Designing for Users with Dementia

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ABSTRACT
The number of people that are diagnosed with dementia is growing every 65 seconds. Alzheimer’s disease accounts to more than 50% of cases of dementia. Today, about “5.7 million Americans live with Alzheimer’s” and the population will continuously grow in the next twenty years (Alzheimer’s Association 2018). But how do these individuals maintain their quality of life and how does it affect the people around them? Dementia is one of the topics that is very difficult for designers and researchers to tackle because there is no cure and every individual has different symptoms. So how do we design a good quality of life for individuals who have dementia?

In this study, we will discuss what dementia is and elaborate on the difficulties of using existing traditional design methodologies such as empathetic and participatory design to test products and services on individuals with dementia. In addition, it is recommended for designers and/or researchers to include traditional tools in their design process such as personas and user journey mapping or even diary studies to really understand symptoms of each participating individual with dementia and include the caregiver during practice. Through an overview of existing case studies, we understand that usability testing will never be intuitive for individuals with dementia and have extra challenges when it comes to completing tasks or getting feedback on expectations and best design solutions. Therefore, designers and researchers who may succeed in this industry must learn to be patient and flexible conducting their research and participate in creating a flexible design process.

KEYWORDS
Alzheimer’s, dementia, design, Human Computer Interaction, design challenges, user experience, inclusive design, universal design/

INTRODUCTION
Dementia is an impairment with more than 90 types of diagnoses [1]. There are three existing stages of dementia: mild, moderate, and advanced. These stages can vary per person. In general, symptoms include memory loss, mood changes and challenges with reasoning and/or communication.

Mild
During the mild stage, the individual demonstrates minor signs of forgetfulness, social anxiety especially with dealing with tasks.

Moderate
During this stage, symptoms accelerate. Individuals start to withdraw from society and have difficulties with everyday routine tasks. In addition, challenges emerge with time and physical orientation.

Advanced
There is no medicine or cure for mitigating the condition. This stage is where the individual loses their self-identity, language skills or even motor skills.

Due to no cure, the best way to help these individuals is to provide the best quality of life for the rest of their remaining days. Since this affects the lives of people with dementia and the ones around them, we must consider all factors, such as tools to help with their memory, language and motor skills to completing simple tasks in their environment. Therefore, designers and researchers are challenged to design products and services that can maximize the quality of life.

This study will aim to increase the knowledge of existing design methodologies that have been used in the past and distinguish differentiation in design methods that have worked well or not so well with people with dementia.

RELATED WORKS
There are many case studies that have been conducted in the past decade to improve the quality of life for people with dementia. For example, major case studies include product testing in labs, exploring game designs to improve social and cognitive impairments, and exploring universal design for a holistic living community that are specifically tailored to dementia patients. Based on these studies, researchers are never quite sure which method to use. They adapt to the needs of each test or service because each individual requires tailored experiences.

Empathetic Design
Based on previous works done by multi-disciplinary team at University of Liverpool along with Research Institute for the
Care of Older People (RICE), we can conclude that people with dementia can demonstrate engrained experiences from their past. However, to bring out their engrained experience to current time can be challenging. Intuitive reactions should not be expected from these individuals during tests. R. Orlwood et al. approached product design based on the familiarities and experiences of the user. For example, engineers designed a music player for a sense of involvement. The patient with dementia can operate the product on their own without the help of the caregiver. The engineer team approached the design based on empathizing the user and getting direct feedback from design prototypes. This centered on exploratory tests, in which were supervised in their own homes over a period of half an hour [6]. In this study, users demonstrated mild to moderate level of dementia. The design evolved based on feedback obtained on each test. The engineers realized that getting the right feedback wasn’t something straightforward because it involved the users in a level of problem solving, which varied by their mood or their intuitive level. (see Figure 1).

![Figure 1. Music Player Design Iteration (Netherlands)](image)

In Figure 1, one of the challenges during the exploratory test of the third prototype was how to get the user turn off the music player by closing the lid. The dementia patient had no clue that the music would stop by closing the lid when they were asked to perform the specific task. The engineers observed that a patient closed the music player only when the patient’s carer called for the patient into another room and their body reacted by closing the lid without thinking. Therefore, they realized that it was necessary to carefully develop “situations that allows the user to operate in a subconscious manner rather than engaging them with problem solving” [6].

In addition, people with dementia are challenged with conversations due their memory problems. When testing a product, some patients were trying to withdraw due to feeling negative during time of failure. This makes it difficult to continue the testing. Thus, ensuring simple clear interactions during a test must be carefully considered.

**Participatory Design**

Participatory design is a common design methodology that encourages users to create valuable ideas or mockups of what products they would like to use in a perfect world scenario. Unlike previous example which is more geared to empathetic design, paying attention to the user’s feelings toward the product, participatory design involves the user to imagine and visualize a product they would love.

In this case, dementia patients are limited to visualization or even possible solutions that designers are trying to get out of testing. “People of dementia experience problems making a choice, understanding assignments or staying on track” [5]. In similarity to previous empathetic design process, dementia patients that felt weak during a participatory design session, stopped participating or withdrew from the study. Most participants were only involved to do designers a favor. For example, according to a case study that involved designers in a participatory design to test a Homing Compass that was first designed by experts themselves, which leads people with dementia back home with clear direction (see Figure 2), designers were able to receive positive results when seven out of the eight participants managed to find their way home using the compass. However, the evaluation did not consider other factors that may have affected the results. Usually dementia people rely on regular navigation skills by using landmarks, however in this situation, users might have felt pressured to use the device just to make the designer feel happy as they followed the participants around from behind. Further, the observation lacks personal feedback on how each participants felt using the compass or even if they initially understood how to use the compass without the designer helping them.

![Figure 2. Homing Compass (Belgium)](image)

Participatory design sessions are difficult as much as empathetic design. These projects do not represent different levels of dementia due to use of only dementia patients in mild to moderate stages during testing. If most of these research projects are controlled by specific user types, it is not an accurate reflection of the large dementia population.
In addition, designers and researchers do not show the in-depth context about individual’s life style and the caregivers that are in their lives. Without this context, we do not know the level of symptoms and how caregivers impact a patient’s daily routine. These factors can have an impact on the results of a test.

DISCUSSION
In this section, we will discuss the ethical aspects to consider when it comes to designing for people with dementia.

Ethical Aspects
Designers and researchers must pay attention carefully when it comes to implementing and testing for people with impairment. As a human factor community, we must be aware that we are not impacting people with dementia negatively since it involves a vulnerable group. To develop an understanding of dementia and improve the knowledge for designing for dementia, training should be considered.

For large participatory design studies, a researcher and/or designer should create a thorough protocol to be approved by Institutional review board. We also want to encourage tests that will demonstrate trust with all parties, including participants and their caregiver.

RECOMMENDATION
This study showcases few challenging case studies that designers and researchers had to face while designing for this particular group. One of the goals of this study is to provide simple guidelines and recommendations to consider when designing for people with dementia. In the future, this can also be applied to other user groups that may include other disabilities. Tools and user guidelines are introduced in this section for any new designers or researchers starting a project that includes people with dementia.

Personas
According to Smashing Magazine, personas boost clarity, productivity and success of design projects. It enables organizations to focus on manageable and memorable cast of characters. This is a critical tool that helps designers to boost their understanding of individuals in their research. Since people with dementia have so many different symptoms, it’s best to observe them and interview caregivers to really understand their daily lives and personalities. In this example, I introduce three generalized personas that represent three different stages of dementia (See Appendix A).

Persona 1 Mild
Steve is 60 years old and having minor memory problems. His wife passed away last year, but has his 35 year old son who lives nearby. He works as a volunteer at a local church couple days a week and picks up his younger grandchild from school Thursday through Friday. Steve made an appointment with his primary doctor before meeting a specialist to discuss his worries, fearing dementia as his mother had this. He hasn’t spoken to his son or other family members so he doesn’t make them worry. He’s also worried about financial costs for treatment.

Since the loss of his wife, Steve likes to spend time in coffee shops and making trips to the cinema to keep things to himself. He does not like large groups or big social gatherings.

Persona 2 Moderate
William is 68 years and is a retired real estate agent. He and his wife have been planning a vacation and to visit their daughter in Florida. The tickets have been booked for couple weeks now, however, William recently was diagnosed with Alzheimer’s, which he is having trouble accepting. He is also losing his driver’s license. He is still hoping that it is a misdiagnosis and trouble remembering what was discussed during consultation. He began to show signs of anger while speaking with his wife. Mood swings vary day by day and he does not want to think about his conditions. He gets more aggressive when people around him use the word ‘dementia’. At this moment, he just wants to visit his daughter in Florida.

He can’t remember where he left his phone most of the time and sometimes house keys. His wife makes sure to follow him when he decided to walk outside of the house.

Persona 3 Severe
Rachel is 80 and lives at a dementia care home. She was diagnosed with dementia for couple of years and also have diabetes. She has been taking medication in early stages for her memory and diabetes, but she forgets to take her medications. She also has trouble going to bathroom time to time because she loses her direction. She has a care giver who makes sure she takes her medication and visits her couple times a day. She spends most of her time in her room, while staring at the window. At times, the caregiver, Sofia brings her out to help her socialize with other patients.

When creating a persona, especially a person with dementia, we must include what’s most important to them, especially their fears, hopes and key challenges. In addition, descriptions like age, gender and personalities are important to portray their personalized experience.

User Journey
Another tool that designers and researchers should incorporate in their design process is a user journey mapping. It is a tool to help empathize user behavior, identify pain points and visualize the ideal solutions for a product or service. It includes users motivations and main tasks that involve their everyday lives.

This tool is very useful when it comes to visualizing a day in the life of a carer. A carer may witness different journeys taking care of their loved ones or a patient with dementia (see
In addition to flow charts, tools like flowcharts can come in handy. This can be done in less time based on expertise while user journey mapping provides great details through observation and interviews (see Appendix C).

**Design Guidelines**

In addition to user methodologies, being aware of existing design guidelines is very important. No individual has to start from scratch because many countries have invested time and effort in creating a thorough guideline for the public.

**Universal Design**

Universal design is the design process of creating products and/or services that include wide range of users, especially users with disabilities. Today, there are complimentary research guidelines that help approach dementia specific design issues. One of them is Universal Design of Dementia Friendly Dwellings for People with Dementia, their Families and Carers (UDHI Guidelines).

This guideline, which is based on a design system in Ireland, is a great foundation for the designing an environment for better quality of life. It should ensure that:

- People can live on their current homes or community by creating a safe environment
- Include home designs that support people with dementia and their families along with carers
- Encompass practical designs that is cost effective
- Enhance the overall well-being for all parties mentioned above

According to the UDHI guidelines, the common design issues to consider in UD approach are:

- Create a flexible participatory design that includes all parties in the design process
- Use recognizable designs that is consistent with the user expectations. In addition, include personalized environment to enhance the design process
- Reduce visual and noise disturbances, creating an environment that can be interpreted easily
- Prompt dwellers with good visual features and remind them of important objects
- Provide secure and safe environment by including assistant technologies such as Ambient Assisted Living (AAL), Telecare or Telehealth.

These are the common design approaches to universal design when designing for people with dementia. In order to understand the specific approaches to different cases, it is best to familiarize and scan over the 100 page UDHI Guidelines.

In addition to these existing guidelines, experts should include these following considerations:

**Be Prepared**

- Always search to connect with local organizations and groups
- Get to know the users in person and understand their pain points
- Always get consent with the person with dementia, especially on various moments of testing
- Approach individuals in formal way and give enough time for practicalities

**Choose a Flexible Method**

- Adapt the design methods so it will take into account the difficulty for people with dementia to envision intangible concepts or notions
- Each method should be personalized towards the person’s background

**Train Yourself and Others**

- Create a well-planned and structured meetings
- Be prepared to be patient when facing repetition and reviewing
- Minimize visual and noise distractions to keep participants focused
- Give carers and trusted family members an important role during a test
- Do not overanalyze utterances of participants

**CONCLUSION**

To become a great designer or researcher, we should challenge ourselves in solving problems in a creative way. It is also important to use what we know in order to shape our design processes. We need to start thinking about designing for people other than the regular population. These kind of studies are not explored as much during academic settings due to ethical aspects, cost and time.

This study was conducted to understand the basic challenges of designing for people with dementia and what design methods and processes we can use to solve challenges for people with dementia and their carers. It is a new perspective for students to understand that we are not only designing digital interfaces, but we can use our knowledge and practices to enhance better quality of life for certain populations. As experts in human factors, we should always be ready to adapt and be flexible in our design methods, especially when it comes to empathizing different types of population and truly grasp the pain points of individuals we are trying to design for.
LIMITATIONS
Due to limited time, I could not recruit people who have experience with dementia patients. For further research, I would like to interview participants who have family members with dementia and understand some of their pain points and see what kind of expectations they have when it comes to taking care of their family member with dementia.

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REFERENCES
APPENDIX A

Steve  mild stage of dementia
60, a father and volunteer

“I didn’t tell anyone about my diagnosis with dementia yet because I do not want my loved ones to worry.”

BIO

Steve is 60 years old and having minor memory problems. His wife passed away last year, but has his 35 year old son who lives nearby. He works as a volunteer at a local church couple days a week and picks up his younger grandchild from school Thursday through Friday. Steve made an appointment with his primary doctor before meeting a specialist to discuss his worries, fearing dementia as his mother had this. He hasn’t spoken to his son or other family members so he doesn’t make them worry. He’s also worried about financial costs for treatment.

DAILY ACTIVITIES

Since the loss of his wife, Steve likes to spend time in coffee shops and making trips to the cinema to keep things to himself. He does not like large groups or big social gatherings.

William  moderate stage of dementia
68, retired real estate agent

“I can’t believe I got diagnosed with Alzheimer’s. I just can’t believe it. We were just planning a trip to Florida to see my daughter.”

BIO

William is 68 years and is a retired real estate agent. He and his wife have been planning a vacation and to visit their daughter in Florida. The tickets have been booked for couple weeks now, however, William recently was diagnosed with Alzheimer’s, which he is having trouble accepting. He is also losing his driver’s license. He is still hoping that it is a misdiagnosis and trouble remembering what was discussed during consultation. He began to show signs of anger while speaking with his wife. Mood swings vary day by day and he does not want to think about his conditions. He gets more aggressive when people around him use the word ‘dementia’. At this moment, he just wants to visit his daughter in Florida.

DAILY ACTIVITIES

Lost his driver’s license. Can’t remember where he left his phone and sometimes house keys. His wife makes sure to follow him when he decided to walk outside of the house.
Rachel 80, dementia and diabetes patient

“Is it time for bed yet?”

BIO

Rachel is 80 and lives at a dementia care home. She was diagnosed with dementia for couple of years and also have diabetes. She has been taking medication in early stages for her memory and diabetes, but she forgets to take her medications. She also has trouble going to bathroom time to time because she loses her direction. She has a caregiver who makes sure she takes her medication and visits her couple times a day. She spends most of her time in her room, while staring at the window. At times, the caregiver, Sofia brings her out to help her socialize with other patients.

DAILY ACTIVITIES

She has a hard time socializing, therefore, she stays in her room staring at the window or lays in bed. Her speech is deteriorating and dislikes social interaction.
Caregiver journey summary

A project of agingwell hub

Phases of disease

Noticing changes (2 years)

Making adjustments (1 year)

Shifting priorities (2 years)

Increasing demands (2 years)

Full-time care (15 years)

End of life (6 months)

Karen's experience

Karen notices issues with her mom: memory problems, decline in eating, and disorientation.
She discusses her concerns with her mom and brother, who are dismissive.
She turns to friends and the Web for information.

Caregiving

Once a week visits

Caregiving Twice a week visits

Caregiving Every other day visits

Caregiving Daily visits

Caregiving 24 hours a day

Caregiving Twice a day visits

Karen's key needs

An understanding of warning signs for dementia
A reputable source for info on symptoms
A way to align her family and gain support
Someone knowledgeable to talk to about her concerns
Flexible schedule at her work

"What will be next? How do I manage this?"

Age 43 when caregiving begins
Care recipient Her mother, Debbie
Diseases Alzheimer's disease, hypertension
Living situation Lives separately, 20 minutes away
Career Full-time office manager

Karen's ecosystem

Debbie Karen's mother
Bill Karen's younger brother
Leanna & Amelia Karen's daughters
Paul Karen's husband

Karen realizes Mom can't drive or take care of her finances anymore, but Mom wants to stay in her own home.
Mom begins wandering and becomes more violent.
Karen starts sleeping at Mom's house sometimes to make sure she is safe.

Karen hires a part-time home care aide that Mom dislikes.
She takes a few days off work when Mom is hospitalized for a fall.
While Mom is in 3 weeks of rehab, Karen researches full-time care options and Medicare/Medicaid.
After discussing the options with her family and brother, they decide Mom will move in with Karen.

Karen moves in with Karen's family, the whole family helps with caregiving (sometimes reluctantly).
Karen moves to part-time work and struggles to find good dependable care workers.
Karen and her brother sell Mom's house to pay for her care.
Karen sleeps very little and her family reaches their breaking point.

Karen visits full time facilities and select a local nursing home they can afford.
She returns to full time work but is constantly pulled away for caregiving responsibilities.
As Mom stops eating and drinking, Karen takes time off work to be with her until her death.
Karen continues to deal with issues of debt, grief, and family discord.

"Is this part of normal aging, but what is it?"

"This is not normal aging, what do I do now?"

"How much longer can I take care of Mom?"

"How do I make sure Mom is safe 24 hours a day?"

"Mom is in a facility. Why is this still so hard?"
William is a 68 year old quite timid man and always worked as a real estate agent. Both his work and social life was very cunning punctual. His wife relied on him to take care of his family. He has 4 children who are all grown up.