Elopement: Occurrence, Prevention, and Mitigation

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Abstract

In 2020, seventy-five million Americans reached 60 years or older, a 25% increase over the last decade.¹ As this group ages, so will the number of Americans living with some form of cognitive impairment.

Dementia, a syndrome typically expressed as progressive cognitive impairment, resulting from one or more diseases and disorders, often includes, at some point during the trajectory of the illness, critical wandering. Often mistakenly called simply "wandering," critical wandering is more challenging to the caregiver and becomes especially dangerous to the person when it progresses to elopement, unplanned or unsupervised exits from a safe environment.

Characterizing the extent of the issue proves difficult for lack of, and inconsistencies in, reporting, the absence of a central data repository, and differing criteria or definitions of what constitutes an incident of a missing person living with Dementia. For our purposes, three key terms are referenced in our analysis.

Wandering: Merriam-Webster defines the term, an adjective, to move about without a fixed course, aim, or goal. For a person living with Dementia, there may be times of constant or repetitive motion, even nervous rambling through possessions and rooms, and it may seem as aimless or disoriented movement. The risks are generally lower for someone trying to find "lost" objects, is a social butterfly, or has excess energy to expend.

However, it's essential to understand that there is a difference between someone wandering, them becoming a critical wanderer, and the act of elopement.

Critical Wanderer: Anyone living with Dementia who cannot be located by their caregiver due to wandering behavior.² This reflects critical wandering from the perspective of the caregiver, the one who reports and assists search and rescue investigators, unlike the missing subject.

Elopement: The act of leaving the caregiving environment, unaware of their situation in terms of place and/or time. The individual is exposed to potential dangers such as falling, traffic accidents, and/or adverse weather conditions.³

Through our review and analysis, the Dementia Society of America[®] projects an elopement incidence rate of 198,000 each year. Although local, state, and national reporting and criteria vary widely from a low of 1 in 4 to a high of 1 in 3, critical wanderers who elope from their environment are found dead or never found.³ The number of lives lost to elopement may approach 63,000 each year.

With this understanding of the extent of the problem, we present preventative tips and tools for caregivers. Dementia symptoms can prevent individuals from expressing conditions that may trigger an elopement attempt. These underlying conditions include Fear, Physical Need, Frustration, Pain, Purpose, and Promise. To mitigate the threat of elopement in a caregiving situation, we recommend that caregivers Review Home Safety, Read and Respond, Revisit Life History, Recruit the Community, Seek Medical Advice, and wear or carry a Medical ID.

Review of Previous Work

A Google Scholar review of wandering and elopement by those living with Dementia revealed a limited dataset in both numbers of cases and methods of data collection. Through significant effort by researchers, incident rates and outcomes have mainly been gathered through examining newspaper reports ³. Silver Alert Programs have the potential to become an important data source, but they are not implemented throughout the United States, individual state programs do not apply uniform reporting criteria⁴, and there is no central data repository. The FBI's National Crime Information Center (NCIC) Missing Persons statistics indicate the age of the missing individual who may also be categorized as having a disability, a useful way to query missing persons with Dementia.^{5,6} However, access to the database is restricted. With no reliable source of incident totals or rates of occurrence, we sought to calculate our own projections.

Methods and Projections:

Our review and analysis of available literature were focused on how to best project the annual occurrence of elopement incidents. The process led to three methods: 1) an age-based population rate, 2) a vulnerability-based rate, and 3) reported missing person statistics.

Population: Several studies refer to Butler and Barnett's 1991 ratio describing the occurrence of elopement within the 65 years and older population as 1:1000. This ratio was applied to the 2019 US population over 65 years of age.⁷

Vulnerability: For refinement, we looked at those within the older than 65-year age group likely to have Dementia. This vulnerable population is described as those living with any sub-type of Dementia and is represented by 17% of the over 65 age group. ⁸⁻¹¹ It is reported that among people living with Dementia, 60 % will wander^{12,} and 1% will have a critical wandering event or an elopement.⁷

Missing Persons: Finally, we examined the National Crime Information Center (NCIC) Missing Persons information for adults over 65 years to estimate the prevalence of Dementia related incidents. The numbers suggest that 15% of reported missing persons are 65 years or older.⁶

For each of these methods, we calculate low- and high-end estimates of incidents per year. Still, reported incidents are far less than the number of actual incidents. The underreporting of

incidents may be due to an unwillingness to publicize information because of the stigma still associated with Dementia, the procedural hurdles to reporting a missing adult, and successful neighborhood and family-driven searches that preempt reporting to authorities. We adjusted for this likely undercount, adjusting the estimates of reported incidents by a factor of two² and three ¹².

The low- and high-end estimates of actual incidents, based on 2019 population numbers, are shown in Table 1. The estimates were averaged, and the median was selected for this initiative. It should be noted that a more representative age group for this review would likely include those 55 years and up. However, we used 65 years and older as this is the most commonly used group in calculating prevalence rates.

Method	Population	Reported	Low-	High-	Median	Calculation
	of Interest	Incidents	End	End (3x)		Note
			(2x)			
U.S. Population	54,000,00	54,000	108,000	162,000	135,000	15% Total US
>65 yrs						Рор
Vulnerable	9,180,000	91,800	183,600	275,400	229,500	17% Population
Population*						>65
Missing Persons	609,275	91,400	182,800	274,200	228,500	15% Total
Population						Missing Persons
Average		79,067	158,133	237,200	197,667	

Table 1: Methods of Estimating Annual Elopement Incidents

Outcomes:

We've adopted the proportion "1 in 3" to describe how many critical wanderers do not return from an elopement event; they are found dead or never found. One quarter to one-third of missing persons with Dementia can be expected to suffer the most serious outcomes.

Thirty-two percent of the individuals represented in Petonito (2012)³ suffered mortality or were not found. Available data on adverse outcomes may be inflated since it was sourced from newspaper accounts of missing persons with Dementia. Newspapers do not typically report on every lost and then found person. Notably, Koester's 1992 and 1998 numbers were prospective studies and suggested a mortality rate of about 23% in a smaller (n=116) sample size.

Negative outcomes are linked to geography as climate and terrain can determine the fate of the critical wanderer. The mode of travel is also a determinant of outcomes. Hunt and colleagues (2010) reported through examination of newspaper reports that 102 of 207 cases (50%) of missing drivers with Dementia were found dead or were not found.³

Data Source	# Dead / Not Found	# Lost with Dementia	Percent Negative Outcome
Muschert and colleagues (2009)	55	140	39%
Lai et al. (2003)	1	10	10%
Koester (1998)	22	87	25%
Rowe and colleagues (2011)	103	325	32%
Koester and Stooksbury (1992)	6	29	21%
Average			31.6%

Table 2: Negative Out	tcomes Reported	in Petonito (2012)

Six Hidden Triggers

With a greater understanding of the extent and risks of elopement, we turn our focus to prevention. Critical wandering and elopement are thought to be a response to biological, psychosocial, and person-environment interactions.¹³ The six triggers listed below represent some, but not all, conditions that might induce a fleeing type response. An elopement event may be averted if caregivers are able to detect these conditions- even though they may not be expressed by the individual living with Dementia.

- 1. **Fear** When a person feels their safety is at risk, the biological reaction is fight or flight. If your surroundings seem foreign and the people unfamiliar, it is natural to be fearful with an urgency to flee. Threats may be real, like an abusive caregiver, or imagined as a delusion (i.e., A hostage situation) takes hold.
- 2. **Frustration** Daily, repeated difficulties in completing ordinary tasks can build frustration levels to a point where a violent or mobile outburst pushes a person to leave the environment. Boredom with daily routines can also build frustration. Wandering or elopement responses may return a sense of control to the person living with Dementia.
- 3. **Physical Needs** The most basic response to hunger is to seek food, to thirst seek fluids, to a toileting need seek privacy. Seeking fulfillment of physiological needs can result in an unplanned, unsupervised exit of an otherwise safe environment an elopement.
- 4. **Pain, Seen & Unseen-** The emotional pain of isolation, unfamiliarity, loss of free will, and others can drive a person to seek a different, more familiar environment. Physical pain may also drive the fight or flight response, leading to an elopement event.
- 5. **Purpose-** Sometimes, routine activities go awry, and a loved one becomes lost. What would have been an everyday task such as a run to the grocery store, walking the dog,

retrieving the newspaper, or taking the garbage out to the curb becomes a confusion of time, space, and place for the person living with Dementia.

 Promise- People living with Dementia may reenact past obligations in their current situations. A promised visit to mother, a shift at the workplace, a friend in the hospital. A person's efforts to fulfill such promises to self and others can lead to an elopement incident.

Six Recommendations

Along with learning to identify and respond to triggers, caregivers can take distinct actions to build a layered approach to the security of their loved one.

- 1. **Review Home Safety** Evaluate the home environment for safety and setting. Inspect door/window locks, consider monitoring and alarm systems, conceal exits, minimize clutter to create a tranquil, safe environment.
- Read & Respond- Learn how to read your loved one's moods, physical needs, emotional states, and activity levels. Such observations may reveal an impending elopement. Respond with appropriate comforting, need fulfillment, redirection, or distraction. Learn more about and practice non-verbal communication between you and your loved one.
- 3. **Recruit Community** If neighbors, first responders, and frequent passers-by are made aware that a person with Dementia lives in their community, a personalized monitoring system is in place. Make them aware and understanding that your loved one could wander away and becoming lost, or they may knock on- or even enter through- doors in the middle of the night. Keep a current photo of your loved one at hand to familiarize your neighbors. While not failproof, enlisting compassionate observers can help ensure a loved one's safety.
- 4. **Revisit Life History** A tool for both prevention and response to elopement incidents is to build and refer to a life history profile of your loved one. Information such as former workplaces and job duties, childhood homes, frequent vacation spots, military service, past traumatic events, and other formative experiences in your loved one's life. This information can help you, and potentially emergency services, predict and respond to behaviors of your loved one should they contemplate or initiate a critical wandering event.
- 5. Get With The Doc- Have a primary care physician or a specialist such as a geriatrician, psychiatrist, or neurologist evaluate your loved one for anxiety, depression, pain, or other treatable conditions that might heighten the risk for elopement. Depression among adults living with Dementia increases the risk for critical wandering by a factor of eight.¹³ Treatment of concurrent disorders may reduce the risk of elopement.

6. Get Medical ID- An individual wearing a medical identification (ID) bracelet who may be exhibiting peculiar behavior is more likely to draw helpful intervention from a good Samaritan. Such an intervention can significantly reduce the risk for negative outcomes¹. Further, when the ID is linked to a personal profile which is accessible online and/or via a 24-hour hotline, medical professionals, police, and others searching for a lost individual can better predict that person's behavior, contact responsible parties and prepare for medical needs.

Conclusion

The challenges and heartbreak of elopement by those living with Dementia are immense and will continue to grow along with the aging American population. Understanding what motivates elopement behavior and how it can be modified is key to reducing adverse outcomes. Managing a loved one's environment for safety is achieved by employing a multi-layered approach that addresses the before- during- and after- stages of elopement.

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CONTACT:



Dementia Society of America[®] 1-800-DEMENTIA[®]

info@dementiasociety.org www.dementiasociety.org www.operationkeepsafe.org Follow us at @DementiaOrg

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