The Role of Adaptive Immersive Technology in Creating Personalised Environments for Emotional Connection and Preservation of Identity 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 personalised multisensory room called SENSE-GARDEN. Thematic analysis resulted in six themes: benefits for all, focus on the individual, past and present, emotional stimulation, shared experiences, and challenges to consider. This paper provides important theoretical considerations for the role of technology in not only the SENSE-GARDEN intervention, but in preserving the identities of people with dementia and providing opportunities for connection with others. Future work in this area should adopt an interdisciplinary approach to using technology in dementia care.

Keywords—dementia; virtual environments; immersive technology; human computer interaction; interpersonal relationships

I. INTRODUCTION

This article builds upon a conference paper presented at the Fourth International Conference on Human and Social Analytics [1]. This extended version of the original paper offers detailed results from a preliminary study on a virtual adaptive environment for people with dementia.

Dementia is a syndromal term and can be caused by a variety of diseases, including neurodegenerative diseases. Memory, behaviour, and communicative abilities are often affected [2]. There are approximately 47 million people living with dementia worldwide [3]. With this number set to increase to 131.5 million by 2050, it is of the utmost importance to tackle dementia’s progressive impact on the wellbeing of people living with this syndrome.

The World Health Organization has called for action on dementia, presenting it as a public health priority at a global level [2]. 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 the management of challenging behaviours, maintenance of social relationships, involvement
of people with cognitive deficits in meaningful activities, and supporting the emotional needs of all [4][5].

Emotion-oriented approaches to care have been shown to be cost-effective ways of improving psychological wellbeing and social behaviour amongst people with dementia [6][7]. These nonpharmacological approaches are 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 nonpharmacological interventions for people with dementia [8][9].

However, this area of study has called for further research in determining what works best for the individual [10]. It has recently been suggested that an individualised multisensory environment for people with dementia would be a highly beneficial intervention, especially if family members are included in the selection of stimuli [11]. Our research is in line with this suggestion, creating not only a personalised multisensory space and intervention, but one that 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 mild to moderately severe dementia. We will first provide a brief overview of the project (Section II), followed by a description of the methodology used in research and development (Section III). We will then discuss the results of the interviews in relation to each of the six themes identified through thematic analysis (Section IV). In Section V, the results are summarised and discussed in relation to the role of technology in preserving the identity of the person with dementia and facilitating an environment in which relationships can be fostered. Finally, in Section VI, 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 individualised 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 several countries in Europe, namely in Norway, Portugal and Romania, with an initial prototype already being tested in Belgium. These rooms are filled with individualised stimuli such as familiar music, soundscapes, 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, to evoke a completely immersive sensation.

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 [12].

SENSE-GARDEN presents an innovative approach to sensory rooms by utilising smart technologies that enable the space to adapt to the individual preferences and needs of the person with dementia. This focus on autobiographical content is achieved through the use of individual user profiles. Each profile has an associated media repository consisting of digital photographs, films, and music that holds significant meaning for the person with dementia.

Radio frequency identification (RFID) is used to allow the SENSE-GARDEN system to identify the user. Upon entering the room, the system automatically projects 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 [13][14]. Their contributions are thought to be of crucial importance, along with input from their caregivers [15]. More recently, user centred design has been recommended for the development and implementation of psychosocial interventions [16].

The SENSE-GARDEN project embraces a user centred design approach 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 next phases of 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.
TABLE I. RESPONDENT INFORMATION

<table>
<thead>
<tr>
<th>Country</th>
<th>People with Mild Cognitive Impairment</th>
<th>Informal Caregivers</th>
<th>Formal Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Age</td>
<td>Gender</td>
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<td>Female</td>
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<tr>
<td>Belgium</td>
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<td>89.6</td>
<td>2</td>
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<tr>
<td>Norway</td>
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<td>84</td>
<td>0</td>
</tr>
<tr>
<td>Portugal</td>
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<td>79.7</td>
<td>0</td>
</tr>
<tr>
<td>Romania</td>
<td>6</td>
<td>67.2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>77.9</td>
<td>5</td>
</tr>
</tbody>
</table>

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 an in-depth exploration of the users’ beliefs surrounding SENSE-GARDEN. The interview was 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 intervention, and potential benefits.

The respondents included 16 people living with a diagnosis of mild cognitive impairment, 19 informal caregivers, and 17 professional caregivers. Table 1 gives an overview of the respondent information.

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 [17]:

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 were considered in their relationship to one another, and a narrative about the dataset was 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 original data. Braun and Clarke [17] emphasise the importance of flexibility in thematic analysis and identify the process as one of continuous reflection on the reading, shaping, and checking of data and themes.

IV. RESULTS

Six themes were identified through the thematic analysis: (A) Benefits for All, (B) Focus on the Individual (C) Past and Present, (D) Emotional Stimulation, (E) Shared Experiences, and (F) Challenges to Consider. A thematic map is shown in Figure 1 to provide a visual summary of all six themes and their respective subthemes.

This thematic map also demonstrates the interactive nature of the themes and their relationship to one another. Numerous subthemes falling under different main themes are related to each other. For example, the subtheme of ‘stimulating emotional memory’ (under the theme of Emotional Stimulation) can be connected to the subtheme of ‘avoiding negative memories’ (under the theme of challenges to consider). In this way, all the themes presented provide an overarching narrative of the users’ beliefs, views, and attitudes towards SENSE-GARDEN and the technology within it.

The following subsections will discuss each of the six themes in turn. The full dataset from the interviews has been made available online, along with the interview guide, and coding from thematic analysis [18].

A. Benefits for All

There was a resounding view from all users that SENSE-GARDEN may be able to provide benefit in some way. These benefits were grouped into five subthemes: benefits for the person with dementia, benefits for the family, benefits for professional caregivers, benefits in practice, and benefits beyond dementia care.

Benefits for the person with dementia. All users believed that SENSE-GARDEN has the potential to provide numerous benefits for people living with dementia. These benefits included improvements in memory, mood and overall quality of life: “Stimulating memory and improving quality of life, the person with dementia and caregivers can enjoy life more”...,”This can enrich their [people with dementia] everyday life”...,”I am sure this will be of value.
The person with dementia gets a good experience every day. In this we have faith”. One person with mild cognitive impairment discussed the role of the intervention in tackling issues of helplessness that are associated with not only dementia, but illness in general: “When ill, it is like you are closed in a dark place you cannot leave by yourself. SENSE-GARDEN can help you out”.

Benefits for the family. Many of the caregivers, both informal and formal, commented on SENSE-GARDEN being able to provide ways for the family to strengthen relationships with loved ones who have dementia: “It’s hard to be a relative, so little competence, dialogue is difficult. This [SENSE-GARDEN] is a great tool for having a nice time together”.

Benefits for the professional. Formal caregivers considered SENSE-GARDEN as a tool for getting to know people with dementia better. The highly personalised nature of the intervention means that staff have the opportunity to gain insight into the resident’s life in a way that is perhaps not possible in day-to-day care: “The advantage is that you can have full focus on the patient, being able to be alone with him or her. We get to know the patient better. It creates security.”..., “This will also mean that the staff become better acquainted with the person with dementia”. Another caregiver commented as follows: “It’s good for the staff to see the person with dementia in another way”. These comments go to suggest that digital media can create opportunities for learning more about individuals with dementia, which could be especially important for people in later stages of dementia, who may not be able to coherently express themselves.

Benefits in practice. As well as presenting individual benefits, users believed that SENSE-GARDEN could benefit the healthcare system in terms of cost and practice: “Why has nobody thought of this before? Many of these things should have already been at the nursing home even if one does not have a SENSE-GARDEN”..., “May become important in terms of reducing the cost of dementia care over time”.

Benefits beyond dementia care. There was a consensus across the respondents that SENSE-GARDEN could also provide benefits to people living without dementia: “It is always good to go back to childhood and youth, for all of us. No need to be a person with dementia”.

The users’ positive outlook on SENSE-GARDEN captures a range of benefits that not only apply to the person with dementia, but also to caregivers and care practice as a whole. Future studies on SENSE-GARDEN will need to incorporate outcome measures that evaluate these various aspects.

B. Focus on the Individual

The key concept of SENSE-GARDEN is creating an environment in which the person with dementia is the central focus. The users not only valued this focus on the person with dementia, but they also offered their suggestions on how best create an individualised environment. These suggestions are grouped into the following subthemes: familiarity, meaningful stimuli, sensory stimulation, and empowering and engaging.

Familiarity. With the SENSE-GARDEN being a new and unfamiliar concept, both informal and formal caregivers stressed the importance of providing a familiar surrounding for the person with dementia: “A familiar environment, familiar objects to touch, is mandatory”..., “At least for the first sessions, the SENSE-GARDEN room must include
familiar items, besides the personal records used for projection and music”.

Meaningful stimuli. Users believed that the stimuli used in SENSE-GARDEN should have significant meaning for the person with dementia: “Family photo album, with photos from important emotional occasions”..., “Meaning from one’s own trips. You must remember a trip, but also the reason you went on that trip, the scope”.

Sensory stimulation. There was an overall positive attitude towards SENSE-GARDEN’s proposed methods of sensory stimulation. Users commented on the ability for such stimulation to trigger memories and improve mood: “Imagine what scent can bring forth, the idea of what this can do, it’s gorgeous”. There were also numerous suggestions for SENSE-GARDEN to broaden its current plans for sensory stimuli, such as including tactile elements: “Maybe something more for the sense of touch. When you see a mountain and smell the fern tree, why not touch a fern tree branch?”.

Empowering and engaging. SENSE-GARDEN was perceived as an opportunity for people with dementia to actively engage and express themselves: “The person with dementia has to be reassured that life has not come to an end when diagnosed with dementia, and reality is not limited by the walls of the bedroom. They still have things to show and share with us all”.

The suggestions given by the users imply that whilst the technology and media within the SENSE-GARDEN needs to be individualized, there are additional ways in which individualisation can be achieved. This is through caregiver facilitation, tactile stimuli, and the physical design of the room. All of these factors will need to be taken into consideration throughout the development of the intervention.

C. Past and Present

Given that SENSE-GARDEN borrows techniques from reminiscence therapy, it is of no surprise that discussion regarding memories arose during the interviews. However, the users identified links between interaction with the past and with the present, as well as the impression of overall improvement of memory in general. Therefore, the subthemes are: interacting with the past, interacting with the present, and improving memory over sessions.

Interacting with the past. In discussing the benefits of SENSE-GARDEN, all respondents believed that the individualised nature of the virtual environment could trigger autobiographical memories. This was linked to helping people with dementia connect with their past: “Personal videos and photos are important. You resonate with your past”.

Improving memories over sessions. As well as stimulating memories of the past, respondents also believed that memory could be strengthened over the course of the SENSE-GARDEN sessions. Some users suggested using visual markers in the SENSE-GARDEN components in order to trigger memory in consequent sessions: “Using memory anchors will improve experience and stimulate reality connection”. An example of this would be to use a recent photograph of a familiar place that holds significant meaning for the person with dementia. The same photograph could then be presented to the user in the next SENSE-GARDEN session to see if they remember the meaning connected to that picture.

Interacting with the present. There was a suggestion that even if the person with dementia does not have the capacity for long term memory of the sessions, the individual could still benefit from the ‘in-the-moment’ experience of SENSE-GARDEN: “They probably do not remember afterwards, but think about being happy one hour every day. That’s a good benefit”. Respondents also considered interaction with the past 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”.

This symbiotic relationship between past and present has been much discussed in regards to selfhood. Surr [19] 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. Technology may have much to offer in this maintenance of self, ideas of which will be given in detail in the discussion section of this paper.

D. Emotional Stimulation

Whilst emotion was a prominent topic amongst all of the themes, the comments from the users proved emotion to be highly complex. It was therefore decided to include a more detailed discussion of emotion. The subthemes are as follows: sensory stimulus and emotion, stimulating emotional memory, emotional self-expression, and shared emotional experiences.

Sensory stimulus and emotion. The users believed that stimulating the senses through imagery and music could stimulate positive emotions in the person with dementia: “One connects so much to music, there are a lot of emotions”..., “Stimulating senses brings joy and memories”. Stimulating emotional memory. The users focused primarily on familiar music in being able to stimulate emotional memory in the person with dementia. “Just three notes will bring back that special moment if music is connected to that moment”..., “When we hear a song, we think of something and then we will be happy”.

Emotional self-expression. Individuals with dementia are capable of experiencing and expressing a wide range of emotions, even in later stages of the disease [6][20]. Building upon the idea of sensory stimulation triggering emotional memories, the users also believed that SENSE-GARDEN could enable people with dementia to express themselves in ways that transcend typical verbal communication: “Some people stop talking, but they can sing”. Furthermore, they believed that people may be able to experience a heightened state of feeling through the intervention: “SENSE-GARDEN is an intermediary space, between the 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”.

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Shared emotional experiences Finally, the discussion of emotion went beyond individual feelings. The users expressed the value of SENSE-GARDEN in being able to help people connect with one another: “Sharing the experience is most important for reconnecting”. One person with mild cognitive impairment also highlighted the importance of how these shared experiences should be shaped: “The therapist is very important and can instil peace and wellbeing. A special emotional environment must be created for SENSE-GARDEN to work.” The idea of creating a “special emotional environment” goes to suggest that it is not the intervention alone that can provide benefits to the relationships, but it is also the individuals present who can shape the experience of SENSE-GARDEN.

This theme has demonstrated the intricate nature of emotions, and how they can be manifested through the stimulation of the senses, through the remembrance of past events, and through our relationships with others.

E. Shared Experiences

SENSE-GARDEN is designed to be a joint experience between the person with dementia and their caregiver. As discussed in the previous subtheme, the users expressed the importance of sharing the experience together. This current theme goes beyond that of emotions and discusses the shared experience in relation to the following subthemes: caregiver facilitation, relationships, communicating, and creating opportunities through technology.

Caregiver facilitation. Many users believed that carefully planned facilitation of SENSE-GARDEN is required for the intervention to work. Particular stress was placed on the importance of being accompanied by a familiar individual: “We must have people accompany us- internal people we know”. Users also believed that effective facilitation could shape a positive environment in which the benefits of the intervention could be maximised: “The caregiver must be well trained and possess good communication skills...to be able to support and fructify the person with dementia’s gains in terms of cognitive and behavioural improvements”.

Relationships. Respondents believed that SENSE-GARDEN could improve understanding and relationships between people with dementia and their caregivers- both formal and informal. There was a sense of the intervention being able to “restore” what dementia had taken away from the relationship, such as self-identify and communication: “Family and friends can be with the patient as they were before”. SENSE-GARDEN was considered a catalyst for fostering relationships and providing opportunities for self-expression and understanding between people with dementia and their families. This improvement in relationships was considered important in easing caregiver burden: “Improving relationships with family members and staff, easing caregiver burden on the staff and family”.

Communicating. During the interviews, discussions turned to benefits of creative activity in dementia care. In particular, there were strong references to the ability of visual media and music to provide alternative forms of communication beyond that of verbal means. Users believed that the inclusion of music and visual imagery in SENSE-GARDEN would be able to provide tools for sharing information: “Being able to tell stories, if one has lost the language, pictures and movies can tell things.” Users also believed that SENSE-GARDEN may be able to play a role in triggering conversation topics: “If I visit, there are always dead moments. This will help to get the life back into the conversations.”

Creating opportunities through technology. Users with mild cognitive impairment displayed a sense of exploration and adventure when discussing the components of SENSE-GARDEN. The use of virtual environments was perceived as providing ways of visiting new places and experiencing an outdoor environment: “Maybe a place you never went to, but you want to see”. One user was particularly impressed with a component of SENSE-GARDEN called “Life Road”, which allows the person with dementia to cycle on a stationary bike in front of a film of a familiar place: “We are afraid to ride outside so this option is great. To be safe on a bike.” This technology was also considered to provide opportunities for individuals to see places that they can no longer visit: “My mother wants to see her old street again, but we can’t do it. With this she can visit again”.

These quotes from the users have highlighted the amount of work that goes into creating meaningful experiences for people with dementia. However, with the right kind of facilitation, SENSE-GARDEN may be able to provide these experiences for not only people with dementia, but also for their caregivers.

F. Challenges to Consider

This final theme is perhaps one of the most important in going forward with the SENSE-GARDEN project. The users raised important issues to be aware of when preparing and implementing the SENSE-GARDEN intervention. These concerns are given in the following subthemes: avoiding negative memories, creating personal databases, integrating physical activity, managing symptoms of dementia, and attitudes towards technology.

Avoiding negative memories. Many users emphasised the importance of avoiding stimuli that could evoke negative emotions, such as photographs of relatives who have passed away, for example: “It is necessary to note that there are memories that are not good, and that it is necessary to have very careful prior fieldwork”.

Creating personal databases. The main purpose of SENSE-GARDEN is to create experiences that are tailored to the individual with dementia and their past. However, users suggested that there might be challenges in collecting necessary information to achieve this. Issues included the lack of information from family and friends, but potential solutions were also offered by the users: “How you create a database for a lonely person- general triggers in an exploratory approach”..., “The reduced availability of family and friends can be a hindrance. The process of collecting personal data can be eased by using a questionnaire developed for the future SENSE-GARDEN users”. A formal caregiver also raised the issue of collecting visual imagery: “We have to see who has videos and films because in this rural area only a few had them”.

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Integrating physical activity. Whilst many of the respondents emphasised the importance of physical health, issues in implementing physical activity were discussed. One user had a concern regarding the use of a stationary bike for the “Life Road” component of SENSE-GARDEN: “One should reassess the issues of physical activity. For example, bicycles must be those where the person rests and pedals almost lying down”.

Managing symptoms of dementia. As in any intervention for people with dementia, it is important to consider how symptoms will be managed and prevented during the sessions: “The person conducting the SENSE-GARDEN session will be essential and must have backup for interventions when disturbed behaviours occur. You don’t know how the person will react, even if what you show was a best experience for him”. Other issues relating to hallucinations and medication were also raised.

Attitudes towards technology. There was quite a strong sense among the respondents that technology should be hidden during the SENSE-GARDEN sessions: “The experience will be richer when the technology is hidden”..., “The room must be very tempting, persuading- all technology must be hidden”. These comments could be interpreted in two ways. Firstly, technology should be hidden to create a more realistic, immersive environment. Contrastingly, it could be that users were referring to the potential reservations that some people have against technology. Some users explicitly expressed negative attitudes towards technology: “Many beware technology”. There were also respondents who preferred experiences in natural environments compared to virtual scenarios: “I’d prefer to walk the person with dementia in a real park”..., “SENSE-GARDEN must be just an intermediary step to outdoor and social activities.”

This theme has highlighted that whilst the users see many potential benefits for SENSE-GARDEN, they are also aware of the challenges that lay ahead. This affirms the inclusion of not only caregivers, but also people with cognitive impairment in the development of interventions, and the value of adopting a user centred design in interventional research.

V. DISCUSSION

The findings from these user interviews have covered a large variety of ideas regarding the SENSE-GARDEN intervention. Firstly, 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 individual with dementia visiting the SENSE-GARDEN. It should be acknowledged that the task of individualisation 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 it a difficult task in designing technology for these users [21][22]. 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.

Secondly, the respondents also emphasised the importance of interaction between the SENSE-GARDEN stimuli, the person with dementia, and the caregiver. The respondents’ numerous ideas regarding this interaction can be taken forward into a theoretical consideration of technology and its role within SENSE-GARDEN.

A. Technology as the Storyteller: The Potential of Digital Media in Preserving Narrative 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 [19][23]. In this study, 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 [24] describe the virtual world as a ‘memory sanctuary’, in which selfhood and relationships are maintained.

In order to understand how technology and media may be able to preserve identity, we have first to consider what identity means to people with dementia and how it can be shaped by other individuals. 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 [25] stresses the importance of others in the maintenance of personhood. Westius, Kallenberg, and Norburg [26] 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 the opportunity for the maintenance of self.

Earlier literature presents similar ideas. Mills [27] 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.

One way of preserving this narrative is through the use of digital life books. Digital storytelling, an activity in which technology is used to create innovative forms of narrative, has been shown to educate nursing home staff about the person with dementia [28]. This is especially important for people with dementia living in care homes with little or no family, a challenge mentioned by one of the users included in the present study. Technology and personalised media contents may be the answer to not only preserving, but also sharing that individual’s life story with care staff.

SENSE-GARDEN could potentially offer a method for assisting professional caregivers, family and friends in preserving the life story of the person with dementia. Furthermore, the technology of SENSE-GARDEN goes beyond the “life book” concept by offering an entire environment shaped around a person’s life. It offers the
opportunity for individuals to become completely immersed in their past. The next section will discuss the technology’s place in the overall environment.

B. Beyond Physical Space: Creating ‘Emotional’ Environments through a Transactional Relationship

The respondents emphasised the significance of creating an environment in which the person with dementia and their caregiver could share an emotional experience together. Here, respondents applied meaning beyond the physical space to include emotional and social factors that contribute to the experience of space. In this sense, it is important to have a holistic understanding of what constitutes as an ‘environment’.

There is growing acknowledgement of the environment being defined as more than just a physical space. According to literature, an environment is composed of psychosocial elements as well as physical factors [29]. In considering how an environment can shape social interaction, Freud’s concept of space is particularly relevant. He writes “space is not merely a place in which social interaction occurs, it structures such interaction” [30].

The way in which an environment simultaneously influences the 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.” [31]. In the context of SENSE-GARDEN, it could be said that a transactional relationship exists between the various technologies (the intervention environment), the person with dementia, and the caregiver. This transactional relationship is conceptualised visually in Figure 2. The figure highlights the numerous interactions that take place between SENSE-GARDEN and its users.

To understand the transactional relationship as a whole, one must consider the individual interactions that take place between each of the three components:

Person with dementia and SENSE-GARDEN stimuli: The SENSE-GARDEN stimuli has a direct effect on the person with dementia, e.g., the system plays a song that evokes a positive reaction in the person with dementia. The SENSE-GARDEN, in turn, will also be influenced by the reactions of the person with dementia. Feedback will enable the system to learn more about the user with each session and therefore, future visits to the SENSE-GARDEN will become increasingly personalised.

Caregiver and SENSE-GARDEN stimuli: The SENSE-GARDEN stimuli may also have an effect on the caregiver. For example, a familiar song might hold significant meaning for an informal caregiver, as well as the person with dementia. In this way, the caregiver may experience their own emotional reaction towards particular stimuli. Alternatively, the caregiver may be indirectly affected by the stimuli through emotional contagion. Emotional contagion refers to the process of an individual’s emotional state becoming triggered by emotions displayed in another person

Figure 2. Conceptual model of the transactional relationship that takes place between the person with dementia, caregiver and the SENSE-GARDEN stimuli during the intervention

[32]. In the context of SENSE-GARDEN, the caregiver’s emotions may be shaped in response to the reactions of the person with dementia. The caregiver will also be able to configure the SENSE-GARDEN environment based on these reactions, e.g., they can choose to immediately stop a video if it prompts negative behaviour in the person with dementia.

Person with dementia and caregiver: The interpersonal relationship between the person with dementia and the caregiver will shape the entire SENSE-GARDEN experience. For example, if the person with dementia and the caregiver are spouses with a close relationship, they might spend the SENSE-GARDEN session reminiscing on shared moments from their past. However, if the session is taking place between a person with dementia and a new professional caregiver who is not so acquainted with the individual, then their session may involve SENSE-GARDEN providing prompts for the caregiver in order for them to ask questions about the person with dementia’s life.

Applying this theoretical frame to the SENSE-GARDEN environment may provide insight into how the intervention works. It will not be possible to gain a full insight into the effects of SENSE-GARDEN without studying the numerous components of the environment. 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 [33].

These ideas can be linked to current thoughts on the nature of technology design, which has been described as “deeply contextual” [22]. Therefore, incorporating the study of context, environment and relationships seems appropriate for both dementia studies and technology development. 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.
VI. CONCLUSION AND FUTURE WORK

This paper has demonstrated the value and usefulness of including user groups in the development of not only innovative technologies, but also of interventions for dementia care. Viewing a project through the lens of the user can offer contrasting perspectives with fresh insight into solutions. In the present study, the user interviews yielded valuable insights for the progression of the SENSE-GARDEN project.

The users’ value for the relationships within the SENSE-GARDEN suggests that the social and emotional aspects of virtual environments should not be underestimated. This view is supported by previous literature which has called for more research on social interaction in dementia care settings [34]. 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 assistive technologies.

The next steps for SENSE-GARDEN include a focus on this emotional aspect. The full trials, planned for summer 2019, will adopt a mixed-methods approach to studying the intervention. Whilst qualitative methods capture rich personal accounts of user experiences, it is important to recognise the value of quantitative measures. Therefore, physiological data will be collected in addition to data from questionnaires, interviews and observation measures. The Empatica E4 wristband [35] will be used to collect information on heart rate and electrodermal activity (EDA). These measures will be assessed during the SENSE-GARDEN visits, as a reaction to different stimuli. Combining this data with qualitative accounts of the SENSE-GARDEN experience will provide a stronger overview of the processes that occur within the intervention.

This research also provides rationale for theoretical work on the role of technology for people with dementia. Firstly, ways of meeting individual needs need to be identified. Respondents stressed the importance of familiarity for the person with dementia, and they raised issues regarding the identification of individual preferences and behaviours.

Secondly, the role of technology as an active contributor to environments, and interactions within those environments, should not go unnoticed. This paper has discussed the SENSE-GARDEN technology in the context of a transactional relationship, but other theories may apply.

Finally, this paper demonstrates the highly interdisciplinary nature of this topic. The users’ comments have formed a piece of work that lays at the intersection of human centred design, technology, psychology, sociology, and arguably the creative arts. Future work within dementia care can benefit from incorporating knowledge from these various disciplines.

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