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Emergency Preparedness and Response in Canada for People Living with Dementia

Executive Summary

Prepared for the Public Health Agency of Canada

Prepared by Narrative Research

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Prepared for the Public Health Agency of Canada

Supplier Name: Narrative Research

February 2024

This public opinion research report presents the results of online focus groups/dyads and in-depth interviews conducted by Narrative Research on behalf of Health Canada and the Public Health Agency of Canada to better understand the current state of emergency preparedness and response guidance and the adequacy of measures to protect and support people living with dementia during emergency situations, with a particular focus on how to better prepare for future climate-related emergency situations. The research included a total of 25 online focus groups of various sizes, two dyad and 11 in-depth interviews conducted from January 25th to February 23rd, 2024, divided into the following categories: people living with dementia who confirmed their ability to participate, unpaid caregivers to people living with dementia, and paid care providers who care for and interact, either directly or indirectly, with people living with dementia in a professional capacity, including paid care and support personnel, first responders, and government/logistical planners. Good geographic coverage was achieved across Canada and various community sizes were represented, including large urban, small/medium size urban, and rural areas.

Cette publication est aussi disponible en français sous le titre :

Préparation et réponse aux situations d'urgence au Canada pour les personnes atteintes de démence

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Background and Research Methodology

Extreme weather events are becoming more common in Canada. While this type of emergency situation can have a significant impact on anyone, it can be especially difficult for those living with dementia. The main objective of this research is to better understand the current state of emergency guidance and the adequacy of information-based measures such as training and tools to protect and support people living with dementia during climate-related emergencies.

More specifically, the research objectives are to:

- Understand the unique needs of people living with dementia and family / friend caregivers during and after emergencies.
- Gather the nature of experiences of people living with dementia and family / friend caregivers during and after emergencies, including types of challenges.
- Understand the impact of emergencies on people living with dementia including on quality of life both during and after the emergency.
- Identify resources and tools needed to protect and support the quality of life of people living with dementia during emergencies and gather assessments of their availability and effectiveness.

To achieve these objectives, a qualitative research approach was undertaken with the fieldwork conducted from January 25th to February 23rd, 2024. While the initial research plan included 28 online focus groups of various sizes, low participation rate in select audiences led to the final methodology including a combination of online focus groups, dyads (e.g. small focus group with two participants), and in-depth interviews. Specifically, the research entailed a total of 25 online focus groups across four regions including the East (ON/NB/NS/PE/NL/NU); West (MB/SK/AB/BC/YT/NT); West/Central (ON/MB/SK/AB/BC/YT/NT); and Quebec, along with two dyads and 11 in-depth interviews.

Five target audiences were included in the research, namely people living with dementia, unpaid caregivers (often friends and family), paid care providers (personal care workers, health aides, and professional care providers), first responders (including emergency responders), as well as representatives from government or community organizations and emergency response planners or logistical experts (referred to as Government/Logistical Planners in this report). Good geographic coverage was achieved across Canada and



various community sizes were represented, including large urban, small/medium urban, rural, and mixed urban, and rural areas.

Sessions were held in English with the exception of those in Quebec, which were conducted in French. Participation incentives ranged from \$150 to \$200 based on the target audience (i.e., professional care providers and people living with dementia each received \$200, while all remaining audiences each received \$150). Across all groups, a total of 171 individuals were recruited and 150 participated. One additional participant had technical issues and could not take part in the sessions but still received remuneration. Focus group length ranged from one to two hours, while the dyad and in-depth interviews lasted between 30 minutes and one hour.

The following table presents the breakdown of sessions by audience, community size, and language, in addition to the number of recruited participants per session.

Number of Online Focus Groups, Dyads and In-depth Interviews (IDIs)									
Audience	Large Urban	Large/ Medium Urban	Small/ Medium Urban	Small Urban/ Rural	Rural	Mixed Urban	Total Sessions	Total Recruits	Total Participants
	English	English	English	English	English	French			
Unpaid Caregivers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	49	45
Paid Care Providers	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	1 Group Quebec	7 Groups	48	42
First Responders	n/a	1 Group East 1 Group West	n/a	1 Group East 1 Group West	n/a	1 Group Quebec	5 Groups 3 IDIs	32	28
Government/ Logistical Planners	n/a	1 Group East 1 Group West	n/a	1 Dyad East 1 Group West	n/a	1 Group Quebec	4 Groups 1 Dyad 5 IDIs	27	24
People Living with Dementia	1 Dyad West	n/a	1 Mini Group East	n/a	1 IDI West/ Central	2 IDIs Quebec (French) 1 Mini Group Mixed Locations (English)	2 Mini Group 1 Dyad 3 IDIs	15	11
TOTAL							25 groups 2 dyads 11 IDIs	171	150



All participants were recruited per the specifications for the Government of Canada. Recruitment was conducted through qualitative panels stored on Canadian servers, with follow up calls to confirm the details provided and to ensure quotas were met. A referral recruitment approach was also accepted for harder-to-reach populations, following industry guidelines to ensure no participant from the same household took part in the study, and to ensure no participants knew each other in the same group.

Those currently employed in, or retired from a sensitive occupation, or who have others in their household in this situation, were excluded from the research. These sectors included marketing, marketing research, public relations, advertising, media, web development, and provincial/territorial or federal positions related to health care. All focus group participants had access to either a computer or tablet with high-speed internet and equipped with a webcam, or a smartphone, to take part in the session.

This report presents the findings from the study. Caution must be exercised when interpreting the results, as qualitative research is exploratory and cannot infer causality. Results cannot be attributed to the overall population under study.

Political Neutrality Certification

I hereby certify as a Representative of Narrative Research that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Directive on the Management of Communications. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed _____

Margaret Brigley, CEO & Partner | Narrative Research

Date: February 26, 2024



Key Findings

The following provides key highlights from the research:

Personal Experience with Climate-Related Emergencies

Research findings suggest that during and after a climate-related emergency, people living with dementia experienced a wide range of unique challenges and corresponding needs, all of which are intrinsically linked to the condition itself. Most notably, people living with dementia face challenges related to their cognitive ability in responding to the emergency situation appropriately. While symptoms can vary significantly across individuals, many may be unable to gauge that a crisis is occurring or the severity of the crisis and the nature of implications for them personally. With a disruption in their regular routine and potential challenges being able to communicate with others and to understand information and guidance, an individual living with dementia may be much less able to cope with a climate-related emergency than others.

During times of evacuation, additional challenges may include a reluctance/hesitation to leave a familiar environment, little clarity on what to pack, a lack of urgency or understanding of the severity for why evacuation is needed, and in what timeframe an action is needed. Moving a person living with dementia to a new location also presents further challenges, most notably related to placement in an unfamiliar and potentially unsafe environment. Surroundings, contacts, and activities that are unfamiliar may present a serious test to a person living with dementia's ability to adapt to the situation and maintain current functional abilities.

Needs Identification Related to Climate-Related Emergencies – People Living with Dementia

The wide range of unique challenges experienced by those living with dementia highlight a variety of corresponding needs for the provision of care when faced with a climate-related emergency. The primary needs of those living with dementia during an emergency revolve around ensuring continuity of care, which is dependent upon ready access to current information to direct their care. This includes, but is not limited to, a clear baseline of their condition, medication listings, key contact information, and strategies to calm or support the individual when needed. In addition, people living with dementia having access to ongoing contact from primary care providers (paid or unpaid) is deemed paramount in their care provision. Throughout the emergency, there is a need for patience, reassurance and ongoing support. Clear, simple messaging is also needed to guide their actions, ideally supported by visual cues.

Needs Identification Related to Climate-Related Emergencies - Unpaid Caregivers

In addition to the significant challenges facing those living with dementia during a climate-related emergency, unpaid dementia caregivers face a range of unique challenges. Across participants, there was general agreement that unpaid caregivers often have difficulty coping with the responsibilities of providing care in the context of this type of emergency and need guidance on how to respond to the changing and increased needs of people living with dementia. Directions for preparedness are needed, as is information on how to provide care during an emergency, such as the importance of checking in during the duration of



the emergency. Unpaid caregivers may be overwhelmed and often exhibit ‘burn out’ as a result of their extended provision of unpaid care to a person living with dementia during a climate-related emergency. They are typically unaware of what resources or supports are available to assist them, as well as what financial programs might be accessible for them during and after such an emergency.

Some unpaid caregivers expressed a need for more direct physical aid, beyond just guidance. During a climate-related emergency, some had experienced staffing issues at facilities, whereby family / friend caregivers were relied upon when there were not enough paid staff to meet needs.

Impact of Climate-Related Emergency Events

Across participants, climate-related emergencies were thought to have an impact on people living with dementia, although the extent was unclear. There was a belief that the situation could be vastly different across individuals living with dementia depending on the type and severity of climate-related emergencies, their past experiences, the range and severity of symptoms experienced, their living conditions during the emergency, and the strength of their support networks. The situation of each person was considered unique and can be difficult to plan for. Nonetheless, the perception was that in many instances, climate-related emergencies can disrupt routines and cause heightened stress for people living with dementia, thus resulting in sudden worsening of their symptoms and/or exaggerated responsive behaviours. Elevated levels of stress were also reported by unpaid caregivers who have to react to the impact of the climate-related emergency on themselves in addition to increasing their support for the person they care for.

An additional impact of climate-related emergency events on people living with dementia was nutritional or other health-related factors, especially among those who live alone. This included eating expired foods during power outages, experiencing mould during floods, or forgetting to eat or drink.

Identification of Tools and Resources

There was limited awareness of existing tools and resources to support people living with dementia and unpaid caregivers during climate-related emergencies. In fact, most of the participants included in the research reported relying on their personal judgement or experiences to inform their interactions with people living with dementia. Paid care providers and first responders reported relying on training or a support network provided by their employer, although nothing specifically designed for responding to the needs of people living with dementia during climate-related emergencies is currently available. The Alzheimer Society of Canada was commonly cited as a good source of support for people living with dementia and unpaid caregivers, although it was not generally thought of as a source for providing climate-related emergency-specific resources or resources for other participants (e.g., first responders and health care professionals). Tools and resources from other sources were far less often cited and tended to be community- or province-specific.

Although few tools are currently relied upon by people living with dementia and unpaid caregivers to prepare for climate-related emergencies, there was interest in additional information and support. Most notably, it was believed that unpaid caregivers play a significant role during climate-related emergencies and should be properly informed and supported in this role.



There was a desire among unpaid caregivers for information to guide interactions with people living with dementia during emergencies, including such things as understanding how climate-related emergencies may impact people living with dementia, the signs to look for when keeping them safe and healthy during the event, how to communicate with them based on different scenarios, actions to take and avoid, where to go, who to call for assistance, and what to include in an emergency kit. Suggestions were also made to develop outreach tools to support people living with dementia and caregivers during a climate-related emergency. Examples given included a secure, centralized national vulnerable person registry to be accessed only by emergency responders or other professionals in appropriate circumstances, and a portal that centralizes information and resources of interest.

In developing tools and information specific to people living with dementia, it was felt that a multi-mode approach should be considered to allow adaptation to the breadth of dementia symptoms that exist. While online and print copies may be of use to unpaid caregivers and some people living with dementia, there was also an expressed need for short, focused videos in different languages, as well as other visual tools, and audio formats. Interactive workshops or discussion groups were believed to be of use to unpaid caregivers as they provide an opportunity for discussions with peers.

A variety of other suggestions were provided, including:

- In-person check-ins by paid health professionals with people living with dementia during the emergency.
- Raising awareness of unpaid caregivers' mental health and providing support resources for them.
- Sending regular weather reports to supportive and long-term care facilities so they can prepare for the impact of climate-related emergencies ahead of time.
- Having a hotline available that families can call to get information quickly, to avoid calling 911.
- Encouraging long-term care homes to develop climate-specific emergency preparedness plans and keep regularly updated records related to people living with dementia.
- Encouraging communities to set up a coordinated climate-related emergency response team/plan specific to people living with dementia.
- Making it easier for paid care providers and first responders to access the medical records of people living with dementia during emergencies.
- Encouraging municipalities to establish an evacuation protocol that is specific to people living with dementia.
- Ensuring long-term care homes conduct regular inspections and evacuation drills.