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ELOPEMENT EVALUATION ON ALZHEIMER DISEASE PATIENTS IN FRANCE. THE EVADE STUDY

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Abstract: *Background:* Elopement is frequently observed among older adults with AD. Little work has been done on this significant problem. *Objectives:* to analyse the prevalence of the phenomenon, to define the profile of those who run away and to describe intervention strategies employed to prevent new intent to elope. *Design and setting:* Prospective study over one year (2009) of 6,649 participants living in nursing homes or long-term care units in the North of France. *Participants:* Prospective survey of elopement incidents that occurred among 65 licensed representative facilities in the North of France. *Measurements:* Our survey describes the circumstances, environmental risks and injuries sustained in 66 elopement incidents involving our residents. *Results:* The distinctive features of people who elope and elopement incidents are described in our communication. All residents who eloped had been diagnosed with AD or other forms of dementia. 35 % had a history of elopement. No resident was found dead. Once the patients got back, caregivers made significant changes (36 %): by adapting organization levels, pharmacological interventions, and activity programmes. However for those who had run away (64 %) and whose carers did not change their strategies; we noted 15 new elopement incidents (versus 3 when changes had been made). There was no legal investigation involved in the course of our study. *Conclusion:* Elopement can be dangerous. It puts both families and caregivers under a lot of stress. Physical restraints are used to prevent wandering and elopement. The problem for physicians, administrators and caregivers is working out how to improve safety enough to prevent elopement incidents for residents without encroaching upon their rights.

Key words: Elopement, old people, nursing home, long-term care unit, Alzheimer disease, France.

France's overall resident population is estimated at 64,700,000.

Twenty years ago, 7,500,000 people were 65 and over (14 % of the population) and the oldest (over 75) accounted for 5.7 % of the population. By 2010 the number of French people aged 65 and over had increased to 10,500,000 (16.8 %) and to 5, 600, 000 (8.9 %) for the oldest (1).

In the North of France, there are 350 nursing homes and long-term-care units for old people who need medical care (2). 70 to 90 % of the residents are officially diagnosed with dementia. In France, in 2010, more than 860,000 people developed Alzheimer's disease (AD) or other forms of dementia and they were predominantly female (3).

Behavioural disturbances can be assessed by using the NPI (NeuroPsychiatric Inventory) based on a standardized caregiver interview (4). The Algase Wandering Scale (AWS) is an appropriate means to measure wandering but the tool has not yet been validated in France (5). The prevalence of wandering among people with dementia is not well known.

In the literature, variability in the way the phenomenon is defined based on the stage of AD, the psychological burden and where the patient lived made research more complex (6, 7).

In their study, Cohen Mansfield et al estimated that 38 % of those suffering from AD are prone to wandering (8). According to Hope (UK), 63 % of AD patients included in his study had run away (9). In 2007, Schonfeld et al (USA) found the proportion of wanderers to be 21 % of male residents with moderate or severe cognitive impairment admitted over a 4-year period in nursing home facilities (10). In France, the REAL.Fr cohort, which studied 571 elderly patients with AD, living in the community, estimated the prevalence of wandering at 12.6 % (11, 12).

Wandering is a dangerous behaviour because old people who run away may encounter life-threatening situations. Elopement-wandering away from a safe place

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of abode is frequently observed among AD patients. Less work has been done on this phenomenon in the literature. The true prevalence of elopement is unclear because studies have analyzed different populations combining community-dwelling and long term care residents (13).

In our study, elopement has been defined as a both spontaneous and unannounced departure of a patient from his place of residence that resulted in his getting lost.

It seems to be an adverse psychological reaction or a flight response triggered by the awareness of their own confinement. Elopement is thus the only way to release the stress (14, 15).

In the States it is estimated that 60 % of those suffering from AD are subject to involuntary wandering and keeping running away (14).

A recent survey made in the south of France (2008) among 4,896 old people living in nursing homes indicates that 6.5 % of patients had attempted to elope (16).

In the literature there is no specific tool to assess elopement. The NPI, the AWS and the Cohen –Mansfield Agitation Inventory (29 items version) should be used to inform care givers of wandering although only given sub items focus on eloping behaviour (4, 5, 8).

Prevalence of elopement may be affected by the stage of AD: among mildly demented patients, people do not intend to leave but are spatially disorientated and wander away. Among moderately or severely demented patients, people may misread a situation and intentionally leave the unit. Ideally it is important not to trivialize eloping behaviour.

The problem of elopement is cause for concern among caregivers. It is a source of constant psychological burden, anxiety, distress and even depression.

Eloping behaviour in AD can cause serious problems. While some elopers are found safe and sound, other patients can get lost and sustain injuries if they fall or get mugged or are involved in accidents. Old people may suffer from dehydration, food deprivation, hypothermia or infection (cold weather) or from their treatment being interrupted (e.g. insulin-dependent diabetes). In some cases their medical condition may require sending them to hospital.

There are a few cases where patient elopement has resulted in death and in other cases the patient was never found.

Our objectives were (1) to assess the incidence of eloping behaviour in our country; (2) to study the profile of those who run away and (3) to analyse the procedures in place to prevent new intent to elope.

Methods

We made a prospective survey of elopement incidents that occurred among 65 licensed representative facilities in the North of France. We called the nursing home and long-term-care units monthly to collect data on the incidents that occurred between January and December 2009. Privacy and confidentiality rules were respected.

Results

6,649 participants, living in nursing homes or long-term care units in the North of France were included in our survey. In 2009, 66 eloping behaviours were listed involving 48 elopers (8 patients did so several times).

The 65 representative facilities

5,272 resident beds were included in the study (30 to 240 beds per care unit).

Specialized care units for patients with AD were observed in 21 units.

54 facilities used commercial electronic security systems.

Nearly half of the institutions had both procedures and traceability.

Institutions affected by runaways

The 66 elopement incidents occurred in 26 facilities (and 6 out of 26 were involved by patients who did so several times). 20 out of 26 used electronic systems such as bracelets, keypads and alarms on exit doors (including the 6 units involved by recurrence).

There were Special Care Units in 12 of the 26 facilities.

The residents who eloped

Of the 6,649 residents monitored, 48 ran away at least once in 2009.

50 % of elopers were institutionalized for less than one year.

All the elderly residents who eloped were predominately male and had been diagnosed with AD or another form of dementia at a moderately severe stage. 35 % had a history of elopement.

We analysed our findings about elopers in table 1.

Elopement data collection

66 elopement incidents occurred among elderly residents over one year.

In the vast majority of cases (92 %) the eloper was alone and in good physical health and all the elopers simply left through the front door.

However clinicians have noted that one old woman eloped with her husband, also an eloper, in his wheelchair.

The time of year affected elopement risks significantly (p=0,001) (figure 1).

Table 1
Characteristics of 48 elopers

- Average age: 82.5 years (61-98 years).
- Gender: male 27 (56 %) / female 21(44 %)
- Marital status: widower 28 (59 %)
- Surrounded by family: 41(85 %)
- No diploma: 34 (71 %)
- Institutionalized for less than a year: 24 (50 %)
- Living in a single room: 39 (81 %)
- Living in a special AD care Unit: 12 (25 %)
- History of dementia: 46(96 %) AD: 29(61 %)
- Average MMS : 12 (0-25)
- ADL score : 2,5 (0-5)
- History of behaviour disorders: 34 (71 %)
  - Wandering: 33(69 %)
  - Elopement: 17(35 %)
  - Circadian rhythm sleep disorders: 16(33 %)
  - Anxiety disorder: 11(23 %)
  - Alcohol problems: 11(23 %)
- Numbers of drugs: average 8 per day (1-13 with median at 6 per day)
  - Antipsychotic medications: 36(75 %)
  - Hypnotic drugs: 17(35 %)
  - Drug treatment of AD : 77 %

(Cholinesterase Inhibitors, Mémantine alone or dual therapy)

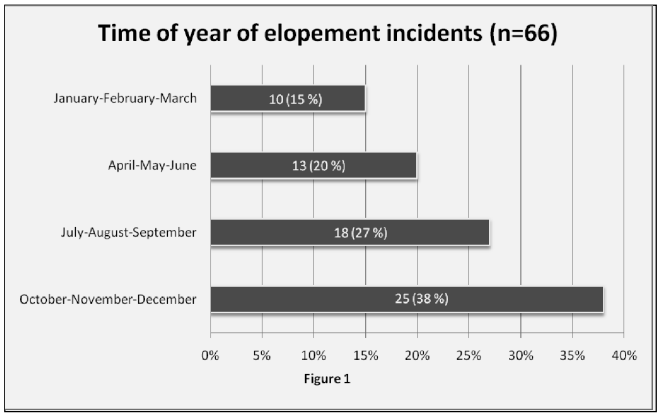

Figure 1.

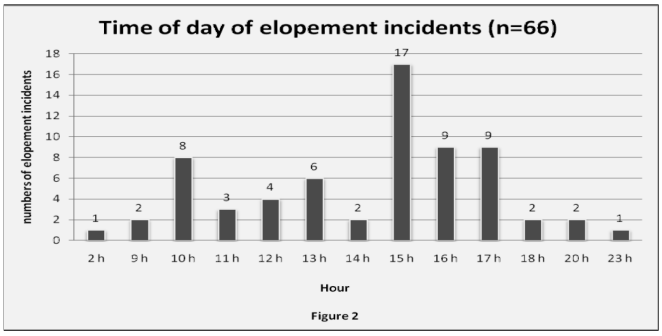

Figure 2.

Most of the incidents (53 %) occurred in the afternoon after lunch (3-5 pm) and before supper. Only 4 elopements were reported during the night (p< 0,001). (figure2)

In most cases (60 %), patients wandered for an hour or less and were found within 3 km of their residence on average. However one incident lasted more than a day.

In our survey, no security system malfunction was reported. In 55 % of cases people intentionally left the unit to go somewhere specific (like going back home for example). Other elopements occurred when the resident did not intend to leave but was spatially disorientated and wandered away (41 %). In 4 % of cases no reason was found.

All the elopement incidents were notified before the elopers returned.

All elopers needed help to get back to the facilities. None called for help. All of the residents were found (56 % by the caregivers, 26 % by citizens, 15 % by the police and 3 % by their families).

No resident was found dead. Fortunately, none of these elopements resulted in serious problems either for the patients or the facilities. Most of the residents who eloped did not sustain any injuries (93 %). However, all of injuries (2) were related to falls and one of the residents was admitted to hospital for a fracture.

Three other eloping residents had to be hospitalized for their health to be monitored after they returned.

Once the patient got back, no adjustment was made to the care plan of 42 (64 %) of the elopers.

However caregivers made significant changes for 24 residents (36 %): by adapting organization levels, pharmacological interventions, and activity programmes. Behavioural modifications were also tried as well as efforts to keep nursing home patients safe -thanks to bracelets, door alarms, and video cameras, or by seeking placement for residents in Alzheimer's special care units…

However for those who had run away (64 %) and whose carers did not change their strategies we noted 15 new elopement incidents (versus 3 where changes had been made).

No legal investigation was involved in the course of our study.

Discussion

The number of elopement incidents is particularly low when compared with the 60,000 missing people reported per year in France.

The 66 elopement incidents mean that less than one elopement occurs per year in each of the 65 facilities.

According to the study, one in 140 institutionalized patients is involved. Finding such a low rate was unexpected. A study in the south of France found a once a week rate. However data in the literature is very scarce (17).

The residents who eloped

Our survey shows the elopement profile of typical wanderers. As in previous studies published in literature, the eloper was more likely to be a man, this gender distribution is noteworthy because women usually outnumber men in facilities (7, 17), ambulatory, elderly (82,5 on average). The eloper was alone (18), a widower (59 %), with a low education level.

All elopers had a history of AD or of another dementia (mean MMSE score 12). 77 % were prescribed drug treatment for AD (Cholinesterase Inhibitors, Mémantine alone or dual therapy). The only treatments currently available in France. These results confirm AUDS's findings. They noted 62 elopement incidents in Missouri (1999-2001), all were dementia-related (14).

In 71 % of our cases they also had a history of behavioural disorders (wandering 69 %). Wandering is frequent among AD patients (65 %). It may be affected by the stage of dementia: 18 % among mildly demented patient, 24 % if moderately affected and 50 % when they have severe cognitive impairment (18).

Although wanderers are physically healthier than nonwanderers, wandering is associated with falls, fractures and may shorten a patient's life expectancy by up to three years (18).

In our study only 35 % had a history of elopement. Indeed the unit hosted residents whilst being completely unaware of the risk and was therefore unable to adjust its strategy. The question is whether a history of elopement may be a real reason for facilities to turn down a patient (19).

Thus prevalence of eloping behaviour is affected by gender and wandering, two characteristics that are associated with an increased risk of running away.

The elopement incidents

In our study 66 elopement incidents were observed during the year 2009. All elopers were found regardless of the way they got back to the facility. This is not always the case as was reported by many U.S (20), Japanese or Canadian articles.

All elopers needed help to make their way back to the facilities. None called for help (18).

The on-duty staff was involved in most of the cases where elopers returned safely.

They know the residents and are aware of the places where they are likely to go (14).

In 26 % of the cases, a "good Samaritan" assisted cognitively impaired old people who had wandered away from home and put themselves at risk. This term has been used to describe individuals in the community who were intrigued by the clothes or the inappropriate behaviour of the elopers (14).

Some countries have devised solutions to look for elopers: "the Silver Alert" in the U.S. (general alert launched in the state), the "SOS Networks" in Japan (based on close collaboration between the authorities and care services), a register of people prone to wandering has been created in Canada, fake bus stops have been built in Germany, mobile patrol search parties using a snail-like pattern (progressive widening of the circle of the search) in Great Britain, and specially trained dogs are used in France.

In our study most of the incidents occurred in the afternoon after lunch and before supper (35-53 %). Our findings are similar to those of Martha Morino (21). We think that the hospital-like structure of our facilities in France may be the cause: there are fewer caregivers after lunch.

We focused on the fact that in most cases (60 %), the length of time the patients spent wandering was less than one hour as described by M Morino (21) and the small number of serious consequences. Most of our elopers did not sustain injuries (93 %). This is not always the case. Many incidents of runaways with fatal outcomes have been described in both the French and international press. WICK et al showed that the longer they are missing, the less likely residents are to be found alive. Alzheimer's patients have only a 54 % chance of survival if not found within 24 hours and 20 % beyond 72 hours. The length of the elopement and the distance between the elopers and the unit are correlated with the risk of death (18).

Reducing elopement incidents and their recurrence

Although runaways are relatively rare and usually harmless, a lot of French institutions have set up systems to prevent runaway incidents with significant costs: GPS bracelets, keypads, alarms on exit doors and cameras.

However any action against eloping behaviour must be the result of genuine consultation with caregivers, the family and the resident. There must be a medical prescription with frequent revaluation. The items must be recorded in the on-going care plan.

Other recommendations are probably as useful to prevent runaway incidents. For example welcoming residents after they are admitted is essential. Admission assessment about patterns of wandering, past elopement attempts and actual elopements (50 % of elopers have been institutionalized for less than one year in our study) must be notified (19). The resident's care plan should reflect staff knowledge of prior elopement behaviour (20).

Among the 48 residents who eloped, 8 did so several times. According to J. WICK, 72 % of patients who elope will attempt to elope again (18). Recurrences should be taken into account. Additionally the resident's care plan must be reviewed and revised properly, staff awareness and reorganization must be performed and if required, the resident should be placed in a special locked AD Unit (20). The resident's consent or refusal (or his family's) should also be mentioned in order to limit further legal consequences.

Protocols about eloping behaviours and caregivers training should be implemented in AD facilities. Talking groups may be set up in order to discuss the stress that elopement incidents may cause among caregivers (18, 22, 23).

Environment and architectural changes are also essential to prevent eloping behaviour (24, 25). In our study, 80 % of the elopers live in a single room.

However many French institutions strive to reduce noise, provide light fitments suited to patient needs, and wandering paths or outdoor wandering parks. Unfortunately none of those measures have so far been scientifically evaluated and have demonstrated effectiveness.

We can suggest advice for reducing elopement incidents:

- Limiting anything that could spark a desire to go outside (such as coats, bags, car keys for example)
- Concealing a label with the eloper's identity in his clothes
- Putting on him a card indicating that he is an AD patient with the names and phone numbers of relatives and the address of the institution
- Notifying neighbours and the authorities of the risk of running away : they can be a great help in case of elopement
- Having a good and recent photograph of each patient on file (eloping behaviour is sometimes unknown)
- Improving the quality of the admission process, keeping an open mind
- Implementing recreational activities, fighting boredom
- Installing wandering paths and outdoor wandering parks
- Improving the use of entry/exit alarm door systems

Elopement: Case law and ethics

Physical restraints are sometimes used to prevent wandering and elopement. We think that in order to reduce elopement incidents, the environment must be modified and resident's care plan must be developed and revised according to the resident's assessments.

AD institutions have to reconcile two opposite constraints: ensuring the freedom of coming and going for their residents on the one hand and ensuring their safety on the other hand. Ethics and law are hard to balance. The problem for physicians, administrators and caregivers is working out how to improve safety enough to prevent elopement incidents for residents without encroaching upon their rights. It appears there is no such thing as a 100% risk free solution.

French case law is filled with judgements where the responsibility of the institutions has been questioned. Overlooking a resident's tendency to elope, insufficient supervision, or failing to retrieve a patient in a timely manner may create a liability risk (20).

In France a working group was set up by the Commission Nationale de l'Informatique et des Libertés (CNIL, a privacy watchdog) to look into the proportionality of expensive security systems to prevent eloping behaviour in facilities and define terms of use.

Conclusion

Preventing runaways should be taken into consideration by directors and physicians of AD institutions. Knowledge by the caregivers of the resident's life, staff training, environment changes are all essential precautions to a proper policy to take care of eloper patients.

The caregivers' main concern is how to ensure a high level of security -so as to rule out any risk of running away without hampering the demented resident's freedom of choice and movement.

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