#43630 Factors related to going missing and getting lost incidents among persons living with dementia in Canada

A Data Management Plan created using DMP Assistant

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Project Administrator: Hector Perez

Affiliation: University of Waterloo

Funder: Digital Research Alliance of Canada

Template: Alliance Template

Project abstract:

Dementia-related missing incidents are a growing concern worldwide. Many people living with dementia wander and get lost, and getting lost is often associated with adverse outcomes such as injuries and death. Current search and rescue strategies remain ineffective because the full picture of the risk factors of going missing remains unclear. Even though there are tools available to prevent missing incidents from occurring such as GPS trackers and medical ID bracelets, the effectiveness of these tools remains unclear. Therefore, there is a need to develop a comprehensive strategy to prevent missing incidents from occurring and find these people when they go missing. No studies have investigated the risk factors associated with missing cases among people living with dementia. We will analyze data from several Canadian police agencies to understand the risk factors of missing incidents. Data from several police agencies will give us a representative sample size to understand the risk factors of missing incidents, uncover blindspots of current SAR strategies, and provide recommendations to modify existing SAR strategies. Benefits of this project include improving current SAR strategies and prevent and manage dementia-related missing incidents. Ultimately, keep Canadians safe. The results of this project will serve to inform and improve current practices to collect, store and analyze data of missing persons living with dementia.

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Data Collection

What types of data will you collect, create, link to, acquire and/or record?

University of Waterloo
Research project

Principal investigators: Lili Liu and Antonio Miguel-Cruz

Title: Factors related to going missing and getting lost incidents among persons living with dementia in Canada

Objective: This project aims to describe and identify the factors associated with missing incidents of people living with dementia.

Research questions:

1. What are the demographic, health status or medical condition, and incident characteristics of older adults reported missing?
2. Which demographic, health status and/or situational characteristics predict (a) the locations older adults are reported missing from; and (b) the locations older adults are found?
3. Which demographic and health characteristics predict repeat missing occurrences within the data collection period and repeat missing classifications?
4. Which demographic, health characteristics and physical characteristics predict being located by police organizations?
5. Which method of location is more effective to locate missing older adults and persons living with dementia?

AMENDMENT (OCT 15, 2021): We include physical characteristics in research question number 4. If available, this field could inform how and which type of descriptors help police organizations, but also first responders to identify and locate a missing person. In this case, we would like to explore this variable associated with persons living with dementia.

Data requirements

1. Data about missing incidents of persons 45 years old and older (*see Notes about Data requirements below*).
2. Data from 2010 onwards

Notes about Data requirements

- We are certain that some adults have early onset of dementia (45 years)
- We understand that some variables listed in the column *Variable name* (see Table below) might not be available.
- We understand that the Example of operationalizations listed in the column *Descriptions/definitions, example of operationalization or categories* (see Table below) are not necessarily the ones you have available in your data set. We just provided the examples in order to help you understand what we are referring to about a particular variable
- We are interested in any kind of TRUE missing incidents. We are not interested in runaways (also called bastard searchers)
- We are referring as a lost person as when *"the search team is unable to find the subject"*.

General note

- We are open to working with the police analysis team to formulate new research questions relevant for the Police analysis team.
- Variables related to physical appearance are important and would be used to answer the research questions, as we are interested in understanding how personal characteristics (i.e. Race, Height, Weight, Eye color, Hair color, Hair description, etc.) are associated with missing incidents in persons with dementia. Not from a physical appearance perspective but to inform, describe and analyze how these personal identifiers are useful to picture preventive strategies and inform data collection strategies.

Variables of interest

Dimension	Variable name	Descriptions/definitions. Examples of operationalization or categories
Demographic/personal characteristics	Age	Description: biological age at the Time of the missing incident
Sex	Description: Sex (Biological) at the Time of the missing incident Example of operationalizations: Male/Female	
Gender	Description: Gender identity, the personal sense of one's own gender at the Time of the missing incident Example of operationalizations: Cisgender/Transgender/etc.	
Medical (Condition)	Description: Health characteristics or medical conditions at the Time of the missing incident Example of operationalizations: Dementia/Stroke/Physical disability/Etc. (could be more than one)	
If the person has dementia: level of dementia	Description: level of dementia Examples of categorization: Mild/Moderate/Severe	
Medication	Description: medication the person is taken Example of operationalizations: (could be more than one)	
Race	Description: Ethno-Racial Groups Example of operationalization: White/Black/Aboriginal (or first nations)/Middle Eastern/Asian/Hispanic/etc.)	
Height	Description: Height in cm at the Time of the missing incident	
Weight	Description: Weight in kg at the Time of the missing incident	

Eye color	Description: Eye color in terms of Martin scale Example of operationalization: Amber/Blue/Brown/Gray	
Hair color	Description: Hair color at the Time of the missing incident Example of operationalization: Brown hair/Blond hair/Black hair/Auburn hair/Red hair/Gray and white hair	
Hair description	Description: hair description in terms of Andre Walker hair types at the Time of the missing incident Example of operationalization: Type 1 straight hair/Type 2 wavy hair/Type 3 curly hair/Type 4 kinky hair	
Languages Spoken	Description: Languages Spoken Example of operationalization: English/French/Spanish/etc.	
Mother tongue (Language)-Language preference	Description: Languages Spoken Example of operationalization: English/French/Spanish/etc.	
Skin complexion	Description: Skin complexion Example of operationalization: Light, pale white/White, fair/Medium white to light brown/Olive, moderate brown/Brown, dark brown/Very dark brown to black	
Visible Marks	Description: Any visible Marks in the body Examples of operationalization: Mole/scar/tattoo/birthmark/etc.	
Repeat Missing in the Past 5 Years (number of times)	Description: Considering previous history of wandering/missing incidents, Repeat Missing in the Past 5 Years Examples of operationalization: Number of times	
Repeat Missing Classification	Description: Considering previous history of wandering/missing incidents Examples of operationalization: Yes/No	
Home and living arrangements	Address Info **L**	Description: Detailed address info where the person lives
City L	Description: City where the person lives	
Area L	Description: Area in which the person was found Example of categorization: Urban/Rural/Wilderness/Suburban/Water	
County/Province L	Definition: A political and administrative division of a state, providing certain local governmental Example of categorization: Alberta/British Columba/etc.	
Population Density L	Definition: Population per unit area where the person lives	
Living arrangement L	Definition: With whom the person involved in the missing incident lives with Example of categorization: With spouse/With spouse & children/With children/Alone/Other	
Housing or Residential arrangement L	Definition: Where the person lives at the Time of the missing incident Example of categorizations: House detached /Condominium/Apartment/ Senior lodge/Supportive living level / Retirement community /Group home/etc Example of categorizations: Own home/apartment; 2 Residence where health/disability/or aging related services or supervision available; 3 Other residential settings where no services provided; 4 Nursing home/another health facility; 5 Other institutional settings (prison); 6 Homeless or Homeless shelter; 7 Unknown. Not stated. Needs definition refinement.	
Data from missing incidents	Who reported	Definition: The person/institution that reported the missing incident Example of categorizations: Good Samaritan/police or law enforcement/family member/care institution/Medic Alert/Silver alert/Community program
Probable Cause of missing incident (Scenario)	Definition: What reportedly caused the subject to be missing Example of categorizations: Avalanche/Criminal/Despondent/Evading/Investigative/Lost/Medical/Near-Drowning/Overdue/Stranded/Trauma	
Date and Time reporting missing (Notify Hours-Time)	Definition: Date and Time of when an individual was reported missing	
Date and Time last seen/heard from	Definition: Date and Time a missing person was last seen or heard from (PLS)	
Date and time search started	Definition: Date and Time on which search activities started	
Date and Time found/located	Definition: Date and Time of when an individual was found (irrespective of the outcome), meaning the case is closed (if no found in blank)	
Find Coordinate (E/W)	Definition: actual location where the person was found, place located	
Find Coordinate (N/S)	Definition: actual location where the person was found, place located	
Last Known Point Coordinate (LKP) (E/W)	Definition: A location at which a significant clue/evidence places the missing subject	
Last Known Point Coordinate (LKP) (N/S)	Definition: A location at which a significant clue/evidence places the missing subject	
Point last seen coordinate (PLS) (E/W)	Definition: The location where the missing person was last seen	
Point last seen coordinate (PLS) (N/S)	Definition: The location where the missing person was last seen	
Area Loc 1 (Find Location)	Description: Actual Area in which the missing person was found Example of categorization: Urban/Rural/Wilderness/Suburban/Water	
Area Loc 2 (Find Location)	Description: Actual more detailed location in which the missing person was found Example of categorization: Buildings/Roads/Drainages/Water/Fields/Home/Same place living arrangement or Home/Neighborhood/etc.	
Weather - Season	Definition: Season when it was reported the missing incident Example of categorizations: spring/summer/fall/winter	

Weather -Temp. (C)	Definition: Temperature in Celsius degrees at the Time of the reporting incident	
Weather- Wind (kph)	Definition: Wind in km/h at the Time of the reporting incident	
Weather- Overall	Definitions: Weather at the moment of the reporting incident Example of categorizations: rain/hail/snow	
Ecoregion Division	Definition: Based on Robert Bailey classification system (where the person is reported missed) Example of categorizations: Icecap/Tundra/Subarctic … warm continental/hot continental/subtropical/marine/prairie/Mediterranean … tropical/subtropical steppe/ tropical/subtropical desert/ temperature steppe/ temperature desert … savanna/rainforest	
Ecoregion Domain	Definition: Based on Robert Bailey classification system (where the person is reported missed) Example of categorizations: Polar/Humid temperature/Dry/Humid tropical	
Terrain-Conditions	Definition: Terrain conditions where the person is reported missed Example of categorizations: Flat-non-Mountainous/Mountainous	
Elevation Change	Definition: Elevation (vertical in meters) change from the IPP	
Clothing	Definition: Clothing or dressing the person was wearing at the moment of the missing incident report Examples of categories: Naked/with clothing/proper clothing for the season/etc.	
Equipment-Program Subscription	Definition: Was the person involved in the missing incident using a GPS and or subscribed to a program, Medic Alert/Safe Return Example of categorization: YES/NO, if YES name of what device or program	
Engraved message	Definition: has the person any engraved message in a bracelet that might help to search Example of categorization: YES/NO	
Intended Destination (EW Destination)	Definition: The intended destination or a significant clue of the person involved in the incident Example of categorization: Examples of statement/clue located en route (e.g. wallet)	
Intended Destination (NS Destination)	Definition: The intended destination or a significant clue of the person involved in the incident Example of categorization: Examples of statement/clue located en route (e.g. wallet)	
Mobility method (Mobility)	Definition: type of mobility method the person is using at the moment of reporting the missing incident Example of categorization: Walking-Foot/Driving/Air plain/etc.	
Free text field	Definition: Free text field used to describe in more detail the missing incident	
Resources/Logistic used to manage the missing incident	Rescue and search method	Example of categorization: use of search and rescue dogs; urban search and rescue in cities; combat search and rescue on the battlefield and air-sea rescue over water (could be more than one)
Initial planning point coordinate (IPP) (E/W)	Definition: The coordinates of the point that is initially used to plan de search incident. Can be the PLS or the LKP	
Initial planning point coordinate (IPP) (N/S)	Definition: The coordinates of the point that is initially used to plan de search incident. Can be the PLS or the LKP	
Total Air Hours	Definition: sum of # of devices * Hours per each device	
Total Dog Hours	Definition: sum of #of Doug * Hours per each dog	
Total Man Hours	Definition: sum of #of men * Hours per each man	
Total Hours	Definition: Total dogs+air+men	
Total Personnel	Definition: Total men used	
Total Cost	Total cost	
Missing incident -Outcomes	Missing incident **outcome 1**-Was the person found?	Definition: Whether the person reported in the missing incident was found or not Example of categorization: YES/NO
Missing incident **outcome 2**-Was the person found dead?	Definition: Whether the person reported in the missing incident was found Dead Example of categorization: YES/NO	
Missing incident **outcome 3**-Was the person found alive and well?	Definition: Whether the person reported in the missing incident was found alive and well Example of categorization: YES/NO	
Missing incident **outcome 4**-Was found alive and injured?	Definition: Whether the person reported in the missing incident was found alive but injured of any kind Example of categorization: YES/NO	
Missing incident **outcome 5**-Response time general population	Definition: Elapsed Time (in hours) between person reported the missing incident and last seen	
Missing incident **outcome 6**-Response time search police-SAR	Definition: Elapsed Time (in hours) between person reported missing and search started	
Missing incident **outcome 7**-Turnaround time or search hours	Definition: Elapsed Time (in hours) between person reported missing and found	
Missing incident **outcome 8**-Survivability	Definition: Elapsed Time (in hours) between person was last being seen alive and found	
Missing incident **outcome 9**-Dispersion Angle	Definition: it is the angle in degree measured between 3 points: Find the location **IPP**-Intended destination	
Missing incident **outcome 10**-Distance from IPP (km)	Definition: it is that distance away measured in a straight line (also called crow's flight distance) between the point last seen (PLS) and the initial planning point (IPP).	
Missing incident **outcome 11**-Mobility (in hours)	Definition: total is the number of hours the person missing is moving	

Missing incident outcome**12**-Track Offset (m)	Definition: the shortest perpendicular distance (in m) from an intended track or route to where the lost person was found

What file formats will your data be collected in? Will these formats allow for data re-use, sharing and long-term access to the data?

1. Formats:

- Data format preferred is .csv or .xls
- Databases: SQL or no-SQL
- Text: .txt, tsv.

2. Data will not be re-used. Data will be stored for 5 years. Following the 5 years, We will destroy all information. We will request a certificate of destruction after that period.

What conventions and procedures will you use to structure, name and version-control your files to help you and others better understand how your data are organized?

We will use best practices for the naming format, where files should be named consistently, using short but descriptive names with no more than 25 characters, avoiding special characters or spaces in a file name, using capitals and underscores instead of periods or spaces or slashes, using the

- Date format ISO 8601: **YYYYMMDD, and including a version number**.
- The folders will be stored using a central folder, organized by project phases.
- We expect to use a data version manager for having better control over versions of data.
- Folder **hierarchies are as simple as possible**.

Documentation and Metadata

What documentation will be needed for the data to be read and interpreted correctly in the future?

We need to define a**data dictionary** (DD) in collaboration with the police agencies. The purpose of this DD is to understand the structure and nature of their data.

How will you make sure that documentation is created or captured consistently throughout your project?

We will create and update a folder with an activity log file to keep track of documentation.
This folder will help to ensure the accuracy, consistency, and completeness of the documentation we will use a researcher journal and track version of datasets.

If you are using a metadata standard and/or tools to document and describe your data, please list here.

If metadata is available, we will request the police agency's data dictionary. It is possible to use DVC to track the changes and identifiers of metadata. DVC is an Open-source Version Control System for Data Management Projects.

Storage and Backup

What are the anticipated storage requirements for your project, in terms of storage space (in megabytes, gigabytes, terabytes, etc.) and the length of time you will be storing it?

1. File size: Unknown. We have enough computing capabilities to store the data. A new piece of equipment was recently purchased, with more than 15 terabytes of storage space.
2. The research team will store all data for 5 years. Following the 5 years, we will destroy all information. We will request a certificate of destruction after that period.

How and where will your data be stored and backed up during your research project?

1. An automatic software will be back up the information every 24 hours. Hector Perez and Antonio Miguel-Cruz will supervise this task.
2. We will store this information in a local computer at the University of Waterloo, with password-protected and encrypted and restricted access.
3. We will not use cloud services in this project.
4. We will password-protect and encrypt the files, and only active researchers in this project will have access to these files. We will also use two-factor authentication.
5. We will follow the "Guidelines for secure data exchange: Choosing information transmission methods based on the security classification." provided by the University of Waterloo.
6. This computer will be located in a safe place where access will be restricted and secured. The data will be stored in a server room, with controlled access.

How will the research team and other collaborators access, modify, and contribute data throughout the project?

1. For this project, we propose to transfer the data using Sendit®, a service provided by the University of Waterloo, that is a secure file transfer service only recommended for large files that contain information classified as restricted, and to some extent provides a safe way to transfer this type information.
2. We will store this data in local computed located at the University of Waterloo to prevent potential loss.
3. Only the research team will have access to this information, and no data will be returned to the police enforcement agency to prevent data and information loss.
4. Collaborators will have a unique password for accessing this information.
5. Access to this data will be encrypted, just research team members will have access using a password and a two-step verification access if possible.

6. We will follow the instructions for using Sendit, provided by the University of Waterloo. This information is updated and available at this link: https://uwaterloo.atlassian.net/wiki/spaces/ISTKB/pages/266995264/Receiving+files+using+Sendit

Sendit is a secure file transfer service only recommended for large files that contain information classified as Restricted. This service uses SFTP/HTTPS as the transfer protocol. By using this service the data transfer is encrypted end-to-end, but the access URLs are exchanged via email which may or may not be encrypted. For this transfer, according to the "Guidelines for secure data exchange: Choosing information transmission methods based on the security classification", we propose the following data transferring process:

1. After the definition of the Data Sharing Agreement and Ethics Approval, the research team will request to the UW the use of SendIt to receive files.
2. A link will be provided by an encrypted email to the person designated by the police enforcement agency.
3. The person designated by the police enforcement agency will upload the files using Sendit and confirm to the research team.
4. The research team will receive the files using Sendit, and download them at a local computer, encrypted, password protected and locked at the University of Waterloo.

Preservation

Where will you deposit your data for long-term preservation and access at the end of your research project?

1. We will not store the data for long-term preservation and access at the end of this research
2. Data will not be re-use. Data will be stored for 5 years. Following the 5 years, We will destroy all information. We will request a certificate of destruction after that period.

Indicate how you will ensure your data is preservation ready. Consider preservation-friendly file formats, ensuring file integrity, anonymization and de-identification, inclusion of supporting documentation.

We will preserve data in the same format as received. Some datasets will need to be prepared for exploration and analysis.
Data, and particularly variables that could identify individuals, will be de-identified as soon as possible. After the reception, use a unique code for every single registry. By doing that we protect the confidentiality and privacy of the individuals. We will create a de-identified copy of the data and destroy the original one as soon as we finish the step above. For this study, we plan to receive anonymized data, at the individual-level data, not aggregated to protect an individual's privacy and confidentiality.

Sharing and Reuse

What data will you be sharing and in what form? (e.g. raw, processed, analyzed, final).

This data is restricted. We are not using a persistent identifier. We will not share data in this project. Everything will be centralized for protection, and access to this information will be encrypted and password protected (using 2-factor authentication).

Have you considered what type of end-user license to include with your data?

What steps will be taken to help the research community know that your data exists?

We plan to disseminate the outcomes of this research to create:

- Profile of persons living with dementia who get lost and go missing.
- Report of findings, including a comparison between different regions.

Responsibilities and Resources

Identify who will be responsible for managing this project's data during and after the project and the major data management tasks for which they will be responsible.

From University of Waterloo:
1. Dr. Antonio Miguel-Cruz, Dr. Lili Liu, Dr. Christine Daum, Dr. Hector Perez, Dr. Noelannah Neubauer.
For this project, we will partner with five Canadian police agencies (listed below). They will provide us data on incidents missing incidents of persons living with dementia.
List of police agencies:
1 Calgary
2 Ontario Provincial Police (OPP)
3 Toronto
4 Vancouver
5 Winnipeg
6 Newfoundland and Labrador
7 Nova Scotia
8 Prince Edward Island
9 Nova Scotia RCMP
10 New Brunswick
11 Halifax
12 St. Johns
13 Victoria Police, BC
AMENDMENT (APR 7, 2022): We included four additional partners.
14 Edmonton Police Service
15 Montréal (Québec)

16 Regina
17 Waterloo
AMENDMENT (NOV 6, 2022):
18 BC SARA
19 SAR Alberta
20 SAR Saskatoon
21 York Regional Police
22 Kahnawake Peacekeepers
23 Hamilton Police Service

How will responsibilities for managing data activities be handled if substantive changes happen in the personnel overseeing the project's data, including a change of Principal Investigator?

We will centralize the data, so no user is the owner of the data. The UW team will be data custodians. When onboarding new students and researchers they will be informed of the responsibilities, ethics protocols and data management plans in place.

What resources will you require to implement your data management plan? What do you estimate the overall cost for data management to be?

For this project, we will use hardware especially purchased for this project. 1 high-performance computer (Server, location: sarnif-rds.nexus.uwaterloo.ca) and three workstations.

Ethics and Legal Compliance

If your research project includes sensitive data, how will you ensure that it is securely managed and accessible only to approved members of the project?

We will store this information in a local computer at the University of Waterloo. The security layers include encrypted data, password-protected access and two-factor authentication. That implies that access will be encrypted and restricted. We will not use cloud services in this project. We will set up two-factor authentication, encrypted and password-protect files, and only active researchers in this project will have access to these files. We will follow the "Guidelines for secure data exchange: Choosing information transmission methods based on the security classification.".

For accessing this computer there are physical and virtual controls: secured location, only authorized personnel can access this facility, a VPN is required to access the virtual machine, including a password, and two-factor authentication, that in most cases is linked to the researcher phone number to provide the access. For being exhaustive in measures of control, a Data Management Plan is in place (https://assistant.portagenetwork.ca/) We will follow the procedure for a safe data sharing process, we had from previous experiences consulting with the IT Staff.

We will inform the organizations involved about the measures to control, protect and destroy the data. For the data transfer, we will follow the "Guidelines for secure data exchange: Choosing information transmission methods based on the security classification, for this transfer." After defining the Data Sharing Agreement(s) and Ethics Approval, the research team will use SendIt to receive files. A link will be provided by an encrypted email to the person designated by the police agency. Then, the person designated by the police agency will upload the files using Sendit and confirm with the research team. Consequently, the research team will receive the files using Sendit and download them at a local computer password protected and locked at the University of Waterloo. For this project, we will follow the University policies regarding the protection of information (https://uwaterloo.ca/secretariat/policies-procedures-guidelines/policies/policy-46-information-management)

If applicable, what strategies will you undertake to address secondary uses of sensitive data?

Not applicable.

How will you manage legal, ethical, and intellectual property issues?

The Human Research Ethics Board is pleased to inform you this study has been reviewed and given ethics clearance.

Initial Approval Date: 10/19/21 (m/d/y)

University of Waterloo Research Ethics Boards are composed in accordance with, and carry out their functions and operate in a manner consistent with, the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS, 2nd edition), International Conference on Harmonization: Good Clinical Practice (ICH-GCP), the Ontario Personal Health Information Protection Act (PHIPA), the applicable laws and regulations of the province of Ontario. Both Boards are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (HREB) and IRB00007409 (CREB).

This study is to be conducted in accordance with the submitted application and the most recently approved versions of all supporting materials.

Expiry Date: 10/20/22 (m/d/y)

Multi-year research must be renewed at least once every 12 months unless a more frequent review has otherwise been specified. Studies will only be renewed if the renewal report is received and approved before the expiry date. Failure to submit renewal reports will result in the investigators being notified ethics clearance has been suspended and Research Finance being notified the ethics clearance is no longer valid.

Level of review: Delegated Review

Signed on behalf of the Human Research Ethics Board

Joanna Eidse, Research Ethics Officer, jeidse@uwaterloo.ca, 519-888-4567, ext. 37163