Policy Brief

Transforming Caregiving for Alzheimer's Disease and Related Dementias in Quebec: A Dyadic and Technological Innovation Approach

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Executive Summary. Alzheimer's disease and related dementias (ADRD) pose a significant and growing challenge in Quebec, affecting over 147,000 individuals as of 2020. Projections suggest an increase to 360,200 by 2030 [1]. A majority of individuals with ADRD depend on informal care, primarily provided by family members. The caregiving burden significantly affects caregivers' mental and physical health, with many experiencing stress, depression, and anxiety.

Based on evidence in this field, policy recommendations include:

1. Recognizing the caregiver-patient dyad as the "unit of care" – This strategy aims to improve health and social care service delivery by focusing on the collective well-being of both caregivers and patients.
2. Expanding successful models – Leveraging insights and frameworks from proven programs like the UCLA Alzheimer's and Dementia Care Program to enhance care practices.
3. Integrating digital and AI tools – Utilizing technology to support individuals with ADRD and their caregivers, improving accessibility and efficiency of care.

These approaches, together with the integration of digital and AI tools, aim to enhance care for individuals with ADRD and their caregivers. Successful models like the UCLA Alzheimer's and Dementia Care Program provide a blueprint for implementing these strategies.

Introduction. Alzheimer's disease and related dementias (ADRD) pose a significant and growing challenge in Quebec, affecting over 147,000 individuals as of 2020 [1]. Projections suggest an increase to 360,200 by 2030, marking the second-largest growth rate in the number of dementia cases in Canada, or a 145% rise [1]. A majority of individuals with ADRD (61%) live at home, mainly depending on informal care [2]. This support is primarily provided by family members, with 58% being adult children and 32% spouses, along with neighbors or friends [1]. In Quebec, the count of informal caregivers for individuals with ADRD was 86,105 in 2020, expected to rise to 211,587 by 2050 [3]. Notably, 58% of these caregivers are working-age adults, between 35 and 65 years old [1], significantly affecting Quebec's workforce and economy. Often untrained and unpaid, these caregivers shoulder a heavy burden, averaging 26 hours weekly on caregiving, significantly more than the 17 hours typically required for other older adult care [4].

Current Status. While many caregivers of individuals with ADRD find their experiences rewarding and feel a sense of satisfaction or fulfillment from caring for a loved one [5, 6], they often become "secondary patients" due to risks to their physical and mental health [7, 8]. ADRD caregiving is frequently used as a model to study the effects of chronic stress on an individual's mental and physical health [9, 10]. Compared to non-caregivers and those caring for individuals with other health conditions, ADRD caregivers exhibit significantly higher levels of stress, depression, and anxiety [11-15]. They also experience greater cognitive decline [16] and have lower levels of subjective well-being and self-efficacy [17, 18]. Furthermore, they face an increased risk of serious health issues, including cardiovascular diseases and stroke [7, 19]. Emotional health (58%) and physical health (32%) emerge as the primary areas of need for ADRD caregivers [20], highlighting the significant impact of caregiving on these dimensions. Data from the Canadian Institute for Health Information indicate that 45% of ADRD caregivers exhibit symptoms of distress, nearly twice the rate of caregivers for other groups (26%) [4].

The mental and physical strains of caregiving also affect care recipients. Distressed caregivers are at a higher risk of engaging in negative caregiving behaviors [21] and are less capable of fulfilling the practical and emotional needs of the care recipient [22, 23]. The distress of one member in the caregiving dyad often leads to distress in the other [24-27]. Individuals with ADRD and their caregivers face illness together, with the coping success of one impacting the well-being of the other [28-30]. A 2020 Lancet Commission report shows a direct correlation between caregiver depression and a 73% increase in emergency department visits for dementia patients [31], highlighting the significant effect of caregiver mental health on healthcare use by community-dwelling people with dementia.

Policy Recommendations

1. ***Adopting a Dyadic Care Approach: Recognizing the caregiver-patient unit as central to care strategies.*** In response to these challenges, recognizing the caregiver-patient dyad as the "unit of care" emerges as a promising strategy for improving health and social care service delivery. This approach acknowledges the intricate and mutual relationship between caregiver well-being and patient health outcomes, focusing on the collective well-being and balance of the caregiver-patient unit [24]. It highlights the need for comprehensive support strategies that cater to their intertwined experiences. Additionally, it provides health and social care professionals with the means to identify and address vulnerabilities caused by misaligned assessments, insufficient collaboration, inadequate harmonization of needs, and health disparities within the dyad [24, 32, 33].
2. ***Expansion of Successful Models: Building upon the first recommendation, this suggests leveraging insights and frameworks from proven programs, such as the UCLA Alzheimer's and Dementia Care Program, to inform and enhance care practices.*** In this context, Quebec's healthcare system, renowned for its patient-centered approach and commitment to innovation, stands to gain significantly from a nuanced integration of the dyadic approach. Tailoring care to the unique dynamics of each caregiver-patient dyad promises immediate benefits for individuals with ADRD and their caregivers, and could also markedly reduce the strain on the healthcare system. Quebec can find inspiration in strategic pathways for implementing a dyadic approach by looking to programs that have already seen clinical success with this model. An example is the Alzheimer's and Dementia Care Program at the University of California, Los Angeles (UCLA ADC) [34, 35].

The UCLA ADC program is embedded within the healthcare system, forming strategic partnerships with community-based organizations to offer comprehensive, coordinated, and patient-centered care for the patient-caregiver dyad. Its goals are to alleviate caregiver stress and burnout, improve independence, dignity, and functionality for individuals with ADRD, and reduce healthcare costs. The program consists of five key components: (**1**) *Structured needs assessments:* Individuals with ADRD and their caregivers participate in a 90-minute in-person session, including structured interviews and examinations to identify their needs and resources. (**2**) *Creation and implementation of Individualized Care Plans:* Based on needs assessments and input from primary care physicians, these tailored plans address the unique requirements of each dyad. (**3**) *Ongoing management by Care Managers:* These professionals are crucial in coordinating and optimizing care, acting as central figures in the care continuum. (**4**) *Monitoring and revising care plans:* Care plans are actively monitored, with at least a telephone call every four months, to ensure they adapt to ADRD's progressive nature and the evolving needs of each dyad. (**5**) *Around-the-clock access:* The program offers 24/7 access to assistance and advice, ensuring support is available whenever needed [34, 36]. The UCLA ADC program has produced significant results, including a 33% reduction in long-term care admissions [37]. A one-year study demonstrated notable improvements in both patient symptoms and caregiver outcomes, with 75% of participants experiencing clinical benefits [34]. By 2021, the program had served over 1,690 dementia patients and their caregivers across 14 sites, with an additional 80 sites interested in adoption [35, 38].

3. ***Integration of Digital and Artificial Intelligence (AI) Tools: Leveraging technology to support care for individuals with ADRD and their caregivers.*** Within the dyadic approach framework, it is crucial to expand the availability of dyadic psychosocial interventions through health and social service providers. Research demonstrates the beneficial effects of these interventions on cognitive and physical functioning, as well as on psychosocial outcomes for both individuals with ADRD and their caregivers [39 -44]. Evidence suggests that interventions aimed at the dyad may be more effective than those focusing on patients or caregivers alone [45-47]. Delivering these interventions via the internet is particularly promising, offering a solution to the social, logistical, economic, and geographical challenges often associated with

face-to-face interventions [48-50]. This digital approach significantly improves accessibility and convenience for users [51-53]. An example of this potential is an ongoing study at the CIUSSS West-Central Montreal exploring the online Mind-AID program, which aims to reduce repetitive negative thinking among ADRD caregivers [54]. If successful, this program could become available to individuals with ADRD and their caregivers, exemplifying a practical dyadic intervention that targets a modifiable transdiagnostic risk factor for multiple emotional disorders [55-58].

Finally, it's worthwhile to briefly explore the role of Artificial Intelligence (AI) in supporting individuals with ADRD and their caregivers. The Quebec Innovation Council's recent report highlights the need for a regulatory framework that promotes AI integration within Quebec society [59]. Experts predict significant benefits from AI's application across various sectors, especially in healthcare, where it's poised to significantly improve patient outcomes, streamline processes, and facilitate personalized care [59, 60]. Thus, exploring AI to provide more personalized, efficient, and proactive care for individuals with ADRD and their caregivers is timely. Here's how AI could contribute: (**1**) *Predictive analytics:* AI can analyze extensive datasets to predict ADRD risks and caregiver stress, enabling early interventions to mitigate severe symptoms and prevent burnout. (**2**) *Personalized care planning:* AI can assist in creating and dynamically adjusting care plans tailored to the unique needs of each individual, ensuring continuous effectiveness. (**3**) *Support for caregivers:* AI can provide 24/7 virtual assistance to caregivers, offering advice, resources, and stress management support. It can also detect caregiver stress through interactions, suggesting appropriate interventions or directing to human support. (**4**) *Improved communication:* AI platforms can improve care coordination by keeping healthcare teams, patients, and caregivers connected, ensuring a cohesive care strategy. (**5**) *Training and education:* AI tools can provide customized training for caregivers, enhancing their care skills, stress management, and healthcare navigation. (6) Remote monitoring: AI-enabled wearables and home systems can provide real-time insights into patients' health and activities, alerting caregivers to potential issues promptly and reducing the need for emergency interventions [60-62].

Conclusion. Adopting innovative care models and AI tools is crucial for reinforcing Quebec's healthcare system, enhancing its efficiency and effectiveness. These advancements could bolster Quebec's position as a leader in dementia care and caregiver support, both nationally and internationally.

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