# Prevalence of and Antecedents to Missing Incidents Amongst Older Adult Medic-Alert ’s Subscribers: A Retrospective Descriptive Study

Antonio Miguel-Cruz, Hector Perez, Yoojin Choi, Emily Rutledge, Christine Daum, Lili Liu

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## *Abstract*

**Background:** With population aging the number of people living with dementia is expected to increase and consequently so is the prevalence of missing incidents due to critical wandering. However, the estimated prevalence of missing incidents due to dementia is inconclusive in some jurisdictions and overlooked in others.

**Objective:** The aims of the study were to examine: (1) the demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among older adult Canadian Medic-Alert Foundation Incorporated (herein Medic-Alert) subscribers, and (2) the characteristics and outcomes of the missing incidents.

**Methods:** Retrospective descriptive design. The sample included 434 older adult Medic-Alert subscribers involved in 560 missing incidents between January 2015 to July 2021

**Results:** The sample was overrepresented by Caucasian. Medic-Alert subscribers reported missing were mostly older females, living in urban areas with at least one family member. Most self-reported to be living with dementia. Medic-Alert subscribers went missing most frequently from their private homes in the community, travelling on foot and public transport, during the afternoon and evening. Most were located by first responders or Good Samaritans. From the total sample of 560 missing incidents, 22.5 % were a repeated incident. The mean time between missing incidents was 11 months. Finally, the majority of Medic-Alert subscribers returned home safely, and reports of harm, injuries and death were very low (i.e., 0.2% of cases).

**Conclusions:** Missing incidents involved mostly old adults living with dementia from an urban area. Most Medic-Alert subscribers involved in missing incidents were safely returned home. This study provides prevalence of missing incidents from one database source. The low frequency of missing incidents may not represent populations that are not Caucasian. Despite the low number of incidents, of the 0.2% cases resulting in injuries or death are devastating experiences that may be mitigated through prevention strategies. Clinical Trial: NA

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# Prevalence of and Antecedents to Missing Incidents Amongst Older Adult Medic-Alert® 's Subscribers: A Retrospective Descriptive Study

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**Conclusions:** Missing incidents involved mostly old adults living with dementia from an urban area. Most Medic-Alert®subscribers involved in missing incidents were safely returned home. This study provides prevalence of missing incidents from one database source. The low frequency of missing incidents may not represent populations that are not Caucasian. Despite the low number of incidents,

of the 0.2% cases resulting in injuries or death are devastating experiences that may be mitigated through prevention strategies.

**Keywords:** Dementia; Alzheimer’s; memory loss; cognitive impairment; missing incident; wandering; critical wandering; older adults; retrospective design

## Introduction

With population aging the number of people living with dementia will increase. Currently, the global prevalence of dementia is approximately 55 million [1]. With approximately 10 million new diagnoses each year, the total number of cases is expected to rise to 78 million by 2030 [1]. Canada is no exception to this trend, with at least 546,000 people currently living with dementia [2]. By 2030, the number of Canadians with dementia will reach at least 1,712,400 [3].

The disease burden cost associated with dementia is sizable in Canada. It was estimated that the direct costs (eg, long-term care) associated with dementia was CAD $10.4 billion in 2016 and it is expected to double by 2030 [2]. Fifty percent of the global cost of dementia is attributed to informal care (ie, family members and friends) [1]. It is estimated that, on average, care partners spend 26 to 35 hours per week caring for persons with dementia [1,4]. This overwhelming number of caregiving hours is attributed to personal care (ie, personal care such as bathing, feeding, and assisting with toileting) [5] and vigilance as a prevention strategy to unattended exits, ultimately keeping persons living with dementia safe in their homes [6].

With increasing numbers of people living with dementia, the prevalence of missing incidents due to critical wandering is rising as well (see section below: *The concept of missingness, critical wandering and its risk factors: a brief theoretical background*). However, research on prevalence estimation on missing incidents due to critical wandering is inconclusive in some jurisdictions and overlooked in others. Limitations of the prior literature on this topic exists. First, there is a lack of consistency on reported prevalence [7], leading to disparate statistics. For example, McShane and colleagues [8] reported that 40% of people with dementia become lost, and 5% do so repeatedly. The Alzheimer's Association estimated that 60% of people with Alzheimer's disease will wander [3], and

a considerably larger set of studies showed that prevalence of wandering varies from 11% to 60% [9,10]. Second, previous studies included low sample sizes from limited secondary data sources (eg, data not retained for more than five years [11]) such as police data, data obtained from newspaper or social media [12–15], leading to a limited scope of the statistical analyses. Third, prevalence studies have been completed in United States of America [16,17], Japan [18–20], and Korea [21,22], leaving Canadian prevalence of missing incidents among the dementia population largely unknown. This is an important gap in our knowledge as Canada has distinct social, healthcare, geographical features and a harsh climate, making it challenging to extrapolate data from other countries for its unique context. As a result, the prevalence and risks factors of missing incidents due to critical wandering for Canadians living with dementia remain largely unknown.

The aims of the study were to examine: (1) the demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among older adult Medic-Alert®subscribers, and (2) the characteristics and outcomes of the missing incidents. We used a retrospective descriptive design. The sample included 434 older adult Medic-Alert® subscribers (from now on just Medic-Alert® subscribers) involved in 560 missing incidents between January 2015 to July 2021.

## The concept of missingness, critical wandering and its risk factors: a brief background

Missingness is the phenomenon of going missing [11]. A missing person is an “individual that cannot be found” [23]. A missing person is “an individual whose whereabouts are unknown to members of their familial, social or professional networks where there is concern for either their own safety and wellbeing or that of others”[24]. A person can go missing intentionally or unintentionally. A person

who goes missing unintentionally is said to be lost if the person is (a) “confused with current location in respect to finding other locations” and (b) “unable to reorient” [23]. In this research, we analyzed missing incidents related to persons (older adults) who go missing unintentionally. People living with dementia are at risk of unintentionally getting lost due to critical wandering. “Critical” wandering occurs when an individual living with dementia “leaves an institution or home [with or without the consent of their care partner] and is unaware of his or her situation in terms of place and/or time” [7]; the person is lost. Critical wandering is a necessary, but not a sufficient, condition for a missing incident to occur. A missing incident in people living with dementia can occur when this person does critical wandering and is left unsupervised for a few minutes, for instance [25]. Therefore, critical wandering and missing incident are two distinct concepts, although literature in this field acknowledge that the former could lead to the latter [26].

Antecedents or risk factors influence the mechanisms preceding and contributing to missing incidents [11,26,27]. One way to classify antecedents is to determine whether characteristics are intrinsic (demographic, and psychopathological or neurocognitive antecedents) or extrinsic (situational or environmental antecedents) to the missing individual. Demographic antecedents comprise of sex, gender, age and ethnicity of the missing individual. Psychopathological or neurocognitive antecedents are manifestation of behaviours related to cognitive or psychological impairment, mental illness, disorders or distress. Finally, environmental antecedents may include social, cultural, political, economic and weather conditions. [11]. Another way to classify antecedents is to determine whether they are fixed or variable. A fixed antecedent is one that does not vary within individuals over time (eg, ethnicity). Conversely, a variable antecedent changes over time (eg, the age of an individual) [28]. Missing incidents can lead to consequences or outcomes to the missing person and their care partners [26]. For a missing person, these outcomes can range from returning home safely to minor injuries, major injuries or even death [26].

## Medic-Alert® service

When a person goes missing, Medic-Alert® is a Canadian-based service that can assist first responders and Good Samaritans in identifying an individual who has gone missing and connecting them with their care partners to help them return to their place of residence. The two primary tools used in the service are a medical identification object and a Personal Health Information Record (PHIR). The identification object, which is typically in the form of a bracelet, contains key health conditions and a unique Medic-Alert® ID number specific to the individual. The Medic-Alert® ID number can then be used by authorized personnel to access a subscriber's PHIR which contains extensive details about the subscriber's medical conditions, medications and information on previous wandering history if provided by the subscriber or care partner. Is important to recognize that information is self-reported instead of provided by or confirmed with health providers. That is, a Medic-Alert® subscriber or care partners are at liberty to disclose details about the person's situation and medical condition. This information is relayed via a 24/7 hotline or by direct digital access by police services dispatchers. The hotline operator or the dispatcher then notifies the care partners about the missing person's location in an emergency [29]. By linking care partners, first responders, and Good Samaritans, the goal is to safely return the missing person back home.

# Methods

## Study design and sample

The University of Waterloo ethics review board approved this study (Protocol: 43164). We used a retrospective descriptive design. The sample included 434 older adult Medic-Alert® subscribers involved in 560 missing incidents between January 2015 to July 2021. Data were obtained from Medic-Alert®'s subscriber database and summary notes made by hotline call operators. Both

databases are linked through a unique Medic-Alert® subscriber identification number.

## Variables and measures

We obtained information on the following variables (see Table A.1 in the supplemental material for more details):

*Demographic antecedents.* Age, sex at birth, ethnic background, Canadian official languages spoken, province, and primary contact.

*Psychopathological antecedents.* Medical conditions.

*Environmental antecedents.* Population density and living arrangement.

*Characteristics of the missing incidents.* Mode of mobility, time of the day and season in which the missing incident occurred, the family care partner's involvement in response to the missing incident, who reported and found the missing person, point last seen or where the person was missing from, location in which the person was found (actual and self-reported), number of missing incidents, repeated missing incident history (actual and self-reported), mean time to the first missing incident (MTFI) (in days), mean time between missing incidents (MTBI) (in days), and survivability.

## Procedures

*Missing incident selection procedure.* Detailed information about the missing incidents were obtained from the summary notes made by the Medic-Alert® hotline operator when a call was received to the Medic-Alert® call centre. These notes are documented by the operator each time a call is received and were in free text format. We included incidents in which the Medic-Alert® subscribers (a) were aged 65 years or older; (b) went missing unintentionally; and (c) there was clear indication

that the subscriber was actually lost (indications of disorientation or confusion or spatial navigation challenges). We excluded missing incidents that: (a) were false positive reports (eg, global position devices were activated and generated a record in the hotline access database, miscommunication between family members, missing incident calls created for training purposes), (b) were duplicate missing incident in which several follow-up calls were associated with the same missing incident, or (c) did not contain enough information to extract data.

Upon receiving the dataset, eight team members (including the authors) explored and immersed themselves in the dataset. Each read 60 different call summary notes and made notes on their contents in relation to free text fields in the Medic-Alert®'s subscriber database (eg, Population Density, see Supplemental Material Table A.1. Variables and measures definition for more details). Team members shared their observations during two subsequent meetings, and these were used to create a preliminary coding framework including key definitions and the operationalization of each variable (see *Categories generation and operationalization of variables section* for more details). Two team members, hereafter referred to as analysts, screened, extracted and coded relevant information from the summary notes made by the Medic-Alert® hotline operator using the coding framework. Analysts then completed a calibration exercise in which they independently applied the inclusion and exclusion criteria as well as coded 10 included incidents. The calibration exercise was conducted as follows: first, 10 cases were selected randomly. Then, two researchers independently assessed the cases based on the inclusion and exclusion criteria. Finally, the two researchers met and debriefed on the main causes of disagreements. In the calibration process, the team achieved a 90% agreement (ie, percent of agreement calculated as the number of times a set of ratings are the same, divided by the total number of units of observation that are rated). The analysts then screened and coded data for another 100 incidents (registries) independently and checked each other's work. The coding framework was revised to improve the clarity of definitions and the operationalization of the

codes. The analysts met weekly to discuss incidents that were unclear or required a second opinion and revised the coding framework to increase clarity. When the coding framework was revised, the analysts reviewed the previously coded data against the revised coding framework and re-coded as necessary. The analysts also sought feedback from the first author when conflicts in their screening and coding arose. In total, 7045 incidents were screened from the hotline access Medic-Alert® database. After applying the inclusion exclusion criteria, 6460 (91.6%) incidents were excluded. The incidents were excluded due to false positive report incidents (72.3%; 5093/7045), not enough information to extract data from the incidents (15.3%; 1076/7045), no indications of disorientation or confusion or spatial navigation challenges (3.8%; 270/7045), and Medic-Alert® subscribers being younger than 65 years old (0.2%; 17/7045).

*Categories generation and operationalization of variables*. After the dataset was cleaned, variables regarding antecedents to the missing incident were coded categorically based on previous research [30,31] and following Statistics Canada's whenever possible [32]. As some variables were stored in the form of free text, categories were generated inductively from the information contained in the free text (see *Missing incident selection procedure*), eg, missing incident notes hotline operator. Finally, all variables were operationalized as follows: Dichotomous variables were coded as ‘‘0’’ or ‘‘1’’ (eg, Medic-Alert® subscriber’s sex) and each polytomous variable was represented by a set of binary design whose values codified each category variables.

## Data analyses

We used descriptive statistics such as the central value of distributions using the mean and standard deviations for continuous variables. We used $\chi^2$ and Fisher’s exact (in the case of small, expected counts) tests for comparing categorical variables. Where appropriate, t-tests or Mann–Whitney U test

(two independent groups), and One-way ANOVA or Kruskal–Wallis test by ranks (more than two groups) were used for determining difference between groups for continuous variables. Where appropriate, we used Cramer's V and Pearson and Spearman's Rho to determine correlations or associations between variables. As a retrospective descriptive study, each variable was examined separately [31]. Statistical analysis was conducted using SPSS statistical analysis software v. 28.0 (SPSS Inc., Chicago, IL). The alpha was set at $P$ =.05.

## Results

### Demographic, psychopathological, and environmental antecedents to missing incidents among Medic-Alert® subscribers

Table 1 shows the demographic and environmental antecedents to missing incidents among Medic-Alert® subscribers. Overall, 434 Medic-Alert®'s subscribers were involved in 560 missing incidents between January 2015 to July 2021. Regarding psychopathological or neurocognitive antecedents, in 79.5% (345/434) of cases, Medic-Alert® subscribers reported to be living with dementia. The remaining 20.5% (89/444) of Medic-Alert® subscribers reported having other medical conditions, the most prevalent being short- and long-term memory loss and mental health issues such as depression, schizophrenia and anxiety disorder. However, it is important to keep in mind that these data are self-disclosed at the time of Medic-Alert® subscription and thus may underestimate the true prevalence of dementia in this sample.

The average age of Medic-Alert® subscribers was 82.56 (SD 7.4), with just over half (53%) being females. The most prevalent age groups were 75-84 (40.8%) and 85-94 (38.7%), together representing 79.5% of the sample. Caucasians represented the vast majority (75.8%) of the

subscribers. In 55.8% of cases, they spoke English with an additional 18.1% who spoke other language(s) in addition to English; notably, 11.6% of the subscribers spoke neither of the two Canadian official languages, English and French. Medic-Alert® subscribers primarily resided in Ontario (58.3%), British Columbia (16.7%) or Quebec (14.7%), and a vast majority or 97.1% lived in urban areas. Living arrangements included with family (63.8%) and in a facility (20.7%), although 13.1% reported living alone. Most subscribers (90.6%) listed family members as their primary contact.

Table 1 Demographics and environmental antecedents of the sample (Unit of analysis: Medic-Alert® subscriber)

| Demographic characteristics | Mean (SD) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | 5ND[a] & D[b] | ND | D | |
| Age [n=434] (Min=65, Max=101) | 82.56 (7.4) | 83.90(7.153) | 82.21 (7.381) | F(1, 429) = [0.934], *P* =.334[c] |
| Age range | (65,101) | (66,101) | (65,99) | |
| **Sex at birth [valid cases, n=431]** | | **n (%)** | | |
| *Female* | 230 (53.0) | 51 (11.8) | 179 (41.5) | $\chi^2(1)=0.936$, *P* =.333[d] |
| *Male* | 201 (46.3) | 37 (8.6) | 164 (38.1) | |
| **Age group [n=434]** | | **n (%)** | | |
| *65-74* | 72 (16.6) | 9 (2.1) | 63 (14.5) | $\chi^2(3)=7.805$, *P* =.05[d] |
| *75-84* | 177 (40.8) | 35 (8.1) | 142 (32.7) | |
| *85-94* | 168 (38.7) | 38 (8.8) | 130 (29.9) | |
| *95-104* | 17 (3.9) | 7 (1.6) | 10 (2.3) | |
| *>105* | 0 (0.0) | 0 (0.0%) | 0 (0.0) | |
| **Ethnic background [valid cases, n=425]** | | **n (%)** | | |
| *White (Caucasian)* | 329 (75.8) | 67 (15.8) | 262 (61.6) | $\chi^2(3)=3.383$, *P* =.336[d] |
| *Black*[e] | 23 (5.3) | 6(1.4) | 17 (4.0) | |
| *Other*[f] | 53 (14.3) | 6(1.4) | 47 (11.1) | |
| *Chinese* | 20 (4.6) | 5 (1.2) | 15 (3.5) | |
| **Canadian official languages spoken [valid cases, n=430]** | | | | |
| *English only* | 240 (55.8) | 47 (10.9) | 193 (44.8) | $\chi^2(5)=6.388$, *P* =.270[d] |
| *English and other* | 78 (18.1) | 11 (2.6) | 67 (15.6) | |
| *Neither English nor French* | 50 (11.6) | 10 (2.3) | 40 (9.3) | |
| *French only* | 30 (7.0) | 10 (2.3) | 20 (4.7) | |
| *English and French* | 27 (6.3) | 6 (1.4) | 21 (4.9) | |
| *French and other* | 5 (1.2) | 2 (0.5) | 3 (0.7) | |
| **Province [valid cases, n=341]** | | | | |
| *Ontario* | 199 (58.3) | 36 (10.6) | 163 (47.8) | $\chi^2(7)=6.637$, *P* =.468[d] |
| *British Columbia* | 57 (16.7) | 11 (3.2) | 46 (13.5) | |
| *Quebec* | 50 (14.7) | 16 (4.7) | 34 (9.9) | |
| *Alberta* | 18 (5.3) | 3 (0.9) | 15 (4.4) | |
| *Manitoba* | 9 (2.6) | 2 (0.6) | 7 (2.1) | |
| *Nova Scotia* | 4 (1.2) | 0 (0.0) | 4 (1.2) | |
| *Saskatchewan* | 3 (0.9) | 1 (0.3) | 2 (0.6) | |
| *New Brunswick* | 1 (0.3) | 0 (0.0) | 1 (0.3) | |
| *Newfoundland and Labrador* | 0 (0.0) | 0 (0.0) | 0 (0.0) | |
| *Prince Edward Island* | 0 (0.0) | 0 (0.0) | 0 (0.0) | |
| *Nunavut/Northwest Territories* | 0 (0.0) | 0 (0.0) | 0 (0.0) | |

| | | | | |
|---|---|---|---|---|
| *Yukon* | 0 (0.0) | 0 (0.0) | 0 (0.0) | |
| **Population Density [valid cases, n=341]** | | **n (%)** | | |
| *Urban* | 331 (97.1) | 66 (19.4) | 265 (77.7) | $\chi^2(1)=0.609$, $P=.435$[d] |
| *Rural* | 10 (2.9) | 3 (0.9) | 7 (2.1) | |
| **Living arrangement [valid cases, n=433]** | | **n (%)** | | |
| *With Family* | 277 (63.8) | 53 (12.2) | 224 (51.7) | |
| *Facility* | 90 (20.7) | 24 (5.5) | 66 (15.2) | $\chi^2(3)=3.222$, $P=.359$[d] |
| *Alone* | 57 (13.1) | 9 (2.1) | 48 (11.1) | |
| *Other* | 9 (2.1) | 2 (0.5) | 7 (1.6) | |
| **Primary contact [valid cases, n=341]** | | **n (%)** | | |
| *Family Member* | 309 (90.6) | 63 (18.5) | 246 (72.1) | |
| *Other* | 16 (4.7) | 5 (1.5) | 11 (3.2) | $\chi^2(3)=3.172$, $P=.366$[d] |
| *Health and social care professionals* | 15 (4.4) | 1 (0.3) | 14 (4.1) | |
| *Staff of living facility* | 1 (0.3) | 0 (0.0) | 1 (0.3) | |

a. Dementia (D): Person living with dementia
b. One way-ANOVA
c. $\chi 2$ test
d. eg, African. Haitian. Jamaican. Somali
e. Others ( Arab/West Asian (eg, Armenian, Egyptian, Iranian), Latin American, South Asian, Korean, Mediterranean, Aboriginal (eg, Inuit, Métis, North American Indian), Filipino, Caribbean/West Indian (Lucia, Antigua), Southeast Asian, and Japanese

Table 2 shows the history of missing incidents among Medic-Alert® subscribers. Subscribers self-reported no prior history of missing incidents at the time of Medic-Alert® subscription in 10.4% of cases, while 89.6% disclosed having been involved in missing incidents repeatedly. Surprisingly, data from actual repeated missing incidents (ie, data that we accessed using the hotline access database) showed the opposite; most of the subscribers went missing repeatedly in only 16.4% of cases. Medic-Alert® subscribers self-reported that the most common places to be found were outdoor public spaces (eg, highway, street) (59.7%) or indoor public or communal spaces (27.6%) (eg, libraries).

Table 2. Missing incidents history (Unit of analysis: Medic-Alert® subscriber)

| Missing incidents history | n (%) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | ND[a] & D[b] | ND | D | |
| **Missing incident history (self-reported) [valid cases, n=433]** | | | | |
| *No* | 45 (10.4) | 7 (1.6) | 38 (8.8) | |
| *Repeated (1[c] to 4 Times)* | 327 (75.5) | 67 (15.5) | 260 (60.0) | $\chi^2(2)=0.897$, $P=.638$[d] |
| *Habitual (Over 4 Times)* | 61 (14.1) | 14 (3.2) | 47 (10.9) | |
| **Repeated missing incident history (actual) [valid cases, n=434]** | | | | |
| *No* | 363 (83.6) | 79 (18.2) | 284 (65.4) | $\chi^2(1)=2.148$, $P=.143$[d] |
| *Yes* | 71 (16.4) | 10 (2.3) | 61 (14.1) | |
| **Possible locations to be found** | | | | |

| | | | | |
|---|---|---|---|---|
| **(self-reported) [valid cases, n=308]** | | | | |
| *Outdoor public space* [e] | 184 (59.7) | 34 (11.0) | 150 (48.7) | |
| *Indoor public or communal space* [f] | 85 (27.6) | 18 (5.8) | 67 (21.7) | $\chi^2(3)=4.373$, $P=.224$[d] |
| *Private home in the community* [g] | 32 (10.4) | 11 (3.8) | 21 (6.8) | |
| *Hospital, day program, day clinic* | 7 (2.3) | 1 (0.3) | 6 (1.9) | |

a. Person living without dementia
b. Person living with dementia
c. After the first incident
d. $\chi 2$ test
e. Highway, street, alley, intersection, park, parking lot, outdoor bus stop, construction, cemetery
f. Grocery store, shopping mall, train station, church, rec centre, library, Dr. office, bus, train, police station, gas station
g. House, apartment, condo, age 55+ condo but without supportive living services

The statistical tests in Tables 1 and 2 showed that Medic-Alert® subscribers with and without dementia involved in missing incidents were similar with respect to mean age, ethnic background, Canadian official languages spoken, province of residence, population density, living arrangement, primary contact, possible location to be found during a missing incident (self-reported), missing incident history (self-reported), and repeated missing incident history (actual missing incidents) and not statistically significant difference were found between the groups. Medic-Alert® subscribers with and without dementia involved in missing incidents are significantly different ($\chi^2(3)=7.805$, $P=.05$) in terms of age groups. This result means that prevalence of wandering was higher among older age groups with dementia, with the peak prevalence between ages 75-84 declining somewhat in the oldest old.

## Characteristics of the missing incidents

*Demographics and psychopathological antecedents*. Missing incidents mostly involved people living with dementia (79.6%), female (53.4%), from age groups 65-74 (16.6%), 75-84 (40.8%), and 85-94 (38.7%), white (Caucasian) (75.8%), English speaking (90.1%), living in an urban area (97.1%), mostly from Ontario (58.4%), British Columbia (16.2%), and Quebec (14.7%), and living with a

family member (64.0%) or in a facility (20.8%)

*Locations.* Locations were analyzed in terms of point last seen or where the Medic-Alert® subscribers were missing from and located. Medic-Alert® subscribers were most frequently missing from private homes in the community (67.1%) or residential living facilities (18.9%); there were no statistical differences in the location from which Medic-Alert® subscribers with and without dementia went missing. Regarding the location found, the most common places (82% of cases) being outdoor and indoor public spaces. Importantly, we found a statistically significant difference between point last seen or where the Medic-Alert®'s subscribers were missing from and where they were located ($\chi^2(25)=42.274$, p=0.017) (see Table 3 for more details). This result indicates the Medic-Alert® subscribers are relatively active with some degree of mobility. Even more interestingly, we found a moderate positive association between the possible locations to be found (self-reported) and the actual location where the person was found (Cramer's V coefficient, $r_{xy}= 0.213$, p =0.002)

Table 3. Characteristics of missing incident. Point last seen or where the person is missing from and location in which the person was found (Unit of analysis: Missing incidents)

| Characteristics of missing incident. (Locations) | n (%) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | ND[a] & D[b] | ND | D | |
| **Point last seen or where the person is missing from [valid cases, n=143]** | | | | |
| *Private home in the community* | 96 (67.1) | 20(14.8) | 76 (51.7) | $\chi^2(5)=3.398$, $P$ =.639[e] |
| *Residential living facility* [c] | 27 (18.9) | 5 (4.0) | 22 (15.4) | |
| *Indoor public space* [d] | 8 (5.6) | 1 (0.7) | 7 (4.7) | |
| *Other* | 5 (3.5) | 2 (1.3) | 3 (2.7) | |
| *Hospital, day program, day clinic* | 5 (3.5) | 0 (0.0) | 5 (3.4) | |
| *Outdoor public space* [f] | 2 (1.4) | 0 (0.0) | 2 (1.3) | |
| **Location in which the person was found [valid cases, n=382]** | | | | |
| *Outdoor public space* | 202 (52.9) | 42 (11.3) | 160 (40.6) | $\chi^2(6)=10.156$, $P$ =.118[e] |
| *Indoor public space* | 111 (29.1) | 27 (7.8) | 84 (22.6) | |
| *Private home in the community* | 40 (10.5) | 5 (1.3) | 35 (8.8) | |
| *Hospital, day program, day clinic* | 12 (3.1) | 2 (1.0) | 10 (2.5) | |
| *Residential living facility* | 11 (2.9) | 2 (0.5) | 9 (8.8) | |
| *Other* | 4 (1.0) | 3 (0.8) | 1 (0.3) | |
| *Combination of more than of the above* | 2 (0.5) | 0 (0.0) | 2 (0.5) | |

a. Person living without dementia

b. Person living with dementia
c. Long term care centre, assisted living facility, supportive living facility, lodge, group home)
d. Grocery store, shopping mall, train station, church, recreation centre, library, Dr office)
e. $\chi 2$ test
f. (eg, highway, street, alley, intersection, park, parking lot)

*Mode of mobility.* While missing, the most common way of travelling was on foot (91.9% of cases). The second most common mode of mobility was public transportation (4.4% of cases) (see Table 4 for more details).

Table 4. Characteristics of missing incident. Mode of mobility (Unit of analysis: Missing incidents)

| Characteristics of missing incident. | (%) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | ND[a] & D[b] | ND | D | |
| **Mode of mobility [valid cases, n=270]** | | | | |
| *On foot* [d] | 248 (91.9) | 57 (21.1) | 191 (70.7) | |
| *Public transit* [e] | 12 (4.4) | 3 (1.1) | 9 (3.3) | |
| *Receiving a ride from someone else* [f] | 3 (1.1) | 1 (0.4) | 2 (0.74) | |
| *Driving own car* | 2 (0.7) | 0 (0.0) | 2 (0.7) | $\chi^2(6)=2.302$, $P=.890$[c] |
| *Other* | 2 (0.7) | 0 (0.0) | 2 (0.7) | |
| *Combination of several of the above* | 2 (0.7) | 0 (0.0) | 2 (0.7) | |
| *Long range/transregional transit* [g] | 1 (0.4) | 0 (0.0) | 1 (0.4) | |

a. Person living without dementia
b. Person living with dementia
c. $\chi 2$ test
d. Walking
e. Bus, LRT, subway, streetcar
f. Hitch-hiking
g. Train, plane, non-commuter bus, ferry

*Temporality (Time and Seasonality).* Table 5 shows the temporality of missing incidents in terms of time of the day and season reported missing. In general, missing incidents occurred mostly in the afternoon (46.8%) and the evening (31.1%), while the most common seasons for these incidents were summer and fall followed by spring (39.6%, 27.5%, and 20.2% respectively). In other words, missing incidents occurred in the warmest months of the year, comprising 64.0% of cases (May-September, ie, May (10.5%), June (12.9%), July (14.5%), August (12.3%), and September (13.8%). No statistical differences for temporality variable by person living with and without dementia were

found.

Table 5. Characteristics of missing incidents. Time and Seasonality (Unit of analysis: Missing incidents)

| Missing incidents characteristics. (Time and Seasonality) | n (%) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | ND[a] & D[b] | ND | D | |
| **Time of the day, [valid cases, n=560]** | | | | |
| *Afternoon (12:00 to 17:59)* | 262 (46.8) | 61 (11) | 201 (35.1) | $\chi^2(2)=7.207$, $P=.027$[d] |
| *Evening (18:00 to 23:59)* | 174 (31.1) | 40 (7.1) | 134 (23.3) | |
| *Morning (0:00 to 11:59)* | 124 (22.1) | 15 (3.9) | 109 (19.2) | |
| **Season, [valid cases, n=560]** | | | | |
| *Summer (June 1 to August 31)* | 222 (39.6) | 47 (8.4) | 175 (31.3) | $\chi^2(3)=3.344$, $P=.342$[d] |
| *Fall (September 1 to November 30)* | 154 (27.5) | 34 (6.1) | 120 (21.4) | |
| *Spring (March 1 to May 31)* | 113 (20.2) | 17 (3.0) | 96 (17.1) | |
| *Winter (December 1 to February 28)* | 71(12.7) | 18 (3.2) | 53 (9.5) | |

a. Person living without dementia
b. Person living with dementia
c. After the first incident
d. $\chi 2$ test

*People involved in the missing incident*

Tables 6 show the people involved in the missing incidents in terms of the care partner involvement with Medic-Alert® in response to the missing incident. In the majority (72.4%) of cases, the family care partner had an involvement in response to the missing incident with Medic-Alert®, with no statistically significant difference found between the groups (people with and without dementia). In 96.1% of cases, the Medic-Alert® subscribers who went missing were located by someone other than the care partner. In most cases, either first responders (47.7%) or Good Samaritans (46.1%) found the missing person. Again, no statistically significant difference was found between the groups involved in missing incidents.

Tables 6. Characteristics of missing incidents. (Unit of analysis: Missing incidents)

| Missing incidents characteristics. (People involved in the missing incident) | n (%) | | | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| | ND[a] & D[b] | ND | D | |
| **Natural care partner involvement in response to incident with Medic-Alert ® [valid cases, n=518]** | | | | |

| | | | | |
|---|---|---|---|---|
| *Yes* | 375 (72.4) | 80 (15.4) | 295 (57.0) | $\chi^2(1)=0.380$, $P=.538$ |
| *No* | 143 (27.6) | 27 (5.2) | 116 (22.4) | |
| **Who reported and found the person [valid cases, n=486]** | | | | |
| *First responder* [d] | 232 (47.7) | 54 (11.1) | 178 (36.6) | $\chi^2(3)=1.340$, $P=.720$[c] |
| *Good Samaritan* [e] | 224 (46.1) | 48 (9.9) | 176 (36.2) | |
| *Family member or friend* [f] | 19 (3.9) | 4 (0.8) | 15 (3.1) | |
| *Other* | 11 (2.3) | 1 (0.2) | 10 (2.1) | |

a. Person living without dementia
b. Person living with dementia
c. $\chi 2$ test
d. Police, SAR member, fire dept, ambulance/paramedic
e. In this case, the Good Sam noticed that something was off with the missing person and called the hotline or was asked by the missing person to call the hotline. Not formally involved in searching for the missing person
f. Informal care partner

## Outcomes of the missing incidents

Table 7 shows the outcomes of the missing incidents in terms of number of missing incidents, repeated missing incidents, time to the first missing incident (in days), mean time between missing incidents (in days), and survivability. Overall, 22.5% of missing incidents were repeated missing incidents, with the mean number of missing incidents per Medic-Alert® subscriber being 1.29 (SD 0.914) (minimum=1, maximum=11). Moreover, the mean number of missing incidents per Medic-Alert® subscriber was almost the same for people living with (1.29 (SD 0.801)) and without dementia (1.30 (SD 1.265)). Time to the first missing incident (since registering with Medic-Alert) was on average 343.8 (SD 376.2) days (11.3 months), whereas the mean time between missing incidents was shorter ie, 328.0 (SD 366.6) days (10.8 months). This is expected as the mean time between missing incidents takes into account repeated missing incidents. In terms of survivability, reports of undergoing harm while missing had a small percentage (9%) of cases, even more rare were missing incidents in which the Medic-Alert® subscribers were found deceased, with only one case (0.2%). There was a trend towards adverse outcomes for Medic-Alert® subscribers living with dementia; they experienced increased repeated missing incidents and injuries, short time to the first missing incident, and the mean time between missing incidents. In other words, they go missing more

frequently than those subscribers who did not have dementia.

Table 7. Missing incidents (outcomes)

| Missing incidents characteristics. (Outcomes) | ND[a] & D[b] | ND | D | Statistical Tests (ND vs. D) |
|---|---|---|---|---|
| **Number of missing incidents [valid cases, n=434]** | | **Mean (SD)** | | |
| *Number of missing incidents (Min=1, Max =11)* | 1.29 (0.914) | 1.30 (1.265) | 1.29 (0.801) | U ($N_{ND}$=89, $U_D$=345)= 14412, z= -0.1.386, *P* =.1.66[c] |
| **Time [valid cases, n=434]** | | **Mean (SD)** | | |
| *MTFI (in days) (Min=6, Max =2249)* | 343.79 (376.2) | 374.82 (410.35) | 335.79 (365.09) | U ($N_{ND}$=89, $U_D$=345)=14000, z=-1.282, *P* =.200[c] |
| *MTBI (in days) (Min=6, Max =2249)* | 328.02 (366.62) | 370.41 (411.34) | 317.08 (354.00) | U ($N_{ND}$=89, $U_D$=345)=13844, z=-1.429, *P* =.153[c] |
| **Survivability [valid cases, n=500]** | | **n(%)** | | |
| *No apparent injuries or compromised health* | 453 (90.6) | 94 (18.8) | 359 (71.8) | $\chi^2(4)=4.869$, *P* =.301[d] |
| *Injuries or compromised health requiring emergency services and/or transfer to hospital* | 35 (7.0) | 8 (1.6) | 27 (5.4) | |
| *Minor injuries or health issues requiring some treatment at home* [e] | 10 (2.0) | 1 (0.2) | 9 (1.8) | |
| *Deceased* | 1 (0.2) | 1 (0.2) | 0 (0.0) | |
| *Injuries and/or concern for health requiring follow up care* [f] | 1 (0.2) | 0 (0.0) | 1 (0.2) | |

a. Person living without dementia
b. Person living with dementia
c. Mann Whitney U test.
d. $\chi 2$ test
e. Getting 'Band-Aids', pain meds, cleaned up, etc.
f. Physician visit, walk-in clinic, etc.

## Discussion

This retrospective descriptive study examined demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering among Medic-Alert® subscribers, as well as the characteristics and outcomes of these incidents. In doing so, we used a national registry of persons as a secondary data source of information (ie, Medic-Alert® database). To date, much of the knowledge about missing individuals with and without dementia is based on studies with small sample sizes that utilize social media and newspaper reports from the United States or elsewhere [7,11]. Thus, we aimed to address these limitations by using an extensive secondary dataset. To our knowledge, this is the first study (see attached confidential abstract of unpublished paper under

review.) that has shed light on the phenomenon of missingness and critical wandering of individuals with and without dementia in Canada. In addition, we were able to report the prevalence of repeated missing incidents, based on this database, an important figure that has been absent in previous studies.

The demographic characteristics of our study population showed that people involved in missing incidents were mostly older adults, females, living in the most populated provinces in Canada and living in urban areas with at least one family member. Importantly, the majority of Medic-Alert® subscribers involved in missing incidents were reported to be living with dementia. More interestingly, except for age group, we did not find statistically significant difference between the people living with and without dementia with respect to demographic, psychopathological, and environmental antecedents to missing incidents due to critical wandering. In addition, Medic-Alert® subscribers were most frequently missing from private homes in the community, as expected, were found in a different place than where they were last seen (most commonly outdoor and indoor public spaces), travelling on foot and by public transportation, during the afternoon and evening, and during the warmest months of the year. Subscribers were located mostly by first responders and Good Samaritans. In terms of outcomes, overall, Medic-Alert® subscribers were involved in one missing incident, with a mean duration between missing incidents being 11 (10.8) months, and the time elapsed between the subscription to Medic-Alert® to the first missing incident being 11 (11.3) months. Finally, the vast majority of Medic-Alert® subscribers involved in missing incidents returned safely home, reports of harm and injuries were very low, and death was a rare event. Nevertheless, absolute numbers that results in minor injuries, serious injuries, and death were 10, 35 and 1 respectively. A 9.4% of the total cases.

We found missing incidents involved mostly older adults, female, Caucasian, living in an urban area

in the cities of Ontario, British Columbia, and Québec. These demographic results are consistent with previous studies [30,33,34] and can be explained by the fact that these groups were more prevalent in our sample and because our sample was not a representative sample. Higher prevalence of missing incidents among females can be attributed to higher prevalence of females living with dementia, as dementia typically affects people at a 2:1 female to male ratio [2]. As there is evidence that demographic characteristics may serve as risk factors for missingness [11,35,36], the next logical step is to determine whether the demographics variables we explored in this study are factors for missingness in this sample. With this, we did not identify statistically significant differences between people living with and without dementia with respect to all our variables. The most plausible explanation for this is that these two groups of people are essentially the same. ie, they have dementia and memory loss, a risk factor that can lead to critical wandering and in turn, a missing incident. Another plausible explanation for the lack of between-group differences could be that individuals: a) had dementia but did not disclose their medical condition at the time of first subscribing to Medic-Alert®, b) had dementia but do not know about their diagnosis, or c) did not have dementia at the time of registration but developed dementia over time or by the time they went missing.

We found that the majority of Medic-Alert® subscribers involved in missing incidents were reported to be living with dementia. Importantly, in those who were involved in missing incidents but did not report to living with dementia, memory loss was self-reported as a medical condition. Our result is aligned with previous studies that found that persons with mental or cognitive disabilities, such as Alzheimer's or dementia, are more prone to going missing [31,37,38]. The literature reports that neurocognitive deficits from dementia predispose individuals to missing incidents and contribute to the inability to independently return home. These neurocognitive deficits could include memory deficits, such as declarative memory (remembering facts and events), episodic memory (short term

memory for recent events and contexts) and visual agnosia (inability to recognize objects or places). Also, executive function impairments and disease-related changes to visuospatial and subperceptual processing (especially in unfamiliar locations), typically manifested as difficulty with navigation, can explain why an individual living with dementia cannot independently return home [26].

The prevalence of Medic-Alert® subscribers who repeatedly went missing was lower in the hotline database in comparison to repeated missing self-reported variables. This result was anticipated as previous studies suggest that care partners are reluctant to contact emergency services, such as 911 or programs to locate missing and critically wandering older adults [37]. As a self-reported variable, this result could be attributed to overreporting by care partners. However, more objective explanations can be given. First, care partners often initiate the search within their homes or places last seen, and as many persons with dementia are found near the place that they were last seen, either on their own property or in their own neighborhood, the care partner could locate the missing person before their decision to request assistance from external organizations [31,37]. Second, it is possible that care partners subscribed their family member into Medic-Alert® programs as a preventative measure. For individuals who repeatedly critically wandered in the past, care partners could implement their own measures or interventions to avoid undesirable missing incidents, including Medic-Alert® subscriptions. The literature reports these interventions include avoiding lapses of supervision, whether planned or unplanned, through the use of technology (eg, global positioning system) to monitor and locate missing older adults with dementia [39]. Third, it might be possible that care partners chose not to use the Medic-Alert® hotline to locate missing individuals to avoid attention and stigma associated with a formal search if initiated. Numerous studies have reported that the uses of technologies and programs by people living with dementia and their care partners aiming to reduce risks of getting lost have highlighted the importance of discreet technologies that are unnoticeable to reduce stigma [40,41].

Our study paves way for new services and interventions that can be offered by Medic-Alert®. The first may include implementing preventative strategies to decrease the risk of going missing through threshold for alerts in mobile phone apps. According to the literature, a leading feature being implemented in mobile phone apps were alert systems, such as wandering alerts [42]. These apps could send threshold for alerts or reminders to care partners when the mean time between missing incidents and the mean time to the first missing incident for a particular Medic-Alert® subscribers is approaching. The same can be true for common months, or time of the day that Medic-Alert® subscribers tend to go missing. As many Medic-Alert® subscribers were located mostly by first responders and Good Samaritans, another option to explore is the use of mobile alert app to engage community volunteers to help locate missing persons with dementia. Community ASAP, a mobile alert system that engages community citizens as volunteers to look out for missing persons with dementia, has demonstrated to be an accurate and useful app [43].

For Medic-Alert® subscribers involved in missing incidents, many were returned home safely, with few reported harms, injuries or death. Literature of mortality rates when a person with dementia goes missing shows high variability between 0.7% and 32% [44,45]. In this study, low reports of harm and death can be explained mainly by two factors. First, environmental conditions at the time Medic-Alert® subscribers went missing were favourable; subscribers went missing in urban areas, travelling on foot and public transportation, and during the day in the warmest months of the year (eg, low chance of severe weather). The literature report that causes to high mortality rates in people with dementia who go missing includes severe weather, driving, and walking near roadways, bodies of water, or isolated areas [46,47]. These scenarios were opposite of what we found in our study. Second, we found that in a high proportion of missing incidents, the Medic-Alert® subscribers were wearing their identification bracelet. We could intuitively affirm that the Medic-Alert® program

prevents injuries and saves lives, but this affirmation would have to be demonstrated in a formal study. Therefore, a next logical step would be to conduct a study to determine if Medic-Alert® programs address the problem for which it was designed; that is, to help those who critically wander return home safely. Our study also shows what some investigators have determined regarding the potential interrelatedness of risk factors for going missing [48]. While most of the outcomes during missing incidents were positive (deaths were rare), the complex interplay of demographic, psychopathological, and environmental antecedents of Medic-Alert® subscribers need further exploration.

## Study limitations

Our study has some limitations. Limitations were posed by the Medic-Alert® dataset itself. First, our source of data is a limitation itself as missing incidents are also captured in data held by first responders (police, SAR, paramedics, etc.); and this is subscription-based data - so there are inherent self-selection biases. Second, while inquiring about the data entry process at the Medic-Alert® subscribers' level, we discovered that a high percentage of data were stored raw and not in analysis-ready format (free text fields). Consequently, the available information did not allow to categorize our data with the desired level of granularity. Third, the self-reported nature of the data caused missing data in some variables (eg, use of de-escalation techniques to avoid missing incidents, whether a Medic-Alert®subscriber has special needs, what constitutes a trigger for a missing incident). As the percentage of missing data in these variables were large (ie, higher than 40%), we excluded them from the analyses as recommended in the literature [49]. The latter will not allow for further comprehensive statistical analysis for these unmeasured confounding variables. Fourth, the database lacked some important outcome variables. For example, we were unable to determine for how long Medic-Alert® subscribers went missing, the response time (ie, time elapsed between the

call to the hotline is made and first responders arrive to assist a missing person) or the turnaround time of the missing incidents (ie, the time it that takes to return a missing person to their residence). In summary, as this study used secondary data source that were not made for research purposes, we faced the same common limitations reported in other studies that use this kind of data source [50–52]. Notwithstanding these limitations, we believe that the results obtained in this study are very valuable for partially understanding the phenomenon of 'going missing,' older adults with dementia and memory loss in Canada. The data set used in this study represents a small portion of people living with dementia in Canada; that by virtue of it being a paid subscription service, not everyone uses it. In future research other sources of data also need to be considered (police and search and rescue data) to get a fuller picture of the prevalence of persons living with dementia who go missing.

## Conclusions

In the dataset used, missing incidents involved mostly older female adults living with dementia from an urban area. Overall, the majority of Medic-Alert® subscribers involved in missing incident returned home safely. However, almost 9.4% of cases resulted in some form of minor or serious injuries, and death. From the total sample of 560 missing incidents, 22.5 % were a repeated incident. This paves the way to more accurately describe the prevalence of missing incidents, their consequences/outcomes, so that we can develop targeted intervention strategies to prevent or locate missing persons.

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## Conflicts of Interest

The authors declare that they have no conflict of interests

## List of abbreviations

MTFI: Time to the first missing incident (in days)

MTBI: Mean time between missing incidents (in days)

PHIR: Personal Health Information Record

SD: Standard deviation

SPSS: Statistical Package for Social Sciences

ANOVA: Analysis of Variance.

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