Tallinn University of Technology
Department of Mechanical and Industrial Engineering
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Department of Design

MSc. Design & Technology Futures

Towards Dementia-Friendly Society: Design and Interactive Technologies for Collaborative Caregiving and Personalised Non-Pharmacological Therapy

Dementsussõbraliku ühiskonna poole: Disain ja interaktiivne tehnoloogia dementsuse koostöiseks hoolduseks ja personaalseks mittefarmakoloogiliseks teraapiaks

MASTER THESIS

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THESIS TASK

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Thesis topic:

Towards Dementia-Friendly Society: Design and Interactive Technologies for Collaborative Caregiving and Personalised Non-Pharmacological Therapy

Dementsussõbraliku ühiskonna poole: Disain ja interaktiivne tehnoloogia dementsuse koostöiseks hoolduseks ja personaalseks mittefarmakoloogiliseks teraapiaks

Thesis main objectives:

1. Utilise design methodologies into dementia research
2. Design and develop tangible/interactive dementia non-pharmacological therapy
3. Evaluate the final deliverables - tangible object, digital assistant, service model

Thesis tasks and time schedule:

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2.	Qualitative Research	31.12.20
3.	Concept Design	31.01.21
4.	Prototyping & Testing	31.03.21
5.	Evaluation & Conclusion	30.04.21
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ABSTRACT

Background: The speed of aging has been increasing and therefore the demand for products/services which would align to elderly people has been getting higher. With the synchronization of aging, the number of people with dementia has been increasing rapidly and it puts a burden on not only people with dementia but also stakeholders and the entire world. Dementia non-pharmacological therapy is one of the most feasible interventions and it includes cognitive, sensory, and psychosocial therapies.

Research Problem: Family caregiver's low accessibility to patient-centred dementia non-pharmacological therapy has caused the low quality of caregiving to people with dementia, the increasing of caregiver's emotional/physical distress, and the low transparency of dementia to medical experts.

Research Question: How can design and interactive technologies make dementia therapy more personalised to patients, accessible to caregivers, and transparent to medical experts?

Research Aim: Explore the possibility of design and interactive technologies for dementia non-pharmacological therapy.

Hypothesis: Giving dementia non-pharmacological therapy more stimulations, playfulness and meaning by design and interactive technology would be beneficial to make it more patient-centred and empower informal caregivers.

Methodologies: The research is mainly based on Design Thinking methodology, DICE approach, and Constructive design wheel. The research is preceded with qualitative methods such as questionnaires, interviews, brainstorming, physical and digital prototyping and expert reviews.

Conclusions: The research would contribute to the enhancement of dementia therapeutic intervention research and therefore the quality of life in people with dementia.

Keywords: Human-Centred Design, Dementia Non-pharmacological Therapy, Human-Computer Interaction, Tangible User Interface, Speech Emotion Recognition

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1. INTRODUCTION

The world's population is aging rapidly - the number of elderly people is increasing with the demand for the elderly-friendly products/services such as healthcare, housing, transportation, and education. Globally, there were 703 million persons aged 65 or over in 2019 and over the next three decades, the number of older persons worldwide is projected to more than double, reaching more than 1.5 billion persons in 2050. [1] The growth of elderly people who have more risks of cognitive impairments indicates the possible market size in this dementia prevention/treatment would increase as well.

Dementia is a brain disease affecting memory, language, thinking that interferes with daily life activities. It is often mistreated as a normal aging because it is similar, for instance, forgetting, falling down, lack of sleep, and so on. Thus it is often too late to be treated properly. And it is a progressive disease. So sooner care to decrease the progression makes better well-being for people with dementia. Alzheimer disease is the most common form of dementia and may contribute to 60-70% of cases. In 2015, dementia affected 47 million people worldwide (or roughly 5% of the world's elderly population), a figure that is predicted to increase to 75 million in 2030 and 152 million by 2050. [2] For decades, the cause of dementia has been investigated from several fields across the world, however, there is no direct treatment. Besides that, due to the lack of public attention and services, dementia is not visible in the society and therefore there are lots of misconceptions of it and people related to it are left alone and excluded from normal societal activities. On top of that, it could happen to anyone - directly and indirectly.

I have a strong motivation to conduct this research because of my personal experience and professional aspiration. My grandmother had dementia in her late stage of life and I experienced her journey with my mother from different perspectives as a family member. It came suddenly. One day she got her legs injured and needed to be hospitalized for weeks and after that her cognitive function started to get dysfunctional - firstly forgetfulness in daily life activities, and disconnection with the surrounding environment and social network. Due to the limited resources and lack of accessibility to a proper treatment, the disease eventually took over her identity and self-recognition. Besides that, it made a negative impact on the entire family - emotional and physical distress coming from miscommunication and misunderstanding, and financial burden to gain several medical services. At that moment, I felt powerless and emptied as a family member.

It has been decades since my family suddenly encountered dementia. We are still on the long way to curing dementia. However, human beings have been utilizing a new tool - interactive technology - for making this world better at an impressive speed. Personally, I am attracted to combining design, a way of creation and problem solving, technology, and venture spirit. Therefore, I found it interesting to drive my intellectual curiosity and utilize my knowledge for addressing issues of dementia from design and engineering points of view, and making a contribution to the world where we can live with dementia in a better way with interactive technology.

This research has been proceeded with a combination of frameworks from the medical and design field - DICE (Describe - Investigate - Create - Evaluate) approach, Constructive Design Wheel, and Design Thinking, to achieve the aim of exploring the possibility of interactive technologies for dementia non-pharmacological therapy which leverages some actions with people with dementia, caregivers, and their physical and social environment.

It has been conducted in Estonia where it is open for technological innovation from individual to country level and a lot of experts are working on activities towards dementia friendly society. Elu Dementsusega and Tartu Health Care College, which founded the Dementia Competence Center, helped this research from the beginning.

As a creator aspiring to enhance the well-being of humans and a family member experiencing dementia - one of the biggest threats on public health, it would be a pleasure to make this master's thesis a milestone showing the power of design and technology for people with cognitive impairments.

2. METHODOLOGY

In this chapter, the general overview of the research, frameworks giving the research an interdisciplinary structure, the scope (research process, timeline, and expected outcomes), and the overview of each chapter will be described.

2.1. Research overview

This research has the following aspects:

Research Problem: Family caregiver's low accessibility to patient-centred dementia non-pharmacological therapy has caused the low quality of caregiving to people with dementia, the increasing of caregiver's emotional/physical distress, and the low transparency of dementia to medical experts.

Research Question: How can design and interactive technologies make dementia therapy more personalised to patients, accessible to caregivers, and transparent to medical experts?

Research Aim: Explore the possibility of design and interactive technologies for dementia non-pharmacological therapy.

Hypothesis: Giving dementia non-pharmacological therapy more stimulations, playfulness and meaning by design and interactive technology would be beneficial to make it more patient-centred and empower informal caregivers.

In order to explain the research question and achieve the aim, I set up one research methodology in combination with the Design Thinking process and two research frameworks from different disciplines.

2.2. Research framework

Two existing frameworks, DICE approach and Constructive Design Wheel, will be explained here so as to highlight what it is and how it is used for this research. These frameworks give medical and constructive design perspectives so that the outcome would be more desirable to stakeholders and the research scope would be continuously refined.

DICE Approach

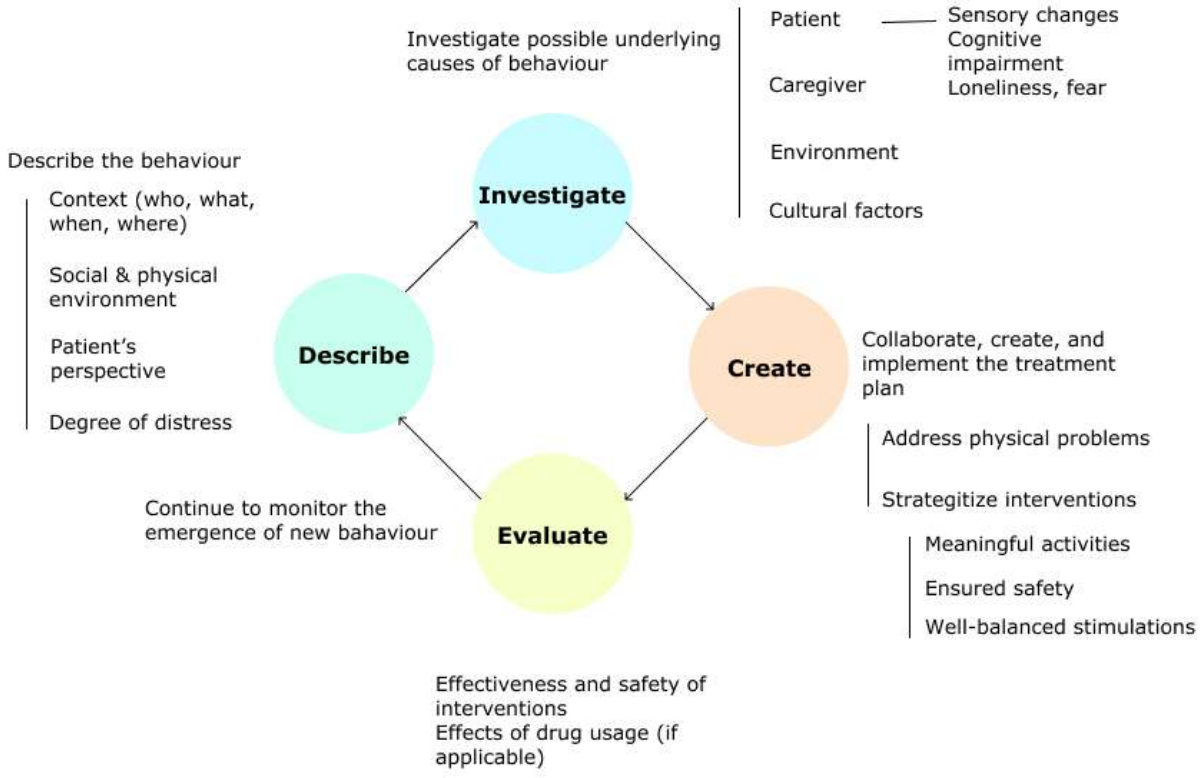

Figure 2.1. DICE approach - Masato Kagiwada, based on Kales HC, et al.

Dementia care management consists of pharmacologic and non-pharmacologic approaches. Although current evidence suggests that non-pharmacologic strategies, such as family caregiver interventions, show greater effect than most drug treatments, medications still have their place.

"**DICE approach**" (Figure 2.1.) was introduced to detect and manage symptoms, carefully consider possible causes, and then integrate pharmacological and nonpharmacological treatments. [3]

Step 1: Describe

The first step is to describe the symptoms by characterizing the symptoms and the context in which they occur through discussion with the caregiver and the person with dementia. This description should include **consideration of possible triggers of the behavior**. It is important to understand which aspects of the symptoms are most distressing or problematic to the person with dementia and the caregiver, as well as their treatment goal.

Step 2: Investigate

Once the symptoms are well characterized, the next step is for the provider to examine, exclude, and identify **possible underlying and modifiable causes**. Similar to the examination of delirium, the key to managing these symptoms is a thorough assessment of the underlying causes. It depicts underlying causes that are potentially modifiable through intervention.

Step 3: Create

In this step, the provider, caregiver, person with dementia (if possible), and team collaborate to create and implement a treatment plan. Treatments can be categorized as medical, non-pharmacologic (referred to as **"behavioral and environmental modifications''** which target the patient, caregiver, or environment (or a combination)) or pharmacologic.

Step 4: Evaluate

The final step is to assess whether recommended strategies were attempted and implemented effectively, whether the **target symptoms** improved, whether the **care giver's distress** was reduced, and whether there were any **unintended side effects or consequences**.

With this approach, the more desirable **non-pharmacologic intervention** for patient, caregiver, and environment could be created with the evaluation of effectiveness. It is used for behavioral analysis of people with dementia and family caregiver, and psychosocial analysis of environment and culture.

Constructive Design Wheel

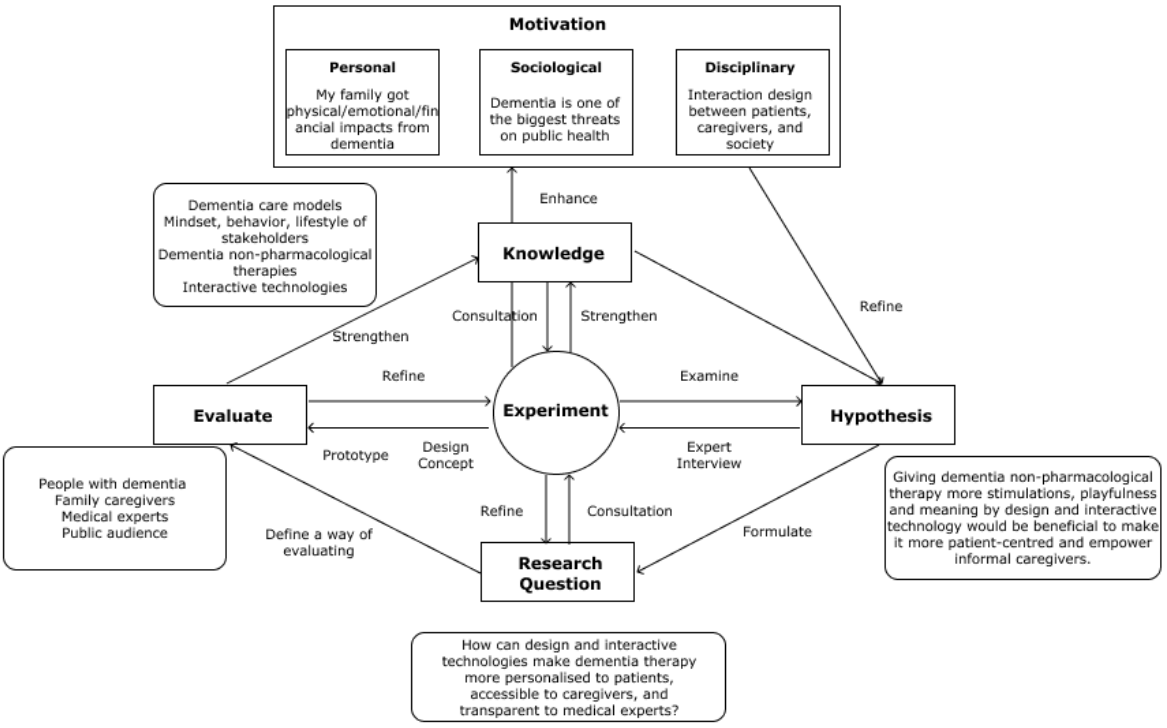

Figure 2.2. Constructive Design Wheel - Masato Kagiwada

Constructive design research wheel model (Figure 2.2.) [4] emphasizes on the continuous evaluation with experiments in research. With the complexity of the topic and the technical feasibility of technology selected, the frequent iteration of this wheel would be significant. It helps me to establish a hypothesis and a research question while strengthening specific knowledge and evaluating outcomes with main stakeholders. It also defines personal, sociological, and disciplinary motivations formulated by personal experiences and interests. With a timely experience in the form of discussion, visual mapping, and prototyping, the quality of research will be enhanced toward a creation of a desirable, feasible, and viable concept for the better well-being in dementia care.

By consolidating these two frameworks with Design Thinking, the customized research methodology would be introduced in the next section.

2.3. Research scope

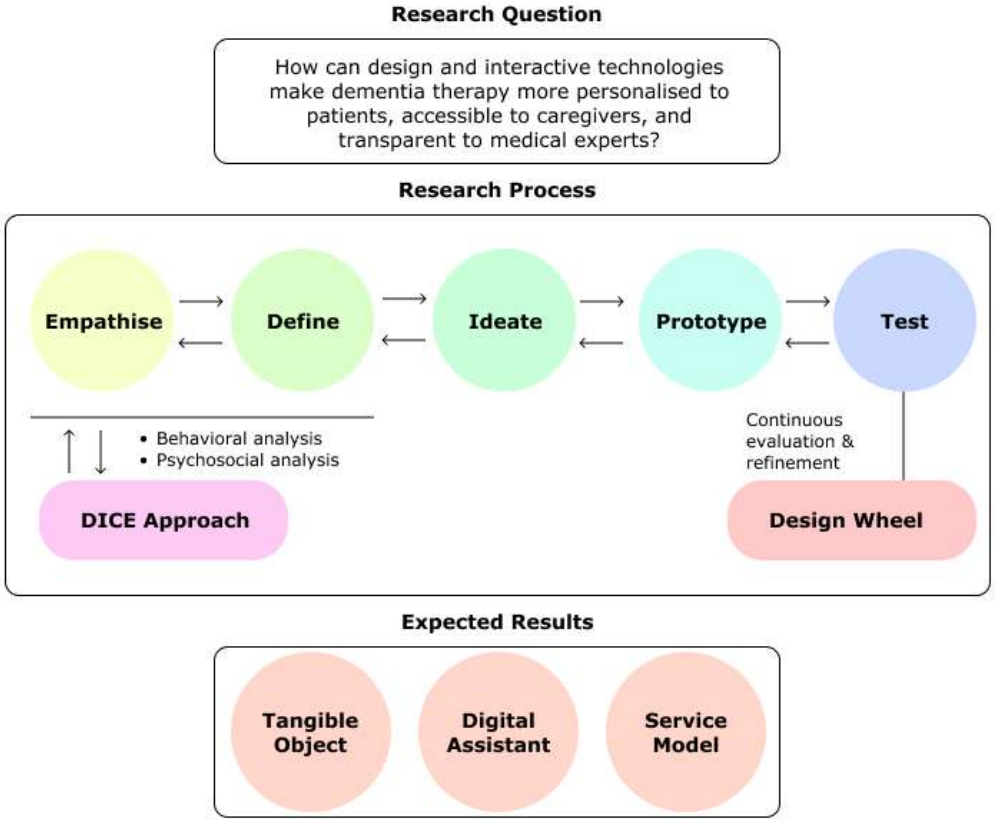

Figure 2.3. Research Scope - Masato Kagiwada

Design Thinking is a methodology that provides a solution-based approach to solving complex problems by understanding human needs, by reframing problems, by creating many ideas, and by adapting a hands-on approach in prototyping and testing. [5] The five-stage Design Thinking model was proposed by the Hasso-Plattner Institute of Design at Stanford and it consists of Empathise, Define, Ideate, Prototype and Test. [6]

To achieve the aim that is to explore the possibility of interactive technologies for dementia non-pharmacological therapy, I have adapted DICE approach (behavioral analysis of people with dementia and family caregiver, and psychosocial analysis of environment and culture) and Design Wheel (continuous evaluation and refinement) into the five-stage Design Thinking model. (Figure 2.3.) The entire process has taken 9 month from September 2020 to May 2021 and details are described as follows.

Empathise (September - October 2020)

- The symptom of dementia
- The current situation of dementia in Estonia
- Non-pharmacological therapy for people with dementia and caregivers
- The research interests, missing points, knowledge gaps
- Problem owners - Patients, caregivers, medical experts
- Stakeholders - Support systems
- (Methods) Literature review, desktop research, questionnaires and interviews

Define (September - November 2020)

- Research question
- Hypothesis of research
- Problems of patients, caregivers, and medical experts
- (Methods) Questionnaires and interviews

Ideate (November 2020 - February 2021)

- Interactive technologies for dementia therapy
- (Methods) Brainstorming and feedback sessions

Prototype (March - April 2021)

- Sketches
- Physical and digital prototyping
- Deep learning algorithm modeling

Test (September 2020 - May 2021)

- The topic and research scope
- The design concept
- The prototype

From this research process, the expected results are the followings:

1. **Tangible Object:** a tangible device for multi-sensory therapeutic interventions
2. **Digital Assistant:** a digital platform for family caregivers and medical experts
3. **Service Model**: a proposal for Estonian Dementia Competence Centre

With this scope, the overview of chapters will be explained in the next section.

2.4. Chapter overview

Chapter 3 gives an overview of dementia symptoms, trajectories, one developmental model, and dementia non-pharmacological therapy.

Chapter 4 gives an overview of contexts in Estonia in the form of description of problem owners and support systems, research landscape, questionnaires and interviews. It concludes with a user persona, a caregiving journey map, and a problem space map.

Chapter 5 gives an overview of interactive technologies that would be suitable to the concept. It includes Tangible User Interface (TUI), Human Language Technology (HLT), and e-Healthcare Information System (e-HIS). It concludes with a solution space map which describes the possible technological interventions to redesign dementia non-pharmacological therapy, and make desirable impacts on problem owners.

Chapter 6 gives the process of concept generation and selection. Design principles supporting the concept are firstly introduced. Four candidates are introduced and discussed with interactions and functionalities, and then evaluated based on the selection criteria. It concludes with the introduction of the final concept "Tunne" which consists of Therapy, Interaction, Detection, and Service module.

Chapter 7 gives the details of Tunne. It starts from overview and user story, and then continues with the folklore-storytelling therapy, digital assistant, storytelling device with tangible and intangible interactions, specifications, the pipeline of speech emotion detection, and the two types of service models. It concludes with the evaluation from domain experts in Estonia.

Chapter 8 gives the discussion of interpretations, implications, limitations, and recommendations on this research.

Chapter 9 gives the conclusion of this research, recommendation for further development, contribution to the academics, and notes for the future.

Chapter 10 summarizes the whole research work.

3. DEMENTIA OVERVIEW

Hereby the characteristics of dementia, the trajectories, issues around it will be firstly introduced to give the overview of the disease. And then one developmental model will be explained to categorize the stage of dementia from an occupational therapist's point of view, and a non-pharmacological therapy to dementia will be described to provide the idea of existing therapies.

3.1. Dementia introduction

Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain the activities of daily living.

Dementia leads to increased costs for governments, communities, families and individuals, and to loss in productivity for economies. In 2015, dementia costs were estimated at EUR 685.8 billion, equivalent to 1.1% of global gross domestic product, ranging from 0.2% for low- and middle-income countries to 1.4% for high income countries. [2]

In this rapidly aging world, the provision of social/medical/technological interventions for better dementia prevention/treatment is becoming one of the biggest challenges for humankinds.

With this background information, the progression of dementia and corresponding issues will be explained as trajectories.

3.2. Dementia trajectories

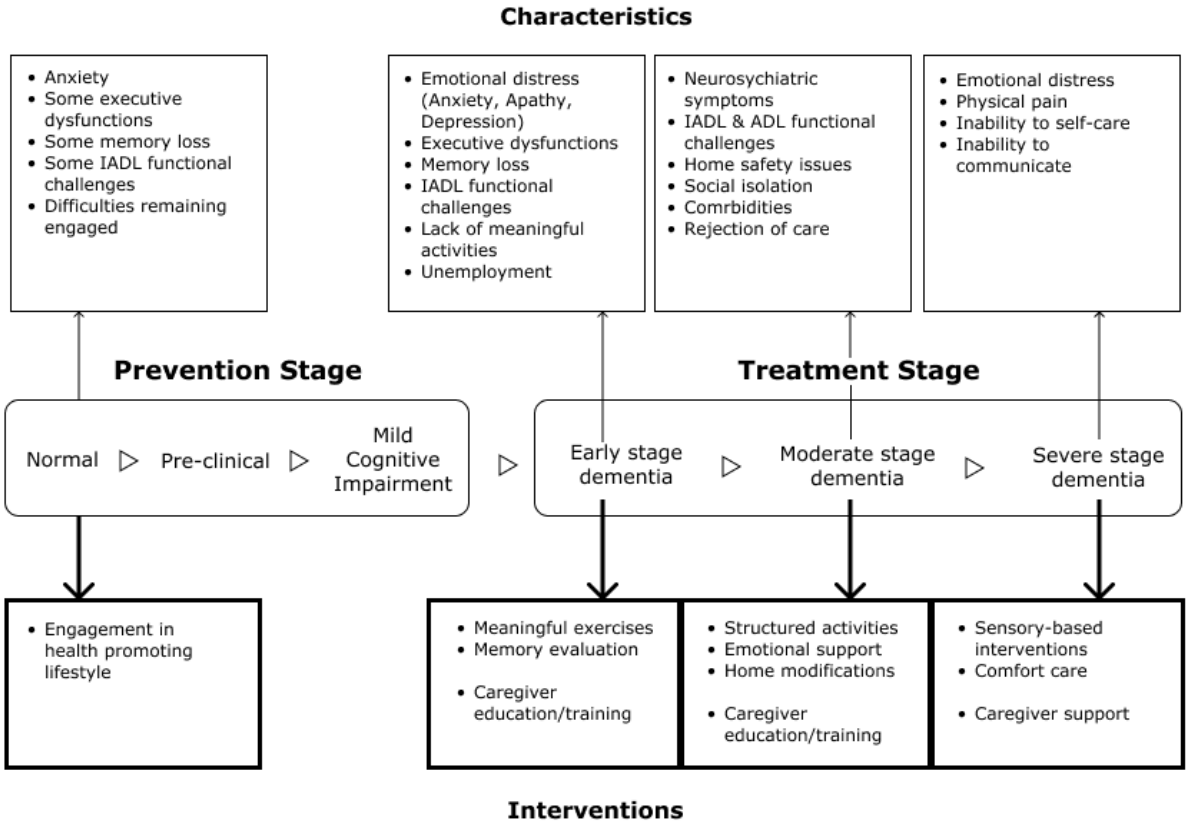

Figure 3.2. Clinical Trajectory For Persons with Dementia, based on Helen et al. - Masato Kagiwada

Dementia is a progressive disease which gets worse chronologically in the following steps [3] (Figure 3.2.):

1. Normal cognitive decline
2. Pre-Clinical
3. Mild Cognitive Impairment
4. Early stage dementia
5. Moderate stage dementia
6. Severe stage dementia

First to third steps are in the prevention stage while fourth to sixth steps are in the management and treatment state.

In the prevention stage, although there are some methods such as biomarkers, it is hard to detect the symptom of cognitive decline. And it is challenging to exclude other treatable conditions that cause memory loss such as depression, urinary infection, vitamin deficiency and brain tumour when making a diagnosis.

Patients have these problems:

- Cognitive issues
    - Some executive dysfunctions - planning, problem-solving, organization, and time management
    - Some memory loss
- Physical issues
    - Some IADL (Instrumental activities of daily living) challenges - housekeeping, using transportation, taking medication, etc.
- Phycological issues
    - Anxiety

In the treatment stage, as the cognitive functionalities of dementia patients are getting worse and worse, there are some serious issues coming up.

Patients have these problems:

- Cognitive issues
    - Memory loss
- Physical issues
    - Disengagement, lack of meaningful activities
- Phycological issues
    - Emotional distress - Anxiety, apathy, depression, rejection

In the meantime, several problems occur to dementia caregivers.

- Physical issues
    - Communication issues with patients
- Phycological issues
    - Stress & Burden
    - Depression

And according to the trajectory map, there are many potential intervention points, for example, Engagement in health promoting lifestyle including physical exercise, diet, social engagement, cognitive stimulation for people in the Mild Cognitive Impairment.

Since it’s essential to set a target phase of dementia in order to frame problems and to ideate solutions, the developmental model to categorize the stage of dementia based on the capability of ‘doing’ will be explained.

3.3. Dementia developmental model

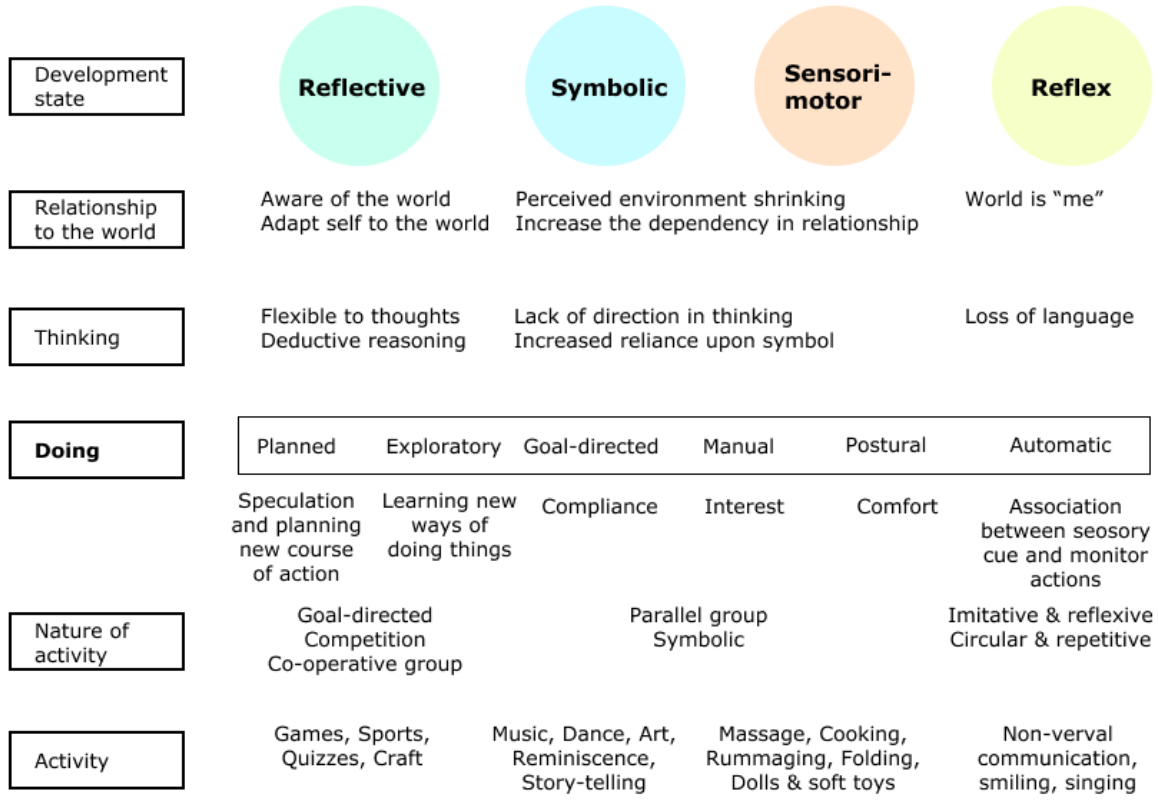

Figure 3.3. A developmental model of practice for dementia care, based on Tessa - Masato Kagiwada

A developmental model of practice for dementia care [7] illustrates the cognitive changes that take place across the course of a dementia, and thereby the changes to an individual's ability to 'do'. (Figure 3.3.) The key to use this model is an understanding of where the person with dementia might be placed within the schema on the basis of clinical experience and an accurate assessment of the person's ability to think and to do.

There are 4 phases in this model:

1. Reflective
2. Symbolic
3. Sensori-monitor
4. Reflex

Phase 1: Reflective

In this phase, the first signs of a dementing condition are starting to intrude into healthy conditions. In general, **any activity categorised by the model at an earlier stage to the one the person is in, has a potential for therapeutic benefit.** There is a large range of possibilities for using music at this stage, from learning an instrument, to forming a small choir, to participating in a music appreciation class, to a karaoke competition.

Phase 2: Symbolic

In this phase, a person is becoming increasingly reliant upon symbols in mental processing, as powers of deductive reasoning diminish. Key features are an increasing egocentricity or a failure to perceive a progressively narrowing environmental field. Given that, practitioners should actively **address and explore the 'fantasy' statement or action, acknowledging its survival function and understanding its creative drive.** Possible activities are artistic one which express themselves in unstructured and free-form ways.

Phase 3: Sensori-monitor

In this phase, as dementia advances, even symbolic activity is gradually lost, and a person is left with only a most primal level of function – the sensorimotor condition. A person in this phase is still able to 'do' – that is, to handle and use objects and tools – but is moving towards a 'doing without understanding'. Motor, rhythmic, repetitive activities such as the group exercise, music and dance, would be appropriate.

Phase 4: Reflex

In this phase, people perceive surroundings as 'the world is me', **changes in facial expression elicit emotion-specific activity in the autonomic nervous system.** Where 'doing' has all but ceased, we can only 'do to'; for example, rocking and stroking, holding and cuddling would be useful.

As the `Doing` model suggested, there are four development phases of dementia regarding the capability and perception of people with dementia. In this research, the main targets are early to middle stage of dementia because most capabilities in communication still remain and thus there is much room to intervene. So targeted phases are **Reflective** and **Symbolic**.

3.4. Dementia non-pharmacological therapy

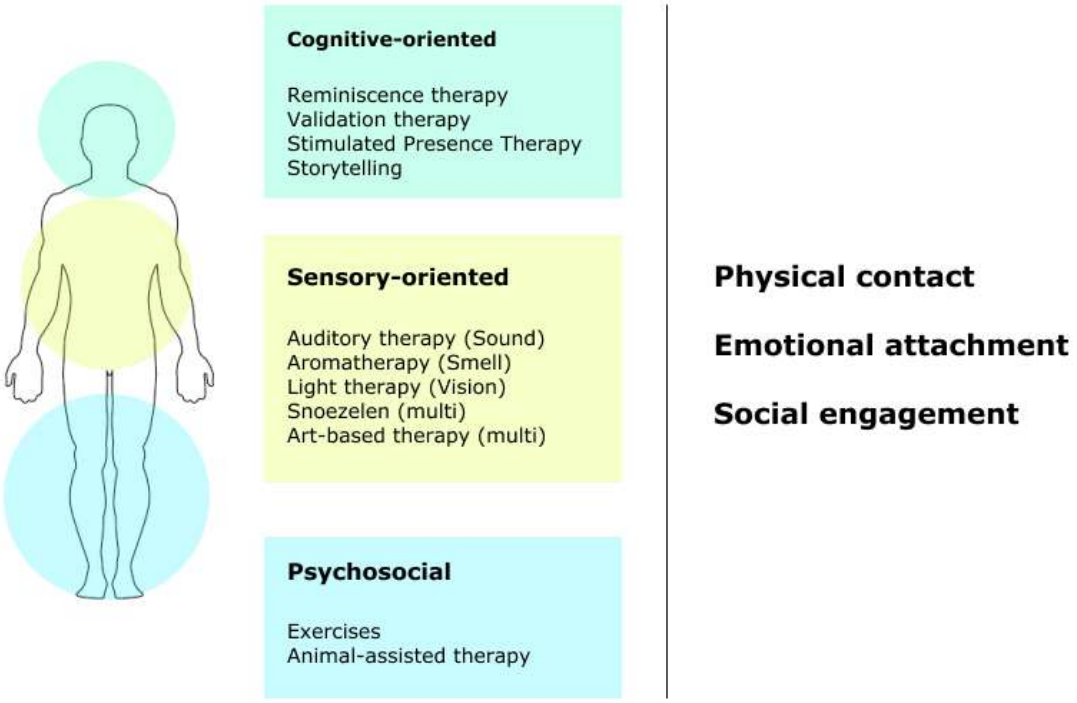

Figure 3.4. Dementia Non-pharmacological Therapy - Masato Kagiwada

Non-pharmacological therapy refers to several approaches involving some action with the patient and/or their physical and social environment. It can be broadly categorized as generalized and or targeted. Either approach may directly involve the **patient** (e.g., exercise) and/or work through another **agent** – typically the caregiver (e.g., use of communication techniques) or physical environment (e.g., relaxing music). [8][9]

It conceptualizes behavioral symptoms as expressions of **unmet needs** (e.g., repetitive vocalizations for auditory stimulation); **inadvertently reinforced behavior in response to environmental triggers** (e.g., screaming for attention); and/or **consequences of a mismatch between the environment and patients' abilities** to process and act upon cues, expectations and demand. It could involve **modifying patient and/or caregiver cognitions, behaviors, environments**, or **precipitating events** contributing to behaviors or instructing in compensatory strategy use to reduce the patient's increased vulnerability to their environment. Several randomized trials have found that engagement in physical activity and pleasant events reduced depression in persons with dementia living at home.

In the following sections, the details of non-pharmacological therapy will be explained by dividing three categories (cognitive- and sensory- oriented, and psychosocial). (Figure 3.4.)

Cognitive-oriented

Major cognitive-oriented therapies are reminiscence therapy, validation therapy, simulated presence therapy, and story-telling. The details are the following.

Reminiscence therapy was introduced to dementia care in the late 1970s, and has taken in a variety of forms. [10] It involves the discussion of **past activities, events and experiences**, usually with **the aid of tangible prompts** (e.g. photographs, household and other familiar items from the past, music and archive sound recordings). Recently, digital media such as videos have become widely used. [11]

Validation therapy is a way of communication with dementia patients. The benefits for patients are restoration of dignity, minimisation of the degree of disconnection from the outside world, promotion of communication and interaction with others, reduction of stress and anxiety, increase of sleeping quality, facilitation of independent living. [12]

Simulated presence therapy is a type treatment that has been used mainly in care homes, involves playing a personalized video or audio recording of family members to the person with dementia when people with dementia become distressed or agitated. [13]

Story-telling is a creative process that encourages people to use their imagination to tell stories about people or objects that are presented to them. Through these means it enables them to express their personalities, experiences and individual characteristics. It differs from reminiscence work, where the focus of the discussions are around a person's life history (both past and present), rather than any imagined scenarios. **TimeSlips** is a group storytelling initiative that was developed in the 1990s and is now used across the world. The aim is to bring out a performance of the self in the present, rather than talkings about their past lives. **Storytelling and Erikson's Developmental Phases** is a group storytelling initiative where people with dementia gather in a circle around a facilitator who follows a pre-planned structure to the activity. [14]

Sensory-oriented

Major sensory-oriented therapies are auditory therapy, aromatherapy, sensory room, and art therapies. The details are the following.

Auditory Therapy is the use of auditory stimulation as a treatment for dementia. Rhythmic Auditory Stimulation is particularly useful for gait training in patients with neurological problems. It uses auditory stimuli such as tones, sounds or music at fixed rhythms, so that patients can coordinate their movements with the sounds. [15] Music therapy is a target-oriented and purposeful activity in which therapists work with individuals or groups, using musical expression and the memories, feelings, and sensations it evokes. It has been found to be particularly beneficial for people with dementia. [16]

Aromatherapy is the use of aromatic plants or essential oils to promote wellbeing through scent. Like any complementary therapy, it is not a replacement for medical treatment and should only be used if it appears to bring some pleasure or calm to the person being treated. Some studies have been conducted into aromatherapy and dementia. They have shown some encouraging results but more research needs to be done. The main findings were into the effects of lavender oil, dripped onto a pillow or applied through massage in the form of a cream, and Lemon Melissa balm, rubbed into the skin. Both oils were found to increase the length of sleeping time, and decrease signs of agitation. [17]

The **Sensory Room**, also called **Snoezelen** or **Multi Sensory Environment** (MSE), is a space for enjoying a variety of sensory experiences and where gentle stimulation of the senses (sight, sound, touch, taste, smell and movement) can be provided in a controlled way. Stimulation can be increased or decreased to match the interests and therapeutic needs of the user. The concept originated in The Netherlands in the early 1980s. Initially, it was used for leisure activities for adults with learning disabilities. Nowadays it is also successfully applied in relation to other user groups including people with cognitive and physical impairments such as autism, acquired head injuries, stroke, and those with limitations of movement, vision and/or hearing. It offers the opportunity for an activity that is free from cognitive demands in a space that can be used by care workers as well as family members and informal carers. The conventional MSE, as provided by industry suppliers, contains a variety of equipment to stimulate the senses such as: bubble columns, solar projector casting themed images, coloured optic fibres

(for stimulating sight), CD player/sound system (sound), optic fibres to stroke and plait (touch), aroma distributor (smell), waterbeds and vibrating chairs (movement), equipment featuring switches (interaction). [18]

Art therapies are generally considered as interventions managing manifestations of dementia, as they may help to slow cognitive deterioration, address symptoms related to psychosocially challenging behaviours and improve quality of life. It's defined as a form of psychotherapy that uses art media as a main medium of communication. Therapists need not have experience or skill in art. They are not primarily concerned with making an aesthetic or diagnostic assessment of the client's image. The overall aim is to enable a therapist to change and grow on a personal skill through art materials in a safe environment. [19]

Psychosocial

Major psychosocial therapies are exercise and animal-assisted therapy. The details are the following.

Exercise assists in gradually slowing down the progression of dementia. It is based on the fact that regular exercise has direct effects on the brain, neuromuscular and cardiovascular functioning, and immune system. [20]

Animal-assisted therapy refers to the use of an animal that is considered suitable to work with human care recipients in the treatment of human physical or psychological disorders, coordinated by a human professional with in-depth knowledge of the animal(s) involved and who has been formally certified. It is designed to promote improvements in human physical, social, emotional, or cognitive functions, and can be provided in individualised or group settings, with documentation and evaluation of the process and outcomes. [21]

Interpretation

Based on the existing non-pharmacological therapies for dementia, it utilizes three aspects:

1. Physical contact
2. Emotional attachment
3. Social engagement

Sensory-oriented therapy is aiming at providing a positive impact on patients by leveraging physical contacts to enhance emotional attachment, for instance, the multi-sensory room modifies the indoor environment by setting different objects (lights, furniture, plants, etc.).

Cognitive-oriented therapy mostly focuses on emotional attachment, for instance, reminiscence therapy invokes a patient's favorite memories with some objects which trigger the pleasant feeling.

Psychosocial therapy is making use of physical contact and social engagement to make a positive emotional effect on patients, for instance, animal-assisted therapy brings pet animals to enhance the non-verbal communication between animals and patients.

With opening up the target phase of dementia and non-pharmacological therapies for dementia, it will proceed with the broad context in the target place - Estonia.

4. DEMENTIA IN ESTONIA

Hereby the context of dementia in Estonia will be explained. It will start from defining problem owners and support systems around them. And then the research landscape in Estonia will be explained with the previous works and special institutes working on dementia. It will proceed with online questionnaires to determine the general problem space and interviews to gain professional insights from different stakeholders. As a conclusion, user personas, a caregiving journey map, and a problem space map will be introduced and visualised.

4.1. Problem owners and support system

Problem owners are **people with dementia, family caregivers**, and **medical experts** (general practitioner and occupational therapist). They will get the most significant effect from dementia emotionally, physically, and economically.

There are also some support systems which help problem owners from their own direction and approach. It consists of 3 groups:

1. Person-focused
2. Environment-focused
3. Strategy-focused

Person-focused support system focuses on collaborating with problem owners so that it can support them on a daily basis. And main actors are:

- Physicians and nurses
- Social group and organization
- Local government and social care center
- Social workers

They have a significant role in helping problem owners to deal with physical, emotional, and social issues around dementia caregiving. All residents in Estonia could access their services via digital platform and communicate through social media.

Environment-focused support system focuses on modifying and improving environmental factors so that it can enhance the well-being of problem owners. And main actors are:

- Home
- Hospital
- Care service provider
- Elderly care home

Occupational therapists have a critical role in assessing, modifying, and assisting the betterment of the support system.

Strategy-focused support system focuses on orchestrating and rendering national-level strategy and programs in collaboration with the support systems to achieve the effective and patient-centred system. And main actors are:

- National government
- Research Institute
- University and educational organizations

In Estonia, the Ministry of Social Affairs (Sotsiaalministeerium) is in charge of dementia care strategy and the Estonian Dementia Competence Centre, the initiative created by a NGO, hospitals, and a university, is under development by consolidating the wisdom and knowledge of experts inside and outside Estonia.

After defining problem owners and support systems, the research landscape in Estonia will be described in the next section to open up the context of the research.

4.2. Research landscape

I looked up for published papers in Estonia regarding the effect of non-pharmacological therapy for people with dementia and caregiving experience. And then the Estonian Dementia Competence Centre will be explained to highlight the client of the research work.

According to the curated list on the website of MTÜ Elu Dementsusega, there are 3 published papers regarding non-pharmacological therapy (reality-oriented, reminiscence, validation) out of around 35 ones as of 1st April 2021. All of them conclude with the positive impacts on cognitive development and stimulation. Besides that, one study focused on the experience and needs of informal caregivers and their expectations for support. [22] The study was conducted with a narrative approach to achieve that and it pointed out that Estonia needs to implement efforts to improve the training and education of medical experts and people with dementia should be involved in the service provision process.

Dementia Competence Centre (DCC) is envisioned to ensure dignified life in Estonia for people with dementia and their relatives. In 2018, the Ministry of Social Affairs entered into an agreement and the project of DCC will be concluded by the end of 2021. It is created by a cooperation of MTÜ Elu Dementsusega, SA Viljandi Hospital, SA EELK Tallinna Deaconess Hospital and Tartu Health Care College. MTÜ Elu Dementsusega is currently providing counseling services and workshops alongside support groups across the country. Since they are an expert of domain experience and knowledge, the collaboration with them is essential to conduct research and provide meaningful outcomes.

With this background information, the field study in Estonia which is aimed at understanding and emphasizing the problem owners and stakeholders will be described in the next section.

4.3. Online questionnaire and interviews

The field study started from an online questionnaire for several stakeholders in Estonia. It is conducted with a collaboration with MTÜ Elu Dementsusega to access as many audiences as possible. It is a combination of closed and open-ended questions not only to understand the general information such as whom caregivers care and how long they care but also to get to know in-depth information such as major difficulties to take care of people with dementia.

There were 9 responses from 7 caregivers, 1 dementia support group, and 1 occupational therapist and the key findings are the followings:

- Support system for caregivers is limited and it brings emotional/financial burden
- There is no patient-centred and tailored support from specialists
- There is low accessibility for dementia therapy
- There are limited technological interventions for caregivers

After that, interviews with 3 experts and 1 caregiver were conducted with the following aims:

1. Gain feedback about the validity of research topic, direction, and possible contributions.
2. Gain in-depth insights about the problem space of caregivers and people with dementia.
3. Gain impressions about potential user's (people with dementia, caregivers, and occupational therapists) reactions to the possible interventions with interactive technologies.

Business owner from a smart sensor provider, Estonia

The interview with one elderly care startup which provides a Home Sensor Information System for caregivers, family members, and care service providers to monitor the motion of elderly people and environmental indicators (temperature, CO2, etc.) through their computers and to get notified of happenings through their mobile phones. The focus of the interview was the interaction between elderly people and the home

environment, the main user's experience journey on the system, and main challenges of users.

In their home environment, people with cognitive impairment would face several risk factors such as falling down by random objects and physical barriers and have difficulty maintaining their comfortness due to the lack of access to modify the environment accordingly. At the same time, caregivers would face several challenges to maintain the safety and security, for example, people with cognitive impairment accidentally switch on the gas and A/C, and leave their home environment unconsciously.

In fact, elderly people are willing to stay in their home environment as long as possible because they have strong emotional connections and established comfortness. Therefore it's very important to keep the safety and security of the home environment while ensuring the independence and privacy of elderly people.

Merle Varik, RN, BScN, MSW - Dementia researcher, Estonia

Ms. Varik is the lecturer at Tartu Healthcare College and one of the most significant figures in dementia research in Estonia. She is also part of developing the Dementia Competence Centre and nationwide dementia strategy. An open-ended interview was conducted by the following steps:

1. Introduction and explanation of the research topic.
2. In-depth questions regarding stakeholders, caregiving environments, dementia support system, dementia therapy, and technological interventions.
3. Conclusion and follow-ups.

Firstly, main issues in dementia care are discussed. There is low accessibility to dementia support systems from family caregivers. Also, patient-centred dementia care is not achieved due to the lack of knowledge in experts and the lack of public awareness.

Secondly, technological interventions are highly needed for non-pharmacological therapy because this domain is not fully explored yet. The combination of interactive technologies and dementia therapy would be also beneficial to the education and training for medical experts and medical/nursing students.

Thirdly, having effective teamwork is a key to tackling dementia. When family members think their relatives need help, they firstly contact a social centre from a local

government to ask for consultation and financial support. And their general physician and family nurses work together to make a treatment plan and then start a treatment. Given the complexity of dementia, it's essential to have the effective teamwork to accomplish patient-centeredness and caregiver-empowerments. However, the Estonian dementia support system has been under development and there is still room to involve local government and social workers because informal caregivers firstly try to access them when they realize the issue of dementia.

As a conclusion, the support system for informal caregivers and people with dementia is not very coordinated and there is a gap between the current situation and the ideal goal. And more technological interventions for dementia treatment should be investigated more in a collaboration with stakeholders.

Hanna-Stiina Heinmets - Occupational therapist, Estonia

Ms. Heiments is a professional occupational therapist at EELK Tallinna Diakooniahaigla and she is also one of the main members of Dementia Competence Center. The research scope and research question were introduced and explained. And then the interview with open-end questions was conducted.

Firstly, the environmental factors should be taken in the use of technology. Ensuring the safety of people with dementia while stimulating their cognitive and emotional well-being is very important for them to gain the benefit from occupational therapy.

Secondly, the assessment of dementia should consider factors of patient, family caregivers, and environment. The challenge to assess the situation of people with dementia is finding a right way to take care of different levels of dementia and time factors such as mood swings. Occupational therapists also assess the issues of family caregivers such as low level of knowledge on dementia and communication, and depression from emotional stress/burden. They emphasize the importance of environmental assessment such as the patient's home environment. For example, many residences of elderly people in Estonia have risk factors (kitchen, heating, toilets, bathroom, etc.) inherited from the USSR era. And although the role of the local government is very important to improve their home environment, sometimes the lack of knowledge of modification prevents the improvements.

Thirdly, the use of non-pharmacological therapy in occupational therapy was discussed. Mainly they prefer to use reminiscence therapy and object-assisted therapy.

Reminiscence therapy is a good way of stimulating a patient's previous memories in a natural way that uses familiar objects such as a theme box (farming, festival, etc) which includes related pictures and goods, and furniture they used long ago. It’s useful because it can be applied for different levels of patients. Object-assisted therapy such as animals, children, and dolls is also beneficial because it also reminds them of favorite moments. Encouragement to participate in these therapies is significant, and to achieve that, occupational therapists would find touching points of patients and choose suitable activities. Since group dynamics is one important factor, they often formulate group therapy so as to enhance a patient's social engagements.

And then the way of measurement was discussed. They conduct observations to assess the level of anxiety, sleepiness, and other behavioural obstacles, and get feedback from family members and care service workers to find issues around them such as security factors.

As a conclusion, the future objectives of dementia care support system in Estonia was discussed. The needs of more interdisciplinary experts such as lawyers, neurologists, and other innovative fields will be one of the most important points of interest.

Family caregiver, Estonia

The interviewee was a family caregiver of people with dementia for more than 10 years. The online open-ended interview was conducted with her.

The personal experiences, challenges, and aspirations were focused in the interview. She had no clue in dealing with the unpredictable progression of dementia and in cooperating with medical professionals and healthcare systems. The progression of dementia was much accelerated after the hospitalization which decreased stimulations and social interactions with others. Also, she was supposed to leave her job due to the lack of knowledge and fragmented support system. Finally, she wished there was a treatment for the disease and reminded the importance of comfortability of human sensations such as an object made of comfortable materials.

As a conclusion, the comprehensive caregiving journey from the very early stage of dementia should be provided but there is no such a system for now.

Based on these 4 interviews, the main takeaways are the followings:

- Creating **homey environment** is essential to create a solid emotional bond for elderly people
- **Sufficient cooperation** between family caregivers and support system from the early stage of dementia is critical for providing proper treatment with people with dementia
- **Technological intervention** for dementia care is highly needed but there are few cases across the globe.

With the outcome of questionnaires and interviews, the persona, caregiving journey map and problem space map will be created to clarify the target and visualize the existing process and problems of caregiving for people with dementia.

4.4. Problem space

After synthesizing the result of field research, I used design tools - user persona, journey mapping, and problem space mapping - to understand and define the design targets, to visualise the sequence of the caregiving journey, and to highlight the problems and gaps of problem owners and support systems in Estonia.

User Persona

After that, 4 personas, Family Caregiver (Figure 4.4.1.), Person with Dementia (Figure 4.4.2.), Occupational Therapist (Figure 4.4.3.), and General Practitioner (Figure 4.4.4.), were created to understand and determine design target, and visualise their problem statement, goals, motivations, habits, and pait points. It helped me to keep eyes on design targets in the later stages of the design process.

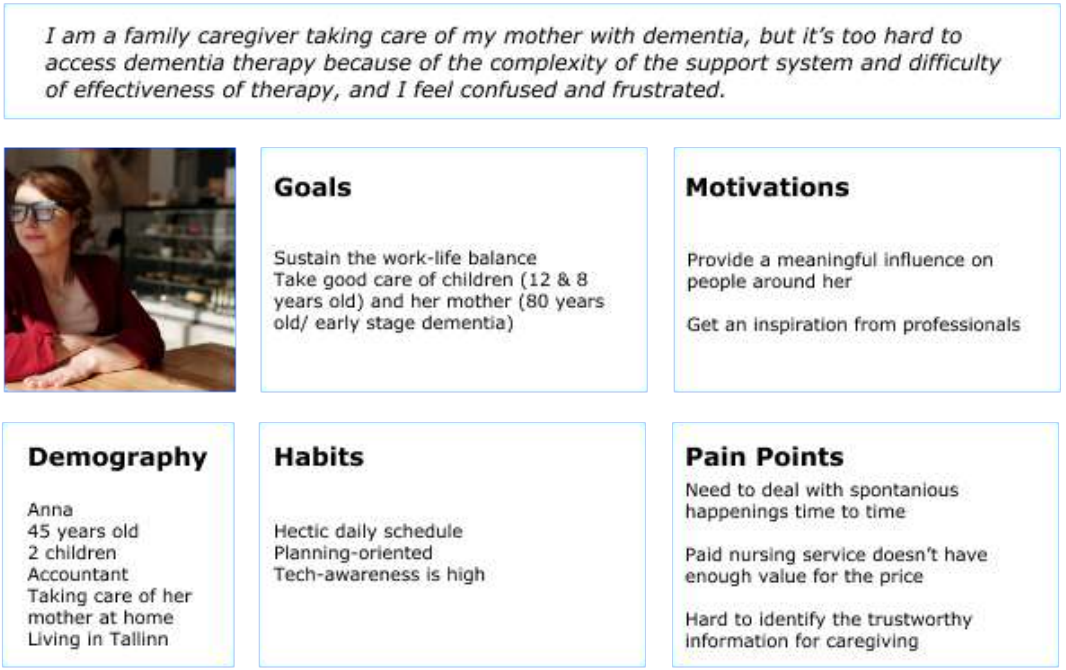

Figure 4.4.1. User persona (family caregiver) - Masato Kagiwada

"I am a dementia patient trying to have a fruitful life, but I have some emotional distresses because of some obstacles related to dementia and I feel depressed."

Goals

Having a peaceful life with people she loves

Motivations

Touch nature and get comforts

Have a conversation with children and grand-children

Demography

Mia
80 years old
4 children
Former Nurse

Habits

Like to decorate her house
Like to do gardening
Get assists from her daughter and GP

Pain Points

Forget daily tasks more often

Have some sleeping issues

Talk and behave inappropriately

Figure 4.4.2. User persona (person with dementia) - Masato Kagiwada

"I am an occupational therapist taking care of dementia patients, but I often misunderstand the progression of symptoms due to the difficulties of detecting dementia and I feel exhausted"

Goals

Keeping on track of latest techniques of occupational therapy

Keeping an eye on the innovations in e-medical field

Motivations

Practicing occupational therapy for enhancing patient's well-being

Demography

Peeter
35 years old
1 child
Occupational Therapist

Habits

Mostly working

Taking care of diets and exercises

Active in online presence

Pain Points

Hard to find a good example of technological interventions

There is still room to make the collaboration among stakeholders

Figure 4.4.3. User persona (occupational therapist) - Masato Kagiwada

Figure 4.4.4. User persona (general practitioner) - Masato Kagiwada

These personas will be included in the caregiving journey map (Appendix 1, 2), problem space map (Figure 4.4.5.), and service blueprint (Appendix 3).

In the following section, the sequence of caregiving journeys of these personas and surrounding stakeholders will be visualized and described.

Caregiving journey map

After that, a caregiving journey map was created to visualise the whole journey from acknowledging the early symptoms of dementia to a palliative care with main stakeholders including:

- People with dementia
- Family caregiver
- General practitioners
- Occupational therapists
- Social worker and social care centre
- Care service provider
- Social welfare department

It shows how each stakeholder acts to provide their profession and ability to contribute to the better well-being of people with dementia. From here, main takeaways are the followings:

- Linear caregiving process of caregivers
- Low interconnectivity between caregivers and support systems
- Limited commitment from pubic sector

Family caregivers have many difficulties to provide proper care - misunderstanding and miscommunication with the patient, and limited knowledge and information about the disease and the support system including medical experts, support groups, and local/national government. Their caregiving process is highly linear and not very interconnected to the patient and the support system. And the public sector provides limited commitment to support the family caregivers and other support systems. The map is shown in Appendix 1.

With the exploration of a caregiving journey and defining the flaws there, the problem space will be explained and analysed in the following section.

Problem Space Map

The problem space map was made to visualise the stakeholders, their main issues, causes and consequences, and interconnections between them. (Figure 4.5.5.)

Since the main target is family caregivers, this map also highlighted some gaps between them and people with dementia, support systems (mainly person-focused and environment-focused one), and dementia non-pharmacological therapy (and occupational therapists).

Main gaps are the followings:

- Family Caregivers - People With Dementia:
    - Mismatched Communication
    - Unbalanced Relationship
    - Inefficient Coping
- Family Caregivers - Person-focused Support System:
    - Exhausting and time-consuming Collaboration

    - Emotional Barriers
    - Financial Obstacles
- Family Caregivers - Occupational Therapist:
    - Inefficient Collaboration
- Environment - Environment-focused Support System:
    - Lack of Comprehensive Assessment
    - Difficulty of Appropriate Determination

Family caregivers are forced to have mismatched communication and an unbalanced relationship with people with dementia due to the inefficient coping with the main reasons behind these issues. It's also related to exhausting and time-consuming collaboration with medical experts and social groups which results from emotional barriers and financial obstacles. Although occupational therapists are the key collaborator to deal with the disease, there is also an inefficient collaboration with caregivers that comes from insufficient competency and low awareness. Furthermore, care homes and hospitals have a difficulty assessing the caregiving environment for different stages of people with dementia, and occupational therapists have more challenges due to the variety of assessing environments.

This map would give the research a comprehensive problem space overview in a way that helps me to understand the relationship and connection among problem owners and support systems, problems of each stakeholder, reasons and consequences.

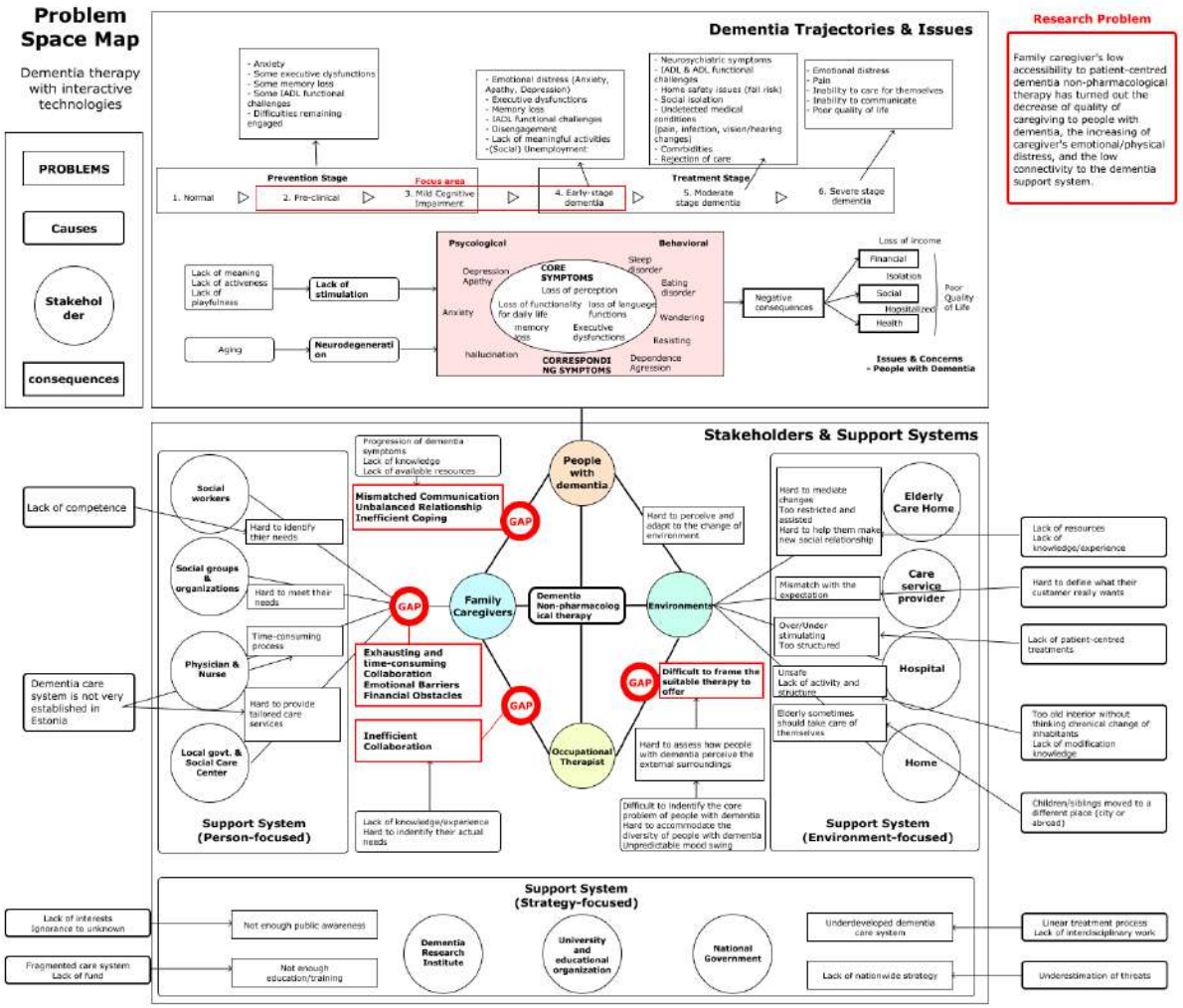

Figure 4.4.5. Problem space map - Masato Kagiwada

With the framed problem space in Estonia, the available technologies for dementia therapy will be introduced and the solution space map will be explained as a conclusion.

5. TECHNOLOGY FOR DEMENTIA THERAPY

Hereby possible technologies for dementia non-pharmacological therapy - Tangible User Interface, Human Language Technology, and Estonian e-Health information system - will be introduced. Each section consists of the definition of technology, related works, opportunities and possible contributions. And then some case studies in this field will be introduced. After all, the solution space for this research will be introduced as a conclusion of this chapter.

5.1. Tangible User Interface (TUI)

Definition

All physical objects can potentially be a part of a digital user interface. For example if an object, which is a part of a TUI, is moved or put in a specific position, a digital signal will be sent from either the tangible object itself or from another device which senses the object. TUI can use physical objects that fit seamlessly into a user's physical environment, often not visible to a normal viewer's eye. The aim is **to take advantage of the haptic interaction skills with the environment**, and the key idea is **to give digital information a physical form**, and letting these physical forms serve as **a representation and a control for the digital information.** This will make it possible to manipulate the digital information with our hands and percept it with our senses. [23]

Application

Although the research about the use of TUI for dementia non-pharmacological therapy is still limited, some studies have focused on reminiscence therapy with interactive furniture, [24] [25] music therapy with interactive music systems, [26] [27] and relevant therapy with a TV system.[28]

There is some academic research about technological interventions to dementia. For example, Eindhoven University of Technology has an initiative called **Dementia and Technology center of expertise** which aims to "design, develop, evaluate and research non-pharmaceutical technological interventions for people living with dementia, and their extended care network such as family members and caregivers." One notable example is "Geurenpalet" which is a tool that enhances memories through scent, especially developed for people with dementia, to stimulate self-esteem, social interaction and remembrance. (Figure 5.1.1.) [29]

Figure 5.1.1. Geurenpalet in box - Jolijn van Sleeuwen

There is one worth-mentioning example which is about to be launched into the market. It's called **Music Memory Box** which is a kit that users fill with objects, photographs and music. (Figure 5.1.2.) [30]

Figure 5.1.2. Music Memory Box® by Studio Meineck

Opportunities

There is still room to open up more opportunities to use TUI for dementia NPT, for example, interactive voice recorder for simulated presence therapy or interactive lights for light therapy. In this sense, developing new TUI for unexplored therapies or refining existing TUI could be a contribution to this domain.

5.2. Human Language Technology (HLT)

Definition

Human language technology (HLT) is a branch of information science regarding written and spoken natural language information. [31] It includes the following key areas:

- Computer speech recognition and understanding
- Natural language understanding and generation
- Text-based information retrieval
- Web-based dialog agents

The example of HLT implementation includes machine translation from one language to another, question answering, voice controlling, and so on.

Application

HLT could be applied for dementia care mainly in two parts:

- Dementia symptom detection
- Neuropsychological score regression with Mini-Mental State Exam (MMSE)

Using HLT for detecting the symptom of dementia for precise diagnosis is getting popular these days. One study utilised NLP (Natural language processing) techniques to classify and analyse the linguistic patterns of Alzheimer's dementia patients using DementiaBank dataset. [32] With the evolution of NLP techniques, the performance of detection is improved. One study showed the improvements with Bidirectional Encoder Representation from Transformer (BERT) text classification models. The combination of HLT and MMSE, a 30-point test to measure capability, is one of the hottest topics recently. One study compared linear and ridge regression models to measure the performance of MMSE prediction. [33]

Opportunities

Although the analysis of linguistic patterns to detect and predict the symptom and status of dementia is getting sophisticated by HLT experts, the use of speech emotion recognition (SER) is not fully opened up in dementia care. SER predicts the emotional state of a speaker based on their speech and brings an additional element for creating more natural human-computer interactions. [34]

5.3. e-Health Information System (e-HIS) in Estonia

Definition

The e-Health Information System (e-HIS) contains health data that hospitals, family doctors and other providers of health services enter there. The health data is digitised and secured by the Keyless Signature Infrastructure (KSI) blockchain in the nationwide digital platform. Three e-Health services are provided in Estonia - e-Health records, e-Prescription, and e-Ambulance - towards better patient's experience and industry efficiency. [35]

Application

In Estonia, there are mainly two applications of e-HIS:

- Personal health data acquisition (patients)
- Clinical decision making (medical experts)

In 2017, Estonia renewed its National Patient Portal [36] which provides e-services and information to all registered in the Estonian Population Register. The personal health data is collected in the system and every resident has an opportunity to see the data from the patient portal. As of 2017, it contains more than 15 million medical documents forwarded by more than 800 medical institutions. The privacy and security of personal data is achieved by using the X-road®, an open-source software and ecosystem solution that provides unified and secure data exchange between organizations. All document integrity is ensured by Keyless Signature Infrastructure (KSI) blockchain technology. In 2020, Estonian family doctors and nurses started using a clinical decision support system which collects and analyzes health data such as diagnosis, medications, and lifestyle indicators. It is developed to achieve more personalised medical care and genetic information-based recommendation with ensuring the alliance with legal regulations. [37]

Opportunities

Health data regarding dementia diagnosis, medications, therapies, and other biometrics could be collected from several touchpoints (medical devices, computers, etc.) so that caregivers could know the condition more clearly with the advice from medical experts and the clinical decisions will be more data-driven and patient-oriented. And secured data sharing and exchange would enhance the communication and collaboration among different stakeholders including social workers and national/local government so that the transparency for society and the friendliness of the community would be achieved.

5.4. Solution space

Hereby it's beneficial to look back the hypothesis as follows:

Giving dementia non-pharmacological therapy more stimulations, playfulness and meaning by design and interactive technology would be beneficial to make it more patient-centred and empower informal caregivers.

Given this, it is necessary to open up how interactive technology would transform the existing therapies into the one manifesting the hypothesis.

In order to highlight the possible interventions, the solution space map (Figure 5.4.) was made and it illustrates the relations around the prospective concept with main users and stakeholders, examples of the implementation of interactive technology into non-pharmacological therapy, and design principles.

Main impacts given by the concept would be the followings:

- **Sensorial Therapeutic Experience** for people with dementia
- **Playful Caregiving** for Caregivers
- **Transparent Careving** for Medical Experts

Since the target stage of dementia is the Reflective and Symbolic phase, invoking stimulation on multiple sensations with not over-simplified interactions would be beneficial to provide sensorial therapeutic experience. Also, the concept would allow caregivers to provide playful caregiving which makes joyful moments among users and thus enhance emotional happiness. And then it would allow medical experts to provide transparent caregiving with stakeholders by utilizing the interactive technology.

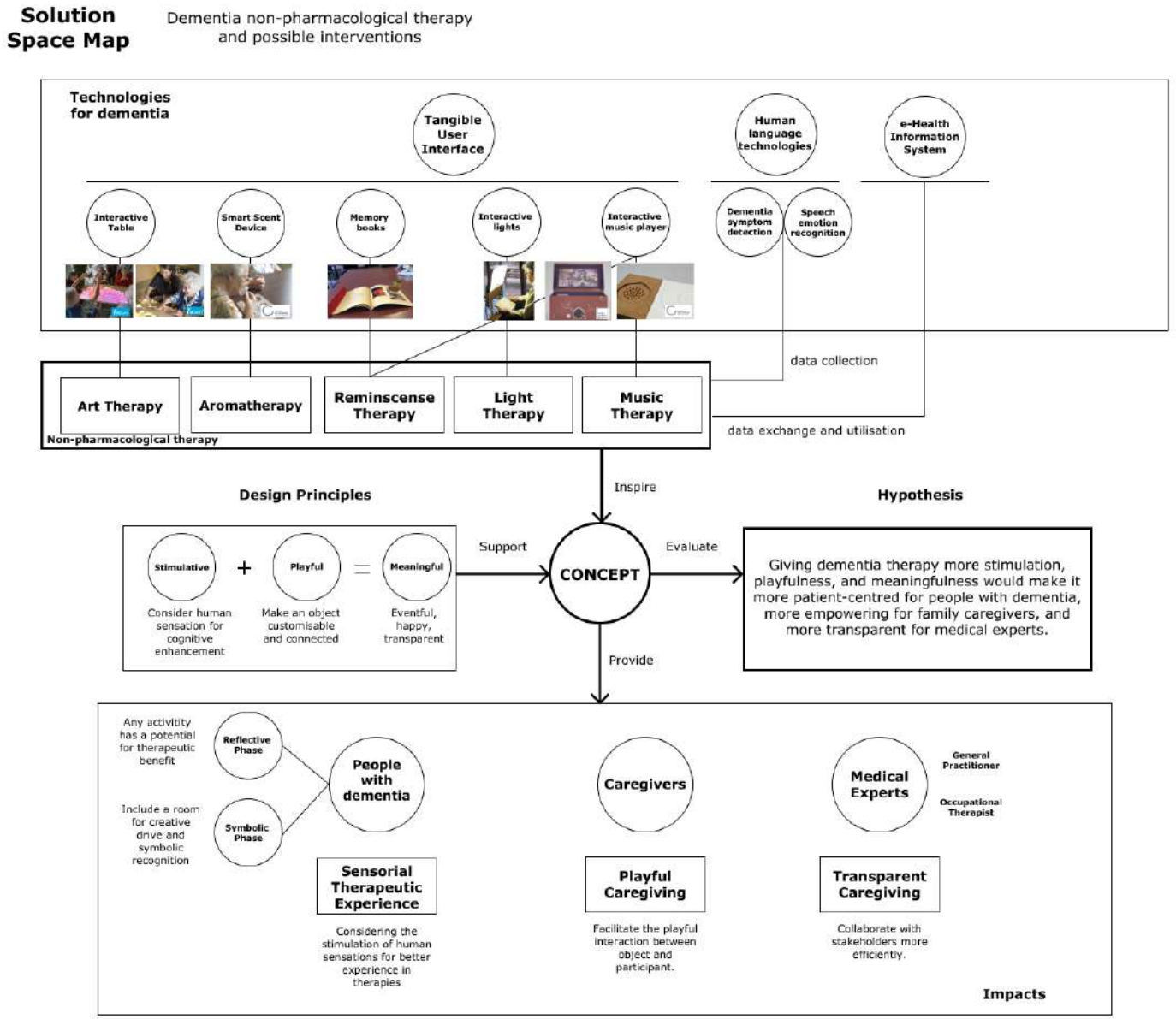

Figure 5.4. Solution space map - Masato Kagiwada

With this explored solution space, the concept will be described with the explanation of the process of development in the next chapter.

6. CONCEPT GENERATION AND SELECTION

In this chapter, the overview of the concept, design principles, concept generation and selection process will be firstly described. And then the final concept "Tunne" will be introduced with a brief overview of modules.

6.1. Concept principles

The principle behind the concept is enhancing stimulation and playfulness of NPT so that it has more meaningfulness for family caregivers and people with dementia. So I determined 3 main factors to formulate the concept:

1. Stimulative
2. Playful
3. Meaningful

Since humans get stimulation through their 5 senses and movements around them, making an interaction stimulative would be helpful to enhance cognitive capability. For example, aromatherapy uses favorite scents to stimulate people's sense of olfactory (ability to smell) naturally.

Since playfulness makes daily life more joyful and eventful, making an object customisable and connected to the patient would be beneficial to achieve playfulness. For example, one design group developed a music memory box in which people with dementia can customise sound and pictures as they wish.

Therefore the combination of stimulation and playfulness would make a meaning for people with dementia (more eventful life), family caregivers (seeing loving person's happiness), and medical experts (more transparency to people with dementia).

With this design principle, the concept candidate will be generated and explained in the following section.

6.2. Concept generation

In this section, four different concepts were generated based on the overall aim of the concept and the design principle.

1. Relaxation Toolkit for multisensory therapy
2. Activation Toolkit for physiotherapy
3. Artist Toolkit for art therapy
4. Interactive plant for multi-sensory therapy

From the next subsection, the overview of the concept, main elements, a description of interaction, initial sketches, and functionality lists will be explained step by step.

Concept No.1 - Relaxation Toolkit for multisensory therapy

The first concept is called **"Relaxation Toolkit"** which allows family caregivers to set up relaxational environment in their home so that they can incorporate therapeutic interventions enhancing people with moderate dementia to heal their emotional distress and improve their behavioral and psychological symptoms.

Main elements are the following and they are packed in the toolkit box.

- Artificial plant pot
- An interactive aroma diffuser with scent capsules
- Interactive projection lamp (Normal/Long bar/Sea Star shape)

The artificial plant pot could be made of their familiar plants such as pine trees and moss so that they can sense nature, touch and craft it, and feel relaxed. And the aroma diffuser could distribute familiar scents around the room so that they can feel comfortable. Additionally, the interactive projection lamp could not only change the atmosphere of the environment but also immerse them into totally different places such as forest and bog. This initial sketch illustrates the aesthetics and sensations to stimulate. The general scheme is described as a sketch. (Figure 6.2.1.)

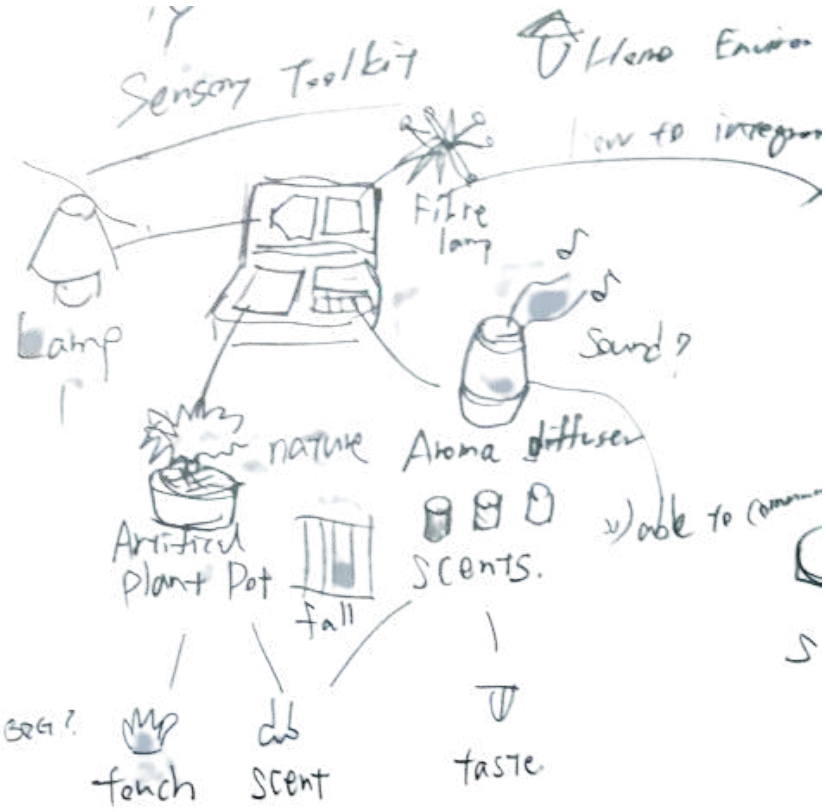

Figure 6.2.1. Relaxation Toolkit - Masato Kagiwada

Concept No.2 - Activation Toolkit for physiotherapy

The second concept is called **"Activation Toolkit"** which allows family caregivers to set up an exercising environment in their home so that they can incorporate physical activities enhancing people with moderate dementia to get physical stimulus with Virtual Reality based exercise games or TV-based ones.

Main elements are the following and they are packed in the toolkit box.

- Smart glass for Virtual Outdoor Activities
- Game console for Virtual Outdoor Activities

Firstly family caregivers (and occupational therapists) set up the exercise game environment - using smart glass and computer or using TV and the game console. After that, PWD can select the favorite scene from the list with the help from caregivers and they can start a physical activity such as walking in the forest and throwing frisbee without going outside. Other players near them could join and make a party. It would be a new way of social engagement which is good for emotional distress. This initial sketch illustrates the aesthetics and sensations to stimulate. The general scheme is described as a sketch. (Figure 6.2.2.)

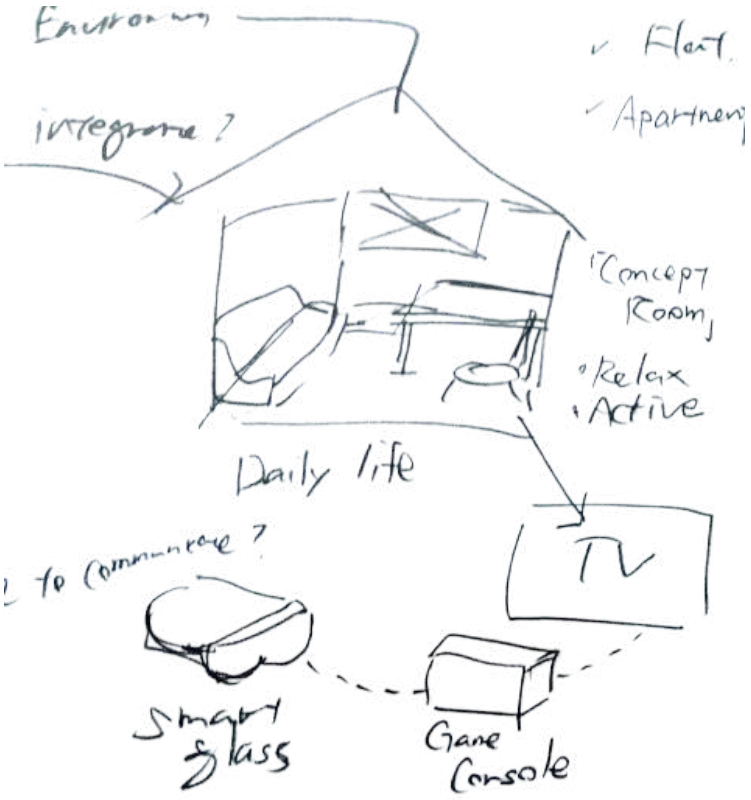

Figure 6.2.2. Activation Toolkit - Masato Kagiwada

Concept No.3 - Artist Toolkit for art therapy

The third concept is called **"Artist Toolkit"** which allows family caregivers and people with dementia to set up an artistic environment in their home so that they can enjoy artistic activities such as drawing and painting to enhance their creativity and mental health.

Main elements are the following and they are packed in the toolkit box.

- A projector and controller for interactive playful painting & drawing
- A screen for projecting and interacting themselves

Firstly family caregivers (and occupational therapists) install the play field in their home environment by setting up the projector with the controller. And then they can use the plain wall or the screen for the drawing field depending on the size of space. They can choose either 'museum mode' or 'creation mode'. In the museum mode, they can visit the museum and enjoy the exhibition without going there. In the creation mode, players can make drawings by touching the screen and moving their body in front of the screen.

This initial sketch illustrates the aesthetics and sensations to stimulate. The general scheme is described as a sketch. (Figure 6.2.3.)

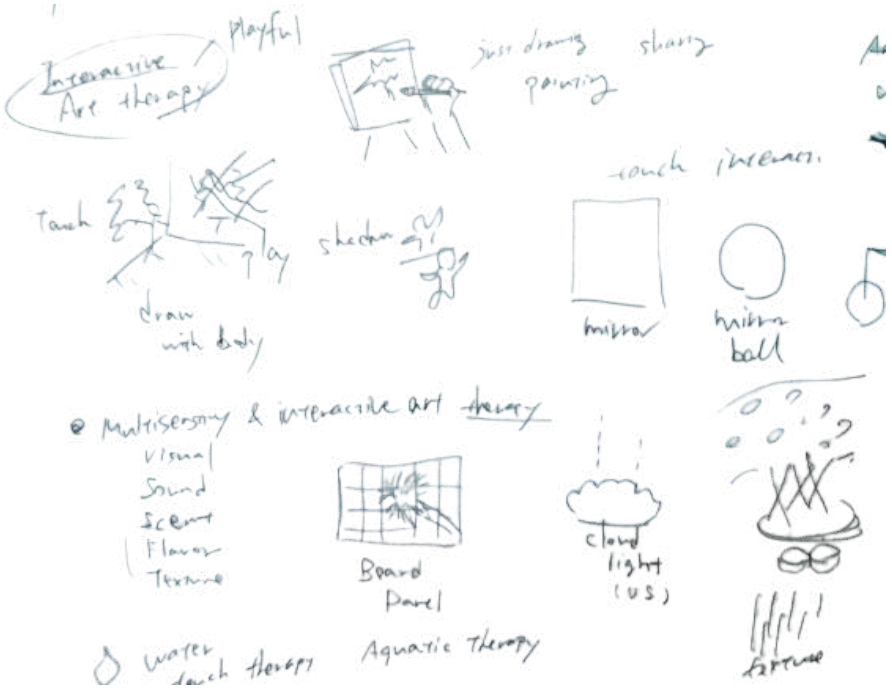

Figure 6.2.3. Artist Toolkit - Masato Kagiwada

Concept No.4 - Interactive plant for multi-sensory therapy

It is an **"Multisensory Interactive Plant"** which allows family caregivers and people with dementia to set up a therapeutic environment in their home so that they can enjoy a new way of plant therapy that detects/stores the linguistic and facial emotion pattern of users.

Main elements are the following and they are packed in the toolkit box.

- Environment module for healing through plants and flowers
- Communication module for communicating to the plants and flowers

Firstly family caregivers (FC) install the plant cube in a place where they want to set up a therapeutic environment. And then FC and people with dementia (PWD) could plant their pre-ordered favorite plants and flowers on the top side of the cube. After that, FC just needs to turn on the switch which will activate all sensors and devices which allow OT and GP to monitor the behavioral patterns and track the linguistic patterns for analysing and thinking about the more patient-centred care plan for PWD. FC and PWD

can interact with the plant cube by their hands (touch), mouth (talk), and nose (smell) so that they can feel emotionally connected to the cube and heal their emotional condition.

The concept also includes a digital platform which allows users (family caregivers and PWD) to keep track of their activity history and environmental metrics, and medical experts (occupational therapists, general practitioners, neurologists, etc.) to analyse the effect of therapeutic interventions, provide a consultation to family caregivers, and improve the care plan for people with dementia. The interface would be both mobile and web-based so that it could be adaptable to different levels of tech savviness.

From the interactive plant, medical experts can get tracking data which includes usage, speech patterns, and facial emotion patterns, and analyzing data which includes behavioral and emotional patterns. These data would be beneficial for medical experts to provide more personalized care and advice with people with dementia and caregivers. The general scheme is described as a sketch. (Figure 6.2.4.)

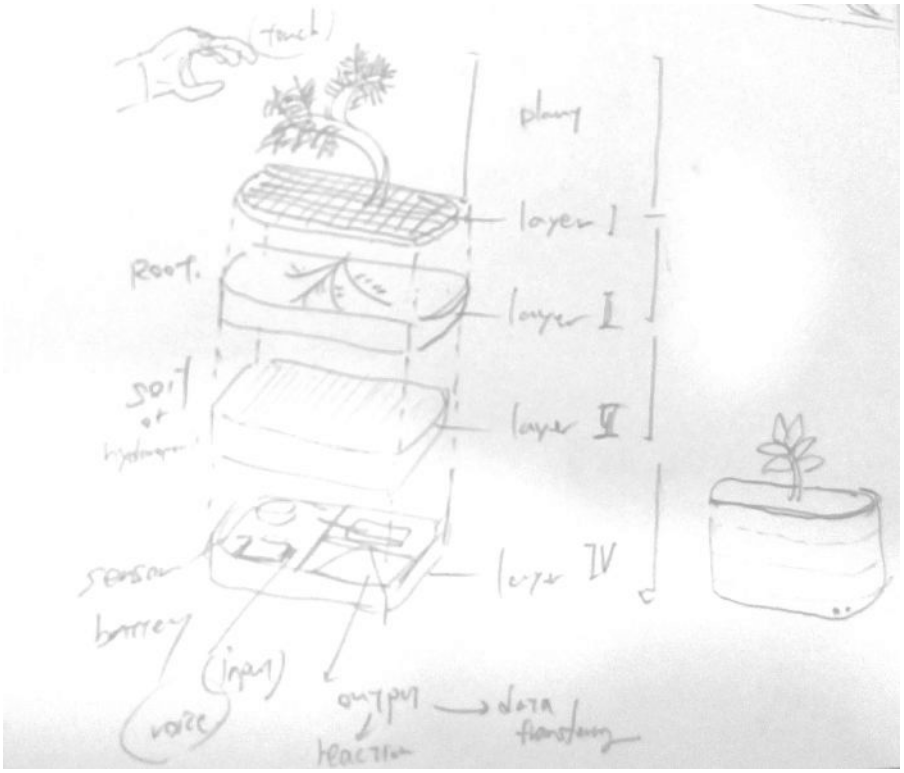

Figure 6.2.4. Interactive Plant - Masato Kagiwada

Now there are four concept candidates with a description of overview and functionality. In the following section, the concept selection process and the decision will be explained.

6.3. Concept evaluation

In this section, the selection criteria will be introduced, the selection process will be described, and then the decision will be made. (Table 6.3.)

Firstly an evaluation criteria is defined as follows:

1. Portability (20 %)
2. Usability (20 %)
3. Controllability (20 %)
4. Adaptability (20 %)
5. Technical feasibility (20 %)

Given that importance, the weight of the criteria is equally distributed. And then all concepts are evaluated with the scale of 1 to 5.

		Relaxation		Activation		Artist		Plant	
SC	weight	rate	score	rate	score	rate	score	rate	score
1	20 %	3	0.6	3	0.6	2	0.4	4	0.8
2	20 %	3	0.6	4	0.8	3	0.6	5	1.0
3	20 %	3	0.6	5	1.0	3	0.6	5	1.0
4	20 %	4	0.8	3	0.6	5	1.0	5	1.0
5	20 %	5	1.0	5	1.0	3	0.6	4	0.8
Total Score		3.6		4.0		3.2		4.6	
Rank		3		2		4		1	

Table 6.3. Evaluation Matrix

Portability and **usability** are evaluated by the complexity of the concept. Since it will be mainly used in the small scale environment (home and care home), the complexity should be optimized. Therefore, having a smaller number of tangible objects is better and 'Interactive Plant' is the strongest in this sense.

Controllability in this context means how much the user can customize the level of simulation. Although all of them enhance the stimulation through human sensations, it's more challenging to control the degree of stimulation according to the condition of people with dementia in the first 3 concepts.

Adaptability means how much the concept could adapt to the surrounding environment so that it creates an environmental harmony. In this sense, the Artist concept and Plant concept are the strongest in a way that it could also be used for enhancing the conformity of interior.

Technical feasibility is evaluated by the difficulty of concept development. With the fact that there are existing physical computing modules and software development kits, Relaxation and Activation concepts are the easiest in a way that it just needs to connect and integrate them. In the meantime, the Plant concept needs some complex algorithm and the Artist concept needs a complex platform which controls sensorial effects.

Based on the selection matrix, the 'Interactive Plant' got the highest score. Although it has a potential to provide an emotional comfort and environmental harmony with dementia patients, it lacks the reminiscence effects and creative stimulation. Therefore, the artefact for the therapy needs to have a connection with their past memories and also to initiate the conversation. Folklore, including fairy tales and poems, is widely used for storytelling in childhood and is closely connected to local culture and history. That is why using folklore and storytelling as a dementia therapy in combination with physical objects and digital assistants could fill the gap in the concept of 'Interactive Plant'.

In the following section, the details of the concept will be explained.

6.4. Concept finalisation

After the evaluation of concept candidates (Relaxation, Activation, Artist, and Plant), the concept is finalised as follows.

Tunne, an Estonian word meaning 'sensation', is a tangible and interactive toolkit for folklore-storytelling dementia therapy. It helps people with dementia to gain emotional happiness with multi-sensorial interactions, family caregivers to initiate therapeutic interactions at home, medical experts to detect the progression of dementia and emotional status, and society to raise public awareness of dementia.

It consists of 4 modules shown as follows (Figure 6.4.):

1. Therapy
2. Interaction
3. Detection
4. Service

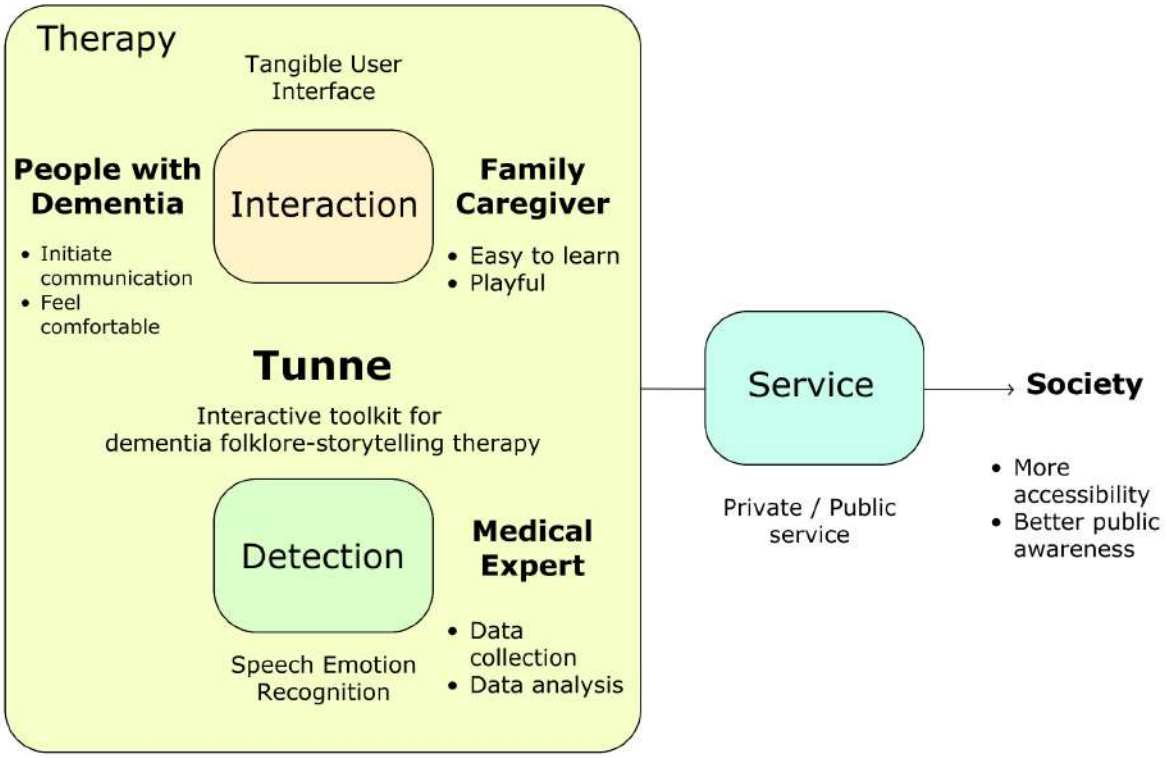

Figure 6.4. Tunne module overview - Masato Kagiwada

The **Therapy** module is created for providing **dementia folklore-storytelling therapy** with people with dementia in their favorite environment. It allows patients to get stimulation by visuals, audios, and conversation, and family caregivers to have easy-to-lean and playful experience by a **digital assistant**.

The **Interaction** module is aiming at **initiating a verbal communication** between people with dementia and family caregivers as a form of **tangible user interface**. Several aids are used as a sensorial trigger to remind nostalgia and enhance verbal communication. It is also aiming at **generating a comfort zone** where they can feel comfortable in the home environment by considering the comformility of materials.

The **Detection** module allows medical experts to collect data (**linguistic patterns** of people with dementia) so that they can interpret it as visualisation of **emotional status** and collaborate with family caregivers to provide more personalised care for people with dementia.

The **Service** module aims to raise accessibility to dementia non-pharmacological therapy and to raise **public awareness** of dementia in Estonia. It would be achieved by delivering Tunne to the society as a public/private service.

In this chapter, four concept candidates were introduced with concept design principles, evaluated with the evaluation matrix, and the final concept "Tunne" was introduced with the overview of modules. The details of Tunne and the result of evaluation with domain experts will be explained in the next chapter.

7. TUNNE

In this chapter, the overview of the Tunne modules with a user story, the details of folklore-storytelling therapy with Therapy and Interaction modules, the way of implementation of Tunne with Detection and Service modules, will be described. It will conclude with the evaluation from domain experts in Estonia.

7.1. Overview

Main modules

Tunne consists of four modules as follows (Figure 7.1.):

1. Therapy module - folklore-storytelling therapy & therapy assistant app
2. Interaction module - storytelling device
3. Detection module - speech emotion recognition & data exchange
4. Service module - Tunne as a business & as a public service

All modules are interconnecting each other to provide the values which are "stimulative" for people with dementia, "accessible" for caregivers, and "transparent" for medical experts. The details will be explained from the next section.

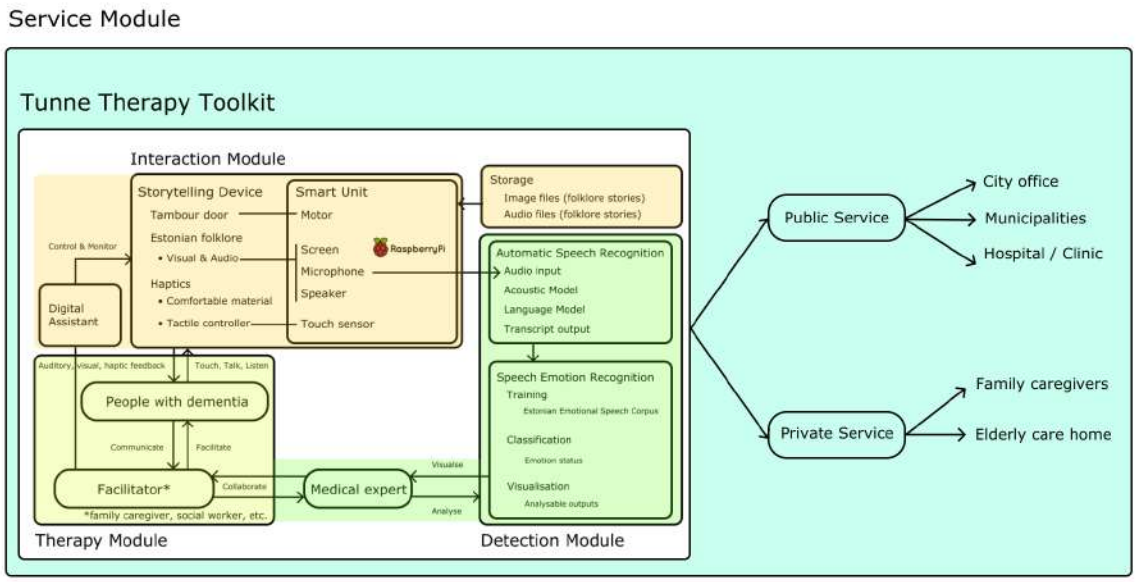

Figure 7.1. Tunne module details - Masato Kagiwada

User story

I also created one user story which describes the user experience of the Tunne. There are 4 characters in this story as follows:

- Anna, 45, family caregiver (Figure 4.4.1.)
- Mia, 80, a mild dementia patient (Figure 4.4.2.)
- Peeter, 35, occupational therapist (Figure 4.4.3.)
- Sille, 27, general practitioner (Figure 4.4.4.)

This story proceeds with 7 scenes: Recognize, Explore, Collaborate, Encounter, Use, Assess, and Refine.

Scene 1: Recognize

Anna lives with her mother, Mia, who has mild dementia for 3 years. Nowadays her capabilities are getting worse (more forgetfulness, some sleep disorders, and some inappropriate communications).

Scene 2: Explore

Anna starts to gain the knowledge of dementia, and also asks her mother's GP "Sille" for the necessary actions. Although Sille realizes the early symptoms of dementia and understands her preferences (like to stay at home as long as possible), she has limited knowledge about the interventions for decreasing the progression of symptoms.

Scene 3: Collaborate

So she asks Peeter, occupational therapist, who has deep insights on technological interventions, so that she can get professional advice. A few days later, all of them meet at Zoom so that they can discuss the issues, preferences, and interventions, and assess the home environment thoroughly. Peeter finds there are lots of books in her house and Mia really likes to read them. So Peeter introduces "Tunne folklore-storytelling therapy" provided by the City of Tallinn.

Scene 4: Encounter

Anna makes an appointment with one social center in Tallinn with the reference from Sille. She can finish this task by using the "Digital Assistant App". A few days later, Anna and Mia visit the social center to join the folklore-storytelling therapy.

Scene 5: Use

A social worker switches on the "Storytelling Device" by touching the top of the device and chooses one story from the Assistant App - "The Beauty and the Beast (Estonian: *Tulipunane lilleke*)" - shown on the front screen of the device. Mia uses a tactile controller (ball and stones) to open the slide door of the device, play the audio of folklore, and record her voice in the storytelling session. After listening to the folklore, she asks Mia some questions about folklore - "What is this about?", "What is the name of the main character?", etc. Mia answers these questions. And then Hele asks her to talk about her impression on the story. Mia tells her story in her childhood with joyfulness and expresses her good feelings. After all, the therapy is finished and Anna makes an appointment for the next therapy.

Scene 6: Assess

The device records this conversation and sends the audio to the microcomputer where the audio file is converted to transcript and it is compared with pre-recorded answers in a calm emotional state so that the algorithm can detect the emotional state. Siie and Peeter can check out the data in the portal in Estonian e-Health Information system and they can create and propose a more personalised treatment plan to Anna.

Scene 7: Refine

Finally, Anna could get more insightful advice from medical experts, that Mia's emotional status is better in the therapy and folklore inspires her intelligence. Although dementia will not be eliminated, Anna becomes more hopeful of how to sustain her life with her mother while ensuring Mia's happiness and well-being.

It describes how all personas interact and relate with one another, where it happens, what happens, and what they feel. With this story, firstly the details of folklore-storytelling therapy alongside physical and digital assistants will be explained in the next section.

7.2. Folklore-storytelling therapy with physical and digital assistant

Therapy module

Therapy module consists of the procedure of **"Estonian folklore-storytelling therapy"** and **"therapy assistant app"**. It is designed for people with dementia to get emotional comfort and for facilitators to conduct the therapy as smoothly as possible.

Overview and procedure

The folklore-storytelling therapy is created for people with dementia to get multi-sensorial stimulation and emotional comfort by encountering nostalgic folklore and an interactive storytelling device. The facilitator could be family caregivers, formal caregivers, and social workers.

"**Estonian folklore**" is picked up for the reason that users know the content well enough to get a nostalgic memory. For the prototype, the story *"Tulipunane lilleke"* is picked up because of its popularity and familiarity for people with dementia. The 20min-therapy consists of the following:

1. Introduction
2. Story-hearing
3. Q&A session
4. Storytelling session
5. Closing

The therapy would be conducted in a small room or an open space (Figure 7.2.1.).

Figure 7.2.1. Therapy scenes - Masato Kagiwada

Therapy Assistant App for facilitators

Facilitators could also use 'Therapy Assistant App' which allows them to conduct folklore-storytelling therapy, to control the storytelling device, and to get the result of the therapy and tips for facilitating therapy.

How do they interact with it? After registering an email address and password, they can go to the home screen which shows several folklores. From there, they can select one story and start conducting the therapy with the device turning on. Firstly the introductory narration is played, and then the audio of the story is played. After that the app shows some questions to ask, and then it helps them to conduct a storytelling session. Simultaneously the device records the conversation among participants. And then they can finish the therapy from the app. After the therapy, they can check the result of previous therapies which includes time/date, speech recordings, and emotion analysis. Also they can get some tips for therapy facilitation, for example, how to use a voice for better comforts, how to encourage verbal communication, and so on. The overall workflow is shown below. (Figure 7.2.2.)

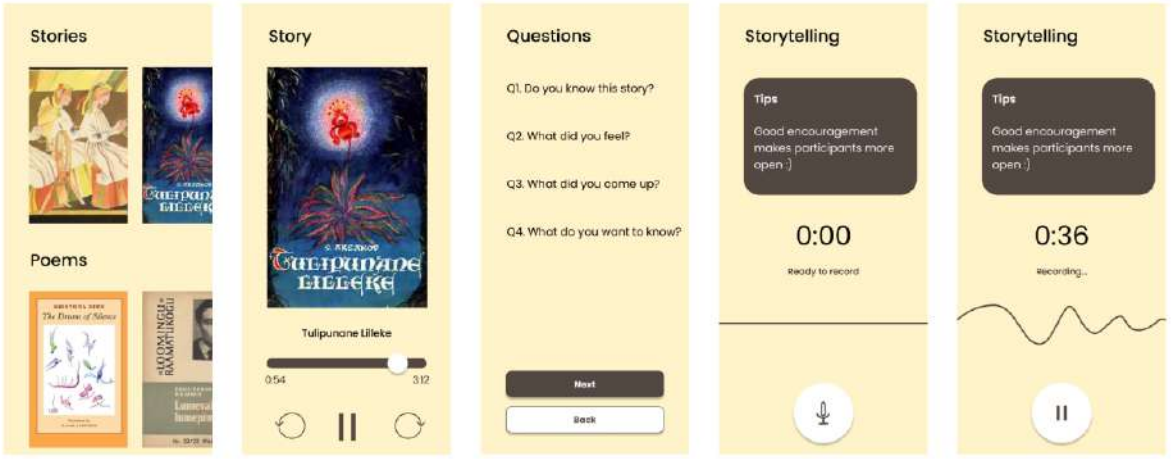

Figure 7.2.2. Workflow of therapy assistant app - Masato Kagiwada

Interaction module

Initiation module consists of a tangible user interface and smart unit so that people with dementia could get **emotional comfort** and foster their **verbal communication** with family caregivers.

Tangible user interface - Storytelling device

"Storytelling device" is aiming at providing multi-sensorial stimulation with people with dementia by using a tangible user interface with a tactile controller. Forming the storytelling device started from sketching to open up several possibilities and to get objective feedback as quickly as possible. (Figure 7.2.3.)

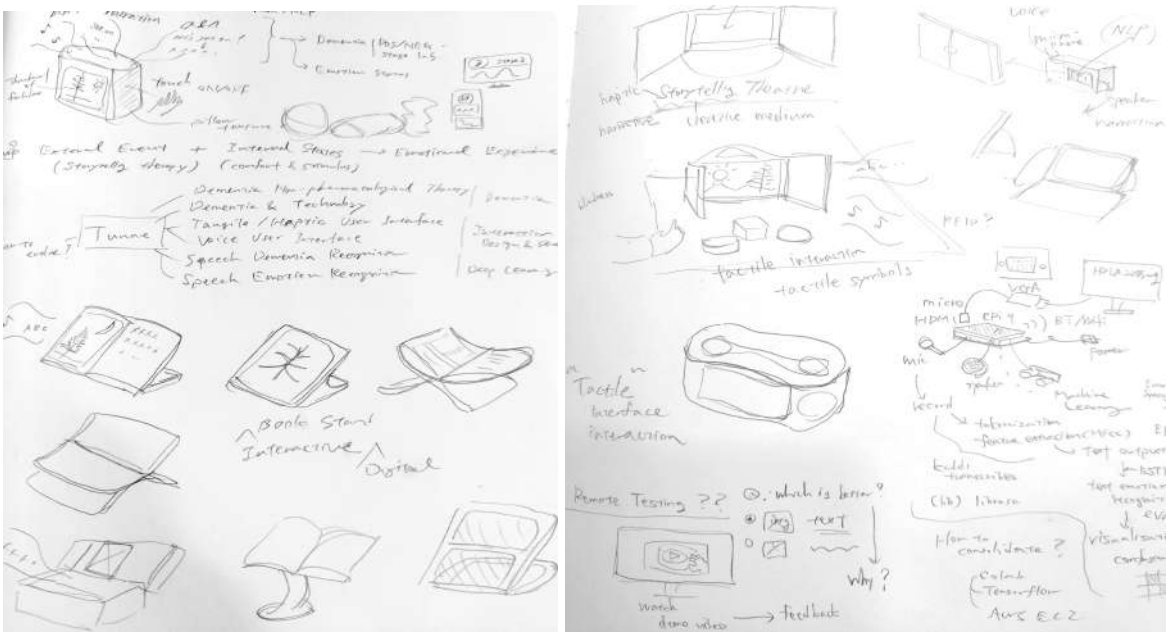

Figure 7.2.3. Tunne concept sketches version 1.0 - Masato Kagiwada

Based on this, the cardboard-based prototype is made. (Figure 7.2.4.) Different kinds of artefacts (book stand, retro TV, mini theater, and *Kamishibai* stand) are made to open up the discussion with testers. Since the object itself needs to demonstrate what it is in an intuitive way, the *Kamishibai* stand was selected to develop further. Kamishibai is a Japanese traditional storytelling theatre which is interactive in a way that storyteller and audience communicate verbally and visually. The concept of Kamishibai has been inspired outside of Japan. (Figure 7.2.5.) [39]

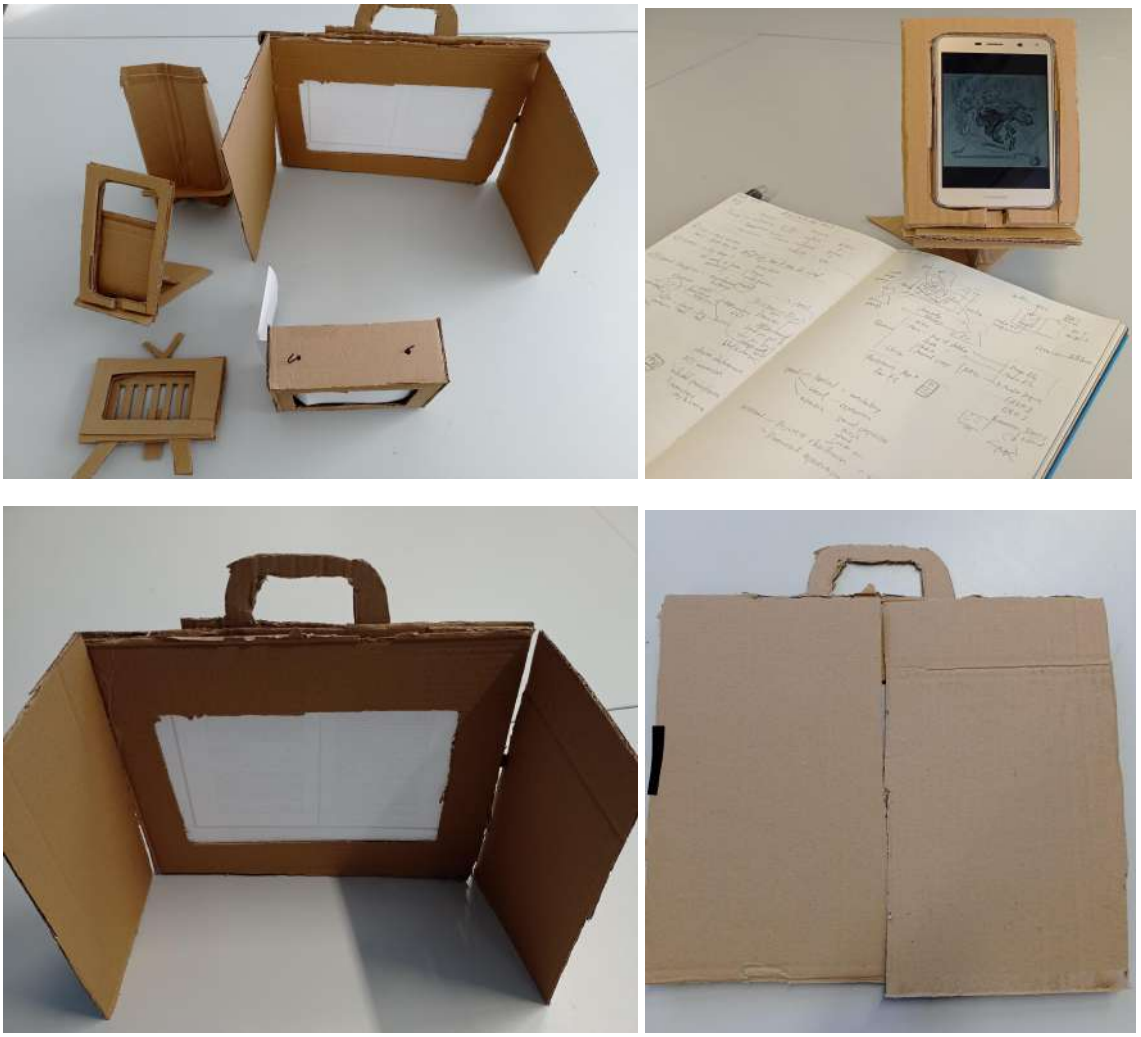

Figure 7.2.4. Cardboard prototype - Masato Kagiwada

Figure 7.2.5. Kamishibai theater - KreaShibai.de

After the cardboard prototyping, the next question is how to make it more interactive and playful by leveraging interactive technologies. To achieve that, I got inspiration from a tambour door cabinet (Figure 7.2.6.) [40] for opening/closing the storytelling device.

Figure 7.2.6. Tambour door cabinet - MWP Furniture Design Studio

With this inspiration, I created one sketch and one render illustrating the details and specifications. (Figure 7.2.7)

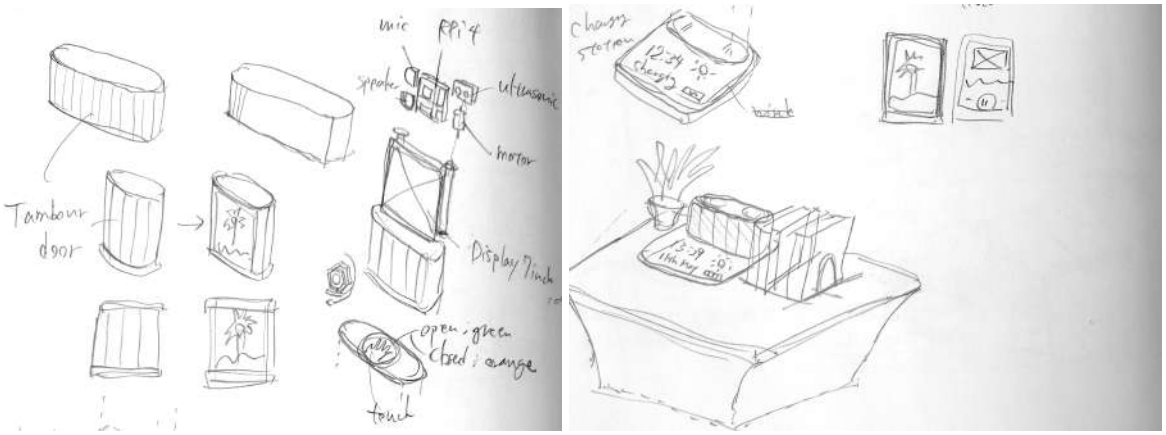

Figure 7.2.7. Tunne concept sketches version 2.0 - Masato Kagiwada

Based on this render, three tactile controllers are added to open/close the tambour door, to play the audio, and to record the speech of people with dementia. (Figure 7.2.8.) It makes interaction more tangible and playful so that people with dementia can get more enjoyment and stimulation. Simultaneously, one cardboard-based tangible object is created to gain insights from potential users and experts. (Figure 7.2.9.)

Figure 7.2.8. Tunne product render - Masato Kagiwada

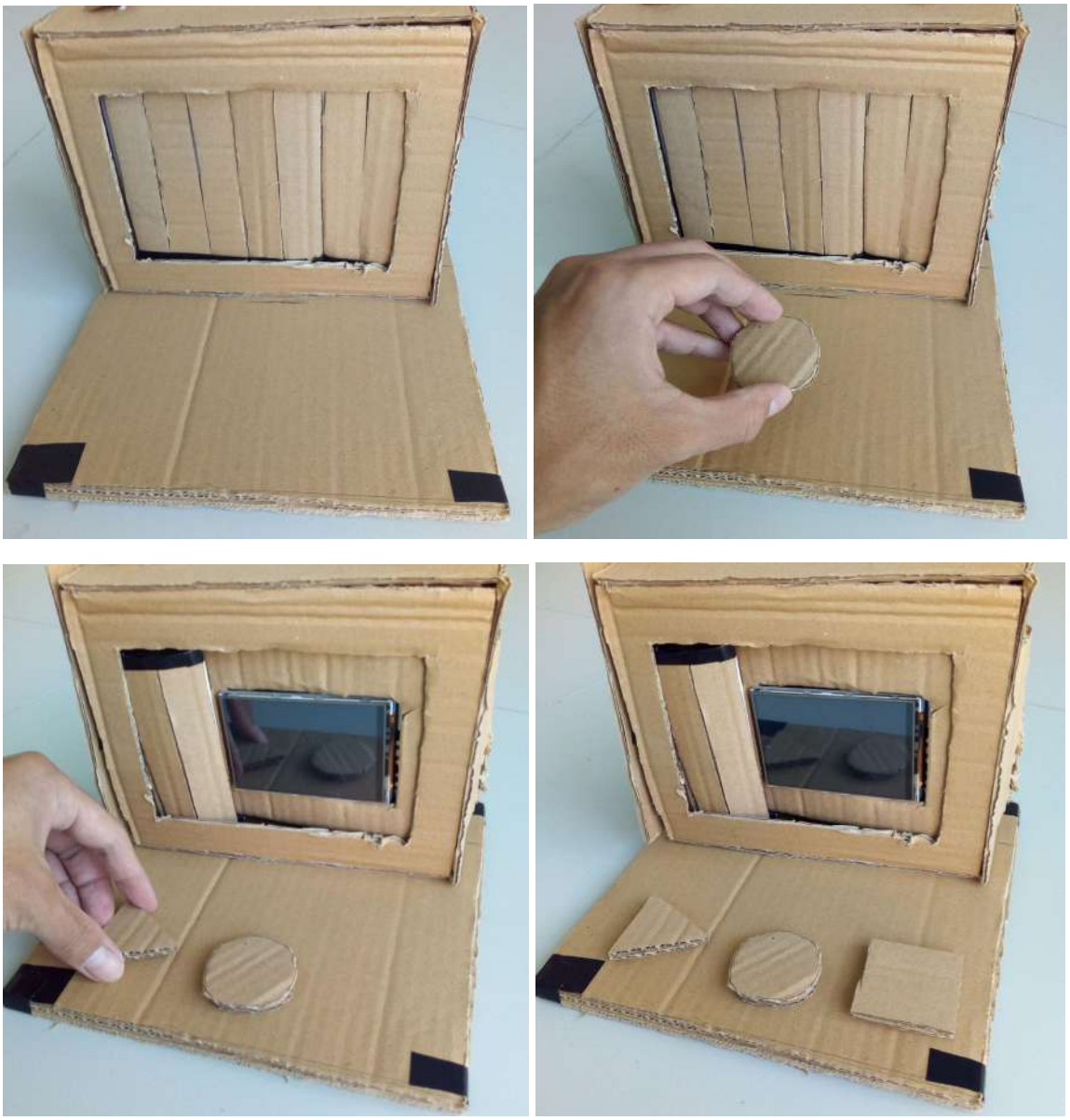

Figure 7.2.9. Storytelling device (cardboard) - Masato Kagiwada

Smart unit

The module also includes electronics components as a smart unit to make itself smart - showing visuals, playing audios, recording speeches, and achieving tactile controls. The following circuit diagram and render show which components will be part of the prototype and how different components interact with each other and the microcontroller that controls everything. It consists of Raspberry Pi Model B, USB microphone, speaker, and ultrasonic sensor to achieve the aforementioned functionalities. (Figure 7.2.10.) The technical drawing is also created. (Appendix 4)

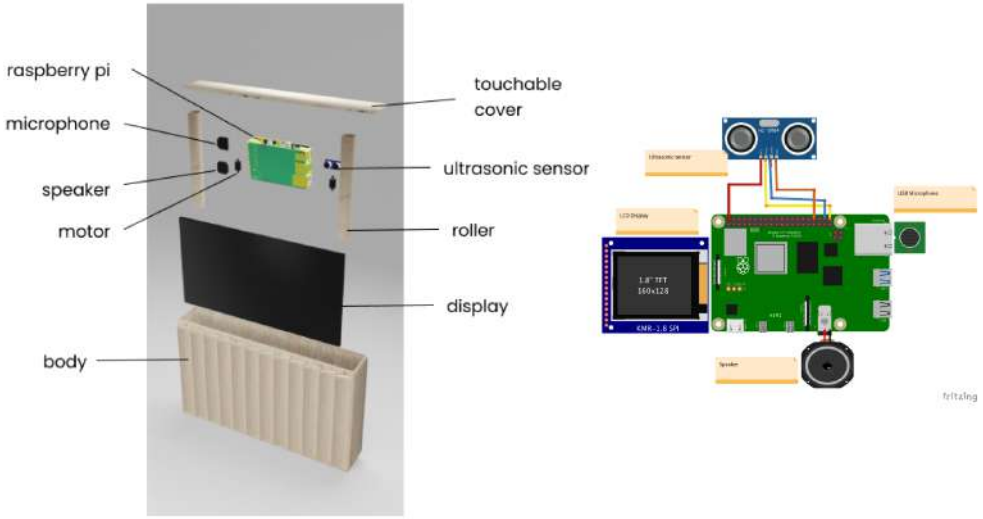

Figure 7.2.10. Device specification - Masato Kagiwada

User interaction storyboard

After defining the form and specification of the device, I made two storyboards to illustrate the tangible and intangible interactions. Tangible interaction is mainly for people with dementia to control the storytelling device with colored objects. The following figure illustrates the interaction that they could open/close the door by the 'open' ball, play/stop the audio of folklore by the 'play' stone, and start/stop recording by the 'record' stone. (Figure 7.2.11.) The facilitator would assist them up to the necessity. With this tangible interaction, they could get more tactile stimulation and get more enjoyment.

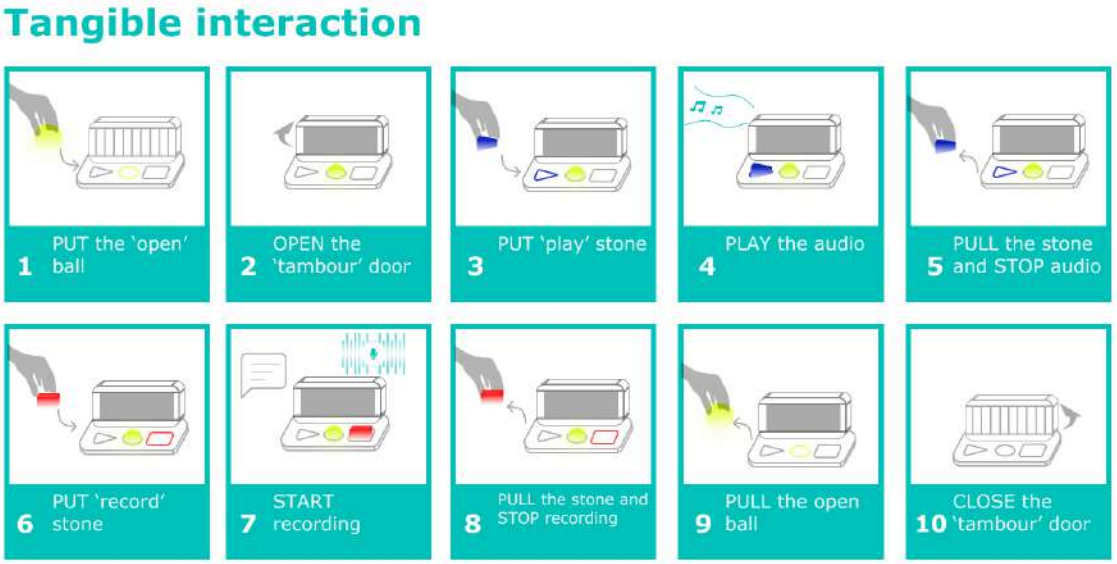

Figure 7.2.11. Tangible interaction - Masato Kagiwada

Intangible interaction is mainly for therapy facilitators to control the device, track the progress, and get helper tips with a digital assistant. The following figure illustrates the interaction that they could utilise the digital assistant to select the folklore upon the preference of people with dementia, to show the visual of the folklore on the device, to track the progress of the therapy, and to get help as they need. (Figure 7.2.12.) With this intangible interaction, they can focus more on the facilitation of the therapy so that people with dementia could get the great caretaking experience.

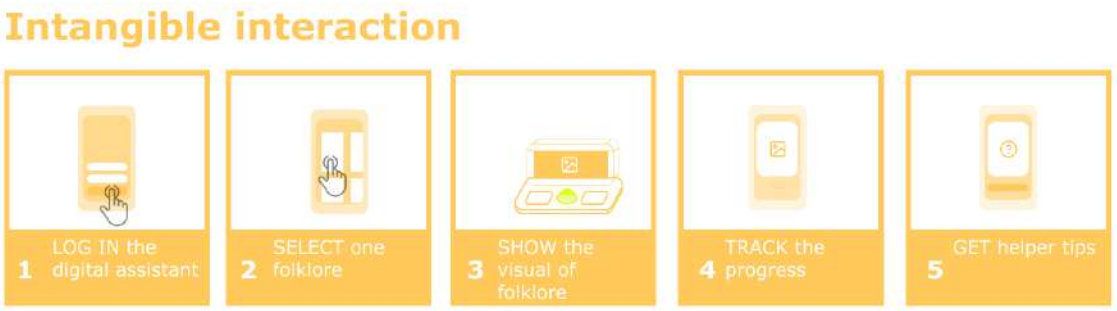

Figure 7.2.12. Intangible interaction - Masato Kagiwada

The following figure consolidates two interactions with the therapy timeline. By setting a clear role on each participant, the effect of the therapy would be optimised. (Figure 7.2.13.)

Figure 7.2.13. Therapy workflow - Masato Kagiwada

With the tangible device for people with dementia and the digital assistant for therapy facilitators introduced in this section, the detection module for medical experts and service module for society will be explained in the next section.

7.3. Data detection and e-healthcare service

Detection module

Detection module consists of a language model to collect speech and detect emotion, and data exchange via X-road infrastructure.

Automatic speech recognition (ASR) and Speech emotion recognition (SER)

The Detection module is aiming at detecting **emotional status** of people with dementia by collecting and analysing the linguistic pattern from audio inputs coming from the conversation in the storytelling therapy. It is based on human language technologies such as ASR and SER. Given the target user's language preference and the uniqueness of Estonian language, the module is developed with "Kaldi Offline Transcriber" , "EstBERT", and "Estonian Emotional Speech Corpus". The process is the followings:

ASR component

1. Collect audio** input from microphone connected to Raspberry Pi (**emotional speech corpus of personal stories from therapy session)
2. Pre-process (tokenization) and feature extraction (MFCCs) with Kaldi
3. Get transcribed texts with Kaldi offline transcriber

SER component

4. Speech Emotion Recognition by Text classification with EstBERT
5. Model training with Estonian Emotional Speech Corpus
6. Evaluate the accuracy of emotion
7. Extract the speech, emotion, and event data for data exchange

The ASR/SER model will be installed in the smart unit described in 7.2.

Data exchange via X-road

The data of therapy, speech and emotion will be stored in the secured database. The database is connected to segmented LAN via X-road gateway so that the data is secured and added to the diagnosis data of the person with dementia registered in the e-Health information system. The updated medical events data will be shown in Patient Portal for authorised people and the Clinical Decision Support System for medical experts.

Service module

Service module consists of private and public service models in Estonia so as to increase the accessibility of dementia non-pharmacological therapy and to promote the public awareness of dementia across the society. Firstly two service models, and then a caregiving journey map with both models, and finally the service blueprint for the public service model will be explained.

Private service model

In this model, caregivers could facilitate the therapy and people with dementia could get patient-centred care from medical experts. They can borrow the device by paying a monthly subscription fee (for maintenance and support) and use the assistant app for free. Meanwhile, medical experts (their GP and others) could check the data of therapy, speech, and emotion, and get recommendations via the Clinical Decision Support System. They could share the updated caregiving plan with their clients through the Patient Portal and the assistant app. (Figure 7.3.1.)

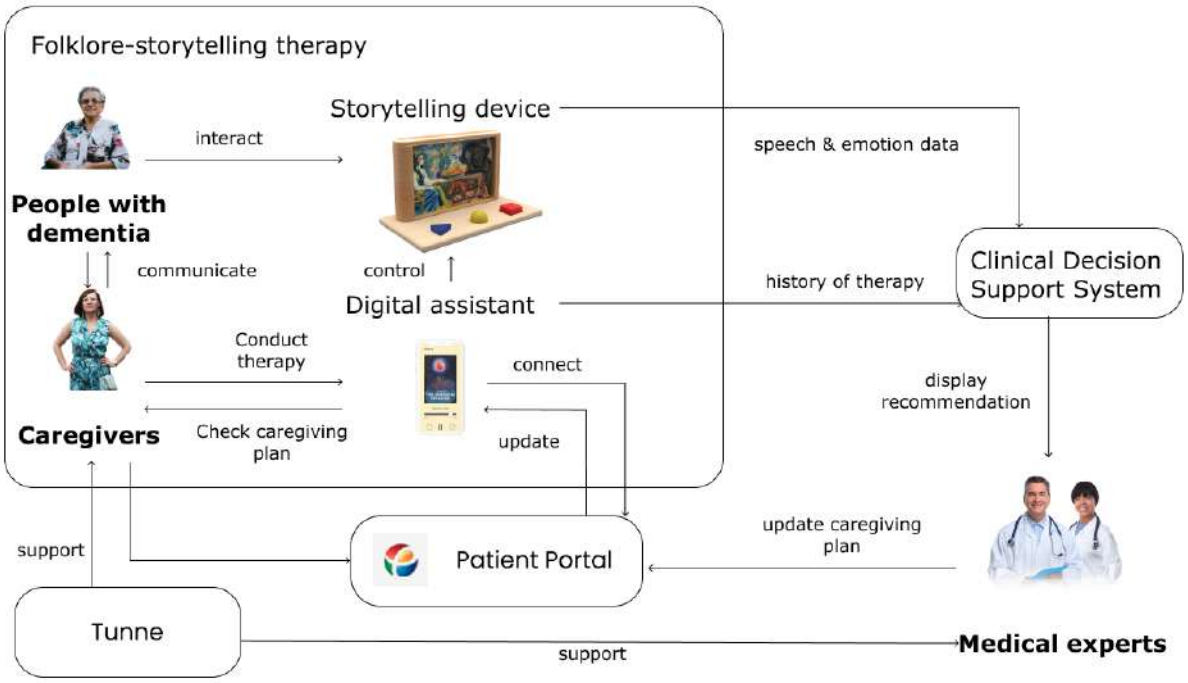

Figure 7.3.1. Private service model - Masato Kagiwada

Public service model

In this model, the provider of the therapy would be social centers of the local government and they get the toolkit which includes storytelling devices and the assistant app. Social workers could get training from the Tunne support team so that they could conduct and facilitate the therapy at the social centre. In Tallinn, there are 3 providers

and residents could apply for the social service based on the residential address. In this case, family members would apply for the day-care service with a referral letter from the GP and a consent from the City of Tallinn. Upon the approval, people with dementia would go to the social centre and get the therapy. After that, the data related to the therapy will be shared with medical experts so that they can share the updated caregiving plan with family members and give feedback on the quality of the service to the service provider. (Figure 7.3.2.)

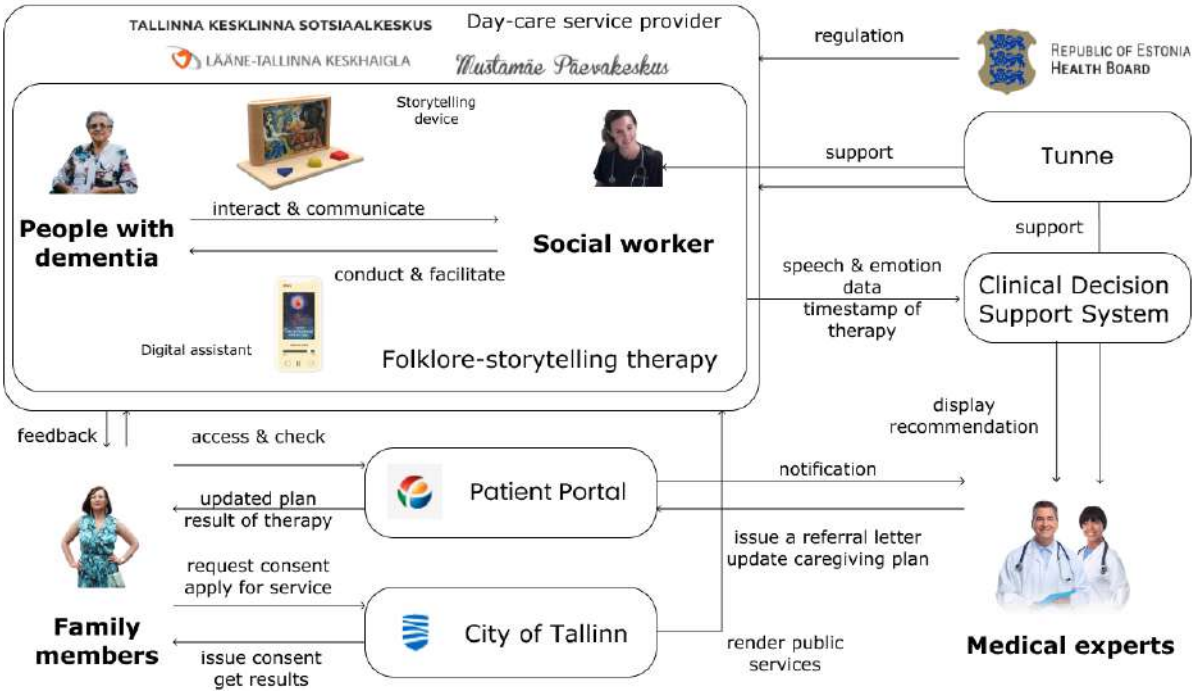

Figure 7.3.2. Public service model - Masato Kagiwada

Since most healthcare services are provided as a public one in Estonia, the following map and blueprint will be created based on the public service model.

Caregiving journey map with Tunne

With these service models, the caregiving journey map is also updated. To include Tunne into stakeholder's life as smoothly as possible, one scenario is that the folklore-storytelling therapy would be conducted in three cases - personal at home, group at social service center, and personal at care home. Firstly one family caregiver and medical experts start to cooperate to make a care plan for a person with dementia. Social workers and local government officers are also involved in the early stage to connect personal caregiving with the public healthcare platform in Estonia as seamlessly as possible. After finishing the planning, the family caregiver gets the Tunne toolkit from

GP's office and learns how to set up and use it. And then she facilitates the therapy while medical experts and social workers can get the result of therapy. Since the social interaction is beneficial for dementia, next the group therapy is conducted in the social service center in Tallinn. Social workers can order the Tunne toolkit via a web-based platform. The caregiver and experts can also get the result of therapy for further caregiving. And as dementia progresses, caregiving by elderly care home becomes a suitable option. The provider and their employee could use the toolkit for daily activities. Given the preference of people with dementia and their family members, they can choose either personal or group sessions. With Tunne, caregivers and support systems could collaborate and cooperate more seamlessly so that people with dementia could get better well-being. (Appendix 2)

Service blueprint with Tunne

Service blueprint is a diagram that visualises the relationships between different service components - people, physical or digital evidence, and processes - that are directly tied to touchpoints in a specific customer journey. It helps service providers to see the big picture of how a service is implemented by the provider and used by the service customers. [41] The blueprint for Tunne provider was created in a case where storytelling therapy is added to one of daily activities provided by social centers in Tallinn so as to increase the accessibility of dementia non-pharmacological therapy.

It includes timeline, patient journey, frontstage (activities and technologies) where caregivers and medical experts would interact with people with dementia directly, and backstage where all invisible activities from people with dementia would be conducted. It visualises relationships and connections among different stakeholders with technologies (mobile/web application, storytelling device) and support process (software application and system). This blueprint is helpful especially for policy makers to converge siloed processes and make public service less bureaucratic. As a conclusion, the blueprint describes how Tunne as a public service is planned, provided, and utilised towards more patient-centred, caregiver-empowering, transparent caregiving, and more seamless collaboration among interdisciplinary caregiving actors. (Appendix 3)

In this section, the detection and service modules were explained to highlight how the data is collected and exchanged, and how Tunne will be provided as a public service in Tallinn. With the overview and details of the modules, Tunne will be evaluated by potential users and domain experts.

7.4. Evaluation

Overview

Tunne has been tested with potential users and domain experts - dementia (researcher and occupational therapist), folkloristics (literacy scholar), and language technology (researcher). It is conducted by an online interview style with a concept presentation.

The main goals are the followings:

- Get the impression on the prototype from potential users and experts
- Evaluate the understandability and usability of the prototype
- Understand how potential users could interact with the prototype

And the structure of the interview is the followings:

- Presentation of background and concept
- Questions
    - What is your impression on this concept?
    - Will the proposed concept solve your issues?
    - How might the concept integrate into your daily life as a dementia expert?
    - What are the top two things you liked about the concept?
    - What are the top two things you disliked about the concept?
    - Based on the explanation, did you understand what the concept is?
    - How often do family caregivers want to use the concept?
    - What is missing on this concept?

Based on that, I conducted expert review sessions as described below.

Expert reviews 1

Aija Sakova - Literary scholar at Estonian Literary Museum, Estonia

Since the main contents are based on Estonian folklore, I contacted the expert of folkloristics to gain insights on the utilisation of folklore for reminiscence effects of people with dementia. Overall feedback is positive and my research attracts her interests. As a feedback, making use of real human voice for folklore narration could

enhance the emotional bond among the participants than machine voice. Also including poems would be also beneficial because of the familiarity for Estonians.

Hanna-Stiina Heinmets & Miret Tuur - Board members of DCC, Estonia

The online expert review is conducted with board members of Estonian dementia competence centre. Firstly the name of 'Tunne' attracts them because it represents the message of concept clearly. And the concept itself sounds well because it is stimulative to people with dementia, accessible to family caregivers, and useful to enhance the communication among family members. Meanwhile, the use of emotional status for medical experts sounds not very useful because it changes unpredictably and how to utilise is still under development. Overall the feedback from them is positive.

Merle Varik, RN, BScN, MSW - Dementia researcher, Estonia

Since it's essential to gain the medical viewpoint, the review with Ms. Varik is conducted online. Overall impression is very positive because there is no implementation of folklore-based narrative and storytelling for dementia therapy in Estonia. Next each module is discussed. The structure of the Therapy module sounds useful and the length of therapy (15 ~ 20 minutes) is appropriate given the capability of keeping attention. The use of Kamishibai theater sounds win-win to both people with dementia and family caregivers because it's useful and understandable. Speech emotion recognition would open up possibilities to gain more insightful analysis for medical experts although the proper guidance would be needed. Besides that I get some possibilities to develop Tunne further - use of music, use of smell, and modification to different people with different cultural backgrounds. The therapy would gain more multi-sensoriality by including music and singing, using an aroma diffuser for the device. And the selection of contents would be different up to the cultural background of people with dementia. So it could be applicable to different countries - Baltic states, Nordic countries, and so on.

Expert reviews 2

Julia Otkidats - Manager at Tallinna Kesklinna Social Center, Estonia

Since Tunne could be used in the public service in Estonia, the feedback from the manager of Tallinna Kesklinna Social Center was also collected by online questionnaires. Generally the feedback is positive and the concept could be added to the memory

training exercises conducted in the Centre. It would help them to connect different stakeholders in a less bureaucratic way and to focus on main clients and necessary activities for preserving their positive state. The therapy itself could be conducted once a week even though the client's feedback is still unclear. Meanwhile, the concept lacks the familiarity and needs more personal touches by human conductors. To gain therapeutic effects successfully, it is essential to ensure a safe and familiar environment alongside familiar people. Currently the concept misses this principle. Also, the therapy is dependent on the person's conversational capability and in this sense the concept is not universal.

Analysis

With the result of expert reviews, two points could be explored further.

1. Balancing familiality and novelty
2. Opening up more possibilities for different stages of dementia

So far, Tunne connected several aspects - the form of non-pharmacological therapy, the aesthetics of tangible user interfaces, the way of aiding caregivers, the integration of interactive and language technologies, and the way of ensuring transparency for medical experts. Now it is essential to look back on the balance of familiality and novelty of Tunne so that it is truly beneficial for main users - people with dementia. And although I have focused on the early and middle stage where people with dementia still have the majority of conversational capability, the possibility that Tunne is used for different stages of dementia could be opened up.

8. DISCUSSION

In this chapter, the work will be discussed by reviewing the meaning, implication, limitation, and recommended practical actions so as to open up possibilities and opportunities.

8.1. Interpretations

The work of Tunne could be reviewed with the DICE approach. In the Describe stage, the possible triggers of behavioral and psychological symptoms are interrogated. (Chapter 3) And then, in the Investigate stage, the intervenable causes such as inefficient collaboration among patients, caregivers, and experts, were defined from qualitative research activities. (Chapter 4) In the Create stage, several brainstorming and discussions with domain experts (dementia, folklore, human language technology, and design) were conducted and as a result the concept of Tunne was formulated. (Chapter 6 & 7) In the Evaluate state, although Tunne got positive feedback from experts, the clinical experiment in social center, care facility, and home is needed to see whether the symptoms are improved, whether caregiver's accessibility to therapy is improved, and whether medical experts have better transparency in dementia symptoms. (Chapter 7)

8.2. Implications

The utilisation of interactive technologies such as tangible user interface and human language technologies for dementia non-pharmacological therapy was explored and examined. Broadening the mediums of interaction by leveraging a tangible object would open up more flexible interaction between human and digital information so that people with different physical and cognitive capabilities could utilise their sensations and perceptions to make their daily life easier and more comfortable.

Also secured data exchange with Estonian e-Health Information System was also explored to balance the personal data protection and get dementia care more personalised and transparent. This well-established data exchange infrastructure and digital healthcare system could accelerate the utilisation of health data from several kinds of touchpoints among patients, doctors, and stakeholders. The feedback from city officials also pointed out this research would enhance the collaboration in both the private and public sector towards the better well-being of people with dementia and caregivers.

8.3. Limitations

Due to the limitations on physical contacts, the online expert reviews were used for evaluation instead of in-person user testing. It prevented me from observing how therapy participants conduct the therapy and interact with the storytelling device and it narrowed down the variety of evaluation on Tunne.

8.4. Recommendations

To implement the design concept as a widely used service, the clinical evaluation should be performed with the approval by the Tallinn Medical Research Ethics Committee. And then the individual and group user testing where people with dementia, caregivers, and social workers interact with a physical and digital assistant, and medical experts review the data through e-Health Information System, would be needed to gain the practical feedback in a real environment.

And personal data protection must be followed. Since the clinical evaluation would receive and process significant amounts of personal data, the consent of the data subject must be submitted before that according to the Personal Data Protection Act.

In this chapter, the result of the work was discussed from four perspectives - interpretations, implications, limitations, and recommendation. It helped Tunne to be evaluated from different perspectives and open up discussions. With this, this research will be concluded in the next chapter from several points.

9. CONCLUSION

9.1. Research answer

How can design and interactive technologies make dementia therapy more personalised to patients, accessible to caregivers, and transparent to medical experts?

The five-stage Design Thinking model with DICE approach and Design Wheel was used in the entire research process. Firstly the needs of main stakeholders - dementia patients, caregivers, and medical experts - were defined by literature review and online questionnaires. And then main problems were continuously reframed by interviews with stakeholders. It was described as the main gaps among people with dementia, caregivers, environment, and support systems (Person- and Environment-focused Support System). For example, mismatched communication, time-consuming collaboration, and lack of comprehensive assessment. After that some concepts were created in several brainstorming and review sessions, and the concept of Tunne was created based on the recommendations from domain experts. The concept was prototyped from hand drawings to 3D models and cardboard versions in collaboration with domain experts such as literature scholars and dementia researchers. It was also tested with domain experts to refine the concept, aesthetics and functionalities.

Research question is finally answered by reviewing main aspects for three main design targets. Tunne folklore-based storytelling therapy allows patients to gain emotional comforts by encountering nostalgic folklores and feel personalised connections by letting them speak out their personal stories. With the high accessibility of Tunne toolkit and playfulness of the therapy, caregivers could feel empowerment and encouraged to live with people with dementia in a more positive way. And with the capability of the storytelling device - speech emotion recognition - and the connectivity with the digital healthcare system, medical experts could review and analyse the health data for more patient-centred care planning and collaboration with stakeholders.

Although the research question was answered by this work, Tunne has a big potential to develop further and the plan will be explained in the next section.

9.2. Further development

For now Tunne is focusing on the initiation of verbal communication by leveraging storytelling as a creative medium and targeting early-stage dementia patients whose verbal communication capability is highly remaining. Given the progression of dementia, the patient would reach the point where sensorial communication replaces verbal communication.

One possibility for the Interaction module is that people with dementia could draw some objects with the input from folklore or make some objects made of clay. It would be the combination of storytelling therapy and art therapy. The other possibility is utilising touchless gesture interaction for the Detection module. For example, patterns of hand gestures of patients could be used for detecting dementia positive or negative by comparing the gesture motion dataset.

Since Tunne consists of customisable modules for dementia non-pharmacological therapy, design and technology interventions could be done for different modules alongside the different stages of dementia.

9.3. Contribution

The research could contribute to two points:

- Broaden the dementia research landscape in Estonia
- Open up the implementation of interdisciplinary design for dementia

Since this work came from the intensive qualitative research such as interviews and brainstorming with several experts in Estonia, it would contribute to enhancing the research and development for dementia not only from medical points but also design and technology points of view. This is the first time to explore the combination of folklore and storytelling therapy in Estonia so it would accelerate the cooperation of literature science and medical science. This work is based on interdisciplinary design which connects several layers of design disciplines - interaction, product, service, environment, and system. It would have a key role in tackling highly complex problems such as dementia which are not addressed by single design discipline. I believe that the consolidation of different layers of design would be essential to design the desirable future.

9.4. Note for the future

As more and more people will go through the elderly phase, the possibility of living with dementia - directly and/or indirectly - will be higher. We are still fighting with dementia, one of the biggest threats in public health, from different perspectives from medical to arts. Someday we will deserve the desirable outcome from countless efforts and collaborations. In 2021, there are still no direct treatments for ‘curing’ dementia. However, it does not mean that we don’t have any means of getting better around dementia.

With implementing the combination of a unique cultural tradition and interactive technologies for dementia non-pharmacological therapy in a larger scale by connecting e-healthcare information system, Tunne would serve not only to make dementia more visible and acceptable to patients, caregivers, and medical experts, but also to encourage our society to be more dementia-friendly.

Tunne is also a statement that the creator's perspective and insights could contribute to addressing this complicated and interconnected topic and harnessing more collaborations among stakeholders. As humans have been continuously evolving from the ancient, we could utilise and leverage our knowledge and wisdom toward the better human well-being in living with dementia. As a creator with the mindset of designer and engineer, I would like to devote myself into working on this challenge for the rest of my career.

10. SUMMARY

Dementia is a neurological and progressive disease which affects people's cognitive capability of having a daily life. Since it is often mistreated as a normal aging, it is often too late to be treated when it is diagnosed. With the lower risks compared to medications, the non-pharmacological therapy such as reminiscence and multi-sensorial therapy has been researched in the last few decades. Storytelling is one of the creative mediums widely used in fostering communication and it would be useful for people with dementia because it would stimulate their creativity and bring nostalgic memories.

The concept of Tunne, an interactive toolkit for folklore-storytelling therapy, is designed for main stakeholders - people with dementia, caregivers, and medical experts - to facilitate the therapy with physical and digital assistants, and to review and analyse the health data for more personalised caregiving. It is based on four customisable modules - Therapy, Interaction, Detection, and Service. All modules are interconnected to provide stimulative effects with people with dementia, high accessibility to dementia therapy and empowerment by playfulness with caregivers, and high transparency of health data through a digital healthcare system with medical experts.

Tunne could be developed further by a clinical evaluation with the approval of the ethic committee and consents of personal data usage towards implementation as a private/public service and other promising technologies such as touchless gesture interaction. It could also enhance the dementia research and development in the collaboration among designers, engineers, and all stakeholders.

KOKKUVÕTE

Dementsus on neuroloogiline ja progresseeruv haigus, mis mõjutab inimeste kognitiivset võimet omada igapäevaelu. Kuna see on sageli väärkoheldud kui tavaline vananemine, on sageli liiga hilja ravida, kui see on diagnoositud. Väiksemate riikidega võrreldes ravimeid on viimase paari aastakümne jooksul uuritud mitte-farmakoloogilise ravi, nagu mälu ja multi-sensoriaalne ravi. Jutuajamine on üks loomingulistest vahenditest, mida laialdaselt kasutatakse kommunikatsiooni edendamisel, ning see oleks kasulik dementsuse all kannatavatele inimestele, sest see stimuleeriks nende loovust ja tooks kaasa nostalgilisi mälestusi.

Kontseptsioon Tunne, interaktiivne tööriist folkloori-jutud teraapia jaoks, on mõeldud peamiste sidusrühmade - dementsuse, haldajate ja meditsiini ekspertide - jaoks, et hõlbustada ravi füüsilise ja digitaalse assistentidega ning vaadata ja analüüsida tervishoiuandmeid isiklikuma hoolduse jaoks. See põhineb neljal kohandataval moodulil - ravi, Interaction, Detection ja Service. Kõik moodulid on omavahel ühendatud, et pakkuda stimuleerivaid mõjusid dementsuse inimestele, kõrge juurdepääs dementsus ravile ja volitused mängitavus hooldajatega, ja kõrge läbipaistvus tervishoiu andmete kaudu digitaalse tervishoiusüsteemi meditsiini ekspertidega.

Tunnet saab edasi arendada eetikakomisjoni heakskiidul ja nõusolekul isikuandmete kasutamise rakendamisel era-/avaliku teenusena ning teiste paljutõotavate tehnoloogiate, nagu puudutamata žestide koostoime. Samuti võiks see suurendada dementsust teadus- ja arendustegevust koostöös disainerid, insenerid ja kõik sidusrühmad.

REFERENCES

1. United Nations, Department of Economic and Social Affairs, Population Division. 2020. World Population Ageing 2019
2. Prince M, et al. 2015. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends
3. Laura N. Gitlin, et al. 2016. Home-Based Interventions Targeting Persons with Dementia: What Is the Evidence and Where Do We Go from Here?
4. A.L. Bang, et al. 2012. The Role of Hypothesis in Constructive Design Research
5. Rikke Friis Dam and Teo Yu Siang. 5 Stages in the Design Thinking Process. Retrieved 23 May 2021, from https://www.interaction-design.org/literature/article/5-stages-in-the-design-thinking-process
6. Hasso Plattner Institute of Design. 2010. An Introduction to Design Thinking PROCESS GUIDE
7. Hazel May and Perrin Tessa. 2008. Wellbeing in Dementia: An Occupational Approach for Therapists and Carers, 2nd Edition, Churchill Livingstone
8. Helen C Kales et al. 2015. Assessment and management of behavioral and psychological symptoms of dementia
9. Laura N. Gitlin, PhD, et al. 2012. Managing Behavioral Symptoms in Dementia Using Nonpharmacologic Approaches: An Overview
10. J M Kiernat. 1979. The use of life review activity with confused nursing home residents
11. Ponnusamy Subramaniam, et al. 2012. The impact of individual reminiscence therapy for people with dementia: systematic review
12. Neal et al, 2003. Validation therapy for dementia
13. Iosief et al, 2017. Simulated presence therapy for dementia
14. Tudose et al, 2018. Creative Drama and Storytelling in Dementia Care: Information for Practitioner
15. Amy Bore. Auditory Stimulation Treatment for Dementia. Retrieved 23 May 2021, from https://www.soundforlife.com/blog/auditory-stimulation-treatment-for-dementia-0
16. Juliann Schaeffer. 2011. Recollection Through Sound
17. Dementia UK. 2020. Aromatherapy
18. Anke et al, 2015. How to make a Sensory Room for people living with dementia
19. Sunita et al, 2018. Art therapy for people with dementia
20. Melody, et al, 2001. A critique of research on the use of activities with persons with Alzheimer's disease: a systematic literature review

21. IAHAIO white paper 2014. The IAHAIO Definitions Animal Assisted Intervention and Guidelines for Wellness of Animals Involved
22. Merle,et al. 2019. Informal caregivers' experiences of caring for persons with dementia in Estonia: A narrative study
23. Ishii, 2008. The tangible user interface and its evolution
24. Nam, et al. 2016. Tangible Interaction Drawers for People with Dementia: Retrieving Living Experiences from Past Memories
25. Stephan, et al. 2019. Tangible Objects for Reminiscing in Dementia Care
26. Alexander, et al. 2017. Designing Interactive Music Systems with and for People with Dementia
27. Myrte, et al. 2019. Sentic: A Tailored Interface Design for People with Dementia to Access Music
28. Carlijin, et al. 2017. Closer to Nature: Interactive Installation Design for Elderly with Dementia
29. Jolijn van Sleeuwen. 2017. Geurenpalet in box, Dementia and Technology centre of expertise. Retrieved 23 May 2021, from https://www.rensbrankaert.nl/dt/portfolio/geurenpalet/
30. Studio Meineck. Music Memory Box. Retrieved 23 May 2021 from https://www.musicmemorybox.com/
31. Department of Linguistics, University of Colorado Boulder. Human Language Technology (HLT). Retrieved 23 May 2021, from https://www.colorado.edu/linguistics/current-students/graduates/human-language-technology-hlt
32. Sweta, et al. 2018. Detecting Linguistic Characteristics of Alzheimer's Dementia by Interpreting Neural Models
33. Aparna, et al. 2020. To BERT or Not To BERT: Comparing Speech and Language-based Approaches for Alzheimer's Disease Detection
34. Sanghyun, et al. 2020. Fusion-ConvBERT: Parallel Convolution and BERT Fusion for Speech Emotion Recognition
35. e-health. Invest in Estonia. Retrieved 23 May 2021, from https://investinestonia.com/business-opportunities/e-health/
36. Health and Welfare Information Systems Centre. Patient Portal. Retrieved 23 May 2021, from https://www.digilugu.ee/
37. e-estonia. E-health – Estonian Digital Solutions for Europe. 2016. Retrieved 23 May 2021, from https://e-estonia.com/e-health-estonian-digital-solutions-for-europe/
38. e-estonia. The best public sector digital service in Estonia is supporting doctors. 2021. Retrieved 23 May 2021, from https://e-estonia.com/the-best-public-sector-digital-service-in-estonia-is-supporting-doctors/

39. KreaShibai.de Retrieved 23 May 2021, from https://www.kreashibai.de/
40. MWP Design. Mid Century Tambour Door Cabinet. Retrieved 23 May 2021, from https://www.mwpdesign.com.au/tambour-door
41. Nielsen Norman Group. Service Blueprints: Definition. Retrieved 23 May 2021, from https://www.nngroup.com/articles/service-blueprints-definition/

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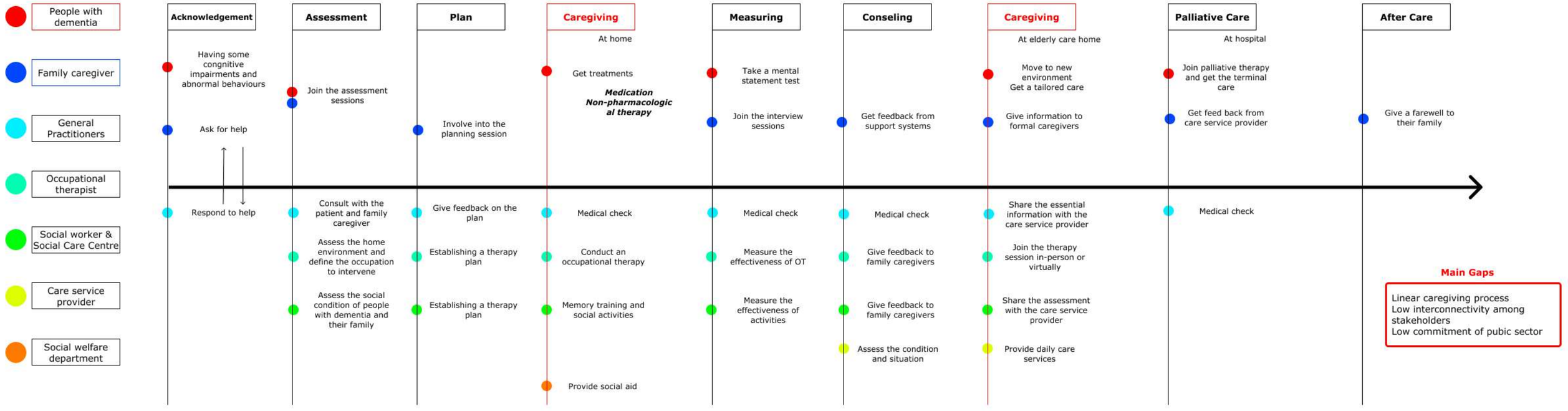
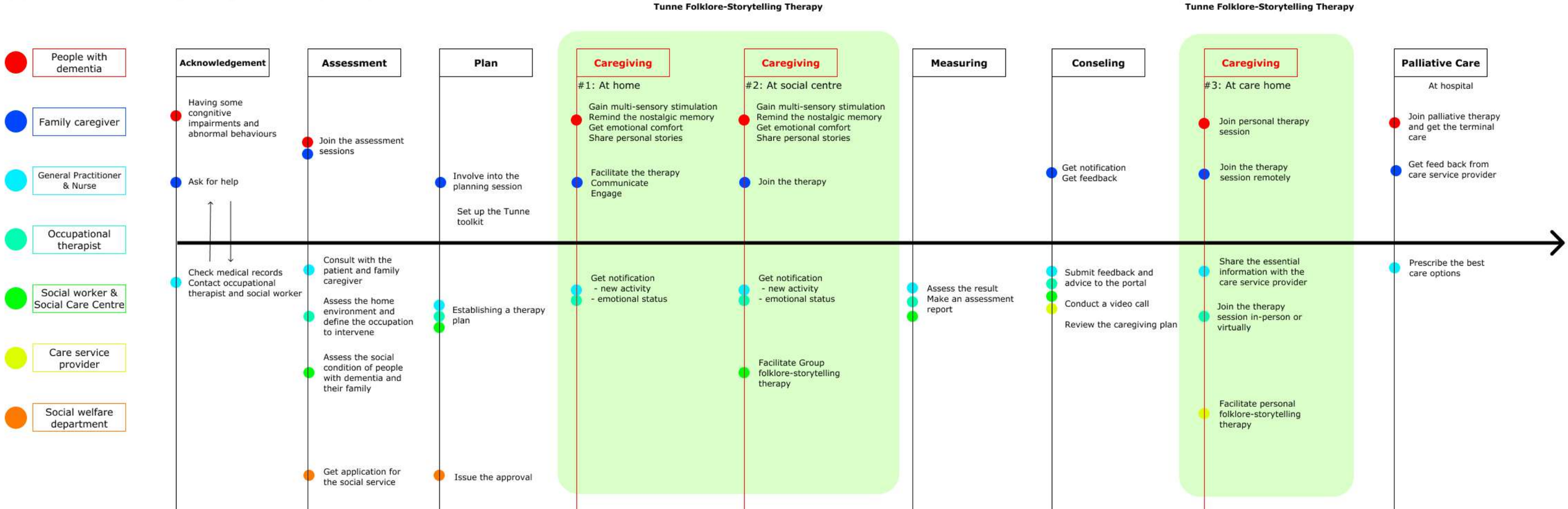
APPENDICES

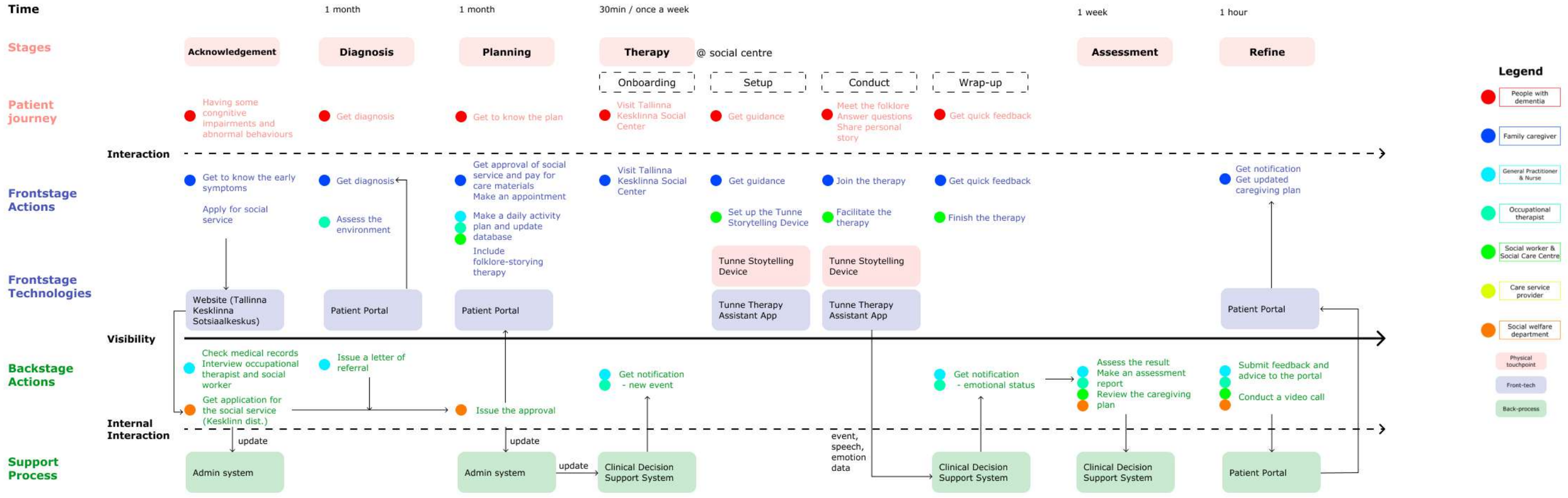
Appendix 1: Caregiving Journey Map



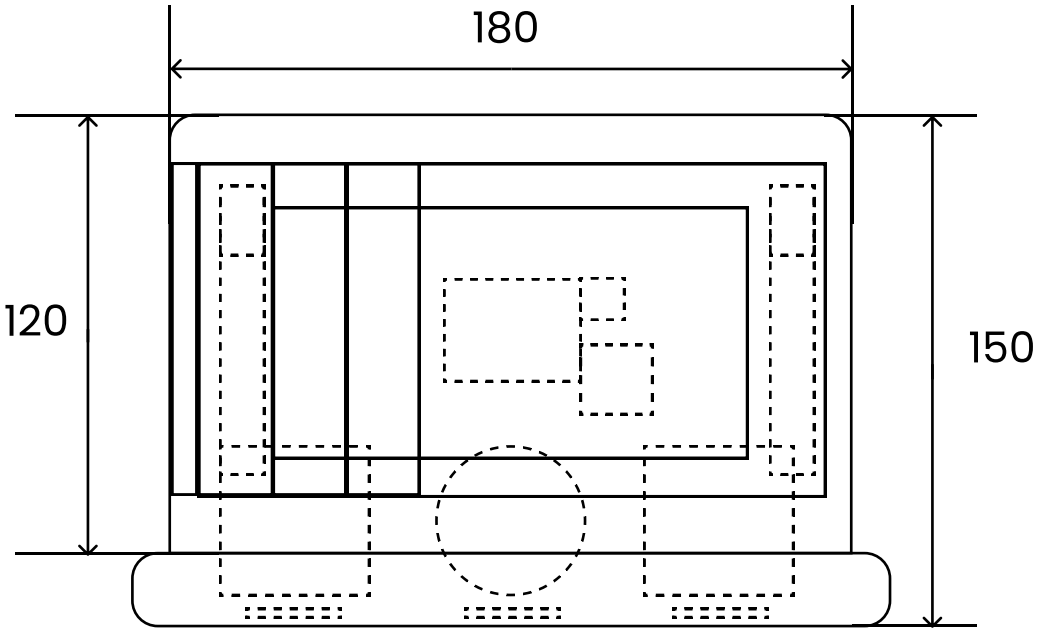
Appendix 2: Caregiving Journey Map with Tunne

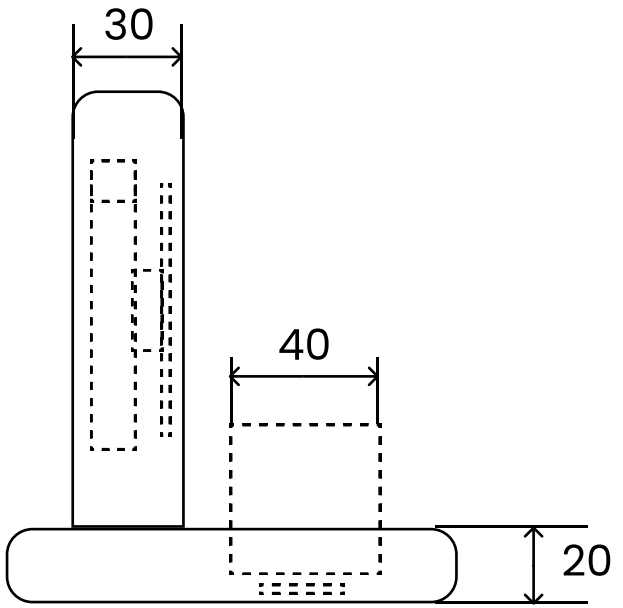


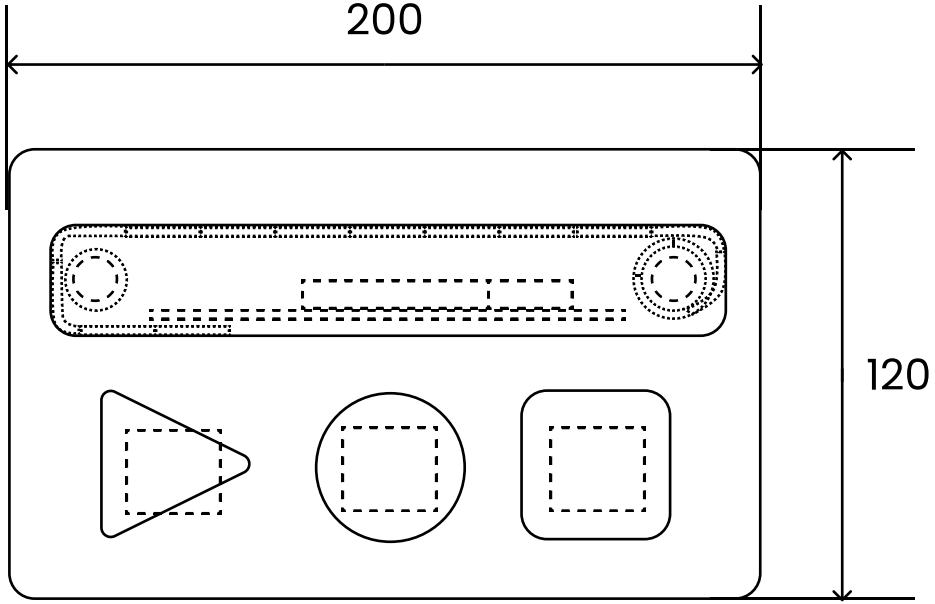
Appendix 3: Service Blueprint



Appendix 4: Technical Drawing







Isometric View (1 : 4)

material	scale	
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author	name	
Masato Kagiwada	TUNNE storytelling device	
Design & Technology Futures	sheet 1/1	date 24.05.2021