

Persons With Dementia Who Become Lost in the Community: A Case Study, Current Research, and Recommendations

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Providing care for persons with dementia presents several serious challenges. Among these is the possibility that a person with dementia will become lost in the community and face the risk of injury or death. Caregivers often cite anxiety about this possibility as a reason for placing their loved ones in a professional-care setting. Our case study and review of research show that all persons with dementia are at risk, regardless of age, past behavior, and sex. Thus, health care providers have an important role to play in educating caregivers about this risk and assisting them in preventing or responding to such situations. In addition, health care providers should ensure that their respective professional-care facilities have appropriate measures in place to prevent and respond to these eventualities. Finally, health care providers can educate local law enforcement personnel about dementia in general and more specifically about research-based strategies for searching for persons with dementia who have become lost in the community.

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Individuals with a dementing illness, such as Alzheimer disease, present many challenges for their caregivers. One of the most important worries for both formal and informal caregivers is that the person with dementia will leave the safety of the caregiving situation and become lost in the community.¹ Most of these individuals are found quickly by their caregivers or good samaritans and are returned safely to their homes; however, some are injured or die as a result of becoming lost. In fact, this concern and the resultant anxiety often prompt informal caregivers to place their loved ones in a formal-care setting like a nursing home.²⁻⁵

Despite the potential seriousness of this problem, little research has been conducted regarding the frequency of these incidents, methods for preventing them, or appropriate responses once they occur. Perhaps as a consequence, health care providers are often ill equipped to assist caregivers in dealing with the potential or the reality of a loved one being lost. We describe a person with dementia who became lost while performing an activity that he had performed numerous times before without incident. We

present this case study, along with a summary of current research on the topic and recommendations to the health care practitioner, to help practitioners become more aware of the potential for such incidents with all persons with dementia and to encourage practitioners to work with caregivers and law enforcement personnel to reduce the risk of occurrence and to increase the likelihood of a safe outcome when persons with dementia become lost.

CASE STUDY

In November 2003, Mr X, a 79-year-old man with moderate to severe dementia, was discharged home from the hospital to the care of his spouse and a paid attendant. Shortly after his return, Mr X became angry when his wife left their independent-living home in the afternoon, and he attempted to follow her on his bicycle. Because Mr X had never become lost or gone far from view in the past, the attendant had been instructed that Mr X could ride alone within the complex (contained assisted and independent-living units in a community that had open egress during the day but was gated at night). Thus, the attendant did not accompany Mr X but remained at the home. Sixty minutes later, the attendant told Mr X's spouse that Mr X had not returned home. Family members conducted the initial search, driving around the neighborhood, but were unable to find Mr X. The local law enforcement agency was contacted, and personnel arrived 2 hours after Mr X disappeared. Their initial search focused on increasing street patrols by automobile, a helicopter flyby of surrounding neighborhoods, and reverse 911 regional telephone dispatch (911 generates an automatic call to homes in the vicinity) to request that citizens be on the lookout for Mr X. These measures continued for about 5 hours, until sunset. Over the next several days, volunteers and authorities thoroughly searched Mr X's community and adjacent neighborhoods and golf course on foot and with vehicle patrols. The situation was highlighted on local media for several days, heightening the community's exposure and interest. On the basis of a remote lead on day 5, authorities attempted to track Mr X using scent-sniffing dogs but were unsuccessful. Many leads were received when the Amber Alert Plan (an emergency system broadcast across numerous media outlets) was used, but none of these leads were

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TABLE 1. Demographic Characteristics of Persons With Dementia Who Became Lost in the Community

	Study		
	1 ⁷ (N=481)	2 ⁸ (N=93)	3 (N=45)
Mean \pm SD age (y) (range)	77.8 \pm 8.3 (48-102)	78 \pm 6.6 (60-91)	79 \pm 8.6 (51-92)
Men (%)	51	67	60

useful. On day 6, a helicopter with special infrared technology searched the area within a 3-mile radius of Mr X's home, including remote locations, without definite leads. Also on day 6, one of the authors (M.A.R.) contacted the law enforcement agency and summarized the research presented subsequently and recommendations for searching. On the basis of the research findings, authorities mapped a grid for the area surrounding Mr X's residence and conducted a massive foot search. Ten volunteer searchers and a law enforcement officer were assigned to each specific search area within the grid. Volunteers were instructed to walk and visually search every space in that area, under brush, in bushes, etc. Sixty-three minutes from the start of this ground search, Mr X was located alive about 300 yards into dense woods, covered in leaves under a tree near his bike. He was about 0.25 miles from his home. Mr X had experienced exposure to the elements and severe dehydration but recovered fully.

RESEARCH ON PERSONS WITH DEMENTIA BECOMING LOST IN THE COMMUNITY

Few studies have addressed the serious issue of persons with dementia becoming lost in the community. In addition, there is no national database of such incidents or of cases in which lost individuals die before being found. However, the findings of a small number of recent studies have begun to paint a more complete picture of who is at risk, what distinguishes cases in which the individuals are found alive from those in which they are found dead, and what search strategies are most likely to lead to the safe return of these individuals to their homes.

In the earliest of these studies, Koester⁶ analyzed 87 cases over 10 years of persons with dementia becoming lost in the community in which the Virginia state search and rescue teams became involved. Individuals were found in both populated and unpopulated areas, such as woods and brush; 27% were found dead, but the author provided no specifics about these cases.

In 3 more recent studies, one of the authors of the current article (M.A.R.) analyzed data on a national level in an attempt to identify critical features. In study 1, Rowe

and Glover⁷ evaluated approximately 550 case reports from the database of Safe Return, a program administered by the Alzheimer's Association to facilitate the safe return of a person with dementia who becomes lost in the community (see Appendix for more information about Safe Return). The researchers examined 3 types of data collected from January 1997 through January 1998: demographic data on the registered individuals and their primary caregivers from the registration files, data on the circumstances surrounding the disappearance based on the missing person reports, and data on the circumstances surrounding the discovery of these individuals based on the discovery reports. Not all cases had all 3 types of data available; thus, in the findings discussed subsequently, the total number varies.

In study 2, Rowe and Bennett⁸ reviewed retrospectively 93 US newspaper articles published from 1998 to 2002 that described cases in which persons with dementia were found dead after becoming lost in the community. To our knowledge, this was the first study conducted to determine characteristics and/or circumstances that might distinguish the relatively few but tragic cases in which individuals die before being found from most cases in which individuals are returned safely to their homes.

Study 3 extends the findings of study 2 to include 45 additional newspaper reports from January through December 2003 in the analysis. This study has not been described in a previous publication. The study was conducted in spring 2004 by one of the authors of the current article (M.A.R.) using the same methodology as that used for study 2. Because of the nature of the data sources, no clinical data were available for any of the 3 studies.

WHO IS AT RISK?

The combined findings from the studies indicate that all persons with dementia are at risk of becoming lost in the community. As shown in Table 1, the ages of the persons with dementia ranged from 48 to 102 years, indicating that even extremely old adults with dementia are at risk. In study 1, individuals were lost from 1 month to more than 5 years after registration with Safe Return.⁷ These findings imply that individuals are at risk at all stages of dementia.

Both men and women were at risk, but men seemed to be at higher risk both for becoming lost and for dying. Although men are estimated to comprise 32% of individuals with Alzheimer disease in the United States, 51% of the persons with dementia in study 1,⁷ 67% in study 2,⁹ and 60% in study 3 were men. This finding could be explained neither by difference in age—there was no significant difference in age between men and women in any of the 3 studies (study 1: $t=1.9$, $P=.06$; study 2/3: $t=0.72$, $P=.47$)—nor by difference in type of residence (institution vs home)

(study 1: $\chi^2=2.84$, $P=.24$; study 2/3: $\chi^2=7.26$, $P=.19$). Men were not more likely to be found farther from the place in which they were last seen than women (study 1: $\chi^2=7.40$, $P=.28$; study 2/3: $\chi^2=5.98$, $P=.31$), and the cause of death did not differ between men and women (study 2/3: $\chi^2=2.90$, $P=.72$).

Although one might assume that individuals residing in professional-care settings would not be at risk, the studies indicated that persons with dementia in all types of living arrangements became lost in the community. A particularly disturbing finding from studies 2 and 3 is that 22% of the persons found dead lived in facilities such as assisted-living facilities and homes providing meals and personal care. This percentage far exceeds the percentage of the population of persons with dementia that resides in this type of facility, estimated to be less than 5%. Furthermore, by 2003 most nursing homes were using alarm technology in dementia units to alert the staff to potentially dangerous situations, like a resident exiting unaccompanied. However, in study 3, conducted using newspaper reports exclusively from 2003, 16% of persons with dementia found dead had resided in nursing homes.

Caregivers and health care professionals may often assume that persons with dementia who have exhibited the behavior of wandering are at risk of becoming lost, whereas those who have not wandered have little to no risk. In this context, *wandering* is defined as inefficient travel that involves random movement and frequent changes in direction, pacing, or lapping.¹⁰ However, we found that wandering was only 1 risk factor and that individuals who had never wandered became lost. It is particularly important that informal caregivers understand this distinction. Often, a caregiver will refuse any counseling regarding the problem of persons with dementia becoming lost because her or his relative has never wandered.

WHAT CONSTITUTES A RISKY SITUATION?

Study 1 examined the context in which persons with dementia had become lost.⁷ Not surprisingly, persons with dementia are at higher risk of becoming lost when they are left unattended, even in their own residences—whether private homes or professional settings—and even for only a moment. As shown in Table 2, 13% of the persons with dementia who became lost had been on an outing that they regularly took alone, such as going for a walk or driving to a specific place. Approximately 65% of the persons with dementia who became lost were actually in the presence of a caregiver at the time: 18% were in a caregiving facility, 34% were with an individual caregiver who was either momentarily distracted or asleep, and 13% had had an argument with their caregiver at home or were otherwise agitated and left the home alone. The 4.8% who became

TABLE 2. Context in Which Persons With Dementia Became Lost in Study 1⁷

Context	% (n=146)
At day care, nursing home, or other caregiving facility	17.9
Outside of home with caregiver	14.3
Agitated/difficult behavior of person with dementia in the home	13.1
Caregiver distracted	13.1
On a normal outing alone and did not return	13.1
Home alone	10.7
Caregiver asleep	7.1
Out driving alone	6.0
Being transported by professional-care services	4.8

lost in the context of being transported by a professional-care service were usually dropped off at the entrance to a facility rather than accompanied inside. These findings highlight the unpredictability of this type of event: not only are all persons with dementia at risk but they also are at risk even in their own homes or during the course of activities that they may have performed without incident hundreds of times before.

WHAT FACTORS INCREASE THE RISK OF DEATH FOR A PERSON WITH DEMENTIA WHO HAS BECOME LOST?

The most striking distinction between the cases in which the person with dementia was found alive and those in which he or she was found dead is that most of those found alive remained out in the open in populated areas of the community,⁷ whereas those who were found dead had generally secluded themselves in natural or sparsely populated areas.⁸ Table 3 lists the places in which persons with dementia were found alive, and Table 4 combines data from studies 2 and 3 to list the places in which they were found dead. All but 18.8% of the persons with dementia who died were found in natural areas such as woods, fields, or ditches or in other isolated locations such as abandoned vehicles. Bodies of water seem to pose particular risk, as nearly 22% had drowned. Only 1.8% of the persons found alive were found in remote areas.

A related difference between the 2 types of cases is the time it took to find the missing persons with dementia (Table 5). Most individuals who were found alive were generally found within 24 hours,⁷ and all were found within 4 days. For those found dead, only 29% were found within 24 hours. It is likely that this difference in time in finding persons with dementia is due, at least in part, to the fact that those who died had chosen to leave populated areas and, in many cases, to seclude themselves further by hiding in brush, ditches, or abandoned structures. Of course, the longer they are lost, the more likely persons with dementia will die because of exposure to the elements, particularly

TABLE 3. Locations in Which Persons With Dementia Were Found Alive in Study 1⁷

Location	% (n=381)
Residential yard	26.0
Street	22.3
Miscellaneous business area	11.8
Hospital/health care facility	9.2
Public access area	5.8
Shopping center	3.9
Sidewalk	3.7
Highway	3.4
Convenience store	3.1
Restaurant	3.1
Remote area	1.8
Parking lot	1.6
Grocery store	1.6
Bank	1.0
Railroad	0.8
Senior care facility	0.8

during the hottest and coldest times of the year. In studies 2 and 3, the highest number of deaths occurred in July (20 cases), followed in descending order by January (19), December (16), February (14), May (13), and August (12). Fewer than 10 deaths occurred in each of the remaining months.

WHAT ARE THE MOST EFFECTIVE SEARCH STRATEGIES?

Several features of these cases stand out as critical for determining effective search strategies. Generally, persons with dementia did not travel far. Of those found alive in study 1, 87% were found within a 5-mile radius of the location in which they had last been seen.⁷ Those who were found dead traveled even shorter distances, with 73% of individuals in study 2 being found within 1 mile of the place last seen and only 7% being found more than 5 miles away. In study 3, 40% were found within 0.5 miles of the place last seen and 74% within 1 mile. Only 2 individuals who traveled on foot were found more than 5 miles away.

Persons with dementia do not often behave in a predictable manner when they become lost. Information from

TABLE 4. Locations in Which Persons With Dementia Were Found Dead*

Location	%
Miscellaneous natural areas (ditches, arroyos, brush, etc)	29.3
Wooded area	20.3
Lake/pond	13.5
Shallow water	8.3
Near creek/river	5.3
Park/refuge	3.0
Abandoned vehicle	1.5
Urban area (hit by vehicle, hiding in abandoned structures, etc)	18.8

*Data from studies 2 and 3.

study 1 showed that it was rare that any of the lost individuals asked for help. Rather, they were found when a good samaritan noticed that the person with dementia was behaving strangely or as the result of a search by law enforcement personnel. Furthermore, in the cases in which missing persons with dementia were found dead, it was frequently discovered that searchers had passed very near the places in which the persons with dementia were eventually found, but the lost individuals had not responded to the searchers' calls. In all 3 studies, predictions of where the individual might have gone, generally made by family members, sent searchers in the wrong direction. Thus, the accuracy of the search was not enhanced when searchers relied on families' predictions to determine the location or direction of the search.

These principles were applicable even when the individual had become lost while driving a vehicle. It is unlikely that a person with dementia can successfully negotiate all the steps required to refuel an automobile. In all 3 studies, only 1 individual drove farther than could be managed on a typical tank of gas (~200 miles). Once the automobile would no longer go (ran out of gas, got stuck off the road, etc), the person with dementia continued on foot. In studies 2 and 3, those found dead after driving were all found within 1 mile of the automobile, and most were found within 0.1 mile.

These findings suggest several strategies for a successful search. First, because family members' predictions of a lost person's actions do not appear to aid in the search efforts, searches should be designed around the general findings of research, rather than around individual characteristics of the missing person with dementia.

Second, caregivers should report that a person with dementia is missing immediately to both Safe Return, in the case of a registered individual, and the local law enforcement agency. An intensive search should begin promptly so that the individual has less time to find a secluded hiding place and has minimal exposure to the elements. Law enforcement personnel typically delay initiating a search for missing persons because the hope is that individuals will return on their own. The search then follows an escalating strategy. However, in cases involving persons with dementia, it is crucial to begin the search as quickly and as thoroughly as possible. It is particularly important to respond immediately in instances involving institutional settings because it can take hours for personnel to discover and/or report that an individual is missing. Searches should continue throughout the night because persons with dementia often continue to wander and are at greater risk of injury.

Third, the initial 6 to 12 hours of the search should cover a 5-mile radius around the location in which the person

with dementia was last seen. These early efforts should focus on the types of locations listed in Table 3, both outside and inside easily accessible buildings. If the individual is not found through these initial efforts, the subsequent search should be devoted to an intensive foot search of natural and sparsely populated areas, beginning within a 1-mile radius around the location in which the individual was last seen and extending from there. Because persons with dementia are often extremely difficult to find and most do not travel more than a mile, it may also be useful to search the area within a 1-mile radius more than once. Of importance, persons with dementia typically neither call for help nor respond to searchers' calls. Thus, it may be advisable to organize a number of searchers closely spaced in a horizontal line to move through an area together. If the individual traveled by automobile, initial search efforts should focus on locating the vehicle. Once the automobile is found, the search should continue as aforementioned, using the automobile as the focal point.

Although persons with dementia were found most commonly by either searchers or passersby traveling on foot, some searches involved more sophisticated techniques, such as scent-sniffing dogs and aircraft. Even though these techniques may occasionally prove useful, it is important to note that the locations in which most of the dead persons with dementia were found were not conducive to either aerial or scent searches because the individuals often took extra measures to seclude themselves.

IMPLICATIONS FOR THE PRACTITIONER

EDUCATING INFORMAL CAREGIVERS

The best way to avoid a tragic outcome is to prevent persons with dementia from becoming lost. Practitioners can play an important role in this endeavor by educating informal and formal caregivers. It is crucial to emphasize to caregivers that all persons with dementia are at risk, regardless of whether they have exhibited any "risky" behavior in the past. Many caregivers assume that persons with dementia who have not wandered or become lost in the past are not at risk of becoming lost in the future. Practitioners can ensure that their patients' caregivers are aware of the problem and help them to identify both high-risk situations and appropriate resources to assist them in preparing for an incident before it occurs.

The risk to persons with dementia of becoming lost is highest when they are left home alone, are able to leave the house unattended during the night or on regular outings during the day, or leave the home when angry. Practitioners can assist informal caregivers in identifying areas of potential risk and ensure that they are aware of appropriate community resources, such as day care and respite-care

TABLE 5. Time Required to Find Person With Dementia

Time	Study 1 ⁷ (%)	Studies 2 ⁸ and 3 (%)
<12 h	78.1	18.3
12.1-24 h	8.8	10.6
1-7 d	13.1	32.0
>7 d	0.0	39.1

facilities, and experts who may be able to provide advice on particular topics. Caregiver support groups, often sponsored by local chapters of the Alzheimer's Association, can also be helpful.

Registration with Safe Return or similar programs is critical. Persons with dementia lost in the community often will not be able to remember their addresses, telephone numbers, or even their full names. Programs like Safe Return (see Appendix) keep this information on file; thus, timely return of these individuals to their homes can be possible.

WORKING WITH PROFESSIONAL CAREGIVERS

Physicians and other health care practitioners have an important role in assisting personnel in formal-care settings prepare adequate safety plans to prevent their clients or residents from becoming lost. On the basis of the aforementioned findings of the research, persons with dementia living in residential-care settings seem to be at particular risk. Thus, it is critical that medical directors of such facilities review mechanisms for preventing residents from leaving. The facility must have a well-functioning system in place and evaluate the actual use of the system. In several cases from the research, employees had actually inactivated the system for some reason before a person disappeared. In addition, each facility should have a formal plan for reporting missing individuals. In our studies, we found that it was not uncommon for residential-care facilities to either delay the beginning of the search substantially or to use only their own resources in the search rather than contacting law enforcement. As mentioned previously, an appropriately designed search begun promptly can make a major—often life-and-death—difference in the outcome.

Of importance, particularly in states or localities where there are few regulations governing safe housing for persons with dementia, the level of security in residential-care facilities varies greatly. When caregivers are considering institutional placement, the practitioner can assist them in identifying facilities that have the strongest safety policies in place or suggest criteria for evaluating those policies.

WORKING WITH LAW ENFORCEMENT

Once an individual has become lost, his or her health care provider can play a useful role as advocate for the caregiver

in interactions with law enforcement agencies. As such, they may identify important search techniques or defuse any concerns expressed about the adequacy of care provided by the caregiver. It might be helpful to provide law enforcement personnel with information about or references to this research so that they can better target their search strategies to find lost persons with dementia quickly.

Health care practitioners might also consider providing training on dementia to local law enforcement personnel. These professionals potentially interact with persons with dementia and their caregivers in a variety of situations, including episodes in which the person with dementia has become lost and instances in which the caregiver requires assistance with an angry or agitated person with dementia. Education on the basics of dementia and Alzheimer disease can help to ensure that law enforcement personnel respond appropriately.

CONCLUSION

The health care practitioner is in a unique situation not only to prevent persons with dementia from becoming lost but also to facilitate an effective search.

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APPENDIX

SAFE RETURN

Safe Return is administered by the Alzheimer's Association. The service provides an identification bracelet, necklace, or clothing tags that can facilitate return to the caregiver if the person with dementia becomes lost in the community. The jewelry or tag indicates that the individual has a memory problem and provides an 800 number to call. Operators at the 800 number use information completed at the time of registration to contact the caregiver and facilitate a return. The program can also assist the caregiver by notifying law enforcement agencies when a person with dementia becomes lost and distributing a picture that was provided at the time of registration. Individuals may be registered through any chapter of the association. Additionally, registration can be facilitated at the Safe Return Web site: www.alz.org/Services/SafeReturn.asp.