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Forum

Assistive Technologies Promoting the Experience of Self for People with Alzheimer's Disease

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Abstract There is growing evidence for the importance of rehabilitation interventions promoting the persistence of the sense of self in people with Alzheimer's disease (AD) and other forms of dementia. Assistive Technologies (AT) may contribute to the development of interventions aimed to improve adaptive responses to environmental demands. This, in turn, can promote self-awareness. At the same time, AT can manage computer interfaces able to record and reproduce autobiographical multimedia contents that can be very useful during reminiscence tasks carried out during conversations with supportive staff. These tasks could promote the self-concept. Globally, AT can be of great help in setting up rehabilitation and leisure environments promoting the experience of self in people with AD and other dementias.
KEYWORDS: Alzheimer's Disease; Assistive Technologies; Reminiscence; Self-awareness; Self-concept.

Riassunto *Tecnologie assistive per promuovere l'esperienza del sé in persone con malattia di Alzheimer* – Emerge con sempre maggiore chiarezza l'importanza di interventi riabilitativi in grado di promuovere l'esperienza del senso di sé in persone con la malattia di Alzheimer (AD) o altre forme di demenza. In particolare, le Tecnologie Assistive (AT) possono contribuire alla messa a punto di interventi in grado di promuovere comportamenti di risposta alle richieste dell'ambiente e questo può, a sua volta, favorire la consapevolezza di sé. Al contempo le AT possono gestire interfacce computerizzate in grado di conservare e riprodurre contenuti multimediali autobiografici che possono risultare di grande utilità durante compiti di *reminiscence* veicolati da conversazioni con i membri dello staff di supporto. Questi compiti possono promuovere il concetto di sé. Globalmente le AT possono risultare di grande aiuto nel costruire ambienti riabilitativi e ricreativi che promuovono la perseveranza del sé in persone con AD e altre forme di demenza.
PAROLE CHIAVE: Malattia di Alzheimer; Tecnologie Assistive; Reminiscenza; Consapevolezza di Sé; Concetto di Sé.

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Introduction

ALZHEIMER'S DISEASE (AD) IS the most frequent neurodegenerative disorder in western countries. AD is characterized by a persistent decline in cognitive and behavioral abilities and the person affected loses his/her daily skills and eventually needs full time care. AD usually starts in old age. Problems with remembering, reasoning, planning actions as well as a variety of psychological symptoms, such as agitation, delusions and depression[1] constitute the most common signs of pathology.

According to the World Alzheimer Reports,[2] there are more than 35 million people living with AD, and this number is going to almost double by 2030 and nearly triple by 2050. According to the World Health Organization[3] the incidence of dementia in general is more than 7 million new cases per year. The average annual increase between 2010 and 2050 will be more than 15 million. Consequently, in the next 40 years more than 600 million new cases will occur without a treatment that delays the onset / progression of the disease. People with AD live for years with the illness. The average length of the disease is thought to be in the range of 4 to 8 years; however this time can be longer.

On the basis of the aforementioned data, it clearly emerges that dealing with the care of people with AD is a serious health and social emergency requiring the collaboration and commitment of family members and voluntary associations. In addition, over the next 40 years the ratio between people with AD and people who are able to take care of them will become largely disadvantageous. The workload required for daily care is normally very heavy for family and for professionals and this is likely to reduce the number / quality of activities specifically designed for people with AD. The reduction of opportunities to participate in activities together with a gradual reduction in their behavioral repertoire relegate the person with AD to a passive existence, a poor quality of life, a state of exhaustion and unhappiness and a vulnerable self.

The argument of vulnerable self is fairly widespread in the literature regarding the advanced stages of AD.[4] Narrative as well as research evidence suggest a progressive loss of the awareness of self in individuals with AD. In the early stages of illness people are intermittently aware of this loss. With further progression of illness the individuals with AD seem to become increasingly less concerned regarding this and other characteristics of their illness. On the other hand, the family and support staff become progressively more worried about it. Phrases like "this is not the person I married", "he/she is the *shell* of him/herself", "he/she is in a continuously fading dream" become very common among staff members.[5]

From our point of view the sense of self encompasses the self-*awareness* that can be described as the ability of individuals to be aware of changing situations and react to these changes in their environment. On the other hand, *Self-concept* can be thought of as the ability to reflect on oneself as an individual comprehensive of a physical body and other important properties as well.[6]

From a practical point of view it is possible to boost self-awareness by developing interventions aimed to save some of the functions available in the past. In this way, people with AD (a) would still be involved in a world of activities and opportunities that would make them more socially acceptable and (b) would be stimulated in a systematic and controlled way, to enhance their attention to changes happening in the environment.

For example, an intervention might help persons with AD prepare a cup of coffee when they receive a visit from their family members. To help them in this task, the entire procedure must be divided into sub tasks through a task analysis, and when the coffee pot produces its characteristic burbling, the attention of the person must be drawn in some way (e.g. acoustic / verbal prompt) so that they begin to serve the coffee to their guests, properly reacting to external stimuli.

Moreover, a very promising research line

is based on findings that autobiographical memory (AM) of the life preceding the illness are relatively well-preserved in individuals with AD and these could aid people to retain their sense of self.[7] AM comprises *autobiographical episodes* (AE) and *personal semantics* (PS). AE refer to specific mentally represented experiences and individual has had, including vivid visual and emotional details.[8] On the other hand, PS refer to generalized, repeated memories of events containing general knowledge of individuals' facts like their own name, names / information regarding family members / friends and general places.[9] AE is associated with a feeling of "remembering" a specific event while PS is associated with a sense of "knowing" without circumstantial details.[10]

Moreover, Singer and colleagues[11] described self-defining memories (SDMs) as particularly important for the self-concept. AE and PS are relevant for SDMs. These memories support people to delineate their self-image, describing to other people who they are. Several studies have stated that AM of people with AD is characterized by a decrease of AE memories and an increase of general / PS retrieval,[12] accompanied by a shift from a sense of remembering to a sense of knowing.[13] Martinelli and colleagues suggested that SDMs are not well preserved in people with AD. Nonetheless, the maintenance of PS and SDMs seemed sufficient for maintaining an effective sense of self in people with normal aging.

These findings support the development of intervention programs based on the use of different aspects of AM and in particular SDMs since they «protect the sense of self against the threats resulting from the onset and progression of AD».[14]

Currently, a series of intervention / rehabilitation strategies aimed at improving the quality of life, supporting the sense of self of individuals with AD and increasing their opportunities for effective and positive social contacts is available. These intervention strategies for people with AD adopt Assistive Technologies (AT). The AT cannot substitute for supportive staff, whose presence and contact with the individuals with AD remain essential, but can support individuals with AD and, indirectly, their caregivers in all those activities that do not require continuous expert intervention and have to be repeated periodically during the day (e.g. self-paced leisure and daily activities) or enrich reality (e.g. providing verbal/pictorial cues for indoor traveling and wayfinding). Secondarily, these strategies seemed to be able to counteract the growing burden associated with care.

AT supporting daily activities and leisure

People with AD generally show a decline in memory and general cognitive functioning. Consequently, they have progressively more difficulty in performing daily tasks such as personal and home care, meal preparation and procurement of goods and medications.

The difficulty in performing these functions often generates a state of irritation, depression and isolation, a sense of failure and loss of sense of self as they no longer able to carry out adequate monitoring of daily functions. Lancioni and colleagues[15] suggested that while people with a moderate level of AD were physically able to perform activities of daily living, they progressively required the intervention of support staff who – step-by-step – verbally instructed them on what to do. The authors supported the idea that verbal instructions can be presented automatically through very simple technology and with only limited interventions from staff members.

AT systems would be able to restore a suitable degree of monitoring of environmental changes through external devices capable of indicating the time at which to perform a specific action. In this sense, AT would be able to contribute to maintaining a good level of self-awareness for people with AD.

AT usually include battery-powered ra-

dio-frequency photocells, light-reflecting paper and MP3 players with a recording of verbal instructions associated with the intended task. A microprocessor-based control unit supplied with a radio-frequency receiver and a programmable command function ensure the presentation of verbal instructions. We report some examples of research devoted to the development and evaluation of AT systems supporting people with AD in daily activities.

For instance, in study 3 by Lancioni and colleagues three people (73-81 years of age with a moderate level of AD) were engaged in a 12-step coffee preparation procedure. Results showed that they were able to perform 2.5 times better with AT (85% of the correct steps) compared to the baseline (without technology, 34% of the correct steps). In Lancioni and colleagues[16] 16 people (58-88 years of age with mild to moderate levels of AD) were engaged in morning toilette/bathroom routines, dressing or table setting activities.

The tasks consisted of 10 to 17 instructional steps depending on the participant and on the task. Results showed that they were able to perform from 2.57 to 3.25 times better with AT (80-90% of the correct steps) compared to the baseline (without technology, 27-37% of correct steps). Moreover, in two other studies[17] Lancioni et al. researched the effectiveness of AT using automatic verbal instructions to manage daily activities also including an assessment of the impact of such activities on the individuals' mood. Thirty people (58-86 years of age, with mild to moderate levels of AD and mild to moderate levels of depression) were engaged in make-up / shaving activities or food preparation (i.e. coffee, tea, snacks and salads).

The tasks consisted of 12 to 34 instructional steps depending on the participant and on the task. Data recording involved the number of correct steps as well as indices of happiness (smiles, positive utterances and laughs during activities). Results showed that the participants were able to perform about two times better with AT (85% of the correct steps) compared to the baseline (without technology, 42% of the correct steps). Moreover the percentage of sessions showing indices of happiness was from two to 15 times higher in the AT condition (up to 46%) than in the Baseline condition (up to 6%).

A more complex AT based on some form of artificial intelligence was also used to autonomously guide an individual with dementia through a specific activity of daily living skill by using audio or audio-video instructions (Cognitive Orthosis for Assisting Activities, COACH).[18] Results showed that, on average, six individuals with dementia were able to complete 11% more correct steps of the intended activity with a 60% decrease in requests for support from the caregivers compared to the baseline performance. Moreover, four out of six participants achieved almost complete independence.

The aforementioned interventions were intended for persons with mild to moderate AD. Unfortunately, very few intervention strategies aimed to reactivate people together with improving participation and mood are available for people in the severe stages of AD. Music experiences appear to have a calming effect on most people with AD and lessen their agitation, anxiety and depression reducing behavioral disturbances as well.[19] Again, AT systems seemed to be able to reengage people with severe dementia in self-regulated music stimulation. Very basic AT systems are deemed useful in allowing a person to control the onset and extension of prerecorded music clips by performing a simple motor response (e.g. pushing a button).

The technology used to help the participants consisted in a microswitch, a laptop computer and an interface connecting the microswitch and computer. During the baseline sessions, the personal computer recorded the microswitch activations due to the performed motor responses. Music stimulation was provided continuously during control sessions. During the intervention the laptop could be activated by pressure on the microswitch.

This simple system served to (a) present a brief audio segment of a song (from those previously selected as favorites by the participants) after each activation of the microswitch, (b) present a pre-recorded verbal prompt (e.g. "Hey [name of the participant], press the button if you want to listen to more music, would you?") after a pre-defined period of inactivity and (c) record the number and the timing of microswitch activations. Four multiple single-case studies[20] involved 34 persons 65-95 years of age with a diagnosis of severe AD and mild to severe depression. In summary, self-regulated music is equal to or more effective than the passive condition, in which music is automatically presented.

However, a more active role, with the participants adopting a simple response (adequately encouraged after an inactivity period) and regulating the music stimulation could allow them to restore a form of adaptive behavior. Actively controlling the environment is relevant in terms of reducing their detachment from their surroundings and contributes to providing them with a more positive and socially acceptable image[21] that, in turn, lays the foundation for strengthening their sense of self.

AT augmenting reality for indoor navigation

Spatial orientation and navigation ability decrease with the progression of Alzheimer's disease although spatial disorientation is not an unavoidable manifestation of AD. Indeed, some studies[22] show that overt orientation disorders or *Topographical Disorientation*[23] (TD) emerge in slightly less than half of the cases. Topographical Disorientation usually evolves in the following way. First, manifestations of TD occur in dimly familiar environments. With the progression of the disease they occur even in familiar surroundings, and finally also in the patient's home.[24]

TD seriously compromises the independence of people with AD since they no longer feel able to explore the environment independently and supportive staff members tend to limit the freedom of movement of persons with AD to stem the risk of their getting lost. Such restrictions contribute substantially to the decay of self-image and social status[25] since independent and self-directed exploration of the environment is a core ability of any mature organism. In addition, in more advanced stages another disorder associated with navigation occurs: *wandering*. This is an incessant walking behavior that may appear to be an exploration of the environment but is not actually aimed at any specific target but rather at reducing the sense of malaise and agitation that plagues people with AD.[26]

Other scholars associate this behavior with the goal of increasing stimulus inputs in a socially-mediated or self-stimulatory manner.[27] Several studies have focused on developing AT systems that help people regain the ability to explore their surroundings with an acceptable degree of independence and self-confidence.

Essentially, two types of interventions have been tested: (a) *restorative* interventions, which aim to enhance residual learning resources for recognizing highly salient landmarks and allowing the person to find his way. They are essentially based on behavioral approaches such as *backward chaining*.[28] Such an approach allows for learning a path previously divided by the research staff into parts. The intervention starts from the point of arrival and progressively new parts of the path are added until participants get to the starting point.

The other type of intervention (b) can be defined as *compensative* since they require very minimal learning skills. It is intended to *enrich reality*: it simply requires the participant to follow very salient and recurrent stimuli, such as simple verbal instructions (e.g. the participant's name coming from speakers placed in the target room and along the hallways), a sound track previously chosen because it was recognized and pleasant for the patient, a visual cue (such as flashing

lights), or a combination of the latter two. The goal is to draw the attention of the participant by means of these high-salient stimuli distributed along the route and/or nearby the target. Compared to other forms of interventions, those that aim to support spatial orientation are relatively rare.[29]

The studies reporting interventions involved a total of 16 persons 71-89 years old with mild to moderate stage of AD. All were recruited in selected day centers. They were known to enjoy travelling and meeting staff but they were not independent in navigating the hallways between the rooms. Overall, the results showed that the first type of intervention (i.e. the restorative one) has a good chance of success in the mild stages of the disease.

The second method is more appropriate in moderate and severe stages of the disease. Both interventions were largely affordable, however the behavioral method was very labor intensive for the staff. Among the compensative interventions visual cues seemed more practical than acoustic ones. Moreover, these interventions seemed to reduce wandering behavior. Indeed, people who committed to reaching a target / completing an activity seemed to have reacquired the ability to manage a purposeful exploratory behavior.

Together with interventions promoting restoration of some daily functions, interventions supporting exploration of the environment are crucial for the onset of a positive change in the social image of persons with AD. The recovery of some simple daily functions and the ability to explore the environment with an acceptable degree of independence contribute to the maintenance of an adequate sense of self, and increase the opportunities for positive social interactions. In this sense these interventions certainly represent an important basis for the promotion of self.

AT and autobiographical memory

As we mentioned in the previous paragraphs, persons with AD tend to gradually reduce their behavioral repertoire with the progress of the disease and the gradual deterioration of short-term memory leads to communication that is focused on repetitive questions and gradually poorer verbalization, including incoherent vocalizations, perseverative speech, echolalia and, sometimes, mutism.[30]

In contrast, long-term memory, and in particular those components related to autobiographical memories, may be relatively less affected by the disease. In this section, we report examples of intervention conducted in this regard that aimed to enhance autobiographical memories and, in turn, facilitate more effective communication with others.

This type of research was characterized by two levels of complexity in the technologies used. In the first period during the 80s and 90s (but still used today), we adopted low-tech systems, essentially memory books and memory wallets: two different collections of personal information similar to *portfolios* with a range of autobiographical information useful for striking up a conversation with others. In the last decade, we developed more sophisticated systems of AT based on PCs, tablets and smartphones which are also able to collect information independently during the day.

Memory portfolios were used by Hanley and Lusty,[31] Bourgeois[32] and Bourgeois and colleagues[33] for people in the moderate stage of dementia. In two early studies, Bourgeois evaluated the effectiveness of teaching 12 individuals (three in the first study and nine in the second one) with middle stage AD to use a memory aid when conversing with their family members.

The memory wallet contained short sentences (e.g. names of relatives, autobiographical events) together with pictures meaningful to the individuals. They learned to use these memory wallets in brief conversations with relatives. Intervention outcomes were recorded within a typical single-case design approach. Results showed that individuals used memory aids to improve the quality of their conversations. They also tended to be more engaged in conversation on topics and

contents unrelated to the intervention. Moreover, three out of nine participants in the second study were able to maintain their improved conversational skills at follow-up almost two months later.

In a third study Burgeois and collaborators assessed the generalized effects (adopting a case-control study approach) of providing memory aids to persons with dementia for their conversations with staff members. Memory books were adapted for each participant in terms of autobiographical information, aspects of their daily living at the nursing center, or concerning an actual problem. The books were illustrated with photographs, drawings or graphics. Sixty-six individuals with dementia, half of them in the treatment group and half in the control group, and an equal number of staff members (trained to use the memory book during the interaction with patients) participated in this study. The authors recorded several 5 min conversations of participant-staff member dyads.

Results showed improvements in quantitative variables such as duration of speaking and frequencies of utterances, comparing treatment (with memory books) and control conditions (without memory books). Moreover, the authors showed an improvement in the quality of conversation. Staff members interviewed during a social validation assessment suggested an overall enhancement in the patients' quality of life, and self-image.

The same approach was used in another series of studies[34] adopting the *reminiscence approach*. Photos, audio - videotapes and other *souvenirs* coming from the individuals' past were used as personalized reminiscences that could be used to improve the fruitfulness of social interactions. Effects of reminiscence sessions reduced behavioral disorders and positively affected levels of self-esteem and psycho-social wellbeing.

More recently Yasuda and colleagues[35] developed an intervention using personalized reminiscence photo-videos with a more sophisticated technology. They set up a slide show of personal photos with narration, background music, and visual effects such as magnified details from photos. When individuals with AD watched personalized reminiscence slide shows they were more engaged than in other kinds of entertainment. De Leo and colleagues[36] extended this line of research by acquiring autobiographical memories from an individual with AD via a smartphone. In fact, the authors were interested in recording and then showing persons with AD videos of their life in an attempt to furnish them with some traces of current daily episodes.

They set the smartphone to take pictures at 5 min intervals during the day. These pictures were collected and put into a video slide show and saved on DVD. Individuals and their supporting staff viewed the DVD weekly. Results indicated that viewing the DVD assisted the individual to better recall recent events.

The aforementioned studies based on slide shows of autobiographical materials have the limitation that the role of patients is somewhat passive and their verbal productions could be limited. A recent study[37] assessed a simple computer-aided program for helping persons with moderate AD to be involved in a task asking them to verbally recover their autobiographical reminiscences. With this aim, a number of life experiences were previously selected and introduced gently by a female research assistant.

She appeared on the computer screen asking the patient to narrate experiences/topics among those previously selected, and providing him or her with positive attention, and possibly verbal prompts or encouragements. Seven out of eight participants showed improvement during the intervention phase. In conclusion, this approach appears to be very promising, since it seems to be able to foster those *self-defining memories*[38] particularly important for preventing the disintegration of self. These memories support people to delineate their self-image, describing to other people and to themselves who they are.

Nonetheless, the experimental contributions on this topic are scarce and its real influence on well-being and protection of self in persons with AD is still under investigation.

In summary, clinicians and supportive staff can derive benefits from the relatively undamaged autobiographical memory of individuals with AD to enable them to engage in more effective social communication with supportive staff and family members. Autobiographical memory data collected and showed via low (e.g. memory wallets or books) or high tech AT (e.g. smartphone or a PC based multimedia systems) can be a viable method to enhance the quality of life of people with dementia and support them in the recovery of their self-image and self-competence.

Conclusion

Currently, there are no existing interventions that can prevent, cure, reverse, or slow the progression of Alzheimer's disease, but there are interventions that can lighten symptoms, reduce unhappiness and potentiate residual skills of individuals with AD together with their sense of self.

However, since persons with AD and their familiars live in a state of discomfort and difficulty, it is especially important that researchers constantly ask themselves if a certain type of intervention can actually make the difference in fostering the patients' and their families' well-being and if the proposed interventions are rigorous and influential enough to curb the effects of this progressive disease. AT systems are relatively inexpensive, moderately demanding for supportive staff and allow staff members to devote more time to other activities which are effective in promoting the well-being and sense of self of patients.

AT systems have been increasingly applied to improve daily living activities, they give tools to individuals that they can use to interact with the environment in a strategic and significant way. AT studies dealing with activities of daily living suggest that technology supporting verbal instructions and pictorial cues can be programmed to assist individuals with AD, especially those at the early stages of disease. Individuals who participated in these studies learned to use the technology fairly rapidly and maintained this learning over short periods of time.

The studies on technology-supported self-regulation of music are also very encouraging because they suggest individuals with AD can re-engage in leisure skills, even at the most severe stage of their illness. The re-engagement of people with dementia in daily activities can be interpreted as a form of support for self-awareness. Through the support of technologies, people with dementia can meet the demands of the environment.

The management of tasks through acoustic and visual prompts or providing verbal instructions can exercise the ability of persons with dementia to respond to external stimuli. Taking care of simple daily tasks increases the opportunities for more effective interpersonal relationships. Indeed, to prepare and enjoy a coffee with relatives or friends enables people with dementia to restore daily habits existing prior to the illness thus boosting the sense of self.

The studies conducted on enriched reality for indoor travel are encouraging as well. They suggest technology-aided travel is possible and can result in secondary benefits, such as (a) social interaction with others along the way, (b) the possibility for employment: delivering the internal mail of the day care center and (c) the reduction of purposeless walking.

There is limited but very promising research on supporting reminiscence and autobiographical memory for people with AD. The use of memory wallets, personalized reminiscences, smartphones to repeatedly collect daily activities data that can later be used in conversations, and computer-based multimedia systems are all encouraging and may result in viable AT for this population. The intervention on autobiographical me-

mory seems very promising for promoting the concept of self of persons with AD.

In all the aforementioned cases the AT improved self-determination and persistence of self. At the same time AT makes the burden of care more affordable for the supportive staff members who can spare time and resources for more effective relationships with persons with AD.

Notes

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