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Exploring the Accessible Design of Virtual Reality Games of Different Intervening Purposes with People with Dementia at Different Stages

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Abstract

Purpose: The virtual reality (VR) game has been considered an emerging and promising method for non-pharmaceutical intervention for dementia. However, previous works lack sufficient discussion of accessible design when games with different intervening purposes are applied to users at different stages of cognitive impairment. **Methods:** We conducted a user study with 11 participants in three stages of cognitive impairment by using a designed cognitive training game developed through the participatory design approach and a commercial recreational game. Video recordings, semi-structured interviews, caregiver feedback, and observation notes were analysed through thematic analysis. **Results:** Three themes were refined for understanding the accessibility of different virtual reality games. Firstly, the virtual reality game with a single intervening purpose may be limited because cognitive training and recreational games have differentiated usefulness to people with different degrees of cognitive impairment. Secondly, the personalized difficulty-matching strategy is crucial for cognitive training games. Thirdly, recreational virtual reality games integrated with social interaction could stimulate positive emotions in users with cognitive impairment. **Conclusion:** Three design implications are extracted for future design: multi-component or multi-dimensional intervention, artificial-intelligence-empowered difficulty matching, and emotionally intelligent virtual agents for social interaction.

Keywords: virtual reality; dementia; accessibility; recreational game; cognitive training; cognitive impairment

Table 1: Abbreviation list.

Abbreviation	Definition
VR	Virtual Reality
SCD	Subjective Cognitive Decline
MCI	Mild Cognitive Impairment
AD	Alzheimer's Dementia
CIBL	Chinese Imaging, Biomarkers and Lifestyle
TAM3	Technology Acceptance Model 3
PEOU	Perceived Ease of Use
PU	Perceived Usefulness
ENJ	Perceived Enjoyment
BI	Behavioral Intention

1 Introduction

The virtual reality (VR) game is regarded as an emerging and promising method for non-pharmaceutical intervention for dementia, outperforming traditional training tools in its natural interaction context, safety from potential real-life dangers, and enhancement of motivation [29]. Potentially, VR games can improve the cognitive, psychological, and physical well-being of people with dementia [10]. Virtual reality games for intervention for people with dementia include serious games designed for therapeutic purposes like cognitive training and recreational games for entertainment [5]. Serious virtual reality games working on physical training and neurological rehabilitation, such as the exergames or task-based cognitive stimulation to exercise activities of daily living, have been considered to positively affect overall cognitive and physical conditions [10, 15]. In contrast, recreational virtual reality games, such as games focusing on leisure activities or social and interpersonal communication, are expected to affect psychological or emotional intervention and pay attention to networks of care [5, 22].

People with dementia will face different symptoms and changes in accessibility as the disease progresses from subjective cognitive decline (SCD) to mild cognitive impairment (MCI) and Alzheimer's dementia (AD) [13]. Existing literature has paved the way for accumulating experience with participatory design and effect validation of virtual reality games for people with dementia. However, most of the established research only targets a specific stage of people with dementia, like mild cognitive impairment, or takes people with dementia as a whole group, which hardly mentions the differentiation of design for subdivided groups of people with dementia [1, 3, 5, 17]. In this way, the users' needs are static, and the users may not be able to use the application once the disease progresses. In addition, as most older adults have never used VR before, evaluated bias may exist due to the novelty effect of virtual reality if the evaluation was only conducted using a single measurement, like a single virtual reality application [6, 12]. Thus, the potential for

further research is to explore the feasibilities and limitations of different virtual reality games when applied to people with dementia at different stages.

For a journal focusing on universal access, this issue is also an accessibility problem. The barriers in VR games for people with dementia are not limited to whether the device can be worn or whether a controller can be held. They include memory load, navigation burden, familiarity of the task, emotional safety, social support, and whether the game purpose fits the user's current cognitive ability. Therefore, the design of VR games for dementia should be discussed not only as intervention design, but also as accessible user interface design for cognitively diverse older adults.

Recent studies have further strengthened the need to understand VR from the perspective of acceptability, ecological validity, and real-world adoption. Older adults have shown a general willingness to consider VR for dementia screening when the perceived usefulness of the technology is clear [21]. Recent reviews also indicate that VR interventions may support memory, attention, information processing speed, and executive function in older adults with MCI, while the quality of evidence and long-term outcomes still require further study [9, 26]. In addition, new VR cognitive assessment tools have been validated for screening cognitive impairment, showing the increasing clinical and design relevance of realistic VR scenarios [16].

In this paper, we explore the design of virtual reality games for people with dementia by utilizing two virtual reality games, a designed grocery shopping game and a commercial dancing game, with intervening purposes: cognitive training and recreational exercising. Additionally, people with cognitive impairment at the stages of SCD, MCI, and AD are involved in the user study to test different user requirements (4 AD, 4 MCI, and 3 SCD). We analyze the differences between different VR games from the perspectives of people with cognitive impairment at different stages through qualitative analysis using thematic analysis. There are two contributions to this work. First, three themes about opportunities and limitations are refined to understand the accessibility of applying different virtual reality games to people with dementia at different stages. Firstly, the virtual reality game with a single intervening purpose may be limited because cognitive training and recreational games have differentiated usefulness to people with dementia at different stages. Secondly, the personalized difficulty-matching strategy is crucial for cognitive training games. Thirdly, recreational virtual reality games integrated with social interaction could stimulate positive emotions in users with cognitive impairment. Apart from the above, three design implications are extracted for future design. Firstly, it is potential for the multi-component or multi-dimensional strategy that combines virtual reality games with different intervening purposes to improve both physical and mental outcomes in people with dementia. Secondly, artificial intelligence could empower the personalized difficulty-matching strategy for cognitive training games. Lastly, the emotionally intelligent virtual agent may enhance the social interaction experience of recreational virtual

reality games, thus further improving positive emotion stimulation.

2 Virtual Reality Games

2.1 A grocery shopping game with the intervening purpose of cognitive training

The grocery shopping game was developed using Unity and deployed for the Oculus Quest 2. We designed and developed the grocery shopping game with local clinical professionals and people with dementia based on human-centered and participatory design principles [3,8,17], as well as regarding the design of the virtual supermarket from previous works [1, 15, 30]. The grocery shopping game focuses on cognitive training including memory, space navigation, and calculation training.

The user journey is displayed in Fig. 1. As for the space navigation training, we selected steering as the locomotion interface for the grocery shopping game. An essential point in the steering method design is that users can control the speed to avoid the flaw of dizziness of steering by shaking the arm up and down using the controller. Moreover, the user will receive light and sound feedback if the product is successfully grabbed. Due to the different cognitive abilities of users at different stages of dementia, games with different difficulty levels need to be designed [8]. Each level of the game demands varied memory, calculation, and navigation abilities adapted to the participants with AD, MCI, and SCD (Table 2). For the controller's interaction, level 2 and level 3 demand learning to use two buttons, while level 1 only needs one. The finalized version of the grocery shopping game was finished with three iterations of design and testing. We began first to specify the product target and the essential functions. Then we developed and tested the first prototype by cooperating with the clinical therapists. Next, we were able to determine the design of difficulty levels with people with dementia (3 AD, 3 MCI, and 3 SCD) in the second prototype and improve the navigating interaction. Finally, for the third prototype, we aimed to consider active aging in visual design. On the one hand, we adjusted all the visual objects to be easily seen, provided category labels on the shelves, and guided signs on the floor. On the other hand, we added localized features to perform familiarity design by unifying the overall visual color with red and replacing items on the shelves with those familiar to older Chinese adults [11, 27], such as "Braised Beef Instant Noodles" and "Zhong Hua Toothpaste".

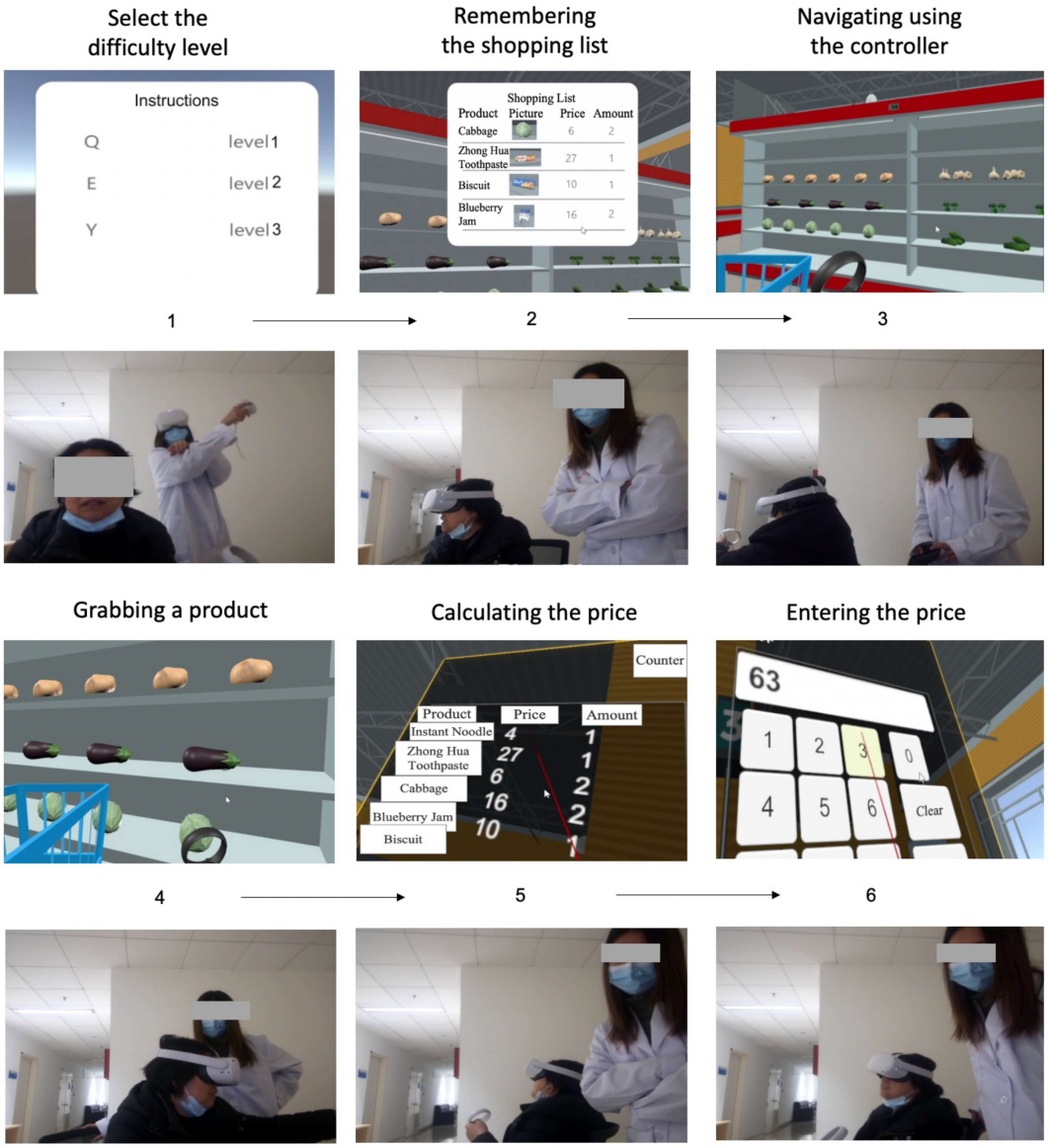


Figure 1: User journey for the grocery shopping game based on the cognitive training purpose and the synchronized interaction process of a participant with subjective cognitive decline (SCD) playing the game. Faces are blurred to account for patient privacy.

Table 2: Difficulty differentiation design of the grocery shopping game for people with dementia at different stages.

Difficulty	Target user	Memory	Calculation	Navigation
Level 1	AD	2 items to memorize	Addition	Not requested
Level 2	MCI	3 items to memorize	Addition	Requested
Level 3	SCD	4 items and their amount to memorize	Addition and multiplication	Requested

2.2 A dancing game based on recreational exercising and social purpose

When considering choosing the recreational game appropriate for people with dementia, we selected the dancing game with a virtual robot in "First Steps" of Oculus Quest 2 because the interactions are simple enough for users with dementia by simply holding the controllers and mimicking the gestures of the little robot (Fig. 2).



Figure 2: A participant with Alzheimer's dementia playing the dancing game based on recreational exercising and social purpose from Oculus "First Steps".

3 User Study

3.1 Participants and procedures

With ethical approval from Beijing University of Posts and Telecommunications's Ethics Committee (No. 202201004), we recruited 11 participants with dementia at three stages among participants of the Chinese Imaging, Biomarkers and Lifestyle (CIBL) Study of Ageing Project of Beijing Tiantan Hospital Affiliated to Capital Medical University. Written informed consent was obtained before participation in the study. Participants are listed in Table 3, with 4 participants with a diagnosis of AD, 4 participants with a diagnosis of MCI, and 3 participants with a diagnosis of SCD. Our small sample size is partly because of COVID-19 and restrictions on informed consent in dementia [19]. Before entering the user study in this paper, all participants took part in the magnetic resonance imaging and the medical questionnaires assessment, validated in the Chinese version. In this way, the diagnosis results of the stage of cognitive impairment were given by the therapists that were blind to this study. Caregivers of AD were specially invited to assist in the study and provide supplementary information when participants could not express themselves accurately due to cognitive abilities. Many participants with SCD and MCI were also accompanied by their caregivers in the study, who finally played a vital role in providing feedback and assistance during the study.

We conducted the user study in a quiet corner provided by the partner hospital. It took approximately 30 minutes to complete the study for each participant. All partic-

ipants played the grocery shopping game for 15 minutes and the dancing game for 5 minutes in random order. The study setup included a swivel chair, a computer on the table with a camera, and a set of Oculus Quest 2. To avoid falling, the participants completed all interactions sitting in a swivel chair while wearing the head-mounted display, and the host of the user study accompanied the participant in the whole process. The process for both games included three parts: tutorial introduction, playing games, and feedback collection. After playing games, participants were asked to take part in a semi-structured interview for nearly 10 minutes to give feedback on the acceptance of the games, as well as some follow-up questions to help researchers learn more about the reason. In the part of the interview, accompanying caregivers were also encouraged to contribute their ideas.

Table 3: Participant information.

Participant	Age	Gender	Stage of cognitive impairment	Participating caregiver
P1	66	Male	AD	Daughter and wife
P2	66	Female	AD	Son and husband
P3	67	Male	AD	Son and wife
P4	88	Male	AD	Son
P5	56	Female	MCI	/
P6	65	Male	MCI	Daughter
P7	50	Female	MCI	Husband
P8	64	Female	MCI	Son and husband
P9	60	Female	SCD	/
P10	76	Female	SCD	Son
P11	64	Female	SCD	Daughter

3.2 Data collection and analysis

During the study, the computer was placed in front of the participant, recording the entire process of both the physical and virtual worlds. Simultaneously, the virtual world was played synchronously on the computer screen for accompanying caregivers to observe. Data were collected through two main ways, video recordings of the interaction process and the semi-structured interview investigating acceptance feedback of the games. The semi-structured interview mainly asked about a series of questions about acceptance of virtual reality games, which is a simplified form referring to the Technology Acceptance Model 3 (TAM3) including four sub-scales [1, 24] (Table 4). TAM3 was used to identify interventions that could influence the adoption and use of new technologies. As all the participants had never used virtual reality before, TAM3 could be beneficial to evaluate the participants' acceptance of virtual reality. For questions of the TAM3 to investigate the acceptance of virtual reality games, perceived ease of use (PEOU) was used to locate

the design flaws. Perceived usefulness (PU) was provided to investigate the personal effectiveness, while perceived enjoyment (ENJ) was used to understand the game's playability. Behavioral intention (BI) was an overall indicator of whether participants would accept the game in the long run.

The video recordings and the semi-structured interview were manually transcribed and divided into three parts for thematic analysis, observation notes, participant feedback, and caregiver feedback. The first author conducted an initial inductive phase using NVivo 12, including creating open codes, cases, maps, and themes for the three parts of the data. Iterations of coding and extracting themes were also conducted by presenting within the group of authors (Figs. 3 and 4). Finally, this paper produced a total of 53 codes for the corpus (Fig. 3), which were categorized into three cases, each of which corresponded to a thematic map (Fig. 4). Some of the codes were not included in the cases due to the small number of textual references. By summarizing and filtering the themes of the thematic map, this paper finally produced three themes, which are (1) virtual reality games with a single intervening purpose may be limited, (2) personalized difficulty matching strategy is crucial for the cognitive training games designed for people with different degrees of cognitive impairment, and (3) recreational virtual reality games integrated with social interaction could stimulate positive emotions in users with cognitive impairment. For each theme, the next chapter will further explore the future design implications of VR for dementia patients in relation to the existing literature.

Table 4: Semi-structured interview questions to investigate the acceptance of the virtual reality games.

Sub-scales of acceptance	Question
Perceived Usefulness (PU)	Do you think this game has effectiveness to your health?
Perceived Ease of Use (PEOU)	Do you think this game is easy to learn and the interaction of the game is easy to use?
Perceived Enjoyment (ENJ)	Do you think you enjoy playing this game?
Behavioral Intention (BI)	Are you willing to play this game in the long term?

4 Findings

In the findings, we dive into understanding the opportunities and limitations of two virtual reality games designed with different intervening purposes when applied to participants with different degrees of cognitive impairment and exploring the design implications for cognitive training and recreational games. Our thematic analysis of data gathered from the user study identified three main themes at the semantic level. Firstly, virtual reality games with a single intervening purpose may be limited as games with cognitive training

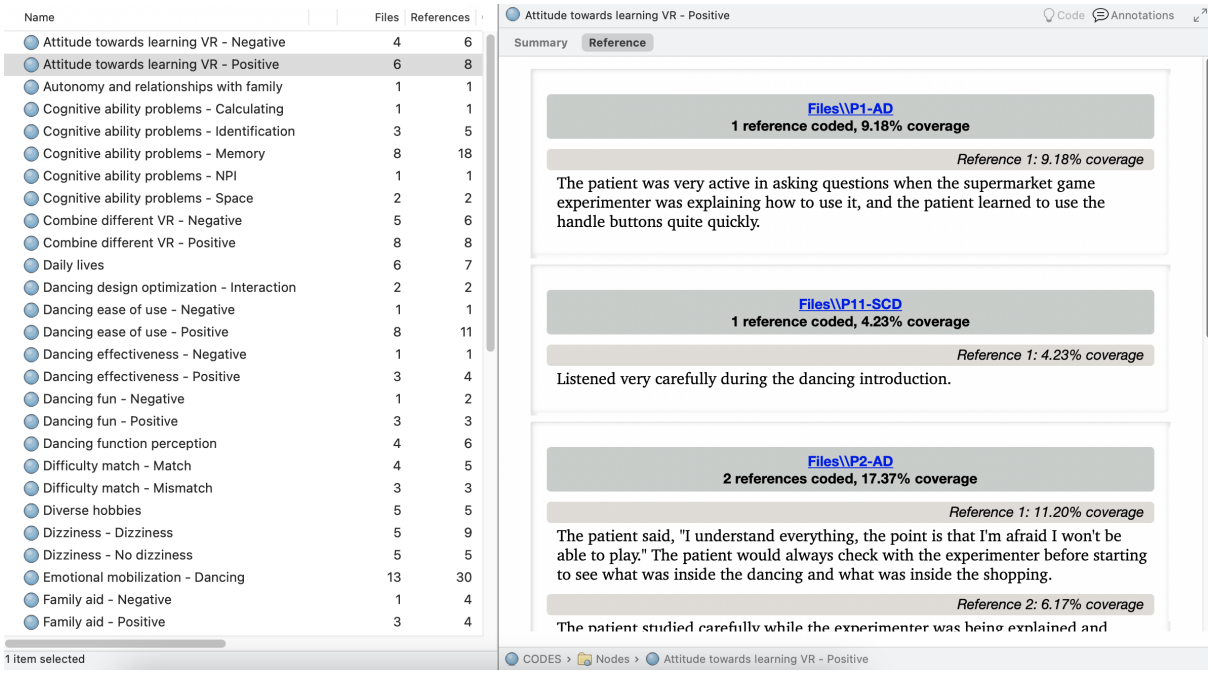


Figure 3: Thematic analysis codes and the textual material corresponding to each code. The figure shows the textual material corresponding to the code "Attitude towards learning VR - Positive".

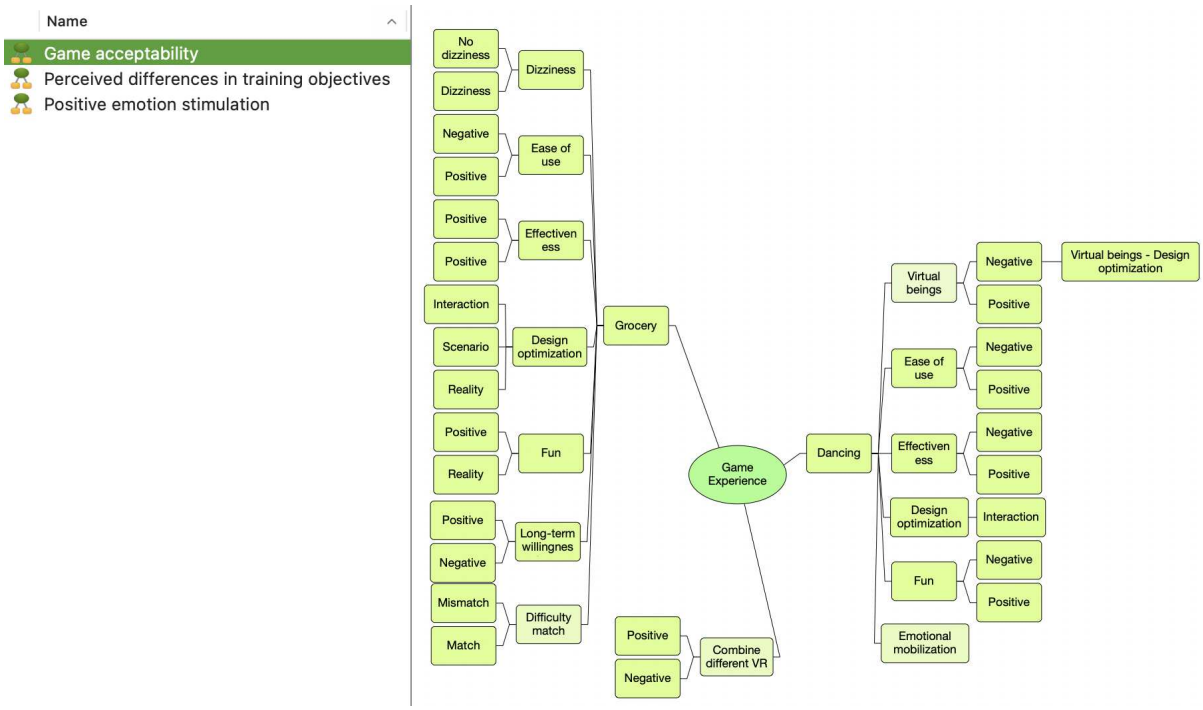


Figure 4: Thematic analysis cases and thematic maps. The figure shows the thematic maps for the case of "game acceptability", which were converged from the four dimensions in Table 4, and each dimension is categorized according to whether users rated the dimension positively or negatively.

or recreational purpose have different usefulness to people with different degrees of cognitive impairment. Secondly, the personalized difficulty matching strategy is crucial for cognitive training games designed for people with different degrees of cognitive impairment. Thirdly, recreational virtual reality games integrated with social interaction could stimulate positive emotions in users with cognitive impairment.

4.1 Virtual reality games with a single intervening purpose may be limited

In the study, the grocery shopping game was positioned to exercise the brain. In contrast, the participants treated the dancing game as somewhat for physical exercise and entertainment. As P5 with MCI mentioned, "Although the shopping game is a bit cumbersome, it is fun and effective because both my hand and brain are practiced. I am ok with the dancing game and can move my arms and legs." P8 with MCI said, "it is interesting and very suitable for the older adults to exercise the coordination of the brain and hands by using the shopping game." P9 with SCD said, "I think the grocery shopping game can be used to train the capability of memory and judgment, and the dancing game can train my coordination, body agility, and reflexes." P2, with mild AD, said, "the dancing game is easier for me and can be used to exercise my body. The shopping game can practice the responsiveness of hands and brain."

We also found that application suitability for different games may depend on user interests in daily life, subjectively perceived effectiveness of the game, or cognitive ability. P9 with SCD, who preferred the grocery shopping game, talked about "Compared to the dancing game, the shopping game is more realistic and interesting for me because I have an interest in organizing activities among friends, especially shopping, cooking and inviting friends to dinner. I am a person who is outgoing and cheerful." For the dancing game, P9 said, "it can train my coordination, body agility, and reflexes. But as my reaction is slow, I don't quite enjoy dancing alone. Simultaneously, the dance training needs to be more complicated because the movements are not difficult enough now." With the same point of view, P11 with SCD also endorsed the grocery shopping game for cognitive training. However, three participants in the study with AD refused to choose the grocery shopping game for long-term training. The son of P2 observed the interaction process all the way. He proposed that "my mom will be more adaptable to the dancing game because she looks more flexible and comfortable in it." When P4, with AD, was asked whether he would be willing to play the grocery shopping game daily, he answered no, and said, "It's boring. I don't want to." His son also approved of him and said, "my father will not take the initiative to do it willingly at home. We can only force him to do it. I think the dancing game is easier for him to play and more effective because he seldom moves at home and gets in touch with new things. We have no better way to help him regain

his vitality. Maybe the stimulation of the dancing game will help."

For users with more severe cognitive impairment, cognitive training VRs have greater limitations, which are not only in terms of the learning burden on the interaction, but may also include psychological offenses to the user. In contrast, there is still room for providing interventions in recreational VR, especially recreational VR with low learning costs for interactions as well as the ability to be pleasurable. VRs with different intervention purposes may be able to serve different populations based on different needs at different degrees of cognitive impairment.

4.2 Personalized difficulty matching strategy is crucial for the cognitive training games

Firstly, difficulty beyond the user's cognitive load will make the user unable to continue the cognitive training. P1 with AD offered to try level 2 at first, which was a more challenging level for the participant with AD. When he entered the supermarket, he was overwhelmed and did not know how to travel to find the items. After his wife taught him by hand, he could move independently using the controller. However, when he arrived at the vegetable shelf, he got cabbage when he forgot that he needed to buy broccoli. Since there was still a short distance from the shelf, he could not reach it and chose to give up. Finally, after the difficulty level was adjusted to level 1, the level specially designed for people with AD, he could grab the targeted ketchup and Liby washing powder by himself. P4 with AD had difficulty using the controller, with one button needed to grab the product. However, he could still recognize the garlic and potato by reaching his arm to touch the object. Therefore, a simpler version without using any button should be designed for the user group in the severer stage of dementia.

P11 with SCD played level 3 and talked about "it is already quite difficult, but you can make it if you remember it with your heart." P8 with MCI told us she felt all right with level 2, "but more than that may not work." P7 with MCI, who played the game with level 2 and never played virtual reality games before, was amazed at first, "this is so amazing that I did not expect to be able to enter a grocery that is very similar to real life," later she expressed that the game underestimated her, "but in terms of effectiveness, it is too simple and does not make any sense to me." It is still not enough for the difficulty levels to be graded, as individual differences exist in the perception of difficulty. No matter for the users in the early or severe stage of dementia, a personalized difficulty matching strategy is required because a static design could not take care of the training demands of all users, even with the same stage of cognitive impairment.

4.3 Recreational virtual reality games integrated with social interaction could stimulate positive emotions

Positive emotion was stimulated when participants played the dancing game. P5 with MCI said, "I am in a good mood after playing the dancing game, and I am thrilled to play this." P8 with MCI also agreed with this, and she said, "while dancing, I was in a happier mood while moving along with the little robot." When asked for further reasons for the happy feeling, she said, "because the little robot gives me a sense of kindness, companionship, and joy. I can interact with him by holding his hands, which may help stimulate the brain to a certain extent. You know what, it would be even better if I could talk to it." The happiness of dancing with the robot was also brought to P11 with SCD, who also stressed the social need for talking to the cute robot. The little robot was too real for P2 with mild AD that she was initially scared when she got into the VR world, "Oh my god, why is he so close to me!" Afterward, with a wide range of movements, she began to dance freely without any prompt, pulling the hands of the little robot to turn in circles, sitting in the swivel chair. When the game finished, P2 was excited and told the researcher that the game was exciting. Then she even recommended the game to her son and said, "Hey, come and try it! You know it is different from the world outside!"

Apart from overtly expressing positive emotions, the dancing game could also trigger positive body signals in participants with severe dementia. The son of P4 with AD reported that his father had lost his interests, changed hobbies, and decreased in activities that significantly affected his daily life for the last ten years. He said, "My father used to be good at engineering, so much in favor of making radios and televisions. However, recent ten years, he was diagnosed with moderate agitation and apathy. He sits before the TV every day, seldom reacting to the dramas or musicals on TV." He expressed his surprise to see his father begin swinging his arm slightly, following the little robot to make small movements and even mimicking it to make an ending pose when he finished the game.

5 Discussion and Conclusion

In this paper, we conducted preliminary research using two virtual reality games with different intervention purposes, the designed grocery shopping game and the commercial dancing game, to explore the design of virtual reality games with different intervening purposes with people with dementia at stages of SCD, MCI, and AD. Through qualitative thematic analysis of the video recordings of the interaction process and semi-structured interviews investigating acceptance feedback of the games, three themes were refined to understand the opportunities and limitations. Based on the results of the thematic analysis, we try to put forward three design insights for future designs.

5.1 It is potential that the multi-component or multi-dimensional strategy that combines virtual reality games with different intervening purposes could be considered

When we asked the participants whether it was possible for two games with cognitive training and recreational purpose to combine, one in four AD (P1) participants, three in four MCI (P5, P6, P7), and all three participants in SCD affirmed with yes. P1 with AD showed a positive answer as he quickly learned the interactions of the grocery shopping game and succeeded in getting the right items. Besides, he has a hobby of playing the violin and likes music. Thus he enjoys playing the dancing game. P5 with MCI shared the same idea with P9 with SCD that the combination of two games is the fusion of two effects, talked about "these two games have different effects, one helps my memory, another one brings me glad." Apart from this, just like learning requires a combination of work and rest, P6 and P7 with MCI proposed that the recreational game could motivate them to participate in cognitive training. Thus, it is potential that multi-component or multi-dimensional strategies of virtual reality games could be considered to improve both physical and mental outcomes in people with dementia [29].

From the perspective of universal access, this result also suggests that accessible VR for dementia should not depend on one fixed game form. A more accessible system may allow users, caregivers, and therapists to move between cognitive training, recreational exercising, and emotional support according to the user's current ability, interest, and fatigue.

This is consistent with recent qualitative evidence that caregivers are not passive users of VR in dementia care, but active mediators who help select suitable content, manage fear or discomfort, and embed VR activities into care routines [4]. Therefore, the multi-component strategy should also include caregiver-facing support for choosing content, pacing sessions, and judging when a participant should stop or switch to another activity.

5.2 The personalized difficulty matching strategy for cognitive training virtual reality games could be empowered by artificial intelligence

As the concept of AI-driven adaptive interfaces has been proposed to support different types of memory for people with dementia [13], an artificial-intelligence-powered difficulty-changing strategy according to the task performance of the users using speed thresholds, success rate, reaction time or different types of errors in the game can be considered to adjust the difficulty level of the virtual reality cognitive training games in a real-time response [1, 18].

For accessible design, this strategy should be understood not only as performance optimization but also as a way to reduce failure experience. The difficulty adaptation needs to protect users' confidence, provide timely guidance, and avoid making users feel that they are being tested or corrected all the time.

5.3 The emotionally intelligent virtual agent may help to enhance the social interaction experience of recreational virtual reality games

Virtual agents have been studied in recent years to support patients with dementia and their caregivers and to improve the user experience in voice assistants like XiaoIce of Microsoft [2, 20, 25, 28]. Therefore, strategies like personality-driven and changing body gestures to increase emotional intelligence could be applied to design virtual agents in virtual reality to improve user engagement in virtual reality recreational games for people with dementia [7, 14, 23].

The findings in this study show that the robot in the dancing game was not merely a visual element. It became a social object that could make the experience more cheerful, less lonely, and easier to understand. In future designs, emotionally intelligent virtual agents may provide companionship, gesture demonstration, repeated instructions, and affective encouragement. Such agents may be especially useful when the user needs a low-pressure and socially meaningful way to engage with VR.

5.4 Limitations and future work

This work remains a preliminary qualitative study. The sample size is small, partly because of COVID-19 and restrictions on informed consent in dementia. The two games also differ in more than the intervening purpose: the grocery shopping game is a designed prototype for cognitive training, while the dancing game is a commercial recreational game. Therefore, the study should not be interpreted as a controlled comparison of clinical effectiveness. It is more appropriate to read the results as design evidence for understanding accessibility, acceptability, and possible intervention matching in VR games for people with dementia.

The next phase of our research is to expand the sample size of the user study to obtain confident quantitative conclusions and design virtual reality games for people with dementia according to the design implications. Future work should also include richer interaction logs, longer-term use, caregiver-centered evaluation, and adaptive VR prototypes that can verify the personalized difficulty matching strategy proposed in this paper.

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Statements and Declarations

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Competing interests. The authors declare that they have no competing interests.

Ethics approval. The study was approved by Beijing University of Posts and Telecommunications's Ethics Committee (No. 202201004).

Consent to participate. Written informed consent was obtained before participation in the study.

Consent for publication. Faces in the figures were blurred to account for patient privacy.

Author contributions. Hefeng Wang was responsible for the overall work, including study organization, manuscript revision and submission preparation. Mingying Lan and Li Gao supervised the study and contributed to study conception and design. Yangcheng Bu, Chenxuan Liu, Tianyang Zeng, Jingqi Li and Jie Dong contributed to manuscript revision and submission preparation. Junhui Li contributed to technical and methodological discussion. All authors reviewed and approved the manuscript.

Data availability. The qualitative data contain sensitive participant and caregiver information and are not publicly available. De-identified excerpts may be available from the corresponding authors upon reasonable request and subject to ethical approval.

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