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Neuropsychiatric symptoms in dementia: How serious games can improve caregiver's education

Authors

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Abstract

Neuropsychiatric symptoms (NPS) are very common in people with dementia-related disorders, and are responsible for a large share of the suffering of patients and caregivers. Current evidence suggests that non-pharmacological treatments are promising solutions to NPS. However, a critical factor in the treatment success is represented by the involvement of professional and family caregivers. Here we briefly present "No panic in the nursing home", an educational "serious game" designed for healthcare professionals working in nursing homes. Based on an educational program previously designed by our group, "No Panic in the Nursing Home" teaches professional caregivers how to deal with NPS of dementia. The player takes the role of a nursing home nurse, and is confronted with practical situations in which he/she needs to decide how to behave. Results collected in three nursing homes suggest that the game is considered as very interesting by nursing home healthcare professionals, even by persons with no previous experience with videogames.

Keywords

serious games; educational games; dementia; caregivers.

Introduction

Neuropsychiatric symptoms (NPS), also known as behavioral and psychological symptoms of dementia (BPSD), are frequent manifestations of Alzheimer's disease (AD) and other dementia types. In a recent systematic review and meta-analysis, Zhao et al.[1] identified 48 articles, which provided data for 12 NPS reported in the Neuropsychiatric Inventory (NPI). The most frequent NPS was apathy, with an overall prevalence of 49% (95% CI, 41–57%), followed by depression, aggression, anxiety and sleep disorder, the pooled prevalence estimates of which were 42% (95% CI, 37–46%), 40% (95% CI, 33–46%), 39% (95% CI, 32–46%) and 39% (95% CI, 30–47%), respectively. The prevalence of NPS increases as the disease progresses,[2] and the presence of NPS is associated with earlier institutionalization.[3] NPS are responsible for a large share of the suffering of patients and caregivers, and they strongly affect

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the patient's lifestyle and management. The causes of NPS include neurobiological related disease factors, but also unmet needs, caregiver-related factors, environmental triggers, and interactions among individual, caregiver and environmental factors.[4] The variety of these causes means that there is no single and always valid solution, and approaches tailored to the patient and the caregiver are needed. Taking into account the limited efficacy and the important side effects observed with psychotropic agents, the majority of the existing guidelines underline the importance of non-pharmacological strategies in the management of NPS. Several systematic literature reviews have been done in order to rate the effectiveness of non-pharmacological treatments for outpatients and patients living in nursing homes. For instance, Livingston et al.[5] showed that sensory interventions, music therapy and protocol-based activities were all effective in reducing NPS such as agitation in nursing home residents, and the positive effects lasted at least for a few months after the end of the intervention. However, a critical factor in determining the intervention success was represented by the involvement of the caregivers and residential care staff. Similarly, a review from Ayalon et al.[6] showed that non-pharmacological interventions addressing behavioral issues and unmet needs of patients with dementia were generally efficacious, but especially when the caregivers were involved. This suggests that training and educating the people around the patient, including family and professional caregivers, is crucial to boost the effects of non-pharmacological interventions meant to reduce NPS. A number of recent studies confirm this view, suggesting that training caregivers and health professional concerning NPS can improve NPS in patients with dementia, and relieve caregivers' burden. For instance, Leone et al.[7] showed that a 4-week educational program for nursing home staff focused on apathy was effective in reducing emotional blunting – one of the dimensions of apathy – in the nursing home residents (see below). Gitlin and Rose[8] found that a 16-week program meant to improve family caregivers' readiness to non-pharmacological treatments was effective in reducing distressing behavioral symptoms, and increase the caregivers' confidence (see Kales et al.[4] for a review of the effects of educational interventions for family caregivers).

Taken together, these results suggest that it is important to organize training programs for professional and family caregivers to educate them on NPS of dementia, and on ways to deal with these symptoms in everyday life. While individual and group face-to-face trainings have been proven to be effective, they are often expensive, and time consuming for both the trainers and the trainees. This is why more and more attention is devoted to the design of trainings employing new information and communication technologies, such as online training platforms, and "serious games", which embed the educational material into a playful context. Both these formats have the advantage that they can be taken wherever and whenever the caregivers want, can be repeated as many times as needed, and, in the case of serious games, the format is entertaining.[9]

The aim of the present paper is to present "No Panic in the Nursing Home" a serious game based on a non-pharmacological training program designed by our group for healthcare professionals working in nursing homes, in order to reduce NPS of dementia.

The standard version of the non-pharmacological educational program for healthcare professionals

In 2007 our group developed a training program for professionals working in nursing homes, under the auspices of the French Health Ministry (DGOS – Direction général de loffre de soins). The aim was to develop an easy-to-use training program for a non-pharmacological intervention to manage agitation and aggression in older people with a diagnosis of dementia. The program, tested in nursing homes, began with a 90-min teaching session on dementia, BPSD and the use of 'how to' instruction cards (Staff Instruction Cards). There were four instruction cards, summarizing practical advice on how to deal with BPSD. They were designed to be small and resistant enough to be easily carried by staff members. The first card gave general guidelines on what to do and what to avoid when faced with opposition, denial of care, aberrant motor activity, agitation, aggression, delusions, hallucinations or screaming. The second card explained how to act during the day to avoid or to decrease the emergence of BPSD, such as what to do at the patient's bedtime or during meals. The other two cards provided recommendations on non-

pharmacological interventions, giving examples and ideas for mini interventions designed to deal with individual instances of BPSD. Examples of the cards are shown in Figure 1. The remainder of the training program consisted of individual and interactive sessions in which trainers provided constructive feedback on how staff members dealt with BPSD. They also emphasized the importance of using the instruction cards in daily practice. The trainers were at each staff member's disposal, rather like a coach, for 2 hours twice a week during the first month, and then once a week during the second month, thus providing an opportunity for more personalized training, advice and feedback. The total training time was thus 24 hours. Results of the study conducted in 16 nursing homes indicated that the intervention successfully reduced BPSD in severely demented nursing home residents, and this effect was still

ABERRANT MOTOR BEHAVIOUS: Dos and Don'ts*

Do:	**Don't:**
1. Check that the resident is wearing suitable shoes for walking. 2. Make it easy for the resident to move around without endangering he safety and well-being of other residents. 3. Maintain a regular presence with the resident. 4. Walk with the resident and take them back to their room or the lounge.	1. Block the resident's path and stop them moving. 2. Insist on them sitting down, even during meals. 3. Leave obstacles in their path (wet floor, etc.) 4. Leave doors open t staff working areas. 5. Leave doors open that give access to the outside.

HINTS AND TECHNIQUES to reduce BPSD at key points in the day

Washing and Bathing**	
• Let the resident know in advance that it will soon be bath time. • Choose the most suitable form of bathing for the resident. • Obtain the resident's consent. • Focus on the resident's autonomy. • Try not to appear intrusive. • Respect the resident's privacy (keep the door closed, etc.)	• Try to delay the activity as far as possible if the resident refuses to cooperate. • Be gentle in manner and voice. • As you go along, explain to the resident what will happen next. • Negotiate care-giving. • Keep talking to the resident during bathing.

MINI INTERVENTIONS

GENERAL RECOMMENDATIONS

- Details of mini interventions are kept in a box in with drawers, one for each type of intervention.
- List the residents' main interests (e.g. history and way of life). List to be kept I the first drawer.

Place: Resident's room or an available activity room (i.e. somewhere quiet).
Duration: Maximum of 15 minutes, including time taken to go the room.
Aim: To decrease behavioural disturbances

WELL-BEING***
Material: refreshing wipes, perfumed moisturizing hand cream.
Description of the activity:
Invite the resident to sit down comfortably in an armchair.
Gently wipe the resident's hands then slowly apply the cream to their hands using circular movements.
While massaging, speak soothingly with words that will increase the resident's self-esteem.
When the resident has calmed down, take them back to the lounge or their room.
DO: sit down facing the resident and establish eye contact.
DON'T: massage the resident's face.

* Instruction cards of this type cover various situations such as opposition/denial of care, agitation, aggressiveness, delusions/hallucinations and screaming.
** Instruction cards of this type cover various key periods of the day: waking up/breakfast, meals, visits, evening and night-time.
*** We create several cards to provide themes for mini interventions. For example, current events, photos, souvenirs, manual activity, walking, music, relaxations/breathing exercises, and "letting off steam".

Figure 1. Instruction cards used during the teaching program to provide caregivers with practical information on what to do and how to respond when faced with neuropsychiatric symptoms

present 3 months after the end of the training intervention.[10] A second training program was developed with the same design in order to manage apathy in nursing homes.[7] Based on these results, the use of intervention materials has been proposed in French nursing homes.

The serious game-based version of the non-pharmacological educational program

Within the field of information & communication technologies, serious games are becoming more innovative and increasingly popular within the healthcare professions. Developed as remote training tools, they support health professionals in a fun way, enabling them to update their knowledge and aptitude when and where they want. Serious games form a balanced combination between challenge and learning. Playing the game is exciting for the user, and ensures that the primary goal (i.e. acquiring knowledge or skills) is reached seemingly effortlessly, thus creating a 'stealth mode' of learning. Players are thus challenged to keep on playing to reach the game objective. Serious games for educational purposes have been developed for several health domains, including surgery, acute and critical care management, and training laparoscopic psychomotor skills,[11] showing promising results in all these settings.

Based on these premises, in 2012 we started the AZ@GAME project[12] under the auspice of the ANR (French National Research Agency grant 'e-health number 1, Investment for the Future'). The project's main objective was to design and test serious games for people with dementia and their caregivers. In this context, thanks to the collaboration of different partners, we developed a serious game named "No Panic in the Nursing Home" ("EHPAD'PANIC"), based on the caregiver training program described in the previous paragraph.

"No Panic in the Nursing Home" is a role-playing game, in which the player takes on the role of a nursing home nurse. During the game, the player is asked to perform various daily tasks, such as providing medications, and simultaneously managing the residents' NPS. This way it is easy to test if the player has a sufficient knowledge and know how to deal with these situations. In case the player does make mistakes, feedback is provided on the correct behavior to undertake. The game scenario and structure (educational material, feedback provided) were designed by clinicians and researchers of the CoBTeK research unit of the University of Nice Sophia Antipolis (France) and Association Innovation Alzheimer. Based on that, Genious Group created the gameplay, including the graphical environment, the characters, the sound/music design, and the score mode (Figure 2). Pilot studies were performed to validate the content and the gameplay aspects of the game among healthcare professionals, and feedback were integrated in the present game version.

The present version of "No Panic in the Nursing Home" was tested in three nursing homes in Nice. Five volunteers among the nursing home staff members were selected in each nursing home to test the game for 3 weeks (30 minutes of game playing, twice a week). Before and after the intervention, participants were administered questionnaires concerning their knowledge of NPS of patients with dementia, as well as on the intervention acceptability. After the end of the intervention, participants were also administered a self-report questionnaire assessing their satisfaction concerning the game. "No Panic in the Nursing Home" was rated as a very interesting tool by nursing home healthcare professionals, even by persons with limited or no previous experience with videogames.[13] As of May 2016, more than 4000 professional careers and 800 teaching companies for health education have used "No Panic in the Nursing Home".

Discussion and Conclusion

The results of our training program designed to help nursing home's healthcare professionals to learn more about how to manage NPS in patients with dementia suggest that educating professional caregivers through the use of serious games can be a promising solution to improve everyday management of NPS, and eventually improve the quality of life of both patients and caregivers.

Although serious games such as "No Panic in the Nursing Home" have proven their usefulness in supporting professional caregivers, it is important to design training programs specifically for family caregivers, who deal with NPS in their everyday family life. A recent survey of the French ministry[14] suggests that there are more than 4.3 million

people in France who regularly act as formal or informal caregivers for persons aged 60 years or more. Around 3.9 million of these caregivers help seniors in aspects concerning their everyday life. These caregivers have a mean age of 59 years, and 53% are females. Half of them are the senior's sons/daughters, one third of them are spouses, and the remainder include other family members (brothers, sisters, etc.) and persons in the immediate environment (friends, neighbors, etc.).

Recent guidelines[15] suggest that new information and communication technologies could also be well adapted to family caregivers. In particular, in order to facilitate the acceptance of these instruments, it would be important to better track the field and frame the issue by collecting relevant data, and to promote national and social conversations on the topic (see Figure 2). Interestingly, programs designed for professional caregivers can often be adapted to family caregivers. This is what we are

Figure 2. "No Panic in the Nursing Home". The serious game is based on the instruction card developed in the study

trying to do in the project Aidant et Eve[16] financed by the French Agency CNSA (Caisse Nationale de Solidarité pour l'Autonomie). The project aims to develop an online platform for family caregivers devoted to education and information sharing, in order to improve their knowledge of the features of patients with Alzheimer's disease or other dementia-related disorders. The online platform will include a serious game based on the logic of "No Panic in the Nursing Home", as well as a moderated discussion forum, where caregivers will be able to exchange their opinions, comment on relevant issues, and ask questions of healthcare professionals.

In a similar vein, we are developing online tools that the family (and professional) caregivers can employ to stimulate the patients and reduce NPS such as apathy in everyday life. In the MeMo project[17] we are developing a set of entertaining exercises to train cognitive functions, such as memory and attention. MeMo was designed to respond to the needs of patients with cognitive impairment, of healthcare professionals working on the prevention of cognitive decline, cognitive training and stimulation, or of any person willing to train his/her memory and concentration.

As stated during the last IGPHE conference,[18] one aim of innovative health education is to foster the relation between all the stakeholders. This includes interprofessional education occurring when two or more professions learn with, about, and from each other to enable effective collaboration and improve health. The other mandatory aim is the involvement of familial caregivers and patients. Only if those aims are accomplished it will be possible to work efficiently for the prevention and for the chronic patient monitoring.

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Conflicts of Interest: PF is director of the Genious Group, involved in the commercialization of serious games.

Author Contributions: During the 15-month period between July 2014 and Designed the clinical aspects of the educational tool: JB, AD, EL, RD, PR. Designed the technical aspects of the educational tool: PF. Collected the data: JB, AD, EL. Wrote the paper: VM, PR.

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