caregivers face an increased risk for negative health outcomes while providing care that ultimately lessens the impact of ADRDs on health care systems. If everyone in a particular region benefits from a less overloaded health care system, it is at a cost to those who provide care and very often lack proper support. Second, as the studies discussed previously demonstrate, socioeconomic status and age influence the health outcomes of caregivers; caregiving is interwoven with other determinants of health. There is also the issue of caregiving and gender. A definition of public health that acknowledges the differential impact of socioeconomic factors could easily include caregiving for persons living with ADRD. However, if caregiving is included in a broad definition of public health, it is open to the charges directed at the broad interpretation of public health. That is, it could be construed as unduly broadening the scope of public health. To assess this charge, I turn to the objections that Powers and Faden’s proposal has faced as well as their rebuttal of these objections.

Several theorists and practitioners working in the domains of health care and population health have applied Powers and Faden’s framework. Notably Horn (29) argues that the problem of fetal alcohol syndrome in South Africa would be better addressed using a public health framework that includes attention to poverty. According to Horn, this is the best way to ensure the recognition of social injustices that worsen a public health issue. In a later article, she makes clear that there should be a close link between social justice and public health especially in low-income contexts (30). She is aware, however, that such a close association can lead to public health mission creep, that is, the broadening of public health to the extent that it includes much larger questions of human rights and socioeconomic inequalities. Rothstein argues that tackling such issues is outside the mandate and expertise of public health officials (31). The fear is that adding questions relating to human rights or socioeconomic inequalities to the public health agenda would lead to a radical transformation of public health. This new public health could end up directing its attention toward social justice rather than health.

Those who worry about public health mission creep, such as Rothstein, acknowledge that socioeconomic status has consequences for health outcomes. Nevertheless, they perceive the two areas as having to remain separate. Powers and Faden have responded that they are sensitive to the dangers of mission creep. However, they write, “the greater, more pervasive risk is lack of moral attentiveness to policies that neither do the best they can to secure the conditions for improved public health or pursue public health in ways that undermine other aims of justice” (32, p.46). Powers and Faden have a point, as it may be difficult or nearly impossible to keep particular determinants of health as concerns of public health separate from considerations of social justice.<sup>4</sup>

If these worries over the expansion of public health are taken seriously, where does it leave the proposal to address caregiving for persons living with ADRD as an issue of public health? I suggest that the question of caregiving is of a different *kind* than that of injustice related to social economic class. Caregiving is a type of activity directed at the wellbeing of the person receiving care. Although it is not medical care, it is instrumental to the health and wellbeing of the person receiving care. Caregiving for persons living with ADRD is akin to the paid caregiving taking place in an institutional setting or the paid caregiving provided by home care aides: both types of assistance, paid and unpaid, involve activities that support health and wellbeing. Socioeconomic class, on the other hand, is the social and economic location of individuals within a particular region. Although it can have an impact on the health status of an individual, it does not directly involve a medical procedure or assistive care aimed at supporting wellbeing. The difference between family caregiving and paid caregiving is a difference of *degree* and not a difference in *kind*.

To illustrate, let us look at an example of a recent Canadian policy introduced to manage the Covid-19 pandemic in the health care workforce. Public Health Ontario, the public health agency of the province of Ontario, published a technical brief updated in December 2021, where it recognizes the risks of infection health care workers face (33). This policy is an example of public health directing efforts to protect the health and wellbeing of paid health care workers in their work environment. One reason was certainly to curb infection rates; another was to ensure that workers were available. Additionally, the government, either

<sup>4</sup> For example, refugee and migrant health is an issue that pertains not only to health but also to social justice.



as a direct employer or as having the responsibility to oversee workplace security, understands that it has a duty to protect workers and prevent infection.<sup>5</sup> If public health can turn a vigilant eye to the protection of paid care workers, it can also do so for unpaid family caregivers. Granting that the government does not pay family directly in Canada, professional health care workers are part of the public health care system and studies have shown they depend on family caregivers (35-37). Although not recognized explicitly, family caregivers are providing essential care.

The reluctance to integrate family caregiving for persons living with ADRD as a question relevant to public health also comes in part because it blurs the boundaries between health care and unpaid care taking place at home.<sup>6</sup> However, that boundary is permeable, as many policies, for example those on home-care, illustrate (38). My point is that the proposal to add caregiving for persons living with ADRD does not expand public health's overall focus, as another service is simply included within its scope. In sum, a broad definition of public health can include caregiving without the worry of mission creep.

The second objection is grounded on the presumption that family caregiving provided to persons living with ADRD is a private matter to be managed by individuals. Regardless of the number of caregivers who may face diminished health outcomes, by its very nature, familial caregiving should remain an issue to be tackled by governmental policies relating to family caregiving and not health care per se. Thus, it is not directly relevant to public health.

Feminist activists and scholars have successfully challenged this presumption and have argued that family care matters to the public realm. The matter has also been the subject of writings in feminist bioethics (39,40). Numerous studies have demonstrated the positive impact of family caregiving on care receivers' health outcomes. Very often, in the case of home care, professional care providers such as nurses rely on family caregivers (35,36). I note one example, even if dated, of Saillant's research on caregiving in Québec in the early 1990's where she established the unquestionable impact of family members, very often women, on the production of positive health outcomes for their families (41,42).<sup>7</sup>

Another critical consideration is that caregiving does not take place *ex nihilo* but is shaped by the social, political and familial contexts in which it takes place. Talley and Crews, in their response to Eckenwiler's comment on their 2007 article, rightly clarify that "[a]lthough care is given to an individual, the caregiving process frequently involves multiple providers and occurs within interactive, dynamic contexts of varying duration and incredible delicacy" (44, p.1931). Eckenwiler's proposed ecological framework for caregiving explicitly acknowledges that the needs and support given to care recipients and to paid and unpaid caregivers is intertwined in a variety of policies, from migration to labour laws as well as health (45). The 2020 American Public Health Agency's policy statement on strengthening the dementia workforce echoes the same observation. The authors of the policy statement recognize that although topics such as service provision to persons living with ADRD "are often thought of as private, family concerns, the broader implications on our health care, economic, social and cultural systems are all encompassing. Flaws there impact us all; rectifying them will help us all" (46, p.7).

## PUBLIC OR POPULATION?

I have shown thus far that caregiving for persons living with ADRD can be integrated into a public health agenda, broadly construed. However, whether a narrow public health perspective is more adequate than a broad one or vice versa has yet to be determined. In their scoping review, Azari and Borisch (27) point out that a clear definition of public health would help those who work in the field and certainly would help the individuals who could benefit from public health policies. If no consensus has been reached as to a clear definition, the authors emphasize the need to re-assess and update definitions of public health. Caregiving provides a useful lens to examine this point.

The narrow view of public health focuses on disease prevention and control. This perspective does not explicitly take into consideration socioeconomic contexts and, as a result, encourages the perception that individuals are mostly responsible for their health.<sup>8</sup> Such a perception erases the uncontrollable aspects of a person's life that will nonetheless have an impact on their health outcomes. This is one of the reasons Powers and Faden insist public health is a matter of social justice. As the studies discussed earlier suggest, a more thorough understanding of the challenges that caregivers may face requires taking into consideration their socioeconomic context. My point is that a thorough reckoning of the negative health outcomes brought about by caregiving requires a broad understanding of public health. To support my claim, I turn to the literature that critically engages populations and migration in relation to public health.

Childress et al. clarify the focus of public health as involving the health of an entire population as opposed to that of an individual (48). If the target of public health seems clear, finding an unambiguous definition of public health has not been straightforward as Azari and Borisch's scoping review demonstrates (27). This is the reason Dawson and Verweij label public health a contested concept (49). In their chapter on the meaning of public in public health, they explain how public health might refer to the health of the public or it might signify the interventions needed to keep the public in good health. Regardless of this

<sup>5</sup> This recognition came rather late. During the pandemic, front-line workers faced a heavy burden according to the Canadian Institute for Health Information (34).

<sup>6</sup> Some activities of care could be a controlled act (such as wound dressing) that a nurse has delegated to a family member. This illustrates how the strict demarcation between paid and unpaid care can be questionable. I owe this point to Michael Lepore.

<sup>7</sup> The question of family contributions has been the focus of later research agendas (43).

<sup>8</sup> This tends to promote an individualistic attitude toward public health measures with state-based interventions negotiated through a delicate balance of limiting individual rights and promoting the greater good. This negotiation can be at times controversial, as witnessed in North America during the Covid-19 pandemic and the rules surrounding masking and vaccines. As for the larger domain of bioethics, Lane et al. maintain that debates in bioethics are moved by concerns that are individualistic, which downplays "the importance and legitimacy of group-level health care dilemmas" (47, p.25).

equivocality, until recently, the accepted understanding of public health is that it involved persons residing in one country, state or region. However, societies have changed: not only are there demographic transformations such as population aging, but there is also increased population mobility across the globe because of political and climate crises (25,50). Moreover, with a greater awareness of global health inequalities, there is growing agreement that such inequalities should be a concern of public health. As can be surmised, the question arising from these changes is whether public health should limit itself to one region or adapt to the changing patterns of human life and respond to the global health inequalities.

These realities have prompted Faden to consider the meaning of public in public health, although from a different perspective than Dawson and Verweij's. She worries that using the term 'public' to define the aim of public health may give the impression that this collective entity is comprised of individuals who must share certain features. She prefers the term population because "characterizing the health we are trying to advance as that of populations, by contrast, may minimize the implication that special shared features or characteristics are needed in order for a group of individuals to constitute a collective unit whose health can be of concern" (51). According to Faden, 'population' is more indicative of the heterogeneity of the individuals inhabiting the entity that is the focus of public health.

Faden concurs with Wikler and Brock's proposal for population level bioethics embracing an internationalist perspective. As Wikler and Brock write,

[t]he bird's eye perspective of this population level bioethics includes consideration not only of health care but also of other social determinants of health, including socio-economic standing, environmental and working conditions, and social exclusion. Its subject therefore is health rather than health care alone, insofar as health can be affected by conditions and interventions in any of these domains (52, p.78).

Since family caregiving for persons living with ADRD is a determinant of health, I submit that caregiving for persons living with ADRD is one of those domains.

Wikler and Brock maintain that population bioethics is not limited to narrowly circumscribed groups but extends in "both space and time" (52, p.79). In emphasizing the importance of time, they point to a larger understanding of relationships between individuals, for example that between generations.<sup>9</sup> Taking Geoffrey Rose's contrasting views on the medical approach and the population approach to social determinants of health, Wikler and Brock clarify that,

[t]he population approach...seeks to reduce the risks of the population as a whole, usually by non-individual and non-medical interventions. For example, while the medical approach would provide drugs for hypertension to the worst cases, the population approach would work toward a reduction in the salt content of processed foods, lowering everyone's risk and thereby the number of deaths attributable to hypertension (52, p.91).

Since a population approach casts a wide net on the types of risk factors affecting health outcomes, a population approach is consistent with a broad understanding of public health.

There is a useful parallel to be drawn between the example given above and caregiving for persons living with ADRD. As is currently the case in Canada at least, the approach to caregivers of persons living with ADRD is what I would call a medical approach, as Wikler and Brock describe it. I do not deny that policies and initiatives that target ADRD as a public health concern include support for caregivers. However, if a caregiver is deemed to be close to a burnout, then either a nurse or a social worker on the case might intervene and facilitate access to support or even respite for the caregiver. If no one is managing the case, the caregiver might do some research to find out what services might be available. Another possibility, which is quite common, is that the caregiver would simply go without support (53). Focusing on caregivers in this manner is similar to prescribing medication for hypertension: the focus and support are on the individual caregivers not on the impact that caregiving has on the caregiving population.

The medical approach to caregiving for persons living with ADRD frames the health outcomes of caregivers as subsidiary to the health outcome of persons living with ADRD. When the focus is on sustaining caregivers in their role as care providers, it essentially instrumentalizes caregivers. Alternatively, a population approach would encourage the development of system wide policies to address the impact of caregiving while taking into account how some caregivers may be more vulnerable. To explain, because a population approach requires a broad understanding of public health, the policies developed under a broad public health agenda could consider other social determinants of health. Crucially, such a perspective supports the development of system wide policies that address an aspect of caregiving that is sadly absent from many policy recommendations: the gendered dimension of caregiving. This dimension has implications for health equity; however, it remains invisible when caregiver support is managed using a medical approach. In their viewpoint in the recent *JAMA Health Forum*, Stall, Shah and Bushan call attention to the fact that in the USA women disproportionately face the burdens of caregiving (54). Moreover, most caregivers carry out medical tasks that professional health workers usually perform. The authors conclude that challenging the

<sup>9</sup> It can potentially include questions related to the health outcomes of migrant workers. See Eckenwiler's ecological framework on the question of migrant care workers (45).

gendered nature of caregiving is a way to better support caregivers and “ensuring that caregiving interventions are equitably implemented” is essential to create an equitable and resilient society (54, p.4).

## AMERICAN AND CANADIAN POLICIES AND INITIATIVES

In this section, I discuss several American and Canadian strategies, initiatives, and recommendations relating to ADRD and caregivers. My first objective is to highlight several of the key recommendations from these various proposals in order to determine whether they fit a narrow or broad view of public health. My second, using caregiving as a critical lens of analysis, is to show that a broad definition of public health is more suitable to the current demographic and global transformations, adding support to the literature on migration and population that argues for a broad definition of public health (25,28,51,52).

### American initiatives

In a 2018 testimony to the American Senate Special Committee on Aging, McGuire acknowledges that although there is a recognition of ADRDs as an issue of public health, much work remains to be done to improve the health and wellbeing of those who have these diseases. She adds that there is a growing need to help these individuals and their families (55). In their 2020 version of a public health Road Map designed to address the increasing prevalence of dementia, Olivari, French and McGuire call for the recognition of ADRD as a problem of public health (56).<sup>10</sup> The authors remark that ADRD had been considered a topic relevant to gerontology but not public health; however, they state that the changing demographics call for considering ADRD a matter of public health. The proposed Road Map is “categorized into four overarching public service actions: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate” (56, p.4). In addition to calling for more research and collaboration, the Road Map targets knowledge mobilization for persons with ADRD, their families and the greater public to shift attitudes and achieve better health outcomes.<sup>11</sup>

There are also several plans to address the health impacts of ADRDs. The National Plan to Address Alzheimer’s Disease is a “federal strategy for reducing the burden of AD/ADRD by accelerating research towards treatments, improving care and support for people facing these conditions now, and reducing the risk of AD/ADRD by promoting brain health” (58) and is housed in the office of the Assistant Secretary for Planning and Evaluation, part of the Department of Health and Human Services (DHHS). If it does not discuss caregiver burden explicitly, it points to the increased need for care for persons living with ADRD. Specifically, it seeks to eliminate or at least ameliorate the management of ADRD in addition to meeting the needs of American families who are facing the disease. Of significance, the National Alzheimer’s Project Act (NAPA) advisory council presented a report to the American Congress in 2021 where they put forward a national strategy to support family caregivers. The strategy is grounded in five priority areas for action: 1) awareness and outreach; 2) engagement of family caregivers as partners in health care and long-term services and supports; 3) services and supports for family caregivers; 4) financial and workplace security; 5) research, data, and evidence-informed practices (59). Many of the stated goals are similar to the ones put forward by the Road Map; however, the objective to engage caregivers as care partners marks them as active participants in the management of ADRDs. If there is a recognition of the contributions of caregivers, the strategy remains gender neutral.

The *RAISE Act* is an important step in the recognition of the impact of caregiving as well as the contributions of all caregivers. It became law in 2018 and its objective is to “Recognize, Assist, Include, Support and Engage family caregivers” (RAISE). The advisory councils of RAISE and the *Supporting Grandparents Raising Grandchildren Act* with input from the public developed the National Strategy to Support Family Caregivers. Greg Link of the Office of Supportive and Caregiver Services of the Administration of Community Living (ACL) explains in his presentation for NAPA<sup>12</sup> that the strategy is a “driver for legislative and policy change” (61). It aims to support all caregivers, regardless of age, where they live and the types of care they provide. It is “a vision and road map for meaningful change, a framework for all types of family caregiving and situations and experiences” (61). It also seeks to include caregivers in underserved communities. In her assessment of the *RAISE Act*, Kenway, who was her dying mother’s caregiver, praises the effort (62). However, she observes that the 2021 initial report to Congress recommends decreasing the negative impact on the finances of family caregivers; and the proposed solution to this specific problem is to make paid care cheaper. However, Kenway deems the solution problematic because it appears as if family caregivers will no longer be providing care (62, p.220). If this is yet another example of erasing caregivers’ contributions, I am also concerned that making care cheaper risks further devaluing this type of work.

The American Public Health Association (APHA) has also weighed in on the increased occurrence of ADRDs and the need to develop strategies to cope. In the 2020 policy statement, *Strengthening the Dementia Care Workforce: A Public Health Priority*, the APHA recognizes that persons living with ADRD, their caregivers as well as society bear the health and social and economic burdens related to the shortcoming in the public health and long-term care systems (46). The APHA emphasizes the need for a dementia-capable workforce as the shift from institutional care to home and community care calls for a workforce trained in dementia care. This is vital to ensure that the care needs of persons living with ADRD are met. According to the policy statement, this would lower the cost the health care costs.

<sup>10</sup> Olivari and McGuire work for the Centers for Disease Control and Prevention, which is part of the Department of Health and Human Services. French works for the Alzheimer’s Association. I mention the affiliations to highlight the close collaboration between government and an association to fight a disease.

<sup>11</sup> In the American context, the Alzheimer’s Association has also put forward a proposal to consider ADRD as of a public health approach (57).

<sup>12</sup> The Secretary of the Department of Health and Human Services established Administration for Community Living (ACL) in 2012. The “ACL advocates across the federal government for older adults, people with disabilities, and families and caregivers” (60).



A greater number of skilled care workers would certainly lessen some of the burden of caregiving for families. The APHA explicitly recognizes that dementia care is complex especially as the disease progresses (46), which implies that eventually the care required may be too much for family caregivers. For the APHA, a competent workforce would not only alleviate the need for family care, but it would also ensure that the care provided is adequate. The APHA statement further emphasizes the importance of knowledge sharing for persons with ADRD and their families so that they can make informed decisions. Significantly, the policy statement refers to the gendered aspect of caregiving: it calls for caregiver support as caregivers, very often women, face discrimination and negative impacts on their mental and physical health (46). It is one of the few documents that explicitly addresses gender.

## Canadian initiatives

Canada has not developed as many policies, strategies or recommendations relating to caregiving for persons living with ADRD as the USA; however, many Canadian initiatives have similar perspectives on caregivers. In 2019, the Public Health Agency of Canada (PHAC) put forward a strategy to address dementia entitled *A Dementia Strategy for Canada: Together We Aspire*, consisting of five pillars: 1) collaboration between governments, researchers and persons living with dementia; 2) research and innovation; 3) surveillance and data; 4) knowledge mobilization for care providers and the wider public; and 5) training a competent workforce.

In 2019, the PHAC commissioned a panel of experts to produce a report, *Improving the Quality of Life and Care of Persons Living with Dementia and their Caregivers* (CAHS report). The report underscores the importance of recognizing the rights of persons living with ADRD, but it also urges the explicit acknowledgement of the fact that caregiver needs are not the same as the needs of those living with ADRD (64). If this is a welcomed addition, the focus is disappointingly narrow as it targets supporting caregivers in their role as caregivers, e.g., by encouraging work-life balance, increasing knowledge dissemination concerning best practices for caregivers (64, s.5). The CAHS report states that a focus on person-centred care is essential: “the quality of life of persons living with dementia and their caregivers can be improved across all stages of the condition through a complex combination of person-centred, high quality health and social care” (64, s.4.3). Although a patient-centred focus indicates a strong attention to the needs of the persons living with ADRD, these needs can/should very often include family caregivers as part of that focus. Nevertheless, there is the risk of failing to take into consideration and address the specific needs of caregivers, especially as the report does not explicitly take into consideration the gendered dimension of caregiving.

In addition to the CAHS report, the PHAC has funded several initiatives, one of which is the Dementia Community Investment program that funds community-based projects. This program “supports community-based projects that ...[embrace] the wellbeing of people living with dementia and family and/or friend caregivers, increase knowledge about dementia and its risks factors, and undertake research to evaluate the effectiveness of project interventions” (65). Successful projects include one that considers the wellbeing of individuals living with ADRD and their caregivers in Inuit communities (65). The Native Women’s Association of Canada received financing for *Supporting a Circle of Care*, a toolkit aimed at Indigenous caregivers of persons living with ADRD (64). Another project focuses on supporting family caregivers of persons living with ADRD in long-term care through a web based social support intervention (65). As these projects illustrate, the initiatives target meeting the needs of specific communities as defined by the communities themselves.

In the 2022 follow-up to the 2019 dementia strategy, the PHAC highlights some of its investments in the report *Together We Achieve* (66). In his opening letter, the honorable Jean-Yves Duclos, federal Minister of Health, explains, “the Dementia Community Investment has to date supported 21 community-based projects designed to improve the wellbeing of people living with dementia and caregivers and to increase knowledge about the dementia risk factors” (66, p.vii). The report affirms its objectives to foster “culturally appropriate and culturally safe [tools] for diverse populations” (66, p.70). In particular, it devotes a section to Indigenous populations and explicitly acknowledges that “... a lack of access to health care in remote, rural and isolated communities and a lack of cultural safety in the health care system may create barriers to equitable and culturally appropriate care” (66, p.61). The report concludes on a hopeful note, stating that increased research funding announced in the 2022 budget “will further efforts on brain health, improved treatments, and support for dementia caregivers.” (66, p.70). If the report emphasizes the importance of culturally safe and appropriate care, it maintains a strong medicalized focus. Caregivers, although mentioned, are not the object of specific recommendations save to say that the guidance they receive must be culturally appropriate.

The Canadian Public Health Association’s mission is to “enhance the health of all people and communities in Canada, particularly those who are structurally disadvantaged, and to contribute to a healthier and more equitable world” (67). In a 2016 post on its website, *Caregiver burden takes a toll on mental health*, the association acknowledges that caregivers are essential to the Canadian health care system as “they care for individuals at home who would otherwise need professional interventions.” The document concludes: that “...as long as the need for informal care exists, the needs of the voluntary caregiver must also be addressed” (68). Aside from recommending awareness of caregiver needs, no further initiative has been undertaken.

## From narrow to broad: Moving forward

The American Road Map and the Canadian strategy *Together We Aspire* have much in common. They both support more research; they understand the need for a competent workforce trained in dementia care; and they emphasize educating caregivers as well as the greater population about ADRDs. One of the prime motivators for these initiatives is the recognition

that ADRDs have an impact on population health and will have consequences for the health care system. Notably, both the American and Canadian public health responses take into account the consequences of the rise in ADRD and the increasing demand for caregiving over an extended period of time. Nevertheless, the American and Canadian initiatives are focused primarily on meeting the care needs of persons living with ADRD. Even if there is a broad acknowledgment that caregivers play a central role in providing essential care and in promoting the wellbeing of the person living with ADRD, the consequences of caregiving on the health of caregivers are not explicitly addressed. Rather the need for supportive services is framed as a way to sustain caregivers in their caregiving role. As is the case for most initiatives, with the exception of the APHA statement (46), gender is noticeably absent.

The Road Map and *Together We Aspire* focus on research and disease prevention. Knowledge strategies are directed at supporting informed decision-making concerning care provision. These are the goals of a narrow version of public health. However, other Canadian and American initiatives might not easily fit a narrow perspective of public health. I turn to these next.

The *RAISE Act* explicitly addresses caregiver need. It might be concluded that this plan could be integrated into a broad public health approach. Although promising, the act focused on initiatives that target individuals. To explain, the supportive programs, such as respite care, are implemented to mitigate the impact of the activities of caregiving and address the needs of individual caregivers. The services are provided on a case-by-case basis. As discussed previously, this is similar to the medical approach described by Wikler and Brock (52). In addition, there is no explicit recognition of the possible impact of age, poverty or education; yet, these factors can decrease caregivers' ability to provide care and to cope. The APHA statement goes a step further because it underscores the importance of the interaction between paid and family caregivers. This signals a recognition of caregivers as care partners, which is also in the *RAISE Act* and in the CAHS report. This acknowledgment is essential, but there needs to be an additional initiative, that is, to recognize that some caregivers may be more vulnerable than others.

The Dementia Community Investment program is designed to take into consideration the different locations or cultures of those living with ADRD and their caregivers. It is grounded in the recognition that not all populations have the same needs, nor do they have the same approach to caregiving. Although these initiatives are vital, they are allocated as singular funding opportunities. And communities must apply for these grants, thus requiring marginalized communities to mobilize significant resources to write proposals that will obtain financing. This is a piecemeal approach: absent is the blanket recognition of the socioeconomic impacts on caregivers. To illustrate my point, I discuss two key issues. The first is the knowledge mobilization plan that is part of the many initiatives and the other concerns caregiving and gender equity.

The knowledge required to care for persons living with ADRD is a central aspect of most proposals. Shaji and Reddy (3) found that caregivers in India were unaware of the behavioural and cognitive changes due to ADRD as most of them tended to think the changes in behaviour were part of the natural aging process. This is certainly not unique to India. As Queluz et al. found in their scoping review, support for caregivers included sharing information about the disease such as the stages of dementia and the prognosis (16). Other topics mentioned pertained to self-care and relationship management (16). There are many facets to the information needed by caregivers, ranging from an awareness of the symptoms and expression of the particular dementia to knowing how to provide adequate care and to access available services. The caregiver's expertise, or lack of it, will have a direct impact on their ability to manage.

Knowledge mobilization initiatives, such as those funded by the Dementia Community Investment program, target culturally safe and appropriate knowledge transmission. It might be surmised that such initiatives are indicative of a broader public health agenda. However, this conclusion is misleading – the shared information is unidirectional. To explain: the knowledge transmitted is from the experts to the caregivers. It does not allow space for the local knowledge of caregivers to emerge, which means that local practices are subordinated to a scientific discourse. Importantly, it erases the many ways to perceive caregiving as well as the location of caregiving within a family or group. In their editorial on aging and families, Keating and de Jong insist on the importance of families for aging adults and the need to understand the diversity of ways family provide care (69). There is little space for this to take place within the initiatives I examined. Ultimately, the type of knowledge transmission that is encouraged in the Canadian initiatives and strategies is one that is coherent with the goal of disease prevention and management. These are the goals of a narrow understanding of public health.

Gender is an aspect of ADRDs that cannot be ignored. First, women are more likely to develop Alzheimer's and, second, women are the ones who will provide care, both paid and unpaid (70,71). The website of the American Alzheimer's Association states that female caregivers provide 2.5 times more care than male caregivers. In addition, "[m]ore than three in five unpaid Alzheimer's caregivers are women" and "more than one-third of dementia caregivers are daughters" (70). Similarly, in Canada, "women do the majority of unpaid caregiving" (72, p.23). If caregiving is a risk factor for negative health outcomes, then women are more at risk. This aspect of health equity eludes a narrow public health perspective.

A broad version of public health can address and redress the negative health outcomes that many women face because of their caregiving. This will involve many areas of policy, from home care to health care. A greater number of trained paid caregivers, as the APHA recommends, could help women in caregiving roles cope. I would also add that better working conditions and salaries would increase the number as well as the retention of care workers. These are small steps that require a broad understanding of public health.

Finally, I call attention to an example of a regional strategy directed at dementia that enlarges the scope of public health. The Geriatric Health Systems Research Group developed a regional dementia strategy for Southwestern Ontario, Canada. The group explicitly recognizes that regional strategies are crucial as each region may have a unique set of issues. However, this does not imply that there should not be attention given to system wide services. In the study, respondents – persons living with dementia, their care partners, health care administrators and policy makers – all indicated the need for improving system-wide quality (73).<sup>13</sup> As the authors explain, there are different levels of dementia strategies serving distinct purposes. For example, initiatives at the national level focus on education and research, whereas regional strategies develop local programming and target service delivery (73). I would add that questions of gender equity could be addressed by national policies while local policies could be directed at communities allowing for local practices to emerge.

## CONCLUSION

In the USA it is estimated that unpaid caregivers can spend more than 60 hours a week providing care (56). According to a compilation of data from Statistics Canada, Eales, Kim and East report that Canadians who care for someone with dementia will spend 1.5 more time performing caregiving tasks than other caregivers (74). There is an explicit acknowledgement, in the literature, if not in actual policies, that individuals will sacrifice their career and their health to provide adequate care (75-77). In Canada, there are various provincial policies to support family caregivers, such as home-care and respite care, but, as studies have shown, the services are usually insufficient (53,78). The person living with ADRD may enter residential care at a later stage of the disease, but before that time, many hours of caregiving will have taken place in the home.

In this paper, I explained why I agree with Shaji and Reddy's proposal (3) to include caregiving for persons living with ADRD as a matter of public health. To support their recommendation, I showed that caregiving for persons living with ADRD is a social determinant of health. If current policies and initiatives focus on caregiver support, then caregiving should explicitly be part of a broad public health agenda. Caregiving is a risk to the physical and mental health of caregivers and this risk varies according to the caregiver's socioeconomic status. Crucially, women are more often the caregivers of persons living with ADRD. The implication is that women face an increased risk to their health. Because of the ways in which caregiving is linked to other determinants of health, caregiving challenges the narrow definition of public health. My discussion of caregiving in the case of persons living with ADRD adds support to the call for a broader public health agenda that tackles questions relating to migrant health.

I focused on caregiving for persons living with ADRD because of the initiatives put forward by the USA and Canada to address ADRD as a question of public health in addition to the clear evidence linking caregiving and negative health outcomes. The American Road Map and the Canadian Strategy are examples of laudable efforts to bring ADRD into the public health arena. However, even with such bold initiatives, the health outcomes of the caregivers of individuals living with ADRD remain marginal. Nonetheless, there are promising initiatives such as the regional strategy developed by the Geriatric Health Systems Research Group (73). It signals the possibility of a broad public health approach to caregiving: a mix of system wide policies, such as federal policies addressing gender and caregiving, in addition to more local priorities such as those supporting alternative models of caregiving. This is certainly achievable in the Canadian context.

I limited my argument to a specific type of caregiving. It is certainly possible to argue for a broader array of caregiving services; however, not all types of caregiving will have an impact on caregivers' health outcomes, and this requires assessing each type of caregiving. Moreover, even if the type of caregiving has health consequences for caregivers, it may involve a different set of policies. For example, caregiving in the case of children with physical and cognitive impairments would likely involve public health, respite care as well as education policies. As I stated earlier, my argument builds on Talley and Crews' important proposal, which I argue, implies recognizing that public health must embrace a larger agenda. This agenda would not only consider health related questions that pertain to individuals located in a specific place and time, but it would also embrace the subject of public health as one of populations extending over space and time, as Wikler and Brock (52) proposed in the case of bioethics. A focus on *population* as opposed to *public* makes clear that the subject of public health must move beyond borders and beyond generations if it is to address current social and demographic transformations.

The Covid-19 pandemic has made the needs of caregivers even more pressing as illustrated by various international studies calling for caregiver support during this time (79,80). As reported by Wang et al., "[t]he international dementia experts and Alzheimer's Disease International,<sup>10</sup> recommend support for people living with dementia and their carers is needed urgently worldwide. In addition to physical protection from virus infection, mental health and psychosocial support should be delivered" (81, p.1191). If the conditions of care changed during the pandemic, they will likely return to a near pre-pandemic state. However, the need for caregiver support will not vanish.

The inclusion of family caregiving of persons living with ADRD under a broad public health framework that addresses gender inequities through policies and incentivizes all individuals to become involved in care work is a small step toward the greater social and political recognition of the importance of care. It stresses how, in the words of Rogers, the political dimensions of public health are inescapable (82).

<sup>13</sup> Increasingly in the literature, the term 'care partner' is used instead of care receiver. The change is to emphasize that the persons who receive care are not passive recipients of care. Although I agree that those receiving care are too often painted as passive, I retain the use of 'caregiver' as it is the term used in policies and because my discussion pertains to the care that is provided by family and to emphasize that this care is work.

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