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Alzheimer's patients Interaction through Digital and Arts (AIDA)

Project n.2021-1-IT02-KA220-ADU-000027077

PR1- AIDA Methodology

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General Description

In recent years, as the number of people suffering from Alzheimer's Disease (AD) has increased and there has been a growing interest in rehabilitation methods that can slow down and alleviate cognitive decline. AD is a complex pathology with a wide array of contributing factors, ranging from genetic and environmental variables to previous physical and psychological conditions. AD affects almost 50 million people in the world and with a new case of AD occurring somewhere globally every 3.2 s (World Alzheimer Report, 2015; 2018). Early cognitive symptoms typically involve progressive memory loss, reduced visuo-spatial attention and topographical disorientation (Kálmán et al., 1995; Smits et al., 2012; Yew et al., 2013). Then, the disease progression spreads on a large scale (Weintraub et al., 2012), causing anterograde amnesia and significant impairment in the realm of executive functions (Perry et al., 2000; Stopford et al., 2012). AD cognitive deficits heavily affect the quality of life of both patients and caregivers while preserved autonomy in performing instrumental activities of daily living and interventions to improve cognitive functions seem to directly improve quality of life scores (Cummings et al., 1998; Bell et al., 2001; Woods et al., 2006). To this date no pharmacological treatment exists to counter this neurodegenerative disease. For this reason, is very important to look into ways and methods to slow the course of AD and to improve the quality of life and health of people affected. Moreover, in the last two years the global pandemic due to Covid-19 weighted heavily on every country national health system and on the psychological status of particularly at-risk people. This emergency added to previous difficulties encountered by caregivers and people with AD (PWAD), resulting in worse overall outcomes for their psychological health.

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As an example, these are some of the main problems that the Alzheimer Association of Ireland (ASI) highlighted in its 2020 and 2021 reports related to Covid-19:

- Loneliness and Isolation due to social distancing
- Boredom and lack of routine
- Anxiety/Fear of contagion for both PWAD and caregivers
- Lack of respite for caregivers
- Lack of social support for caregivers

These problems are additive to the "typical" difficulties of PWAD:

- Lack of confidence
- Sadness and Depression
- Lack of independence and difficulties in daily life
- Low well-being and sense of identity (Hoe & Thompson, 2010)

The aim of rehabilitation strategies is mainly to improve the autonomy of the person suffering from AD. These are rehabilitation programs that aim to establish a new personal, family and social balance; thus, in addition to increasing and preserving as much as possible the autonomy of the person affected by Alzheimer's, the workload and stress for the family/caregiver are also reduced.

Recent research demonstrated that older adults who are cognitively impaired are significantly less likely to be socially and cognitively active than older adults without a cognitive impairment (Johnson et al., 2014), and that engaging in meaningful activity in the early stages of dementia can help people to focus on their residual abilities and offset a sense of loss (Genoe and Dupuis, 2014). This also includes art viewing and art making, which have consistently been shown to have multidimensional benefits for people with dementia (Zeilig et al., 2014). As an example of possible benefits, results from empirical studies have indicated positive outcomes in terms of increased

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subjective psychological wellbeing, a sense of broadening of horizons, and social inclusion (Flatt et al., 2015; Young et al., 2015) from using art-based interventions in dementia care, while other findings demonstrated increase in sustained attention and intellectual engagement (Camic et al., 2014) and stimulation of episodic memories and communication (Eekelaar et al., 2012). Art and museum-based interventions draw inspiration from the so-called aging paradox (Prakash et al., 2014), according to which the progressive atrophy of prefrontal regions, with consequent decline of cognitive processing, is associated with the enhancement of the preserved emotional ones (Bucks and Radford, 2004; Klein-Koerkamp et al., 2012). The channel of emotion processing becomes, for elderly people, a preferential way to reach and be reached by the external world and a way for rehabilitators to facilitate the compensation of other abilities or scaffold the decaying cognitive ones. Importantly, art appreciation and production seem to be maintained during healthy aging (Kim, 2013; Istvandity, 2017) and there is also evidence that the brain mechanisms and the cognitive processes involved in creative art activities are not irreparably damaged in PWAD (Ehresman, 2013). Furthermore, Graham and colleagues (2013) demonstrated that, for people with Alzheimer's, aesthetic judgments are similar to those of healthy adults, providing further evidence that art-based interventions may draw on residual abilities even when cognitive impairment is present. It is also very important to note that previous research suggested that art gallery-based interventions can provide social and psychological support even to caregivers in ways different from traditional support groups (Roberts et al., 2011). Taken together, results from literature seems to support that art-based and museum-based interventions are a good way to access and promote preserved abilities and functions in PWAD and that these types of interventions could improve the quality of life and well-being in both PWAD and caregivers.

For these reasons, the Alzheimer patients Interaction through Digital and Arts (AIDA) project involves different field of research and practice, namely

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the Clinical field, the Museum and Art field and the Digital and Technological field. The AIDA project created a novel methodology and procedures from the collection of the different good practices in these three fields and tested the beneficial properties of the created procedures on AD patients and their caregivers across different countries involved in the project. In particular, the AIDA project is divided into three different phases, each one addressing a different combination of digital and artistical tools:

- Art-Exploring: Guided tours in museums and places of historical/naturalistic significance; manipulation of works of art; collective discussions with facilitators and caregivers.
- Art-Making: First-person involvement in creating, digitally or analogically, art in different forms, ranging from painting to photography. Assisted by trained facilitators and guided through shared discussions.
- Personal Gallery: A small session in which participants and caregiver are showed a virtual museum of the project. For those interested, a collection of works from the previous phases will be arranged in the same virtual environment as a "personal museum", in which participantsprivately showcase, assisted by their caregivers and facilitators, work of arts particularly appreciated or made by them.

Aims

The aim of this project is to compile the advancements in the fields of Museum- and Art-Therapy, Clinical experience and Digital/Computerized programs in order to create a comprehensive methodology and procedures which takes into account the needs and capabilities of AD patients and helps them to improve their quality of life, perceived well-being and their social relationships.

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Art-Exploring and Art-Making Sessions

The AIDA project took place in different locations, according to each partner availability. Art-Exploring and Art-Making Sessions entail the following activities, three of them are chosen by availability by each partner involved:

- *Personal Expression through Mindful Colouring:*
    - A variety of colouring in sheets and art materials is set out on the tables. A range of materials is offered for colouring in such as markers, crayons, or colour pencils. The participant chooses which materials suit their mood in the moment. At the end of the session, each participant is encouraged to say something about their image to the group as a whole. The participants is encouraged to take their personal art work home with them.
- *Creative storytelling using four senses:*
    - Each participant pulls out a random object from a fabric bag and tells a short story. They select an object from the bag based on touch rather than sight. The facilitator encourages the participant to engage with the object uses their senses, sight, sound, smell and touch.As a group-based activity this can increase a feeling of social inclusion in participants.
- *Collaging colours:*
    - The idea of collaging colours is to use bright contrasting colours such as reds, oranges, mustards, purples, pinks, blues and greens to create a picture. Participants are offered a range of coloured paper cut to different sizes and shapes. They can arrange them on a sheet of paper and glue them down. They can then create a picture by drawing or colouring over the collage in markers, pencils or crayons. As a group task, this fosters a sense of self-worth and social connection to the group and gallery.
- *Choose, think, speak:*
    - An exhibit is shown to the people with dementia and with the help of facilitator they will try to develop a story together about the history of the shown object. It is possible to give the option each person to choose one object from the museum and then to develop one common story using all of the chosen objects.Each person with dementia can add something to the story and the facilitator either has to write or draw it on a sheet of paper or on a white board, so that everybody can see how the story is developing. In

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the end, the facilitator can read the story to all people with dementia and acknowledge them as creators of the story.

- *Actor for a day:*
    - The people with dementia will perform a story (they have prepared previously in the activity "Choose, think, speak") as a theatre play and they will also use the objects they have already chosen in the museum for their performance.
- *Music path:*
    - Organize tours in museums for people with dementia that are accompanied with appropriate music. In this way, by hearing music connected to the exhibits in the museums, they are stimulated to talk. The caregivers can ask them questions to help them explain better how they feel. The caregiver can also ask the person with dementia to sing/hum whichever song/melody comes to their mind when they see a specific exhibit, so that he can play it for the patient. They can sing along with the song, or they can be stimulated to talk about what the song and the object brings to their minds.
- *Draw & chat:*
    - Taking inspiration from a painting or an object at the museum, the people with dementia create a story and draw their own sketch and talk with the facilitator about their creation. Alternatively, they describe their story and the facilitator creates the drawing while they discuss the shapes, colour, ideas, emotions related to the story and the drawing.
- *Red riding hood:*
    - Different sounds and background visual stimuli guide people with dementia to adapt different roles. Walking in front of different visual effects and listening to different sounds inspires them to adapt their movement and their role accordingly.
- *Digital Museum Navigation:*
    - Different images from their hometowns or the cities they reside are provided to people with dementia. They are encouraged to discuss the pictures and recollect some memories of specific experiences they had in their hometowns/cities.
- *Nature through the artists' eyes:*

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- Being outdoors has social, physical and mental benefits. It facilitates social interaction and helps people remain active in the wider community. It also improves memory and attention, multisensory engagement, as well as a sense of well-being, self-esteem and a sense of belonging in the community. Where a number of walks in the same area are offered, participants and their carers begin to feel a familiarity with the site and become part of the community of walkers that visit the site. It expands their view of their world and increases a sense of social inclusion and community. This type of activity can promote that connection to others that relieves isolation.

- *On the floor:*
  - Participants are encouraged to dance in the rhythm provided by a specialised instructor.The people with dementia are asked for their favourite songs/music to dance to. Alternatively, there are provided with the music to dance to.
- *Clay your thoughts:*
  - After completing a museum tour and inspired by the museum collection, people with dementia create their own objects using clay. They can choose to work individually or in larger groups to create one larger object by connecting the different pieces they have created.
- *Sound impressions:*
  - Music produces very positive effects on people with Alzheimer's disease. The activity proposed in this scenario involves using music to stimulate participants and support them in regaining their role in society. Using local events or manifestations is a great way to involve participants in a socially familiar context and stimulate them to feel included and part of the city where they live.
- *The mask of feelings:*
  - The purpose of this scenario is to stimulate participants to share their feelings and moods. The instrument used is the mask. Participants will be asked to construct a mask in order to become part of the work being examined (a figurative work is suggested) and become the protagonist of it, together with the subjects already represented. The aim is to make them express the feelings the work conveys and share them with others.
- *Ball band:*

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- Participants will create music on Pilates balls with the help of two sticks (drumsticks or similar) and singing. The music they will play will be folk and well-known on the national level, which touches the folk heritage, because with this activity we promote the preservation of the cultural heritage. Activity can also include grandchildren, children for kindergarten, carers, family, relatives, and employees in homes for elderly.

- *Manual for daily art journaling:*
  - In the workshop, participants will draw in an art journal and receive a printed copy of the Manual for daily art journaling, to use later on. The manual guides a person with dementia to write a diary/daily journaling through expressive art therapy. Guided journaling directs focus on their memory and positive emotions, where the user draws what happened in the past day. The manual also allows a look into the past days, therefore refreshing their memories. The main two aims are to strengthen cognitive functions, as the person is invited to think about what happened during the day. At the same time, the expression of emotions through art provides relief and consequently improves the quality of life.

- *Pieces of us:*
  - The purpose of this scenario is to stimulate participants to share their feelings and moods. The tool used is photos and the reworking of works in the museum. The photos are a stimulus to encourage processes of exploration and self-knowledge aimed at change. With photographs one has access to the unconscious. It is about using photographs to communicate concepts, emotions, or experiences that are difficult to express with words. It is also a useful technique to bring out the personality of the participants so that they can recognise and identify themselves.

- *When the fairytale comes to life*:
  - Dynamic fairytale telling, including singing and art creation, strengthens cooperation, communication, and intergenerational collaboration. It is a workshop, where the participants tell their relatives, family, grandchildren, children from kindergarten a traditional fairytale, which touches the folk heritage, because this activity promote the preservation of the cultural heritage. The activity includes singing and art workshops on creating objects/persons that are the main part of the chosen fairytale.

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Measures and tools

Tests and a semi-structured interview are administered to participants and caregivers at the start and at the end of the program. The main tools used for the AIDA procedures and collection of experimental data are tablets, pen and paper, and AIDA Hubs. Tests measure the quality of life of the AD patient along different dimensions, such as ability in performing daily living activities, self-reported emotional states, and perceived well-being.

Participants

10 participants affected by mild-to-moderate Alzheimer's Disease (hypothesized diagnosis)are recruited by each partner of the project, for a total of 60 participants plus their caregivers. Given the multi-country nature of the project, we relied on diagnosis procedures usually employed in each of the country in which recruiting will take place. For each partner of the project the 10 participants are divided into 2 groups of 5 plus their respective caregivers to provide a calmer and more receptive environment with less people. These two groups performed the same activities. Participants are recruited on a voluntary basis from January 2023 until the end of the project.

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