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Annals of Physical and Rehabilitation Medicine 52 (2009) 579–587

Clinical case / Cas clinique

Electronic tracking system and wandering in Alzheimer's disease: A case study

Système de géolocalisation et errance dans la maladie d'Alzheimer : une étude de cas

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Received 14 April 2009; accepted 10 July 2009

Abstract

Introduction. – Wandering is a behavioural disorder, which occurs in Alzheimer's disease or other dementia. People who wander are at risk of physical harm and untimely death. Moreover, wandering behaviour causes a lot of stress to the caregivers. In the last few years, different geolocation devices have been developed in order to minimise risk and manage unsafe wandering. These detection systems rarely meet patients and caregivers' needs because they are not involved in the devices building process.
Aim. – The aim is to explore the needs and perceptions of wandering persons and their caregivers towards existing tracking devices as well as their acceptability and usability. This paper reports a dyad case.
Materials. – The tracking system tested is presented as a mobile Global Positioning System (GPS) receiver-shaped, including function of telephony and data transfer via GSM/GPRS.
Method. – Dyad patient/caregiver expressed their needs and perceptions towards tracking devices and gave their impressions about the functioning of the tested device at the end of the test.
Results. – The patient focused on the device's shape which he found too voluminous and unaesthetic, and was unable to give an opinion about the device's functioning. The spouse highlighted malfunctions and usage difficulties, which made the device not appropriate to her needs.
Conclusion. – Involving end-users in the co-design of new technologies is necessary for building tailored devices. Moreover, in this area of dementia care, the person-centred approach is essential to a tailored wandering management.

Keywords: Wandering; Patient tracking; Needs; Acceptability; Usability

Résumé

Introduction. – L'errance d'une personne souffrant de troubles cognitifs est une source de stress pour son entourage et l'expose à un risque d'accidents, voire de mortalité prématurée. De nombreux dispositifs de géolocalisation ont été développés ces dernières années pour limiter ces risques et éviter le confinement de la personne à son domicile, mais ils sont encore insuffisamment évalués par les usagers.
Objectif. – L'objectif est de connaître les besoins et attentes des personnes déambulantes et de leurs aidants vis-à-vis des systèmes de géolocalisation existants et de tester leur acceptabilité et leur utilisabilité. Ce papier expose le cas d'un tandem patient–aidant.
Matériel. – Le système de suivi à distance testé se présente sous la forme d'un terminal mobile intégrant un récepteur *Global Positioning System* (GPS) et des fonctions de téléphonie et de transfert de données via les réseaux GSM/GPRS.
Méthode. – Le tandem patient–aidant a évoqué ses besoins et ses attentes vis-à-vis de systèmes de géolocalisation et, à la fin du test, a donné son appréciation du dispositif.
Résultats. – Le patient s'est focalisé sur le design du dispositif qu'il trouve trop volumineux et peu esthétique et a été incapable de donner un avis sur son fonctionnement. Son épouse a mis l'accent sur des dysfonctionnements ou des difficultés d'utilisation qui rendent le dispositif testé peu approprié à ses besoins.

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1877-0657/$ – see front matter
doi:10.1016/j.rehab.2009.07.034

Conclusion. – L'implication des utilisateurs finaux dans la co-conception des technologies est nécessaire pour construire des dispositifs adaptés. De plus, dans la prise en charge de ce trouble, l'approche centrée sur le patient est essentielle.

Mots clés : Errance ; Géolocalisation ; Besoins ; Acceptabilité ; Utilisabilité

1. English version

1.1. Introduction

Wandering is a behavioural disorder which occurs in Alzheimer's disease or related disorders. The causes are unknown. The prevalence which is difficult to estimate might be close to 12.6% among community-dwelling people with dementia in France [12]. People who wander are prone to straying when outdoors and are at risk of physical harm (falls, fractures) and untimely death. The safety of missing elderly persons may be seriously jeopardized if caretakers cannot locate them within the ''golden 24 hours'' [4]. Moreover, wandering behaviour may pose a source of distress to caregivers and may influence their decision to place their proxy in institutional care [5].

A clear definition and understanding of this disorder are lacking. Strategies including different non-pharmacological interventions (behavioural therapy, exercises, music therapy, environmental modifications, etc.) are implemented. Among these interventions, electronic tracking systems are available technologies which allow to manage these crisis situations, to locate more quickly the person who wanders outdoors and thus to reduce anxiety and psychological burden of informal caregivers.

These devices allow wandering people to avoid confinement at home and thus promote autonomy. However, these devices, largely commercialized with various shapes (wristwatch, cell phone, etc.), have been developed without enough knowledge of end-users' needs.

Moreover, the acceptability and the usability of these products have rarely been assessed [3,6], and ethical issues associated with their use are raised [7,10,13]. The underlined arguments are the breach of privacy and dignity of the person and the loss of liberty. Another raised issue is the capacity to consent. Conflicting ethical principles are discussed in relations to tracking devices. These include tensions between the principles of beneficence (''doing good'') and non-maleficence (''avoiding harm''), and between safety and rights to autonomy, dignity and privacy, that is the balance between societal/legal values versus person-centred/individual values [11].

There are not many studies focused on perceptions of gerontechnologies by informal caregivers, patients and professionals. The ALICE study [9] reports the views, perceptions and expectations of family caregivers of patients suffering from cognitive disorders regarding 14 innovative technologies including electronic tracking system. The most appreciated technology, the tracking device, collected the greatest number of favourable responses (53.3%). To our knowledge, no study has reported patients' views so far.

In the Broca Hospital, we have initiated the TANDEM-RNTS project aimed at developing a computerized device, tailored to people suffering from cognitive disorders, acting as home assistant in order to improve the quality of life of people with Alzheimer's disease and their family caregivers. In addition to different services using technologies such as web-conference or computerized cognitive stimulation programmes, this project includes an electronic tracking device. Before integrating these services into a platform (TANDEM platform), this device is tested by people interested in such a tool.

This preliminary work reports the opinion of a dyad patient/caregiver on the electronic tracking devices' concept and on the functioning of the tested device after using it.

1.2. Methods

1.2.1. Case study

1.2.1.1. Introduction of Mr B.. Mr B., 84 years old, is an artist and lives at home with his spouse. He suffers from Alzheimer's disease at a moderate stage (MMSE 12/30). He essentially complains of anxiety related to the lack of creative thinking. Since going out for a walk allows him to stimulate his creative capacities, he still goes out alone for several hours every day in the hope to find again the energy required to create new art pieces. He also notices that walking reduces his anxiety. The urges to go out are sudden, unpredictable and imperative. These outings may take place in the evening or even in the night. If the family opposes or tries to postpone the outing, Mr B. becomes more anxious and more aggressive, in particular verbally. He admits that the need of wandering is immoderate and that he gets lost outdoors.

1.2.1.2. Introduction of Mrs B.. In his daily life, Mr B. is supported by his wife and by a personal care attendant. Mrs B., 68 years old, worries about her husband's untimely outings, especially during the night. However, she does not want to oppose because Mr B. is very determined and she wants to respect his independence and his willingness. She is very interested in electronic tracking devices and is motivated to test our device.

1.2.2. Electronic tracking device functionality

The device is a Global Positioning System (GPS) receiver and a mobile phone sit side-by-side in the same box. It is in the shape of a mobile phone attached to the person with a belt clip (Fig. 1). The unit uses the GPS to determine the precise location of the person. At regular intervals, the phone sends a text message via SMS, containing the data from the GPS receiver. The recorded location data is transmitted to an Internet-connected computer, using a cellular (GPRS) embedded in the unit.