Creating with Care: Co-Designing Immersive Experiences through Art-Making with People Living with Dementia

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Figure 1: Creating "meaningful places" through care and collaborative art-making.

Abstract

This paper explores the integration of co-design and art-making in developing technologies that support personhood in dementia care. While technologies for dementia care have advanced, there remains a gap in creating solutions that are directly informed by the experiences of people living with dementia and support their individuality. In collaboration with the specialist arts organisation Bright Shadow CIO, our work involves engaging people living with dementia in the design process. Over five weeks of co-design sessions, 44 participants worked alongside artists to craft four physical boxes that represent *"meaningful places."* The physical boxes were then transformed into VR environments, allowing participants to immerse themselves in and interact with their creations from a first-person perspective. Our findings demonstrate that VR alone is insufficient in dementia care. For VR to be meaningful, it must be be part of a broader intervention that includes trust-building, sensory engagement, and creative involvement. Within this process, art-making serves as both a method and medium, providing a means of self-expression and connection to identity. Our findings challenge conventional approaches to dementia-focused VR, advocating for a shift toward inclusive and care-driven technology design.

CCS Concepts

• **Human-centered computing** → **Participatory design**.

Keywords

Dementia, Care, Virtual Reality, Co-creation, Collaborative Art-Making, Places

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1 Introduction

"I feel as if I'm losing all my leaves. The branches, and the wind, and the rain. I don't know what's happening anymore."

This quote from Florian Zeller's *The Father* perfectly encapsulates the confusion and emotional disintegration that many individuals living with dementia experience. For over 55 million people worldwide, dementia strips away not only memory and cognitive abilities but the very fabric of *selfhood* [59, 79]. Everyday tasks

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become unfamiliar, and once-comfortable spaces transform into disorienting landscapes. As dementia progresses, individuals often find themselves retreating from social life – not out of choice, but because their worlds become increasingly difficult to navigate. Until a few decades ago, dementia was largely understood as a straightforward narrative of decline, with the focus primarily on cognitive impairment and functional loss [80]. The medical model dominated, emphasising the pathological aspects of the condition and neglecting the broader social, emotional, and experiential dimensions of living with dementia [109]. This perspective, often reflected in dementia care technology design, can unintentionally position individuals as passive recipients, limiting their ability to take initiative and overlooking their valuable skills and experiences [40, 62].

More recently, however, the field of Human-Computer Interaction (HCI) has begun to challenge the deficit-based model in technology design, advocating for a shift towards person-centred designs that acknowledge the full scope of personhood in dementia. These approaches emphasise the importance of considering context, embodiment, sensory experiences, and emotion alongside cognitive function [27, 41, 109], through concepts like personhood [110, 111], felt experience [77], or the Third Hand, a concept from art therapy proposed by Lazar et al. [67] that describes the empowering role of facilitators in supporting creative expression without overtaking the process. Such ideas align with the concept of "critical dementia," which, as articulated by Lazar et al. [68], critiques the dominance of biomedical narratives and embraces a broader understanding of knowledge and personhood in dementia care. Rather than seeking to "fix" cognitive impairments, this perspective encourages a shift towards supporting existing abilities and facilitating new forms of engagement that acknowledge and value the lived experiences of people with dementia [11, 62, 87, 109].

Emerging tools and platforms, such as interactive storytelling systems [42, 67, 109], sensory stimulation devices [77, 110], and immersive technologies like Virtual Reality (VR) [76, 99], offer a glimpse into a future where they could help individuals reminisce about the past, connect with others in the present, and continue to participate in meaningful activities that enrich their lives. However, to realise this potential, research recommends a person-centred approach that tailors solutions to individual needs, preferences, and abilities, while upholding dignity, autonomy, and privacy [27, 69]. Achieving this involves participatory methods that make older adults co-creators, yielding insights into their lived experiences and ensuring that resulting technologies are both meaningful and transformative. Yet, an analysis of 644 HCI papers on ageing and technology design by Vines et al. [109] showed persistent gaps in involving older adults as active participants – particularly in ways that accommodate the diversity of their experiences and capabilities. Creative art-based therapies (cABT) may help address these challenges. As Irfan Manji and Fallavollita [54] showed in their scoping review, engaging individuals living with dementia in personal expression and meaningful activities can reinforce identity and emotional well-being. Still, more work is needed to integrate their varied communication needs and cognitive abilities into technology design. Additionally, the potential to support embodiment and sensory engagement – essential for identity and emotional connection – remains under-explored.

Our research addresses the need for more inclusive and participatory methods that prioritise personal expression, sensory engagement, and personhood in designing technology for people living with dementia. Central to this approach is *creating with care* – not simply as a design principle, but as an ethos that places relationships, trust, and creative agency at the heart of technological development. Drawing on Joan Tronto's ethics of care [104, 105], we show that designing with care requires *attentiveness* to the lived experiences of people with dementia, *responsibility* in how interventions are shaped, *competence* in ensuring meaningful engagement, and *responsiveness* to how participants experience and contribute to the process. Beyond these ethical commitments, we also highlight *plurality* – the recognition that care is inherently collective and must include diverse perspectives. Designing with care is therefore not the work of a single individual or discipline, but a shared, co-creative process that values the voices of people living with dementia, caregivers, artists, and researchers alike. To embody this framework, we integrated cABT-inspired methods and person-centred design practices into an immersive intervention shaped directly by the lived experiences of people living with dementia. Over several weeks, we worked closely with 34 individuals living with dementia, their caregivers, and professional artists to co-create small-scale physical worlds, engage in storytelling, and layer soundscapes, before translating these creative expressions into immersive VR representations of these environments.

This holistic process – from art-making and storytelling to virtual immersion – did more than produce a technological artifact. It actively engaged participants in shaping the resulting intervention. By centring their perspectives and abilities, our approach challenged traditional deficit-based models and enabled meaningful engagement, emotional connection, and an affirmation of identity. Rather than relying on technology alone, it was the thoughtful, human-centred integration of creative practices that made a transformative difference in reconnecting participants with their sense of self and creativity. Our work builds on and extends previous efforts to align technology with the lived realities of individuals living with dementia, showing how participatory, person-centred approaches grounded in creative art-making can harmonise technology's potential with the nuanced experiences it aims to support. In sharing these guiding principles and insights, we demonstrate how future interventions can become more inclusive and meaningful by embracing critical dementia perspectives.

2 Background

Here we begin by examining the development of person-centred technologies and their role in fostering attentiveness to the emotional and sensory needs of people living with dementia. We then consider how immersive and sensory systems like VR can build on these ideas, offering new ways to support memory, identity, and self-expression through responsive and competent design. Finally, we explore co-creation as a pluralistic approach to technology development—one that values the voices of people living with dementia, caregivers, and designers alike.

2.1 Creativity and emotional engagement in dementia care

For decades, the prevailing narrative surrounding dementia often presents it as a relentless decline, a "death of the self" in which individuals progressively lose memory, identity, and social roles [33]. Such deficit-based viewpoints marginalise those affected, often reducing them to passive recipients of care and overlooking their agency and intrinsic value. In contrast, an emerging perspective – rooted in the dialogical approach to identity – emphasises that personhood is co-constructed through social and relational interactions. Rather than viewing people living with dementia as diminished versions of their former selves, person-centred care [12] recognises them as whole, evolving individuals, who continue to be shaped by their unique emotions and experiences. From this standpoint, Kitwood [59] argued that personhood is not inherently lost with cognitive decline, but can be maintained and reinforced through social recognition and meaningful participation. Acknowledging personhood thus involves creating opportunities for people living with dementia to retain agency, express themselves, and sustain their sense of selfhood, even as their cognitive abilities change.

Creative approaches in dementia care, rooted in the concept of creative ageing, build on a person-centred understanding of care and are underpinned by principles such as Animation, Transcendence, Selfhood, Humanity, Expression, Connection, Possibility, Involvement, and Awareness [30]. These approaches offer concrete opportunities for self-expression and engagement, even as cognitive abilities decline [103, 112]. Activities like painting, music, and collaborative art-making empower individuals living with dementia to maintain agency and interact meaningfully with their surroundings [16, 54, 95], thereby affirming their intrinsic creativity and reinforcing personhood [7, 55]. Research highlights that aesthetic experiences – such as selecting colours, textures, or sounds – offer sensory stimulation that reconnects individuals with their identity [23, 96] and allow emotions, skills, and memories once thought lost to dementia to resurface through embodied expression. When these expressions recognised and valued, they affirm a person's continued role in shaping their own narrative [17]. In group settings, shared artistic activities further promote a sense of belonging and social connection [29, 57, 89], strengthening both local and broader communities of care [102].

2.2 Personhood-centred technologies for emotional and sensory engagement

Building on the recognition that creativity and self-expression are central to affirming personhood in dementia care, HCI research has increasingly embraced these principles to reimagine the role of technology. Historically, dementia care technologies have prioritised compensation for cognitive decline, but research by Holbø et al. [50], Kitwood [60], Knowles et al. [62], Lazar et al. [68], Vines et al. [109], Wallace et al. [111] shows these designs often reinforce ageist stereotypes and overlook the social and emotional aspects of personhood. Over the past two decades, HCI has increasingly embraced creative and participatory elements in designing technologies that align with the principles of person-centred care, creating opportunities for agency and meaningful connections. For example, Jayne Wallace's work exemplifies the integration of creative approaches, being grounded in the understanding that personhood is "internally changing and externally nurtured through relational and social contexts" [111]. Their projects include the redesign of a *reminiscence room* in a dementia care ward [110] and a thoughtful, exploration of selfhood through the co-creation of digital jewellery with a couple navigating dementia [111]. Similarly, Lazar et al. [67] explored how art therapy, guided by the concept of the "Third Hand," empowers older adults through creating and sharing, enhancing social bonds and identity. Projects like Mariana's Song [21] have demonstrated how blended physical/digital installations can support self-expression and emotional engagement. Other approaches, such as craft-based interventions [92, 93], showed how physical objects and activities can preserve self-defining memories and evoke emotional recall. Music and performance also hold transformative potential. For example, participatory music sessions have been shown to create opportunities for connection, touch, and sensory engagement while fostering community [77].

Immersive and sensory technologies, including VR, offer new opportunities to deepen engagement and sustain personhood through tailored, multisensory experiences. Early projects like CIRCA [41] and multimedia biographies [24] demonstrated how interactive systems can evoke memories and affirm identity through personalised content such as photographs, music, and narratives. Complementary methods, including screen-based interfaces [38, 110], mobile devices [2, 4], sound players [51, 107], or olfactory devices [3], have shown the role of aesthetic embodiment [63], where physical and sensory interaction enables self-expression and reconnection with personal history [18]. These approaches align with attentiveness in care ethics through their focus on individual experiences and emotional needs.

Building on these earlier efforts, VR has introduced immersive environments that support reminiscence, identity, and emotional engagement, such as virtual reminiscence rooms, nature simulations, and personalised experiences like concerts or landscapes [49, 98] have shown promise in promoting well-being and rekindling identity. However, meaningful engagement in dementia care requires responsiveness – ensuring that technologies adapt to the evolving needs of individuals. Despite these advancements, as Skurla et al. [99] observe in their systematic review, VR research in dementia care remains predominantly focused on cognitive training and assessment, often overlooking subjective lived experiences and emotional well-being. While applications like the Virtual Supermarket [114] or Tai Chi exercises offer cognitive and physical benefits [52], they fail to address the sensory and relational dimensions of care. Instead of focusing on task-based outcomes, there is a growing need to explore how immersive technologies can enhance creativity, connection, and self-expression, supporting identity through emotionally engaging, multisensory interactions [36, 45]. Understanding how to design and integrate these systems effectively, while ensuring they prioritise emotional resonance and person-centred care, is essential for supporting personhood in dementia care. The following section examines co-creation as a critical approach to achieving these objectives.

2.3 Co-creation in dementia care

What distinguishes some of the projects we presented in Section 2.2 is their commitment to two principles: **(1)** empowering individuals living with dementia to shape their own experiences, spaces, and objects, thereby reinforcing their connection to identity and personhood; **(2)** meaningfully including them as co-designers in the creation of artworks and technologies that reflect their life stories. This line of research, initiated and developed by scholars like Lindsay et al. [73], Hendriks et al. [47, 48], Holbø et al. [50], Wallace et al. [110, 111], Lazar et al. [67, 69, 70], among others, uses traditional participatory design methods to explore how people living with dementia can be actively included in the co-design process. At the same time, co-design with individuals living with dementia presents distinct challenges. Cognitive impairments can hinder engagement with complex design activities [43, 101], while the brevity of many co-design engagements can limit the depth of involvement. Research often treats co-design as instrumental – a practical means to an end – without fully exploring its potential for empowerment and emotional connection throughout the process itself. Deepening this understanding requires sensitivity, patience, and adaptable methods that support varying levels of participation [47, 86, 106].

Despite the potential of co-creation, it is still underutilised in many areas of technology design for dementia care. As Goodall et al. [40] highlight, technologies are still predominantly designed *for* older adults rather than *by or with them*, leading to solutions that may not fully align with their lived experiences or needs. Furthermore, individuals living with dementia and their caregivers are often unfairly labelled as "technophobes," a stereotype that oversimplifies their relationship with technology [71]. Although including caregivers and family members in the design process has been shown to enhance practical and emotional outcomes [37], current research often lacks systematic approaches for engaging these stakeholders meaningfully and consistently. Moreover, there is limited exploration of the diverse roles caregivers play and how their varying perspectives influence design outcomes. Evidence suggests that both individuals living with dementia and their caregivers, when thoughtfully engaged, can contribute to unexpected and innovative uses of technology. However, the processes that facilitate such creativity and the barriers to broader participation remain under-explored, highlighting the need for more inclusive and nuanced approaches to co-design.

3 Methodology

3.1 Our approach

Our approach integrates co-design through art-making with experiencing VR, combining the strengths of creative expression and immersive technology to support individuals living with dementia. Rooted in a *creating with care* perspective, we viewed participants as active, relational partners in shaping both the process and outcomes. Rather than using VR and art-making as separate tools, we sought to create a continuum of engagement – where artistic expression allowed individuals to reflect on their experiences, and immersive technology enabled them to re-inhabit and interact with their creations in sensory-rich and embodied ways.

The study consisted of five weekly collaborative art-making sessions, followed by a final VR session where participants experienced their creations in a virtual environment. The entire process is summarised in Figure 2 and images from the workshop are presented in Figure 3. We collaborated with 44 participants across four locations, in partnership with a specialised arts organisation. Out of the participants, 22 people living with dementia experienced the resulting VR environments, and we conducted interviews with 10 of them. During the five-week process, participants engaged in 2-hour long sessions, supported by different artists (including a writer, a model-box maker, and a sound designer) at various stages, co-created *model boxes* (i.e., scaled-down 3D physical representations of elements they found meaningful). These boxes incorporated visual, tactile and auditory elements, allowing participants to express their memories and identities in a tangible form [110]. In the final session, Session 6, participants were immersed in VR environments that were specifically created based on the physical model boxes developed by their respective groups. Each participant experienced only the VR environment corresponding to the model their group had created, and did not explore environments developed by other groups. This approach was intended to enhance sensory and emotional engagement though aesthetic embodiment by allowing participants to experience their work from a new perspective. In our study, we examined the full process of creating immersive environments. This included: (i) participants' reflections and conceptualisations of meaningful places; (ii) their collaborative efforts in building physical representations of these places, and (iii) the ways in which the experience of the VR content was shaped by their active involvement in its co-production. Finally, we explored (iv) the emotional impact of being immersed in the VR environments they had helped create [74].

3.2 Our participants

We collaborated with Bright Shadow, a specialist arts organisation, which facilitated recruitment for our study and managed participant selection. They identified **44 participants**, 34 of whom were living with dementia at various stages – ranging from early to mid-stage, with one participant in a more advanced stage – and 10 participants who were caregivers or family members. The organisation's existing relationships with participants ensured a seamless and inclusive selection process. While we did not independently collect detailed demographic data (e.g., disease stage, years since diagnosis), this decision aligned with the charity's established approach to participant engagement and data privacy. However, the group included a balanced representation of genders and ages, reflecting a diverse range of experiences. The primary focus of our study was to explore creative and emotional engagement rather than to make comparisons based on individual characteristics such as age or gender. In this study, we intentionally chose not to refer to participants by anonymous identifiers, as this approach can feel dehumanising and inconsistent with our person-centred methodology. Instead, we assigned each participant a pseudonym, allowing us to refer to them by name when presenting findings.

To ensure the highest standard of ethical care, one researcher completed two NHS-certified courses: one on dementia care, focusing on supporting well-being and understanding the condition,

and another on the Mental Capacity Act, covering areas such as assessing mental capacity, making best-interest decisions, and safeguarding vulnerable individuals. This preparation ensured that participants who might lack capacity were fully supported, and their rights were upheld throughout the study. The researcher's training equipped the team to make ethically sound decisions and respond sensitively to participants' cognitive abilities. Throughout the sessions, staff from the arts organisation and some participants' caregivers were present, providing support and creating a comfortable, secure environment. This collaborative approach ensured participants felt at ease and supported during the workshops.

The study received approval from the Central Research Ethics Advisory Group of University of Kent (application CREAG059-04-22). All participants gave informed consent, signing forms designed with simplified language and images to aid comprehension. Consent was re-confirmed before each session, and participants could withdraw from the study at any time, with no obligation to participate in the final VR experience if they preferred not to.

3.3 Immersive co-creation journey

To facilitate the exploration and co-creation of personal and meaningful places, we conducted a series of six workshop sessions, which we detail below and illustrate in Figure 2.

3.3.1 ***A personal narrative collage - Session 1.*** This activity was carried out in collaboration with *the writer*, whose role was to help participants articulate and narrate their personal stories, enhancing emotional connections to *"meaningful places"*. For this, we asked each participant to create a 2D collage based on the brief *"What is a meaningful place for you"*? Before the session, we asked participants to bring photos or objects associated with their favourite places. These were scanned and reprinted to be used as collage materials together with pastels, markers, paints, textured paper/fabric and graphic-designed collage books. While the participants worked on their collages, the research team engaged in conversations with them about their creations. The final collages (see Figure 5 for a selection) were shared during a group discussion, where common themes were collaboratively identified by the facilitators – including researchers, artists, and the organisation's staff members – for use in the *model box* co-creation in the next session.

3.3.2 ***Model box co-creation for building shared visions - Sessions 2 and 3.*** Based on an analysis of the collages from Session 1, we identified key themes such as *woodlands*, *farmland*, and *beach* settings. These themes became the foundation for the collaborative creation of *model boxes*, which took place during Sessions 2 and 3 across four different locations. Each group of participants worked together on a single model box, bringing their individual and collective ideas to life within a shared, tangible representation of "meaningful places". We collaborated with a *model maker artist* to guide this process because we wanted to transform the participants' abstract ideas into structured, three-dimensional environments. Each model box was crafted with a base and three walls, resembling a theatre stage.

In Session 2, participants began by designing and constructing low-fidelity model boxes, incorporating their chosen themes. By Session 3, they added more detailed elements, personalising the

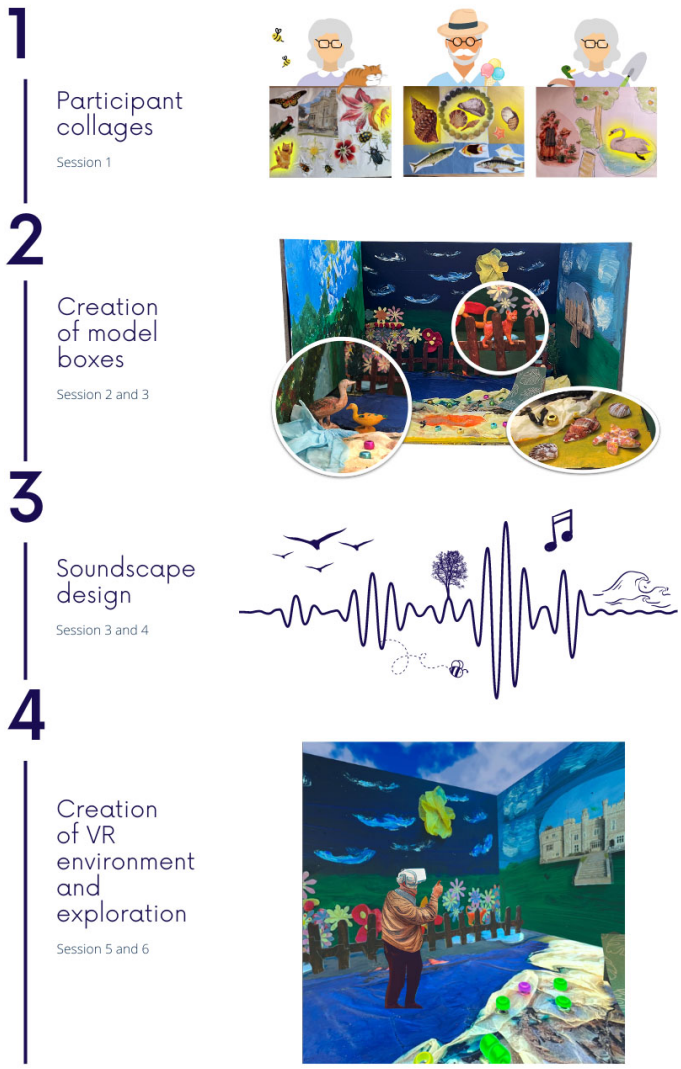

Figure 2: Overview of the VR creation process across six sessions: Participants created collages, which informed group model boxes. Soundscapes were added, and everything was transformed into immersive VR environments for the final session.

spaces with artwork and props that represented their interests, such as pets, trees, or gardening tools. The model maker and facilitators provided technical guidance, while also encouraging meaningful conversations about the participants' creations, deepening their engagement with the process.

3.3.3 ***Soundscape design - Session 3 and Session 4.*** In the final phase of the co-creation process, participants collaborated with a sound designer to enhance their *model boxes* with personalised soundscapes, transforming them into immersive, multisensory experiences. Session 3 was shared between continuing the creation of the model boxes and initiating the soundscape design. Participants began by identifying and recording ambient sounds connected to

Figure 3: Images from workshop activities where participants engaged in art activities like collage-making and model box co-creation

their chosen locations, using these sounds to evoke personal memories and emotions, deepening connections within the group. In Session 4, further exploration of sounds took place, with activities like recreating journeys through forest environments using violin sounds and spoken word to inspire movement and expression. Participants were also invited to imagine themselves in environments like "The enchanted forest" or "Under the sea" through guided poetry and spoken word activities. This provided them an opportunity to write and read aloud their creative pieces, which were recorded for inclusion in the final soundscapes. To strengthen the communal experience, a group singing segment was incorporated. Songs like "Somewhere over the Rainbow" were sung in different versions, both a cappella and with accompaniment, with participants singing together. The recordings were integrated into the soundscapes, enhancing the emotional and collective aspects of the final virtual environments. The inclusion of singing was meant to create a sense of identity, belonging, and shared memory, reinforcing personhood through collective and individual expression.

3.3.4 ***From model boxes to virtual reality experiences - Session 5 and implementation.*** The co-creation phase culminated in Session 5 with a final presentation where each group showcased their model boxes alongside their bespoke soundscapes (see Figure 1). After this, we thoroughly documented the *model boxes* and their accompanying soundscapes. These materials served as the foundation for developing their immersive versions using the Unity 3D game engine. Our goal was to remain as faithful as possible to the original artwork produced by the participants because the creative process and the personal meanings embedded in their art were central to their sense of identity and emotional connection. Preserving the authenticity of their work in the virtual environment helped ensure participants could recognise and feel connected to their creations during the immersive experience. This approach respected their contributions and reinforced the participatory *designing with*, person-centred nature of the project.

To translate the physical boxes into digital environments, we used Maya 2023 to model the objects and Substance Painter for texturing and colouring. Unity 3D was then used to assemble the digital assets into immersive environments (see Figure 4). We carefully referenced photos and image documentation to accurately replicate the proportions of the physical objects, while the participants' original drawings were used as textures in the virtual spaces. We also integrated the soundscapes created during the sessions to enhance the multi-sensory experience of the virtual environments. To unify the work of the four groups into a cohesive art piece, we connected the four spaces as extensions of a single gallery. When users entered the experience, they began in a lobby (see Figure 6b), which featured four doors representing the locations of the workshops. Users could select which environment to explore from there. The lobby's design drew inspiration from the tea & biscuit gatherings during the workshops, where participants would come together, share stories, and connect over tea and snacks. This communal atmosphere was mirrored in the virtual space, maintaining the sense of familiarity participants experienced during the workshops.

3.3.5 ***VR immersion – Session 6.*** After creating the VR environments, we organised a Session 6 at all four workshop locations to allow participants to experience the virtual environments they had helped create and to explore their reactions to these immersive spaces. Session 6 began with a reintroduction to the project, where participants were reminded of their work by showcasing the physical model boxes they had previously built. This was followed

Figure 4: Model boxes created by participants were transformed into virtual spaces in Unity

by an icebreaker activity to re-engage them. Those interested in experiencing the VR environments were invited one by one to a quiet space where the setup was introduced carefully to ensure their comfort. Using Meta Quest 2 headsets, participants were immersed in the digital recreation of their group's model box, giving them the freedom to explore by walking around or sitting and observing.

Of the groups, 22 participants chose to engage with VR, and 10 of them agreed to participate in follow-up interviews. The semi-structured interviews, lasting 15 to 30 minutes, were conducted to gather their reactions and insights. Some of the questions explored how participants felt during the experience and whether they made personal connections to the virtual environment. For instance, they were asked, *"How does the environment make you feel?"* and *"Does this place remind you of anywhere or anyone?"*

3.4 Data collection and analysis

In our data collection we adopted a flexible, experience-centred approach rather than a rigid methodological framework. Aligned with the third wave of HCI [15, 28, 44], this approach acknowledges the importance of situated action and the phenomenological nature of interactions. Our focus was on the lived experiences of participants and the relational dynamics that emerged throughout the co-design process. Through this, we allowed participants to shape the process organically, ensuring the technology supported their personhood rather than compensating for cognitive decline.

During the workshops, observational notes were systematically taken to document participants' emotional and creative expressions, as well as their interactions with facilitators, peers, and the artistic or virtual environments. These observations were complemented by audio recordings, which captured verbal contributions and discussions during both the workshop sessions and the semi-structured interviews, which were later transcribed for detailed analysis. Additionally, occasional photographs were taken to visually document the creative process, the artwork produced, and participant engagement. These photographs were used to contextualise the discussions and provide visual references during analysis. Altogether, these materials — transcriptions, observational notes, and photographs — formed the primary data set for analysis. For data analysis, we employed reflexive thematic analysis (RTA) [9, 10], a flexible method well-suited for capturing the complexity of participant experiences and integrating multiple data sources. Consistent with the principles of RTA, which emphasise reflective engagement rather than rigid procedural adherence [9], we intentionally did not seek inter-coder reliability. Instead, we embraced our own perspectives and assumptions throughout the process, recognising that our interpretations were shaped by our roles as researchers. This approach allowed us to focus on participants' subjective meanings and emotional responses, which was crucial given the deeply personal nature of the project. To complement this, we applied the *critical incident technique* (CIT) [32, 108] to identify significant moments during the workshop. CIT enabled us to pinpoint key shifts in engagement, creativity, and interaction, offering deeper insights into how participants responded to the co-design process and VR experiences. The critical incidents illustrated how participants' behaviours, emotions, and interactions evolved, as well as the role of the creative environment and facilitation in shaping these changes. To further contextualise our insights, we crafted *vignettes* – narrative snapshots of specific critical moments – to bring the experiences of participants to life.

A sub-group of three researchers, with backgrounds in HCI, immersive technologies, and dementia care (two of whom were present at the workshops), conducted the analysis. Throughout the analysis stage, we held regular meetings to identify data patterns related to themes such as *agency*, *emotional engagement*, *creative expression*, and *the transition from physical to virtual interaction*. These meetings allowed us to iteratively refine the codes, determining which were most useful for interpreting relevant themes, how they could be grouped by shared meanings, and which could be discarded. Following the initial identification of potential themes, two additional meetings with the wider research team provided opportunities for others to enrich the analysis with their diverse perspectives and experiences. Through this iterative and reflective process, we identified six themes aligned with our research objectives. In a final session with the entire team, we critically discussed and collectively agreed on the final content of the analysis.

4 Findings

As outlined in the Section 3.4, we used *vignettes* to capture pivotal moments identified through the CIT. Each vignette, written from *the first-person perspective of the researchers*, *focuses on the experience of a single participant* while reflecting *broader patterns observed across the group*. Drawing on observational notes, transcriptions,

and reflective accounts, these narratives bring to life the critical incidents where participants engaged with the co-creation process or the VR environments. Following our commitment to focusing on experience as the central object of study [61], and inspired by Collingham et al. [21] and Gamboa [35], the vignettes provide a grounded and relatable entry point into our findings [91]. Each vignette introduces a result theme, offering insights into participants' lived and emotional realities. These narratives are followed by a broader reflection, linking the critical moments to the theme being explored, the wider dataset, and relevant literature.

4.1 Caring for identity by anchoring memory and sensory experience in personal landscapes

Vignette 1: Holly adds a lighthouse. *During the workshop, Holly began by drawing her own version of Woolacombe Bay, not exactly as she remembered it but as she envisions it now. She did not engage much with the collage materials at first, preferring to sketch from her own memory. When shown some shells, she decided to include them in her design to represent the beach. Fond of rabbits, she added a hare in the scene. Finally, she placed a lighthouse overlooking the sea – a feature not part of her original memory, but one she felt belonged to the landscape she was now creating. This blending of memory and imagination stood out to us, as it reflected how memories, even those of familiar places, can evolve and transform in the moment.*

The workshops often began with personal memories – childhood landscapes, meaningful places, and relationships that had shaped participants' lives. However, as they engaged in the creative process, these memories became a foundation for new ideas (see a selection of collages reflecting this in Figure 5). Holly's creative process highlights how personal memories and imagination work together to reframe meaningful places, offering a connection to identity. Holly's design blended remembered details with imagined elements – like the lighthouse – showing that memory is not a static repository but an evolving construct influenced by present emotions and perspectives. Michael recalled the stream at the bottom of his garden, where he would splash in Wellington boots, watching wildlife. As the art-making process unfolded, his collage became more imaginative, featuring exotic animals. He later wrote onto his collage, "Where is Michael?" suggesting a deeper reflection on his identity and sense of self as dementia shaped his experience. Abby recalled the garden where she was evacuated during the war as a safe space during childhood uncertainty. Similarly, Adam described his Whitstable garden full of insects and butterflies, a symbol of his lifelong connection to nature and a reminder of loss as the wildlife diminished over time. Other participants focused on places tied to social bonds, such as Penny's memories of Nepal, where she formed deep connections with a community, or Jill's recollections of family holidays on Cornwall beaches, which celebrated shared joy and togetherness.

Sensory details, particularly sounds, emerged as powerful anchors for these memories. Cowbells from Austrian meadows, seagulls calling in Whitstable, and the hum of supermarket checkouts brought immediacy and emotional depth to participants' stories. For Bertie, the sound of waves and eagles at Walpole Bay evoked feelings of being "cool, free, calm, and happy," while Rosemary associated the noise of children running with pure joy. For Doris, the Norwegian Church in Rotherhithe brought memories of her father playing the organ and Christmas carols sung around a tree. Trevor remembered the bugle from his sea cadet days, and the smell of seaweed, while Penny described the delicate chime of prayer bells. These sensory cues often provided stronger emotional connections than visuals alone, reinforcing the multi-dimensional nature of the meaningful places of our participants.

Many of these sensory and cultural details were deeply tied to participants' heritage, highlighting the need for technological interventions to embrace cultural sensitivity. However, current designs often fail in this regard as shown by Khan et al. [56] in their review, where they report that only 3.5% of dementia-focused technology explicitly integrates cultural contexts. This lack of cultural awareness risks making such interventions less inclusive and less effective for diverse populations. For individuals like Liz, whose memories revolved around Indian ashrams with chattering monkeys, or Amber, who cherished ice skating on Dutch lakes, embedding these culturally resonant elements into sensory-focused technologies could significantly enhance their engagement and emotional well-being.

Technological interventions for people living with dementia should move beyond static memories and generic experiences to embrace the evolving and multifaceted nature of personal narratives. Many current applications, including VR, rely on serene but impersonal settings like forests or gardens [1, 13, 49], which may offer relaxation but fail to engage with the deeper, more personal layers of memory, identity, sensory experiences, and cultural heritage. This highlights the critical need for technologies to incorporate culturally resonant and sensory-rich elements that reflect users' diverse backgrounds, fostering inclusivity and emotional well-being [56]. Personalisation in technological design should leverage sensory triggers – such as sound, touch, and visuals – not only to anchor users in familiar contexts but also to offer opportunities for self-expression and reflection [66, 83]. Whether through immersive VR, tactile installations, or soundscapes, these flexible, multisensory approaches could empower individuals to shape experiences that align with their evolving narratives.

4.2 Art as a medium of care for expression and recognition

Vignette #2: Nora is painting a blue sea. *Nora was not particularly talkative when we first met her, offering only brief responses to questions about a memorable place. But as soon as the collage-making session started, something changed. As her hands moved through the materials, memories began to emerge. She had brought along a postcard of a beach from her home in New Zealand and softly shared how much she missed it. "Nothing will beat the beaches in my country," she said with pride while painting a blue sea. The art activity helped Nora to open up. As she grew more comfortable, her stories began to flow. Creating art provided her with a new way to express herself, blending memory and creativity in ways that words alone could not capture.*

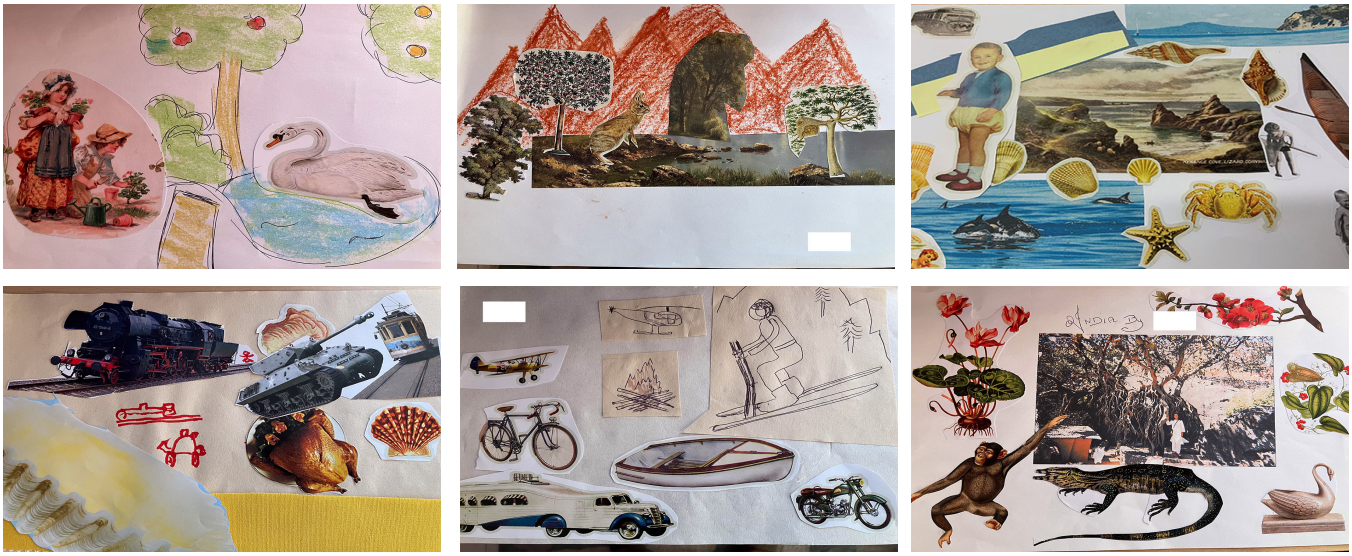

Figure 5: A selection of six collages created by participants to represent their perceptions of meaningful places. These collages express personal memories, preferences, and emotional connections to locations that hold significant meaning in their lives.

Art was our primary form of communication throughout the project, helping us connect with participants and build rapport. For individuals living with dementia, verbal communication can often be fragmented or challenging [88], and this was true for many of our participants. Creative activities gave participants a way to share personal memories, emotions, and stories that might not have come up in conversation [72], helping to bridge communication gaps while respecting their individuality and letting them express themselves in their own way. Nora's story in *Vignette #2* illustrates how art can become a powerful alternative to verbal communication, particularly for individuals living with dementia.

Similarly, Liz was initially reluctant to speak much, but as she worked with one of us on creating a Banyan tree model, she gradually opened up, sharing stories of her time in India and her deep connection to nature. This art-making activity was not just about being creative as it opened the door to memories and emotions. It turned the process into a shared experience, where Liz and the researcher worked together, almost like a team, connecting through the act of creating. The playful addition of a clay monkey (see Figure 6a) – suggested by the researcher, inspired by her stories – made Liz feel proud and remark, *"I'm proud of what we've done."* This also shows the bond which has formed between participant and researcher as a result of the co-creative activities. Through this process, the participants felt seen, valued, and understood, this supporting relational personhood [34]. Interestingly, several weeks later, when Liz returned to try on the VR headset and see her group's final creation, she expressed her disappointment when she did not see her Banyan tree in the virtual world, saying, *"We haven't got anything that we did there… you made a lovely monkey."* Liz's reaction at not seeing the Banyan tree in the final VR environment points to the importance of both the creative process and the final representation in co-designed projects. Undeniably, much of the power of participatory art lies in the shared experience of creation. However, Liz's emotional reaction reminds us that participants also form strong attachments to the tangible outcomes of their creative work. For Liz, the Banyan tree represented a meaningful connection to her past and identity, and at the same time a materialisation of the bond she created with the researcher. The process of creating art enables emotional connection and self-expression, and the final product serves as an important validation of that journey, reinforcing a sense of ownership and representation [73].

What became evident during the sessions was that artistic skills did not matter – everyone found ways to express themselves, regardless of ability. While some participants, like Alice, created detailed and elaborate collages, others, like Nora, painted simple images such as a blue sea. The wide range of artistic responses allowed participants to feel comfortable and encouraged creativity without the pressure of artistic perfection. This ensured that no one felt intimidated by their skills, making the art-making process a space for exploration and self-expression.

Beyond serving as a tool for researchers to connect with participants, art also played a vital role in nurturing connections between the participants themselves. Throughout the sessions, participants often shared materials, commented on each other's creations, and reflected on shared experiences. For instance, during one of the sessions, participants began working with natural objects like tree bark, which led to discussions about their love of nature and past outdoor adventures. These moments reflect how shared creativity can stimulate conversations about common interests and experiences, building a sense of community within the group [94]. Art became the common thread linking their diverse experiences, offering a space where they could reflect on their lives, interests, and memories in a collaborative way and make meaningful connections not only with the researchers but also with each other.

4.3 Caring across time – balancing past, present, and future

Vignette #3: Bruce's dad. *During the VR session, Bruce surprised us with a moment of deep reflection. When asked what he might want to experience again, he paused and said, "I'd like to see my Dad again." It was a poignant revelation, a desire to use VR as a way to reconnect with a deeply personal piece of his past. But almost as quickly, his practical side surfaced: "I don't know if that's a good thing, actually," he added, with a trace of hesitation. This tension between longing for the past and guarding against its emotional weight seemed to echo Bruce's character throughout the workshops.*

The nuanced role of memory in dementia care indicates the importance of engaging with the past, present, and future. While reminiscence can provide comfort and continuity, it must be balanced with activities that foster present engagement and future aspirations to avoid frustration and promote well-being [6, 53]. Our study found that removing the pressure to remember allowed participants to engage more naturally with their memories while also exploring new possibilities.

Engaging participants across temporal dimensions revealed diverse approaches to connecting with identity. Reminiscence brought joy and a sense of continuity, as seen in Michael's recollection of splashing in a stream during childhood. Present-focused activities encouraged creativity and active participation. During the workshops, participants started by recalling memories and then they reimagined them. For instance, Bruce moved from pragmatic survival memories to crafting a surreal, Monty Python-inspired scene. These activities reinforced their sense of agency and belonging [14, 90, 111], showing that creativity enhances engagement and connection in the moment. Looking toward the future brought hope and motivation, demonstrating the enduring importance of aspirations in dementia care. In the VR sessions, participants imagined new possibilities. Richard envisioned a 3D flying simulation after describing flying through the clouds as *"one of the best days I've ever had."* Holly expressed a desire to virtually visit Venice and London. Bruce's wish to "see his dad again" demonstrated how immersive technologies can tap into deeply personal memories while inspiring forward-looking aspirations.

Immersive experiences added a new layer to participants' creative journeys, enabling them to move beyond memories explored during the workshops. Tools like VR allowed participants to revisit the past and to actively connect with it in the present, creating emotional and sensory bridges between timeframes [63]. For many, these experiences became a means of navigating time, evoking profound reflections and inspiring future-oriented creativity. Bruce's wish to *"see his dad again"* exemplified the emotional depth of these interactions. Similarly, Richard's description of flying through the clouds as *"one of the best days I've ever had"* highlights the capacity of immersive environments to foster joy and a sense of freedom. These experiences often extended beyond reminiscence, sparking imaginative ambitions, such as Richard's vision to create a 3D flying simulation: *"I'd like to create a flying version of me flying an aircraft above ground."*

These findings indicate the potential of technologies – not just VR but any immersive, creative, or interactive systems – to empower individuals living with dementia to engage with the past while envisioning new possibilities. This approach shifts the focus from static reminiscence to a more dynamic engagement with memory and imagination, providing meaningful opportunities to shape narratives that extend across past, present, and future, as recommended by Basting [6].

(a) Liz's Banyan tree and the playful guest

(b) The lobby of the experience

Figure 6: Assets produced by participants and VR replica of tea and biscuits time.

4.4 Balancing realism and abstraction in dementia-focused design

Vignette #4: Dan's castle and Holly's sky. *Dan brought a photo of a castle, a symbol of his memories, which became a centrepiece in the group's model box and was later translated into the VR world. As each participant entered the virtual environment, their reactions brought new interpretations. Bruce immediately exclaimed, "Canterbury Tales!" – the VR castle sparking reflections on his past, leading to a deep conversation about architecture and survival. Holly was enchanted by the "lovely sky" and familiar elements, like birds and the castle, which made the experience comforting. Ron, struggling to recognise the castle, recalled a thrilling memory of a double-decker bus ride through the West Gate Towers. Though the castle remained a puzzle for him, the VR brought joy and connection, reminding him of past adventures.*

Research on memory and perception highlights the importance of both authentic and abstract elements in triggering meaningful engagement with virtual environments [100]. Authentic, realistic elements can anchor a participant in a familiar reality, helping to evoke memories and emotions associated with specific places or events. For example, studies have shown that people tend to respond to certain visual cues or environmental triggers that help evoke autobiographical memory [58]. In our study, participants like Bruce and Ron made these connections when they saw the VR castle, interpreting it through the lens of their own experiences, such as Bruce's reflections on architecture and survival, or Ron's memory of riding a double-decker bus near the West Gate Towers, which look similar to the castle.

However, abstraction plays a key role by creating space for personal interpretation, imagination, and emotional resonance. Abstract elements can be more flexible, allowing participants to "fill in the gaps" with their own memories or emotional responses [25, 78]. The generic VR castle, for example, enabled different participants to associate it with various locations or memories, leading to diverse interpretations. Holly was comforted by the abstract blend of the sky, birds, and castle, creating an emotionally meaningful connection for her. Visual elements like landscapes or the sky are often easier to abstract, as they naturally lend themselves to broader associations. Yet, some abstract elements designed to imitate real-world interactions were less convincing for participants, who expressed dissatisfaction when these elements fell short of their real-world counterparts. This highlighted the importance of ensuring that certain aspects of the virtual world meet user expectations. For example, attempts to mimic realistic object interactions, such as opening doors or picking up objects, sometimes failed to engage participants when they did not function as expected.

This raises design questions about how technologies for individuals living with dementia should be constructed. Should these technology-mediated experiences focus on authentic, realistic elements to anchor participants in familiar memories, or use abstraction to allow for personal interpretation and imagination? Abeele et al. [1] identified digital nature and scenic views as particularly engaging for older adults. In our case, we also leaned toward representing outdoor spaces because these were the environments participants found meaningful in the first session. However, by combining different elements from each participant's memories and translating them into VR, the result was far from a simple representation of the physical world. The final VR experience became something surreal – an unexpected blend of real places and personal memories that did not resemble a true-to-life environment. Despite this, participants still connected with this world in personal ways. This interplay between abstraction and connection aligns closely with Dewey's theory of aesthetic experience [26]. Dewey describes art as a dynamic process that engages the imagination, emotions, and senses, creating a sense of wholeness and continuity. His emphasis on imagination as a bridge between the known and the novel resonates strongly with the potential of personalised technology experiences for individuals living with dementia. Rather than aiming for realism, these technologies could engage users by creating spaces that invite personal interpretation and connection.

4.5 Technology for *being and doing*

Vignette #5: For Sofia, ο ήλιος (i.e., the sun in Greek) is magic. *Sofia was initially hesitant about the VR experience, but with encouragement from her friend and our conversation in Greek (i.e., her native language), she agreed to try it. Her reactions focused more on the immediate sensory experience than the virtual content or its connection to the physical model box. She seemed emotionally stirred by our shared Greek heritage rather than the technology itself. For Sofia, the VR was less about understanding the connection to the model box, and more about enjoying the sensory and aesthetic experience of the moment.*

The VR experience evoked a range of emotional responses, often rooted in a sense of awe and immersion. In Sofia's case, the technology offered a momentary pleasure, without prompting a deeper connection. Others were similarly drawn to elements like the sun, the sky, or the overall ambiance, focusing on the aesthetic and immediate experience rather than any specific narrative. These moments of being fully present, however brief, carry immense value for individuals living with dementia. They provide opportunities to inspire curiosity and spark meaningful engagement. Studies support this notion, showing that minimal sensory interaction, even when not connected to a narrative, can positively influence emotional well-being in dementia care [21, 31].

While some participants, like Sofia, engaged with VR as a space for simply *being*, enjoying the sensory novelty and aesthetic immersion, others, like Richard, sought opportunities for *doing* [5]. His attention was first drawn to the *"amazing blue sky,"* but soon after, he related it to a personal memory, saying, *"I used to fly like this... the blue sky is lovely."* This initial observation led to a creative impulse as he shared, *"I'd love to do a painting like this, a 3D painting,"* and then asked, *"Do you use special inks?"* He then shared his idea: *"I'd like to make a Christmas scene, in a forest of green conifers with a Christmas tree and white baubles on the end of it"*, which he made sure to communicate it to the carer with a sense of pride after the interview was over. Richard's comment on the *"amazing blue sky"* transitioned into a memory of flying and led to creative action, embodying a form of self-expression. This flow shows how people living with dementia continue to make meaning through relational, social, and embodied contexts, where memories are not confined to

an internal process but are actively shaped by their surroundings. Similarly, Ben's appreciation of the sensory aspects led him to express curiosity: *"I would be tempted to search the background, and see what it's all about,"* shifting from passive engagement to an active search for meaning. Jack, too, found value in the novelty of the experience, remarking, *"It made a nice change... nice to experiment with different things,"* reflecting a desire for exploration and new experiences. In each case, the participants moved between aesthetic embodiment, by being immersed in the sensory experience, and cognitive engagement, as they sought deeper connections or new opportunities within the virtual environment.

For some participants, like Holly, the absence of a clear purpose created uncertainty. She remarked, *"It's a bit weird but it's very interesting. Sunny bright place. Nice. So what's meant to happen?"* Once prompted to explore, she began engaging with the environment, suggesting the importance of balancing open-ended sensory experiences with some direction. However, for Debby, even these cues were insufficient, as she expressed dissatisfaction: *"I don't really know what it [the VR art] is meant to be... I'd like to know what I'm looking at in there, and you know, real. It wasn't interesting."* When asked how the experience could be improved, she reflected on her fondness for narratives: *"I do know, I quite liked storyboard things... when I was young, we didn't have television, so what we did was storybooks."*

These varying responses highlight the need to balance technology designed for being with that designed for doing. While moments of sensory immersion can provide emotional well-being and human flourishing [19–21, 81, 97, 111], opportunities for purposeful interaction can enhance the experience for users seeking narrative or agency. Designing for dementia care requires flexible environments that cater to both, allowing users to just be when they wish while also enabling them to do when ready.

4.6 Social reinforcement in technology adoption

Vignette #6: Maya's first step, leading the way. *At first, interest in trying VR remained lukewarm, the VR headset sat untouched. Then, Maya's daughter quietly broke the silence by trying it first. Her excitement was contagious, "That was amazing," she said, her excitement quietly spreading to the others. Soon after, Maya tried the VR herself. A quiet smile on her face revealing her enjoyment as she shared the moment with her daughter. Gradually others grew curious by her reaction. At first, they hesitated, but one by one, they stepped forward and gave it a try. Their expressions of wonder were unmistakable, and a few participants even walked around the room with the headset, exploring the virtual world. What began as a typical tea and biscuits gathering had transformed into a moment of shared discovery, where curiosity, not biscuits, became the treat everyone savoured.*

There was a certain hesitation among the participants in trying the VR. Unlike the art-making activities, where they readily participated, the VR headset was met with some resistance. For some, it was viewed as something that might *"take over the world,"* while others expressed fears of disorientation, discomfort, triggering anxiety, or skepticism about its realism. This led us to adjust our approach, as we decided to introduce the VR experience during the familiar tea and biscuits session for some participants. We hoped the shared energy of the group setting would encourage more organic interactions with the VR experience.

We observed that after Maya's daughter tried the VR headset, her reaction motivated the other participants, demonstrating the role of social reinforcement in encouraging technology adoption. Though Maya's own verbal feedback was minimal, her willingness to engage with VR after her daughter's excitement illustrated how peer influence can break down barriers of hesitation and change perceptions around unfamiliar technologies. On another occasion, Drew, who had initially avoided VR, agreed to try it after a carer briefly encouraged him. He thoroughly enjoyed it, prompting the carer to try it as well. We encountered a similar resistance from Sofia, who only agreed after repeated encouragement from a friend who had tried it. Her friend's positive reaction, along with the researcher speaking to her in her native language, eased her concerns and made the experience less intimidating. This is something we observed repeatedly throughout the project, demonstrating the significance of community and familiar social dynamics in promoting curiosity and overcoming technological anxiety among older adults [65].

5 Discussion

We embarked on this project to explore how VR can be designed to help people living with dementia connect with their identity, strengthen their personhood, and enhance their well-being. We built on inspiring previous work in the area [21, 49, 68, 110, 111], we collaborated with a team of artists, and took a person-centred approach to *create with care*. We began with physical art-making sessions, where participants co-created meaningful places, explored and conveyed their emotions, memories, and experiences in a creative way that words alone might not capture. Through art, participants could visually represent important aspects of their identity, shaping a narrative that was deeply personal and reflective of their life stories. These sessions also facilitated connection – both with themselves and with others. By sharing their creations and stories, participants were able to form deeper bonds with the researchers, caregivers, and fellow participants. The art-making process created a collaborative and social environment, where participants felt seen and understood, reinforcing a sense of belonging and community. These personal creations were then transformed into immersive VR experiences, allowing participants to explore the environments they had designed. This enabled a sense of aesthetic embodiment for some, deepening their engagement with their memories and enhancing the connection between past experiences and present realities.

Through our process, we found that while VR holds great potential for engaging individuals living with dementia in new ways, it cannot be the sole focus of an intervention. VR's immersive qualities can evoke powerful memories and sensory experiences, but on its own, it often falls short of creating a meaningful, lasting impact. The challenge, therefore, is not just about designing a VR experience but rather developing a comprehensive intervention that addresses the limitations of this technology while amplifying its benefits. This intervention should include co-design, creative pre-engagement activities, human support, multi-sensory integration, and post-VR

reflection to enhance personalisation and emotional connection. This ensures the technology is part of a holistic, person-centred approach rather than a stand-alone experience. Below we reflect on the challenges and successes we encountered and we propose a series of insights that can inform the design of such interventions.

5.1 Do not disenfranchise people living with dementia in the design of technology

Involving people living with dementia in meaningful co-design activities of VR experiences is key to making sure the technology truly fits their needs and feels personal. Our project demonstrated that, despite cognitive challenges, participants showed a strong ability and desire to make decisions, express preferences, and contribute meaningfully to their creative outputs. This participatory approach provided them with a sense of ownership, purpose, and accomplishment, reinforcing their personhood and agency. This aligns with findings from Kontos et al. [64], who noted that individuals living with dementia retain their capacity for creative expression when supported in the right environment. However, to best of our knowledge, most studies in this space fail to meaningfully involve users in the design process [99], and focus primarily on evaluating the final product or the cognitive abilities of the users. This misses an opportunity to create tools that are both functional and deeply personal [1, 49]. For instance, Hodge et al. [49] reflected on their limited time for true co-design with participants but noted how essential it was to have even a brief, meaningful engagement that informed the creation of a tailored VR environment. Similarly, Abeele et al. [1] compiled guidelines for designing VR environments for people living with dementia based on existing literature, but rather than developing new experiences, they evaluated an existing commercial app using those guidelines. This highlights a gap between theory and practical, user-driven design. As noted by Knowles et al. [62], excluding older adults from tech design leads to missed opportunities for insight and risks creating technologies that do not fit their needs.

While we initially envisioned the co-design process as a stepping stone toward creating a technology (in our case, a VR experience), it quickly became evident that the journey itself was profoundly transformative for our participants. The artists' presence and guidance created a safe and supportive environment where individuals felt comfortable expressing themselves and exploring their creativity. Over several weeks of shared artistic endeavours, we witnessed a remarkable blossoming of confidence, connection, and self-discovery. Participants like Liz, initially hesitant, opened up and shared stories as she crafted her Banyan tree. Nora, once quiet, found her voice through vibrant paintings. As researchers, we too were transformed by the process. Our participants became collaborators, offering insights into their needs and perspectives that would have remained hidden in a purely technological or short-term approach. This experience revealed that co-design is not just a means to an end but a vital part of designing meaningful and inclusive technology.

Co-design in dementia research extends beyond the typical goals of fostering ownership and agency by addressing the specific challenges faced by individuals living with cognitive impairments. In our study, participants demonstrated the ability to express preferences and contribute meaningfully, despite these challenges, gaining a sense of purpose and reinforcing their personhood. Unique to this context, co-design creates supportive environments that accommodate non-verbal expression, facilitate emotional connection, and encourage creativity – key needs for people living with dementia. Unlike many studies that focus on pairs (e.g., participant-caregiver dyads) [49, 111], our approach engaged participants in larger groups. This setting fostered a sense of community and mutual inspiration, as participants could draw on each other's ideas and energy. The involvement of specialists, such as artists, was crucial in demonstrating competence by bridging gaps left by traditional, verbal approaches, enabling participants to share emotions and memories in alternative ways. By integrating co-design into the technology development process itself – rather than treating it as a preliminary step – our study demonstrated its capacity to build trust and responsibility through tailored activities and creative engagement. Thoughtful projects that engage users over extended periods [49, 68, 77, 93, 110, 111] reinforce the importance of designing with responsiveness to participants' evolving abilities and involving specialists in delivery. To advance these practices, we propose creating a centralised, accessible library of documented co-design projects. This resource could provide concrete examples of tailored activities, strategies for data collection, and shared challenges, equipping researchers and designers with the tools to navigate the complexities of co-design with vulnerable populations.

5.2 Building trust takes time but it is essential for creating with care

Trust was a cornerstone of our project, shaping the success of both the process and the outcomes. Collaborating with a specialised arts organisation allowed us to prioritise meaningful engagement and creative expression while also streamlining recruitment and selection. This freed us, as HCI researchers, to focus entirely on facilitating the art-making process and ensuring participants felt comfortable and willing to immerse themselves in the activities.

A strong foundation of trust, built over time, was key to overcoming initial hesitations. Many participants were reluctant to try VR or found aspects of it physically or emotionally uncomfortable. Complaints about the weight of the headset, visual disorientation, or the inability to see their own feet highlighted the challenges of adapting technology to users' needs. Others expressed apprehension about using unfamiliar tools, fearing they might be judged or laughed at. In these moments, the trust we had established became crucial. Having a trusted facilitator to guide participants through the VR sessions, explain what to expect, and offer reassurance during moments of uncertainty made a significant difference. This aligns with findings from Kontos et al. [64], emphasising the importance of relational engagement in dementia care.

The involvement of artists further reinforced this trust. Artists from various disciplines – storytelling, sound design, visual arts – helped participants translate abstract ideas into tangible outputs. For example, a sound designer worked with participants to create custom audio, such as bird sounds or personal music preferences, which were then integrated into the VR environments. These personalised details not only enriched the virtual worlds but also

strengthened participants' sense of connection to the process. Visual artists helped participants bring abstract ideas like "a happy place" or "a childhood memory" to life through models that were later recreated in VR. This approach demonstrated how trust, combined with interdisciplinary collaboration, could unlock deeper engagement and emotional expression. Over several weeks of shared artistic activities, participants became more confident and expressive, developing connections that would not have been possible in a shorter-term project. Care ethics, as articulated by Tronto [104] and Held [46], emphasises attentiveness, responsiveness, and relational engagement – principles that are particularly vital when working with vulnerable populations. In the context of our project, trust-building activities, such as facilitation by familiar and supportive facilitators or artists, embody these principles of care. They prioritise participants' comfort and sense of agency, creating an environment where individuals feel safe to express themselves and engage with the process. Trust as a form of care can help future researchers and designers show how important it is for meaningful collaboration and co-design, especially when working with the complex needs of individuals living with dementia.

5.3 Art can take one places

Throughout the project, art was central – not just as an outcome but as a method. Participants were involved in the creation process from the beginning, shaping the environments they would later explore in VR. It is known that art has a powerful impact on our emotional and cognitive well-being. Research shows that both creating and experiencing art are essential to being human—they allow us to express ourselves, release emotions, and reflect on our identities [8, 26]. Unfortunately, people living with dementia – some of them in care homes – have fewer opportunities to access art. Care environments often focus on practicality, leaving little room for creative or sensory experiences. There is also a misconception that art might not be relevant for people living with dementia, or that cognitive decline diminishes the value of engaging with art [17]. Thankfully, initiatives like [21, 68, 110] are changing this, showing how much impact sensory-rich aesthetic experience can have in care homes, helping residents reconnect with memories, emotions, and creativity, even in the later stages of dementia.

Our project builds on this work and shows technologies such as VR can be a powerful tool for sensory and artistic engagement. It felt rewarding to watch participants create and then connect with VR worlds that reflected their own artistic visions. The VR environments we created prompted different reactions from participants. For Richard, it inspired artistic expression – the vivid blue sky reminded him of his flying days, and he became motivated to create a 3D Christmas painting. Sofia, on the other hand, found emotional comfort in the soft light and soothing bird sounds, which gave her a moment of peace and calm. Jack saw the VR experience as a chance for exploration and discovery, enjoying the novelty and finding excitement in trying something new. These varied reactions show that sensory-rich and interactive technologies offer much more than just a digital experience. They create spaces for self-expression, comfort, and exploration. What sets immersive technologies apart from traditional art is their ability to *be inside*, to immerse participants in the artwork, allowing them to interact with the environment [75]. Just as musicians experimenting with different virtual spaces find that the environment itself shapes their creative output [82], our participants' experiences were deeply influenced by the sensory and spatial qualities of the VR worlds they entered. This kind of active participation gives people a sense of control and independence, which can be especially empowering for those facing cognitive challenges.

5.4 Personalisation and customisation in dementia care design

One of the key insights from our study is the distinction between personalisation and customisation when creating meaningful experiences for people living with dementia. Customisation refers to tailoring a design to an individual's specific needs or preferences, often requiring significant resources and one-to-one effort. In contrast, personalisation, as we observed, can emerge dynamically when shared environments are designed with flexible, multi-sensory elements that allow users to connect with what resonates most for them. Personalisation here is not about pre-defining an experience for each participant but enabling them to interpret and shape the experience in ways that feel personal.

In our study, customisation was evident in moments where participants' individual inputs directly influenced the design. For instance, elements like Holly's lighthouse, Ron's recollections of a bus ride, or Bruce's request to see his feet in VR were integrated into the virtual world based on their specific contributions during the workshops. Personalisation, however, extended beyond these customisations to encompass how participants engaged with shared environments. Participants in our VR sessions interpreted the same digital spaces differently, drawing from their memories and preferences. This reflects what Gaver et al. [39] term interpretive flexibility, where users make meaning through their own associations. For instance, while one participant associated a VR castle with the Canterbury Tales, another recalled a double-decker bus ride, and a third found comfort simply in observing the birds and the sky.

In our study, we achieved personalisation by incorporating multisensory elements – like visuals, sounds, and tactile cues – that participants could engage with in ways that resonated with their personal histories. These flexible elements gave them the freedom to connect with whatever parts of the environment mattered most to them, showing that personalisation can come through sensory engagement rather than direct customisation. By giving individuals the space to project their own stories onto the experience, we created a deeper, more personal connection without needing to design specifically for each person.

The distinction between customisation and personalisation has important implications for technology design, particularly in dementia care. Customisation can address specific individual needs and foster trust, while personalisation through interpretive flexibility enables richer, more inclusive engagement. By designing environments that balance these approaches, incorporating shared spaces rich enough to support diverse interpretations alongside individualised elements, designers can create meaningful, empowering experiences for people living with dementia.

5.5 Give it a body! Anchor the self in the world

One aspect we had not initially considered in designing VR for people living with dementia was how their physical bodies would or would not align with the virtual world. While this typically does not affect most users, it proved to be an issue for some of the people living with dementia we worked with, sometimes causing disorientation and discomfort. During one session, Bruce looked down and, seeing nothing where his feet should be, said, *"It's weird. I know my feet are there, but they've disappeared."* This disconnect between what he felt physically and what he saw in VR caused a sense of disorientation, and he was not alone. Other participants also experienced confusion, particularly when the virtual environment did not align with their bodily sensations.

This reaction reflects something deeper: embodiment [84] – the idea that our ability to think, perceive, and make sense of the world is closely tied to our physical bodies. When the virtual world breaks that connection, it can be unsettling, especially for individuals living with dementia who may already struggle with processing sensory information. A sense of self is often rooted in physicality, not just through seeing one's body in an environment but also through physically engaging with it. Activities like art-making, where participants use their hands to shape, paint, or build, reinforce this embodiment, offering a tangible way to connect with their sense of self through physical action.

To create more accessible and comfortable experiences, whether mediated by technology or through hands-on creative activities, ensuring bodily continuity is important. Features that reflect or respond to participants' physical presence – such as tools that incorporate hand gestures, tactile responses, or visible bodily representations – can help users feel anchored and reduce feelings of disconnection. This aligns with the concept of embodied cognition [85], which emphasises that thinking, perception, and a sense of self are deeply tied to our physical interactions with the world. Misaligned sensory inputs or a lack of physical engagement can disrupt this connection, as we saw with Bruce's reaction. This approach also supports person-centred care, helping individuals feel secure and connected to both their physical and virtual surroundings. Whether through designing physical tools for hands-on creative expression or ensuring that sensory cues align in digital tools[22], the goal should be to activate a sense of agency and accomplishment through physical engagement [17].

6 Limitations

While our study produced promising results in enhancing emotional well-being and fostering personhood through co-design and virtual reality, several limitations must be acknowledged. These factors could influence the generalisability of our findings and point to areas for improvement in future research and application.

- *Focus on specific stages of dementia:* Most participants were in early to mid-stages of dementia, which may not fully reflect the needs and abilities of individuals in later stages of the condition.
- *Data collection methods:* The qualitative nature of our data collection was often messy and fragmented, with participants' cognitive challenges making it difficult to capture consistent responses or fully structured feedback, which impacted the clarity and completeness of our findings.
- *Limited VR exposure and participation:* Participants only experienced the VR environments once, limiting insights into long-term engagement and potential benefits. Additionally, not all participants chose to engage with VR, reducing the comprehensiveness of our findings and potentially overlooking barriers to adoption.

7 Conclusion and future work

We began this study seeking to create VR experiences for people living with dementia. Yet, through the process and the people who shared their stories, we discovered that what truly matters is not just building technology, but creating with care. Co-design and art became more than methods – they became vessels for self-expression, connection, and relational care, inviting participants to weave memories and emotions into the present in ways that deficit-based models cannot hold.

Our findings show the need to shift from technology-driven approaches to care-centred co-design, prioritising emotional well-being, creativity, and inclusivity. While this work captures only a fraction of that journey, the richness and sensitivity of these experiences cannot be fully conveyed through traditional academic outputs alone. We encourage future research to explore alternative ways of presenting and engaging with this kind of deeply human data, ensuring that the voices and stories that emerge through co-design are represented with the depth they deserve [113].

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