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Risk Factors Associated with Missing Incidents among Persons Living with Dementia: A Scoping Review

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Article

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Résumé

Plus de 55 millions de personnes sont atteintes de démence dans le monde, et leur nombre triplera d'ici 2050. Les personnes atteintes de démence sont exposées à des risques secondaires aux problèmes cognitifs, notamment celui de se perdre. Les conséquences négatives de la perte de repères comprennent les blessures, la mort et l'institutionnalisation prématurée. Dans cette étude de portée, nous examinons les facteurs de risque associés au fait de s'égarer chez les personnes atteintes de démence. Nous avons recherché et sélectionné des études dans quatre bases de données électroniques (Medline, CINAHL, Embase, Scopus) et en avons extrait des données pertinentes. Nous avons recensé 3 376 articles, dont 73 répondaient aux critères d'inclusion. La plupart des études ont utilisé des méthodes de recherche quantitatives. Nous avons défini 27 variables regroupées en trois domaines de facteurs de risque : (a) caractéristiques démographiques et personnelles, (b) état de santé et symptômes, et (c) antécédents environnementaux et contextuels. L'identification des facteurs de risque associés au fait de se perdre permet d'anticiper les incidents de disparition. Les facteurs de risque peuvent être associés à des stratégies proactives pour prévenir les incidents et informer les politiques afin de créer des communautés plus sûres.

Abstract

Worldwide, over 55-million people have dementia, and the number will triple by 2050. Persons living with dementia are exposed to risks secondary to cognitive challenges including getting lost. The adverse outcomes of going missing include injuries, death, and premature institutionalization. In this scoping review, we investigate risk factors associated with going missing among persons living with dementia. We searched and screened studies from four electronic databases (Medline, CINAHL, Embase, and Scopus), and extracted relevant data. We identified 3,376 articles, of which 73 met the inclusion criteria. Most studies used quantitative research methods. We identified 27 variables grouped into three risk factor domains: (a) demographics and personal characteristics, (b) health conditions and symptoms, and (c) environmental and contextual antecedents. Identification of risk factors associated with getting lost helps to anticipate missing incidents. Risk factors can be paired with proactive strategies to prevent incidents and inform policies to create safer communities.

Introduction

Worldwide, over 55-million people live with dementia (Livingston et al., 2020), and the number is projected to triple by 2050 (Nichols et al., 2022). Dementia is a progressive medical condition associated with a decline in cognitive functions, including judgment, behaviour, language, and thinking (Duong et al., 2017; Emmady et al., 2022). Persons living with dementia are exposed to multiple risks secondary to these cognitive challenges, including falls, injuries, becoming disoriented, and getting lost (Alzheimer Society of Ontario, 2022; Gilmour et al., 2003; Lach, 2017; Petersen et al., 2018).

Persons living with dementia are at higher risk of getting lost and going missing than other populations (Neubauer et al., 2021c), as their wayfinding abilities can be diminished due to cognitive decline (Liu et al., 1991; Puthusseryppady et al., 2019). Indeed, missing incidents can occur during everyday activities (Rowe et al., 2011), including walking, and driving, even while

they are with a care partner (Kowalski, 2020; MacAndrew et al., 2018; Rowe et al., 2012a). According to the Alzheimer's Association (2022), 6 in 10 persons living with dementia will wander at least once during their disease. Indeed, because of critical wandering, or wandering that results in walking with no orientation to time and place, older adults could go missing and become lost (Neubauer et al., 2018; Petonito et al., 2013). However, the scholarly evidence (Kikuchi et al., 2019; Kowalski, 2020; Kwok et al., 2010) suggests that the estimated prevalence of missing incidents due to critical wandering in persons living with dementia is still unclear.

Persons living with dementia can go missing even in familiar places and be exposed to severe outcomes (Kikuchi et al., 2019; Kowalski, 2020). The most common consequences include hypothermia and drowning (Byard & Langlois, 2019; Kikuchi et al., 2019). In severe cases, missing incidents can lead to death (Murata et al., 2021). Mortality rates related to missing incidents are notable (Murata et al., 2021); when disoriented, a person living with dementia could be easily hit by a car or a train (Rowe et al., 2011; Young et al., 2018) and depending on the season and terrain (e.g., weather conditions, or getting lost in highways or crowded areas) could experience multiple sources of danger. Persons with dementia could have a reduced ability to process pain and thermoregulate (Fletcher et al., 2015), further increasing their risk of harm. Risks of going missing increase stress on care partners (Lim et al., 2008; Rolland et al., 2003; White et al., 2010) and impose a high demand on police, public safety services, and resources (e.g., equipment, helicopters, tracking dogs, paramedics and search, rescue personnel, and search and rescue programs) (Neubauer et al., 2021a; Shalev-Greene & Pakes, 2014).

Strategies exist to limit the risk of getting lost including locks, alarm systems, and location tracking devices (Adekoya & Guse, 2019; Neubauer & Liu, 2021b). While these systems can mitigate the risks of getting lost, they are usually adopted after a missing incident occurs (Bantry White & Montgomery, 2015a; Neubauer & Liu, 2021b). Despite an increasing body of knowledge about locator devices and tracking systems for use with persons who have dementia (Neubauer et al., 2021c; Neubauer & Liu, 2021a; Rasquin et al., 2007; Wojtusiak & Mogharab Nia, 2019; Emrich-Mills et al. 2021), the usefulness of these devices in preventing missing incidents remains mixed (Neubauer et al., 2018). The effectiveness of these strategies could be restricted by the limited understanding of the risk factors for getting lost and going missing because of critical wandering among persons living with dementia. Thus, proactive approaches should be informed by a comprehensive understanding of risk factors associated with missing incidents (Neubauer & Liu, 2021a) to contribute to predictive models (Barrett et al., 2018; Homdee et al., 2019; Khaertdinov et al., 2021) that can mitigate the risks for missing incidents. A combination of proactive strategies and predictive models would be a preventative approach that enhances the safety of persons living with dementia. This has the potential to reduce stress for care partners and possibly reduce the demand for public services involved in a dementia-related missing incident search and rescue operation.

An understanding of the associated risk factors contributes to the mitigation of adverse outcomes and the development of ways to manage the risks of missing incidents (Bantry White & Montgomery, 2016; MacAndrew et al., 2018; Murata et al., 2021). A risk factor can be understood as the measurable characteristic of each person living with dementia in a specified population that precedes the outcome of interest (Kraemer et al., 1997). Despite the known harms resulting from missing incidents, few studies have identified the risk factors associated with getting lost and going missing among persons living with dementia (Chung & Lai, 2011; McShane et al., 1998), and to date, no comprehensive review has systematically described the risks factors associated with these incidents. To address this gap, we conducted a scoping review to investigate the risk factors associated with getting lost and going missing in persons living with dementia.

Methods

Design

Our scoping review drew on the approach described by Daudt et al. (2013) and Arksey and O'Malley (2005) to investigate the existing risk factors associated with getting lost and going missing due to critical wandering in persons living with dementia in the literature. This approach was to: (a) determine the research questions and search strategy using the Population, Concept, Context framework (Peters et al., 2015); (b) identify relevant studies; (c) screen and select studies; (d) chart the data; (e) summarize and aggregate the data; and (f) report the results. This approach included an interprofessional team in step (b) and used a three-tiered approach to cross-check studies in step (c). The research question that guided this scoping review was: What are the existing risk factors (concept) associated with getting lost and going missing due to critical wandering (context) in persons living with dementia (population). Finally, this study aligns with what is suggested by the PRISMA extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018), and followed the suggested checklist accordingly.

Data sources and search strategy

We searched four electronic databases: Medline, CINAHL, EMBASE, and Scopus and examined peer-reviewed literature published from January 1980 to October 2020 to obtain information from the largest amount of available academic literature published in recent years. We utilized Medical Subject Headings, keywords, and combinations of both using operators (e.g., AND and OR) related to missing incidents, disappearing cases, getting lost, and wayfinding difficulties associated with critical wandering in persons living with dementia, such as boundary transgression, elopement behaviour, critical wandering, walkabouts, and actual missing incidents. We validated the search strategy through consultation with a health sciences librarian. The search occurred in October 2020. The search strategy is reported in Supplementary Table A1.

Screening and eligibility

HP exported all studies into reference management software (i.e., EndNote version 20) to remove duplicates. The remaining studies were uploaded to Covidence, a screening and data extraction tool, where further duplicates were removed automatically. Following this, reviewers were calibrated to ensure consistency in applying the inclusion and exclusion criteria (HP, AMC, and CD). Two additional reviewers (SM and EL) were trained to apply the inclusion and exclusion criteria independently before the full-text screening phase. Each study title, and abstract and full study, was reviewed independently by two team members. Then each reviewer voted independently to include or exclude each study (HP, EL, SM, CD and AMC). Reviewers engaged in discussions to resolve conflicts, and a third reviewer (CD and AMC) outside the discordant

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pair made the final decision to include or exclude the study. We obtained 74 per cent agreement during the full-text screening phase, which is considered a high level according to Garritty et al. (2021).

Inclusion and exclusion criteria

Inclusion criteria

We included studies that:

1. reported risk factors (e.g., behavioural, cultural, environmental) associated with getting lost, going missing due to critical wandering, or resulting in a hazardous situation for persons living with dementia;
2. included persons living with dementia, Alzheimer's disease, or cognitive impairment;
3. published in any language;
4. published from 1980 and onwards using any research design or method (e.g., quantitative, qualitative, mixed methods, literature reviews, and meta-analyses) regardless of the results.

Exclusion criteria

We excluded studies that:

1. did not involve primary data collection, secondary analysis, or a systematic way of collecting or synthesizing primary data (e.g., opinion papers, magazine articles, short papers, abstracts, and collections of opinions);
2. did not include persons living with dementia, Alzheimer's disease, or cognitive impairment as the study population;
3. did not provide enough information for categorization or data extraction;
4. were not available in full text;
5. were out of the scope of this review (e.g., pharmacological intervention and genetics).

Data extraction

Three members of the research team (HP and EL) completed data extraction under the supervision of two senior authors (AMC and CD). We extracted data from studies in a spreadsheet where we operationalized the variables. We reviewed each study and extracted data according to the scope and objective of the scoping review (HP, EL, SM, AC, CD, and AMC). The entire team met regularly to discuss and resolve disagreements or uncertainties about the extracted information. Each study was reviewed independently to identify what factors were described, explained, associated, or related to critical wandering in persons living with dementia. During several rounds of discussion, the authors agreed on the risk factors that were identified. For each study, we extracted information on the following areas:

1. bibliometric information (e.g., year, country, type of document, and journal information);
2. participants' information (e.g., type of participants involved, sample size, sex and age, and study population);
3. study population (e.g., objective, study design, design type, outcome variable(s), and data collection instruments);
4. definitions for critical wandering or getting lost in persons living with dementia;
5. description and operationalization of risk factors associated with critical wandering in persons living with dementia.

Data analysis and synthesis

Three research team members (AC, EL, and HPH) completed the data analysis. Before this began, we coded categorical variables numerically and categorized studies based on the primary impairment (e.g., dementia, cognitive impairment, and Alzheimer's disease). To address the objective of this review, we searched and extracted risk factors associated with missing incidents of persons living with dementia, either reported lost or at risk of getting lost due to critical wandering (Algase, 2006; Petonito et al., 2013). In order to account for the inconsistent terminologies across the literature, which all address the same concept, we also included terms relevant to boundary transgression, elopement behaviour, critical wandering, walkabouts, and actual missing incidents. We used descriptive statistics to summarize and analyse bibliometric and sample details, study design, risk factors, and variables that were associated with a lost or missing incident. Due to the complexity of the included risk factors, we engaged in discussions with experts (i.e., nurses, occupational therapists, and engineers) to facilitate a synthesis of the identified risk factors and variables. Specifically, health-related professionals discussed how these factors are observed and related to persons living with dementia. In addition, they provided feedback during synthesizing risk factors and constructing definitions. For this paper, we defined risk factors are 'clusters' of variables, acting as a group of measurable variables or characteristics that increase or reduce chances of getting lost or going missing for a person living with dementia.

Operational definitions for the risk factors

According to the literature, it is a challenge to find consistent definitions of risk factors about missing incidents involving the general population, including persons living with dementia (Algase et al., 2007; Ferguson, 2022; Rowe et al., 2015). Thus, using operational definitions is an important step to classify and describe risk factors. To define the risk factors and variables, we followed the best practice suggested by Beecher et al. (2019), including concept analysis, clarification, and exploration. First, we examined available definitions for concept analysis. Second, we clarified these definitions by integrating evidence extracted from the selected studies. Finally, we explored the definitions after several iterations with an interdisciplinary team and generated operational definitions for each risk factor. This approach was consistent with similar studies (Hummer et al., 2020; Jogerst et al., 2011) that attempted to develop concepts where a topic was underexplored. We endeavoured to provide background and to inform the results of this scoping review using examples in the definitions of the risk factors. These definitions are intended to be illustrative and not exhaustive of each risk factor extracted in this review. The review included a range of types of studies. In Table 1, we provide characteristics of selected studies.

Potential for bias assessment

For this scoping review, we made a substantial effort to reduce the potential for bias in the study selection process and during the data extraction and analysis phases (Liberati et al., 2009). First, we searched different academic databases. Second, we included studies regardless of positive or negative results. Third, we included studies in various languages, not only English. Fourth, we included various publications, such as master's or Ph.D. theses and journal articles. Fifth, we addressed the raters' biases by having multiple rounds of screening and selection. Each study was screened twice

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Table 1. Characteristics of selected studies (*n* = 73)

	Design type		
Summary (*n*)	Quantitative (*n*)	Qualitative (*n*)	Mixed methods (*n*)
Quantitative (46) Literature review (11) Mixed methods (7) Not applicable (6) Qualitative (3)	Correlational (21) Cross-sectional (11) Evaluation of assessment tool (5) Descriptive (3) Case study (2) Single case (1) Pre and post test [no control group] (1) Case–control (1) Exploratory ecological (1)	Ethnography (1) Case study (1) Exploratory retrospective review (1)	Explanatory (3) Convergent (2) Exploratory (2)

independently, and we used a third rater to resolve disagreements. Our approach was consistent with methods for reducing the potential for bias reported in the literature (Miguel Cruz et al., 2023; Page et al., 2018; Rios Rincon et al., 2021).

Results

Bibliometric analysis

Figure 1 shows the scoping review process. The initial search identified 3,376 studies, and after deduplication, 1,638 (48.51%, 1,638/3,376) studies were screened by title and abstract and 1,365 (40.43%, 1,365/3,376) were excluded. We could not retrieve 21 studies (0.62%, 21/3,376) because we did not have full-text access, even after attempting to obtain interlibrary loans through two universities. Then 252 (7.76%, 252/3,376) studies were assessed in full, and 179 (71%, 179/252) studies were excluded based on the inclusion and exclusion criteria. Finally, 73 (2.16%, 73/3,376) studies were included in the data analysis and synthesis phase and reported. The list of selected studies, including study titles, is reported in Supplementary Table A2.

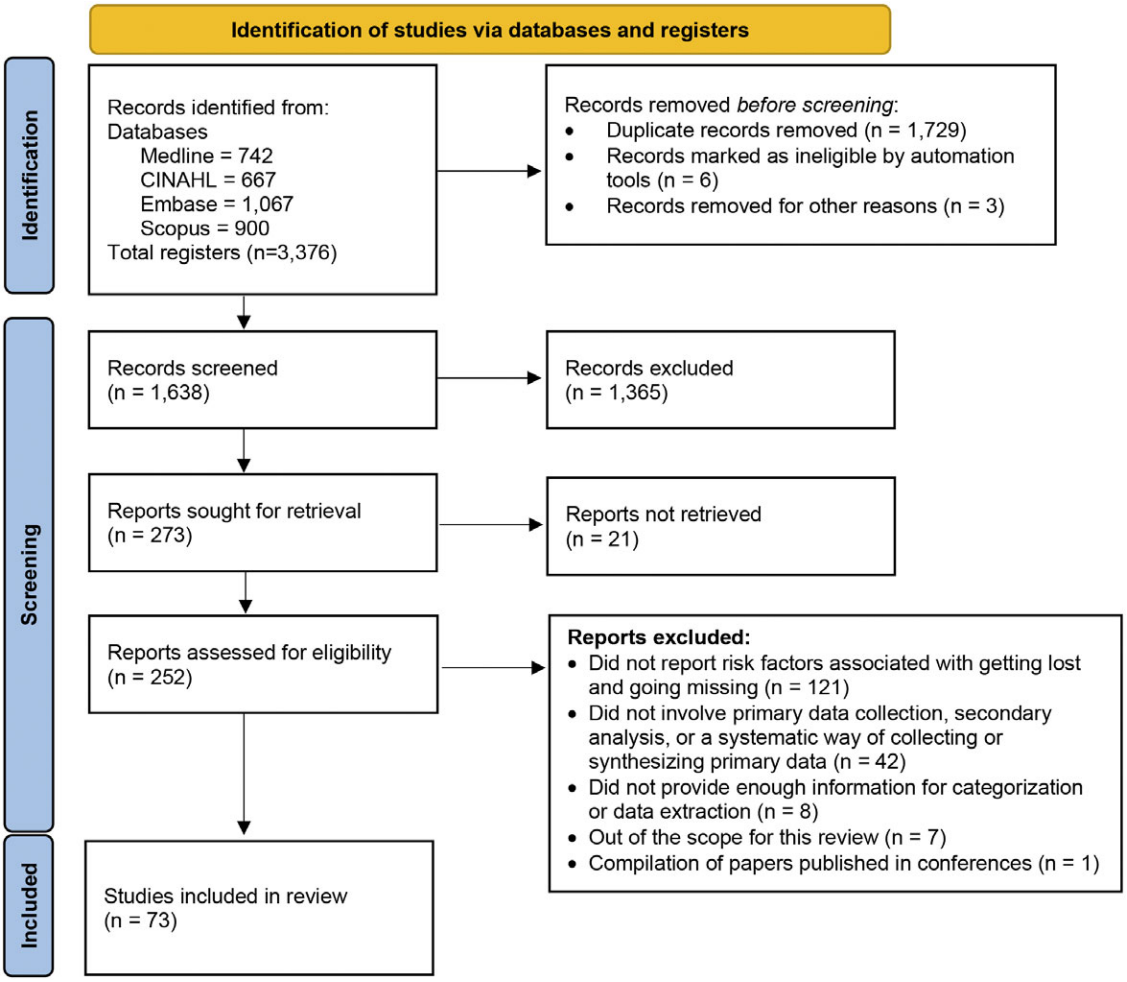

Figure 1. Scoping review process

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Studies were published by 93 authors from 17 different countries, most after 1997 (91.78%, 67/73). The majority were from the United States (46.24%, 43/93), Australia (10.75%, 10/93), Great Britain (9.68%, 9/93), and Korea (6.45%, 6/93). Most of the selected studies were published as journal articles (93.15%, 68/73), and were published as research papers (71.23%, 52/73), literature reviews (21.92%, 16/73), and theoretical models and seminal papers (6.85%, 5/73).

For this scoping review, we extracted 39 studies published in quartile 1 (54.93%, 39/73), 17 studies published in quartile 2 (23.94%, 17/73), 7 studies published in quartile 3 (9.86%, 7/73), and 4 studies published in quartile 4 (5.63%, 4/73) of the Scimago Journal and Country Rank (SCImago, n.d.), which is a ranking that allows researchers to measure the scientific influence of the scholarly published literature. For six studies (8.45%), the quartile score was not reported or impossible to estimate. Additionally, we used Sackett's (2000) approach to classifying the level of evidence. Of our studies, only seven were systematic reviews (9.5%, 7/73), two were case studies (2.73%, 2/73), one was single case study (1.36%, 1/73), and one was case–control study (1.36%, 1/73).

Study features and settings

Table 2 shows a detailed description of the specific research design and methods of the selected studies. The majority were quantitative (63.01%, 46/73), followed by literature reviews (15.07%, 11/73), mixed methods studies (9.59%, 7/73), and qualitative studies (4.11%, 3/73). Six studies (8.21%, 6/73) did not report methods, or the method used could not be determined.

In terms of population of the selected studies, 27 studies (36.99%, 27/73) reported persons living with dementia as the primary participant type, 19 studies (26.03%, 19/73) reported persons living with dementia and care partners (e.g., carers, care partners, and nursing staff) as participants, a small group of the studies reported care partners and nursing staff as participants (5.48%, 4/73), and other types of participants (i.e., dementia researchers, health or social care workers, and residents of long-term care facilities in general) (4.11%, 3/73). Twenty studies (27.40%, 20/73) did not report the types of participants. In addition, most of the selected studies reported dementia (46.58%, 34/73) as a primary medical condition of the participants, followed by a combination of dementia and Alzheimer's disease (24.66%, 18/73) and Alzheimer's disease exclusively (13.70%, 10/73). The sample details of the selected studies classified by the primary medical condition of participants are provided in Supplementary Table A3.

Table 2. Summary of risk factors and variables reported in the literature

Risk factor	Variables	Percentage or % (*n*) of studies reporting risk factor
Demographics and personal characteristics	Personal characteristics	32.88 (24)
	Age	24.66 (18)
	Locomotion	23.29 (17)
	Personal history	21.92 (16)
	Sex	19.18 (14)
	Wandering	13.70 (10)
	Basic activities of daily living	10.96 (8)
	Race	6.85 (5)
	Education	2.74 (2)
Health conditions and symptoms	Cognitive impairment	56.16 (41)
	Responsive behaviour	34.25 (25)
	Spatial navigation	21.92 (16)
	Type of dementia	19.18 (14)
	Neurologic and circadian changes	16.44 (12)
	Other medical conditions and precipitating factors (mental)	13.70 (10)
	Medication side effects	13.70 (10)
	Other medical conditions and precipitating factors (physical)	9.59 (7)
	Memory impairment	6.85 (5)
	Executive functioning	5.48 (4)
	Attention issues	1.37 (1)
Environmental and contextual antecedents	Physical environment	39.73 (29)
	Unmet needs	24.66 (18)
	Situational environment	20.55 (15)
	Concentration of services and resources	17.81 (13)
	Living situation	10.96 (8)
	Population density	4.11 (3)
	Accessibility to support	1.30 (7)

Risk factors for getting lost and going missing due to critical wandering in persons living with dementia

Naturally, different studies reported the same risk factors using multiple names and concepts. HP and EL worked with CD and AMC to review the definitions or context provided in each study to cluster the risk factor into a common name. For instance, age was reported as age, older age, or older than 65 years old. Further, many studies reported more than one variable, which we extracted and counted separately. We identified 27 variables that were grouped into three risk factor domains. The domains were: (a) demographics and personal characteristics, which included the core characteristics of persons living with dementia, such as age, sex, race, and education, also called sociodemographic data (Jelastopulu et al., 2014) and personal characteristics (i.e., individual attributes of persons living with dementia, including changes in moods and traits) (National Institute on Aging, 2022), individual history of locomotion and wandering, and one's ability to perform activities of daily living; (b) health conditions and symptoms, which include physical or mental features of a disease condition (National Institute of Aging, 2022), such as cognitive impairment, neurologic and circadian changes, memory impairment and executive functioning and attention issues, and health conditions, that is, the health status of a persons living with dementia, including the physical, mental, and psychosocial health, type of dementia, and other mental and physical medical conditions, precipitating factors and

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medication side effects; and (c) environmental and contextual antecedents that relate to the immediate surroundings or situation of persons living with dementia, such as the physical environment, unmet needs, situational environment, concentration of services and resources, living situation, population density, and accessibility to support.

The most common risk factors reported in the selected studies were (a) cognitive impairment (11.85%, 41/73) (e.g., cognitive decline, deficits and functioning, decreased cognitive ability, and lower scores on the Mini-Mental State Exam); (b) physical environment (8.38%, 29/73) (e.g., ambiance, monotonous architecture, environment modifications and stimuli, stressful lights and noises, security systems, crowdedness, architectural design, and person–environment interactions); (c) responsive behaviours (7.23%, 25/73) (e.g., abusive behaviour, aggression and agitation, and behavioural disturbances); (d) personal characteristics (6.94%, 24/73), including premorbid personality and extraverted personality, agreeableness, conscientiousness, emotions, need for security, and negative emotional states; (e) unmet needs (5.20%, 24/73) (e.g., expressed interest to go home, hunger, lack of exercise or meaningful activities, looking for someone or something familiar, need for security, need to use the toilet, pain, and physical or emotional needs); and (f) advancing age (5.20%, 24/73). A summary of the risk factors and variables reported in the literature is presented in Table 3.

Discussion

Summary of evidence

This scoping review identified the risk factors associated with getting lost or going missing due to critical wandering in persons living with dementia. We included a total of 73 studies that reported risk factors. Overall, we identified 27 variables that were grouped into three risk factors domains: (a) demographics and personal characteristics; (b) health conditions and symptoms; and (c) environmental and contextual antecedents. In this scoping review, cognitive impairment was the most frequent variable reported in the selected studies related to missing incidents due to critical wandering in persons with dementia. Cognitive impairment was observed and linked to other variables in previous studies (Hong & Song, 2009; Kwok et al., 2010; Marquardt, 2011; Rowe et al., 2015; Song & Algase, 2008).

The second risk factor most mentioned in the selected studies was the physical environment (Ferguson, 2022; Taylor et al., 2014). Existing evidence suggests that modifications to the surrounding physical environment such as light intensity, variations in temperature, increase or decrease of noise, humidity levels, and the appearance of visual stimuli can have an impact on the behavioural and psychological symptoms of dementia and the spatial behaviour of persons living with dementia (Algase et al., 2010; Bautrant et al., 2019; Carlson et al., 1995; Caspi, 2014; Hodgkinson et al., 2007;

Table 3. Definitions of risk factors and variables

Risk factor: demographics and personal characteristics	
Variables	Definition
Personal characteristics	Past and present mental and emotional traits and moods unique to each individual (American Psychological Association, 2022; Kiely et al., 2000; Vuong et al., 2014). This includes methods of coping with stress (Gu, 2015), personality (MacAndrew et al., 2018) (defined by the American Psychological Association as the 'individual differences in characteristic patterns of thinking, feeling and behaving' – e.g., outgoing vs. introverted and neuroticism), phasic emotional states and habits (Kiely et al., 2000).
Age	The time someone has been alive (Cambridge University Press, n.d.-a). Age, which is also a risk factor for dementia (Livingston et al., 2020), has been associated with the risk of getting lost in persons living with dementia (Kikuchi et al., 2016; Lester et al., 2012; Sheth et al., 2014).
Locomotion	The method of one moving through space, most often by walking, with or without the use of assistive devices (e.g., walker and wheelchair) as well as the patterns of locomotion (e.g., walking in the evenings) (Algase et al., 2007; Hope & Fairburn, 1990; MacAndrew et al., 2017a,b). Locomotion is a motor response or emotional reaction to the environment (Yao, 2004) and motor disturbances (Martin et al., 2015).
Personal history	Past observable events are specific to an individual (Chung & Lai, 2011), including past exit/elopement attempts (Dewing, 2005; Hope & Fairburn, 1990), previous missing incidents (Dawson & Reid, 1987; Dewing, 2005; Rowe et al., 2012b), fall history (J.-A. Song et al., 2008a), previous work (Cipriani et al., 2014; Klein et al., 1999), lifestyle and hobbies (J.-A. Song et al., 2008a), and history of coping with stress (Goldsmith et al., 1995).
Sex	A set of biological attributes in humans primarily associated with physical and physiological features, including chromosomes, gene expression, hormone levels and function, and reproductive/sexual anatomy. Sex is usually categorized as female or male (CIHR, n.d.).
Wandering	'A syndrome of dementia-related locomotion behavior having a frequent, repetitive, temporally-disordered and spatially-disoriented nature manifested in lapping, random and pacing patterns, some of which are associated with eloping, eloping attempts or getting lost unless accompanied' (Algase et al., 2007). A lack of a standardized definition for wandering has been a persistent problem to understanding the issue (Algase et al., 2007; Cipriani et al., 2014; Neubauer et al., 2021c). Wandering has also been conceptualized as a challenging behaviour, a disruptive behaviour, and a behavioural symptom of dementia (Algase et al., 1996; Hodgkinson et al., 2007). Critical wandering is associated with missing incidents, while eloping is typically associated with leaving a facility rather than one's home in the community (Aud, 2004).
Basic activities of daily living	Routine tasks comprise everyday living tasks (Merrilees, 2014), and the associated skills required to ensure that one's basic physical needs are met, including eating, drinking, and hygiene (Bucks et al., 1996). Someone's ability to perform activities of daily living has been observed as having an impact on persons living with dementia risk of going missing, that is, physical dependency in activities of daily living (Hong & Song, 2009) and ability to carry out these activities (Cipriani et al., 2014; J.-A. Song et al., 2008a).

(Continued)

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Table 3. *Continued*

Risk factor: demographics and personal characteristics	
Variables	Definition
Race	Group to which people belong to based on physical characteristics that they are perceived to share, such as skin colour and eye shape (Cambridge University Press, n.d.-b). This variable has been related to missing incidents in persons living with dementia (Beattie et al., 2005; Lee, 2011; Vuong et al., 2014)
Education	The total time in the number of years a person attended formal education (Statistics Canada, 2021). Education is commonly associated with the cognitive ability of persons living with dementia. Higher childhood education levels and lifelong higher educational attainment may reduce dementia risk (Livingston et al., 2020).
Risk factor: health conditions and symptoms	
Risk factor	Definition
Cognitive impairment	A decline in thinking, memory, judgment, or language (Mayo Clinic, 2022). Cognitive impairment falls on a spectrum from mild to severe (dementia), where mild cognitive impairment often does not impair function enough to impact normal daily activities, but severe levels of impairment may affect the performance of everyday tasks and lead to loss of independence (Alzheimer Society of Canada, 2018; Centers for Disease Control and Prevention, 2011). Cognitive impairment has been observed as a significant variable associated with getting lost for persons living with dementia. Commonly associated with issues in cognitive ability (Kwok et al., 2010; Marquardt, 2011), and cognitive decline (Algase et al., 2004; Dawson & Reid, 1987).
Responsive behaviour	Words, actions, or gestures expressed in response to frustrating, confusing, or negative physical, environmental, emotional, intellectual, or social stimuli are due to changes in the brain that may affect the ability to regulate behaviour. Examples of common responsive behaviours include agitation, aggression, making unexpected noises, and wandering (Algase et al., 2004; Bowen et al., 2011; Chung & Lai, 2011; Dawson & Reid, 1987; Detweiler et al., 2008; Dewing, 2005; Goldsmith et al., 1995; Kiely et al., 2000; Lester et al., 2012; Rowe et al., 2012b; Volicer et al., 2013).
Spatial navigation	A fundamental behaviour of animals and humans involves processes of planning a route and executing movements towards environmental goals (Laczó et al., 2018; Liu et al., 1991; Puthusseryppady et al., 2019). It can be categorized as either allocentric or egocentric. Impairment in allocentric spatial orientation involves difficulties locating objects in relation to other objects. In contrast, impairments in egocentric spatial orientation involve difficulties with locating objects in relation to the self (Laczó et al., 2018). A person's ability to navigate through space is often impacted among persons living (Liu et al., 1991; Puthusseryppady et al., 2019, 2020; Tu et al., 2015).
Type of dementia	Various forms of dementia are uniquely influenced by different factors and disorders that manifest from mild to severe. The most common forms of dementia include (a) Alzheimer's disease, (b) frontotemporal dementia, (c) Lewy body dementia, (d) vascular dementia, and (e) mixed dementia (National Institute on Aging, 2021). This variable considers the type, stage, and severity of dementia (Hope et al., 2001; Klein et al., 1999; MacAndrew et al., 2017b; Okita et al., 2016).
Neurologic and circadian changes	The variation in the functioning or anatomy of the nervous system (National Cancer Institute, 2022). Circadian rhythms are internal processes within the body that create mental, physical, and behavioural changes over a 24-hour cycle (i.e., sleep-wake cycle) (Algase et al., 2009). These natural processes may be altered by disease or exogenous sources. Emerging evidence suggests that circadian changes may increase the risk of neurological disorders (Edgerly & Donovick, 1998; National Institute of General Medical Sciences, 2021; Videnovic & Zee, 2015), and it can be manifested in diurnal rhythm disturbance (Hope & Fairburn, 1990), night sundowning (Hope & Fairburn, 1990; Marcus et al., 2007), and poor sleep patterns (Lester et al., 2012), such as sleep disorder or disturbances (Hodgkinson et al., 2007; Klein et al., 1999; Lai & Arthur, 2003; MacAndrew et al., 2018; Marcus et al., 2007).
Other medical conditions and precipitating factors (mental)	Any diagnosable mental disorder or symptom, such as those classified in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). Examples include depression, anxiety, and delusions (Hodgkinson et al., 2007; Jeong et al., 2016; Klein et al., 1999; MacAndrew et al., 2017b; Marcus et al., 2007; Thomas et al., 2006).
Medication side effects	'Harmful and unintended responses' to a medication taken for a different reason (Health Canada, 2018). This can include physical, cognitive, and mental/emotional responses (Carlson et al., 1995; Hodgkinson et al., 2007; Hope et al., 2001; Klein et al., 1999; Lester et al., 2012).
Other medical conditions and precipitating factors (physical)	Any physical health conditions or general status, not including medications, circadian changes, cognitive impairment, or executive functioning. Examples include weight loss, constipation, and pneumonia (Hope et al., 2001; Kiely et al., 2000; Schonfeld et al., 2007)
Memory impairment	Also identified as memory loss (Rowe et al., 2012) which ranges on a spectrum from normal (age-associated) to severe (dementia). For example, normal aging involves occasional difficulties in remembering things, such as the name of an acquaintance. In contrast, severe memory impairment involves difficulty learning new things (Rowe et al., 2012b), recalling details of a recent conversation or event, or inability to complete daily tasks and stick to a normal routine (Alzheimer Society of Canada, n.d.; Bowen et al., 2011; National Institute on Aging, 2020).
Executive functioning	A disruption in core neurocognitive abilities, including inhibitory control, cognitive shifting, flexibility, and working memory, involved in goal-directed problem-solving. In everyday life, this may appear as difficulties with planning, organization, multitasking, self-control, or decision making (Algase et al., 2003; S. M. Carlson et al., 2013; Chiu, 2002; Rabinovici et al., 2015; Rowe et al., 2012a).

(Continued)

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Table 3. *Continued*

Risk factor: health conditions and symptoms	
Risk factor	Definition
Attention issues	Also described as inattention, difficulty staying on task, remaining focused, and staying persistent and organized (National Institute of Mental Health, 2021). Attention includes four types: selective attention, divided attention, sustained attention, and executive attention (Yang et al., 2019). Inefficient directed attention is related to getting lost behaviour in familiar and unfamiliar environments for persons living with dementia (Chiu, 2002).
Risk factor: environmental and contextual antecedents	
Risk factor	Definition
Physical environment	The characteristics of an individual's perceptible (usually by one of the senses or body sensors – e.g., vision and temperature sensors) surroundings. This includes the quality and contents of immediate surroundings (e.g., architecture, light level, mirrors, and humidity) as well as other factors that impact the surroundings but that may not be immediately perceptible by persons living with dementia (e.g., home security system and ambiance) (Algase et al., 2010; Hodgkinson et al., 2007; Rowe, 2003).
Unmet needs	A lack of fulfilling physical, mental, emotional, or spiritual needs. Examples of physical needs include urination, hunger, and pain. Mental and emotional needs include social interaction, meaningful activities, sense of familiarity, and other psychosocial and spiritual needs (e.g., need to be connected with nature) (Lester et al., 2012; Unruh et al., 2002; Yao & Algase, 2008).
Situational environment	The non-physical surroundings of an individual. This includes social interactions, familiarity with the environment, and other contextual factors (Rowe et al., 2015). The situational environment can be presented in the form of environmental stimuli (Carlson et al., 1995), ineffective use of alarm devices to prevent missing incidents (Aud, 2004), and unusual situations in the environment of persons living with dementia (Bowen et al., 2011; Rowe et al., 2011), for example, being invited to walk or someone approaching private or personal areas of persons living with dementia (Algase et al., 2010; Dewing, 2005; Hong & Song, 2009; Lester et al., 2012; MacAndrew et al., 2017b).
Concentration of services and resources	The concentration of all the health care services available to support persons living with dementia in their communities. Examples include hospitals, clinics, long-term care facilities, and health care support organizations (Gu, 2015). It also considers social support services (Murata et al., 2021) such as police services, nursing, and welfare support for persons living with dementia (Bantry White & Montgomery, 2016; Hodgkinson et al., 2007; Passini et al., 2000; Rowe et al., 2012; Rowe & Glover, 2001) and care partners (Lester et al., 2012; MacAndrew et al., 2018; McShane et al., 1998; Rowe et al., 2012a).
Living situation	The type of living area a person occupies regularly and who else occupies that area. This includes location, privacy, and unit type (Algase et al., 2010; MacAndrew et al., 2017a; Sheth et al., 2014; Winden et al., 2017).
Population density	The number of individuals per unit geographic area, for example, number per square metre, per hectare, or per square kilometre (Tarsi & Tuff, 2012). Population density is related to whether the person living with dementia lives in an urban or rural area (Kowalski, 2020; Murata et al., 2021), with or without higher landmark density and the geographical area (Davis & Weisbeck, 2016; Puthusseryppady et al., 2019; Sheehan et al., 2006).
Accessibility to support	The possible financial limitations to accessing care, such as welfare costs for older adults, medical expenses, and specialized transportation (Murata et al., 2021).

Mazzei et al., 2014; Yao, 2004). For example, when a physical environment is modified, even with the intention of making it safer, the space can become unfamiliar to persons living with dementia and pose a risk for disorientation (Chaudhury et al., 2017; Marquardt, 2011). This influence, in turn, can trigger a missing incident (Ferguson, 2022; Lai & Arthur, 2003; Puthusseryppady et al., 2020; Rowe, 2003). In this case, the physical environment is something external to an individual living with dementia, and the alteration of this environment might be out of an individual's control.

The third most common variable was responsive behaviours such as abusive behaviour, aggression and agitation, angering situations, and hyperactivity (Algase et al., 2004; Bowen et al., 2011; Chung & Lai, 2011; Dawson & Reid, 1987; Detweiler et al., 2008; Dewing, 2005; Goldsmith et al., 1995; Kiely et al., 2000; Lester et al., 2012; Rowe et al., 2012; Rowe & Glover, 2001; Volicer et al., 2013). Responsive behaviours are especially relevant to missing incidents as persons living with dementia in advanced stages have been reported to try to leave the place they occupy in response to agitation or anxiety-provoking events (Dawson & Reid, 1987; Goldsmith et al., 1995; Rowe et al., 2012), or due to their place of residence no longer being familiar to them (Carlson et al., 1995). Authors have described the importance of addressing responsive behaviours in persons living with dementia. For example, Wilkinson et al. (2017) described using nonpharmacological strategies, such as music therapy, to manage responsive behaviours. Responsive behaviours may act as a moderator and proxy for other variables, such as medication side effects, locomotion, and physical environment (Holt et al., 2021; Wilkinson et al., 2017). The literature suggests that responsive behaviours are a *response* to something else, for example, unmet needs, physical environment, or emotional, intellectual, or social stimuli (Algase et al., 2004; Detweiler et al., 2008). Responsive behaviours should be addressed in a supportive and positive manner by speaking calmly or ensuring that the needs of persons living with dementia are understood and managed (Hartung et al., 2020). It stands to reason that the efficient management of this variable could reduce the risk of getting lost in persons living with dementia (Neubauer, 2020).

The fourth most common variable was personal characteristics and history. This variable includes personality types, emotions, and moods such as openness, agreeableness, extraversion, negativity, neuroticism, outgoing personality, passivity (Kiely et al., 2000; Lee,

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2011; MacAndrew et al., 2018; Sutin et al., 2018; Thomas et al., 2006), and methods of coping with stress (Algase, 2008; Gu, 2015; Hodgkinson et al., 2007; Klein et al., 1999; Sheehan et al., 2006; Thomas et al., 2006). For example, life events include changes in routines or relocation to another residence (Beattie et al., 2005; Dewing, 2005; Hong & Song, 2009; Jeong et al., 2016; Lester et al., 2012). In fact, in a study conducted by Sutin et al. (2018), participants who scored higher in neuroticism were at greater risk of experiencing behavioural and psychological symptoms of dementia, including getting lost in familiar places and wandering. Also, agreeableness was associated with less risk of getting lost in familiar, thus explaining how personalities may influence the risk of getting lost for persons living with dementia.

The fifth most common variable was unmet needs. These include expressed interest in going home, engaging in past activities, hunger, lack of exercise and meaningful activities, looking for someone familiar, pain and physical discomfort, physical and biological needs, and need for security (Algase et al., 2004; Carlson et al., 1995; Chung & Lai, 2011; Cipriani et al., 2014; Dewing, 2005; Goldsmith et al., 1995; Gu, 2015; Klein et al., 1999; Lai & Arthur, 2003; Lester et al., 2012; Lucero, 2002; MacAndrew et al., 2017b; Rowe et al., 2012; Thomas et al., 2006; Volicer et al., 2013). Unmet needs could trigger missing incidents, as persons living with dementia may be inclined to take action to meet their needs without weighing the risk, for example, going out without notifying care partners. In circumstances where certain needs are unmet, such as urination or bowel movement and hunger, they find ways to meet these needs, which can lead them to leave their home (Algase et al., 2004; Carlson et al., 1995; MacAndrew et al., 2017b). Based on the identified risk factor and available literature, there is evidence to suggest that many of these factors, such as responsive behaviours, personal characteristics and history, and unmet needs paired with problems related to cognitive impairment, could lead to a missing incident among persons living with dementia. However, the specific relationships between these risk factor categories are poorly understood.

Although we identified three risk factor domains, we acknowledge that the risk factors can be presented in alternate ways, such as internal or personal, external, and fixed and variable risk factors (Kraemer et al., 1997). The literature suggests that some risk factors and variables overlap, moderate the effect of other risk factors, mediate or intervene in the outcome (i.e., getting lost), and act as a proxy for other risk factors (Ferguson, 2022). This is because a factor comprises a 'cluster of variables that are correlated among themselves' (Portney & Watkins, 2008). Indeed, we observed how some variables included in the risk factors might overlap with other factors, such as cognitive impairment, which can moderate or mediate spatial navigation (Vlček & Laczó, 2014). Thus, risk factors domains and variables should not be analysed in isolation (Ferguson, 2022; Kraemer et al., 2001), and should focus on examining how risk factors may overlap proxy risk factors or how risk factors and variables act as moderators on the effect of other risk factors and mediate another risk factors as related to getting lost in persons living with dementia. This scoping review confirms that risk factors might be interrelated and may require additional exploration in practice (Ferguson, 2022). This has implications for how we should collect data to prevent future missing incidents because the information collected on missing incidents involving persons living with dementia is limited and, in some cases, nonexistent (Ferguson & Huey, 2020; Neubauer et al., 2021a).

Neubauer and Liu (2021b), Rowe et al. (2015) and Yevchak et al. (2012) have proposed models that describe risk factors associated with getting lost in persons living with dementia. However, these models have yet to be validated. Grant et al. (2018) noted that validation studies that determine the discriminative and face validity, calibration, and clinical effectiveness are essential to determine the risk prediction model's usefulness. In addition, all three models capture a portion but not all existing risk factors. Neubauer and Liu (2021b) included the culture and geography of the individual as risk factors, whereas Rowe et al. (2015) captured contextual, situational, and neurocognitive antecedents, and Yevchak et al., (2012) identified antecedent and precipitating factors. Thus, the description and analysis of risk factors associated with missing incidents in persons living with dementia due to critical wandering have not been comprehensive.

In addition to a need for a comprehensive and validated risk model, there is a need to investigate and understand how specific risk factors evolve over time with the progression of dementia. For example, specific demographics can be considered an initial risk factor and medical conditions later in time (Ferguson, 2022; Kraemer et al., 1997). This would enable appropriate and customized interventions to mitigate the risks of getting lost and going missing based on the individual circumstances of a person living with dementia. Consequently, the inclusion of more specific risk factors or the exploration of combinations of risk factors that determine the risk would greatly enhance the practical relevance and applicability of our findings.

In this scoping review, we attempted to provide operational definitions for the risk factors, acknowledging that the lack of definitions is a common challenge related to risk factors associated with missing incidents of persons living with dementia (Algase et al., 2007; Rowe et al., 2015), which in turn is also an issue for the analysing of risk factors (Ferguson, 2022). Thus, defining variables and risk factors by proposing operational definitions is an essential step in analysing and describing risk factors. These definitions provide a solid foundation for additional research into each risk factor and for developing predictive models.

Very few of the 73 included papers systematically validated the proposed risk factors. Additionally, the level of scientific evidence in the included studies was low (Straus et al., 2018). However, while the evidence may be low, given the nature of a scoping review to summarize all existing literature, this is not prohibitive to our results. Most selected studies included data from police reports and newspapers; their credibility is as good as the quality of the data (Güss et al., 2020; Miguel-Cruz et al., 2022; O'Connor et al., 2021). Interestingly, few studies included the perspectives of persons living with dementia and care partners. We consider this as an opportunity for future studies.

In summary, through this scoping review, we confirm that there is a need to increase the level of evidence that identifies clear outcomes pointing to risk factors in this population and recommend this to be addressed by future research. The lack of studies backed with evidence raises questions about the degree of credibility of each associated risk factor to be used in predictive models to estimate and mitigate the risk of someone living with dementia getting lost and going missing. An increased focus on high-quality validation studies would enable researchers to develop and combine predictive risk models with available, proactive approaches to enhance the autonomy and safety of persons living with dementia. High-quality validation studies could also reduce stress for care partners and minimize the high demand for public services, especially those related to search and rescue processes.

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Future research

We support the literature that recommends the creation of models that incorporate associated risk factors for getting lost and going missing due to critical wandering in persons living with dementia. For example, Neubauer and Liu (2021b) recommend building a mathematical predictive model to quantify risk factors that would enable those living with dementia and family care partners to understand which risk factors they should focus on when choosing a strategy to manage missing incidents. In addition, Rowe et al. (2015) suggest that understanding how different types of personal antecedents interact in their model can promote more accurate preventative and response strategies. These authors recommended that future research confirm the antecedents and how they can lead to missing incidents. Finally, Yevchak et al. (2012) suggest that building a model that can weigh and quantify different sundown behaviours into the risk of going missing would be beneficial in preventing the risk of going missing among persons with cognitive impairments.

Future work may include developing assessment tools, validating risk factors, and, finally, developing predictive models to individually assess the risk of getting lost and going missing in persons living with dementia due to critical wandering, considering the risk factors identified in this review. As well, future research should delve deeper into identifying and elucidating these specific risk factor combinations that determine the risk of individuals with dementia going missing. By examining and highlighting these interdependencies, we can provide a more meaningful and practical understanding of the factors contributing to missing incidents. Additionally, more research is needed to describe related risk factors to inform preventive strategies for persons living with dementia, care partners, and health care professionals. Also important, we should consider the feasibility of data collection and propose alternative approaches, such as collaborations with police or first responders' organizations and health care institutions, to gather more comprehensive and individualized data. Lastly, future research should aim to validate the observed risk factors with persons living with dementia, care partners, and health care professionals and develop prospective studies to describe further and understand the lost person's behaviour, exploring multiple sources of information, including police records, or cross-referencing vulnerable person registries with police and search and rescue records. This analysis could inform best practices for prevention, risk assessment, and risk mitigation.

Limitations

After thoroughly searching the available literature, we extracted and described risk factors, categorized into three risk factors domains associated with missing incidents due to critical wandering in persons living with dementia. Despite our rigorous search strategy, we may have missed relevant studies because of the inconsistency in how authors utilized terms, such as 'getting lost' and 'going missing', and how the risk factors were understood and reported. We recognize that a duplication of studies included could happen when we include primary data articles and secondary sources, but this was not the case for this study. Our inclusion and exclusion criteria, as well as selection and extraction process, were designed to ensure a comprehensive and inclusive review of the literature, having in mind integrating as much relevant and informative sources as possible, without compromising the clarity and focus of the scoping review. A limitation of this study was that we did not assess the risk of bias due to the heterogeneous nature of the study designs included. Lastly, our scoping review could not evaluate the identified risk factors due to the lack of experimental evidence.

Conclusions

Despite the vast literature on missing persons (Greene & Alys, 2016; C. Taylor et al., 2019), few studies were identified in our review that explored the risk factors associated with missing incidents due to critical wandering among persons living with dementia (Ali et al., 2016; Bantry White & Montgomery, 2015b; Barnard-Brak et al., 2018). Of those that were included, three risk factor domains emerged: (a) demographics and personal characteristics, (b) health conditions and symptoms, and (c) environmental and contextual antecedents. This scoping review identified that the existing literature also contains weak empirical evidence about the risk factors for getting lost and going missing in persons living with dementia.

Persons living with dementia are at risk of getting lost and going missing in their communities. These incidents are a threat to their safety. Many adverse outcomes associated with persons living with dementia who go missing and become lost have been reported. As the number of persons living with dementia and experiencing cognitive impairment continues to grow (Hallam et al., 2022; Nichols et al., 2022), an understanding of the risk factors related to missing incidents is necessary to mitigate negative outcomes. This can also inform predictive models of risk, tools, and strategies to support the decision-making processes of persons living with dementia and care partners can support their quality of life and safety.

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