Alzheimer's Research Paper

Behavioral profile of possible Alzheimer's disease patients in Virginia search and rescue incidents

Robert J. Koester, MS and David E. Stooksbury PhD

Wilderness and Environmental Medicine, **6**,34-43 (1995)

We performed a retrospective study of the behavior of lost Dementia of Alzheimer's Type (DAT) patients who became the subjects of organized Search and Rescue efforts. We compared the DAT patients behavior to the behavior of elderly lost victims that possessed normal cognitive abilities. Data for both populations was from the Virginia Department of Emergency Services lost subject database. We found that normal elderly individuals on average traveled a greater straight line distance (2.56 km) from the Point Last Seen (PLS) than DAT patients (0.88 km). The median straight line distance from the PLS was the same for both populations (0.8 km). The mortality rate for DAT patients was 19 percent. Mortality was caused by hypothermia, dehydration, and drowning. No fatalities were found among DAT patients when they were located within 24 hours. A mortality rate of 46 percent was found for patients requiring more than 24 hours to locate. This 24 hour survivability window suggests that lost DAT patients require an immediate and aggressive search response.

Keywords: Wandering, Alzheimer's Disease, Lost person behavior, missing person, Behavioral profile

Introduction

Our goals are to create a preliminary behavioral profile of lost Dementia of Alzheimer's Type (DAT) patients, determine factors that impact survivability, and to create a database. Incident commanders in missing person searches rely on lost person behavior profiles and statistics for the initial deployment of resources, development of objectives, and predicting survivability. The major textbooks and field guides currently used by incident commanders combine both Alzheimer's with Elderly subjects or fail to give any numbers [1,2]. Unfortunately, search subjects suffering from Alzheimer's disease are grouped with elderly subjects or undocumented.

Current estimates of Alzheimer's Disease are four million based upon an estimated 10.3% of the population over the age of 65 suffers from probable Alzheimer's disease [3]. An estimated 12-14 million Americans will be affected by the year 2040 [4]. The increase is believed to be due to an increase in awareness of the disease and an increase in the age of the U.S. population [5]. Regional demographics also will affect the percentage of Alzheimer's cases found in each state. Indeed there appears to be a higher prevalence in rural areas [6] and among those with less education [7,8]. It is this particular subset of DAT patients that often results in search and rescue incidents.

Alzheimer's disease (AD) is a disease of exclusion since only after the patients' death can it be diagnosed positively. However, DAT [9] or probable AD is characterized well and can be documented with behavioral tests [10,11,12]. Wandering significantly increases with further deterioration of the DAT patient. Among mild cases of DAT, 18% of the patients wander, while in severe cases, wandering increases to 50% [13]. Other studies have made estimates of the prevalence of wanderers ranging from twelve to thirty-nine percent [14,15]. Another study reported twenty-six percent of AD patients getting lost in the outdoors in the preceding week [16].

Wanderers are distinguishable from non-wanderers by constant disorientation, inability to know when lost, better social skills, and are more active [17]. These traits have serious consequences when the patient wanders into a wilderness or rural location. Looking at several factors that affect survival in patients with DAT only the severity of DAT, behavioral problems, and wandering or falling correlate to decreased longevity [18]. One law enforcement agency reported four deaths out of 450 (1%) separate episodes of critical wandering [19]. Nova Scotia's Emergency Measures Organization reported a mortality rate of seven out of fifteen (47%) among "walk-a-ways" (Alzheimer's, other senile dementia, mentally retarded, and psychosis). All fatalities were attributable to hypothermia [20]. In another study, six out of twenty-nine patients died (21%) when search and rescue groups responded only after law enforcement search attempts were unsuccessful. Deceased patients appeared to have succumbed to hypothermia or drowned. Twelve patients (36%) were found alive but required evacuation. Based upon field diagnosis all the patients suffered from hypothermia and/or dehydration. DAT patients have usually wandered before, are generally unresponsive even when uninjured, leave few physical clues, and wander across roads [21].

Materials and Methods

The Virginia Department of Emergency Services (DES) is responsible for coordinating Search and Rescue (SAR) activities throughout the state. In 1986, DES introduced a new management system that uses selected operations personnel to handle all requests for SAR assistance. The new management system initiated a record keeping and data base system [22]. This retrospective study begins in June 1986 with the first state recorded mission (VA001) and ends in January 1992 (VA277). Due to duplications in the numbering of some missions, 295 incidents are covered.

Criteria For Inclusion

Only searches issued a DES mission number are included. Mission number issuing occurs only when DES dispatches state SAR resources to an incident. The DES Missing Person Reports, DES After Action Reports, and Virginia SAR Council Mission Summaries are the sources for all data. The incident commander or a general staff member generally completes these reports. The DES SAR office often completes missing information later. The SAR office furnished us copies of the original reports.

The caregiver's description of the patient is the sole basis for classification of a subject as a DAT patient. The patient has to be older than 40 years old with the possible age of onset of dementia between 40-90 years of age. If there was a history of mental retardation, or psychosis (before onset of dementia), the subject was excluded. Further classification of the missing person as potentially suffering from degenerating dementia was made by the primary investigator based solely upon the information provided on the data forms. If information was missing from the data form the Incident Commander was contacted by the primary investigator. Incident Commanders have no specific training to allow them to determine the validity of degenerating dementia. The data collection form has no specific question concerning a DAT description or mental status of the search patient. Therefore, it is completely voluntary for the compiler to fill in a DAT description in the "other pertinent information" blank. If the compiler did not mention Alzheimer's disease, confused, dementia, or senility, the missing person was classified as either elderly (if > 60 years of age) or placed into another category (retarded, despondent, etc.). No attempt was made to isolate other potential causes of dementia.

Data Coding

If the information provided on the state form leads to a classification of DAT, the following information is collected: state mission number, age, sex, race, time the patient was last seen, date patient was last seen, type of location where last seen (nursing home, residence, etc.), straight line distance from patient last seen location to where patient was found, time patient located, search technique that located patient, description of terrain where patient located, and a brief summary of patients medical condition. We entered the data (hand written forms) into a Microsoft Excel 4.0 spreadsheet [23].

Statistical Methods

We performed the statistical analysis using the software package, StatView 512+ [24]. For descriptive purposes and for future reference, we present the mean, standard deviation and standard error within categories. Analysis of variance (ANOVA) is performed with significant F-values being reported. The level of significance is the traditional $p<0.05$. If the ANOVA is significant, the conservative Scheffe's test for differences between specific means is performed [25]. We report only significant F-values.

Results

Forty-two (15%) of 295 recorded state incidents involved possible DAT sufferers (Figure 1). One search involved two DAT patients that remained together. This particular category was the largest in the data set. In all 42 searches, the search effort or others located the patient. The other most prevalent search types included suicidal (12%),

children (12%), drowning (11%), murders (9%), and hikers (8%). The drowning and murder cases usually reflect requests for dog teams only. The DAT searches occurred over a five year period. There has been an increase in both the numbers of DAT searches and the percentage of total search load (Table 1).

We divided the patients into three classes based on their medical condition at the time of the find. Team leaders with basic first-aid training make the field classifications summarized below.

Class One: Require no medical treatment and can walkout without assistance

Class Two: Require medical assistance and an evacuation

Class Three: Dead on Arrival

The medical condition of the DAT patients after being found varied greatly. Twenty patients (47%) could be escorted back to their residence and required no medical attention (class one). Fifteen patients (35%) required an evacuation team (class two). The state forms do not always specify the specific medical problem and any field diagnosis was not verified by hospital records. Experienced EMTs with supplemental training in wilderness disorders made the field diagnosis. DAT patients requiring an evacuation (n=13) suffered from hypothermia (67%) and/or dehydration (33%). In two cases, patients were field diagnosed as suffering from both disorders. All evacuated patients survived and were discharged from the hospital. Eight patients (19%) were found deceased (class three) and appeared to have succumbed to hypothermia (n=6) or drowned (n=1). For one patient, the cause of death was neither determined nor recorded. No evacuated or deceased patients demonstrated any trauma based upon field evaluation. In searches for elderly subjects not suffering from DAT (n=10), six subjects were class one (60%); one subject was class two (10%) due to hypothermia and dehydration; and three subjects (30%) were deceased (heart attack, drowning, unrecorded).

There is no relationship between the age of the DAT patient and outcome (class) of the patient. There is also no relationship between the age of elderly patients and the outcome of the subject.

Thirty-seven (37) of the DAT searches and all eleven (11) elderly searches had the patient's distance from the Point Last Seen (PLS) recorded. The missing data points represent a failure to complete the data form correctly. The mean distance the DAT patient was found from the PLS is 0.9 km (0.6 miles). The median distance is 0.8 km (0.5 miles) with a range of 0-2.4 km (0-1.5 miles). For elderly cases without DAT the mean distance found from the PLS is 2.6 km (1.6 miles). The median distance is 0.8 km (0.5 miles) with a range of 0-12.8 km (0-8.0 miles) (Table 3). There is no relationship between the DAT patient's age and distance from the PLS, or the distance from the PLS and patient class (Table 3).

There was a significant increase in morbidity or mortality as the total time elapsed to find the patient increased (Tables 4). There was also a significant increase in morbidity or mortality as the time increased from when trained SAR resources were notified and the patient was located (Table 5). The one uninjured DAT patient located after a considerable delay was in an uninhabited former residence. Among those patients located within 24 hours of being last seen, no deaths occurred (Table 6). In two cases the search was suspended (on day number four and seven) without the patient being found. These searches are not included in the analysis though the body was eventually located within the search area. Most DAT patients are last seen at either their own residence or a nursing home (Table 7). In addition, all eight patients spotted on a road initially departed from a nursing home or residence. The terrain in which the patient was located was recorded in thirty-six cases (Table 8). The majority of patients are in drainages/creeks or heavy brush/briars. In the four cases in which patients were in a house, two were hiding in their own house and two traveled to a previous residence. In most searches the patient is not found by search teams but found wandering by others. This includes searches where the state issued a mission number but the patient was found before the arrival of search and rescue resources. Sweep and scratch (hasty) teams are the most successful organized technique used to find DAT patients (Table 9).

Discussion

During the investigative component of the search, the caregivers provide the data characterizing missing persons as suffering from DAT. Investigators within Virginia are suspicious of the potential of DAT in all elderly subjects. The Lost Person Questionnaire, a standard data collection tool used on all state searches, prompts the investigator to pursue mental alterations. We did not use rigid criteria for inclusion as a Dementia of Alzheimer's Type in any of the cases. There was no follow-up behavioral testing due to both the circumstances of a search and the retrospective nature of this study. While several other conditions can cause dementia and therefore be confused with Alzheimer's Disease (AD) [26], this has minimal impact on the usefulness of this study for search planners. During searches (by definition the subject is not present), a definitive classification as DAT is impossible unless it was made previously by a physician. Most persons with AD receive care from a primary care physician or are not recognized as having the condition. Since most primary care physicians fail to use cognitive status tests [26], they only correctly identify fifty-eight percent of the cases as possible dementia [27]. This is particularly true of patients who become lost in wilderness and rural settings, who often belong to a low socioeconomic group and receive less health care. Even after locating the patient, possible hypothermia and/or dehydration would confound the administrating and results of a simple diagnostic test such as the Mini-Mental State Exam (MMSE). Even a well-constructed prospective study would face difficulties since it would still be impossible to test deceased patients and difficult to follow-up on patients that required evacuation. Therefore, search managers will almost always be unable to

differentiate between dementia caused by other reasons and DAT. Even establishing that the patient suffers a true dementia may be a challenge. The results of this study addresses the behavior lost elderly subjects demonstrate when suffering from potentially degenerating dementia. If the predictive data base (this study) potentially includes both groups, then this dilemma is controlled. However, future attempts to differentiate between Alzheimer's, Multi-Infarct, or Parkinson's dementia may lead to more precise patient profiles. The distribution of search incidents for the different patient profiles reflects two major study factors. In Virginia state mission numbers are only given after local law enforcement efforts have failed to locate the subject. In addition, the terrain and number of trails and roads make it difficult to become truly lost in the state. In fact, the profiles of DAT, mentally retarded, despondent, psychotic, and child all represent decreased spatial and/or cognitive abilities and together account for 47% of the state case load. Using current estimates of the prevalence of AD [3] and the 1990 population of elderly within Virginia [28], an estimated 68,500 Virginians suffer from DAT. This represents 1% of the population compared to the 15% of all searches for DAT patients. The data allows the development of a preliminary DAT patient profile. Patients usually disappear from their private residence or a nursing home. Once the patients become lost they are generally found close to the PLS. This data supports the few anecdotal case studies reported in the literature [29,30]. In addition it supports the personal experience of the authors reported elsewhere [21]. This finding is somewhat surprising considering DAT sufferers may be healthier than other age controlled elderly [31] and by definition only suffer initially from a loss in cognitive domains [12]. A possible explanation is that moderate DAT patients who showed shorter step length, lower gait speed, lower stepping frequency, greater step-to-step variability, and greater sway path [32]. While the investigators have heard many reports of Alzheimer's patients walking great distances (10-15 miles), no such case appeared in the Virginia case load. As a larger data pool develops the mean distance of 0.9 km will almost certainly increase. However, the median distance of 0.8 km may remain stable. It is unknown if patients spend considerable time wandering or if they walk a fairly direct path. The considerable number (28%) of DAT patients found in drainages or creeks supports the following a path of least resistance hypothesis. This indicates they walked downhill. Another 33% of the patients appear to have become stuck in thick brush or briars (a feature untrained searchers often avoid). Together (61%), both terrain features indicate a scenario of the patient traveling a path of least resistance till they reach a creek or get stuck in briars.

The age of the patient has no predictive value in the patients' outcome (class) or distance from the PLS. This corresponds well to studies that show that age has no relationship with cognitive or behavioral disturbance or the rate of progression of DAT [34,34]. It would be worthwhile to investigate the relationship between the severity of DAT (mild, moderate, severe) with search outcome and distance from the PLS. The relationship between the class of the patient and distance from the PLS previously reported as significant [21] showed no relationship in this study. This relationship has little operational use since during a search the distance the patient is from the PLS is unknown. The relationship between patients' outcome and the time elapsed to locate does have clear implications. Family members must not hesitate to contact law enforcement officers when a DAT patient becomes missing. In turn, once law enforcement officials have

determined the need for a search effort they must not hesitate to activate specialized SAR resources. These resources include management teams, trackers, tracking dogs, air-scent dogs, helicopters, and clue aware scratch (hasty) teams. The twenty-four hours for optimal results requires an immediate and aggressive response from all parties concerned.

Unfortunately, the state forms do not consistently provide information about the exact medical condition of the patient when found. If the patient was deceased, the Incident Commander did not receive a copy of the autopsy or the autopsy did not specify the exact cause of death. In those patients requiring evacuation, making a field diagnosis is often difficult. However, none of the data forms report trauma. This is rather surprising considering the large number of DAT patients (29-36%) that experience serious falls [13,16]. In fact, falls are more likely to occur in DAT patients than in elderly controls [35]. The lack of any falls may be due to either the small database, lack of any autopsy results, or perhaps the difficulty in detecting evidence of a fall in a hypothermic patient. The only recorded disorders included hypothermia, dehydration, drowning, and unknown. Therefore, it appears DAT patients are most likely to succumb to the environment and not to any injuries or pre-existing diseases.

To better predict DAT missing patient behavior requires a much larger data pool. As Alzheimer's continues to increase in prevalence it unfortunately will become easier to collect data. It is important to recognize the critical role local terrain may have in distances covered. Virginia consists of a swampy tidewater region, rolling hills piedmont region, and a heavily forested mountainous region. We expect that the distances traveled by DAT patients will be greater in less densely vegetative regions. Numerous roads and paths criss-cross even the most wilderness regions in the East thus limiting the distance that one can travel without crossing a road. An obvious need to expand the database on a national basis in various types of terrain under more controlled prospective conditions must be pursued. More rigid criteria for classifying patients as DAT or possible dementia must be considered.

Summary

These preliminary findings indicate Dementia of Alzheimer's Type patients generally leave their own residence or nursing home and start traveling along roads. The patient is usually located (89% of all cases) within one mile (1.2 km) of the Point Last Seen. If the patients were not on the road itself (14%), they are usually in a creek/drainage (28%), and/or caught in briars/bushes (33%). The majority of patients succumb to the environment (hypothermia, dehydration) and require evacuation (35%) or are deceased (19%). Therefore, searches for DAT patients are urgent and require an aggressive SAR response.

Acknowledgments

We would like to thank Winnie Pennington and Ralph Wilfong of the Virginia Department of Emergency Services for supplying copies of State mission records.

References

1. NASAR. Managing the Search Function. Fairfax, VA: NASAR 1987

2. NASAR. Incident Commander field handbook: Search and rescue. Fairfax, VA: NASAR 1987

3. Evans, D., Funkenstein, H.H., Albert, M.S., et al. Prevalence of Alzheimer's Disease in a community population of older persons. JAMA 1989;262(18)2551-6

4. Evans, D.A., Scherr, P.A., Cook, N.R., et al. Estimated prevalence of Alzheimer's disease in the United States. Milbank Mem. Fund. Q. 1990;68:2267-89

5. CDC Editorial note: Mortality Patterns - United States - 1987 MMWR 1990;39:12:193-6.

6. Rocca, W.A., Bonairto, S., Lippi, A., et al. Prevalence of clinically diagnosed Alzheimer's disease and other dementing disorder: a door-to-door survey in Appignano, Macerata Province, Italy. Neurology 1990;10:626-31

7. Durtigues, J., Gagnon, M., Michel, P., et al. The Paquid research program on the epidemiology of dementia. Methods and initial results. Revue Neurologique 1991;117(3)225-30

8. Fratiglioni, L., Grut, M., Forsell, Y., et al. Prevalence of Alzheimer's disease and other dementias in an elderly urban population: relationship with age, sex, and education. Neurology 1991;11(12)1886-92

9. American Psychiatric Association. Diagnostic and Statistical Manual-III. 1980 American Psychiatric Press, Washington, DC.

10. Folstein, M.R., Folstein, S., Mc Hugh, P.R., Mini-Mental state: A practical method for grading the cognitive state of patients for the clinician. J. Psychiatric Res. 1975;12:189.

11. Blessed, G., Tomlinson, B., Roth, M., The association between quantitative methods of dementia and senile change in the cerebral gray matter of elderly subjects. Br. J. Psychiatry 1968;114:797.

12. McKhann G., Drachman, D., Folstein, M., Katzman, R., Price, D., Stadlan, E.M., Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force of Alzheimer's Disease. Neurology 1984;34:939-44.

13. Teri L., Larson, E., Reifler, B., Behavioral disturbance in Dementia of the Alzheimer's Type. J. American Geriatrics Society 1988;36:1-6.

14. Cohen-Mansfield, J., Werner, P., Marx, M., Freedman, L., Two studies of pacing in the nursing home. J. of Gerontology 1991;46(3)M77-83.

15. Cooper, J., Mungas D., Weiler, P., Relation of Cognitive status and abnormal behaviors in Alzheimer's Disease. J. Am. Geriatrics Soc. 1990;38:867-870.

16. Baumgarten, M., Becker, R., Gauthier, S., Validity and reliability of the Dementia Behavior Disturbance Scale. J. Am. Geriatrics Soc. 1990;38:221-226.

17. Dawson, P., Reid, D.W., Behavioral dimensions of patients at risk of wandering. The Gerontologist 1987;27(1)104-7

18. Walsh J.S., Gilbert Welch, H., Larson, E.B., Survival of Outpatients with Alzheimer-Type Dementia. Annals of Internal Medicine 1990;113(6)429-34

19. Butler, J.P., Window of wandering. Geriatric Nursing September/October 1991

20. Hill, K., Predicting the behavior of lost persons. NASAR Conference Proceedings. NASAR, Fairfax, VA. 1991.

21. Koester R.J., Stooksbury, D.E., Lost subject profile for Dementia of Alzheimer's Type in Virginia in National Association for Search and Rescue Conference Proceedings. 1992 May 27-30; Phoenix: NASAR, Fairfax, 1992

22. Wilfong, R., Time frame for survival-minutes and counting-Virginia enhances search and rescue capabilities. Lifeline 1987;11(2)10-3.

23 . Microsoft, Excel 4.0 [computer program] Redmond, WA:Microsoft Corporation., 1992

24. Cuneo, M., Feldman, D. S., Jr., Hofmann, R., Simpson, J. StatView 512+ [computer program]. Calabasas, CA: BrainPower Inc., 1986.

25. Snedecor, G.W., Cochran, W.G. Statistical Methods. 7th ed. Ames, Iowa: Iowa State U. Press, 1980.

26. Somerfield, M.R., Weisman, C.S., Ury, W., et al. Physician practices in the diagnosis of dementing disorders. J. Am. Geriatr. Soc. 1991;39:172-175.

27. O'Conner, D.W., Pollitt, P.A., Hyde, J.B., et al. Do general practitioners miss dementia in elderly patients. Br. Med. J. 1988;297:1107-1110.

28. 1990 Census Summary Data Files-Virginia [Computer Laser Optical Disk STF1A] MS-DOS Version. U.S. Department of commerce, Bureau of the Census, Data User Services Division, Vol. 1, 1991.

29. Burnside, I.M., Wandering behavior. In: Burnside, I.M., ed. Psychosocial nursing care of the aged Second Edition. New York, NY.: McGraw-Hill, 1980:298-309

30. Hindlian, N.S., Case histories of wandering. The Am. J. of Alzheimer's Care and Related Disorders & Research. Jan/Feb. 1988:38-39.

31. Wolf-Klein, G.P., Silverstone, F.A., Brod, M.S., et al. Are Alzheimer's patients healthier? J. of Am. Geriatric. Soc. 1988;36:219-224.

32. Visser, H., Gait and balance in senile dementia of Alzheimer's Type. Age and Ageing 1983;12:296-301.

33. Burns, A., Jacoby, R., Levy, R., Progression of cognitive impairment in Alzheimer's Disease. J. of Am. Geriatrics Soc. 1991;39:39-45.

34. Ortof, E., Crystal, H.A., Rate of progression of Alzheimer's Disease. J. of Am. Geriatrics Soc. 1989;37:511-514.

35. Morris, J.C., Rubin, E.H., Morris, E.J., Mandel, S.A., Senile Dementia of the Alzheimer's Type: An important risk factor for serious falls. J. of Gerontology 1987;42(4)412-417.