

A look at deaths occurring in persons with dementia lost in the community

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Abstract

The purpose of this study was to examine cause of death in persons with dementia (PWDs) who have become lost in the community. The study was a retrospective review of 93 US newspaper articles describing PWDs being found dead in the community after leaving their caregiving situations unattended. Of these PWDs, 87 percent were found dead in natural, secluded, unpopulated areas, such as woods, fields, ditches, and bodies of water. They were generally found less than a mile from where they left, but often were not found for extended periods. Males and persons from community-based residential facilities appear to be at higher risk of dying after leaving unattended than females and those living at home.

Key words: Alzheimer's disease, wandering, searching

Introduction

One clinical consequence of dementing illnesses such as Alzheimer's disease (AD) is the inability to recognize familiar places or find a familiar location.^{1,2} Persons with dementia (PWDs) are thus at risk of becoming lost even in familiar environments.^{3,4} The Alzheimer's Association estimates that 60 percent of those with AD will at some point become lost in the community during the course of their disease.⁵

Little research has been done on the specific problem of PWDs becoming lost.^{3,4} Rowe and Glover conducted a study on persons found through the Alzheimer's

Association Safe Return program,³ but since almost all of these individuals were found alive, the specific circumstances of those found dead could not be studied. Of note, however, was that the four persons who were found dead were all found in natural, secluded areas, such as woods, parks, or fields.

Koester studied cases in which the Virginia State Search and Rescue teams were requested to assist in a local search that had been unsuccessful.⁴ In 18 (27 percent) of these 87 cases, the person was found dead, but little subanalysis of this specific group was reported. For the whole group, persons were found an average of 0.6 miles from the place last seen and were found in both natural areas (brush, creeks, woods) and populated areas (roads or houses). Walking-type search methods were the most effective in finding the individual; in some cases, the individual was found by air scent dogs or through a helicopter search. The PWD left their caregivers between the hours of 7 AM and midnight; there was no peak during the sundowning time in the evening hours. In 54 percent of the 87 cases, the subjects lived in their home; the remaining 46 percent lived in professional care settings.

Of note is the lack of any empiric evidence detailing the rates of PWDs becoming lost in the community. Although the Alzheimer's Association reports that this problem will occur in 60 percent of those with dementia,⁵ it provides few other details. We could find no estimates of the percentage of PWDs who become lost and are not found alive, or of how many persons become lost in a given year.

In general, research has focused on the problem of wandering, or the behavior of walking in repetitive cycles or aimlessly.⁶⁻¹¹ However, it is incorrect to equate these two problems, since PWDs who wander, as well as those who don't, become lost in the community. While

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wandering is a significant behavioral problem in dementia, becoming lost in the community can happen to anyone with dementia throughout the process of the disease. Several circumstances can lead to PWDs becoming lost in the community: being unable to find their way home from routine outings; becoming separated from their caregivers; being left unattended for even a short period of time; or leaving home in an agitated or angry state.³ AD results in brain damage that impairs the wayfinding ability of its victims, causing deficits in problem-solving abilities and spatial orientation that leave all PWDs at risk for becoming lost in the community.¹²

The majority of PWDs who become lost are found and returned home safely.³ However, a small number suffer injury or death as a result of becoming lost. To date, no study has investigated the factors that may influence whether a PWD who has become lost in the community will survive the experience. In this study, we examined newspaper reports of PWDs who died as a result of becoming lost in the community in order to better understand the characteristics of these individuals and the specific circumstances surrounding their deaths. Knowledge of these factors should lead to improvements in search strategies and outcomes.

Design and methods

We used a retrospective descriptive design for this study. Data were gathered from US newspaper reports published from 1998 to 2002 that described incidents in which PWDs died as a result of becoming lost in the community. To locate appropriate reports, we used four Internet search engines: NexusLexis Academic, Dow Jones Interactive, Google, and Teoma. The highest yield of articles was obtained with the search terms *Alzheimer's*, *missing*, and *dead*. Synonyms of these terms were also used (dementia, lost, deceased, etc.). Most articles came from daily newspapers of or near the city where the individual was found. Inclusion criteria for the reports were that the person described had a dementing illness, had become lost in the community on their own, and had subsequently been found dead. The report also had to provide information on at least 50 percent of the variables in the study: age, gender, residence, when and how the individual left, when and where the individual was found, who found the individual, how long had the individual been missing, and how far away the individual was from the place last seen. All the stories that met these criteria were used. To collect the data, we retrieved the original newspaper article.

We analyzed 93 cases of PWDs dying as a result of becoming lost in the community. Of these, 62 involved male PWDs and 31 female PWDs, with an average age

of 78 for the entire group (range 60 to 91). The incidents occurred in 36 states, with Florida having the most cases at 11, followed by California and Virginia with seven each. Of the PWDs, 61 percent lived at home, 16 percent lived in nursing homes, and 21 percent lived in community-based assisted living facilities.

Results

The most common cause of death reported in these cases was exposure (68 percent), followed by drowning (23 percent). Other causes of death included sustaining an injury or falling (4 percent), being hit by a vehicle (3 percent), and asphyxiating in mud (1 percent).

Deaths from all causes occurred with greater frequency during the coldest (November through February, 33 deaths) and warmest (June through August, 32 deaths) months than during the rest of the year when temperatures are more moderate (28 deaths). The fewest deaths occurred in April (two) and October (three); the highest number occurred in July (19) and December (11). The following case illustrates the higher risk in extreme temperatures:

[Subject] fell into a cactus bed just 40 feet away from her nursing home Monday afternoon. By the time EMS arrived, her body temperature was 108 degrees. She was taken to . . . Medical Center, where she was pronounced dead.¹³

Table 1 provides frequencies for time elapsed between the last sighting of the PWD and discovery of the body (data were missing for three subjects). Only 25 percent of the subjects were found within 24 hours; of these, more than half had died from drowning. This finding is likely due to the fact that drowning leads to a rapid death and that remains can be spotted in bodies of water more easily than in wooded or remote settings. The three PWDs who died after being hit by a vehicle were all found within six hours of becoming lost. In 33 percent of the cases, it took more than a week to find the victim. One subject's skeletal remains were found just 400 yards from her home more than four years after her disappearance.

Most of the PWDs became lost in the community after eloping on foot (81 percent), while 15 percent became lost after leaving in their own vehicles, and 4 percent became lost when they were on a normal outing, such as a daily walk. Most (39 percent) left between 9 PM and 7 AM. The others left between noon and 6 PM (35 percent), 7 AM and noon (18 percent), and 6 PM and 9 PM (8 percent). Of those who left in their vehicle, all left during daylight hours.

The majority of the individuals who left on foot were found within one mile of the location in which they were

Table 1. Time between last sighting of PWD and discovery

Time	Frequency	Percent*	Cumulative percent*
Less than 6 hours	13	14.4	14.4
6 to 12 hours	4	4.4	18.8
12.1 to 18 hours	4	4.4	23.2
18.1 to 24 hours	2	2.2	25.4
2 days	13	14.4	39.8
3 days	7	7.8	47.6
4 days	6	6.7	54.3
5 days	4	4.4	58.7
6 days	2	2.2	60.9
1 week	6	6.7	67.6
1.1 to 2 weeks	14	15.6	83.2
2.1 to 3 weeks	2	2.2	85.4
3.1 to 4 weeks	2	2.2	87.6
More than 1 month	11	12.2	99.8
Total	90	99.8	

*Totals slightly less than 100% due to rounding.

last seen (74 percent), with 51 percent being found less than half a mile away. Only 6 percent of the individuals traveled more than five miles on foot. Those who became lost while driving their vehicles drove between half a mile and 200 miles before abandoning the vehicle to travel on foot (with the exception of one individual, who drove his vehicle into a river). All of these individuals were found within one mile of their vehicles; most (66 percent) were found within 0.1 mile.

In this case example, "an elderly . . . man whose disappearance triggered more than a month of aerial and foot searches was found dead in the woods of a state wildlife refuge. . . . [Subject] was discovered by a wildlife ranger about 5:30 PM Saturday lying on the ground roughly 100 yards from his car at . . . Wildlife Refuge."¹⁴

Table 2 lists the types of locations in which the individuals were found. Almost all (87 percent) were found in unpopulated natural areas such as woods, bodies of water, fields, ditches, brush, wetlands, ravines, or canals. The 13 percent found in urban areas had either died quickly (getting hit by a vehicle or dying of exposure) or had found secluded locations within the busier surroundings (e.g., junkyard, construction site, top of a building, vacant lot, an abandoned shed).

Throughout these cases, a recurring theme was the

attempt these individuals made to find a secluded spot, where they remained until they succumbed to the elements. Not only did they go into natural or wooded areas, but they then made further attempts to hide under brush or other cover. Examples include:

- A male subject who found an overgrown trail on the property and followed it back to a cypress swamp, where he drowned.
- A woman who left a greenbelt recreation area, swam across an adjacent creek to a nearby island, and died in a wooded area.
- A body so well-hidden among cornstalks that searchers had to "walk right on top" of the spot to find it.
- A man who went into a secluded junkyard and lay down on the floorboard of an abandoned car.
- A body so concealed in bushes that it was discovered only after the search was expanded to include search dogs.

Table 2. Types of locations in which PWDs were found

Type of location	Frequency	Percent*
Natural areas (ditches, arroyos, fields, etc.)	30	33.3
Wooded area	14	15.6
Lake/pond	11	12.2
Shallow water	11	12.2
Near creek/river	6	6.7
Park/refuge	4	4.4
Abandoned vehicle	2	2.2
Urban area	12	13.3
Total	90	99.9

*Totals slightly less than 100% due to rounding.

Other discovery sites included thick vegetation, a pile of brush, thick creekside brush hidden from nearby roads and houses, and piles of cornstalks.

Although significant search and rescue efforts were launched in most cases, formal search parties only succeeded in finding the individuals in 50 percent of the cases (Table 3). The other victims were found by individuals not connected with the search who came across the body, either while search and rescue efforts were ongoing or after they had been called off. For instance, "[subject], who was living at . . . Alzheimer's dementia care center, went for a walk two weeks ago and never returned. . . . [A] teen riding an ATV apparently discovered the body in a ravine."¹⁵

Also of note is that walking searches produced the greatest number of discoveries. More technical means of searching (e.g. dogs and aircraft) managed to find only a small number of individuals.

Discovery of the body occurred between noon and 6 PM in 36 percent of the cases, 7 AM to noon 31 percent of the time, 9 PM to 7 AM in 24 percent of the cases, and 6 PM to 9 PM 9 percent of the time.

Discussion

The findings of this study can be compared to those in which Rowe and Glover³ examined records of persons found alive in the community using the Alzheimer's Association Safe Return database. In that study, the majority of PWDs found alive after becoming lost in the community were found in populated

areas such as neighborhoods, businesses, stores, or streets/highways. That is remarkably different from the findings of the current study, where nearly all the bodies of PWDs who had died as a result of becoming lost in the community were secluded in some way, generally because the individuals had wandered into natural areas away from people.

The reports reviewed for the current study provide four pieces of evidence that the PWDs who died sought out secluded places very soon after they became lost. First, most were found very close to their homes. Second, despite intensive search efforts, they were generally not found for several days. If they had not become secluded very quickly, the intensive search efforts would likely have found them earlier. Third, the newspaper articles gave little indication that these individuals had been sighted in the community after they had become lost, despite media reports being released about the missing individuals. Fourth, even those found very quickly were discovered in unpopulated places such as lakes, swamps, and ditches.

These findings highlight how intensive the search must be to find these individuals before they succumb to death by exposure. Except under the most extreme temperatures, searchers likely have at least 24 hours to find these individuals alive. However, this is a difficult task, not only because the PWDs may seclude themselves quickly, but also because it appears that they often fail to respond to efforts to find them. In a number of stories, searchers remarked how close they had come to the area in which the person was eventually found. But the PWDs

Table 3. Who discovered the body of the lost PWD

Person(s) making discovery	Frequency	Percent*
Searchers walking	22	31.0
Employee/property owner	14	19.7
Walking passerby	12	16.9
Search dogs	5	7.0
Kids playing	5	7.0
Motorist	4	5.6
Searchers in air	3	4.2
Hunter/fisherman	3	4.2
Marine patrol	2	2.8
Searchers on horseback	1	1.4
Total	71	99.8

*Totals slightly less than 100% due to rounding.

had not responded to the searchers by calling out or walking to them. In many cases, searchers or others had to walk right by the individual to find them. Additionally, all these victims were eventually found, often by citizens who happened upon the body. More focused search efforts could potentially lead to earlier discoveries of the PWD.

These searches employed many different techniques of search and rescue, but, as in Koester,⁴ walking-type searches were the most effective in finding the individual. One of the difficulties in using newer technologies such as a Global Positioning System (GPS) or heat-seeking radar is that these individuals seemed to make efforts to preclude being found, such as hiding in brush, forested areas, or abandoned buildings. This type of cover can prevent these technologies from finding the body. Furthermore, in the case of GPS, the PWD would need to wear a transmitter; outfitting all PWDs with a wrist-worn transmitter is neither practical nor acceptable.

Our findings also indicate that some persons are at higher risk than others for dying as a result of becoming lost in the community. Males were over-represented in our sample. In this study, 61 percent of the individuals were male, whereas only approximately 32 percent of those diagnosed with AD in the US are male.¹ In our previous study, males accounted for 51 percent of those found alive.³ Also over-represented were those living in community-based assisted living or "board-and-care"-type facilities. Of those found dead, 22 percent had become lost after leaving one of these facilities unattended, but

only a small percentage of PWDs live in this type of facility (about 70 percent reside at home, and about 20 percent live in a nursing home). In the previous study, only 17 percent lived in all types of professional care settings; in this study, that figure was 37 percent. Those who become lost in months during which their communities typically experience temperature extremes are also at greater risk of dying. This is likely due to the temperature extremes and not an increased incidence of becoming lost in these months, since data from our previous study show that the frequency of becoming lost is relatively even throughout the year (unpublished data³).

The findings of this study and the previous one emphasize that all PWDs are at risk for becoming lost in the community. While PWDs who tend to wander in their environment may be at greater risk, those going about their daily routine are also at risk of being separated from their caregiver and becoming lost. Neither the data in this study nor in the previous studies demonstrated a higher rate of becoming lost during the sundowning syndrome time of the evening hours.^{3,4} This finding also substantiates the significant difference between wandering, which typically increases in the sundowning period, and becoming lost in the community.

Limitations

Because data on PWDs who become lost in the community is not collected in any organized manner, we were limited to accessing data through Internet searches.

This worked well for newspapers with online versions, but many local newspapers are not available online. Although this limitation was reflected in our ability to collect data from only 37 states, we were able to collect data from communities large and small. Still, the sample size was limited by the difficulty in accessing the needed information.

Recommendations

The findings from this study suggest several strategies for increasing the likelihood that PWDs who become lost in the community will be found before they die. First, law enforcement must conduct a high-intensity search strategy from the beginning, rather than employing an escalating strategy in which efforts are increased each day until the individual is found. It is critically important to find the individual before they become secluded.

Second, since most PWDs who become lost in the community are found alive, during the initial hours of the search, it is important to focus on areas such as residential yards, businesses, streets, highways, and sidewalks. However, once the person has been missing for six to 12 hours, serious consideration should be given to searching the natural and secluded areas within a 1-mile radius of the location in which the lost person was last seen. Because of the tendency of PWDs to stay hidden even when searchers are nearby, searchers should visually inspect the search area at close range. One strategy would be to form a search line with individuals three to five feet away from each other. All areas within this 1-mile radius should be searched, including bodies of water, thick vegetation or crops, abandoned structures and vehicles, bottoms of cliffs, and fields.

Third, if an initial search is unsuccessful, re-searching the area within a 1-mile radius of the PWD's last known location will likely be more successful than expanding the search boundaries beyond one mile. In this study, however, a small number of individuals were found two to five miles away from where they were last seen.

Fourth, if a PWD has become lost while driving an automobile, the search should first focus on finding the vehicle, which this study showed could be up to 200 miles away. If the PWD is not found in or with the car, an intense search should then be conducted in the natural areas within a short distance from the car.

Finally, searchers should resist the temptation to plot the search based on logical deductions about where the individual might have been going, such as to a former

residence. In this study, such reasoning more often than not led searchers away from the location in which the missing person was eventually found.

It is an inevitable consequence of dementing diseases that, no matter how good the care, PWDs will become lost in the community. It is the community's responsibility to return them safely to their homes. With enhanced and more focused search efforts, we can come closer to attaining this goal. Materials for community education of caregivers, law enforcement personnel, and the general public about this problem can be found at www.alzonline.org. They can be downloaded and used free of charge.

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References

1. Rizzo M, Nawrot M: Perception of movement and shape in Alzheimer's disease. *Brain*. 1998; 121 (Pt. 12): 2259-2270.
2. Tetewsky SJ, Duffy CJ: Visual loss and getting lost in Alzheimer's disease. *Neurology*. 1999; 52(5): 958-965.
3. Rowe M, Glover, J: Antecedents, descriptions and consequences of wandering in cognitively impaired adults and the Safe Return program. *Am J Alzheimer's Dis Other Dement*. 2001; 16(6): 344-352.
4. Koester RJ: The lost Alzheimer's and related disorders subject: New research and perspectives. In *Response 98 NASAR Proceedings*. Chantilly, VA: National Association of Search and Rescue, 1998.
5. *Statistics and prevalence of Alzheimer's disease*. Alzheimer's Disease and Related Disorders Association, Chicago: 1998.
6. Algase DL: Cognitive discriminants of wandering among nursing home residents. *Nurs Res*. 1992; 41(2): 78-81.
7. Algase DL, Beattie ER, Therrien B: Impact of cognitive impairment on wandering behavior. *West J Nurs Res*. 2001; 23(3): 283-295.
8. Fopma-Loy J: Wandering: Causes, consequences and care. *J Psychosoc Nurs*. 1988; 26(5): 8-18.
9. Hope T, Tilling KM, Gedling K, et al.: The structure of wandering in dementia. *Int J of Geriatric Psychiatry*. 1994; 9(2): 149-155.
10. Klein, DA, Steinberg M, Galik E, et al: Wandering behaviour in community-residing persons with dementia. *Int J Geriatric Psychiatry*. 1999; 14(4): 272-279.
11. Logsdon R, Teri L, McCurry SM, et al.: Wandering: A significant problem among community-residing individuals with Alzheimer's disease. *J Gerontology: Psychological Sciences*. 1998; 53B(5): P294-P299.
12. Passini, R, Rainville C, Marchand N, et al.: Wayfinding in dementia of the Alzheimer type: planning abilities. *J Clin Exp Neuropsychol*. 1995, 17(6): 820-832.
13. Laurel L: Heat suspected in woman's death. *San Antonio Express-News*. 2000; Aug. 9: 3B
14. Stepzinski T: Missing Georgia man found dead; Alzheimer's victim last seen May 13. *Florida Times-Union*. 1999; July 6: B-1
15. Toomer-Cook J: Former Midvale mayor found dead. *The Deseret News*. (Salt Lake City) 2000; July 16, p. B01