

Life's Tapestry : Rewriting the
Narrative of Dementia, One
Conversation at a Time

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A thesis
submitted in partial fulfillment of
the requirements for the degree
of
Master of Design

University of Washington

2024

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Program Authorized to
Offer Degree: School of Art
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Abstract

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Currently there are over 50 million people living with dementia and this number is said to triple by 2050. Dementia was conventionally regarded as an irreversible progression leading to the eventual loss of essential human attributes and the sense of self. The accompanied social isolation and loneliness further decreases quality of life, it was also linked with quick declines of memory and language fluency.

Frequent and meaningful social interactions can cause significant improvements. The use of Reminiscence Therapy is proven to bring a sense of accomplishment and provide joy through storytelling and can significantly support feelings of identity and confidence. Life's Tapestry is a conversational prompt card game that focuses on using Reminiscence Therapy to help individuals with early stage dementia improve their quality of social interactions

Life's Tapestry : Rewriting the narrative of dementia through conversations

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How can meaningful conversations about episodic memories improve the sense of personhood for individuals with early stage dementia?

Introduction

The aging population

Epidemiological research indicates that 11% of the global population is currently aged 60 years or older. However, it is projected that by the year 2050, this percentage will double (Kanasi et al., 2016). The increase in life expectancy is attributed to advancements in sanitation, medical technology, and healthcare services, along with growing individual prosperity (Heese, 2015). Within our progressively aging population, there is a growing prevalence of individuals grappling with chronic illnesses.

Although many older adults will continue to enjoy good health and remain productive, this demographic as a whole experiences a greater likelihood of physical and cognitive decline compared to their younger counterparts (Pollack, 2005). Currently more than 55 million people have dementia worldwide, over 60% of whom live in low-and middle-income countries. Every year, there are nearly 10 million new cases. (Greenblat, 2023)

Dementia

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. Alzheimer's is the most common cause of dementia. People with dementia often experience memory loss. This is because dementia is caused by damage to the brain, and this damage can affect areas of the brain involved in creating and retrieving memories (Greenblat, 2023).

Dementia affects the memory in three ways (Society, n.d.)

1. Not being able to retrieve information

Even though the person may be able to create new memories, they are not able to access them when needed. They may get lost in familiar surroundings or on journeys they have taken many times.

2. Not being able to create new memories

Recent events are not 'recorded' in the person's memory and so cannot be recalled later. The person may forget a conversation they have just had.

3. Taking longer to retrieve information

Even though the person is still able to recall things, this takes them much longer or they might need a prompt. For example, they might need more time to find the name for an object.

The medical industry is hyper-focused on seeking cures and improving functional well-being rather than improving emotional well-being. A shift in perspective is required from just talking about disabilities and symptoms to capacity and potential.

Those afflicted with dementia often experience a decline in their capacity to remember names, past experiences, and objects. This not only impacts the individuals dealing with dementia but also has repercussions for their families, friends, and caregivers. Moreover, the frequent lapses in memory can lead to feelings of frustration, an increased risk of social isolation, and a diminished capacity to sustain independent living within their homes (Hallberg et al., n.d.)

Early Stage Dementia

Research suggests that a person's sense of self can be impacted in the early stages of dementia (Orona, 1990). This is likely because dementia affects autobiographical memory, which is the collection of memories that define who we are (Baddeley, 1992). It includes both factual details (semantic) and specific experiences (episodic). There seems to be a two-way street at play. Our sense of self is built on these episodic memories, but how easily we can access and integrate new information about ourselves also influences how we see ourselves. This dynamic relationship between memory and self-perception is highlighted by Conway and Pleydell-Pearce (2000).

Episodic autobiographical memory, encompassing recollections of factual details and personal experiences, can also be compromised in individuals experiencing memory decline. However, research suggests a fascinating phenomenon: remote memories, particularly those frequently retrieved and recounted throughout one's lifespan, exhibit greater resilience to such decline compared to more recent experiences (De Simone et al., 2016). This differential preservation potentially reflects the process of memory consolidation, whereby frequently rehearsed memories are thought to become progressively more ingrained within neural networks,

enhancing their resistance to subsequent memory degradation.

Personhood

The concept of human personhood can be viewed through two lenses: one, an existential perspective positing that personhood is an inherent and indispensable attribute of the human species, and two, a relational standpoint suggesting that personhood is a contingent state of worth determined by societal norms (White, 2013). During this research we look at the combination of both these lenses and how they impact each other.

A key aspect of self-identity involves maintaining a consistent sense of being the same person throughout one's life. The construction of self is never a solely individual act but requires the cooperation of others. Selfhood, rather than being ascribed to an individual, is co-constructed in social relationships of reciprocity (Bassett & Graham, 2007). Interpersonal relationships, the social context, and the generation of stories are important in maintenance of self. Singer (2001) and Buber (1996) stated that the establishment and sustenance of one's self-identity are intertwined with the concepts of recognition and equality within interpersonal relationships. Conversely, as suggested by Laing (1998), the erosion of self can manifest when others fail to acknowledge an individual, and their relationships are limited to receiving without reciprocal giving. These ideas closely align with Kitwood's (1997) theory of personhood in the context of dementia.

Reflecting on past experiences, or reminiscing, plays a vital role in shaping our identity. By revisiting our life stories, we gain a deeper understanding of how we've changed and grown over time. Sharing these stories can further strengthen our sense of self. Reminiscing can also boost our sense of purpose by reminding us of positive experiences, values we've acquired, and past and future goals. It empowers us to overcome challenges and negative memories by fostering a sense of mastery and control. Ultimately, reminiscing can lead to a more positive self-image, a sense of acceptance towards the past, successful aging, and a greater overall well-being.

The threat to personhood

In the past, dementia was conventionally regarded as an irreversible progression leading to the eventual loss of essential human attributes, including one's sense of self. Mead (1934) argues that an individual's self is shaped by the social responses they receive within their interpersonal connections and the attitudes held toward them by the broader community or the "generalized other" that represents the societal or communal context they are a part of. One's sense of self is intricately shaped through language and interactions, as proposed by Sarup (1996). It's important to note that each facet of an individual's multiple selves holds equal significance and authenticity when it comes to portraying who they are, both in their own perception and in the eyes of others.

As much as the health effects of dementia affect an individual's sense of personhood, the cognitive decline is also caused by social isolation and stigmatization caused by an ageist society. It is important to note that each facet of an individual's multiple selves holds equal significance and authenticity when it comes to portraying who they are, both in their own perception and in the eyes of others. A key aspect of self-identity involves maintaining a consistent sense of being the same person throughout one's life. Interpersonal relationships, the social context, and the generation of stories are important in maintenance of self. Therefore it is extremely important to help individuals with dementia maintain their personhood for as long as possible.

Social Isolation

Due to the stigmatization of people with dementia, they are often socially isolated in their homes or care facilities. Individuals with dementia often experience a faster deterioration of their condition when their social interactions are limited. Loneliness is defined as the subjective experience of feeling socially and emotionally isolated. Dononvans's (2016) Research has demonstrated that in cognitively intact older adults, loneliness can impact brain physiology by elevating the amyloid burden, a biomarker of Alzheimer's disease

(AD) dementia. Donovan (2016) proposed that we should regard loneliness as a potential risk factor when assessing preclinical AD, as self-reported loneliness was linked to a higher amyloid burden (Abbott & Pachucki, 2017; Rosenberg, 2016) Loneliness was linked to quicker declines in memory and language fluency compared to non lonely individuals during a 10-year follow-up of the English Longitudinal Study of Ageing (Yin et al., 2019). Porcelli et al. (2019) came to the conclusion that social deprivation has an adverse impact on cognitive abilities in individuals with dementia. Therefore it is important to ensure that people with dementia are part of society and involved in social, cultural and economic activities. They shouldn't have to constantly have to determine the best method of navigating within and engaging with their communities (Organization, 2021).

Social interactions are correlated with increased Quality of Life for people with dementia. Social interactions play a crucial role in easing some of dementia's most devastating symptoms (Curelaru et al., 2021) therefore it is important for individuals with dementia to feel welcome and safe in society

Also, society benefits from the active involvement of individuals with dementia. Their objectives encompass fostering understanding of their needs and extending peer support to those grappling with dementia-related challenges. Ultimately, they aspire to enhance the quality

Background

Personal Motivation

I have always been a nostalgic person, I cherished moments captured in photographs — whether it was images of my own infancy or memories featuring friends and family. I would look at these images and I couldn't help but weave stories around them. I'd imagine the laughter, the shared glances, and the conversations frozen in those frames. It fascinated me to think about what might have transpired in those moments — what brought people joy, what made them laugh, and whether they faced similar struggles to those we experience today. Are they the same person they are now?

As a child who moved around frequently, memories became my anchors — fragments of what I did, whom I encountered, where I was, and, most significantly, who I was. The transient nature of my lifestyle made it challenging to stay connected with people or preserve every token of their presence. Often, when I reflect on my past, I perceive my life as unremarkable, lacking in noteworthy stories. However, this perspective shifts when I delve into photographs or recollections of specific individuals. These moments serve as a vivid testament to the richness of my life, transforming what may seem ordinary into a remarkable adventure. My extensive vault of memories encapsulates the essence of who I was, who I am, and the potential of who I will become.

I dedicate this thesis to my two grandfathers. My paternal grandfather, who had dementia due to Parkinson's, passed away in March 2023. In contrast, my maternal grandfather, carrying the Parkinson's gene, has not exhibited signs of dementia or the disease. This personal connection not only sparks contemplation about my own genetic predisposition but also prompts a reflective consideration of the societal and environmental conditions I would aspire to navigate if confronted with such a diagnosis.

For the thesis I conducted extensive secondary research to understand dementia from a non-medical perspective. The medical industry is hyper-focused on seeking cures and improving functional well-being rather than improving emotional well-being as well.

Why Design?

The medical industry is hyper-focused on seeking cures and improving functional well-being rather than improving emotional well being as well. There needs to be a shift in perspectives from disabilities & symptoms to capacity and potential. The fields of healthcare and dementia care have witnessed a paradigm shift, characterized by a philosophical and substantive move towards person-centered care models that emphasize self-management (Brankaert & Kenning, 2020). In the transition from an experience economy to a transformation economy, design professionals are prioritizing the application of local knowledge and infrastructure to address global societal challenges through targeted solutions (Brand & Rocchi, 2010). The paradigm shift in dementia care from a patient-centered to a person-centered approach necessitates the exploration of design solutions that can optimize the lived experience of individuals with dementia. Human centered design practices foster autonomy and independence while valuing preferences and choices.

Dementia, a multifaceted and emotionally charged neurological disorder, necessitates a design approach characterized by sensitivity, empathetic comprehension, and compassionate consideration (Prince et al., 2015). Design interventions have the potential to cultivate a reframing of self-perception in individuals with dementia, while simultaneously fostering a societal shift in perspective. This shift would move beyond viewing them solely as patients or statistics, and instead recognize them as multifaceted individuals with rich personal narratives and a wealth of past experiences. The efficacy of non-pharmacological interventions for dementia management can be significantly enhanced through the strategic application of human-centered design (HCD) principles. This approach fosters the development of interventions that are not only evidence-based and clinically sound, but also user-centered, promoting greater engagement, adherence, and ultimately, improved quality of life for individuals living with dementia.

The Reframing

Original Idea

Initially when I started out the journey of the Masters of Design thesis I wanted to do a speculative design project imagining the future of a dementia inclusive society. A society in which people with dementia and their carers fully participate in society and can belong. It is a society where they enjoy respect, freedom, dignity, equality, accessibility and quality of life. Striving to create such a society would help individuals with dementia reduce their steep decline of quality of life and their cognitive abilities. My focus was on the steps to take to create a dementia inclusive society. This would be done by creating better accommodations in physical environments to reduce attitudinal and environmental barriers that hinder their full and effective participation in society. I intended to speculate about a dementia inclusive society where accommodations in public spaces help individuals to be more social, interact with more people in public spaces and feel confident in using such spaces. Using personhood as the foundational concept, I intended to design solutions that promoted cognition and social interaction by creating opportunities for them to be a part of society again.

A leap to the new path

I spent a great amount of time researching, reading and talking to professionals in the space about the future of the world that cares about individuals with dementia the same way it cares about individuals without dementia. Along with doing all that I was also spending a great amount of time at the Memory Hub — a dementia friendly community center. Here, I immersed myself in various activities, events, and conversations with experts in dementia and Alzheimer's care. However, the more I engaged with the community, the more I realized the inadequacy of my project. It became apparent that I was receiving invaluable insights and support from a community to which I had yet to give back. In all my interactions at the Memory Hub, one consistent element stood out: conversations. Each dialogue I engaged in with individuals living with dementia and their partners held profound meaning and significance. I confronted a challenging decision regarding the speculative aspect of my thesis. Recognizing the immediate impact of the people I was engaging with, I made the conscious choice to pivot and reframe my focus. Rather than exploring speculative futures, I shifted my attention to the present and reexamined the concept of personhood through

a different lens. This decision allowed me to continue addressing issues directly impacting the individuals I was interacting with in the present moment.

Process

Secondary Research

A critical review of existing literature on the concept of personhood in dementia informed the project's reframing and guided further research endeavors. This review process facilitated the identification of potential design strategies to enhance the lived experience of individuals with dementia.

Reminiscence Therapy

Reminiscence therapy (RT) constitutes a widely implemented therapeutic intervention within aged care environments. This intervention centers on prompting the recall of past memories with the objective of stimulating cognitive function and enhancing overall well-being in the target population.

Sharing stories, especially personal life stories, offers a powerful tool for enhancing well-being in individuals with dementia (Ferring & Tournier, 2017). By tapping into autobiographical memories, storytelling can bring joy and a sense of accomplishment. Furthermore, storytelling fosters reflection on one's life and strengthens a sense of identity, which is often closely linked to self-worth and a sense of being a person (Kitwood & Bredin, 1992). This is especially true when stories involve sharing life experiences and engaging with others who can contribute to the narrative (Fels & Astell, 2011; Johnston & Narayanasamy, 2016)

Storytelling in a social setting encourages a shift from a single storyteller to a dynamic interaction with others (Hydén, 2013). This collaborative nature fosters social engagement. Additionally, storytelling often involves physical cues like touch and eye contact, which strengthen feelings of connection and togetherness (Phinney & Chesla, 2003). These relational aspects, combined with reflecting on life experiences and achievements, can significantly support feelings of identity and confidence, ultimately leading to a greater sense of agency (having control and purpose) (Fels & Astell, 2011). Integrating elements of mindfulness into

storytelling can further enhance these benefits. Reminiscence therapy (RT) encourages participants to share fond memories. This process requires them to access and organize their thoughts in a specific way, referred to as “nostalgic recounts.” A study by (Merriam, 1989) examined the structure of these recounts in healthy older adults and identified four key components: selecting a memory, elaborating on it, transitioning out of the story, and concluding. Interestingly, this structure aligns with how healthy adults typically structure their stories (Whitworth et al., 2015).

The act of recounting memories likely relies on similar cognitive and language skills used in other storytelling contexts, such as recalling everyday events or explaining procedures. Both nostalgic recounts and other forms of storytelling involve planning and organizing the narrative (e.g., choosing a perspective, focusing on key details, sequencing events chronologically), and utilizing language skills to construct a clear and well-structured story (Levelt et al., 1999).

A study by Okumura et al. (Okumura et al., 2008) compared two groups: one participating in RT and another engaging in everyday conversation. The study found that those in the RT group experienced significant improvement in verbal fluency, meaning they were able to recall more words, compared to no change in the conversation group. Interestingly, the RT group also showed improvement in non-verbal communication compared to the conversation group. While the study didn’t explain exactly how RT facilitates communication or why it leads to improvement, the results suggest a clear benefit for people with dementia.

The Memory Hub

Over the last year I have been working with the Memory Hub as a designer and a volunteer. It is a memory loss friendly community center on First Hill. The Memory Hub has 5 collaborators

The Memory Hub has 5 collaborators -

UW Memory and Brain Wellness Center

The University of Washington Memory and Brain Wellness Center (MBWC) champions the well-being of those with memory loss and their families. Through exceptional care, innovative research, and the creation

of a dementia-friendly community hub (Memory Hub), the MBWC empowers individuals with memory loss to thrive and redefine how society views living with the condition. Their strengths-based approach emphasizes potential, adaptation, and improved quality of life.

Frye Art Museum

The Frye Art Museum, a partner in the Memory Hub's creation, has a 10+ year history of offering Creative Aging programs. These programs promote lifelong learning and community well-being for older adults. The Frye actively supports the Memory Hub by co-hosting events like the monthly Alzheimer's Café.

Alzheimer's Association

The Alzheimer's Association, a leading dementia care organization founded in 1980, offers support at the Memory Hub. Their "Memory Navigator" provides consultations, resources, and program referrals twice weekly during public hours. They also co-host the "Wellness Wednesdays" webinar series.

Elderwise

Elderwise, founded in 1997, fosters meaningful engagement for adults with memory loss through art, discussion, movement, and shared meals in their adult day program. They offer this program at the Memory Hub twice weekly.

Full Life Care

A non-profit supporting individuals with disabilities since the 1970s, offers dementia caregiver education at the Memory Hub through their evidence-based STAR-Full Life program.

The University of Washington Memory and Brain Wellness Center (UW MBWC) had long envisioned a dedicated space for its support, education, and engagement programs. This space, ideally located outside a clinical setting, would foster a warm and welcoming environment where individuals with memory loss and their caregivers could be seen simply as people, not patients or research subjects. In 2016, this vision gained significant momentum with the philanthropic interest of founding donor Richard M. Ferry. His potential funding for a transformative project aimed to demonstrably improve the lives of those affected by memory loss. Coincidentally, a suitable location became available on the nearby campus of the Frye Art Museum, a longstanding collaborator of the UW MBWC known

for its successful Creative Aging programs geared toward individuals with dementia. The space, originally a residence for Christian Brothers who taught at O’Dea High School and later repurposed by the Hugo House for public events and classes, offered a welcoming atmosphere. Its features included a central, light-filled atrium, a former chapel, a dining room, a library, and various adaptable rooms for programs and events. Additionally, the building incorporated numerous converted apartments serving as offices and a charming, enclosed “secret garden.” This location proved to be ideal, not only for the UW MBWC’s initial vision but also for an expanded one encompassing multiple partner organizations and a broader range of programs. Fueled by the potential of financial backing and the exciting possibilities presented by the newly identified space, the comprehensive vision for the Memory Hub fully materialized. (Our Story - The Memory Hub, n.d.) I have been a part of various programs at the Memory Hub and conducting Primary research by talking to volunteers, neuropsychologists, science writers, social workers, clinical managers, individuals with dementia, their partners and caregivers

Programs at the Memory Hub

My experiences at the Memory Hub revealed a fundamental truth: conversation holds immense power in the lives of individuals with dementia. Witnessing firsthand the profound impact of interactions, whether simple exchanges with loved ones or friendly chats with fellow visitors, prompted a significant shift in the direction of my research efforts. Initially, I had envisioned pursuing a speculative design project, exploring possibilities for a future society that seamlessly integrates individuals with dementia.

However, the transformative power of conversation observed at the Memory Hub inspired a focus on more immediate and impactful solutions. Recognizing the critical role of social interaction, I pivoted my research focus towards facilitating and promoting meaningful conversations, particularly among individuals who may not know each other beforehand. This shift stemmed from the observation that even seemingly ordinary conversations could significantly enhance the lives of those living with dementia. Beyond observing, I actively participated in interactions at the Memory Hub, seeking opportunities to understand and improve the quality

of conversation within this context. Through these experiences, I gained valuable insights into effective communication strategies that could enhance social engagement and build connections.

This shift in focus, driven by the observed power of conversation, underscores the importance of prioritizing communication and social interaction in dementia care. Further exploration is needed to develop and evaluate evidence-based strategies that facilitate meaningful conversation and foster a sense of connection for individuals with dementia within various social settings. I participated in various programs over the last year.

Legacy Letters

My participation in the Legacy Letters program, a six-week initiative pairing University of Washington students with individuals diagnosed with dementia, provided a valuable opportunity to explore effective communication strategies within this population. The program utilized a multifaceted approach, incorporating journaling exercises, one-on-one discussions, and group activities to guide participants through the creation of a legacy letter. This program offered a unique lens through which to examine the potential of cross-generational interaction in mitigating social isolation and loneliness often experienced by individuals with dementia. By facilitating the sharing of life stories and experiences, Legacy Letters fostered intergenerational connection and understanding, bridging the gap between diverse perspectives and histories.

The program's effectiveness was demonstrably evident through its impact on participants. Over the course of the six weeks, I witnessed a significant transformation in the individuals with dementia. Initially hesitant or unwilling to engage in conversation, participants progressively shared memories and stories that had seemingly been inaccessible for years. These observations provided a powerful testament to the transformative power of quality social interaction for individuals with dementia.

Through this immersive research experience, I gained invaluable insights into the specific challenges and opportunities associated with communication in the context of dementia. By observing successful interactions facilitated by the program, I was able to identify and refine communication strategies that fostered engagement and connection with individuals experiencing cognitive decline. This experiential learning proved instrumental in developing a deeper understanding of how to create, navigate, and engage in

meaningful conversations with those living with dementia.

Open house

My involvement in the Memory Hub Open House provided a valuable opportunity to contribute to the “Community Weaving” project, an initiative designed to promote social engagement and creative expression for individuals with dementia and their caregivers. The project utilized a variety of materials, including fabric scraps, thread, ribbons, and lace, inviting participants to contribute to a collaborative textile artwork.

This experience offered a unique window into the social dynamics and creative potential of individuals with dementia. Observing participants interact with the materials and collaborate with others on the weaving project proved to be particularly insightful. While some participants engaged independently, demonstrating a sense of focus and dexterity as they wove the materials, others interacted more collaboratively, working alongside caregivers or fellow participants.

Throughout the event, I had the opportunity to interact with various caregivers who expressed their desire to keep individuals with dementia mentally and physically stimulated. Their concerns highlighted the importance of creating engaging activities that promote cognitive function and physical activity, potentially contributing to a sense of purpose and well-being in individuals with dementia. The “Community Weaving” project, in its focus on collaborative creativity, served as a potential example of such an activity.

The experience underscored the significance of fostering social engagement and meaningful activities for individuals with dementia. Further research exploring the impact of creative and collaborative activities on cognitive function, social interaction, and overall well-being in this population is warranted.

SOAR

The Shared Outdoor Adventures for Resilience (SOAR) program offers a unique and valuable intervention for individuals diagnosed with dementia before the age of 65. Designed to foster community and social engagement, SOAR utilizes outdoor activities such as group hikes to provide a platform for connection and shared experiences. My participation in a SOAR program held at Carkeek Park during the salmon migration season allowed me to interact with a diverse group of individuals living with early-onset dementia alongside their family members or friends.

This experience provided a firsthand opportunity to observe the program's impact on social engagement and well-being in this population. Witnessing participants navigating the natural environment and engaging in shared activities offered valuable insights into the potential of outdoor experiences to promote social interaction and combat feelings of isolation often associated with dementia.

The program also served as a platform to connect with various forms of caregivers, including professional caregivers, partners, and family members. These interactions provided a deeper understanding of the challenges and rewards associated with caregiving for individuals with early-onset dementia. Through open conversations, caregivers shared their experiences, struggles, and coping mechanisms, offering a rich tapestry of perspectives on the caregiving journey. By combining social engagement with physical activity in a natural setting, the SOAR program demonstrates a promising approach to supporting individuals with early-onset dementia and their caregivers. Further research is necessary to explore the long-term impact of such programs on social interaction, emotional well-being, and overall quality of life for this population.

Talking to Friends with Dementia

The Partners in Dementia program, a University of Washington initiative, pairs medical students with older adults diagnosed with dementia and their care partners. Designed to foster social engagement and support, the program facilitates weekly hour-long meetings over a six-month period. This research delves into the program's initial stages, focusing on the challenges and opportunities associated with navigating conversation within this context.

Through semi-structured interviews, data was collected from both student volunteers (mentees) and participating older adults with dementia (mentors) alongside their care partners. A recurring theme emerged – the initial difficulty establishing rapport and maintaining conversation flow during the program's first few meetings. Several mentees reported experiencing anxiety related to the intergenerational nature of the friendships and a lack of clarity regarding appropriate conversation topics. These initial sessions often concluded within the first 20-30 minutes, highlighting the initial awkwardness and need for establishing comfort and trust.

Conversely, both mentors and their care partners

expressed a clear preference for conversations centered around personal histories. Topics such as family, childhood experiences, children, and travel emerged as preferred conversation starters. Interestingly, care partners specifically mentioned a desire to record these stories for future reference, potentially serving as a valuable resource for preserving memories and fostering connection despite the challenges of dementia. The interviews also revealed the importance of structure in facilitating conversation. Both mentors and care partners indicated a preference for structured conversations that provided prompts and triggers to maintain conversational flow. This finding suggests that initial support and guidance may be crucial for navigating the unique challenges of communication with individuals with dementia.

The mentees' observations further corroborated the need for initial support. Despite mentors demonstrating the potential to independently drive conversations, care



partners often assumed a central role, prompting their partners and actively guiding conversation flow. This highlights the vital role of care partners in supporting communication within the program. Finally, the research explored the use of conversation prompt questions. Interviewing mentees regarding their comfort with potential

prompts served as a preliminary investigation into the potential benefits of incorporating structured conversation tools within the program. Further research is needed to evaluate the effectiveness of specific prompt strategies in facilitating meaningful conversation and fostering lasting connections within the Partners in Dementia program.

This initial exploration underscores the importance of acknowledging and addressing the initial challenges associated with conversation in dementia care. By recognizing the need for structured support, fostering trust, and providing guidance on navigating conversation topics, programs like Partners in Dementia can pave the way for meaningful social interaction and a deeper understanding between individuals with dementia, their care partners, and the wider community.

Creating Questions

This research investigated the development and potential benefits of a card game designed to stimulate meaningful conversations for individuals with dementia. The game drew upon the combined insights of primary research conducted through the Legacy Letters program and a review of existing literature on personhood and reminiscence therapy.

Primary Research: Understanding Preferred Conversational Themes

Participation in the Legacy Letters program, which fostered intergenerational connection through biographical narrative creation, provided crucial insights into the preferred conversational themes of individuals with dementia. The program revealed a strong preference for discussions centered around:

Family: Sharing stories about loved ones strengthened feelings of connection and belonging.

Childhood: Reminiscing about early life experiences served as a source of comfort and joy.

Intergenerational Learning: Demonstrating interest in the lives of younger generations fostered a sense of purpose and belonging.

Life Lessons: Sharing wisdom and advice gleaned from life experiences empowered individuals with dementia to feel valued and contribute to their communities.

Secondary Research: Leveraging Reminiscence Therapy Principles

A review of the principles of reminiscence therapy informed the content of the conversation prompt cards. Reminiscence therapy utilized discussion of past experiences to stimulate cognitive function, emotional well-being, and social connection in individuals with dementia.

The Conversational Prompt Card Game: Eliciting Memories and Fostering Connection

By focusing on the core themes identified through

primary research, the conversation prompt card game aimed to:

Elicit Episodic Autobiographical Memories: The prompts were designed to trigger specific memories from an individual's life, promoting detailed and engaging storytelling.

Promote Intergenerational Connection: Engaging with younger generations through conversation combated feelings of isolation and fostered a sense of purpose.

Maintain a Sense of Personhood: By encouraging the sharing of life stories, the game validated the experiences and wisdom of individuals with dementia.

Existing Products in the Market

Currently a lot of conversational games exist in the market, while some are general, some are hyper specific to certain relationships and scenarios.

One prominent example is the "Let's Get Closer" series, which features various themed sets catering to specific audiences. This research examines the "Let's Get Closer: Family Edition" within the broader context of relationship-specific conversational prompt card games. A defining characteristic of the "Let's Get Closer" series is its tiered structure based on intimacy levels. Each set features prompts categorized as "Close," "Closer," and "Closest," guiding players towards progressively deeper conversations as comfort and trust build.

The "Let's Get Closer: Family Edition" specifically tailors its prompts to family dynamics. The game reportedly draws inspiration from positive psychology, focusing on fostering positive emotions and strengthening family bonds. The language employed on the cards is likely geared towards positive affirmation, encouraging open communication and shared experiences within the family unit. The design of the "Let's Get Closer: Family Edition" box, while not directly analyzed in this research, can offer further insights. It is likely that the chosen imagery and color scheme evoke a sense of warmth, togetherness, and positive emotions, reinforcing the game's focus on strengthening family relationships.

The existence of the "Let's Get Closer" series, with its diverse themed sets, highlights the potential for targeted conversational tools to address specific relationship needs. The tiered structure and focus on positive psychology offer a framework for fostering connection,

while the tailored themes within each set ensure the prompts resonate with the intended audience.

Building upon the analysis of the “Let’s Get Closer” series, another prominent player in the conversational prompt card game market: “We’re Not Really Strangers: Family Edition.” Similar to its counterpart, this game focuses on fostering meaningful connections, but with a distinct approach. Unlike “Let’s Get Closer,” which utilizes a tiered structure based on intimacy levels, “We’re Not Really Strangers: Family Edition” employs a different organizational framework. The game reportedly features 150 pre-determined questions categorized into three distinct sets, along with a selection of wildcard prompts. While the specific themes of these sets are not available for this research, it can be assumed they deviate from the intimacy-based progression seen in “Let’s Get Closer.” The inclusion of wildcard prompts suggests an element of surprise and potential for unexpected conversation paths. This approach could introduce a sense of spontaneity and encourage participants to explore diverse conversational territories within the family dynamic.

Game Structure and Categories

Through my research at the Memory Hub and research about Reminiscence Therapy uses prompting to help the individuals with dementia to recall their memories and episodic life experiences so I decided to focus on providing scaffolding for the conversations through prompts. The game has 5 categories of which 4 have main questions and multiple sub prompt/trigger questions to supplement the conversations and the memories of the individuals with dementia Reminiscence therapy utilizes prompting techniques to stimulate discussion of past experiences, fostering cognitive function, emotional well-being, and social connection in individuals with dementia (Edmeads & Metatla, 2019). Observations and research conducted at the Memory Hub, provided further insights into the specific needs and preferences of this population. Building upon these combined areas of research,



Life's Tapestry investigates the potential of facilitated storytelling interventions for individuals experiencing early-stage dementia. This focus on autobiographical narratives aims to promote a multifaceted sense of personhood in individuals with dementia.



the card game employs a scaffolded approach to conversation. The game features five distinct categories, four containing a set of main questions. These main questions serve as a starting point for conversation, focusing on themes that resonate. To further support memory recall and encourage detailed storytelling, each main question is accompanied by multiple sub-prompts and trigger questions. These sub-prompts and trigger questions act as scaffolding – providing additional context, prompting specific details, and offering alternative avenues for exploration within the chosen theme. This scaffolded approach aims to provide enough structure to guide the conversation while also allowing for flexibility and exploration of individual memories. The use of familiar themes and scaffolded prompts can facilitate memory recall and encourage the sharing of episodic life experiences.

Based on the research of existing conversational games and the primary research at the Memory Hub I decided to focus on 5 categories.

First Threads

Structured conversations can sometimes feel forced and awkward, especially in settings like community centers. First Threads is a set of ice breaker questions that help the conversation partners break the ice and feel more comfortable with each other.

Eliciting Personal Information: The questions serve as a springboard for participants to share details about themselves, their interests, and their experiences. This exchange of personal information is a fundamental building block in establishing rapport and fostering a sense of connection.

Generating Lightheartedness and Laughter: The “fun” nature of the questions is intended to create a more relaxed and enjoyable environment. Humor can act as a social lubricant, easing tension and encouraging participants to feel more comfortable engaging with one another.

Childhood

This category encourages the conversation partners to elicit memories of their formative years. It helps them relive their earlier experiences through communal recollection of past experiences. This category of prompts encourages participants to engage in a process of memory retrieval focused on their formative years. By sharing these memories, individuals have the opportunity to revisit and potentially reinterpret their earlier experiences. This process can foster a sense of

self-understanding and connection with others who share similar experiences.

This category delves into critical aspects of an individual's formative years, fostering deeper understanding and connection through shared experiences and diverse perspectives.

Educational Background: Memories of school life provide valuable insights into learning styles, childhood friendships, personas, personalities and experiences in their educational journeys, fostering a sense of intellectual connection.

Childhood Social Networks: By recounting experiences with childhood friendships, individuals offer a glimpse into their early social development and the process of forming interpersonal bonds. Discussing these experiences can provide insights into shared values, interests, and the dynamics of early social interactions. This exploration fosters understanding of how childhood relationships can shape an individual's social skills and communication styles.

Domestic Environments: Prompts that encourage reminiscing about childhood homes can reveal details about family structure and cultural influences. Alternatively, it can spark conversations around cultural and social diversity, fostering appreciation for different experiences.

Aspirations and Dreams: Exploring participants' childhood aspirations allows them to revisit their earlier hopes and dreams. This introspective process can be insightful, especially in light of their current life trajectories. It can spark discussions on personal growth, the evolution of ambitions, and the impact of experiences on shaping one's future goals.

By incorporating these diverse facets of childhood, this category offers a rich and multifaceted exploration of a person's formative years. This exploration goes beyond simple nostalgia, encouraging participants to reflect on how their childhood experiences have shaped them into the individuals they are today. Furthermore, it fosters connections based on shared experiences, contrasting perspectives, and an appreciation for the rich tapestry of human development.

Family

This category recognizes the inherent significance of family in their lives, providing a springboard for reminiscing and fostering a sense of connection. The focus on family delves into two key areas:

Relationships with Family Members: The questions within this category encourage exploration of past and present

relationships with siblings, partners, and other close relatives. Sharing anecdotes about these relationships allows individuals with dementia to revisit cherished memories and potentially reconnect with their personal histories. This process can be emotionally rewarding, promoting a sense of self-worth and identity.

Additionally, discussing the current state of these relationships can provide valuable insights into the individual's emotional well-being and social support network. Caregivers can leverage this information to tailor support plans and ensure the individual feels connected to loved ones.

Conceptualization of Family and Quality Time: This category delves deeper, exploring the individual's personal understanding of the concept of "family" and the significance they place on quality time with loved ones. Prompts may encourage reminiscing about past family traditions, celebrations, or simply spending time together. Sharing these recollections can provide caregivers with valuable cultural and social context, aiding in understanding the individual's values and priorities. Furthermore, it can spark conversations about the importance of replicating these positive experiences in the present, fostering a sense of connection and well-being.

At My Age

At My Age is specifically designed to bridge the generational gap and foster connection through the exploration of parallel lives. This category encourages conversation partners of different ages to discover similarities and differences in their experiences across time. It achieves this by focusing on two key areas:
Everyday Life in Historical Context: Prompts within this category invite the older partner to share details about their everyday life during a specific year in the past. This could encompass details about:

Daily routines and activities: Discussions on work schedules, school life, leisure pursuits, and household chores can reveal fascinating insights into the historical context of everyday living. These details can spark comparisons with the younger partner's current experiences, highlighting both similarities and differences in the way people navigate daily life across generations.
Popular culture and entertainment: Sharing memories of music, movies, television shows, or popular hobbies can create a sense of shared nostalgia for the older partner

Based on these categories I created multiple rounds of prototypes for the cards and tested versions out with members of the Friends with Dementia program. A final round of prototype cards were designed which were tested at the Memory Hub through an event called “Beyond The Years”. This event paired a University of Washington Masters student with an individual with memory loss issues and also their caregiver/partner if they’re accompanied.

Prototype Test Session

I conducted the event “Beyond The Years” at the Memory Hub, an event designed to foster intergenerational communication within a memory care setting. The event, held on February 27th, 2024, at the Memory Hub, aimed to create a space where older adults experiencing memory loss could engage in meaningful conversations with university students.

Dissemination and Recruitment Strategies:

A multi-pronged approach was adopted to recruit participants. Flyers and posters containing details about the event were distributed electronically via the Memory Hub’s mailing list. Additionally, physical posters were displayed prominently within the Memory Hub itself. Collaboration with the Elderwise day program further expanded the outreach, inviting participation from their program attendees.

Participant Demographics and Pairing:

The recruitment efforts yielded a total of six older adult participants. Two individuals arrived independently, while the remaining four were accompanied by either a partner (2 participants), a formal caregiver (1 participant), or a volunteer from their nursing home (1 participant). To facilitate conversation, participants were paired with six university students from the University of Washington, representing diverse academic backgrounds.

Event Structure and Facilitation:

The event unfolded in two distinct sections, each lasting approximately 30 minutes. To create a welcoming atmosphere, light refreshments were provided in the afternoon, allowing participants to mingle and enjoy snacks before the formal program commenced. Each participant was assigned a name placard to facilitate introductions and create a comfortable environment. Tables were arranged to seat two to three individuals:

a student volunteer, an older adult participant, and their accompanying individual (if applicable). The pairings were determined randomly to encourage new connections. The initial section of the event focused on informal interaction. Participants were encouraged to engage in casual conversation with their tablemates without any predefined prompts or topics. This unstructured approach allowed for organic conversation flow and exploration of shared interests. A designated bell signaled the end of this initial conversation period, prompting a short break. During the break, participants were free to refresh themselves with additional snacks and engage in further social interaction beyond their assigned tablemates. To prepare the student volunteers for the next phase, a briefing session was conducted. This session equipped them with an understanding of the conversational prompt cards that would be utilized in the following section.

Structured Conversation with Prompt Cards:

The second half of the event introduced a more structured approach to conversation. Each participant received a set of conversational prompt cards designed to stimulate discussion and guide the conversation flow. While the allotted time for this structured interaction was 30 minutes, the conversations organically extended beyond the designated timeframe, exceeding an hour in duration. A final bell was rung to gently remind participants of the time constraints.

Observations and Potential Impact:

The “Beyond the Years” event serves as a valuable case study in exploring the potential of intergenerational communication within a memory care setting. The random pairing approach facilitated new connections, potentially fostering a sense of social engagement and combating feelings of isolation among older adult participants. The use of conversational prompt cards in the latter half of the event provided a framework for structured discussion, potentially stimulating cognitive function and memory recall in participants experiencing memory loss. The extended duration of the conversations beyond the allotted time frame suggests a high level of participant engagement and a genuine desire for connection across generations.

Rationale for Olfactory Cues

The inclusion of scent cards stemmed from the well-established link between olfactory memory and autobiographical recall. Research suggests that odors have a unique ability to trigger vivid memories due to

the direct connection between the olfactory bulb and the limbic system, the brain's emotional center. This connection can potentially evoke powerful memories and emotional responses in individuals. In the context of the program, the goal was to utilize scent cards as a tool to unlock cherished memories for older adult participants, fostering a deeper level of engagement and connection.

Unexpected Participant Response:

However, the pilot program revealed a surprising outcome. Contrary to expectations, the use of scent cards did not evoke positive responses from the majority of participants. Instead, most participants reported feelings of confusion and frustration when presented with the scents. They expressed difficulty in pinpointing the exact origin of the smells, leading to a sense of disorientation and a negative impact on the overall experience.

Potential Explanations and Future Considerations:

Several factors contributed to this unexpected outcome. Firstly, all the chosen scents did not have been personally relevant to the participants' life experiences. Alternatively, the olfactory function of some participants were diminished due to age-related changes, hindering their ability to accurately identify the scents. Furthermore, the act of attempting to identify the source of an unknown scent proved cognitively taxing for participants experiencing memory loss, leading to frustration. These findings suggest the need for further research and refinement before incorporating olfactory cues into intergenerational communication programs within memory care settings. While the initial excitement surrounding the use of olfactory cues was not fully realized in the pilot program, these findings offer valuable insights for future research.

Post event interviews

Analysis of the interview data revealed a clear distinction between the two conversation styles. Participants described the first conversation, utilizing open-ended questions, as "free flowing" and focused on familiar topics. This suggests a level of comfort and predictability with this style of interaction. However, participants also noted a lack of substantial depth in the conversation, potentially due to the absence of specific prompts to guide reminiscence.

In contrast, participants described the second conversation, facilitated by the card game, as initially feeling structured due to the presence of prompts. Despite this initial perception, the interviews revealed a shift in the conversation's depth. Participants reported "diving deep" into meaningful conversations, likely due to the scaffolding provided by the sub-prompts and trigger questions. These additional prompts may have stimulated specific memories and encouraged participants to elaborate on their experiences.



Results

Life's Tapestry presents a novel approach to facilitating meaningful conversations and memory retention in individuals diagnosed with early-mid stage dementia. This game, designed specifically for this population, utilizes carefully curated conversational prompts to encourage storytelling and episodic memory recall.

Theoretical Underpinnings

Life's Tapestry draws upon the well-established concept of reminiscence therapy. This therapeutic intervention centers on the power of storytelling and memory sharing to promote emotional well-being, self-awareness, and cognitive stimulation in individuals experiencing memory decline. By prompting the narration of past experiences, the game aims to achieve several key objectives:

Episodic Memory Consolidation: The act of recounting personal stories strengthens the neural pathways associated with those memories. This repetition can contribute to the consolidation of episodic memories, potentially slowing cognitive decline.

Reinforcement of Personal Identity: Sharing stories from one's life history plays a crucial role in maintaining a sense of self and personal identity. Life's Tapestry provides a platform for individuals to express their unique narratives, fostering a sense of personhood despite memory challenges.

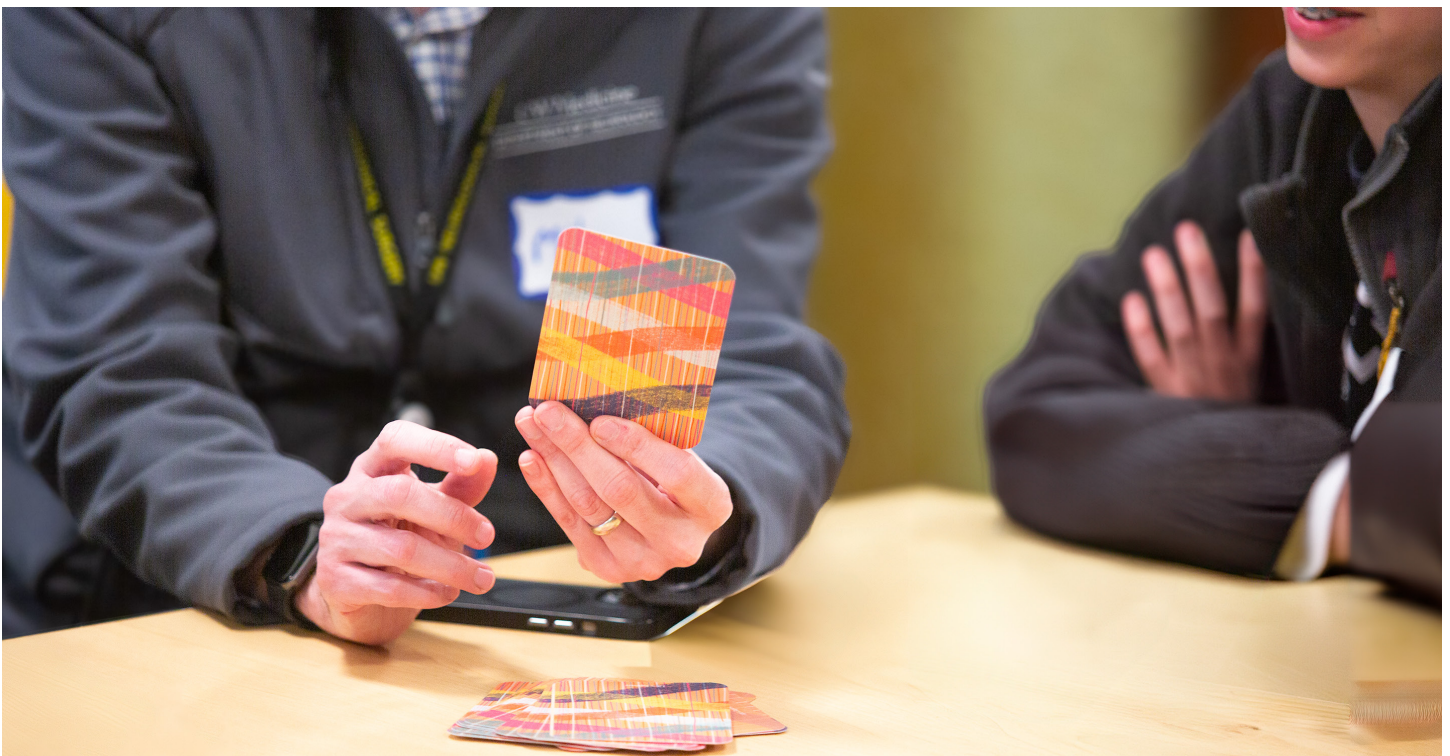
Enhanced Communication and Socialization: The game inherently promotes conversation and social interaction. By engaging in storytelling with others, individuals can maintain communication skills and experience a sense of connection.

Thematic Inspiration and Design Considerations: The name "Life's Tapestry" draws inspiration from a community weaving project at the Memory Hub. This project serves as a powerful metaphor, representing the intricate tapestry of experiences woven throughout a person's life. Each thread or piece of fabric symbolizes a memory, highlighting the richness and diversity of an individual's life journey. Furthermore, the communal nature of weaving reflects the collaborative construction of our personal narratives, shaped by the significant individuals who contribute to our life experiences. The design of the game incorporates these thematic

elements. The prompt cards themselves are likely to be visually appealing and potentially evocative of memories. The language used on the cards should be clear, concise, and tailored to the cognitive abilities of the target population. The game can be played individually or in small groups, fostering a sense of community and shared experience.

Fabricating the Boxes

Three rounds of prototypes were meticulously crafted, culminating in a final iteration that emerged just hours before my departure flight back to Seattle. This compressed timeframe underscored the dedication and collaborative spirit of the printing team in Bangalore. However, the story transcends geographical boundaries. Following my return to Seattle, the project continued through a transcontinental dialogue. Phone calls and WhatsApp messages became our primary means of communication, bridging the physical distance and fostering a continued synergy. I was able to leverage problem-solving skills and clear communication strategies to bridge these gaps. Yet, through perseverance and a shared commitment to excellence, we emerged triumphant. Two sets of samples were made and sent to Seattle from Bangalore.



Conclusion

In conclusion, this research project explored the design and potential benefits of a conversational prompt card game for individuals with dementia. Inspired by the principles of reminiscence therapy and observations at the Memory Hub, the game utilizes a scaffolded approach with familiar themes and sub-prompts to stimulate memory recall and foster meaningful conversations. While initial user experiences suggest a perceived difference in conversation flow between open-ended and prompt-based approaches, post-event interviews revealed a shift towards deeper reminiscence with the card game. This pilot study highlights the potential of the game as a tool for enhancing reminiscence in individuals with dementia. Further research is warranted to explore the long-term impact of the game on cognitive function, emotional well-being, and social connection within dementia care facilities. By providing a structured yet flexible framework for reminiscence, this card game has the potential to become a valuable tool for enriching the lives of individuals with dementia and their families.



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