# **AD-Pedia**

A tool for informal caregivers to improve personalized nursing experience of people-with-dementia

**Graduation Thesis by Shuyan Zhuang** 

# **AD-Pedia**

A tool for informal caregivers to improve personalized nursing experience of people-with-dementia

### **Author**

Shuyan Zhuang

# **Supervisor Team**

ir I.A.Ruiter MEng Gubing Wang

# **Preface**

Due to the Covid-19, I was not able to return the Netherlands, the project context was in China. This project cannot be completed without the support from many people in such a special situation.

#### I would like to appreciate:

lemkje and Gubing. You always shared the most thoughtful comments and incredibly helpful suggestions through the different phases of the project. You provided me with a lot of help and support in the difficult remote cooperation.

My parents. I lived at home during the project. It was a precious time for us because I have been abroad since I started university (7 years). During the past five months, we lived together and felt close to each other.

Xingyu, yiling, Junyao and other friends. We built the good friendships from Master and created nice memories in the Netherlands. And thank you for sharing your experience of graduation with me and encouraging me every time when I encountered difficulties.

All participants. Thank you for trusting me and sharing valuable experiences, stories, and feelings with me during the research phase and evaluation phase. Your information and insights are essential to this project.

# **Executive Summary**

This project is about designing a tool to help informal caregivers provide better dementia care experiences for the people-with-dementia. There are many different non-pharmacological interventions that can be applied to help deal with the symptoms of dementia. Both understanding the knowledge of non-pharmacological interventions and knowing the people-with-dementia is necessary for informal caregivers to personalized apply these interventions during the daily care. This project is researching this topic and developing a tool to support informal caregivers.

The project follows the double-diamond model.

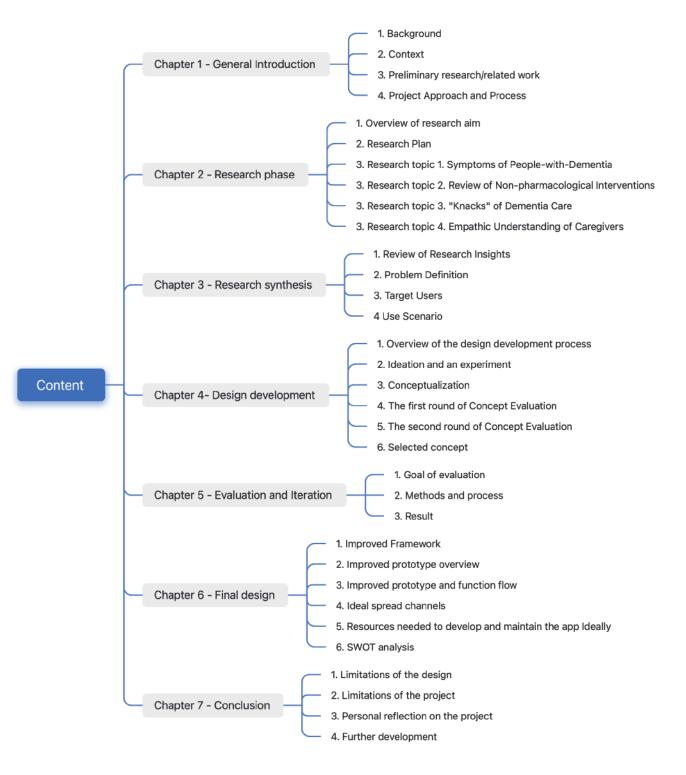
Discover: desk research, context inquiry, in-depth interview and collage were applied and different stakeholders were involved to dig deeper into the research questions.

Define: The research results were summarized and the design problem, target users and use scenario were defined.

Develop: Multiple concepts were created and evaluated by the Objective Weighted during the develop phase. Deliver: One concept was chosen to further detailed, evaluated, iterated and finally delivered.

The outcome is a platform, which is an app, for informal caregivers to search and learn dementia-related knowledge and discuss with each other or with the experts. Users can learn different non-pharmacological interventions and knacks on the platform as well.

# **Content**



# **Chapter 1**

# General Introduction

This chapter starts with the background of this project and demonstrates the holistic context of this project. Then, the preliminary research inspires the open threads for the problem solving. The last part of this chapter is the project approach and process, where the detailed research and design process are explained.

# **Chapter 1**

2.1 Introduction of two dementia care provide models
2.2 Project Scope
2.3 Problem statement
2.4 Designing goal
2.5 Project challenge
2.6 Design challenge
3. Preliminary research/related work
4.1 Project Approach
4.2 Project Process



# 1. Background

Dementia is a worldwide common disease that is incurable and the progression cannot be stopped, but some symptoms can be alleviated by medical treatments and non-pharmacological interventions (Alzheimer association, 2021). Normally, people-with-dementia need extra care support due to the degeneration of cognitive and physical capabilities that interfere with daily activities. Some patients live in the nursing home or care center and are cared for by nurses, while others live with and are cared for by the informal caregivers at home, depending on the circumstances of each patient and their own or families' choice.

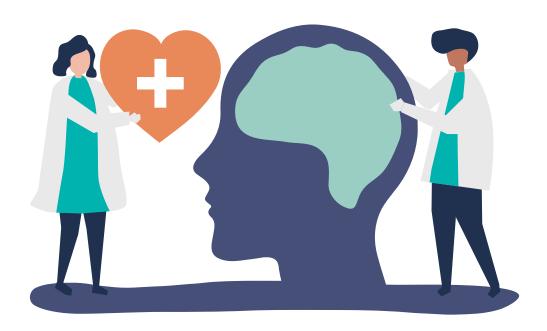
The informal caregivers are usually the people-with-dementia's spouse, children, other family members, or a paid worker. However, these informal caregivers are lacking relevant knowledge or training. Inappropriate nursing will lead to a poor dementia care experience. Even inadequate or excessive care can have counterproductive effects. How can informal caregivers learn the relevant knowledge and provide the appropriate care to the people-with-dementia?

# 2. Context

# 2.1 Introduction of two dementia care provide models

There are two main popular ways to achieve dementia care:

- 1. living in the care center and cared for by nurses and caregivers
- 2. living at home and cared for by informal caregivers.



## **Model 1** living in the care center and cared for by nurses and caregivers

Referring to the situation in China, not all caregivers in care centers are professional caregivers who have passed professional nursing training and obtained official certifications. These people are belonging to informal caregivers as well, and their duty includes ensuring that the PwD takes the medication prescribed by the doctor, helping the PwD have meals and shower, ensuring the PwD's safety, and taking care of the PwD's emotion (interview note, 2021). Besides, during the leisure time, the PwD will be given recreational activities by the caregivers depending on each PwD's remaining capabilities and personal habits, such as chatting and enjoying the sunshine with other people, walking around the park, playing chess, watching TV programs, etc (interview note, 2021). Moreover, sometimes the PwD will participate in the non-pharmacological interventions depending on the doctor's suggestions, whether their family

considers the non-pharmacological interventions are required and whether they are willing to pay the additional costs. In the care center, the professional medical team includes doctors, nurses, therapists, caregivers, other staff (housekeeping, cook, etc.), and facilities including training equipment, medication, rehabilitation rooms, activity rooms, etc (observation note, 2021) are equipped.



The PwD lives with other patients or the elderly together. Some caregivers live in the care center while others come before breakfast (interview note, 2021). The PwD's family will come to accompany them sometimes. The stakeholder map and functions relationships among the care center are demonstrated in Figure 1 and Figure 2.



Figure 1: Stakeholder map in the care center model

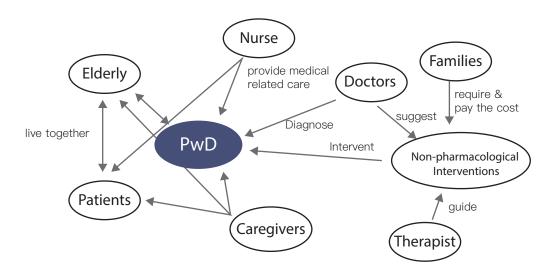


Figure 2: Functions relationships among the care center

#### if there is such a tool...

PwD: achieve better dementia care

Caregivers: can play a more important role in this context

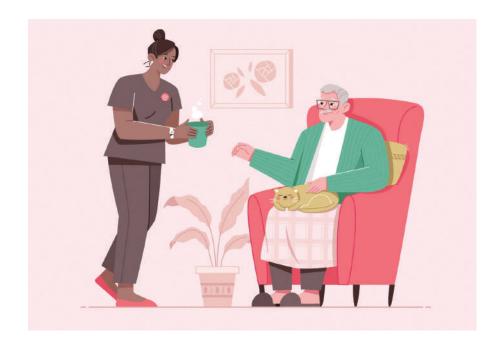
Nurses: handle more methods to treat unexpected behavioural and emotional symptom

Families: relatively reduce the cost spent on the nonpharmacological inventions

Other patients and Elderly: less disturbed by the PwD

## **Model 2** living at home and cared for by informal caregivers

Another way to achieve dementia care is living at home and being cared for by informal caregivers. The informal caregivers usually consist of the people-with-dementia's spouse, children, other family members, or a paid worker. The caregiver's duty is similar. The main difference is that a caregiver usually takes care of several patients (some of whom are not PwD) in the care center (interview note, 2021), whereas at home the PwD are usually nursed by one or more caregivers. The caregiver can accompany the PwD all day even during the evening (interview note, 2021). Therefore, the PwD's behavior and needs are noted in more detail. However, the professional medical resources and community atmosphere are not available immediately, compared to living in the care center. The stakeholder map and service functions relationships among the home-centered model are shown in Figure 3 and Figure 4.



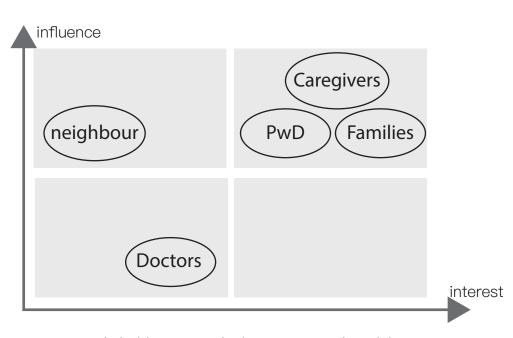


Figure 3: Stakeholder map in the home-centered model

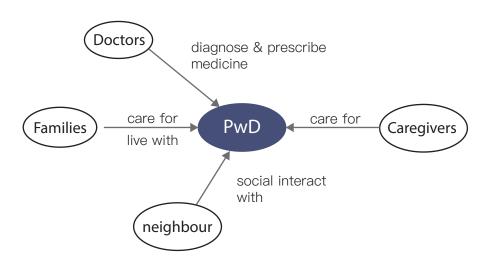


Figure 4: Service functions relationships among the home-centered model

#### if there is such a tool...

PwD: achieve better dementia care

Caregivers & families: be able to apply personalized non-pharmacological inventions to alleviate the symptoms of the PwD; handle more methods to treat unexpected behavioural and emotional symptom

Overall, although the PwD living in the care center seems to be able to acquire more professional care support and systematic service, it still has many problems. For example, normally a caregiver takes care of several patients, the caregiver does not have enough energy and attention to know each patient well (interview note, 2021). Therefore, care is lacking in personalization. However, the process of each patient's disease and the response to different types of care methods vary greatly from patient to patient. So, there is a need for personalized nursing. Moreover, due to the limited care center resources, model 2 is more common in China (NHC, 2021).

In model 2, the informal caregivers are usually very aware of the PwD. They can apply personalized nursing only if they learn the relevant knowledge. In summary, considering all the factors, model 2 was chosen to be the main research target group.

# 2.2 Project Scope

Due to the current pandemic condition, this project was based in China. The model of the PwD living at home with the informal caregivers is the target group. This model is more common in China as well, due to the limited care center resource (NHC, 2021) s. Besides, the dementia care service in China needs further development comparing to the developed western medical system, and designing for this is of great significance.

#### 2.3 Problem Statement

In order to provide a better dementia care experience to the PwD, the informal caregivers need to understand how to apply personalized intervention and nursing, but it's difficult due to the lack of knowledge, tools, and channels.

Non-pharmacological interventions have been already well developed. There are many different types of non-pharmacological therapies applied to manage the symptoms of dementia due to many benefits, such as no side effects (Gubing, 2019). However, they are unsystematic and recondite. There exists barriers for informal caregivers to understand it. Besides, personalizing or redesigning without any design tools or guide tools is difficult for them. Moreover, channels to introduce professional knowledge and design (guide) tools to the people who need help are missing.

# 2.4 Designing goal

The design goal of this project is to help informal caregivers understand how to apply personalized nursing on the PwD to alleviate the symptoms.

# 2.5 Project challenge

Design for dementia is a comprehensive topic, which requires large amount of dementia-related medical knowledge. Another challenge is that it is difficult to conduct effective communication with PwD because of the degradation of PwD's language skills.

# 2.6 Design challenge

For a designer, it's a challenge to find an inclusive solution to help informal caregivers bridge the gap of the knowledge of non-pharmacological interventions, both theoretical and practical. It requires an in-depth understanding of the informal caregivers, and an extensive understanding of non-pharmacological interventions, symptoms of dementia, and the context.

# 3. Preliminary research/related work

There are many different types of non-pharmacological therapies applied to manage symptoms of dementia due to many benefits, such as no side effects (Gubing, 2019). However, the response to different types of interventions and the process of each patient's disease varies greatly from patient to patient (Kezia, 2017). So, there is a need for personalized nursing by redesigning the non-pharmacological intervention.

Researching well-experienced informal caregivers would be a good starting point. The well-experienced informal caregiver lacks systematic and professional training but has a lot of practical experience. They developed a few special knacks through practical experience. Actually, these special knacks are modified or redesigned applications of non-pharmacological interventions, which are based on medical theories.

For example, a knack collected from the preliminary research is that playing Chinese opera for patients can make them turn to positive emotion, which actually applied music therapy (Tomomi, 2013).



Playing Chinese opera for patients can make her turn to positive emotion

Another knack is asking the patients to count beans when they are irritable, which can calm them down. This method actually distracts the patient from the annoying things first, then concentrating on the counting, thus calming the mind. Such knacks work well for the patients as they are personalized according to the patient's conditions. Whereas, personalized nursing requires not only the knowledge of non-pharmacological interventions but also knowing the patient's condition, including habits, life experience, etc. Therefore, the integration of the knowledge of Non-pharmacological intervention and personal information about the PwD is necessary to provide better dementia care for PwD, which is missing in the current situation.



# 4. Project Approach and Proces

# 4.1 Project Approach

The project consists of research, design, evaluation and iteration.

The first phase is the research and analysis phase. The project will start with literature review and desk research on the non-pharmaceutical therapy and the personalized nursing methods and cases. After the knowledge is acquired, field research will be conducted in the care center, including interviews and observations with caregivers. The main aim is to gain the insights of their professional nursing methods. Meanwhile, in-depth interviews and observation with informal caregivers will be conducted to understand their nursing experience and knacks (personalized nursing application), as well as their learning experience of caring for

a people-with-dementia(in order to investigating the effective way to introduce the design tool). Besides, context inquiry with the main stakeholders also needs to be done to gain in-depth understanding of their latent needs. The research plan will be designed according to Know-me(a toolkit for designers) as well.

The second phase is the ideation and conceptualization phase. The initial design ideas and concepts will be formed. This is a diverging phase, so multiple concepts will be created during the ideation workshop. But after the discussion and evaluation with the mentors, no more than three concepts with different focuses and strategies will be selected to be presented at the mid-term meeting, and eventually one suitable concept will be chosen for further development.

The third phase is the design detailing and evaluation phase. A more concrete concept and prototype will be formed and tested. Experts and real users will be recruited to test and evaluate the concept. In addition, the efficiency of the way to spread the tool to the target users (who want to improve the personalized nursing experience) will be evaluated as well. The results and insights will be collected for improving the final design, which will be discussed in the green-light meeting.

The last phase of the project includes final design improvement, report writing, presentation preparation and graduation ceremony.

## **4.2 Project Process**

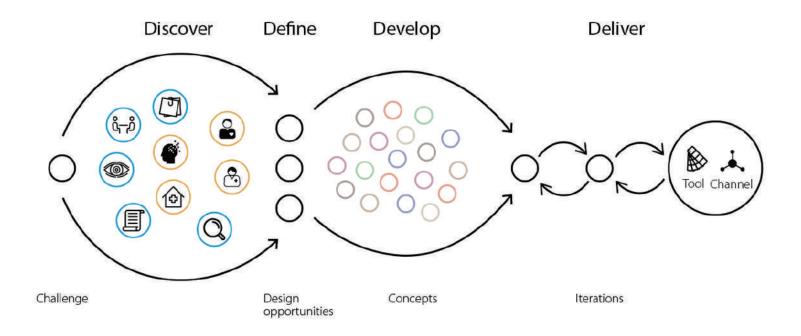
This project follows the double-diamond model (Design Council, 2021), including the Discover phase, Define phase, Develop phase and Deliver phase.

**Discover phase:** the discover phase applied different research methods and involves different stockholders to figure out the research questions.

**Define phase:** the research results were summarized during the define phase. The design direction and design requirements were defined.

**Develop phase:** multiple concepts were created during the develop phase.

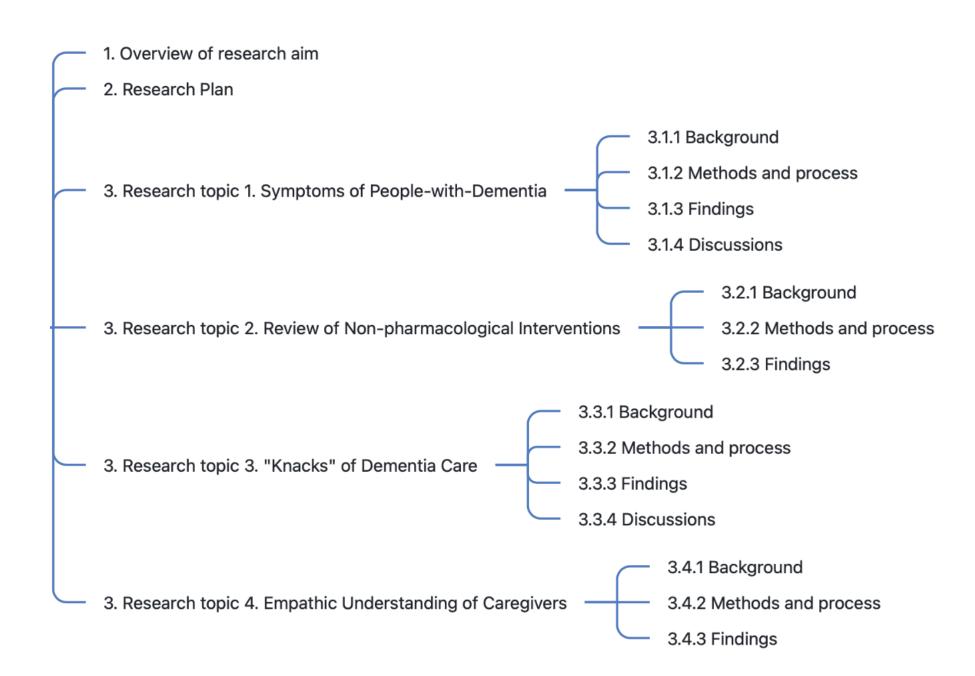
**Deliver phase:** one concept was chosen to further detailed, evaluated, iterated and finally delivered.



# **Chapter 2**

# Research phase

This chapter describes the research phase of this project, including the research aim, research plan, the detailed background, methods, process and results of the four research topics.



# 1. Overview of research aim

Overall, there are four main research aim:

- 1. understanding and clustering the holistic symptoms of people-with-dementia
- 2. acquiring the knowledge of non-pharmacological intervention
- 3. collecting "knacks" of dementia care
- 4. investigating and empathetic understanding the informal caregivers



# 2. Research plan

#### Research aim:

Symptoms of the PwD

non-pharmacological intervention

"knacks" of dementia care

understanding the informal caregivers

#### Research methods:

**Expert consulting** 

Desk research

**Interview** 

Desk research

Desk research

Interview

**Context inquiry** 

**Observation** 

**In-depth interviews** 

**Context inquiry** 

Co-design

#### Research period:

Symptoms of the PwD

non-pharmacological intervention

"knacks" of dementia care

understanding the informal caregivers

2 months

# 3.1 Research topic 1: Symptoms of People-with-Dementia

## 3.1.1 Background

Dementia will damage the brain, not only causing a decline in memory and cognitive functions but also degenerating physical, behavioral, psychosocial, and other aspects of the patient's capabilities in daily live, resulting in a low quality of life and poor wellbeing (AIZ, 2021). Due to the specific features of dementia, as well as other common concomitant illnesses to the elderly, each individual will have very different symptoms. Besides, as the

disease progresses, these symptoms become progressively severer (NIA, 2021). Moreover, in different contexts, the performance of the symptom and the efficacy of the corresponding care method might be different. Therefore, the first step of the research phase is to collect and figure out the holistic symptoms of dementia.

### 3.1.2 Methods and process

The overview of the methods and research process can be seen in figure5:

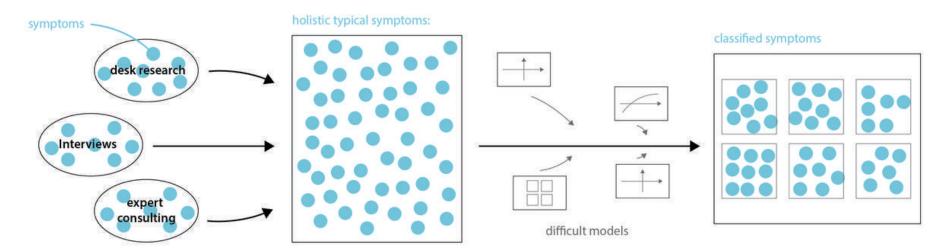


Figure 5: The overview of the methods and research process

Desk research and expert consulting are the main methods to be applied to collect the holistic typical symptoms of dementia. Desk research includes reviews of articles and papers. Symptoms discovered by chance during interviews with users were replenished as well. After holistic symptoms of dementia were collected, different models from different perspectives were searched to make clusters and map all the symptoms appropriately. There are three main purposes for classification: 1. aggregating the symptoms with similar attributes reasonably and effectively, considering some symptoms are similar to end-users and they will apply the same dementia care towards them. 2. making it possible to match corresponding suitable non-pharmacological interventions to apply. 3. Making it easier for end-users to conduct retrieval effectively

Therefore, there are two research questions in this part of the research topic:

- 1. What are the typical symptoms of PwD?
- 2. How could symptoms of PwD be categorized and how could they be reasonably and easily retrieved by the end-user in order to apply personalized non-pharmacological interventions?

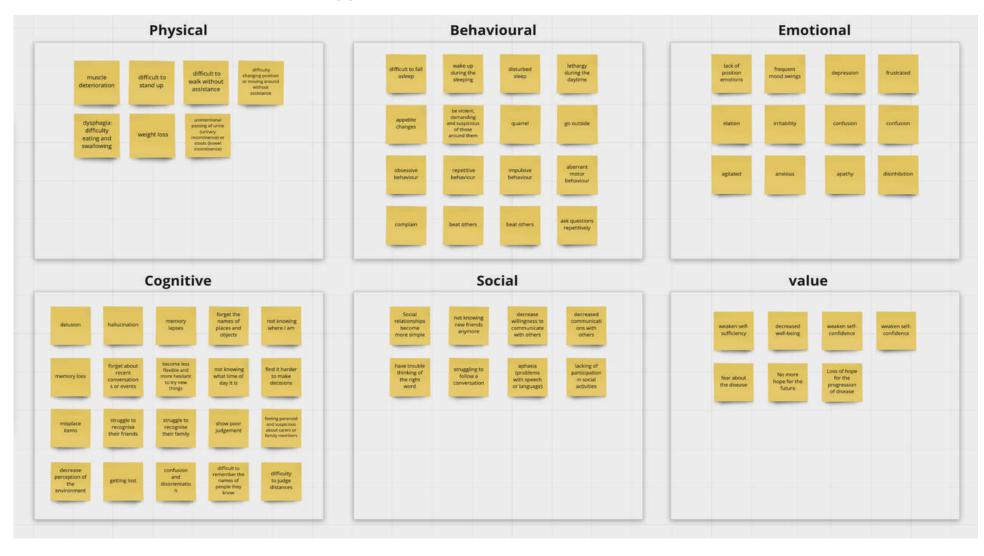
**Desk research:** the typical symptoms of dementia were collected both from websites of dementia or health-related official organizations and articles, papers, and literature reviews.

**Interview:** the family and informal caregivers shared the stories about symptoms of the PwD during the interviews

**Expert resulting:** two dementia-specific Neurologists in Charge were consulted about the typical symptoms of dementia

## 3.1.3 Findings

According to the combination of the psychosocial framework (HCDI, 2016) and BPSD model (Anna, 2018), all the symptoms were classified into six categories: physical, cognitive, emotional, behavioral, social, and value. The full version can be found in the appendix 2.



#### 3.1.4 Discussions

1. Some emotional symptoms of PwD were similar to end-users because their care methods were the same. For example, during the three context inquiries, when I referred to agitation and excitement, the responses of three caregivers were looked confused and hesitant through my observation. So I further asked them if they could tell the difference between these two emotions and how the corresponding care methods were different. Three of the users agreed that these were two different emotions and that they could distinguish them if the subjects were themselves. However, two of the caregivers said that if the subjects were PwD, it would be difficult to tell the difference, because the performance was similar, such as making strange noises and waving their arms. They only knew that the PwD had the emotional changes and needed to calm down, but it was difficult to tell whether it was agitation or exciting. Besides, they thought there was no need to distinguish them.

The only thing they wanted to know was how to soothe the PwD effectively.

- 2. According to the results in context inquiries, three end-users all hoped the physical capabilities of the PwD can be improved. However, when referring to the most possible to be improved, they ranked emotional and behavioral in the top order.
- 3. In the PwD in middle and late stages families, none of the stakeholders had expectations of improvements in cognitive functions of the PwD. One member of the families explained that, based on the doctor's diagnosis and his knowledge of dementia, it was clear to him that once the PwD's brain was damaged, the deterioration of cognitive functions of PwD was irreversible and he had already accepted this reality. However, In the PwD in early stages' families, both the PwD andthe caregiver (his spouse) expressed worries and fears about the degradation of cognitive functions.

4. As for social and value aspects, caregivers and families were not very concerned. For PwD who still can communicate with others, both the family and caregiver agree that although the frequency and quality of social interaction were reduced, it was sufficient and they were satisfied with it. For PwD who couldn't communicate through language, then their family thought the need of social was not such important comparing to other aspects. For the value part, one of the users thought that if other aspects were improved and met, then the value would be achieved as a result.

# Takeaway:

The holistic symptoms of PwD were classified into six categories. The informal caregivers and family members were concerned more about emotional and behavioral symptoms. The PwD and stakeholders in the early-stage wanted to improve cognitive functions most.

# 3.2 Research topic 2: Review of Non-pharmacological Interventionst

## 3.2.1 Background

There are many different types of non-pharmacological therapies applied to manage symptoms of dementia due to many benefits, such as no side effects. In China, users can obtain non-pharmacological therapies in well-equipped rehabilitation centers. And the cost is comparatively expensive. Besides, the response to different types of interventions varies greatly from patient to patient. So, the threshold for trying non-pharmacological interventions needs to be lower.

## 3.2.2 Methods and process

Desk research was the research method, including reviewing systematic reviews and literature reviews. The research aim was to understand which non-pharmacological intervention was effective to which symptom. Besides, how the non-pharmacological interventions work, and what detailed information needs to be known for personalization need to be figured out.

## 3.2.3 Findings

Actually, it's difficult to gauge non-pharmacological intervention from literature, due to the lack of uniform definitions and norms. So I created this form (includes the name of the therapy; active ingredient; things needs to pay attention to; investment and the effect) to organize the important information of non-pharmacological interventions. According to the research, the "active ingredient" makes the non-pharmacological intervention effective (Cohen-Mansfield, 2018). Besides, each therapy has detailed aspects that need the therapies to pay attention to. Lastly, investment is rated as low, moderate, or high, in relation to time needed for training and implementation, specialized care provider requirements, and equipment or capital requirements, based on an adaptation of an existing framework. (The full version can be found in the appendix 3.

Non- pharmacological intervention	Active ingredient	Things needs to pay attention to	Investment	Effect
Aromatherapy	<ul> <li>Long-standing practice of using scented oils</li> <li>The link between smell and memory</li> <li>Room diffusion, sachets, a patch or skin cream</li> <li>Social and physical contact</li> </ul>	<ul> <li>Essential oil may have a direct effect on the brain</li> <li>Aromatherapy has been no effective when assessors are masked to the treatment</li> </ul>	<ul> <li>Overall: low</li> <li>minimal time needed for learning and implementation</li> <li>no need for a specialized care proider</li> <li>modest resource requirements</li> </ul>	<ul> <li>Improve individual's mood</li> <li>Agitation; aggression</li> </ul>

## 3.3 Research topic 3: "Knacks" of Dementia Care

### 3.3.1 Background

As explained in the preliminary research, the research target group was experienced informal caregivers, who lacked systematic and professional training but had a lot of practical experience. They developed a few special knacks through practical experience. Actually, these special knacks were the modified or redesigned applications of non-pharmacological interventions, which were based on medical theories. The research aim was to collect special knacks and figure out why and how they work.

## 3.3.2 Methods and process

The main research methods were interviews, context inquiry, observation, and desk research. The main data source came from interviews with

well-experienced caregivers and nurses. Overall, 12 interviewees (4 families of the PwD; 6 well-experienced caregivers and 2 nurses) participated in the in-depth interviews (well-experienced caregivers or nurses) or the context inquiries (families of the PwD). The in-depth interview and context inquiry was conducted together in the 5 field research.



# 3.3.3 Findings

All the collected knacks were written into the form. Here are 4 examples, the detailed content can be found in the appendix 4.

PwD	This PwD as a person (handle for the personalization)	Personalized designs (knacks)	Symptoms
1.	Used to be an accountant	Provide paper money to her to count	Emotional: apathetic
2.	Like Beijing opera	Play TV programmes with Beijing opera	Emotional: depressed
3.	Have a son	Tell her that her son will come soon	Behavioral: lethargy
4.	Like outdoor activities previously, but cannot stand up due to the stroke	Equipped with wheelchair to go outside and enjoy the sunshine, chat with neighbours	Behavioral: lethargy, not willing to move

#### 3.3.4 Discussions

- 1. Such knacks work well for the patients because they were personalized according to the patients' conditions.
- 2. Personalized nursing requires not only the knowledge of non-pharmacological intervention but also knowing the patient's condition, including habits, history, etc.
- 3. There were detailed successful elements within the knacks. Here is an example collected from the field research, the PwD liked Huangmei opera, a specific type of traditional Chinese opera. Huangmei opera had a specific meaning to the PwD because the PwD sang Huangmei opera when the PwD was young. After the PwD entered the advanced stages of Alzheimer's disease, the PwD was barely responsive to surroundings and the PwD was apathetic during the daytime. Due to the degeneration of the audition, the family brought

a player for her. However, the paid worker (do cleaning work, not specific for caring for the PwD) always played the TV programs to watch rather than Huangmei opera. The interviewee told me that the PwD would give a stronger response when playing the Huangmei opera. So, in this case, the successful element is Huangmei opera rather than simple music or sound to arouse her attention and stimulate her senses.

# **Takeaway:**

Personalized nursing requires not only the knowledge of non-pharmacological intervention but also knowing the patient's condition

# 3.4 Research topic 4: Empathic Understanding of Caregivers

## 3.4.1 Background

Caregivers were the main target user in this project, therefore in-depth and empathic understandings of their latent needs and features are required to be understood. There were 3 research questions:

- 1. Does the user know non-pharmacological intervention, and do they need such a tool to help them apply non-pharmacological intervention on the PwD?
- 2. Who knows the PwD best and how to effectively acquire and communicate the PwD's information.
- 3. Which channel is the most preferred one? In order to make the outcome more inclusive to suit more potential users and become more convenient for spread, the preference of caregivers towards the form of the tool needs to be researched.



### 3.4 Research topic 4: Empathic Understanding of Caregivers

#### 3.4.2 Methods and process

In-depth interviews, context inquiry, and co-design sessions were applied in this research part. In-depth interviews were conducted to investigate the learning experience and habits. The research aim was to figure out if the user keeps learning dementia-related knowledge; figure out how the user studies relevant knowledge; find out if the user has the will and opportunity to keep learning; find out the preferred learning style.

The co-design session involved two PwD who still can communicate participated in the research. Collage was applied in the co-design session, by choosing from a pile of pictures of what the PwD would like to do ideally in the future. The family and caregivers made their choices separately and then compared the results with the PwD's choices,

to test how well the stakeholders knew about the PwD and whether the dementia care they think the PwD need was consistent with what the PwD themselves wanted.

There was also a simple session to know which channel was more popular. 7 different demonstration ways of the tool (short video; TV programs; podcast; tool books; app; magazine; books) were written on the cards. Then asked users to rank the cards according to their preference.



#### 3.4.3 Findings

1. Stakeholders were interested and wanted to know the non-pharmacological intervention. One of the informal caregivers (the spouse of the PwD) said that she was introduced to the non-pharmacological interventions by the doctor and she wanted the PwD to participate in the non-pharmacological intervention therapy, especially the language capability rehabilitations. However, the cost in the care center was too expensive for her. She also wanted to try to apply some simple exercises on the PwD by herself. But she didn't know how to do it. Therefore, she wanted such a tool to teach her how to apply interventions by herself. In addition, a nurse from a care center also needed such a tool to deal with the aberrant behavior or emotions. She wanted to learn more different effective ways to cope with symptoms of dementia that she may meet during daily work. So, the research confirmed that it's of great significance to develop such a tool

- to help caregivers apply the non-pharmacological intervention to alleviate the symptoms of dementia or to cope with unfamiliar aberrant behaviors and emotions.
- 2. Collage was conducted twice in two field research. For the first time, the user was a PwD in the early stage of Alzheimer's disease and his informal caregiver (his wife). The results were almost the same. This showed that the family knew the PwD very well when the PwD still has adequate communication skills. For the second time, three users participated in the college, a PwD in the middle stage, her son, and her caregiver. Although the caregiver has been caring for the PwD for 3 years and has been accompanying her almost every day, she did not know the PwD as expected. However, the caregiver was very aware of the PwD's typical symptoms, such as the PwD liked to go outside, the PwD had slightly obsessive behavior of cleaning things, etc.

3. 12 people participated in the channels ranking session. The result was that the most preferred channels were the App, due to the convenience and timeliness. However, when ranking according to authoritativeness, apps and short videos are ranked lower. This means the designer needs to take how to ensure the tool trustworthy and authentic into account during the designing phase.

### **Takeaway:**

The research confirmed that it was significant to develop such a tool to help caregivers apply the non-pharmacological intervention to alleviate the symptoms of dementia. The app was the most preferred form.

## **Chapter 3**

## Research synthesis

This chapter reviews the research insight, clarifies the problem definition, summarizes the target users and use scenario.

## **Chapter 3**

- 1. Review of Research Insights
- 2. Problem Definition
- 3. Target Users
- 4 Use Scenario



## 1. Review of Research Insights

- Based on the combination of psychosocial framework and BPSD model, all the typical symptoms were classified into six categories: physical, cognitive, emotional, behavioral, social, and value. In addition, users think they need extra help to deal with the emotional and behavioral symptoms of the PwD, even in the family who has a family member as a doctor.
- The integration of the knowledge of the non-pharmacological intervention, personal information about the PwD, and personalized design skills was necessary to provide better dementia care for the PwD.
- Both the caregiver in a care center with experience in caring for many PwD and the family members who have been caring for Pwd at home for

- years, their techniques for dealing with the symptoms of the PwD are relatively homogeneous. Although they have explored some useful knacks on their own, they always use the same knack to deal with the different symptoms of PwD. They were keen to learn more useful knacks.
- The most common use scenario for caregivers to proactively use the tool to ask for help is when the PwD has a symptom and they can use the tool to quickly find out what that symptom is and how to deal with it (knacks)
- Currently, non-pharmacological interventions are more often explained in academic articles and rarely described in an easy-to-understand manner. Especially in China, the majority of users even don't have access to the relevant information of

non-pharmacological intervention via the internet. Furthermore, there are no uniform standards and guidelines to standardize non-pharmacological interventions. Some scholars believe that it is the "active ingredient" that makes the non-pharmacological intervention effective.

- The user's most preferred channels were apps, due to the convenience and timeliness.

## 2. Problem definition

Designing a tool to help informal caregivers apply better dementia care to alleviate the emotional and behavioral symptoms of the PwD by personalized non-pharmacological intervention.

# 3. Target users

The main target users are caregivers, including untrained home based caregivers, novice caregivers without much experience, and family members.



They can learn about the symptoms, non-pharmacological interventions, and knacks of dementia through the tool.

Potential users also includes people who live with elderly people with similar symptoms. A typical disease of dementia is Alzheimer's disease. And it is a disease that is better to be prevented and treated early.

#### Potential users

people who live with elderly people with similar symptoms.

It is good to learn and understand some basic knowledge.

## 4. Use Scenario

There are three main use scenarios:

#### **Scenario 1: searching information**

the PwD shows the symptom, then the caregivers use the tool to find this symptom, then check what kind of interventions they can apply to treat this symptom

#### **Scenario 2: learning information**

the nurses or the caregivers want to use the tool to learn different non-pharmacological interventions

#### **Scenario 3: sharing information**

A caregiver comes up with a good and effective idea about personalized application of a non-pharmacological intervention, he wants to use the tool to share with others.

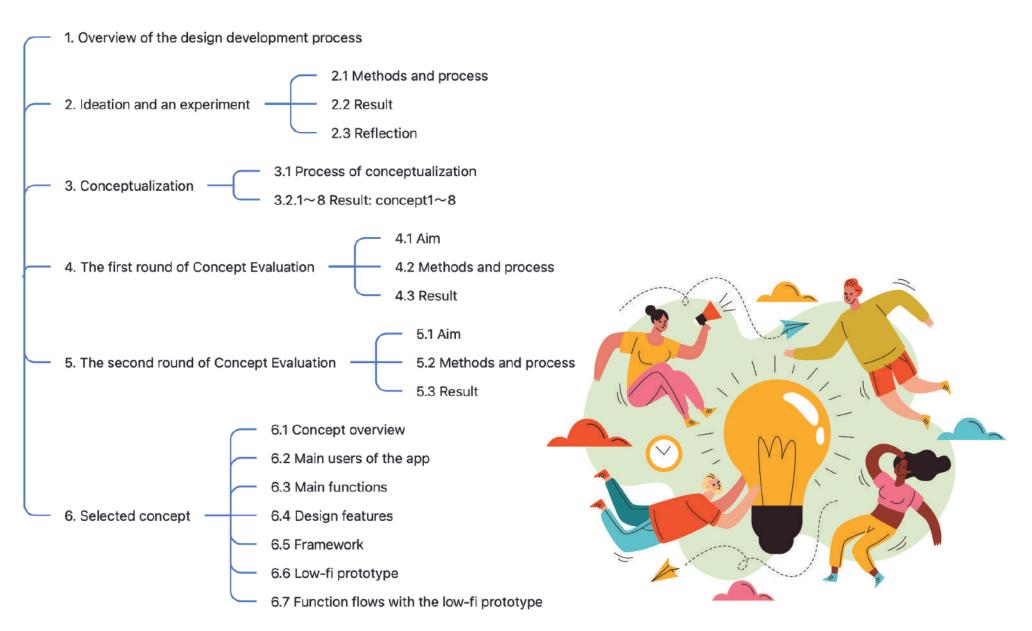
A caregiver wants to use the tool to find other's experiences about taking care for a PwD.

## **Chapter 4**

Design development

This chapter describes the ideation, conceptualization and evaluation processes and results.

## **Chapter 4**



## 1. Overview of the design development process

#### Phases of design development

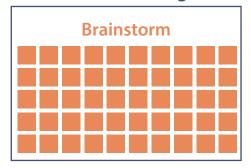
Ideation

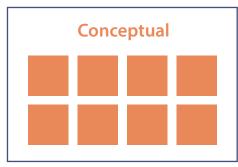
Conceptualization

The 1st round of evaluation

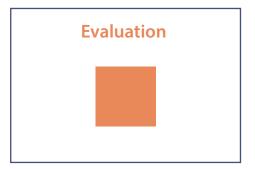
The 2nd round of evaluation

#### Process of the design









#### Time period:

Group brainstorm

Mapping the results

Conceptualization

1st round of evaluation

2nd round of evaluation

1.5 months

## 2. Ideation and an experiment

### 2.1 Methods and process:

Individual brainstorm and group brainstorm were the main methods for the ideation stage. Preparation of the brainstorm includes recruiting participants, preparing the facilitated materials, designing the brainstorm process and questions, and arranging the time. Before the official brainstorm session took place, participants received homework. There were 4 questions that they need to answer. The design of the homework had three main purposes:

- 1. to let the participants give good ideas/examples/designs out of the structure when they know nothing about the context.
- 2. to make the participants more sensitized and aware of the upcoming brainstorm session.
- 3. to let the participants do some preparation in advance. If the participants have some ready-made materials or preparations, they can get into the groove quickly.

#### Can you share 3 best ideas for each question?

- 1. Can you share a good idea/example/design of finding information efficiently?
- 2. Can you share a good idea/example/design of learning information effectively?
- 3. Can you share a good idea/example/design of sharing experience with others?
- 4. Can you share a good idea/example/design of personalized application of anything?

Flow was the online brainstorm facilitate platform, which is shown in Figure 6. The overall flow can be found in the appendix 5. According to the outline prepared in advance, there were three parts in total. A specific scenario was introduced by the facilitator at the beginning of each part and the

brainstorm questions will be briefly elaborated. Different ideas were come up from the discussion. At the end of the brainstorm, there was an experiment session to see whether the designer had a better way of personalizing the non-pharmacological interventions.

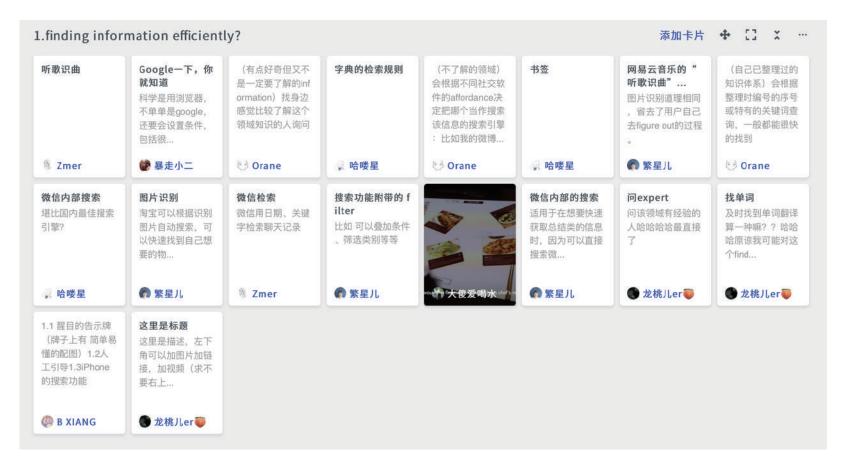
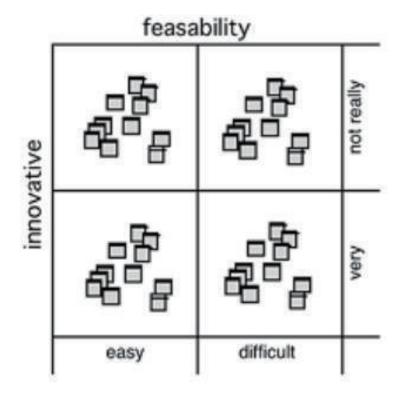


Figure 6: the online brainstorm facilitate platform——Flow

The brainstorm results included the ideas from submitted homework by the participant, the cards created in the Flow, and the communication content in the session. These different forms of information need to be organized into materials that can be further analyzed. I expressed the ideas in the participator's own words and used some draft images to recreate the diversity of ideas as much as possible. The C-Box, a matrix to generate an overview from a multitude of early ideas, was used to map the results of the brainstorm (Tassoul, 2006).

In a C-Box, "creativity" and "feasibility" were used as the criteria. The C-Box is usually applied during the brainstorm session to roughly classify numerous ideas. All the relevant ideas were collated into three matrixes, based on the themes of the three panels. Some ideas with similar features were clustered and summarized into themes using different color blocks for visualization.



The first part was about how to search for information quickly, and efficiency was important in this context. The results are shown in Figure 7.

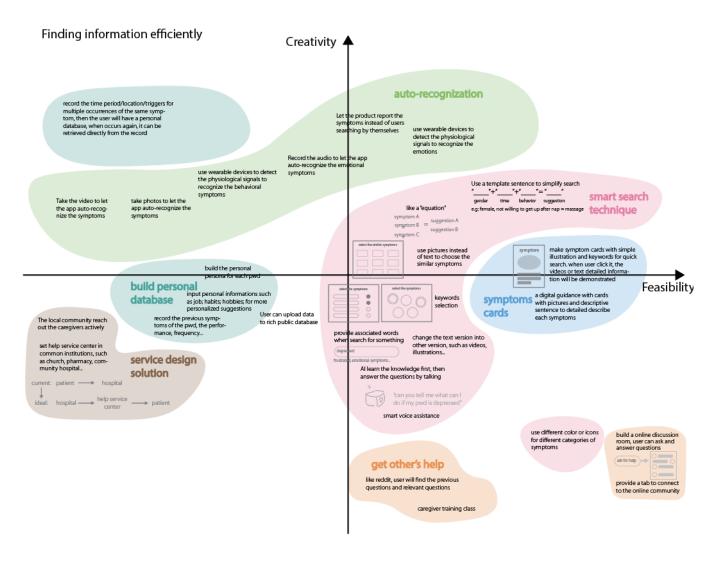


Figure 7: the result of brainstorm

The second part was about how to learn knowledge, where effective learning was more important. The results are shown in Figure 8

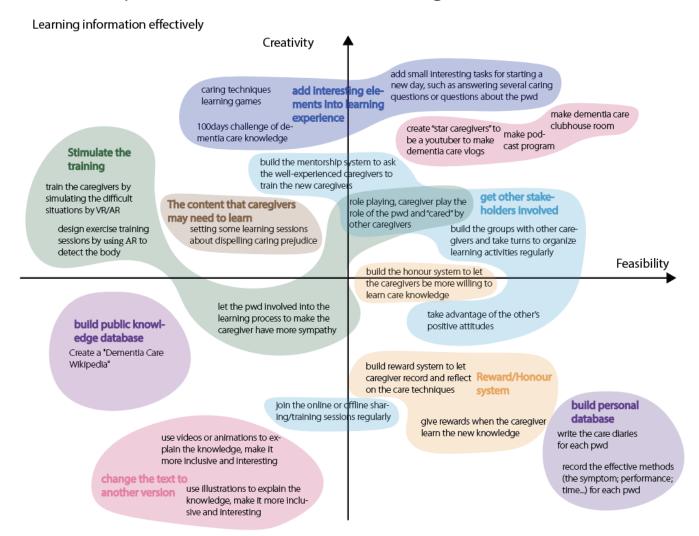


Figure 8: the result of brainstorm

The third part was about sharing information, and in this context the active atmosphere was very important. The results are shown in Figure 9.

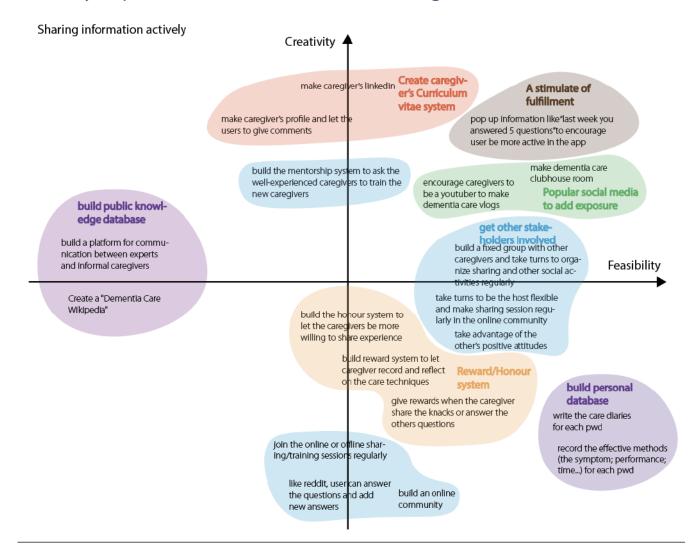


Figure 9: the result of brainstorm

#### 2.3 Reflection of brainstorm

After the brainstorm session, I asked several participants for their feelings and comments. I reflected on the whole brainstorm process. I thought the brainstorm was relatively successful, but four things could be improved in the following areas.

1. Time management needed to be strengthened in the preparation. Some participants felt that the breaks were not sufficient, resulting in not having enough energy to respond quickly to the last few questions. In addition, due to the high motivation of the participants, there were so many ideas for each part out of expectation. As a result, each part was slightly over time. Therefore, the total length of the brainstorm session was 30 minutes longer than expected.

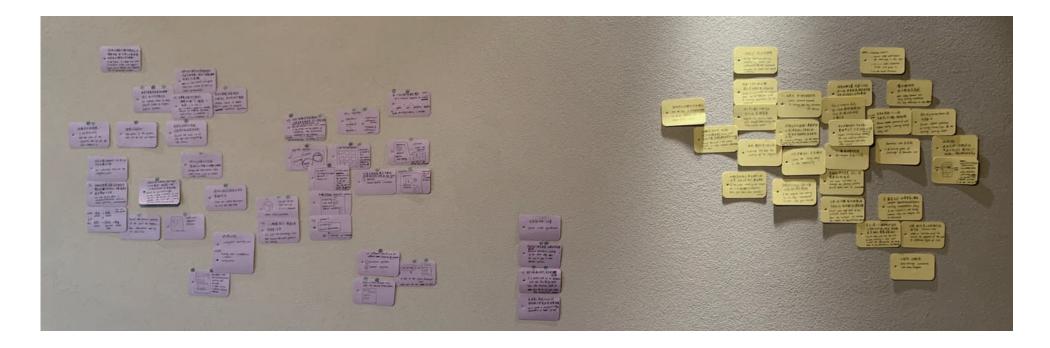
- 2. The topic was not well focused all the time. The reason could be the participants had finished the homework and knew the questions ahead of time. During the brainstorm, there was another part of the ideas that appear on this part of questions occasionally. Or because the participants were so motivated and active that their inspiration was spread too far, leading to a little off-topic. Therefore, delineating a general scope at the beginning would be better so that the facilitator can decide when to interrupt the conversation.
- 3. As the brainstorm session was held online, it was difficult for the facilitator to check the status of each participant. Some participants were not noticed. Although it was considered that this would happen, when actually moderating a discussion with ten people, it was impossible to check the status of participants in time, especially those who did not join the discussion.

4. The fourth part is about how to demonstrate the deliverables could revivificate the impressive ideas that appear during the talking. During the brainstorm, some of the ideas came up in the content of a conversation between several people. I found it difficult to summarize the great conversations into a sentence. This may required the facilitator to plan and conceptualize the format of the output during the preparation.

## 3. Conceptualization

### 3.1 Process of conceptualization

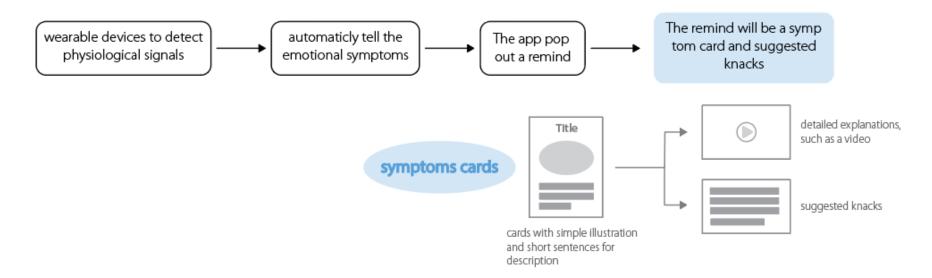
After organizing the demonstration of the ideas (see chapter 1.4), the ideas were written in more vivid sentences and with simple visuals. These refined ideas were written on cards and posted on the white wall. Similar ideas were posted close to each other. The interesting ideas were marked for emphasis. Therefore, I was able to construct 8 different concepts from different directions but in the same level of detailedness to avoid the bias of selecting the most developed concept.



### 3.2.1 Result: concept 1

Using wearable devices to detect physical signals to tell the emotional symptoms of the PwD, then the app will remind the caregivers and popup a card with a simple illustration and the suggested knacks.

Auto-recognize the symptoms and report



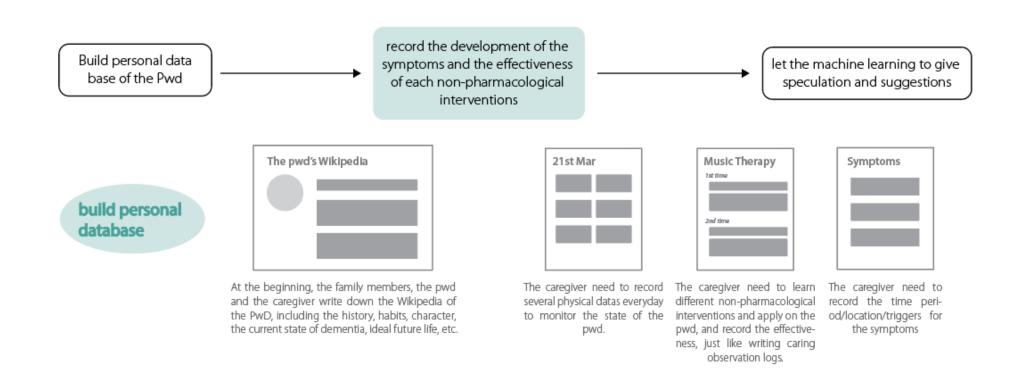
### 3.2.2 Result: concept 2

Using smart searching techniques to find out the symptom efficiently, then the app will show the symptom cards with simple illustrations and the suggested knacks.

The user search the symptom activity the pwd show/have The search result will be a the user can use smart some performance of search techniques to symptom card and sug the symptoms search efficiently gested knacks • Provide a template sentence detailed explanations, Title for quick search such as a video smart search symptoms cards technique • provide associated words • provide series of pictures of suggested knacks symptoms for user to choose the similar one cards with simple illustration and short sentences for · provide series of keywords description for selection to narrow down

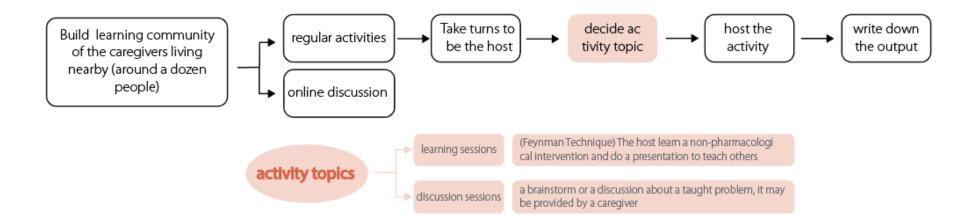
### 3.2.3 Result: concept 3

Build each PwD's personal database, like the PwD's Wikipedia. And record the development of the symptoms and effectiveness of each non-pharmacological intervention by caregivers. Then let the machine learning give speculation and suggestions.



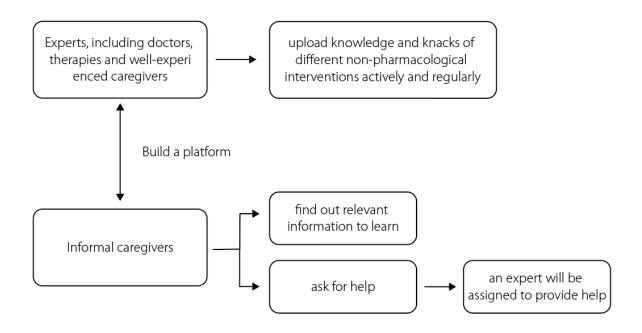
### 3.2.4 Result: concept 4

Build a learning community of the caregivers living nearby (around a dozen people). Take turns to be the host to organize activities regularly and ensure to write down the output. The activities can be the learning sessions or the discussion sessions. Besides, the caregivers also can ask for help within the community when the PwD shows some symptoms that they do not know how to treat.



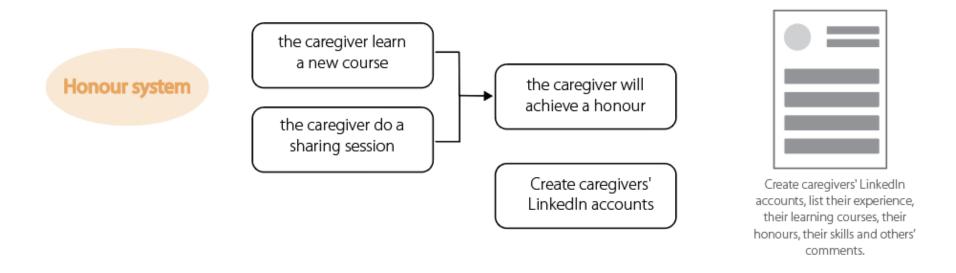
### 3.2.5 Result: concept 5

Build a platform as a communication bridge between experts and informal caregivers. Experts, including doctors, therapies, and well-experienced caregivers can upload knowledge and knacks of different non-pharmacological interventions actively and regularly, therefore the informal caregivers can find out relevant information to learn. Besides, the platform also can have a feature to allow the informal caregivers to ask for help, then the informal caregiver will be assigned by an expert.



### 3.2.6 Result: concept 6

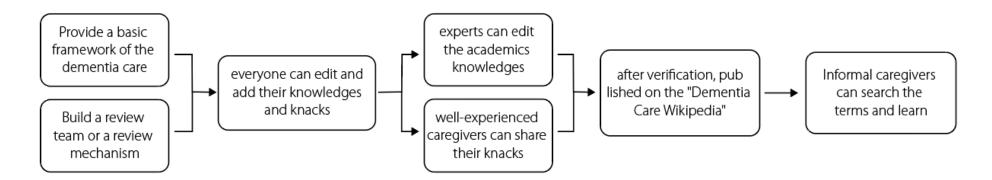
Create an honor system to manage the caregivers from a formal and larger caregiver community. When the caregiver learns a new course or does a sharing session, then he can get the honor. Create caregivers' LinkedIn accounts, list their experience, their learning courses, their honors, their skills, and others' comments.



### 3.2.7 Result: concept 7

Create a "Dementia Care Wikipedia" to let everyone edit and add their knowledge and knacks about dementia care. There's no such a database and it's impossible to build a public database by a single person or team. Why not invite all relevant stakeholders to build it together. They can gain knowledge during this process as well.

"Dementia Care Wikipedia"



### 3.2.8 Result: concept 8

A strategy is to add the exposure of dementia care on popular social media. Therefore, developing good content for caregivers to learn, increasing social attention, and getting more resources. The methods can build social influencers, they can share impressive stories or the knacks or other useful and interesting content. Another method is holding a campaign about dementia care. The aims are all to inspire caregivers.

## 4. The first round of Evaluation

#### **4.1 Aim**

The overall aim of the evaluation was to select a concept having the most potential for further development.

### 4.2 Methods and process

Weighted Objective (Roozenburg, 1998) was applied to evaluate the 8 concepts systematically. The evaluation criteria and the weight were discussed with the mentor and a designer. There were 17 criteria in total that I came up with. Each criteria's weight was from 1 to 10, for a total of 100. The trade-offs between the weight of each criterion were the most difficult part. The criteria that were necessary to take into account were 10. The other criteria were ranked according to the importance by discussing with an experienced designer who had applied this method before.

### 4.2 Methods and process

Here are the results of the Weighted objective. The following figure 10 showed the results of the evaluation of the 8 concepts applying the Weighted Objective. Each concept was scored from 1-10 according to each criterion. Each concept was then calculated by adding weighted scores to get a final score.

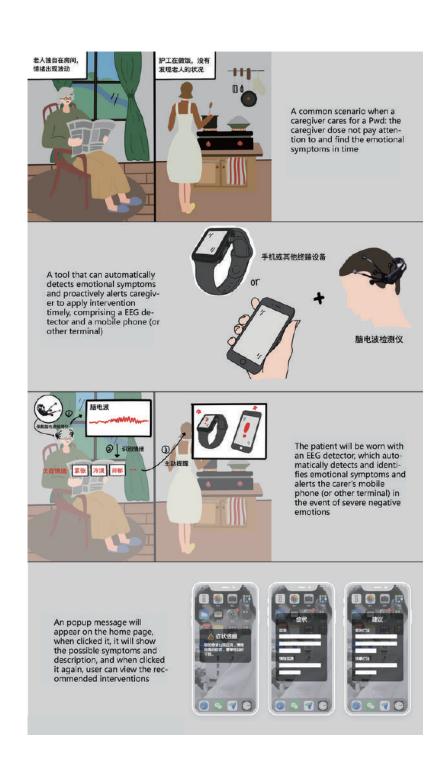
Concept 1,2,5,7 got the higher scores. As the direction and features of concept1&2 and5&7 were similar, they were combined into 2 final concepts.

4	Α	В	С	D	E	F	G	Н	1	J
1		weight	concept1	concept2	concept3	concept4	concept5	concept6	concept7	concept8
2	Ethic concern	10	1	5	1	4	5	3	5	4
3	Legal risks	10	5	5	4	5	4	5	4	4
4	Technical Feasibility	7	3	3	3	5	5	5	5	5
5	Business Variability	4	2	3	3	3	3	3	3	4
6	Caregiver Burden	10	5	4	2	1	4	1	4	3
7	Time scale	3	5	5	2	4	3	1	2	1
8	Cost Investment	3	3	4	3	4	4	3	4	1
9	Launch difficulty	5	3	4	3	3	3	3	4	1
10	Social impact	7	2	1	5	4	4	4	4	5
11	Longterm impact	7	3	1	5	4	5	5	5	5
12	How long does user	4	5	5	1	2	3	2	3	1
13	Does it can aspire u	5	1	2	4	4	3	5	3	5
14	Creativity	3	5	4	5	2	3	3	3	5
15	Suit more scenarios	4	3	3	3	3	5	1	5	1
16	Accuracy	3	5	4	4	2	4	3	3	1
17	Authentic	10	5	4	4	2	5	3	5	3
18	Does it can be teste	5	3	4	1	2	5	4	5	2
19	score	100	345	360	311	320	419	332	418	333

Figure 10: the result of the Weighted Objective

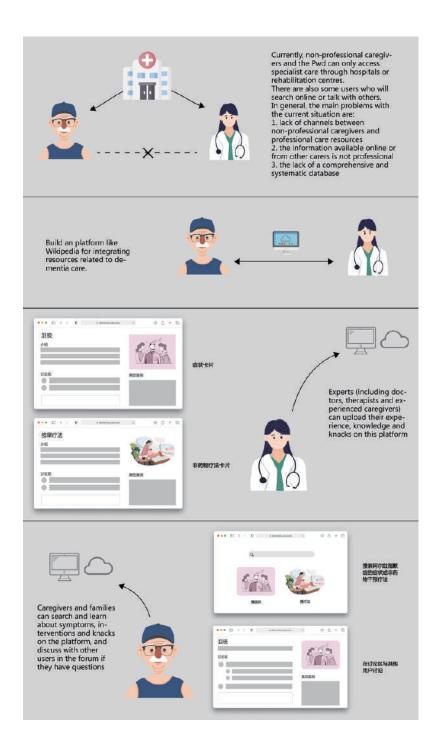
### **Concept A** (combined with concept 1&2)

The basic logic was to develop a tool to detect and automatically report symptoms to the caregiver and provide suggestions on the personal intervention methods. From research insight, the emotional and behavioral symptoms burdened the caregivers most. Detecting the EEG signal could tell a relatively accurate emotion, so an EEG detector can be used to continuously detect and observe the PwD's emotional state. The detector is connected to the caregiver's phone so that when an emotional symptom occurs, a message pops out to remind, the suggested intervention and knacks are shown as well. While for behavioral symptoms, after researching wearable technology and behavioral symptoms of the PwD, I thought it was not feasible because there were no suitable wearable devices that could accurately detect the behavioral symptoms. Therefore, at the current stage, the solution would target more emotional symptoms.



### **Concept B** (combined with concept 5&7)

Concept B is going to build a platform as a bridge for experts and caregivers to communicate and as a repository to popularize dementia-related knowledge. Experts, including doctors, nurses, therapists, and experienced caregivers, can upload their knowledge of symptoms, interventions, and knacks. Informal caregivers, including home-based caregivers, novice caregivers, and family members can search and learn this knowledge on the platform. Besides, they also can discuss with each other and with the experts in the forum, a functional block of the platform.



## 5. The second round of Evaluation

#### 4.1 Aim

The main aim of the second round of evaluation was to decide which concept to be the final concept for further development and iterations.

### **5.2 Methods and process**

Concept A and concept B focued on the different directions and they solved the different scenarios and pain points. Therefore, opinions from real users could help the decision. Both qualitative and quantitative research were conducted to collect users' opinions.

In qualitative research, the storyboards of two concepts were created to demonstrate the scenario and how the tool would be designed to solve the problem. Then the storyboards were printed

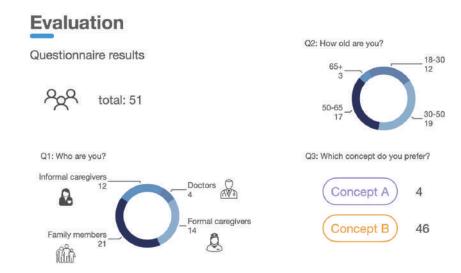
and distributed to the users, including the previous users in the research phase (the family members and home-based informal caregivers) and the users in the Jinghua Rehabilitation Care Center (nurses and caregivers). Their comments and preferences were asked and discussed.

In quantitative research, a simple online questionnaire was created to know more users' preferences. There were only three questions in the questionnaire: 1. ask users' job to know what kind of stakeholders they belong to. 2. ask the user's age group to understand what age groups of users' preferences are represented by the result of this questionnaire. 3. ask whether the user prefers concept A or concept B.

#### 5.3 Result

In the quantitative research, a total of 51 questionnaire responses were received. Such results were also presented in qualitative research. The main reason was that they found it was very convenient and reliable to find information on such a platform. In addition, they also liked the forum block. "Seeing someone share a story about a useful knack inspires me and gives me a sense of hope. Because dementia cannot be cured, so this feeling of hope is very important to me" said from a user whose father is a PwD. Concept A was not feasible at this moment. Experienced caregivers thought it would be impossible to let the PwD wear the EEG detector. "My patient won't want to cooperate. Even if I wear it on for him, within a few minutes he will grab it and drop it."

After combining the users' feedback on concept A and concept B, and the results of quantitative research, concept B was selected as the final design concept.



## 6. Selected concept

#### **6.1 Concept overview**

A platform was built for integrating resources related to dementia care. It was a repository to popularize dementia-related knowledge and a channel for experts and caregivers to communicate. Experts (including doctors, nurses, therapists and experienced caregivers) could upload their knowledge of symptoms, interventions and knacks. Informal caregivers (including home-based caregivers, novice caregivers and family members) could search and learn this knowledge on the platform. Besides, they also could discuss with each other and with the experts in the forum, a functional block of the platform.

#### 6.2 Main users of the app

There were two groups of target users. One was experts, including therapists to update and edit knowledge on non-pharmacological interventions, experienced caregivers to share caregiving knacks and stories, and doctors and nurses to disseminate dementia-related knowledge and content. The other main category of users were caregivers, including untrained home-based caregivers, novice caregivers without much experience, and family members. They could search and learn about dementia on the platform.

Potential users also include people who live with elderly people with similar symptoms. Alzheimer's (a typical disease of dementia) is a disease that is better to be prevented and treated early. So, it is good to learn and understand some basic knowledge.

#### 6.3 Main functions

This product has three main functions.

- The first function is to allow caregivers to search for items. Both symptoms and interventions can be searched on the search page. According to the insights from the research phase, a very common usage scenario was that the PwD had some symptoms and then the caregiver used this product to search for symptoms, and then checked the recommended interventions. Therefore, the page of searching symptoms is the first page when the user opens the app.
- -The second function is to allow experts to upload and edit entries. Experts can edit existing entries and create new entries, either for the symptom or for intervention. Experienced caregivers can add knacks or stories about the personalized application of the interventions to the entries as well.

Other users can also post questions to the discussion forum and invite experts to answer them.

-The third function is to provide a discussion forum for communication among users. Not only can users discuss with each other, but also communicate with experts. In addition, users can also view the history of posts and replies. They can like/tag/share posts or replies that resonate with them. They can reply to posts that they want to communicate with as well.

#### 6.4 Design features

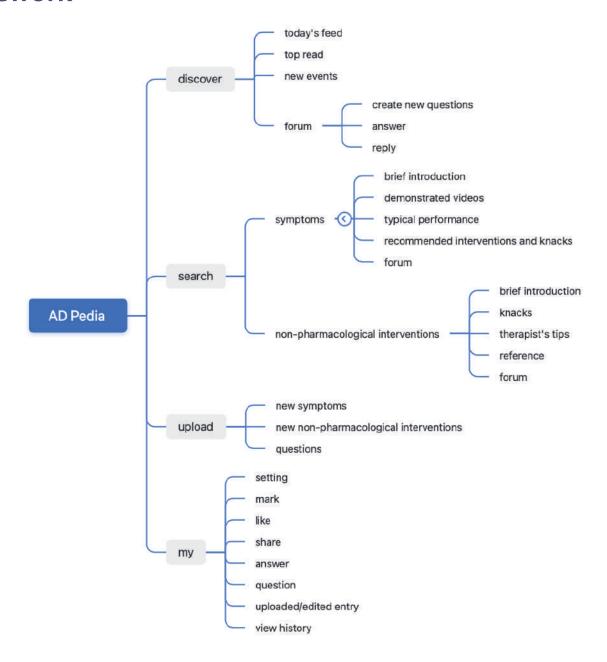
In summary, there are three main features:

- Firstly, the product was decided to be an app. Because based on the insight from the research phase, the most preferred form of the product was the app. Caregivers thought it was very convenient to use it anywhere, anytime. And from the product perspective, it's easier to update and disseminate as well.
- Besides, the app is inclusive in terms of both interaction and content. It's an age-friendly product. For interaction, it supports voice input and photo recognition. The form of interaction is similar to other apps that are commonly used. So, it is easy for users to get started and become familiar with the app. For content, videos and images were used to make it easier for users to understand the content in the entries. Furthermore, there are many knacks and

stories uploaded by experienced caregivers. Therefore the language is more easily understood, compared to academic papers.

- Apart from these, the product is very simple and it's a lightweight product. As a tool-based product, presenting effective information is of utmost importance. So only important and relevant information will be presented especially in entires. Even in the discussion forum, key information is highlighted, e.g. relevant symptoms and interventions are presented in the form of tags for emphasis.

#### 6.5 Framework



## 6.6 Low-fi prototype

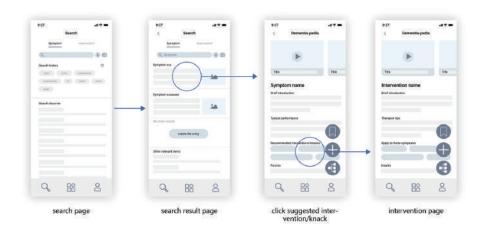


#### 6.7 Function flows with the low-fi prototypet

#### - Search symptoms and check the suggested interventions.

On the search page, the search history is retained. Because some symptoms may not have appeared for the first time, search history makes it easier for the user to guickly search. Besides, the user can also input content via voice or by taking photos. Based on the searching terms and the user's history data, the closest entries to what the user wants to search for are listed. The user can click on the entry to view the detailed content. On the symptom entry page, users can view short videos or photos to quickly learn this entry. Furthermore, there is a navigation bar in the bottom right corner, considering that the content of an entry often would out of the content be displayed on a single screen.

In recommended interventions/knacks, the user can click and go to an intervention's entry to see the details of the intervention. In addition, on the entry page, there is a simple discussion forum where users can share their queries or comments. Then the expert can answer them and edit the entry to improve it.



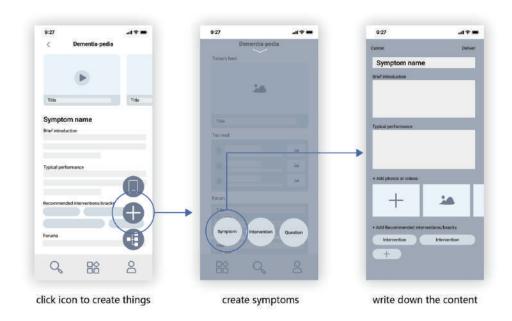
#### View posts in the forums, check all the replies.

The forum is on the discover page. The user can go to the forum page and view all the posts after click it. The user can click an interesting post to view the detailed content. Relevant symptoms and interventions are presented in the form of tags for emphasis. In addition, users can also view all replies to the post. They can like/tag/share posts or replies that resonate with them. They can reply to posts that they want to communicate with as well.



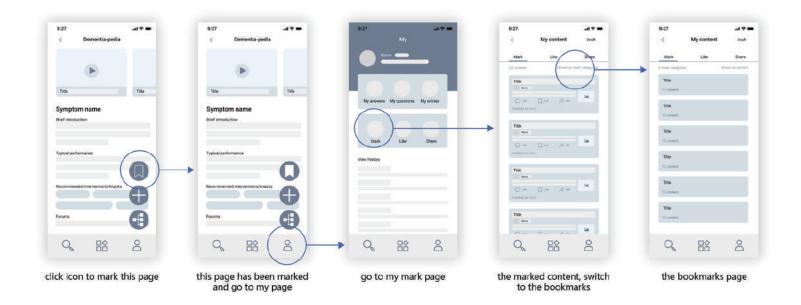
#### - Create an entry of a symptom.

By clicking on the create icon in the bottom right corner, the user can add symptoms (and also interventions and questions). In the page of adding detailed content, in addition to the basic information, pictures/videos of the description and the recommended interventions/knacks are necessary in order to ensure the inclusiveness of the product.



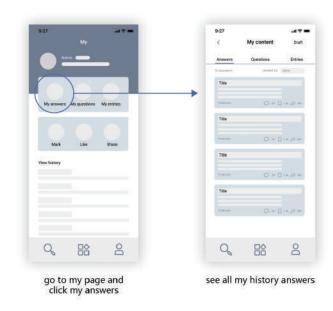
#### - Mark this symptom and check my mark and bookmarks.

The user can mark this entry by clicking on the mark icon. In addition, the user can manage the content they have marked on the my mark page. Besides, the user can create bookmarks to personalize the content they have collected.



#### - Go to my page and check my history answers.

There are two main categories of content on my page. The content created by the user, including my questions, my answers and my entries, is in one block, while the content viewed and interacted with by the user, including my mark, like and share are in another block.



# **Chapter 5**

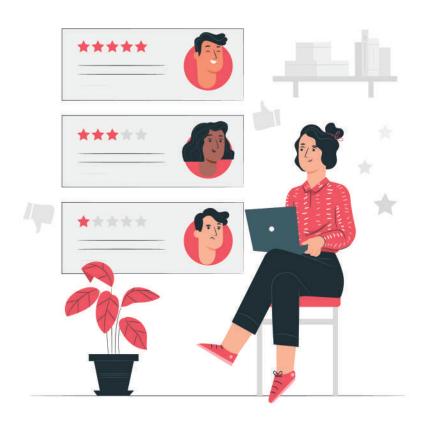
## **Evaluation and Iteration**

This chapter describes the iteration of the selected concept. usability test and expert review were applied to collect users' feedback.

# **Chapter 5**



- 1. Goal of evaluation
- 2. Methods and process
- 3. Result



## 1. Goal of evaluation

There were 3 main purposes of the evaluation

- 1. Identifying usability problems of the current design
- Test whether the logical relationship between pages was reasonable and understandable to users.
- Test whether the user experience of the main functions was smooth and if they feel confused during each step.
- 2. Uncover the design opportunities to improve the app, such as add any other features that the user requires.
- Test whether the current product features can meet the needs of users
- Test whether there were still many other features that the user requires

- 3. Learning about the target user's behavior and preferences
- Test whether if the current user flow and layout of the specific interfaces met the users' usage habits

# 2. Methods and process

Usability tests and Expert review were the main methods to evaluate the usability of current function flows and specific interfaces and uncover the opportunities to improve. to be performed, covering all pages and the main functions.

#### - Usability test

I invited 5 users (2 nurses, 2 caregivers, and 1 family member) to participate in the usability test. Considering the time cost, 5 users was enough (Jakob, 2000) to discover the majority of usability problems. There are four tasks in total that were asked

#### - Expert review

2 UX designers were invited to conduct the expert reviews remotely to check for possible usability issues, according to their previous experience and design principles. Suggestions and feedback were required to reply.

Task 1: search the symptom of "memory disorder" and mark this symptom page.

Task 2: view posts of questions in the forum, check the replies, and answer questions.

Task 3: Find a post of "Is there any methods to help older people train their memory ability?" on my mark page.

Task 4: Find the symptom of "frustrated", if not, create an entry.

# 3. Results

According to the result of usability test, 3 parts that need to be modified were summarized.

1. There was a problem with the mechanism. The experts (users who have been certified as doctors, nurses, therapists) should have more authorities than common caregivers. Their answers should be different from those of common users. Besides, only experts can edit entries. This would increase the authority and reliability of the app. Therefore, I created a user growth system. For those experts, they can go to verify as the experts, then they will have a verification title and their answers will be shown at the higher place. For those common users, they start from "the novice caregiver" and they can level up through answer questions and share stories to achieve marks/likes/shares. When they collect 100 marks/likes/shares, then they will

become "the active star caregivers". When they collect 200 marks/likes/shares, then they will become "well-experienced caregivers". Only experienced caregivers have the ability to edit or create entries. But the edited content needs to be reviewed and approved by experts before the publish. After describing the user growth system to an designer, he believed that such a user growth system would make users more active in answering questions.

2. The second is about how to classify the bookmarks. A caregiver thought a page of selecting or creating the bookmarks should be added. So that it allows users to immediately classify the content of the mark. Besides, the name of the bookmark can be edited by users, so that it is convenient for users to manage the content.

3. The third one is about the content in the "my mark page". An expert thought it was a good idea to tell what each piece of content was on the "my mark page". It could be in the form of a label on the card. This would make it easier for the user to see what the content is.

# **Chapter 6**

# Final design

The improved design is shown in this chapter. The future development including ideal spread channels and required resources are described as well. Besides, there is a SWOT analysis of this app in Chinese market at the end.

# **Chapter 6**

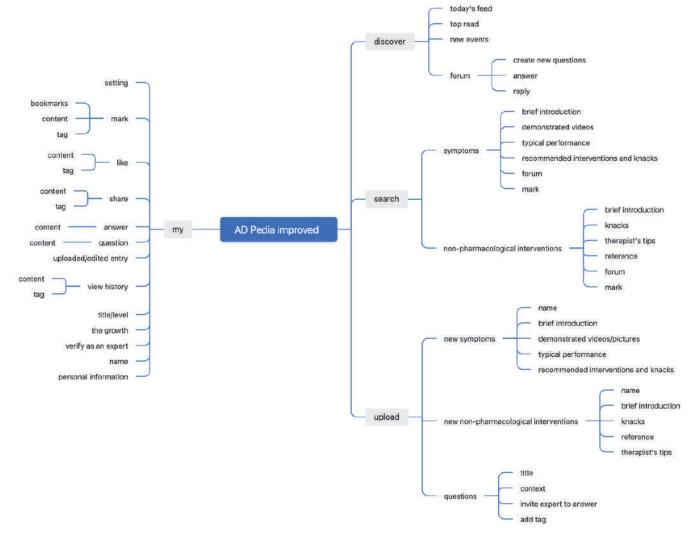
- 1. Improved Framework
- 2. Improved prototype overview
- 3. Improved prototype and function flow
- 4. Ideal spread channels
- 5. Resources needed to develop and maintain the app Ideally
- 6. SWOT analysis



# 1. Improved Framework

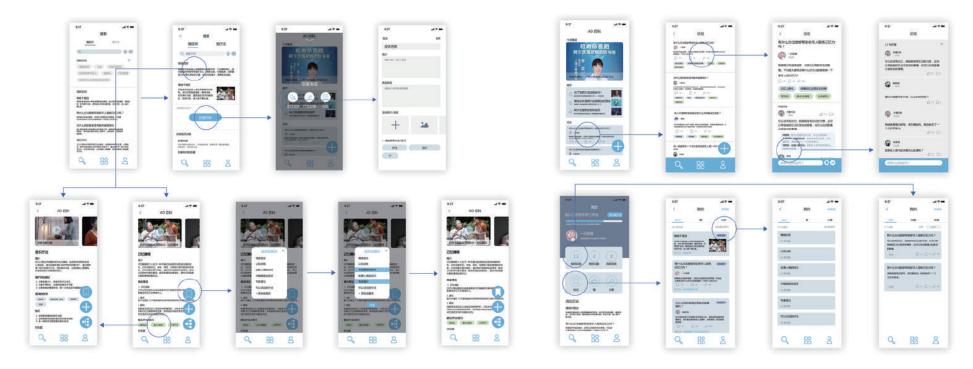
The prototype of final design can be found in the appendix 6. According to the feedback from users and the results of the usability test, the content and functions of the app were adjusted. Here is the improved frame-

work of the app.



# 2. Improved prototype overview

Since the realistic users who participated in the usability test can only read Chinese, and the project context were in China, the prototype for the final test was in the Chinese version. Besides, in order to make the app more realistic and simulate the real usage scenario, the high-fi prototype was more suitable for the usability test. Therefore, the example content, pictures, color blending, and icons were filled in. Here is the improved high-fi prototype of the app.



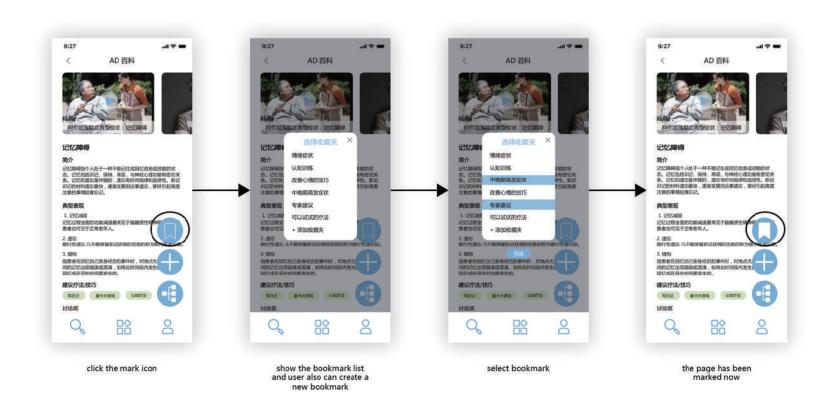
# 3. Improved prototype and function flow

Overall, three main parts (including a function flow and two specific interfaces) were improved:

- The improved "my page" with a user growth system.



## - The improved process of "mark a symptom page"



## - The improved "my mark page"

9:27

标记

120 条约容

情绪不稳定

單類老午倫梁成人常有新傳教說的或 稅。他们委而指述與實,應例此半,要 而情不凸頭,賴笑說之學的形態而起, 怒发冲冠,使人提不着头戲。

我的

有什么办法能够帮助老年人锻炼 **全域**的 记忆力吗?

取締結合性無余制度、原原布尼和配皮生的事情。不知道 大家有限有什么对办法能够和第一下仓标人的记忆力

为什么我的爸爸变得越来越情 结化?

自从取的爸爸三年高聯於老年指案之后,換減发緊他越來越 情味化,每天要名同於地球人发脾气,没有媒体,而且越来 越報報。

OH DIM AH

草鸦柏

分享

the symptom tag

- the post tag

接收原来展示

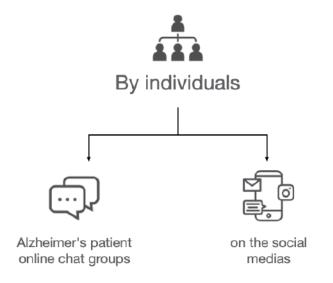
(SERVINE

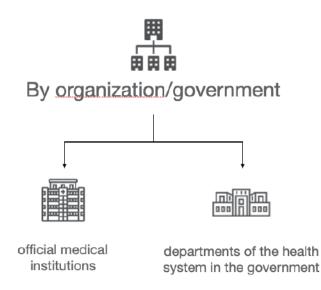




# 4. Ideal spread channels

In terms of the efforts that can be made by individuals, the app can be spread through the patient online chat groups or be shared on social media. Besides, official medical institutions or departments of the health system in the government could be the organizations to take the responsibility to promote this app.

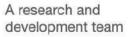




# 5. Resources needed to develop and maintain the app in the future

If the product is going to be launched, a research and development team is needed to develop the app and take the day-to-day maintenance. In addition, it is necessary to find the appropriate channels to promote the product to the users. For example, official medical institutions or departments of the health system in the government are able to lead these promotions effectively and efficiently. In addition to this, not only a team of experts is required to take the responsibility for inputting content regularly, but also users need to actively engage in communication to form an active online community.







The appropriate channels



A team of experts to take the responsibility for inputting content regularly



Form an active atmosphere for online community

# 6. SWOT analysis

SWOT analysis was applied to form an strategic overview of this app in Chinese market. (The competitors include Naoyuekang, Baike, Alzheimer's Light and Cognifit)

- The product is inclusive and age-friendly, which can suit more potential users.
- Build the gap between the user and Alzheimer-related resources.
- Provide immediate help.
- Form an online community where users can encourage and help each other.

- Not certified or recommended by the official institution or medial organization which leads to the lack of authority.
- Not only the research and develop team but also the expert team are required for regular maintenance.

- 90 percent of the elderly in China are living at home (NFC, 2021). There is a huge potential to satisfy the need in the scenario of providing the home-based care.
- There's no Family Physicians system in China and the community medical system was not well developed. Therefore, the user is lacking of the channels to achieve Alzheimer-related resources.
- Although, users are interested in the non-pharmacological intervention. The majority of people had no awareness of this concept.
- The non-pharmacological interventions are expensive. Experts and other related resources will be hired and collected by Profit-making rehabilitation centers.

# **Chapter 7**

## Conclusion

The improved design is shown in this chapter. The future development including ideal spread channels and required resources are described as well. Besides, there is a SWOT analysis of this app in Chinese market at the end.

# **Chapter 7**

- 1. Limitations of the design
- 2. Limitations of the project
- 3. Personal reflection on the project
- 4. Further development



# 1. Limitations of the design

- Although there were examples and templates for symptoms and intervention, the app lacked the content. It was not possible to fill the content with one person's effort, it required input from many people in academia and the medical profession. Furthermore, it is better to have several teams of experts who can take on the input work for a regular time.
- Currently, there are no accessible mature channels to disseminate or promote this app. If the app is spread from a personal perspective, it can be spread through the patient online chat groups or by sharing the app on social media. But, I believed that letting an official medical institution or government to promote the app would be better, and this official promotion can also increase the authority of the product as well.

- The testing period was short. If the app is put into long-term use, problems and extra needs may appear. Such as, a need to design an award system to keep users motivated in sharing content and form an active community atmosphere.

# 2. Limitations of the project

- When recruiting users for the project, only the users who provided good dementia care for the Pw D were willing to participate in the research. So the collected research insights were more representative of those who provided a relatively good experience of dementia care. Besides, due to the large variation in dementia, the number of people selected to participate in research was limited, therefore it was not possible to include all types of users.
- During the preliminary research, China was also in the epidemic. An advanced care center that specific to dementia, which was initially selected as the research target, was not allowed to access and perform field research.

- In China, there was no community system, which made it difficult to find official institutions and organizations interested in taking on the development and maintenance of the product from a service design perspective.
- The design was tested for a short period of time and the results of iterations only optimize the experience of use in the short term. If the product is put into long-term use, subsequent iterations are essential.
- The product was not launched due to the lack of a suitable client.

# 3. Personal reflection on the project

- There was less research on how the app would be developed in long term use in the future.
- During the research phase, I read a lot of papers to learn about various symptoms and interventions, but only a few of them were used in the end.
- Time management needs to be strengthened. There was a problem in processing of brainstorm results. Even though it was back on track, it consumed a lot of time, which led to a need to speed up the progress in the later stages to meet the expected deadline.

- As the project was conducted online and remotely, I had regular update emails and meetings to report the progress, but I felt that I was not active enough to ask for help from the mentor and chair when I encountered problems. However, both the mentor and chair were very nice and helpful.

# 4. Further development

- There is a need to find and contact an organization to further develop the app to launch. This organization should preferably be an official health organization or a department of the health system in government.

- In addition, I wonder if it is possible to involve more stakeholders from business aspects. For example, building a profitable business model to create more value from business aspects for this tool to attract investment from companies.



An official health <u>organization</u> or a department of the health system in government



Create business model

## Reference

Alves, S., Brito, F., Cordeiro, A., Carriço, L., & Guerreiro, T. (2019). Designing Personalized Therapy Tools for People with Dementia. Proceedings of the 16th International Web for All Conference, 1–10. https://doi.org/10.1145/3315002.3317571

Black, A., Carey, C., Matthews, V., & Solomons, L. (2019). Designing information for families caring for people with dementia. Design for Health, 3(2), 199–219. https://-

doi.org/10.1080/24735132.2019.1629766

C-Box—WiklD, the Industrial Design Engineering wiki. (n.d.). Retrieved May 23, 2021, from http://wikid.io.tudelft.nl/WiklD/index.php/C-Box

Cheung, G., & Peri, K. (2020). Challenges to dementia care during COVID-19: Innovations in remote delivery of group Cognitive Stimulation Therapy. Aging & Mental Health, 0(0), 1–3. https://doi.org/10.1080/13607863.2020.1789945

Christie, H. L., Martin, J. L., Connor, J., Tange, H. J., Verhey, F. R. J., de Vugt, M. E., & Orrell, M. (2019). EHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready? Internet Interventions, 18, 100260. https://doi.org/10.1016/j.invent.2019.100260

Cloak, N., & Al Khalili, Y. (2021). Behavioral And Psychological Symptoms In Dementia. In StatPearls. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK551552/

Cohen-Mansfield, J. (2018). Non-pharmacological interventions for persons with dementia: What are they and how should they be studied? International Psychogeriatrics, 30(3), 281–283. https://doi.org/10.1017/S104161021800039X

Cook, E. D. M., Swift, K., James, I., Malouf, R., Vugt, M. D., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. Cochrane Database of Systematic Reviews, 2. https://doi.org/10.1002/14651858.CD006929.pub2

Dementia: Stages, Causes, Symptoms, and Treatments. (n.d.).

Retrieved May 23, 2021, from https://www.webmd.com/alzheimers/types-dementia

Dementia—Early signs—Better Health Channel. (n.d.). Retrieved May 23, 2021, from https://www.betterhealth.vic.gov-au/health/Condition-

sAndTreatments/dementia-early-signs#early-symptoms-of-dement ia

Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. Advances in Psychiatric Treatment, 10(3), 171–177. https://doi.org/10.1192/apt.10.3.171

Dyer, S. M., Harrison, S. L., Laver, K., Whitehead, C., & Crotty, M. (2018). An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. International Psychogeriatrics, 30(3), 295–309. https://doi.org/10.1017/S1041610217002344

ElevenLessons\_Design\_Council (2).pdf. (n.d.). Retrieved May 23, 2021, from https://www.designcouncil.org.uk/sites/default/files/asset/document/ElevenLessons\_Design\_Council%20(2).pdf

Experience, W. L. in R.-B. U. (n.d.). Why You Only Need to Test with 5 Users. Nielsen Norman Group. Retrieved May 23, 2021, from https://www.nngroup.com/articles/why-you-on-ly-need-to-test-with-5-users/

Forrester, L. T., Maayan, N., Orrell, M., Spector, A. E., Buchan, L. D., & Soares-Weiser, K. (2014). Aromatherapy for dementia. Cochrane Database of Systematic Reviews, 2. https://doi.org/10.1002/14651858.CD003150.pub2

Key dimensions. (n.d.). Dimensions. Retrieved May 23, 2021, from https://yonghunlim83.wixsite.com/dimensions

Klimova, B., Maresova, P., & Kuca, K. (2016). Non-Pharmacological Approaches to the Prevention and Treatment of Alzheimer's Disease with Respect to the Rising Treatment Costs. Current Alzheimer Research, 13(11), 1249–1258.

Larrivee, D. (2019). Redirecting Alzheimer Strategy: Tracing Memory Loss to Self Pathology. BoD – Books on Demand.

Laver, K., Dyer, S., Whitehead, C., Clemson, L., & Crotty, M. (2016). Interventions to delay functional decline in people with dementia: A systematic review of systematic reviews. BMJ Open, 6(4), e010767. https://doi.org/10.1136/bmjopen-2015-010767

Lee, G. E., Kim, J. Y., Jung, J. H., Kang, H. won, & Jung, I. C. (2019). Non-pharmacological interventions for patients with dementia: A protocol for a systematic review and meta-analysis. Medicine, 98(38), e17279. https://doi.org/10.1097/MD.000000000017279

Lyketsos, C. G., Carrillo, M. C., Ryan, J. M., Khachaturian, A. S., Trzepacz, P., Amatniek, J., Cedarbaum, J., Brashear, R., & Miller, D. S. (2011). Neuropsychiatric symptoms in Alzheimer's disease. Alzheimer's & Dementia, 7(5), 532–539. https://doi.org/10.1016/j.jalz.2011.05.2410

Merriam, A. E., Aronson, M. K., Gaston, P., Wey, S.-L., & Katz, I. (1988). The Psychiatric Symptoms of Alzheimer's Disease. Journal of the American Geriatrics Society, 36(1), 7–22. https://doi.org/10.1111/j.1532-5415.1988.tb03427.x

Moretti, D. (2016). Update on Dementia. BoD – Books on Demand.

Pfeffer, A., Munder, T., Schreyer, S., Klein, C., Rasińska, J., Winter, Y., & Steiner, B. (2018). Behavioral and psychological symptoms of dementia (BPSD) and impaired cognition reflect unsuccessful neuronal compensation in the pre-plaque stage and serve as early markers for Alzheimer's disease in the APP23 mouse model. Behavioural Brain Research, 347, 300–313. https://-

doi.org/10.1016/j.bbr.2018.03.030

Pieper, M. J. C., van Dalen-Kok, A. H., Francke, A. L., van der Steen, J. T., Scherder, E. J. A., Husebø, B. S., & Achterberg, W. P. (2013). Interventions targeting pain or behaviour in dementia: A systematic review. Ageing Research Reviews, 12(4), 1042–1055. https://doi.org/10.1016/j.arr.2013.05.002

Scales, K., Zimmerman, S., & Miller, S. J. (2018). Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia. The Gerontologist, 58(suppl\_1), S88–S102. https://doi.org/10.1093/geront/gnx167

Symptoms of dementia—NHS. (2017, December 21). Nhs.Uk. https://www.nhs.uk/conditions/dementia/symptoms/

Ueda, T., Suzukamo, Y., Sato, M., & Izumi, S.-I. (2013). Effects of music therapy on behavioral and psychological symptoms of dementia: A systematic review and meta-analysis. Ageing Research Reviews, 12(2), 628–641. https://doi.org/10.1016/j.arr.2013.02.003

Van't Leven, N., Prick, A.-E. J. C., Groenewoud, J. G., Roelofs, P. D. D. M., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. International Psychogeriatrics, 25(10), 1581–1603. https://doi.org/10.1017/S1041610213000860

Wang, G., Albayrak, A., & Cammen, T. J. M. van der. (2019). A systematic review of non-pharmacological interventions for BPSD in nursing home residents with dementia: From a perspective of ergonomics. International Psychogeriatrics, 31(8), 1137–1149. https://doi.org/10.1017/S1041610218001679

Wang, G., Albayrak, A., Molenbroek, J., & van der Cammen, T. (2019). Non-pharmacological Interventions for People with Dementia: Design Recommendations from an Ergonomics Perspective. In S. Bagnara, R. Tartaglia, S. Albolino, T. Alexander, & Y. Fujita (Eds.), Proceedings of the 20th Congress of the International Ergonomics Association (IEA 2018) (pp. 112–122). Springer International Publishing. https://doi.org/10.1007/978-3-319-96065-4\_15

Wang, G., Gong, H., Albayrak, A., van der Cammen, T. J. M., & Kortuem, G. (2020). Personalising Management of Behavioural and Psychological Symptoms of Dementia in Nursing Homes: Exploring the Synergy of Quantitative and Qualitative Data. BioMed Research International, 2020, e3920284. https://-

doi.org/10.1155/2020/3920284

Wang, G., Marradi, C., Albayrak, A., & Cammen, T. J. M. van der. (2019). Co-designing with people with dementia: A scoping review of involving people with dementia in design research. Maturitas, 127, 55–63. https://doi.org/10.1016/j.maturitas.2019.06.003 What Are the Signs of Alzheimer's Disease? (n.d.). National Institute on Aging. Retrieved May 23, 2021, from http://www.nia.nih.gov/health/what-are-signs-alzheimers-disease

What is Alzheimer's? (n.d.). Alzheimer's Disease and Dementia. Retrieved May 23, 2021, from https://alz.org/alzheimers-dementia/what-is-alzheimers

Whitehead, L. (2016). Psychological Treatments for Depression and Anxiety in Dementia and Mild Cognitive Impairment. Issues in Mental Health Nursing, 37(10), 773–774. https://doi.org/10.1080/01612840.2016.1221677

Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews, 2. https://doi.org/10.1002/14651858.CD005562.pub2

Wragg, R. E., & Jeste, D. V. (1989). Overview of depression and psychosis in Alzheimer's disease. The American Journal of Psychiatry, 146(5), 577–587. https://doi.org/10.1176/ajp.146.5.577

Zec, R. F., & Burkett, N. R. (2008). Non-pharmacological and pharmacological treatment of the cognitive and behavioral symptoms of Alzheimer disease. NeuroRehabilitation, 23(5), 425–438. https://doi.org/10.3233/NRE-2008-23506

Zwaanswijk, M., Peeters, J. M., van Beek, A. P., Meerveld, J. H., & Francke, A. L. (2013). Informal Caregivers of People with Dementia: Problems, Needs and Support in the Initial Stage and in Subsequent Stages of Dementia: A Questionnaire Survey. The Open Nursing Journal, 7, 6–13. https://doi.org/10.2174/1874434601307010006

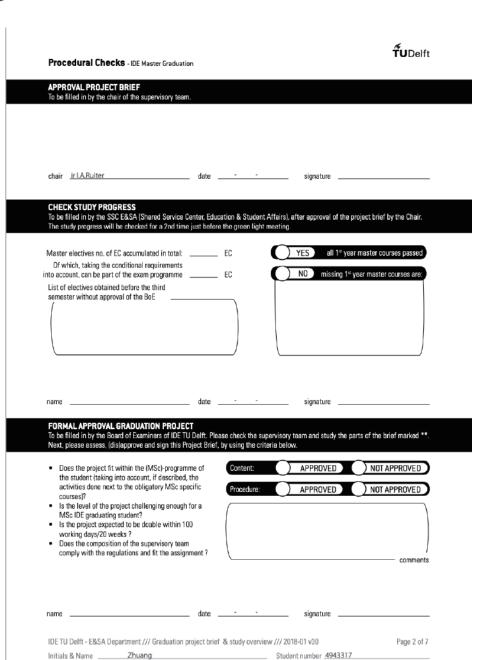
刘爽, 明东, 全晶晶, 郭冬月, 安兴伟, 许敏鹏, 綦宏志, 何峰, & 周鹏. (2016). 基于心电和呼吸信号同步性特征的情绪检测方法 (China Patent No. CN106236117A). https://patents.google.com/pat-

ent/CN106236117A/zh

国家卫生健康委员会2021年4月8日例行新闻发布会文字实录. (n.d.). Retrieved May 23, 2021, from http://www.nhc.gov.cn/xcs/s3574/202104/0c1cf92f2b7b4cfe890234a1c3d5593f.shtml 张迪, 万柏坤, & 明东. (2015). 基于生理信号的情绪识别研究进展. 生物医学工程学杂志, 32(01), 229–234.

# **Appendix 1: Graduation Project Brief**

#### TUDelft **IDE Master Graduation** Project team, Procedural checks and personal Project brief This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document: · The student defines the team, what he/she is going to do/deliver and how that will come about. SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress. IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project. USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser. STUDENT DATA & MASTER PROGRAMME Save this form according the format "IDE Master Graduation Project Brief\_familyname\_firstname\_studentnumber\_dd-mm-yyyy". Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1. Your master programme (only select the options that apply to you): family name Zhuang IDE master(s): () IPD () Dfl initials given name Shuyan student number 4943317 2<sup>rd</sup> non-IDE master: \_\_ individual programme: \_\_\_\_\_ (give date of approval) street & no. zipcode & city honours programme: ( ) Honours Programme Master specialisation / annotation: ( ) Medisign country Tech, in Sustainable Design phone ( ) Entrepeneurship Chair should request the IDE Board of Examiners for approval \*\* chair \_ir.l.A.Ruiter dept. / section: HCD/AED of a non-IDE mentor, including a \*\* mentor MEng Gubing Wang dept. / section: HCD/AED motivation letter and c.v... Second mentor only applies in case the assignment is hosted by an external organisation. comments Ensure a heterogeneous team. (optional) In case you wish to include two team members from the same section, please explain why. IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Page 1 of 7



Title of Project A tool for informal caregiver to improve personalized nursing experience

#### TUDelft

#### Personal Project Brief - IDE Master Graduation

#### A tool for informal caregiver to improve personalized nursing experience project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 04 - 01 - 2021 28 - 05 - 2021 end date

#### INTRODUCTION \*

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money....), technology, ...].

This project focuses on developing a systematic and professional guide tool for informal caregivers to improve personalized nursing experience of people-with-dementia.

Context: There are many different types of non-pharmacological therapies applied to manage Behavioural and Psychological Symptoms of Dementia due to many benefits, such as no side effects. However, the response to different types of interventions and the process of each patient's disease varies greatly from patient to patient. So, there is a need for personalised nursing (non-pharmacological intervention).

Currently, patients are nursed in the care center or by the informal caregivers at home. In China, the latter is more popular.

There are several stakeholders included in this context, including people with dementia, informal caregiver, professional caregiver, the care center, and so on. The main target group is informal caregiver, who lacks systematic and professional training but has a lot of practical experience. They developed a few special knacks through practical experience. Actually, these special knacks are the modified or redesigned applications of non-pharmacological interventions, which are based on medical theories. For example, a knack collected from the preliminary research is that playing Chinese opera for patients can make them turn to positive emotion, which actually applied music therapy. Another knack is asking the patients to count beans when they are irritable, which can calm them down. This method actually distracts the patient from the annoying things first, then concentrating on the counting, thus calming the mind. Such knacks work well for the patients as they are personalized according to the patient's conditions. Whereas, personalized nursing requires not only the knowledge of non-pharmacological interventions, but also knowing the patient's condition, including habits, history, etc. Therefore, the collaboration between formal caregivers and informal caregivers (especially families who know the patient mostly) is necessary, which is missing in the current situation. In addition to the knacks from informal caregivers, the care center also has developed some methodologies for nursing.

Opportunity and benefits: Considering there are many different types of non-pharmacological interventions, a systematic classification can be built to mapping the knacks (personalized intervention applications). A guide tool based on the medical theories can be developed. Therefore, it can be used by informal caregivers to choose the suitable non-pharmacological interventions based on the patient's condition. Besides, with this tool, patients can have better personalized nursing experience. Moreover, for the care center and professional caregivers, they can train their ability to apply personalized treatment in a more efficient way.

Support and Resource: 1. This project will be based in China, due to the current pandemic condition. The field research is allowed to be conducted in China, which is of great significance and convenience. 2. Futian Rehabilitation Center (a general care center but with rich experience on people-with-dementia) and Hangzhou Hekang Rehabilitation Hospital (Dementia specific care center) present the opportunities for this research and design project. The nurses and caregivers value this project and show great passion for cooperation. 3, people-with-dementia nursed by informal caregivers is more popular in China, and through these medical care centers, this research target group can be easily reached. 4. Know-me, (which has been developed by Ms. Wang Gubing) a design toolkit for personalizing dementia care, in which each tool is developed based on a publication, can be used as the literature study material.

Limitations: the conditions of the patients (who may be difficult to communicate effectively); the privacy of patient data; relevantly scarce dementia-specific care center in China, etc.

space available for images / figures on next page

IDE TU Delft - E8	Page 3 of 7		
Initials & Name	Zhuang	Student number 4943317	
Title of Project	A tool for informal caregiver to impre		



#### Personal Project Brief - IDE Master Graduation

introduction (continued): space for images



image / figure 1: Personalized nursing (non-pharmacological therapy) for people with dementia

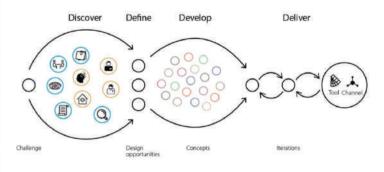


Figure 2: Process of the research and design project

image / figure 2: The process of the research and design project

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30			Page 4 of 7
Initials & Name	Zhuang	Student number 4943317	
Title of Project	A tool for informal caregiver to impro	rmal caregiver to improve personalized nursing experience	

### **TU**Delft

### Personal Project Brief - IDE Master Graduation

### PROBLEM DEFINITION \*\*

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

The Informal caregivers need to understand how to apply personalized intervention and nursing, but it's difficult due to the lack of knowledge, tools and channels.

Non-pharmacological interventions have been already well developed. There are many different types of treatments, but unsystematic and recondite. There exists barriers for informal caregivers to understand it. Besides, personalizing or redesigning without any design tools or guide tools is difficult for them. Moreover, channels to introduce professional knowledge and design (quide) tools to the people who need help are missing.

### ASSIGNMENT \*\*

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, .... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Develop a tool for informal	caregivers to improve	personalized	nursing experience	(non-pharmace)	utical therapy) of
eonle-with-dementia					

- 1. Literature research on non-pharmaceutical therapy
- 2. Collecting data of knocks (personalized intervention applications) through field research
- 3. Develop a tool for informal caregivers based on Know-me (a toolkit for designer)

IDE TU Delft - E8	ASA Department /// Graduation project br	ief & study overview /// 2018-01 v30	Page 5 of 7
Initials & Name	Zhuang	Student number 4943317	
Title of Project	A tool for informal caregiver to impro	ove personalized nursing experience	

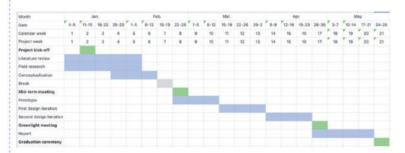


### Personal Project Brief - IDE Master Graduation

### PLANNING AND APPROACH \*\*

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of bolidays or parallel activities.

start date 4 - 1 - 2021 end date



The project consists of research, design, evaluation and iteration.

- 1. Research and analysis phase: The project will start with literature review and desk research on the personalized nursing methods and cases. After the knowledge is acquired, field research will be conducted in the care center, including interviews and observations with general caregivers. The main aim is to gain the insights of their professional nursing methods. Meanwhile, in-depth interviews and observation with informal caregivers will be conducted to understand their nursing experience and knacks (personalized nursing application), as well as their learning experience of caring for a people-with-dementia(in order to investigating the effective way to introduce the design tool). Besides, context mapping for empathy mapping) with the main stakeholders also needs to be done to gain in-depth understanding of their latent needs. The research plan will be designed according to Know-me as well.
- 2. Ideation and conceptualization phase: The initial design ideas and concepts will be formed. This is a diverging phase, so multiple concepts will be created during the ideation workshop. But after the discussion and evaluation with the mentors, no more than three concepts with different focuses and strategies will be selected to be presented at the mid-term meeting, and eventually one suitable concept will be chosen for further development.
- 3. Design detailing and evaluation phase. A more concrete concept and prototype will be formed and tested. Experts and real users will be recruited to test and evaluate the concept. In addition, the efficiency of the way to spread the tool to the target users (who want to improve the personalized nursing experience) will be evaluated as well. The results and insights will be collected for improving the final design, which will be discussed in the green-light meeting.
  4. The last phase of the project includes final design improvement, report writing, presentation preparation and graduation ceremony.

IDE TU Delft - E8	&SA Department /// Graduation project bri	ief & study overview /// 2018-01 v30	Page 6 of 7
Initials & Name	Zhuang	Student number 4943317	
Title of Project	A tool for informal caregiver to impro	ove personalized nursing experience	

### **Tu**Delft

### Personal Project Brief - IDE Master Graduation

### MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example, acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, .... Stick to no more than five ambitions.

I am interested in the topic of design for people with dementia, because my grandmother is an Alzheimer's patient. I have always been paying close attention to this group. They do need help and I believe that my research and design is of significance.

Besides, I want to gain more experience and knowledge in design for people with dementia, not only focusing on the patient, but also taking the view angle from other stakeholders, including the caregivers and family members.

Moreover, since the disease progress of different patients varies greatly, personalized nursing is necessary. Ms. Wang Gubing is working on this topic and I see it as a great opportunity.

In addition, informal caregivers are more popular in China, and non-pharmacological therapies are developed slowly in China due to some restrictions, etc. Considering all of these factors, I think that this topic is very necessary and of great significance.

After two years of further study, I want to practice the methods and knowledge I learned at TU Delft and improve my research and design skills through the graduation project. I want to develop myself into a designer driven by research. During this project, I will apply multiple research methods and tools, I'm looking forward to seeing how I organize and conduct a comprehensive research plan.

### FINAL COMMENTS

n case your project brief needs final comments, please add any information you think is relevant.

IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30			Page 7 of 7
Initials & Name	Zhuang	Student number 4943317	
Title of Project	A tool for informal caregiver to impro	ove personalized nursing experience	

# Appendix 2: the holistic symptoms of dementia:

https://miro.com/app/board/o9J\_IWD1TQE=/

### **Appendix 3: Non-pharmacological interventions**

Non- pharmacological intervention	Active ingredient	Things needs to pay attention to	Investment	Effect
Aromatherapy	<ul> <li>Long-standing practice of using scented oils</li> <li>The link between smell and memory</li> <li>Room diffusion, sachets, a patch or skin cream</li> <li>Social and physical contact</li> </ul>	<ul> <li>Essential oil may have a direct effect on the brain</li> <li>Aromatherapy has been no effective when assessors are masked to the treatment</li> </ul>	Overall: low  • minimal time needed for learning and implementation  • no need for a specialized care proider  • modest resource requirements	<ul> <li>Improve individual's mood</li> <li>Agitation; aggression</li> </ul>
Massage	a nonverbal means of communication or connection	Increased stimulation may increase agitation	Overall: minimal  minimal time demands  No need for a specialized care proider  Few capital resources	<ul> <li>help offset the social isolation that triggers negative affect and related behaviors</li> <li>Agitation; aggression; stress; anxiety; depression; disruptive vocalization in the immediate or short term</li> </ul>

Multisensory	<ul> <li>A stress free entertaining environment both to stimulate and to relax</li> <li>Promote control and autonomy</li> <li>A combination of light effects, calming sounds, smells, tactile stimulation</li> <li>Incorporation of sensory stimulation into daily care routine</li> </ul>		moderate investment in resources and time is required     Once resources are secured, care provider time is the primary ongoing cost	Reduce short-term anxiety, agitation, and apathy
Bright Light Therapy	<ul><li>Light strength</li><li>exposure time</li></ul>	Monitoring is critically important to ensure that bright light does not increase agitation	Overall: moderate  • investment requirements decreased by using natural light or ambient light rather than individual light boxes	Therapeutic benefit for reducing agitation, depression, and/or sleep disturbance in some individuals living with dementia,
Validation Therapy	<ul> <li>using nonthreatening words to establish understanding</li> <li>rephrasing the person's words</li> <li>maintaining eye contact and a gentle tone of voice</li> <li>responding in general terms when meanings are unclear</li> <li>using touch if appropriate</li> </ul>		Overall: Low  It can be integrated into care by usual care providers after modest investment in communication training	alleviate negative feelings and enhance positive feelings by focusing empathically on the emotional content of a person's words or expressions

Reminiscence Therapy	<ul> <li>discussion of past events and experiences</li> <li>specific stimuli (e.g., photographs, music)</li> </ul>	<ul> <li>Learn about each person's personal history and meaningful events</li> </ul>	Overall: moderate     Training and implementation	<ul> <li>Increase well-being and providing pleasure and cognitive stimulation</li> </ul>
Music Therapy	receptive (listening to music) or participatory (making music)		Overall: moderate  time and training are required to set up and sustain a music program  more resources are required over the long term for group sessions	Prevent or alleviate distressing symptoms of dementia
Pet Therapy	Live or robotic pets	<ul> <li>Allergic reactions,</li> <li>Hygiene concerns</li> <li>Anxiety/agitation among some individuals, such as those who had negative experiences with animals in the past</li> </ul>	Overall: moderate  Initial or ongoing costs of acquiring and/or caring for the animal  Specialized training and resource allocation may be required	<ul> <li>Reduce agitation and disruptive behavior</li> <li>Increase social and verbal interactions, and decreased passivity</li> </ul>

Meaningful Activities	A range of leisure and social activities usually tailored to the individual's preferences, lifelong habits and memories	<ul> <li>individualized</li> <li>ensure that individuals are able to fully participate and benefit</li> </ul>	meaningful activities     take time, but can     often be facilitated by     regular care providers     or informal caregivers     without extensive     additional training	Prevent or alleviate BPSDs by enhancing overall quality of life through engagement, enhanced social interaction, and opportunities for self-expression and self-determination
Bathing	<ul> <li>Person-centered showers or bed baths</li> <li>Enhance the bathing environment through preferred music or calming sounds.</li> </ul>		Overall: low  can be incorporated into ongoing care by usual staff, with some training and support.	<ul> <li>Reducing agitation, aggression, irritability, and anxiety as well as physical discomfort</li> </ul>

### **Appendix 4: Collected Knacks**

PwD	This PwD as a person (handle for the personalization)	Personalized designs (knacks)	Symptoms
1.	Used to be an accountant	Provide paper money to her to count	Emotional: apathetic
2.	Like Beijing opera	Play TV programmes with Beijing opera	Emotional: depressed
3.	Have a son	Tell her that her son will come soon	Behavioral: lethargy
4.	Like outdoor activities previously, but cannot stand up due to the stroke	Equipped with wheelchair to go outside and enjoy the sunshine, chat with neighbours	Behavioral: lethargy, not willing to move
5.	Growing up with his cousin XiaoHong, XiaoHong is an important symbol for him in his memory	Telling him XiaoHong is coming; using XiaoHong to calm him down	Behavioral: make noise and wave arms Behavioral: crying Emotional: depressed; agitated
6.	He can write and reading	Give him diary, ask him to keep writing diaries	Cognitive: forget recent activities

Have a special waterbottle	Ask him to remember the place he keeps his waterbottle, then ask him to find it out in the next day	Cognitive: forget recent activities, misplace products
He experienced a period of poverty in his youth	Tell him this month's salary is in his account	Emotional: depressed
Have the skills of sewing	Give her a piece of cloth and a doll	Behavioral: move arms and try to grab something obsessively
Cultivate close friendship with his roommate	Ask his roommate to calm him down	Emotional: depressed, agitated Behavioral: crying
Less strength in left arm due to stroke	Massage her left arm	Physical: muscular degeneration
Has fallen twice in the same day, then she became cowardly	Walk with her and encourage her verbally	Physical: difficult to walk Emotional: fear
Has fallen twice in the same day, then she became cowardly	Sleep with her and accompany with her to provide feeling of safety	Behavioral: wake up during the night time
	He experienced a period of poverty in his youth  Have the skills of sewing  Cultivate close friendship with his roommate  Less strength in left arm due to stroke  Has fallen twice in the same day, then she became cowardly  Has fallen twice in the same	place he keeps his waterbottle, then ask him to find it out in the next day  He experienced a period of poverty in his youth  Have the skills of sewing  Give her a piece of cloth and a doll  Cultivate close friendship with his roommate  Ask his roommate to calm him down  Less strength in left arm due to stroke  Has fallen twice in the same day, then she became cowardly  Has fallen twice in the same day, then she became cowardly  Sleep with her and accompany with her to

14.	missing his family and not willing to live in the care center	Play a video call with his son	Behavioral: not willing to lister to the caregiver's words; staring at the door Emotional: unreasonable, frustrated
15.	Used to be a manager, a rigorous mother	Obey her at that moment, give positive and affirmative response to what she says	Behavioral: quarrel with others; complain Emotional: irritably
16.	Used to be a teacher, and love Chinese Calligraphy	Ask him for a help to write something	Behavioral: repetitive teach and ask other people to do something
17.	Used to raise ducks in childhood	Tell her that's true, we will go to play with ducks later	Cognitive:hallucinations  Behavioral: Looking ahead and saying there are ducks
18.	Stronger personality	Answer the questions patiently	Behavioral: repetitive asking what's this and what's that
19.	Live with roommates and trust roommates	Let his roommates tell him that they have already had the meals	Behavioral: forget having the meals  Cognitive: delusions

20.	Quiet and introverted	Sitting with her for a moment and ask her what she's looking at, then start the chatting	Emotional: apathetic  Behavioral: staring at the sky
21.	Only remember the daughter	Calling her "Mum" out loud	Emotional: apathetic  Behavioral: lower perception  with environment and people
22.	Like dancing, but cannot stand up anymore	Play Tiktok of the content of dancing to her	Emotional: depressed; frustrated; boring

### Appendix 5: the flow of brainstorm:

https://flow.yitopia.co/board/Y76yxp8oywl1

# Appendix 6: the prototype for usability test:

https://www.figma.com/proto/3BzvwBw5rxUqOIN-hw5BPrQ/AD-CH-Low-fi?node-id=1%3A821&viewport=-121%2C228%2C0.20337936282157898&scaling=min-zoom&page-id=0%3A1