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LAES 462

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An Exploration Into the Design of a Portable Music Player for People With Alzheimer's and
Dementia

Introduction

“I can't listen to anything.”

Hearing this from my grandmother surprised me. It had been a year since her diagnosis, but yet the symptoms were visible. She was looping questions and phrases, and tending to get lost a little. I had recently learned that music helps with managing the progression of Alzheimer's, and as a burgeoning music nerd who had recently joined the campus radio station, I had wondered if this may be a viable intervention to, at the very least, make her symptoms less rough. Something like a podcast or a fondly-remembered album may help with stimulating the mind, particularly while she went on her walks or around the house? Yet iPhones were out of the question, and the TV remote to put on a music-playing channel was already complicated enough for someone with normal cognitive function. I looked online, yet everything that was on Amazon seemed to be exceptionally redundant and very much not portable. For someone with early-onset Alzheimer's like my grandmother, especially at the stage she was then, she could still navigate interfaces that offered simple interfaces with tactile feedback, which is why she stuck with a flip phone over switching to an iPhone. Feeling inspired, I drew up some sketches and promptly shelved the idea to meet the demands of a new quarter's worth of classes and challenges.

However, when given the opportunity, the opportunity to create a portable music-playing device for people facing Alzheimer's, dementia, or cognitive decline in the face of age felt like a truly meaningful challenge to improve the lives of those around me. I had initially been skeptical about taking on this idea, as I had figured that either something existed out there or it was a dumb idea. After talking with various experts and conducting product reviews, I learned that there was a need for something like this, and that the best products on the market were an amalgamation of various low-fidelity mp3 players and outdated iPods. But I think what I learned the most was that, beyond any of the proven cognitive benefits that music brings to those facing Alzheimer's (Bakerjian et al., 2020; Nair et al., 2013; Witzke et al., 2008), music is an inherently meaningful artform that matters to so many different people for an infinite number of reasons. That to restore some small sense of meaning and agency through being able to play the music one connects deeply with is an inherently worthy goal.

Background

Alzheimer's is a neurodegenerative disorder in which the brain is unable to deal with the wear and tear associated with cognitive function, leading to the build up of beta-amyloid protein fragments between neurons, and neurofibrillary tangles that disturb the integrity of neurons. Both processes cause the death of neurons.

In terms of lived experience, the disease tends to first appear in patients having trouble with their memory, particularly recent memories and those having to do with events occurring at certain dates, as well as affecting planning. As the disease progresses, patients begin to have difficulties with orienting themselves in space, as well as issues with language. An example of this can be seen in the novel *Still Alice*, in which the main character gets lost in Harvard Square, a place where she had attended and taught at for decades (Genova, 2007). By the late stages of the disease, patients feel massive confusion caused by declines in the working memory. Leading to not being able to make sense of what is going on all the time. Patients also suffer major memory loss and issues with recognition. They also begin to face issues with their bodily function. One interesting point is that implicit memory, that which is associated with conditioning and procedural memory, remains intact throughout much of the disease.

Issues such as these certainly are large driving factors for developments that help to mitigate and soothe many of the symptoms that Alzheimer's patients face. Throughout multiple studies, music-based treatments and therapies have been associated with reduced usage of psychotropic medication and improvements of mood (Bakerjian et al., 2020), improvements in swallowing for individuals with advanced dementia (Cohen et al., 2020), as well as short-term verbal fluency and memory enhancement (Matziorinis & Koelsch, 2022). Beyond this, certain studies have shown music being able to activate regions of the brain unaffected by Alzheimer's (Kish, 2018), as well as results that speculatively suggest that music may have a role in neurogenesis (generation of new neurons) in the hippocampus (Koelsch, 2020). Finally, beyond any medical studies supporting music as a positive intervention in Alzheimer's patient's lives, music is an inherently meaningful artform that carries stories, emotions, and whole spectrum of meanings all unique to a given listener. To deprive a person of an artform like music, or music that is personally meaningful to them is in a lot of ways a violation of the dignity that they are entitled to. Most technological development tends to be focused on younger demographics, and while there is a growing age-tech field, the simple fact is that the needs of millions are currently not being designed for. Right now, the millions of people with Alzheimer's, as in the words of the late John Prine, "waiting for someone to say hello in there, hello." (Prine, 1971)

Yet access to accessible music devices for patients is still hard to come by, multiple academics and experts remarked anecdotally about how relevant of a problem this was, as well as multiple pages of caregivers asking about music playing products for their loved ones on social media sites like Reddit, and the presence of programs like the Music and Memory program (*Music and*

Memory, n.d.) and the Music Mends Minds program (*Musical Support Groups / Music Mends Minds, Inc. / United States*, n.d.) seem to evidence a need amongst those with Alzheimer's and other neurological conditions like dementia. Especially as while evidence is hard to find about the level of training and resources that memory care facilities and caregivers have to conduct music-based therapies, estimates by advocacy organization Right to Music estimate that only 10% of assisted living facilities have incorporated personalized playlists into their care (Miller, 2021). This does not take into account the significant economic burden that diseases like Alzheimer's leaves on caregivers and loved ones, with a study in the American Journal of Managed Care estimating that annual Medicare and Medicaid expenditures to be \$10,814 and \$6234 respectively (Winston Wong, 2020). The Alzheimer's Association estimates cost of care to be \$1113 per week for in-home care, \$55,620 per year for Assisted Living Facility expenses, and \$111,657 per year for a private room at a nursing home (*Planning for Care Costs*, n.d.). With, at the time of writing, inflation increasing prices of goods and services, and wages not rising to keep up (*Wage-Price Spiral Risks Appear Contained Despite High Inflation*, 2022), the cost of care for patients seems to only grow more massive of a problem.

Looking at existing products to fill the need that caregivers have to provide music to Alzheimer's patients, we generally can break it into three categories: static music players that sit on a table or piece of furniture that are not intended (per the designed affordances on a given device) to be portably carried with a patient, virtual music players that exist as an app within a smart-device, and portable music players specifically designed to play music and to be carried around with a given user.

In terms of products that have the most variety for and are the most extensively designed for caregivers and people with Alzheimer's, static music players seem to fit the criteria. Generally, they tend to play music from either radio broadcasts (FM/AM signal or internet radio stations), or from pre-uploaded mp3 files. They tend to have highly simplified interfaces with 1-3 control features. They may also mimic design features from devices made in past decades when a given patient was younger, as to evoke a sense of reminiscence through the much more embedded memories a patient has. However, these highly simplified and streamlined interfaces do come at the cost at extra work to caregivers, as evidenced by the device in figure 3, where the volume control buttons are located on the bottom of the device and can only be reached through the utilization of an object like a pencil to change the volume. Moreover, in devices that play from pre-uploaded mp3 files, caregivers are the ones having to spend money on mp3





music files and time to upload those files. They may also have to spend time downloading and converting audiobook and podcast files (and even music files, if bought off of the Apple iTunes store) into mp3 format. As well, none of these devices seem to have a dedicated shuffle feature or feature to return to a given song, which—while seeming superfluous—may cause slight agitation amongst patients.

A special subcategory of static music players exist for smart-devices with embedded voice assistants such as the Google Home or Amazon Echo devices. These seem to be an option with growing popularity as evidenced by the growing references to these devices on social media postings seeking opinions on music players. Yet, anecdotal evidence from professors and experts I spoke to seems to paint these devices with mixed success with some patients being disturbed by the disembodied voice-assistants, and others never being able to pick up the device completely. However, the ability for caregivers to remotely control these devices, as well as to use these devices to check in with their loved ones is seen by some online commenters as a huge benefit that allows them to take care of their loved one while still adhering to the responsibilities of their lives.



In terms of virtual applications, there seems to be scant products specifically designed for Alzheimer's patients. While streaming services like Spotify and Apple Music are certainly useful for caregivers who are physically present or who are able to remotely control a speaker connected to their account, the interfaces of these apps are not well designed for patients. So far, an app called Vera

Figs. 1-3: Representative static music players advertised for use for Alzheimer's patients and caregivers (The Alzheimer's Store)

seems to be the only known virtual application designed specifically for Alzheimer's patients and caregivers in-mind (Vera, n.d.). It is a subscription-based streaming service with separate interfaces for caregivers (VeraPro) and patients (Vera). So far this service has been able to security rights to the music by Universal Music Group ("Universal Music Powers Innovative Australian Dementia App," 2022), but this application may not necessarily have the wide catalog of music that Spotify or Apple Music may have. Certainly, while it has had a lot of press coverage, there seems to be no published study detailing how successfully this app meets the needs of patients and caregivers. While I certainly by no means have the experiences of those

with Alzheimer's, initial tests I conducted left me feeling like the UX of the application was a little too busy for patients, and that the player window could be better integrated into the main window. Moreover, it is hard to say currently just how successful smartphone/tablet-based interventions are with patients, as a meta-analysis found mixed evidence to support such interventions (Wilson et al., 2022). Moreover, the varied nature of Alzheimer's disease means that certain patients may not be able to use a smartphone or tablet successfully, certainly anecdotal evidence via conversations seem to support that.

For products that fall under the category of portable players, they tend to be small devices specifically designed for music playback and management. Currently, there exists no devices specifically advertised around meeting the needs of people with Alzheimer's. However, this has not stopped practitioners from repurposing existing portable music players to meet the needs of patients. One such product that has been heavily utilized by music and memory programs (Hand, 2015; "iPod Shuffle Archives," n.d.) is the Apple iPod Shuffle, specifically the 4th generation model of the Shuffle. This is due to its highly simplified interface, discreet profile, and clip that allows the device to be attached securely to a patient. However, since Apple discontinued the Shuffle in 2017, the devices have become less available and harder to support. Another device that fits many qualifications is the SanDisk Clip Jam mp3 player, which while nothing in my research indicated it has been used by memory care programs, still is advertised within certain retailers as a device for elderly people (*Mp3 Players For Elderly - Best Buy*, n.d.). The Clip Jam, like the Shuffle, has a simplified interface and a clip on the back of the device, but it lacks Apple's iTunes digital infrastructure, making the procurement and uploading of digital music, audiobook, and podcast files more troublesome than the Shuffle. Additionally, there yet seems to exist a portable music player that incorporates streaming services into the device. This could be attributed to several challenges such as music licensing and the necessity of a constant internet connection to interact with some of the features. Yet, the incorporation of streaming services within an increasing number of objects with the Internet-of-Things seems to provide a possibility that maybe the barriers to incorporating a streaming service within a portable music player are not as insurmountable as believed. Beyond this, none of the simplified interfaces incorporate higher-order features that patients within the early-stages may want to utilize, such as specific song/album/playlist/media selection or shuffle functionality. Even a simplified feedback mechanism where patients could give ratings to certain tracks would be invaluable for the caregivers adding music to these devices.



Figure 4: iPod Shuffle 4th Generation (Apple)

In short, with all existing devices either being patronizing, too complex, or discontinued, there is nothing on the market currently that is designed smartly, intelligently, and effectively enough to meet the needs and wants of patients and caregivers.

Beyond this, some important considerations for music and memory care include the importance of over-ear headphones for patients listening to music, something that many anecdotes remarked were more comfortable and less stressful for a patient to wear. As well, the importance of building a proper playlist of songs was noted in many websites, as to ensure all tracks were grounded in a particular mood that a patient was desiring to feel.

Design

One of the most recommended ways to design for those with Alzheimer's is to work with them directly in the creation of the design (Devin, 2021). This is something I deeply wanted to incorporate in my work, as it is my personal belief that good design cannot be conducted without user inclusion. It is my belief that to do so is through collaborative design practices.

Collaborative design, or what is referred as Codesign, participatory design, or cooperative design, is a design approach that seeks to foreground the communities and people being served by a design process in every step of the process, essentially moving the designer from creative head to a more facilitative role. It can be messy and nonlinear (Burkett & Fair Deal Forum, 2016), but the point is creating something collaboratively and together. As John Bruce writes, “Participatory artistic- and design-based research encounters—being with people, things, and situations—and embodied learning that centers attunement, reflection, reciprocity, and care... to show up and come together in ways free from titles, roles, or expertise; to privilege curiosity; to engage in peer-to-peer learning and co-creation; to live boldly, messily, and gracefully in a state of not knowing.” (Bruce, 2022)

This approach is not far removed from current conceptions of best practice among memory care practices. Particularly, as it has been noted that collaborative design principles align strongly with the framework of Patient-Centered Care (Hendriks et al., 2018). For Patient-Centered Care (PCC), “an individual’s specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements. Patients are partners with their health care providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective.” (Catalyst, 2017) This leads to 3 major principles to consider when working with patients with dementia (Hendriks et al., 2018):

1. The concept of personhood in relation to a patient(s), implying recognition, respect and trust.
2. Who the patient was and is, particularly when considering their current lived experience.
3. The patient’s body as a communication tool of embodied intentionalities, containing within it an awareness and sense of agency.

Combining PCC with codesign can lead to a number of strategies, such as an embodied reflexive approach emphasizing the importance of role-playing and storytelling (Hendriks et al., 2018), or the utilization of props to create connection and communication through touch, movement, materiality, and intimacy (Morrissey et al., 2016).

Beyond the process of collaborative design, it felt necessary that any being done to be situated within the framework of the ontological lived experiences of Alzheimer's patients. Escobar writes that an ontological approach to design is necessary to generate new meanings and conceptual approaches towards meeting the needs of communities being designed with together (Escobar, 2018). This is important, as work within the Science and Technology studies field has shown that a lack of grounding in the communities being served by and affected by new technologies leads to the embedding of political ideologies within the design or implementation of a given technology (Benjamin, 2019; Winner, 2020). These formulations have led to much inaccessible technology and spaces for various minoritized groups, in which they are rendered disabled or less worthy through technological formulations (Costanza-Chock, 2020; Hendren, 2020).

With this in mind, my initial feelings of the best way to achieve user inclusion was take a multipronged approach in how to learn about the people I was seeking to design with:

- Speaking to experts, particularly those in the field of psychology, to achieve a high-level understanding of the disease and to understand good research practices when observing, speaking to, and working with people facing Alzheimer's.
- Speaking to people associated in the space of Alzheimer's care to see what the ground-level needs of users may be and how these needs intersect with the services and spaces users interact with.
- From this, being able to take the knowledge and experiences gained from speaking with caregivers and experts to develop an understanding of and to work directly with those with Alzheimer's and Dementia.

In speaking with experts in the fields of psychology and user experience, they were able to share a great deal about dementia and Alzheimer's from a medical point of view, about the underlying neurological biological factors for the disease and symptomology, as described in the background section. Professors working in the field of user experience were helpful to obtain a broad overview of some the important things to note when designing interfaces and interactive products for people with Alzheimer's.

From there, I had hoped to speak and work with both caregivers and patients. However, since such work falls under the domain of what is considered as human subjects research, it was necessary to seek out Institutional Review Board approval for any interviews, participant observation, or codesign work conducted. This proved to be more challenging than initially

expected for a number of factors, with the challenge of obtaining consent from patients being the biggest hurdle towards approval.

Alzheimer's patients are a highly vulnerable group that unfortunately cannot give informed consent for participation in any research interview or project due to the nature of the disease (Kim, 2011). This raises a big ethical question of how to conduct design with a user who may not realize that they are conducting design together or forget that they are doing so. So far, while this has been an emerging field of research within medical ethics, there seems to be no clear-cut answers (Kim, 2011). While surrogate consent is certainly a possible avenue to conduct research, it still does not eliminate the very real ethical quandaries that exist within the project. Moreover, another huge issue is the existence of COVID, and the necessary precautions assisted living facilities are taking to protect their patients from the disease. Despite proclamations and a return to normalcy for most Americans, COVID still poses huge risks for vulnerable groups like elderly (Zhang, 2022). This necessitates increased screenings and security measures to prevent any patients from contracting COVID, something that is clearly necessary given the current situation as of writing. However, this means that places like assisted living facilities are less likely to let researchers conduct work on their premises due to fears of spreading diseases like COVID, something that will be expanded upon later in this section.

However, these challenges raised a huge question. How do I conduct a codesign project with these barriers? After asking amongst experts, it was stated that doing this work meant to reframe my approach from a purely research-oriented project, and more see a codesign approach leading to something that prioritized an approach of reciprocity and cultural grounding. In the words of one of the experts, consent is iterative. To conduct community work, it was necessary to be part of the community to nurture and grow relationships through care and reciprocity. This brought its own set of challenges, as it was unclear of how to fit this within an IRB prospectus, and any further challenges (while minimized) would still need to be addressed.

Overall, the IRB board found the ethical challenges of informed consent with Alzheimer's patients too troublesome without existing data dictating the necessity. They advocated to begin with interviews of caregivers before moving forward to seek approval to conduct codesign work with Alzheimer's patients, something that the subsequently approved when I submitted the research protocol following the exact approach they recommended. This felt congruent with the process of nurturing relationships with the community of caregivers and patients.

I reached out to various memory care centers in San Luis Obispo and the North County. Overall, there were 5 specific centers and 1 day-center that were contacted either via phone call or email to request interviews. Unfortunately, all centers never returned any messages or follow-up messages. While I cannot know exactly what their rationale was, it can be presumed that with the stress that the COVID pandemic had put on nursing staff and caregivers across the country, as well as any perceived risk of exposure to COVID must have made the staff in all 6 sites unable

or wary to answer any request. While it didn't stop the project completely, it represented a significant hurdle to the progress of the project, and one threatened to derail the project from its core principles and goal.

While the lack of access to user interviews had formed a significant barrier towards any interactions with the community of caregivers and patients I was hoping to design with, there was one other way to engage in this space that could help give this project momentum. During his studies of nuclear scientists and antinuclear activists, Hugh Gusterson was unable to access the laboratory where the nuclear scientists worked. Because of this, Gusterson had to seek out alternative means of research and connection to understand the scientists. What he termed as "polymorphous engagement" represented a means to understand a culture through "interacting with informants across a number of dispersed sites, not just in local communities, and sometimes in virtual form; and it means collecting data eclectically from a disparate array of sources in many different ways." (Gusterson, 1997) One fruitful avenue of data collection was through analysis of previous case studies to understand the process, methodologies, principles, and products that they produced.

No case study perhaps provided the greatest site of analysis than that of the Sentic music player. Created by a team



Figure 5: Image of Sentic Music Player

from Eindhoven University of Technology who worked directly with Alzheimer's patients, it was a static music player with a much more highly realized and thoughtful approach to the design of their interface and product than any of the current static music players on the market (Thoolen et al., 2019).

The player has 5 modalities for playing music, a mobile app which users interact with the physical device through tokens, a physical record-playing base, a discrete control interface with buttons and knobs, an exploratory interface, and a featureless interface base.

Sentic is an ingenious way to incorporate user functionalities smartly and without pandering to patients, something that they achieved through working with Alzheimer's. Beyond this, various

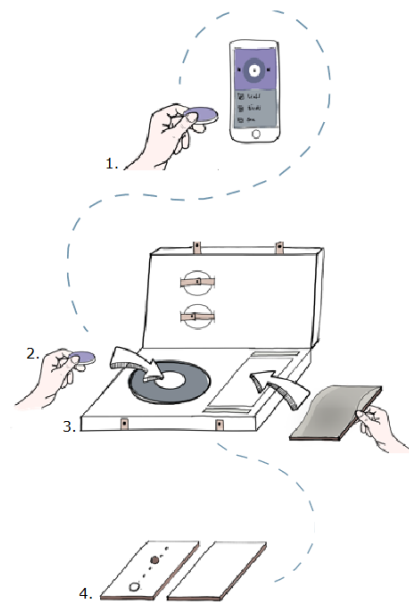


Figure 1: Sentic is provided with a mobile application for configuration of personalized music playlists (1), physical input tokens to activate these playlists (2), a tangible record player base (3), and three adaptable interfaces to control music (4).

Figure 6: Multimodal means of engagement with Sentic music player

sites of engagement included social media sites, medical literature, and other studies, all of which provided most of the detail for the background section.

Through this engagement and grounded analysis, certain preliminary design principles emerged that helped with the shape and direction of the project:

1. Everything is new all the time
 - a. While this is a bit of a gross oversimplification of the lived experience of those with Alzheimer's, it can be presumed the disorientation and confusion of the later stages of the disease can lead to forgetfulness on the part of the operations of a system or interface they recently have been introduced to. So therefore interfaces must be easy to pick up and relearn.
2. Consider contextually relevant interfaces to gather inspiration from
 - a. Building upon principle 1, a highly efficient way for people to learn a given interface, is if it matches cues, signifiers, and allowances that they are familiar with through previous devices. In particular for people with Alzheimer's, memories of experiences from when one is younger tend to stick around longer than more recent memories, therefore building an interface around one that a person might have been exposed to when they were young is a useful way to ensure that they are able to pick up on the interface quickly.
3. Importance of tactile and visual feedback
 - a. Tactile and visual feedback are important no matter the context, but given the context of people with Alzheimer's, they become important cues to remind the user of the state the device is currently in.
4. Simplicity in design, language, and content
 - a. Increased complexity requires increased brain power to engage with. When cognitive resources are getting lower, a more simplistic design interface can save cognitive load to be dedicated towards using a device rather than just making sense of it.
5. Role of caregivers
 - a. Caregivers are essential to the functioning and care of patients in various domains. However, in the context of music, they are essential for everything from curation and procurement of music and other audio files, to helping manage and set up a given device, to many other highly important factors. To make the device easy for caregivers is to make something that can help take a little load off of their already overloaded plate. As well, power-user controls can help patients quickly and efficiently when they run into trouble utilizing a given device.
6. Familiarity and preventing recognition errors
 - a. Utilizing familiar icons and symbols are a nice visual shorthand to help patients make sense of what is going on with a device. Moreover, having multiple means

of presenting information creates a means where if a patient forgets one symbol, another form of feedback can be there to inform them of the state of the device.

7. The role of playlists

a. As mentioned in the background section, playlists are essential to help create moods and facilitate reminiscing on previous memories.

8. How can the most essential features be preserved across stages?

a. While most of development in User Experience emphasizes creating base features for new users and higher-order features for power-users, for this device it is useful to allow a patient with the early-stages of Alzheimer's to be able to access most of the features of the device, and as they begin to enter later stages of disease, they can still operate the most core features of the device.

Application/Product (Prototyping?)

While thoughtful design is essential towards setting a direction most congruent with meanings and experiences of those you are designing with, prototyping is still essential to how principles and practices can work at scale. Due to this, it was encouraged to prototype to generate an idea of how such a device may operate and be fully realized. However, it is important to note that this

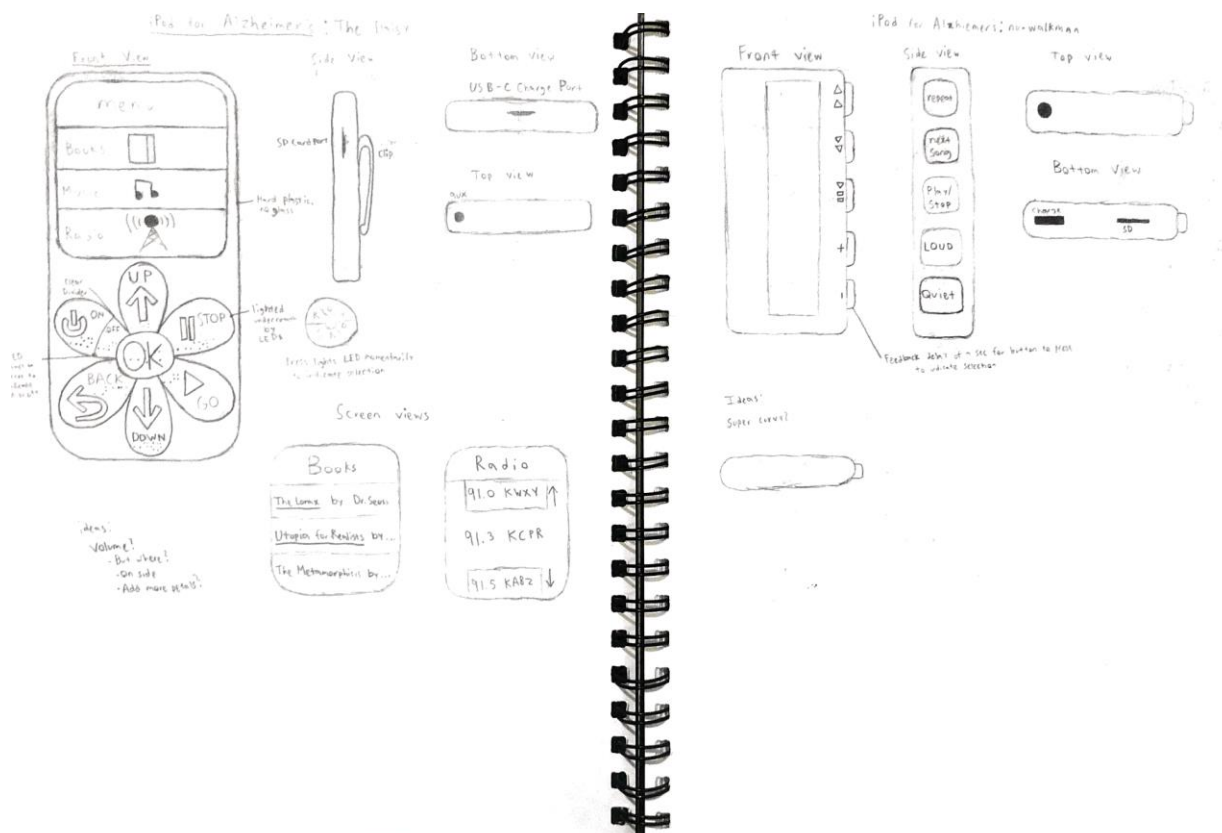


Figure 7: Preliminary ideation sketches - Dec. 2019

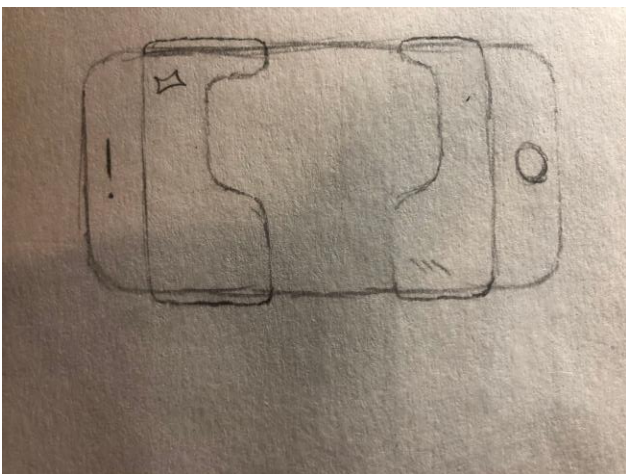
work is exploratory, as without proper grounding in the communities being worked with on this project, this prototype can risk replicating pre-existing disabling technological formations.

When I had first conceptualized of this project in December 2019, I had drawn preliminary sketches of devices that I had felt would meet the needs of my grandmother as I saw at the time.

The primary ideas for the interface were inspired by interfaces of previous products, with the sketch on the left being inspired by the interface of a classic iPod, while the sketch on the right being inspired by the design of the Sony Walkman. Both devices were intended to have digital interfaces, to reduce any sort of confusion that may arise from navigating various folders and playlists. A user in this way would be able to access the most core features to accessing and playing music, but able to quickly determine an action if they found themselves confused or unsure of how to do so. The actual device was envisioned to be made of a hard plastic shell with a relatively simple LCD screen for purposes of durability. These devices would utilize digital music files and management due to the high amount of music that can be stored on a digital device compared to devices that utilize cassettes or CDs as their primary storage medium.

However, through my conversations with various experts and people associated with the realm of Alzheimer's, I found that there were various other means to achieve similar outcomes that I had not previously considered.

One idea generated through discussions with experts was the idea of a rubber or plastic overlay



Figures 8-9: Ideation sketches for plastic overlay idea

that could be put on top of a tablet or smartphone, as seen in the figure above. This overlay would have a few simple buttons to access and connect to the device to allow users to interact with applications via the overlay. Another idea that has been discussed has been the creation of an app with a simple user interface that is congruent with design principles that have been found to be effective for users with cognitive decline (Devin, 2021).

Owing to time, it made sense to pursue the creation of one device. With the initial sketches created, it seemed useful to update the interface with the new principles that outlined in the design section.

For this, it seemed ideal an interface both simplified yet elegant that fit within design principles 1-4 and 6. Don Norman writes that one of the best ways to indicate to users about functionalities and ways to achieve those functions is through the creation of affordances to the user that

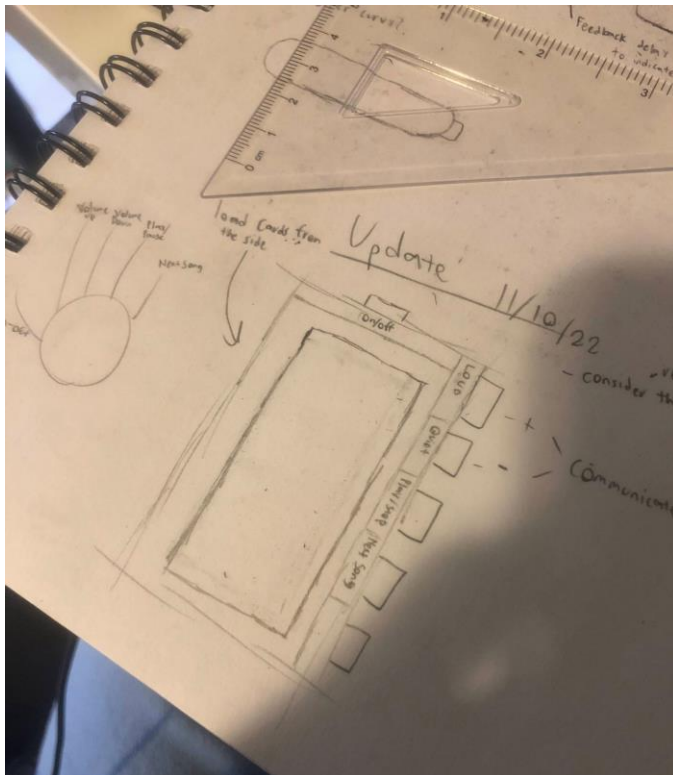


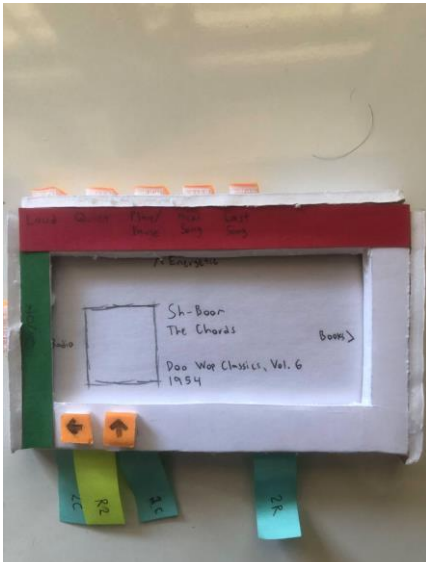
Figure 10: Final ideation sketch - Nov. 2022

communicate what a given piece of the interface can do (Norman, 2013). All buttons and features would need to be easily learned and relearned. Because of this, the core buttons of the device were mapped to a left hand. Thumb would be for power; index finger for volume up (+); middle finger for volume down(-); ring finger for play/pause (▶); and pink finger for toggling between skipping to the next song (▶▶) and returning to a previous song (◀◀). This also allows for both visual and tactile means to adapt to a given interface while being simple enough to not cause any extraneous cognitive loading. As well, simplified language and familiar icons gives a user the sense of what function each button is for, such as the word “loud” and the symbol “+” for increasing the volume. Beyond this, it was felt that a good way to build familiarity with the device was to choose to model it off an adapted version

of my initial idea that I had with the Sony Walkman, a device that has been noted for its ubiquity in popular culture and its well designed and easy to learn interface. (Wilhide, 2016) Furthermore, to emulate some of the design features of the Walkman that may be familiar to users, it was envisioned for certain buttons to stay down when pressed, such as the play/pause button, to further incorporate tactile feedback into the device that users could directly observe and draw a quick finding from.

Moving from sketches to actual prototype, an additional two buttons on the bottom left hand corner of the device were added, in order to facilitate a seamless means to change playlists (Λ) in order to meet principle 7 and to change audio formats (◀). With all buttons accounted for, I felt like the interface schema met principle 8.

In terms of choosing a physical prototype over a digital rendering of the device, the device needed to be tested to understand how the interface would be used and physically felt, something which would be done music easier through a physical prototype over a digital one. This prototype was made with an exterior shell made of poster board that was held together in place with adhesives and clear tape. The buttons that comprise the interface of the device were made from the Command velcro strips, as it seemed like better way to simulate the tactile sensation of the buttons, and the sponginess of the velcro and foam comprising the strips allows a (albeit faint) simulation of the press of button. The red and green bars on the front of the device also



Figures 11-13: Images of prototype I

help to distinguish the two sides of the device with buttons chromatically, with green corresponding to the power button and red corresponding to the function buttons. Finally, the actual display of the device was made via various decks of index cards through which various modes and displays could be simulated.

Analysis/Verification

Due to the challenges and barriers faced with being able to interview and run codesign experiments with Alzheimer's patients and caregivers, alternate means of testing were to be resorted to. The main questions were whether the interface could be picked up and utilized easily under states of high mental load or stress, and how congruent the device was to meet design principles 1-4 in an actual test scenario.

With this in mind, testing was approached by seeing if a test user could be put in a state that could approximate the experiences of someone with Alzheimer's. While there has certainly been much written about Alzheimer's simulations, much of it focuses upon utilizing virtual reality (VR) or videos to bring a sense of empathy and understanding amongst users towards those with

Alzheimer's, and not for user testing. And that's for good reason, while certainly the utilization of "old age suits" has seen notable benefits in terms of user understanding of mobility needs of elderly adults (Lee & Teh, 2020), simulation practices like that of the suit or user personas tend to incorporate the biases of the designers creating the personas or simulation suits (Costanza-Chock, 2020; Westerholm-Smyth, 2022). Therefore, it must be stated that while my testing results are informative, we cannot find them conclusive as I and the people for whom I tested do have the requisite lived experience to fully understand the experiences of those with Alzheimer's or dementia.

The Baycrest Center for Learning, Research, and Innovation in Long-Term Care identifies 8 key areas of lived experience of those with Alzheimer's that a given simulation can work to induce within users (*Dementia Simulation Toolkit*, 2018). Those key areas or "A's" as they are described are:

1. Anosognosia
 - a. A patient is unable to understand that something has changed or that anything is wrong. For example, a patient may not understand why they have cognitive problems or that they have cognitive problems at all.
2. Agnosia
 - a. A patient is unable to recognize things through their senses: sight, sound, touch, taste, and smell. A patient may be unable to sort out what they see or hear, or be able to recognize familiar people.
3. Aphasia
 - a. A patient is unable to utilize or properly decode language. This includes the ability to speak, understand, read, or write. For example, a patient may be able to speak, but unable to comprehend what others are telling them.
4. Apraxia
 - a. A patient has lost the ability to tell their body how to carry out purposeful movement. It may become difficult for a patient to do activities like tying their shoes, doing up buttons and zippers, or any activity involving coordination.
5. Altered Perception
 - a. A patient misinterprets the information their senses are giving them. This can lead to something like loss of depth perception.
6. Amnesia
 - a. A patient's loss of memory. Earlier in the disease, short-term memory is affected, however as the disease progresses a patient's long-term memory will begin to be harder to retrieve.
7. Apathy
 - a. A patient loses the ability to take initiative. They may have a hard time beginning activities or may need someone to give them cues to keep them involved in a task.
8. Attentional Deficits

- a. A patient's complex attention span is lacking. They may not be able to complete a task or get easily distracted.

This schema of lived-experience sits well within my design criteria, From this my testing developed as such:

1. Phase 1

- a. Explain test procedure and purpose to user
- b. Explain the device/prototype and allow users to acquire a level of familiarity with it
- c. Move device from view and ask reader to read an article (Amnesia - replace knowledge of device that they have in their short term memory with the article)
- d. Subsequently quiz the user on the article they just read
- e. Ask user to spin 10 times rapidly (Apraxia - user gains less control over purposeful movement through disorientation)

2. Phase 2

- a. Ask users to put on headphones with semi-loud white noise playing and glasses that impair users vision (simulate a loss of cognition and understanding of sensory inputs across a range of factors)
- b. Ask participant to please sit in the chair in front of them
 - i. Refer to the chair as a different color than the one in front of them (Altered Perception/Agnosia)
- c. Ask user to grab the device
 - i. An important point: the conductor of the test must “misphrase” statements to simulate what a person with dementia would hear. Instead of “please grab the device”, it becomes “Please map the crevice.” (Aphasia)
- d. Ask user to turn on device
 - i. Under similar pronunciation procedures: “Weaze press on cotton.” (Please press on button)
- e. Ask user to turn on music
 - i. “Please quest blay.” (Please press play)
 - ii. Once the user has pressed the play button (▶), turn on music in headphones via the device the headphones are connected to.
- f. Ask user to change the music
 - i. “Okay, wonder way, do you kite in song?” (Do you like the song?)
 - ii. “West range the song” (Let’s change the song”
 - iii. Once user has changed the song via the next song button (▶) or the change playlist button (Λ), change the song being played.
- g. Ask user to change the format
 - i. “Beer, boing to range to radio. Breeze range to radio”

- ii. Change to radio once user has pressed format button (<).
- h. Ask user to change volume
 - i. “Is the ballroom due crowd?” (Is the volume too loud?)
 - ii. “Press town in height” (Press down on quiet (-))

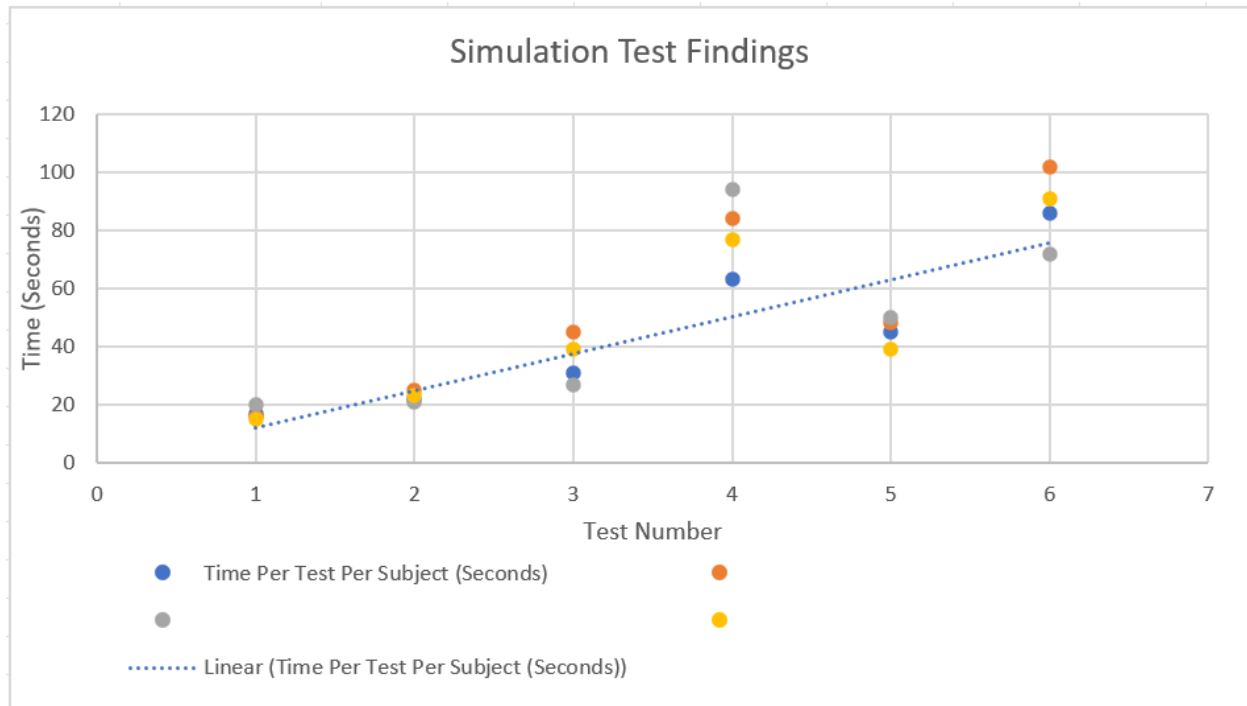
3. Test is finished. Politely ask the user to take off headphones and glasses for debrief.

In terms of validation for the methodology, the 5 users tested via these methods remarked about the definite disorientation and confusion they felt during the test, which is in-line with what is described about the lived experience of those with Alzheimer’s. Overall, users were quick to turn on the device and turn on music. Users experienced greater difficulty making sense of the device when it came to the specific function buttons, especially those dedicated to changing playlists (Λ) and formats (<). It was recommended by 1 user to maybe state the outcome of those functions above the buttons themselves rather than off to the sides of the display. As well, there was a desire by another user to provide an explanation of the playlist and format buttons on the device to make better sense of what they were. Finally, multiple users remarked the importance of the device being a compact size, as they had a hard time holding it in their hands, and being able to map the function buttons to their fingers. A former caregiver who worked in memory care also was able to look over the device, and was impressed with the device overall, but mentioned many of the same problems illuminated through the previous user tests.

Data from User Simulation Tests:

	Subject 1	Subject 2	Subject 3	Subject 4	Subject 5
Device Grab (Test 1)	15 Seconds	17 Seconds	16 Seconds	20 Seconds	15 Seconds
Power On (Test 2)	20 Seconds	22 Seconds	25 Seconds	21 Seconds	23 Seconds
Turn On Music (Test 3)	35 Seconds	31 Seconds	45 Seconds	27 Seconds	39 Seconds
Change Music (Test 4)	72 Seconds	63 Seconds	84 Seconds	94 Seconds	77 Seconds
Change Volume (Test 5)	44 Seconds	45 Seconds	48 Seconds	50 Seconds	39 Seconds

Change Format (Test 6)	90 Seconds	86 Seconds	102 Seconds	72 Seconds	91 Seconds
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Figures 14-15: Table of simulation test data and plot of data

I was also able to receive input about the prototype device from various professors and organizations. A member of the Music and Memory program told me that the prototype as it stands would make a good start for a working prototype. As well, an administrator within the central coast chapter of the Alzheimer’s Association said that they too enjoyed the design and liked the fact that it was similar to a Walkman. Furthermore, one professor noted that it would be important to incorporate some sort of mechanism for feedback from patients on their thoughts and feelings about a given song. They also suggested it may be worthwhile to include other images and signifiers that tie the song further to a given memory.

Future Steps

After talking the data from the tests and the reviews into account, a rough secondary prototype was sketched that better meets some of the issues outlined by the testing data.

The device itself still needs a great deal of testing and iterative cycles to truly be seen as something that can be introduced to patients and communities. Further interviews and user testing will help further augment this device to match the needs and wants of patients and caregivers. Some important considerations include how patients adapt existing interfaces to meet their needs, what sort of errors are highly common amongst interface design for patients, how the

lived experiences of Alzheimer's differ from other forms of dementia and how that translates into different experiences with interfaces, and more detail about the lived experiences of caregivers and memory care staff. Furthermore, some possible methods to refine and conduct future design steps include 3D modeling of the device and higher fidelity prototypes to test with.

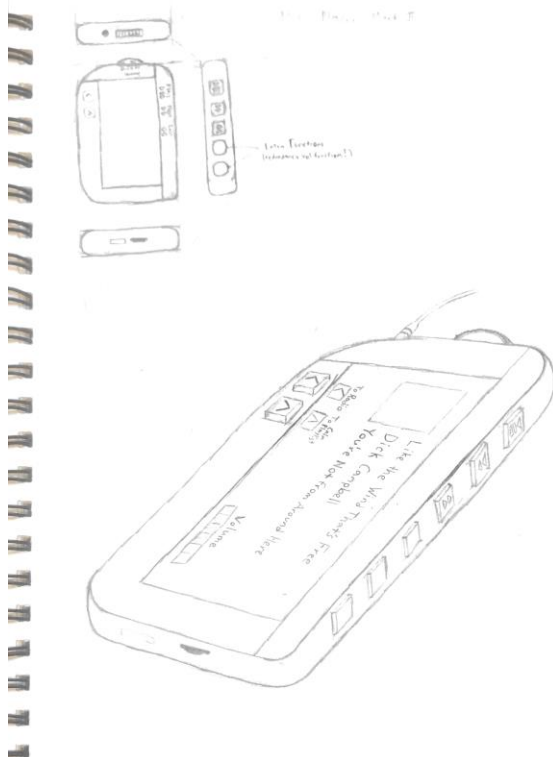


Figure 16: Prototype II ideation sketch - Dec. 2022

Some other important future considerations include questions of manufacturability, distribution, cost, and life-cycle analysis.

Moving forward in this project, collaborative design principles will be critical towards grounding this design in the lived experiences of caregivers and patients, as well as being to create a generative situated learning within a community, something that I think is important for several factors. Placing the development process within the community will not just help to create a device that better reflects the lived experiences of those with Alzheimer's, but I think could inspire the exploration of new avenues of inquiry that are not even known of yet. Beyond this, a community-led practice could also lead towards a self-generating design praxis, something where patients and caregivers can take the reins of the design process

themselves, and work to create and advocate for themselves and the dignity that they deserve.

Conclusion

Music is an inherently meaningful artform. It is the type of artform that will inspire people to travel thousands of miles to see their favorite band, or remain with a person for their lives in the form of an experience like the first dance at a wedding with their spouse. Yet, for people with Alzheimer's and dementia, the music that connects them to therapies, to their most precious memories, and their sense of joy is hard to reach for. While there are half-measures that can provide music to patients, music can be a space where patients can be given a small portion of their agency and dignity back, through well-designed and intentional means. The design principles, device, and testing methods described in this paper are an attempt to create those well-designed means, something that is in concert with the work others are doing globally to achieve the same ends. In that regard, I hope this paper may be utilized as a useful stepping stone for future efforts towards bringing accessibility, if even just to access music, to those millions

with Alzheimer's and dementia. A professor once told me that we are all just temporarily able-bodied. I think this proves that the world that we create for those who are most vulnerable dictates the world that we create for all of ourselves. I hope that efforts like these can be utilized to create a much more relational, dignified, and meaningful world accessible for all.

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