Using Adaptive Immersive Environments to Stimulate Emotional Expression and Connection in Dementia Care

Insights from User Perspectives towards SENSE-GARDEN

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Abstract— **This paper presents early stage research on the development of an immersive, multisensory room for people living with dementia. Dementia is considered to be a public health priority on a global level. Our research addresses the challenge of meeting individual needs in dementia care, particularly in relation to social and emotional wellbeing. We draw upon findings from 52 interviews with users, including people with mild cognitive impairment, professional caregivers, and informal caregivers. These interviews were conducted to explore initial responses towards a multisensory room called SENSE-GARDEN. Findings indicate that users view the immersive environment as a space in which a person with dementia's sense of self can be supported and expressed with others. SENSE-GARDEN was considered to be a tool for creating emotional environments in which users can explore their life stories together with loved ones. Technology's role in fostering emotional spaces is discussed in terms of a transactional relationship between the person with dementia, the caregiver, and the immersive environment. This research provides rationale for the study of emotional engagement and interaction not only in the SENSE-GARDEN project, but also in the wider context of welfare technology as a whole.**

Keywords-dementia; virtual environments; immersive technology; emotions; interpersonal relationships

I. INTRODUCTION

Dementia is an umbrella term for a variety of neurodegenerative diseases that most often affect memory, behaviour, and communicative abilities [1]. There are approximately 47 million people living with dementia worldwide [2]. With this number set to increase to 131 million by 2050, it is of the utmost importance to tackle dementia's progressive impact on the wellbeing of people living with a diagnosis.

The World Health Organization has called for action on dementia, presenting it as a public health priority at a global level [1]. This action includes a call for research to identify ways of supporting the needs of people living with dementia, their caregivers, and the needs of society in the context of costs, understanding, and awareness.

In recent years, studies have identified numerous complex needs of people with dementia living in long-term care. These include management of challenging behaviours, maintenance of social relationships, involvement of people with cognitive deficits in meaningful activities, and supporting the emotional needs of all [3][4].

Emotion-oriented approaches to care have been shown to be cost-effective ways of improving psychological wellbeing and social behaviour amongst people with dementia [5][6]. These nonpharmacological approaches are

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often person-centred, focusing on the social and emotional needs of the individual. Reminiscence rooms, virtual gardens and virtual reality forests are examples of how immersive technologies have been integrated in emotion-oriented approaches designed to create effective interventions for people with dementia [7][8].

However, this area of study has called for further research in determining what works best for the individual [9]. It has recently been suggested that an individualized multisensory environment for people with dementia would be a highly beneficial intervention, especially if family members are included in the selection of stimuli [10]. Our research builds on this suggestion, creating not only a personalized multisensory intervention, but one which also incorporates immersive technology, all with the inclusion of family members, friends, and professional care staff.

This paper presents early stage research on a multisensory room, SENSE-GARDEN, that is currently being developed as an adaptive, immersive environment integrating technology and multisensory stimulation for reminiscence in people living with dementia. We will first provide a brief overview of the project (Section II), followed by the description of the methodology used in research and development (Section III). We will then discuss the results of the interviews in terms of self-identity (Section IV) and shared emotional experiences (Section V). In Section VI, these results are summarised and discussed in the theoretical frame of a transactional relationship between users and the immersive environment. Finally, in Section VII, we conclude with final remarks, the next steps for SENSE-GARDEN, and suggestions for future research.

II. SENSE-GARDEN: AN OVERVIEW

SENSE-GARDEN is a psychosocial intervention that is being developed to create individualized reminiscence sessions for people living with dementia in residential care. The intervention combines the use of technology for reminiscence and multisensory stimulation, with human-to-human informational and emotional communication.

Prototypes of the SENSE-GARDEN room are currently being built across Belgium, Norway, Portugal and Romania. These rooms are filled with individualized stimuli such as familiar music, imagery, films and scents in order to stimulate memory and encourage active participation of the person with dementia in reminiscing activities. Particular emphasis is placed on using autobiographical content such as family photographs, music from childhood, and films of life events.

The use of large projection screens, scent dispensers, and surround sound systems will integrate the various multimedia of the room, creating an immersive environment. For example, high-definition imagery of a forest could be accompanied with the smell of pine trees and the sound of birds.

SENSE-GARDEN will expand on currently established sensory rooms, which are also known as 'Snoezelen' rooms. Deriving from the Dutch terms for 'sniffing' and 'dozing', Snoezelen was originally developed in the Netherlands as a therapy for individuals with learning difficulties [11].

SENSE-GARDEN presents an innovative approach to sensory rooms by utilising smart technologies that enable the space to adapt to individual preferences and needs of the person with dementia. Radio frequency identification (RFID) will be used to allow the SENSE-GARDEN system to identify the user. Upon entering the room, the system will automatically project autobiographical multimedia from the person with dementia's user profile.

The room is designed to be used by two main categories of users. The first is the person with dementia (PwD), who is also considered the primary user. The second is the caregiver, who will either be informal (family/friend) or formal (professional care staff). It is anticipated that together, the PwD-caregiver dyad will interact with the immersive environment to stimulate memory, conversation, sharing and engagement.

III. METHODOLOGICAL APPROACH

SENSE-GARDEN is a multidisciplinary project involving partners in Belgium, Norway, Portugal, and Romania. The consortium brings together multiple professions and competencies including technology development, architecture, care home management, health sciences and research.

There have been numerous calls to involve people with dementia in the process of designing assistive technologies [12][13]. Their contributions are thought to be of crucial importance, along with input from their caregivers [14]. More recently, user-centred design has been recommended for the development and implementation of psychosocial interventions [15].

The SENSE-GARDEN project embraces a user-centred design and is working co-creatively with user groups throughout all its phases. The aim of this preliminary research was to explore initial responses from user groups, so that their ideas and feedback may be integrated into the development of SENSE-GARDEN.

Thus far, 52 qualitative semi-structured interviews have been conducted with user groups across Belgium, Norway, Portugal, and Romania. The aims of these interviews were to collect responses and attitudes towards the SENSE-GARDEN room concept, and to identify challenges that may arise during the course of the project.

The specific research questions for this study were as follows: (1) What are the users' attitudes towards the concept of SENSE-GARDEN? (2) What benefits, if any, do users think SENSE-GARDEN could provide in the care of people living with dementia? In order to answer these research questions, the interview was designed in a way that allowed for in-depth exploration of the users' beliefs surrounding SENSE-GARDEN. The interviews were semi-structured with open-ended questions, and lasted for approximately 30 minutes. Interview questions focused on the overall concept of SENSE-GARDEN, the individual components of the

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TABLE I. RESPONDENT INFORMATION

Country	People with Mild Cognitive Impairment				Informal Caregivers				Formal Caregivers			
	N	Mean Age	Gender		N	Mean Age	Gender		N	Mean Age	Gender	
			Male	Female			Male	Female			Male	Female
Belgium	3	89.6	2	1	6	57	1	5	4	31.5	1	3
Norway	4	84	0	4	4	59.3	0	4	4	38.8	1	3
Portugal	3	79.7	0	3	3	55.7	0	3	3	44.3	0	3
Romania	6	67.2	3	3	6	50.7	0	6	6	42.7	2	4
Total	**16**	**77.9**	**5**	**11**	**19**	**55.3**	**1**	**18**	**17**	**39.4**	**4**	**13**

intervention, and potential benefits.

The respondents included 16 people living with a diagnosis of mild cognitive impairment (MCI), 19 informal caregivers, and 17 professional caregivers. In this study, informal caregivers are defined as individuals who are the spouse, relative, or close friend of a person living with dementia or MCI. Professional caregivers are individuals working within environments that administer care for people living with dementia.

Table 1 gives an overview of the respondent information. Despite the relatively small sample size, a diversity of age groups are represented. There is a visible age difference across the three user groups, with almost 20 years in between each. The majority of the respondents were women, especially within the two caregiving groups.

In order to conduct an in-depth exploration of the ideas and perspectives given by the users, data was analysed using thematic analysis. Thematic analysis is a qualitative method in which prevalent patterns of ideas and responses are identified amongst data. The analysis procedure for this study undertook the following phases, given by Braun and Clarke [16]:

1) Familiarisation with the data: All the data was thoroughly read and re-read, along with notating initial ideas and interpretations of the dataset

2) Coding: The ideas were used to generate codes, which identify interesting features across the data. In this study, data was manually coded in an inductive manner, meaning that the codes and themes were developed directly from the content of the data, rather than being developed by pre-existing ideas.

3) Searching for themes: The codes were used to search for themes, which represent patterned responses or meanings across the data.

4) Reviewing themes: The themes were reviewed to ensure that they accurately represent the views of the users and the view from the entire dataset.

5) Defining and naming themes: The essence of each theme was identified, along with its relevance to the research questions.

6) Producing the report: Finally, the themes are considered in their relationship to one another, and a narrative about the dataset is created. This narrative is supported by direct quotes from the dataset.

In order to stay true to the 'voice' of the users, codes and themes were constantly checked back against the original data. Braun and Clarke [16] emphasize the importance of the flexibility in thematic analysis and identify the process as one of continuous reflection on the reading, shaping, and checking of data and themes.

Six themes were generated from analysis: (1) benefits for all, (2) past and present, (3) focus on the individual, (4) shared experiences, (5) emotional stimulation, and (6) challenges to consider. Given its strong prevalence and common occurrence across all themes, this short paper will focus on user feedback regarding emotion. Results will be discussed in terms of recovering self-identity and expressing and sharing emotional experiences.

The full dataset from the interviews has been made available online, along with the interview guide, and coding from thematic analysis [17].

IV. RECOVERING SELF-IDENTITY

Dementia's impact on memory, behaviour and communicative abilities can have detrimental implications for a person's identity. However, there is evidence to suggest that individuals may preserve a sense of self to some extent, even in more severe stages of dementia [18][19]. In discussing the benefits of SENSE-GARDEN, all respondents believed that the individualized nature of the virtual environment could trigger autobiographical memories. This was linked by the respondents to helping people with dementia connect with their past: "Just only three notes will bring back that special moment"…, "Personal videos and photos are important. You resonate with your past."

Respondents considered interaction with the past as an activity for strengthening self-identity in the present moment: "Nowadays we forget who we are. SENSE-GARDEN will help us all relive forgotten events and identities"…, "Awareness of time passing by associating the child in the past with today the adult." This strengthening of selfhood was

also considered to 'bring back' the person with dementia, as if a separate identity existed prior to the onset of the disease: "Family and friends can be with the patient as they were before".

This symbiotic relationship between past and present has been much discussed in regards to selfhood. Surr [18] adopts a socio-biographical approach to explain how people with dementia use their past in the context of telling their life story to others, in order to maintain a sense of self in the present.

Along with allowing family members to be reconnected with their loved one, there was an impression that professional caregivers would also be able to view the person with dementia in a modified perspective, after sharing life story experiences: "Good for the staff to see the person with dementia in another way". Digital storytelling, an activity in which technology is used to create innovative forms of narrative, has been shown to educate nursing home staff [20].

The role of others should not be underestimated in maintaining the identity of the person with dementia. In discussing the needs of people with dementia, Kitwood [21] stresses the importance of others in the maintenance of personhood. Westius, Kallenberg, and Norburg [22] present the notion of 'intertwined narrative', in which the life story of the person with dementia is integrated with the narrative of their family carer. Thus, if the person with dementia should become unable to independently recall their story, the intertwined narrative of the caring relationship may provide opportunity for maintenance of self.

Earlier literature presents similar ideas. Mills [23] suggests that people with dementia bestow their life stories to another, therefore continuing their sense of identity. Mills states that in this sense, the narrative of the individual never disappears, regardless of the inevitable fading of the person's memory.

SENSE-GARDEN could potentially offer a method for assisting family and friends in preserving the life story of the person with dementia. Additionally, SENSE-GARDEN offers the opportunity for individuals to explore their life story in a new and innovative way (through the use of interactive touchscreens, immersive film and sound): "We can explore old and new places"..., "My mother wants to see her old street again but we can't do it, with this she can visit it again"

V. Expressing and Sharing Emotional Experiences

The users' value for sharing experiences together resonated across all of the interviews. Respondents saw SENSE-GARDEN as a means to alleviating communicative issues in the caring relationship: "It's hard being a relative, so little competence, dialogue is difficult. This is a great tool for having a nice time together"…, "If I visit, there are always dead moments. This will help get the life back into the conversations". SENSE-GARDEN's perceived ability to revive communication suggests technology may act as a catalyst for emotional connection. This was echoed in other responses regarding relationships: "It improves relationships with others"…, "Sharing the experience is the most important for reconnecting".

SENSE-GARDEN was also considered as a potentially helpful tool for stimulating nonverbal communication and expression. There was a particular emphasis on the ability to express oneself through the use of imagery and music: "Being able to tell stories, if one has lost the language, pictures and movies can tell things"…, "Some people stop talking, but they can sing."

Individuals living with the disease are capable of experiencing and expressing a wide range of emotions, even in later stages of dementia [5][24]. Incorporating creative activity into the immersive environment has the potential to elicit positive expressions of emotion and of self.

However, one respondent with mild cognitive impairment brought an important consideration to light in stating that the facilitation from the caregiver is vital for the success of the intervention: "The therapist is very important and can instil peace and wellbeing. A special emotional environment must be created for SENSE-GARDEN to work." This concept of creating a 'special emotional environment' goes to suggest that it is not the intervention alone that can benefit the caring relationship, but also the individuals present who can shape the experience of SENSE-GARDEN.

This idea is supported by respondents' concepts of 'space' as something more than just a physical environment: "SENSE-GARDEN is an intermediary space, between memories and the here and now, a space we can all access and we can remember how to feel, by one's self and together, without shame or fear."

The above quote, given by an informal caregiver, encapsulates the essence of what SENSE-GARDEN is aiming to achieve. By adopting a holistic approach to the environment, the individuals within it, and the relationships that take place, the project aims to create an intervention that can facilitate connection and wellbeing for all users.

VI. Discussion

These findings highlight users' values for emotional and social benefits in SENSE-GARDEN. There was an overall sense of the immersive environment being able to stimulate autobiographical memory, which was valued as important for preserving a sense of identity. The perspectives of respondents are in agreement with previous research on virtual environments for people with dementia. Siraraya and Ang [25] describe the virtual world as a 'memory sanctuary', in which selfhood and relationships are maintained.

The respondents were persistent in their beliefs that the environment, the facilitation of the intervention, and the stimuli all need to be tailored to the specific traits of the person with dementia visiting the SENSE-GARDEN. It should be acknowledged that the task of individualization is not an easy feat. As human beings, we are all individualistic by nature, with different tastes, preferences, and desires. Adding the constantly fluctuating progression of dementia to this individuality makes for a difficult task in designing

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technology for these users [26][27]. This is something that the SENSE-GARDEN project will have to tackle through rigorous work and collaboration with users, technology developers, and researchers of various disciplines.

Respondents also emphasized the importance of interaction between the SENSE-GARDEN stimuli, the person with dementia, and the caregiver. The way in which an environment simultaneously influences behaviour of individuals and interpersonal relationships, and yet is shaped by those persons, can be referred to as the transactional relationship.

The notion of 'transaction' was firstly used in this context by the philosopher John Dewey, who asserted "Everything that exists in far as it is known and knowable is in interaction with other things. It is associated, as well as solitary, single." [28]. In the context of SENSE-GARDEN, it could be said that a transactional relationship exists between the various technologies (the immersive environment), the person with dementia, and the caregiver.

This transactional relationship is conceptualized visually in Figure 1. The figure shows how numerous interactions may take place between each user and SENSE-GARDEN to form an overall relationship. The SENSE-GARDEN system is influenced by the users, but, at the same time, the users' emotions and interpersonal interaction with each other are shaped by the immersive environment that SENSE-GARDEN creates.

Later literature on emotion echoes Dewey's view, suggesting a need to study the complex relationship between person and environment, for emotions cannot be comprehended by one or the other alone [29]. These ideas can be linked to current thought on the nature of technology design, which has been described as 'deeply contextual' [27]. Therefore, incorporating the study of context, environment and relationships seems appropriate for both dementia studies and technology development.

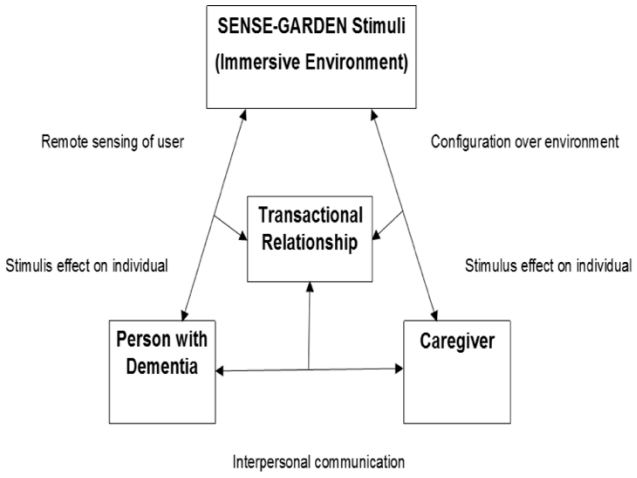

Figure 1. Conceptual model of the transactional relationship that takes place within the SENSE-GARDEN intervention

Understanding the interaction between environment and the people within it is vital. How does SENSE-GARDEN, and technology as a whole, fit into this interaction? What role does it play? Going forward, research should adopt a holistic approach to evaluating technology, considering the wider context in which the technology is situated.

VII. Conclusion and Future Work

The user interviews yielded valuable insights for the progression of the SENSE-GARDEN project, with findings demonstrating the importance that users hold for emotional and social wellbeing. This paper has demonstrated the value and usefulness of including user groups in the development of not only immersive spaces, but also of interventions for care.

Finally, the social and emotional aspects of virtual environments should not be underestimated. The results highlight the significance users find in fostering relationships through means of self-identity and emotional relationships. A focus on social and emotional interactions between technology, users, and interpersonal relationships could provide very fruitful results in the context of dementia care. This research provides rationale for the study of emotional engagement and interaction not only in the SENSE-GARDEN project, but also in the wider context of welfare technology studies.

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