

# Antecedents, descriptions and consequences of wandering in cognitively-impaired adults and the Safe Return (SR) program

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## Abstract

*Unattended wandering is a major problem in cognitively impaired (CI) individuals and can result in those individuals becoming lost in the community. The purpose of this study was to identify important characteristics of unattended wandering and important prevention strategies. Data were compiled from registration files and missing and discovery reports collected through the Safe Return (SR) program. These data were analyzed to determine where individuals were found, who found them, from what setting they left, what mode of transportation they used, and what circumstances surrounded the unattended wandering. The study highlights the unpredictable and varied nature of unattended wandering. Recommendations are provided for communities to develop strategies to minimize unattended wandering and to determine effective methods of locating CI individuals when they become lost.*

*Key words: Alzheimer's disease, cognitively impaired (CI), Safe Return (SR) program, wandering*

## Introduction

Unattended wandering, defined as forays into the community without the supervision of a caregiver, is a major problem in cognitively impaired (CI) individuals. The Alzheimer's Association estimates that 60 percent of people with Alzheimer's disease will wander and become lost in the community during the course of their disease.<sup>1</sup> Since the CI individual has limited intellectual resources to negotiate a way home or to a safe situation, it is up to other persons to

locate the CI individual and assist in the safe return to the caregiver. Often, this occurs when caregivers initiate a search for the individual, or neighbors recognize the unsafe situation and facilitate a return to the home. However, little is known about times when these strategies have not located the CI individual. Although wandering is known to be a common, and sometimes dangerous, behavior of CI individuals,<sup>2,3</sup> very little concrete data have been compiled nationally on unattended wandering, and none at all on deaths attributable to this behavior. However, community newspapers regularly report individual cases of such deaths, and these stories underscore the seriousness of the problem.<sup>4,6</sup>

The Alzheimer's Association administers a program called Safe Return (SR), which is designed to facilitate the safe return of CI persons who have left their care settings unattended and become lost in the community. Since 1993, the SR program has facilitated the return of over 5,000 CI persons found wandering in the community. Currently, over 60,000 individuals are registered with the program. Registered individuals wear identification jewelry to indicate that they have a memory problem and lists a 24-hour toll-free emergency crisis telephone number to be called in the event of a discovery. Once SR operators receive report of a discovery, they assist in a safe and timely return of CI individuals to their homes or care settings.

As part of the program, SR collects demographic data on all registered individuals as well as additional data related to both missing and discovery reports, making its database the most comprehensive source of information available about such incidents. These data were reviewed and analyzed in an effort to gain greater insight into this widespread but poorly understood problem. The hope is that a better understanding of the phenomenon of unattended wandering will allow for more targeted education programs and, ultimately, to a greater success in prevention and safe return efforts.

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**Table 1. Living situations of the CI individuals**

Caregiver	Lived with (percent) (n = 531)	Primary caregiver of those residing alone (percent) (n = 86)
Spouse	36.5	0
Daughter	17.9	39.2
Self	15.4	
Nursing home	13.4	
Son	7.3	25.3
Board and care facility	3.4	
Other relative	3.2	17.7
Nonpaid, nonprofessional	1.9	11.4
Daughter-in-law	0.4	0
Son-in-law	0.4	0
Professional (paid caregivers or case managers)	0.2	8.4

## Methods

### *Design*

The data for this descriptive study were compiled from registration files and missing and discovery reports collected by the SR program from January 1997 through January 1998. Registration files, which SR creates for all persons who register with the program, contain demographic information on the CI individual, descriptive data related to the caregiver, and a unique SR identification number. The SR identification number is also included in the missing and discovery files; thus, it was used to match data from the three types of files.

Missing files, which SR generates upon receiving a report that a registered individual is missing, contain the date and time the individual left the care setting or became separated from the caregiver, if known; the location from which he or she left; and any other remarkable characteristics about the incident. Many discovery incidents have no corresponding missing reports on file. Such a situation may arise, for example, because the CI individual lives alone, or has been left alone, or leaves on his or her own to partake in normal activities and is subsequently unable to

find the way home. In addition, a caregiver may initiate a search for a missing individual without filing a missing report, perhaps out of concern that filing such a report may reflect poorly on the care being provided.

Discovery files are generated when someone who has discovered a lost or confused CI individual contacts SR. These files contain data detailing the circumstances of the discovery, including the date, time, and location of the discovery; the identity of the person who found the CI individual; the condition of the CI individual when found; and the process used to return the individual to her or his home setting. In most cases, discoveries are reported when a person in the community finds a seemingly lost CI individual who is registered with the program and calls the toll-free number listed on that individual's SR bracelet or ID card. However, a small number of discovery files are generated when someone who has prior knowledge about the program finds an individual that seems to be cognitively impaired and contacts SR, even though there may be no indication that the individual is registered with the program.

### *Sample*

During the 13-month study period, SR collected 675

**Table 2. Discovery locations of wandering CI individuals**

Location	Percent (n = 381)
Residential yard	26.0
Street	22.3
Miscellaneous business	11.8
Hospital or 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
Food store	1.6
Bank	1.0
Railroad	0.8
Senior care	0.8

records of missing or discovery incidents. Of these, 60 incidents consisted only of a missing file; limited analyses were done on these records. Of the remaining 615 incident records, 146 included both a discovery and a missing file and 469 consisted of a discovery file only. Because these data were originally collected as part of a public-service program rather than for research purposes, there are data missing in most categories. Since no missing data were inputted, the sample size for each variable analyzed will be reported.

## Results

### *Discovery conditions*

The mean age of persons discovered was 77.8 years

( $\pm 8.3$ ) with a range of 48 to 102 years old ( $n = 478$ ). Males accounted for 51.3 percent, or 331, of those discovered ( $n = 610$ ). This finding is significant since the gender ratio for those with Alzheimer's disease in the United States is approximately 68 percent female and 32 percent male.<sup>1</sup>

The time between the date of registration with SR and the date of the discovery varied widely, with the mean number of months being 15.0 ( $\pm 13.1$ ) and the range being 0 to 56 months ( $n = 465$ ). During the study period, 536 CI individuals were involved in only one incident and 38 individuals were involved in multiple, separate incidents. Of those involved in multiple incidents, 20 were involved twice, 11 were involved three times, five were involved four times, and two were involved five times.

Table 1 presents data on the caregiving situations for the registered CI individuals associated with the discovery records ( $n = 531$ ). One notable finding is that 16.8 percent of the discovery incidents involved individuals who were residing in professional care settings. Since these settings are considered to be more secure than community-dwelling settings, a lower number may have been expected. In addition, almost 30 percent of the individuals involved in discovery incidents were living with a relative other than a spouse; this percentage is higher than the proportion of CI individuals in the general population estimated to have a similar living arrangement and may indicate an increased risk of unattended wandering for CI individuals living with relatives other than spouses.

The second column of Table 1 lists the primary caregivers for the individuals with dementia who lived alone. The caregivers were primarily adult children and other relative caregivers (*e.g.*, niece, and granddaughter).

As illustrated in Table 2, discoveries occurred in a wide variety of places. CI individuals were often discovered while doing something out of the ordinary. For instance, the most common situations involved neighbors or strangers discovering the individuals wandering in their yards (listed in Table 2 as "residential yard"). Other common situations involved the discovery of confused individuals standing in the middle of intersections, walking along busy streets or highways, or individuals who were displaying such unusual behavior in stores that employees became concerned and were prompted to investigate further. The majority of wanderers were found within five miles of their home, with 37 percent found within a one-mile radius and 50 percent found in a one- to five-mile radius. Only 7 percent of individuals were found more than 10 miles from their home.

Table 3 presents data on the identity of persons who discovered lost CI individuals and the time of day of the discoveries. The last column indicates what percentage of the discoveries also had SR missing reports associated with them. Those discovering the CI individuals were primarily "Good Samaritans" and law enforcement officers in almost

**Table 3. Persons discovering wandering CI individuals**

<b>Identity of discoverer</b>	<b>All discoveries (percent) (n = 463)</b>	<b>Daylight (percent) (n = 383)</b>	<b>Night (percent) (n = 80)</b>	<b>Missing report filed (percent) (n = 146)</b>
Law enforcement officer	33.4	33.0	46.3	48.7
Good Samaritan	35.8	36.4	26.3	14.8
Business employee	14.6	14.9	12.5	9.6
Health care professional	4.2	4.3	3.8	0.0
None (returned on their own)	3.9	3.7	1.3	12.2
Neighbor	2.9	2.9	3.8	4.3
Relative	1.8	1.9	2.5	6.1
Firefighter	1.8	1.9	1.3	0.9
Friend	0.8	0.3	1.3	2.6
Public service	0.8	0.8	1.3	0.9

equal numbers. It is interesting to note that law enforcement officers were involved in almost half of the nighttime discoveries. The characteristics of the people that found the missing individuals changed significantly when a missing report had been filed. In almost 50 percent of the incidents for which missing reports had been generated, the CI individuals were discovered by law enforcement officers; conversely, very few of these incidents involved discovery by Good Samaritans.

The majority of all discoveries occurred during the afternoon hours (noon to 6 p.m.; 42.9 percent). Significant numbers occurred during the evening (6 p.m. to 9 p.m.; 19.6 percent) and night hours (9 p.m. to 7 a.m.; 17.8 percent) as well.

The discovery files included reports of injuries to some of the discovered individuals. These included five head injuries, 20 incidents of what appeared to be new skin injuries, four instances of dehydration, and one injury resulting from exposure to cold. In addition, the files included reports of four deaths: three were due to prolonged exposure and one individual was hit by a train.

*Incidents with both missing and discovery reports*

The large majority of individuals were discovered

without having been reported missing to SR. However, 146 incidents involved both missing and discovery files. Data from these incidents were analyzed to determine more about the circumstances surrounding unattended departures as well as the time to discovery.

The circumstances surrounding the unattended departures varied widely (see Table 4). One notable finding is the high percentage of incidents of unattended wandering that followed agitated or angry encounters with caregivers (13.1 percent). It is also significant that a large proportion of these incidents involved professional caregivers (at least 22.7 percent).

Table 5 presents data from the missing reports about the time of day during which someone first noticed that the CI individuals were missing. Almost one-quarter of these individuals (24.7 percent) left during the especially risky times of evening and night.

Almost half of the CI individuals were discovered within one to five hours of their time of departure (46.1 percent), with 82.3 percent being discovered in under 12 hours. Thirteen individuals (9.2 percent) were missing for more than 24 hours, and one was missing for four days.

The majority of individuals wandered on foot (84 percent), with only a small percentage becoming lost while driving a car (5.6 percent). Other transportation methods

**Table 4. Context in which CI individual began the unattended wandering**

Context	Percent (n = 146)
At day care, nursing home, or other caregiving facility	17.9
Outside home with caregiver	14.3
Agitated or difficult behavior of CI individual in the home setting	13.1
Caregiver distracted	13.1
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 services	4.8

included public transportation, trains, and hitchhiking. All of those who were driving a car were found within 24 hours. All but one of the individuals who were missing for more than 24 hours were on foot. The one exception had taken a train.

### Qualitative data from missing and discovery reports

The SR missing and discovery files also contain qualitative descriptions of the circumstances surrounding the unattended wanderings. Excerpts from these reports provide a more in-depth description of the problems associated with unattended wandering.

The following excerpts involve the manner in which CI individuals tended to get away from the caregiver:

- Caller last saw her mother when she put her to bed. She awoke to find her mother missing; her pajama bottoms were wet and lying on the floor.
- Wife went to check on husband at 4:00 a.m. and found him gone from his bed and the front door open.
- [Missing individual] was transported from his Alzheimer's day program at about 3:00 this afternoon. The driver of the transport vehicle escorted him to the door of the building but left him there and did not escort him to his apartment door. He has not been seen since.

- Wife was delusional and told husband she wanted to go visit her mother and sister who are dead. Wife got mad and left.
- Caller reported that registrant left in the car while caller was showering.
- He walked out of the facility. He is not registered in Safe Return program. He was wearing a "code alert" bracelet, which is supposed to alert the staff if he leaves the facility, but the bracelet did not work.
- Registrant was separated from caregiver while shopping at the mall.

The following excerpts are examples of typical discoveries:

- Police were called to business where wanderer was noticed by employees as being confused and [was] unable to tell them where he lived.
- [Individual] was walking through a yard banging on doors, confused about where he lived and claiming he owned a car which was not his.
- [Wanderer] was picked up by a cab driver in Miami [who] took him all the way to Daytona Beach—200 miles away. Wanderer had no

money on him, so the cab driver took him to the police (\$900 bill).

- Police called to get the identity of a man who was lying unconscious on the street. They were trying to assess his medical condition at the time of call.
- Caller reported that wanderer was brought into the hospital by paramedics. Condition is okay, just trying to find out where she belongs.
- Good Samaritan found man wandering on the highway and was concerned about him.
- Individual was discovered wandering the halls of the local hospital.

The following excerpts highlight the danger to CI individuals of wandering unattended:

- Missing individual was found (dead) in the woods, under some brush about 1/2 mile from the nursing home.
- Individual was found (dead) in cornfield behind the nursing home where he disappeared from.
- Badly decomposed remains were found last night near a large airport. Someone had called the police reporting that a woman matching the missing person's description was seen being pursued by a vagrant male. Preliminary autopsy revealed no foul play.
- [Caller] called to report the death of registrant. Police reported that she was hit by a train.
- [Wanderer] was found on a sidewalk close to the hospital. He had fallen and has a laceration on the back of his head. Doctor is working him up at the hospital. He saw the Safe Return ID bracelet and called us.
- [Wanderer was] found searching through the garbage in downtown Manhattan at 4:00 a.m.
- A train engineer reported wanderer to the police. She was nearly hit by a train. The police found her wandering beside the tracks and took her to the station.
- Officer called to report that registrant had been

**Table 5. Time of day that wandering CI individual was first noticed as missing**

Time of day	Percent (n = 146)
Afternoon (noon - 6 p.m.)	44.5
Morning (7 a.m. - noon)	30.8
Night (9 p.m. - 7 a.m.)	13.7
Evening (6 p.m. - 9 p.m.)	11.0

found wandering around 4th St. and Vermont. He was completely naked. They were very concerned because of the low temperatures.

- Registrant was found wandering through the streets. Officer suspects that registrant is intoxicated, but is unsure. Registrant is confused and has no identification on him.
- A Good Samaritan saw wanderer in a parking lot. When he noticed him there a second day, in the same clothing, etc., he phoned police. Does not know his name, or even that he is lost.
- [Wanderer] is badly dehydrated and will be taken to the hospital once caregivers have been notified.
- [Wanderer was] found at 3:05 a.m. She speaks only Italian. She was about seven miles from her house and had been missing about 15 hours. Family took her to hospital due to her swollen feet and face.
- [Wanderer] was found Friday night about 10:30 p.m. He was not very far from home at that point, but had apparently been walking most of the 25 hours he had been missing. He was exhausted but okay.

These excerpts illustrate the dangers of failing to register a CI individual with the SR program:

- Discovered individual was involved in an auto

accident. Police were trying to locate someone to pick him up and take him home. He lives in the city, and police had checked his home and spoke with neighbors but could find no one to help. The police decided to take individual to his home and leave him. They will check on the apartment but feel he will be okay overnight.

- [Individual] wandered into the rescue mission, possibly yesterday. He is confused. He is now entered as a discovery and Safe Return will be on alert for any missing person reports about this individual. Adult protective services have been notified.

Finally, the following excerpts indicate that there is still much work to be done to maximize the chances of returning wandering individuals safely to their homes or caregivers:

- [Wanderer] walked out of the home for a walk and didn't come back. Police were contacted that day but did not begin a search. They will begin search now that he has been gone 24 hours.
- [Good Samaritan] called in to report that wanderer showed up at her door. He did have an ID bracelet on his wrist. I tried to contact his wife, but found out that the nursing home listed as his second caregiver is now primary residence. The personnel there were unable to comprehend the situation or be of any assistance. They did tell me that he was now living at a board and care. I tried to get a phone number for them, but none was listed. I gave this information to Good Samaritan along with the brother-in-law's number, but there was no answer. The Good Samaritan called the police, but they had not arrived when I spoke with her last. I will speak with the police and continue to try to contact brother-in-law.

It was evident from the reports that, for some individuals, unattended wandering was a repeated problem; however, for others, the reports would note that they had never wandered before. It was also evident from the reports that, even though caregivers or institutions had enacted significant prevention strategies, the incidents of unattended wandering were always unpredictable. Finally, while the reports did not note the occurrence of many physical injuries, they did highlight a notable amount of psychological distress on the part of the caregivers. Often, the SR operator would note in the files that the caregiver was upset, crying, or very worried because

of the weather conditions in which the CI person had gone missing.

## Discussion and recommendations

One of the most striking results of these findings is the extent to which they highlight the unpredictability of the behavior of unattended wandering in CI individuals. For instance, individuals who have taken independent walks in the community on a regular basis may, on any given day, become lost and find themselves unable to return home on their own. Or, individuals who had previously been safe during the night inexplicably awaken and leave the home unattended. It is likely that this unpredictability compounds caregiver stress by necessitating 24-hour supervision for at-risk individuals. The ongoing psychological strain often contributes to the decision to place a CI individual in a nursing home or some other professional care facility. However, another finding of note is that, even with the sophisticated monitoring systems available in professional settings, CI individuals living in these remain at risk of unattended wandering. It is apparent that CI persons in all situations are at risk.

The unpredictability of the behavior makes it particularly important that all persons who provide care for the CI individual are educated about unattended wandering. This study highlights a number of situations in which the risk for unattended wandering seems to increase. Not surprisingly, CI individuals seem to be particularly vulnerable when they are in unfamiliar situations and their caregivers become distracted for even short periods of time. CI individuals living in a home setting with an adult-child caregiver seem to be more at risk than those living in similar settings with spouses as caregivers. The increased risk may be due to the fact that those with adult-child caregivers are more likely to be left alone while the caregivers are tending to other family and job responsibilities. Another high-risk situation appears to be instances where the CI individual is agitated or angry with the caregiver. At these times, the caregivers' use of reason or restraint as a mechanism to keep the individual in the home or with them may be particularly fruitless.

Health care practitioners must educate caregivers about the possibility and unpredictability of unattended wandering and work with them to determine strategies to prevent this behavior. Such strategies include the following:

- Using respite services when available to avoid leaving the CI individual alone.
- Ensuring that CI individuals who live alone are

in regular contact with someone who is able to accurately assess their safety.

- Reporting increased agitation and aggression on the part of the CI individual to a health care practitioner so that nonpharmacologic strategies can be employed early in an episode. If these strategies are not effective, pharmacologic strategies may need to be considered.
- Following CI individuals who have left their home in an angry or agitated state to ensure that they are able to return safely.
- Restricting CI individuals' access to driving a car.
- Asking those in the immediate neighborhood to call caregivers if CI individuals are ever seen out of the home unattended.
- Altering the home environment to make unattended exit more difficult for a CI individual. Examples of such alterations include changing the form of the door lock, placing the lock in a different position on the door, or hiding the door handle or lock behind a piece of cloth. Of course, the ability to exit the home easily when necessary is another safety concern that must also be considered.

Even with these strategies in place, the unpredictable nature of this problem means that unattended wandering may still occur. Though no comparable national data exist for the population of CI individuals as a whole and considering the high level of vulnerability of this population, it is notable how few injuries to registrants are reported in the SR discovery files reviewed for this study. To ensure that CI individuals are registered with SR, regardless of their living situations, likely increases the chances of achieving safe returns. Professional care facilities should consider requiring that all CI individuals in their care be registered with the program.

In several of the records that were reviewed, the person phoning in the missing report could not indicate how long the CI individual had been gone. Sometimes no one had checked on the individual for days, and in one case the last known contact had occurred four months earlier. Even if it is necessary that a CI individual live alone, caregivers should make some arrangement for a daily check on the individual. These cases also highlight the importance of ensuring that CI individuals living alone are registered with SR.

Because SR enables rapid return of CI individuals in the community, it is important to maximize the advantages of this program. However, only a small percentage of appropriate individuals are registered. Therefore, it is critical that communities work to increase registration of CI individuals with SR. Some mechanisms that communities may consider to increase registration in SR are the following:

- *Community awareness campaigns targeting specific groups:*
- Individuals in the community who are likely to have contact with persons with Alzheimer's disease and could facilitate a registration;
- The caregivers and the adult children of CI individuals;
- Community-service organizations (such as Junior League, Rotary Club, Elk's Club), veterans' organizations, senior citizen centers, and workplaces;
- Religious organizations, which may provide direct interventions to the caregiver with existing institutions, such as parish nursing, and thus may be able to identify and register appropriate individuals.
- *Media campaigns involving promotional spots, paid advertisements, and community-service announcements using TV, radio, and printed media.*
- *Provision of information and registration opportunities during popular public events such as Alzheimer's Awareness Month, Memory Walk, community festivals, etc.*

Registration of CI individuals alone will not ensure safe returns. Another finding of note in the analysis of the discovery files was the difficulty SR experienced in locating a caregiver when a missing CI individual was found. Sometimes this was because all caregivers listed in the file were out looking for the individual, and sometimes it was because the SR staff had phone numbers for the caregivers that were no longer accurate. To avoid this delay in returning CI individuals to their homes, it is crucial that caregivers determine ahead of time a strategy to be followed in the event that a CI individual becomes lost. SR registration requires that three caregivers be listed in the file. A caregiver's strategy should include ensuring that all three can be reached easily by phone. If possible, one person should remain at the primary caregiver's number to receive calls

whenever a registered CI individual is missing. In addition, caregivers should be certain to contact SR to update the registration file when changes to contact information or living situations occur. To facilitate such communication, SR now sends a yearly reminder to caregivers to update the information, though they were not doing so at the time that the data for this study were collected.

In addition to contacting SR when CI individuals are missing, caregivers should be encouraged to file a missing report with the local police department. This action has two benefits: (1) caregivers can inform police of the best ways to contact them when the individual is discovered; and (2) The police are more successful in finding missing CI individuals in cases where missing reports have been filed. However, communities should examine the policies of law enforcement agencies regarding the activation of a search for a CI individual. Often, searches for missing adults are initiated only after a significant delay, under the assumption that the adults may return home on their own. Policies need to be different for CI adults. Searches in these cases must begin immediately and be concentrated within a five-mile radius of the individual's home. Searchers should look in easily accessible areas, such as convenience stores and public buildings, but nonresidential, nonbusiness areas of the community—fields, train tracks, or woods—must also be covered, particularly in cases where the missing individuals suffer from severe dementia. It is important to note that all four reported deaths in this study occurred in such areas. It is also crucial to continue to search for missing CI individuals throughout the night hours, as they often continue to wander during that time and there is a chance of locating them before injuries occur.

Safe Return follows up missing reports by faxing a photograph of the CI individual to all appropriate law enforcement agencies. It may also be helpful for caregivers or law enforcement agencies to fax the photographs to area hospitals as well, because lost individuals, at times, wander into hospitals or are taken there when caregivers cannot be immediately found. Additionally, the staff of local chapters of the Alzheimer's Association follow up on all missing or discovery reports to ensure that caregivers are aware of the available community services.

When the community as a whole is involved in identifying CI individuals who may be lost and working to

facilitate their safe return home, the chances of avoiding the more serious consequences of unattended wandering can be reduced. Thus, it would be valuable for communities to institute programs designed to educate the public regarding the identification of CI individuals who may have become lost and the procedure for returning them safely. The following are some suggested mechanisms for such public education:

- Public awareness media campaigns about the problem of unattended wandering, including information on looking for and recognizing the safe return bracelet or ID card.
- Presentations to various public service organizations to educate members about recognizing signs that a CI individual may be in need of assistance and about the SR program.
- Requests of all community members that they ensure that CI individuals they know have been registered with SR.

Safe Return is a highly effective national program designed to assist in the safe return of lost CI individuals to their caregivers. The program will be most effective if CI individuals, caregivers, health care practitioners, law enforcement agencies, and communities as whole unite to form an effective team in the effort to prevent unattended wandering and to ensure the safe return of missing CI individuals.

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