Free of Walls: Participatory Design of an Out-World Experience via Virtual Reality for Dementia In-patients

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ABSTRACT

Many people with dementia residing in long-term care may face barriers in accessing experiences beyond their physical premises; this may be due to location, mobility constraints, legal act and/or mental health restrictions. Previous research has suggested that institutionalization increases the co-existing symptoms of dementia, such as aggression, depression, apathy, lack of motivation and loss of interest in oneself and others. Despite the importance of supporting the mental well-being of people with dementia, in many cases, it remains undertreated. In recent years, there has been growing research interest in designing non-pharmacological interventions aiming to improve the Health-Related Quality of Life for people with dementia within long-term care. With computer technology and especially Virtual Reality offering endless opportunities for mental support, we must consider how Virtual Reality for people with dementia can be sensitively designed to provide comfortable, enriching out-world experiences. Working closely with 24 dementia patients and 51 medical and paramedical personnel, we co-designed an intelligent and personalized Virtual Reality system to enhance symptom management of dementia patients residing in long-term care. Through this paper, we thoroughly explain the screening process and analysis we run to identify which environments patients would like to receive as a Virtual Reality intervention to minimize the aforementioned co-existing symptoms of dementia, and the development of an intelligent system using the selected environments, that adapts the content of the Virtual Reality experience based on physiological and eye-tracking data from the patients and their personal preferences.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); HCI design and evaluation methods; User studies.

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KEYWORDS

Virtual Reality, Dementia, Patient-Centered Design, Person-Centered Care, Physiological Data, Personalization

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1 INTRODUCTION

The World Health Organization (WHO) estimates that in 2021 over 55 million people lived with dementia worldwide [1]. As the global population is increasingly ageing, it is expected that the number of people living with dementia (PwD) will increase to 139 million within the following 30 years [1]. This expected growth has made imperative the need to support PwD [2]. The Dementia Global Action Plan has set out to improve the Health-Related Quality of Life (HRQoL) for PwD characterizing it as a public health priority [3]. It also emphasized the drive for improvements in related research and innovation [3].

Previous research has shown that pharmacological interventions are overprescribed among PwD compared to other older adults [4], and are ineffective in treating side symptoms [5]. As a result, and in line with the Global Action Plan, it was recommended that best practices reflect the use of pharmacological interventions only as a last resort to treat complex cases where non-pharmacological interventions have proven unsuccessful [3]. The goal, therefore, remains to deliver non-pharmacological innovations, enhanced by the development of proper information systems for dementia, that can support patients' HRQoL.

Technology is increasingly taking over the way we relate to the world, and in particular, Virtual Reality (VR) is now becoming a massive success in the gaming industry, due to the miniaturization of electronics and the declining hardware costs. Fully immersive VR systems, using dedicated head-mounted displays to enclose the vision of the user, can now provide an immersive experience that can be perceived by the brain as real. Such experiences also allow the user to interact within the Virtual Environments (VE) using controllers or sensors that promote natural interaction [6].

Over the last two decades, VR has slowly begun to have a presence in the healthcare sector introducing innovative non-pharmacological ways of delivering treatment and care. The technology has found use in areas such as pain management [7][8][9][10][11], physical rehabilitation [12][13][14][15][16], and mental health disorders [17][18]. One of the advantages of VR is that it can create naturalistic environments and replicate experiences that may be difficult to achieve or are inaccessible in the real world [19].

Apathy is a common symptom in dementia, affecting over a quarter of the demented population. As a result, they may avoid taking part in activities and restrict their interactions with others. This could have negative consequences on their mental health and limit the therapeutic benefit of various activities. VR has the potential to provide consistent care within a controlled environment, and allow PwD to revisit VE and activities they enjoy on-demand, without the risk of extraneous variables such as weather, etc. [20].

VR has also been used with PwD as an intervention tool to reduce anxiety and agitated behaviours [21][22]. For example, in [21] PwD were exposed to a virtual nature experience, through the use of a semi-immersive VR system. The reduction of anxiety and agitation after the VR session was validated using heart rate measurements and observational data. More recently, in a similar work [22], which followed a single-case design and used a fully-immersive VR system, it was shown that VR can be an effective intervention to decrease agitation in PwD. The evidence, from both of the above studies, even though limited, supports the efficacy of VR for such purposes and warrants further exploration.

In line with the above guidance, we present the participatory design process of a non-pharmacological based intervention, to regulate the emotional state of PwD, reduce stress levels, and lead to behaviour change with a reduction of agitation and displayed behaviours of challenge. The intervention, which is designed for use in healthcare facilities, includes two components, starting with the monitoring of physiological data (i.e., heart rate and stress levels) of PwD using a smartwatch worn throughout the day. The second component, allows PwD to experience various VEs in a fully immersive VR system that dynamically adapts the displayed content and personalizes the experience based on recorded physiological, and gaze data, and the user's preferences.

2 METHODS

2.1 Ethics

Participants were recruited from a National Health in-patient hospital that specialises in progressive neurological conditions, including dementia and Alzheimer's disease. The hospital provides specialized care to older adults who present physical and cognitive decline. Ethical approval was received from the hospital as well as the National Health bioethics research committee (Reference Number: EEBK EP2019.01.98). All participants signed a consent form before the study, and all employed procedures were per the Declaration of Helsinki. Where concerns were expressed with regards to individuals' capacity to consent to their participation, capacity assessments were completed using the Mental Capacity Act (MCA) 2005 Assessment Checklist. For any individuals that lacked capacity, consent was received on their behalf from a relevant party.

2.2 Participants

In total, 75 PwD and medical and paramedical personnel were involved in the study. Specifically, 24 PwD (14 male, 10 female) with a mean age of 82.61 years (SD = 7.8), and a total of 51 medical and paramedical personnel (22 male, 29 female), aged between 23 to 54 years (M = 35.7, SD = 9.87) participated. Most of the PwD (16/24) were at the second stage of dementia (i.e., moderate), while the rest were dealing with third (i.e., severe) (5/24), and first (i.e., mild) (3/24) stage. The medical and paramedical personnel were mostly nursing staff and formal caregivers (32/51), psychiatrists, psychologists, social workers, speech, and art therapists (10/51), physiotherapists and occupational therapists (6/51), managers, and research directors (3/51).

2.3 Study Design and Procedure

The study design emerged from rigorous discussions with experts in the field of healthcare, specializing in dementia care, social and computer scientists, and Human-Computer Interaction (HCI). To be informed by the bibliography systematic reviews of research that examined the effectiveness of VR for PwD [23] and neurological diseases [24] were carried out. Data were collected over a month via questionnaires and focus groups.

2.4 Materials

Questionnaires. Demographic characteristics of the participants were collected (i.e., sex, age, stage of dementia, healthcare profession). The initial preferences for the content were measured through open questions (e.g., "Let us know where you would like to be (give as much information as you can)").

Focus groups (n = 2). Focus groups were organized at a National Health in-patient hospital offering treatment to PwD. The focus groups were conducted to reflect on patients' and healthcare experts' preferences on VR content to complement their mental health care and define the aspects that must be avoided. Notes were taken to identify potential VE focused on the patients' interests and needs.

3 RESULTS

3.1 VEs Selection

A two-hour annual conference was conducted at the participating National Health in-patient hospital. Attendees were a group of 34 specialists in dementia care such as clinical psychologists, psychiatrists, nurses, and managers, and 11 PwD. At the conference, the researchers presented an introduction to VR technology and the results of the systematic literature reviews along with some preliminary findings from interventions using VR with PwD [23][24][25][26][27].

Afterwards, attendees were asked to brainstorm the type of VR content suitable for PwD. Attendees suggested the following themes: 1) Travel (e.g., google maps, cities around the world, cruise); 2) Nature (e.g., beach, woodland, parks); 3) Arts Experiences (e.g., music, cinema, museum); 4) Hobbies and Sports (e.g., football, fishing, golf, bowling); 5) Social (e.g., restaurant, pub); 6) Home (e.g., kitchen, workshop, and garden); 7) Pets (e.g., puppies, kittens); 8)

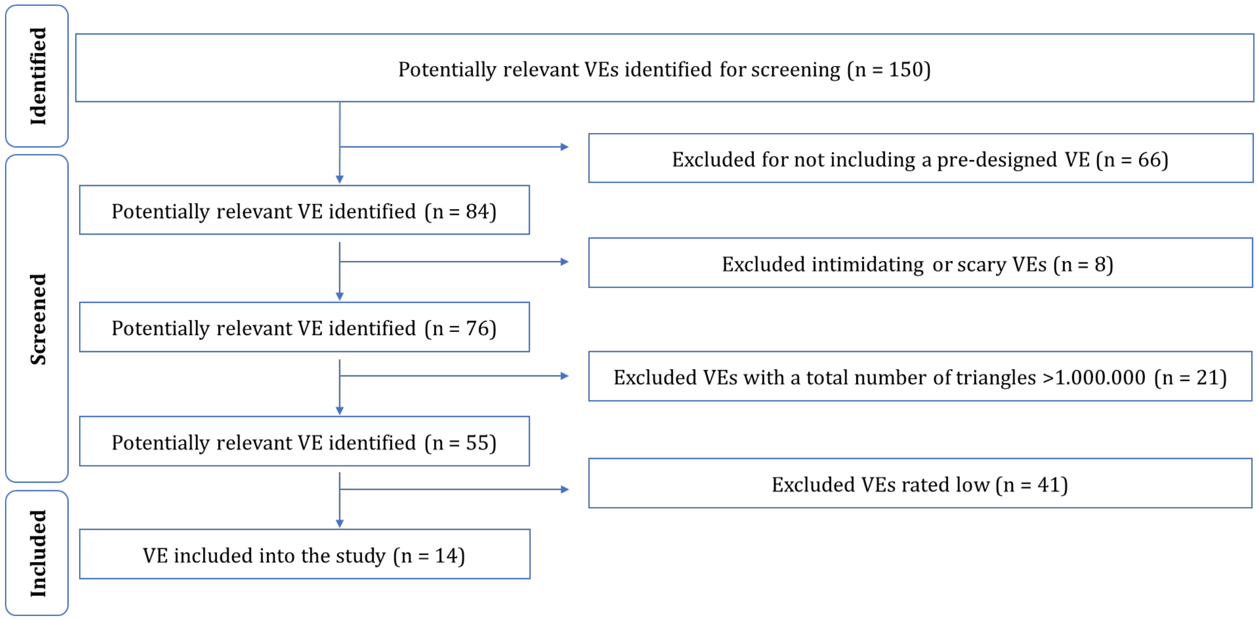

Figure 1: Identification and selection process of the VE included in the system.

Familiar Patient-Content (e.g., Christmas or a thanksgiving content with the family, locations from earlier life).

After the conclusion of the conference, we searched systematically in Unity's Asset Store[1] for relevant assets using the HCI Bargas-Avila and Hornbæk methodology [28]. We used the following search terms aiming to cover any type of relevant VE in each theme:

- ***Arts Experiences:*** Cinema; Concert; Exhibits; Museums; Sculptures.
- ***Familiar Patient-Content:*** Birthday; Christmas; Celebration; Church; Infant; Office; School; Temple; Village.
- ***Hobbies and Sports:*** Earth; Gym; Hobbies; Pool; Sailing; Ship; Space; Sports.
- ***Home:*** Apartment; Bedroom; Furniture; Garden; Home; House; Kitchen; Living Room.
- ***Nature:*** Beach; Flowers; Forest; Mountains; Meadow; Nature; Ocean; Park; Sea; Trees; Valley.
- ***Pets:*** Animas; Birds; Cats; Cow; Dogs; Ferrets; Fish; Gerbils; Goat; Guinea Pigs; Hamsters; Horses; Pets; Rabbits.
- ***Social:*** Bowling; Café; Club; Gardening; Golf; Library; Pub; Restaurant.
- ***Travel:*** Austria; Belgium; Bulgaria; China; City; Cyprus; Czechia; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Ireland; Italy; Latvia; Lithuania; Luxembourg; Malta; Netherlands; Poland; Portugal; Romania; Sights; Slovakia; Slovenia; Spain; Sweden; Travel; United Kingdom; United States[2].

Overall, we identified 150 potentially relevant VEs which were collected for further exploration (Figure 1). We manually excluded any content which was not consistent with the following inclusion criteria that were agreed upon by the research team: 1) Pre-designed VE (i.e., we excluded packages that only included individual models or did not include a pre-designed VE) to provide the PwD with the sense of being in the VE; 2) elements of the VE cannot be perceived as intimidating or scary by the PwD; 3) the VE has a total number of triangles less than 1,000,000 to avoid simulator sickness and long loading times. Based on these criteria, we identified a total of 55 VEs across all themes (Table 1).

Seventeen specialists in dementia care such as nursing staff (4/17), physiotherapists (4/17), psychiatrists and psychologists (3/17), physical trainers (2/17), a social worker (1/17), speech therapist (1/17), and other (1/17), and 13 PwD (8 male, 5 female) with mean age 82.61 years (SD = 7.8), and mild (1/13), moderate (9/13), and severe (3/17) dementia participated in this phase for the final selection of the VEs. At the beginning of the session, all participants were presented with a laminated A3 paper that included the title and a representative picture from each of the selected VEs and were asked to rate positively their preferred VEs. Through this process 14 VEs were selected for final inclusion as shown in Table 1.

Once the final selection of the VEs was completed, an iterative process followed for their enhancement with additional elements to personalize them for PwD. The process included the addition of cultural-related elements (i.e., a video playing on the TV with local dancers, commonly used decorations/equipment, etc.) that would increase the familiarity with the VEs. Furthermore, placeholder elements were also added that would allow further personalization of the environments with personal items from the PwD (i.e., picture frames for family photos, landscape drawings could be added, etc.).

[1]https://assetstore.unity.com/

[2]Since the study run in the European Union, we restricted our search mostly in European Union Member States. We also added the United States since it is a common country to travel for our population.

Table 1: VEs identified and included in the study per theme

Theme	Identified through search	Selected for Evaluation	Included in the study
Arts Experiences	11	5	0
Familiar Patient-Content	23	10	2
Hobbies and Sports	12	4	1
Home	10	5	3
Nature	54	10	6
Pets	9	8	0
Social	14	4	0
Travel	17	9	2
Total	150	55	14

3.2 Development of an Intelligent Personalized Assistive System

The selected VEs from the above selection process were then used for the development of an intelligent personalized assistive system that can enhance the HRQoL of PwD. The system aims to offer PwD an empowering space capable of a) managing and reducing the co-existing symptoms of dementia, such as depression, apathy, lack of motivation, and loss of interest in oneself and others and b) helping the demented patient maintain emotional well-being. The system comprises two components, one for monitoring patients, and a VR-based intervention.

3.2.1 Patient Monitoring. A smartwatch (i.e., Samsung Galaxy Active 2[3]) is worn by the demented in-patients throughout the day. A dedicated smartwatch application was developed using Tizen Studio, which uses the sensors of the smartwatch to record the patients' heart rate and stress level every second. The recorded data are sent via Bluetooth every minute to a mobile application, which in turn forwards the data to a back-end server for monitoring. Based on research, elevated heart rate corresponds to an indication of stress [9], and therefore once an elevated heart rate is detected, the system informs the caregiver to administer a VR intervention. To prolong the battery life on the smartwatch the Wi-Fi, GPS, and vibrations are disabled, and the display is set to low brightness. In our testing, we found the specific model to have a battery life of a bit over 2 days and a 2-hour charge time.

3.2.2 VR-based Intervention. The VR intervention, which was developed using the Unity3D[4] game engine, aims to reduce any negative emotions PwD are experiencing. To accomplish this, users get to experience and explore various VEs that meet their interests. For the intervention, the VIVE Pro Eye VR system[5] is used since it provides an integrated eye tracker, that records data related to where the user is looking at. The VEs that are included in the intervention, were selected through the systematic selection process described above. Within each VE, an optimal viewpoint was selected where the user starts the experience. Since PwD are prone to disorientation, and dizziness, and thus run a risk of falling, all experiences are viewed from a pre-defined viewpoint, without the ability to move around.

An HCI expert and a computer scientist examined each VE and identified areas of interest (AOI) within them. An AOI is defined as an object or region in the environment that can act as a stimulus to the user. The annotations for the AOIs are implemented within the development framework of the system, following an ontology-based approach based on W3C's Web Ontology Language (OWL2)[6]. Classes were defined for entities that can be found in the VEs (i.e., animals, people, furniture, etc.). For each class, various properties were identified based on relevant characteristics, and the overall themes identified above. For example, a bird, like other animals, has a property *isPet*, which identifies if it is domesticated or in the wild. Properties can be either static, like the above that do not change during an experience, or dynamic. Dynamic properties change values based on the behaviour of an individual's instance within a VE. For instance, a cat can transition between different states (i.e., sitting, walking, playing with a toy), which in turn can change the results of related properties.

For each user of the system, a profile is maintained with demographic information and a reference to the ontology with preferences towards different classes and property values. During an intervention, the user starts by selecting a VE they would like to experience first. Figure 1 depicts views from the starting menu, with the option to select from the available themes. Once, within a VE, physiological data (i.e., heart rate, and stress level) of the user are analyzed in real-time, after the application of exponential moving average (constant smoothing factor = 0.5) for filtering noise. More specifically, in the event of increasing heart rate and stress level, a negative score is assigned, while decreases in the above metrics are assigned a positive score. The scores are proportional to the amount of change observed between recordings.

The scores are then coupled with data recorded using an eye tracker to update the displayed content. The AOIs the user fixated on during the prior 5-second period are computed, and the associated semantic information based on the ontology defined above is identified. In the simplest form, annotations are updated based on the class hierarchies. Directly associated (1st level subclasses/superclasses) annotations receive a greater change, while ones at further levels receive a smaller change. For example, if a negative event is identified when the user is looking at a cat with

[3]https://www.samsung.com/global/galaxy/galaxy-watch-active2/#galaxy-watch-active2
[4]www.unity3d.com
[5]www.vive.com/eu/product/vive-pro-eye
[6]https://www.w3.org/TR/owl2-overview/

Figure 2: Snapshots of the VEs offered to the PwD as displayed in the menu of the VR intervention.

a score of -1, the class "cat" in the user's profile will decrease in preferability by 1, while the class "animal", that is a direct superclass of "cat", will receive a deduction of 0.5. This level-based deduction follows an exponential decay, based on the distance from the affected element. A similar idea is used to affect various properties related to the classes.

The content in the VR intervention updates accordingly at fixed intervals (i.e., by default every 10 seconds), driven by the observed updates to the users' profile based on the process described above. These changes can vary in scale, based on the change from the last interval and the current physiological state of the user (i.e., how stressed they are or not). Greater changes (i.e., removing certain elements from the VE) occur when the user is currently stressed, with his condition not improving significantly. On the other hand, if the user is becoming less agitated, the current environment and elements are maintained with only minor changes occurring. An illustration of the model guiding the above changes can be seen in Figure 2. The same model is also used to guide the transition between different VEs. Transitions between VEs occur at greater intervals (i.e., by default every 45 seconds) but again following the above process.

4 DISCUSSION

Our results drawn from the focus groups identified eight main themes of VEs relevant for PwD. It is valuable to correlate the findings of this work with previous design research. Particularly, our survey of patients and medical and paramedical staff suggested that the system should incorporate the following themes:

Animals/Pets. Previous research shows the benefits of pet therapy for PwD. In particular, being exposed to an animal for a couple of hours per week, within nursing homes offering care to PwD was found to decrease agitated behaviours and a statistically significant increase in social interactions for dementia patients [28][29]. It also showed a significant reduction in aggression or behavioural disturbances [30]. A very promising finding was the increase in verbal communication. In particular, being exposed to an animal helped PwD to express themselves in more words containing meaningful information [30]. This is because interaction with pets is linked with positive emotions, feelings of accomplishment, and higher HRQoL [30][31]. Interestingly, previous studies suggest that animals can enhance therapeutic healing with statistically significant health benefits and improvements in blood pressure, heart rate, and salivary immunoglobulin A levels, and offer a reduction in depression and anxiety [32][33][34][35]. There are also indications that the above benefits can transfer even when viewing content with animals on a screen. Research shows that viewing animal content on a screen can have positive health benefits such as a reduction in cardiovascular responses, stress, and anxiety [36]. For these reasons, we enhanced all the VR environments with animals and pets to maximize the expected benefits for PwD. For example, within a VE of a forest, we added birds flying around happily chirping and tweeting, while in a VE of a dining room we added a playful kitten.

Arts Experiences were also suggested as content. Previous research recommends artistic content and art interventions to create meaningful, positive experiences for PwD [37][38][39]. It was further suggested that being exposed to art can also enhance and improve HRQoL for PwD [37]. These findings were further supported by physiological responses related to stress hormone levels, heart rate, blood pressure, and respiration [41][42][43][44]. These findings suggest that for PwD, a positive affect and improvements in their mental health supported by physiological responses emerge in the context of arts interventions. It is also worth mentioning that arts-based interventions can improve communication between the caregiver and the demented person, which in response improves the overall care the PwD receives [40].

As for *Nature*, the findings of previous studies advised that viewing nature can improve physiological and psychological responses. For example, heart rate and blood pressure tend to decline within a few minutes of viewing nature [45], while it can also enhance emotional well-being and aid recovery from stress [46]. Also, several studies demonstrated that specific environmental features and particularly the way nature is designed could enhance PwD HRQoL [47]. It was suggested that for PwD, nature and the ability to be in touch with it, support relaxation and connotate the sense of freedom [48].

Familiar patient content / Personalized Content and *Home* environment were also suggested. This is because many PwD are either living within hospital care units for care to be provided to them or

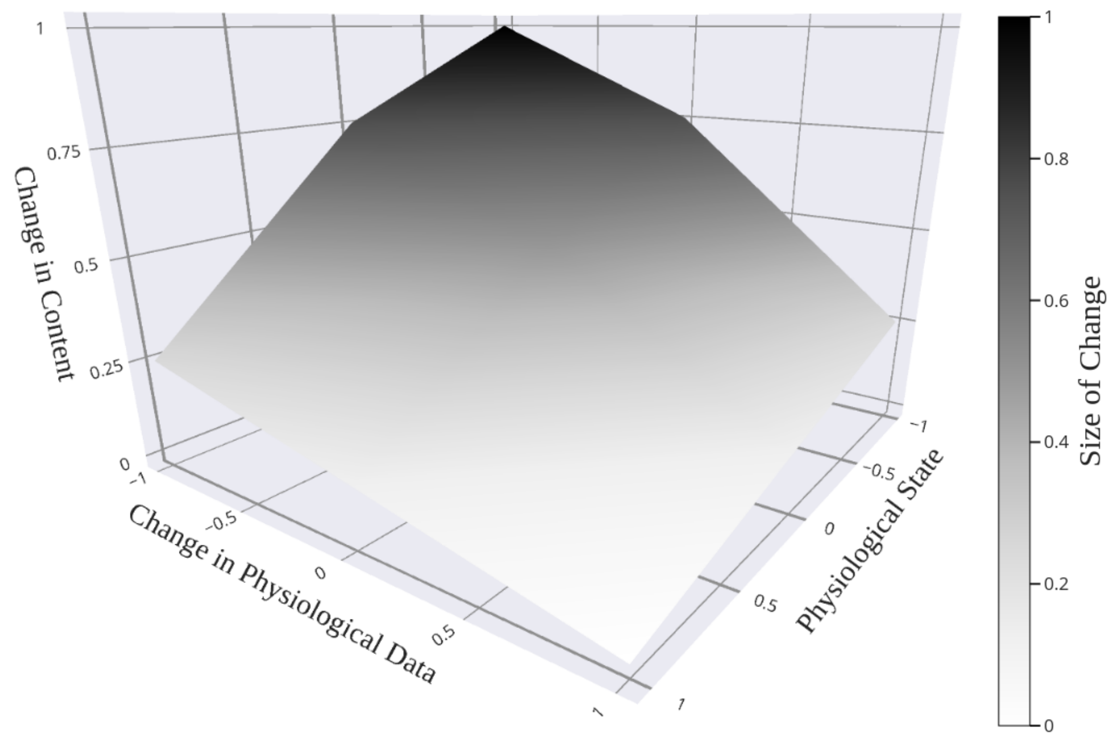

Figure 3: Model describing the size of the changes to the environment during the experience, based on the change in the physiological data and the current physiological state (i.e., heart rate, stress level) of the user during the experience.

have limited capacity to travel. Those patients usually wish to visit a memorable place or even return to their homes [49]. Also, and being consistent with previous studies, we found our findings to suggest that PwD reminisced through the similarity and resemblance of environments [19] and cultural themes [50]. Therefore, it is important PwD be exposed to elements that can remind them of memories. VR can offer the possibility of "home-return", disregarding the hospital boundaries restrictions.

Hobbies and Sports were also reported as preferable content by both patients and health care professionals. In line with previous research, it is suggested that caregivers believe that being able to offer terminal patients the ability to engage with preferable hobbies during the end life period is empowering for both the patient and the therapist [51][52]. In addition, engagement with such activities can enhance the HRQoL for the patient by managing pain [53], which has been stated as one of the most important challenges in offering care to dementia patients [54]. VR was shown to have the ability to successfully tackle these challenges [55][56].

Social-interaction features were also suggested as previous research documented that the sense of belongingness can enhance the HRQoL for dementia patients [57][58][59]. Particularly, it was found that access to social support and a sense of belongingness can improve resilience coping mechanisms in dementia patients which supports the reduction of anxiety and depression. This is contrary to the common preconception that VR is an isolating experience [60]. Opposite to that notion, and in line with a study that examined the suitable types of VR for PwD [61], we believe that VR can be a space where social interactions can be held. This was further supported by studies that suggested that VR can be the medium through which patients open-up and communicate even more their feelings and ideas [17][62].

Finally, *Travel* was also suggested as a relevant theme. Based on previous research, dementia patients express a desire to travel [63][64]. Assistive technology which was used to expose PwD to travel destinations was found to have positive effects on their well-being by improving their confidence and self-esteem and by motivating them toward rehabilitation and independent living [63].

5 FUTURE WORK

Beyond the selection of the VE, we also presented the design of a personalized system, using VEs from the above themes, that aims to elicit positive emotions from PwD using it. This will in turn lead to reduced stress levels, reduction in the display of behaviours of challenge and agitation, and thus help with the long-term behaviour change of PwD. The behavioural change is driven by the personalization of the VEs, and the adaptation of the experiences based on data recorded from the user. Physiological data captured from a smartwatch worn by the user, and gaze data from an eye tracker integraded in the head-mounted display will be used to guide this process. The analyzed physiological data, along with information about AOIs within the VE that the user is fixated on,

Figure 4: The interface of the VR intervention with a visualization of the gaze of the user (green line) that shows what the PwD is looking at, and their current heart rate (bottom left of the picture)

are mapped together and used to compute the size of the change that should occur in the environment to achieve the goal of the system. These changes follow the users' preferences based on their profile which is maintained and updated during each experience. This results in the continuous improvement of the system, based on its use.

For the future deployment of the intervention, the VR content will be streamed to an external monitor, mirroring the virtual interactions of the PwD in the VE. Additionally, and only visible to the therapist, and not to the PwD having the experience, will be the data recorded from the user. The gaze will be visualized as a ray toward what the user is looking at, allowing caregivers to provide relevant prompts and support during the exposure (Figure 3). Also visible, will be the heart rate and stress level recorded from the smartwatch.

6 CONCLUSION

This paper presented the co-design process of an assistive application for PwD. The process included a total of 75 dementia patients and medical and paramedical personnel focusing on the co-design of system. Through an iterative design process, we discussed the design of eight different VR themes. Through a systematic search, we identified 150 different VEs corresponding to the suggested themes. The VEs were screened against a set of inclusion criteria and then rated again by healthcare personnel and PwD. The evaluation resulted in the selection of 14 VEs across five themes that were used for the development of an intelligent personalised assistive system comprised of a patient monitoring component and a VR-based intervention for dementia patients. In the future, we aim to evaluate the proposed system with dementia patients to explicitly assess and explore the acceptability and effectiveness of these VEs in a hospital setting to manage behaviour that challenges, as well as decrease depressive and stress episodes, and at the same time improve the patients' HRQoL.

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