

**Towards Personalised Dementia Care
Approaches, Recommendations and Tools from Design**

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Towards Personalised Dementia Care:

**Approaches, Recommendations
and Tools from Design**

Gubing Wang

Towards Personalised Dementia Care: Approaches, Recommendations and Tools from Design

Dissertation

For the purpose of obtaining the degree of doctor
at Delft University of Technology
by the authority of the Rector Magnificus Prof.dr.ir. T.H.J.J. van der Hagen
chair of the Board for Doctorates
to be defended publicly on

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Keywords: Human-centered design; Dementia; Person-centred care; Ergonomics; Co-design; Data-enabled design; Design tools; Research through design; Personalisation; Personalised care

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EXECUTIVE SUMMARY

According to Person-Centred Care, as far as possible, people with dementia should be cared for in a way that takes into account their personality, life experiences and preferences. Personalisation is hence the core of Person-Centred Care, yet the approaches, recommendations and tools are lacking for this purpose. Therefore, the author investigated how this personalisation could be facilitated by design. Specifically, the author explored how to personalise the care for Behavioural and Psychosocial Symptoms of Dementia (BPSD). This is because BPSD contributes to the most stressful, complex, and costly aspects of dementia care. Non-pharmacological interventions for BPSD care have been developed, which offers ample room for personalisation.

From the field of healthcare, the author drew on Person-Centred Care, and from there, she looked at BPSD from the lens of the Need-driven Dementia-compromised Behaviour (NDB) model, where BPSD is interpreted as a way for people with dementia to express their unmet needs. Factors contributing to BPSD have been categorised by this model, which could be unique for each person with dementia. From the field of design, she approached the challenge from the lens of Human-Centered Design and explored three design approaches that are most relevant in designing for personalised BPSD care, namely, Ergonomics in Ageing, Co-design and Data-enabled Design.

The author hypothesised that a combination of these three design approaches could reveal insights into the factors contributing to BPSD, as mentioned in the NDB model, for each person with dementia exhibiting BPSD symptoms. She further hypothesised that gaining insights about these factors could facilitate the design of personalised dementia care. The author implemented a series of steps in evaluating these hypotheses from the literature and from the field. The learnings gained throughout the literature and field research enabled the integration of the three design approaches into Know-me, a toolkit for designing for personalised dementia care. The author concludes with a summary of research findings, a reflection on the research approach, and ends with recommendations for future work.

American spelling is used for Human-Centered Design to coincide with the name of the department that the author works in (Department of Human-Centered Design).

ACRONYM LIST

AI: Artificial intelligence

BPSD: Behavioural and Psychological Symptoms of Dementia

HCD: Human-Centered Design

(American spelling is used for this term to coincide with the name of the faculty the author works in)

IDE: Industrial Design Engineering

IoT: Internet of Things

IPS: Indoor Positioning System

NDB model: Need-driven Dementia-compromised Behaviour Model

PwD: People with Dementia

RtD: Research through Design



Introduction

1.1 CONTEXT AND USER GROUP

Person-centred dementia care

The World Health Organisation (WHO) predicted that the number of people living with dementia would be increased to 132 million by 2050 worldwide [1]. Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement [2]. These symptoms lead to an increased cost in governments, communities, families and individuals and a loss in productivity for economies [3].

In response, WHO initiated the global action plan on public response to dementia spanning from 2017 to 2050, aiming to improve the physical, mental and social wellbeing of People with Dementia (PwD), their caregivers and families [1]. This plan highlighted that the current gap between the care needed by PwD and the care provided to them is wide [1]. As dementia progresses, impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour, or motivation [2], which add extra challenge and burden to dementia care. Around the 1990s, there was a movement in the field of dementia care, suggesting that PwD should be cared for in a person-centred manner. The “person-centred” perspective on dementia care was introduced in the care practice by Kitwood [4], where “the personality, past experiences, health, and other aspects of the person with dementia also influence how the person will behave in addition to neurological impairments”. Hence, neurological impairment is important, but not the only component to be considered when caring for PwD. Each person with dementia is different, they do not lose their individuality, and therefore, as far as possible, PwD should be treated in an individualised way, taking into account their personality, life experiences and preferences. Therefore, personalisation is the core of Person-Centred Care.

Design for personalised dementia care

In the field of design, personalisation has been found to have positive impacts on person-centred dementia care [5]. First, personalisation can provide cues to the identities of PwD. Secondly, it provides reminiscence tools for family members and friends to use to communicate with the person with dementia. Thirdly, in the nursing home setting, it helps care staff to see the residents as individuals with their own experiences. There might be a bigger role for designers in developing personalised dementia care. In this thesis, personalised dementia care is defined as the care focusing on personal aspects of PwD, which is a key component of Person-Centred Care.

It is indeed challenging to design for PwD, as most of them can no longer express what they want and how they feel due to their cognitive impairments. Despite this difficulty, some researchers and designers have been investigating how to manage the most stressful, complex and costly aspects of dementia care [6], that is, the care for Behavioural and Psychological Symptoms of Dementia (BPSD). Specifically, 97% of PwD will develop at least one behavioural or psychological symptom over a five-year period [7]. These symptoms include agitation, aggression, depression, apathy etc. [8]. BPSD has been identified as a predictor of nursing home placement [9]. This is because the severity of BPSD usually exacerbates over the course of dementia. Hence, most people in the moderate to late stages of dementia who require nursing home care will also require care for symptoms of BPSD [10]. The context of this doctorate is set on designing for personalised dementia care, with special attention to personalised BPSD care in nursing homes.

Antipsychotic medications are frequently prescribed to relieve BPSD symptoms in nursing homes, yet, they have serious side effects such as increased mortality and stroke occurrence [11]. Consequently, non-pharmacological interventions (also referred to as “interventions” in this thesis) have been developed in an attempt to reduce the use of antipsychotic medication in the care of BPSD. Nowadays, an increasing number of studies has been focusing on personalising these non-pharmacological interventions [12-15]. However, the perceived workload for implementing personalised interventions is high. For instance, when asked to identify hindering factors for implementing a personalised Snoezelen therapy (an intervention aimed to soothe or activate PwD by providing multisensorial stimulations), caregivers ranked “perceived workload” as the highest hindering factor [15].

- **Designs by professional designers**

To address the high perceived workload during personalising dementia care, designs for facilitating personalised interventions for BPSD care need to be explored. The author uses “facilitating” instead of “developing” because designers usually do not have the expertise and budget to develop an intervention, which involves gathering evidence on its effectiveness from large sample double-blind, randomised controlled trials. Rather, designers are good at providing new insights to existing practices and coming up with designs that facilitate the delivery of current interventions. For example, inspired by Snoezelen therapy, Tovertafel (In English: Magic Table) was designed to use playful and interactive light projections and music to activate PwD who are apathetic to move [16]. Tovertafel makes Snoezelen therapy more accessible in nursing homes. With clicking a button and a few guidance, the senses of PwD can be stimulated appropriately at the table. Regarding personalisation, it offers a wide range of games, some of which could be tailored by the family members, and the favourite games of the person could be chosen for a personalised intervention. In comparison, in traditional Snoezelen

therapy, a Snoezelen therapist and a dedicated room is usually required for ensuring the stimuli received by PwD is appropriate. Although a few designs, such as Tovertafel, has helped many PwD with their quality of life, the designs for facilitating personalised interventions for dementia care and specifically BPSD care are scarce on the market. At the beginning of her PhD, the author did a market review of the largest online store for dementia care in the Netherlands (dementie-winkel.nl). This store contained more than 1000 products and services for PwD, yet only 37 of them were identified to contribute to BPSD care, and few of them can be personalised easily. The details of these products and services can be found in Appendix A.

- **Designs by healthcare professionals**

The author also found that these commercial products and services are rarely used in nursing homes (she has visited nursing homes in the Netherlands, China and the United Kingdom at the beginning of her PhD). According to the care teams, these commercial products and services are not always affordable, difficult to troubleshoot, and sometimes the residents lose interest in them quickly. Instead, some care teams made personalised designs themselves for their residents. For example, according to the observation notes made by the author in a nursing home in China, a caregiver has invented a beanbag game with a person with dementia (the full observation note can be found in Appendix B). Throwing and catching a hand-held beanbag is a common game played among children in China. Yet, not all PwD would like to play the beanbag game for reminiscence. This person with dementia, however, showed great interest in playing the beanbag game, so that this game was kept as a physical exercise for reducing her apathy. Such tailor-made solutions are inspiring and effective, yet these are often not reported in nursing homes and hence not applied on a big scale. From this example, it can be seen that creating effective personalised designs does not need sophisticated materials and techniques, and the creators are not necessarily professional designers. These creators are usually healthcare professionals who know the residents well and have rich experience in interacting with them. More healthcare professionals should be empowered in creating more personalised designs for PwD as well.

The research question

To conclude, within the context of designing for personalised BPSD care in nursing homes, the author aimed to answer the main research question:

What are the design approaches, recommendations, and tools that could facilitate personalised dementia care?

“Personalised dementia care”, “Personalised interventions”, and “Personalised design” have similar connotations in this dissertation. A personalised design for a person with

dementia might enable an intervention to be carried out in a personalised manner for this person and hence contribute to the personalised care the person receives.

The target audience

The answer to the research question is valuable to both professional designers and healthcare professionals caring for PwD (e.g., doctor, caregiver, psychologist, dietitian etc.). In this thesis, “caregiver” implies professional caregivers in the nursing homes and “care team” implies the team in which these healthcare professionals are working together. Hence, the author aimed to empower professional designers and healthcare professionals with the findings of this doctorate and involved them in the research process.

The approaches and the set of recommendations and tools generated could be used by both the creative industries and healthcare providers for personalising non-pharmacological interventions and for personalising dementia care in general. For instance, the professional designers could, by co-designing with the care teams, develop products, services, and product-service systems for offering personalised BPSD care. Through this process, care teams could learn about the role of design in personalising dementia care, gain insights about their residents, and realise their important roles in the design process. The care teams could then use these insights themselves for developing and adapting their working procedures, interaction strategies, interior environments for delivering personalised BPSD care.

1.2 RESEARCH METHODOLOGY

The theoretical framing of this doctorate was based on the synergy of the discipline of healthcare and the discipline of design. The framework of this doctorate is shown in Figure 1, and how these two disciplines are integrated will be introduced below.

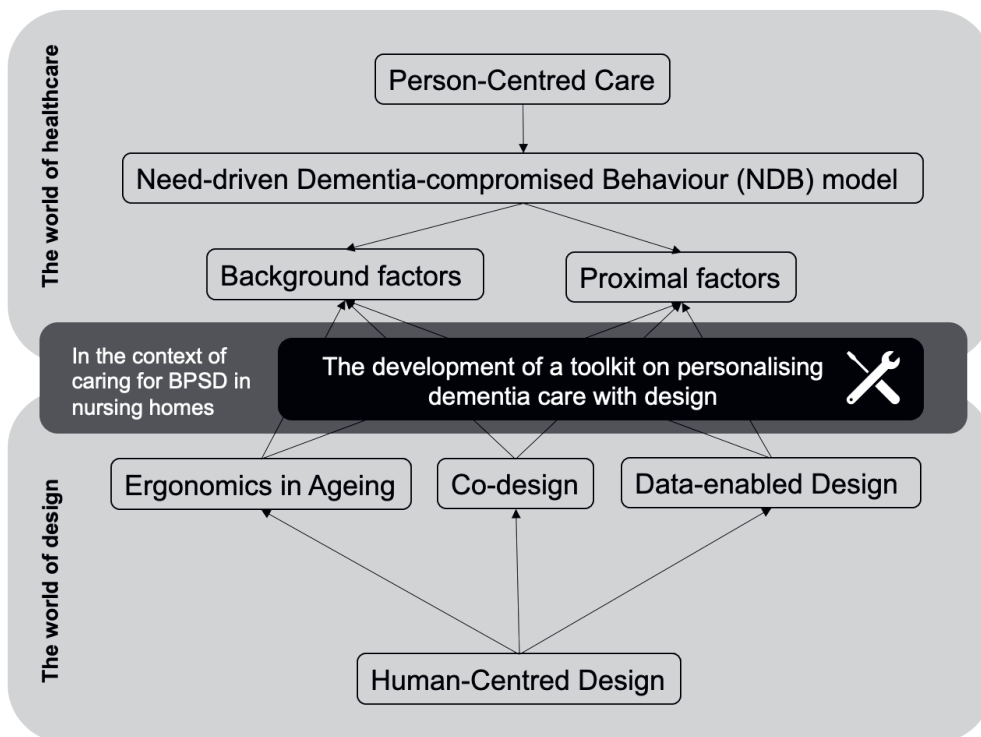


Figure 1. The framework of the doctorate.

From the Person-Centred Care perspective

The concept of the person being central is increasingly emphasised both in practice and academia as an approach to deliver high-quality care to PwD. The essence of Person-Centred Care is to recognise the personhood of the PwD in all aspects of their care. This generally includes acknowledging that the personality of the person is increasingly concealed rather than lost as dementia progresses, personalising the care and the environment around the person, interpreting the symptoms from the perspective of the person, and offering shared decision-making [18]. The current practice and knowledge of Person-Centred Care have crystallised into a few theoretical models [19-22]. The Need-Driven Dementia-compromised Behaviour (NDB) model has been proposed by Algate et al. in 1996 and is the most-cited model for explaining BPSD (Figure 2). According to the NDB model [19], BPSD is a way for PwD to express their unmet needs and goals. Paying close attention to these symptoms could help one to identify how PwD feel and what they want. Hence, fortunately, BPSD might lead designers to understand the needs and feelings of PwD. The author hypothesises that paying close attention to these BPSD symptoms for each person with dementia could enable designers to come up with ways to address specific unmet needs for each individual and thus contribute to personalised BPSD care.

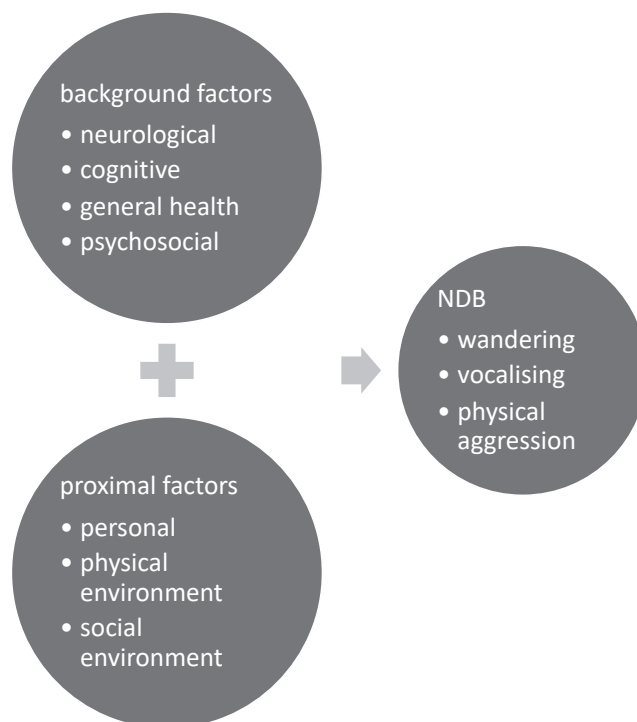


Figure 2. Need-driven Dementia-compromised Behaviour (NDB) model (Adapted from [19]).

As shown in Figure 2, the factors contributing to BPSD are categorised into “background” and “proximal” according to the NDB model [19]. The background factors are the **root causes** of BPSD, which include neurological, cognitive, general health and psychosocial factors. Specifically, the neurological factors include regional damages in the central nervous system, neurotransmitters imbalance, circadian circuitry impairments and motor ability decline. The cognitive factors include the declines in memory, attention, perceptual and sensory skills, and language. As for general health factors, BPSD symptoms are positively correlated with declines in general health and functional ability and negatively correlated with the positive affective state. The psychosocial factors are even more diverse and include gender, education, occupation, personality type, history of psychosocial stress and personal behavioural response to stress.

The proximal factors are the **triggers** of BPSD and contain personal factors, factors in the physical environment and factors in the social environment around the person. The personal factors include negative emotional states of the person, unmet physiological needs and a mismatch between functional ability and functional performance.

The factors in the physical environment around the person include light level, noise level, and temperature; the factors in the social environment contain ward ambience, caregiver stability and caregiver demeanour.

From this model, one can see that the unmet needs of two persons with dementia could be very different due to their own background and proximal factors, which highlights the importance of personalisation in Person-Centred Care.

From the Human-Centered Design perspective

As Herbert Simon stated in 1996, “design” is about changing existing situations into preferred ones [24]. Hence, not only physical products but also services, procedures, rituals, strategies and policies are considered as the outcome of “design”. To take care of this broad field, design researchers have developed a range of mindsets, approaches, processes, methods, principles and tools to facilitate designers. The author focused on Human-Centered Design (HCD), which is a group of methods and principles aimed at supporting the design of useful, usable, pleasurable and meaningful products or services for people (“product or services” here acts as a shorthand for “any outcome that can change existing situations into preferred ones”). This is because the mindset of HCD coincides with that of Person-Centred Care; to be specific, both disciplines keep the “human” or “person” in the centre of their working process. This choice was also based on the research context that the author is in. The author is a member of the Department of Human-Centered Design within the Faculty of Industrial Design Engineering (IDE) at Delft University of Technology (TU Delft), where researchers and students are exploring and implementing HCD in real-world contexts.

There is a large variety of HCD methods and principles, each having its own specific purpose within a specific design context. The essence shared by these methods and principles is describing how to gain and apply knowledge about human beings and their interactions with the environment to design products or services that meet their needs and aspirations [25]. The author has chosen three design approaches from HCD as potential candidates in personalising dementia care, which are Ergonomics in Ageing, Co-design and Data-enabled Design. Each design approach describes ways for how to go about a design activity and offers a comprehensive design process that spans across phases [23]. The author will begin with a brief history of HCD and then explain her choice of the three design approaches.

HCD starts with the earliest reported formal methods that put human beings at the centre of the design process, which was developed after the Second World War, to increase the efficiency of industrial production by “fitting the task to the worker” and led to the establishment of the discipline: Ergonomics (also referred to as Human Factors or Human Factors and Ergonomics) [26]. Its underlying working principle was

introduced to the broader consumer product design field by Dreyfuss in the fifties, who spearheaded the creation of anthropometric data sets about the population [27].

Ergonomics in Ageing (also referred to as Design for Ageing), a sub-discipline of Ergonomics, is about how products and services could be designed if they are to be used safely and effectively by older adults [28]. To start from an informed position about how to design for PwD, the author reviewed literature in Ergonomics in Ageing. This is because there was no ergonomics study specifically about PwD back then, and the majority of PwD are older adults (i.e., over the age of 65). Ergonomics in Ageing could facilitate the personalisation of dementia care by raising the awareness on the capability declines of PwD, their remaining capabilities, and how these capabilities differ from person to person.

Originated from the Scandinavian participatory design movement in the 1990s, **Co-design** is about involving users and other stakeholders as partners in the design process. This is because some designers began to acknowledge the creativity of people who are not trained in the design field but are the experts of their lived experiences [29]. The author would like to tap into the lived experiences of PwD to understand their needs and wishes from a person-centred way, and she hypothesised that co-design would help with her fulfilling this goal. Co-design could also allow the author to pay close attention to each person with dementia, which contributes to personalised dementia care.

Data-enabled Design has recently been developed since personal data can be collected more securely and reliably by sensors. Coined by Bogers and van Kollenburg, Data-enabled Design is about using quantitative data collected by sensors and qualitative data collected by users as creative design materials, which can inspire and inform the design process [30]. The author finds that, with Data-enabled Design, designers and healthcare professionals can reach out to the insights beyond the capabilities of human eyes; and she hypothesised this could offer an additional perspective to understand each person with dementia. Besides, given the progressive nature of dementia, Data-enabled Design could keep track of the current status of each PwD and thus enable the personalisation to be up to date.

Connecting the two perspectives for personalising dementia care

Putting the theories into context, the author hypothesised that, for each person with dementia exhibiting BPSD symptoms, a combination of the three design approaches mentioned above could reveal insights in both the background and proximal factors mentioned by the NDB model. The author further hypothesised that the insights about these NDB factors could facilitate the design for personalised BPSD care. This exploration was done under the context of personalising BPSD care with design, and

the findings could contribute to design for personalised dementia care in general. A design toolkit for personalising dementia care was hence developed by crystallising knowledge gained from theories and practice during this doctorate. How each design approach is hypothesised to contribute to the NDB factors is briefly described in the below section.

- **NDB model and Ergonomics in Ageing**

From an ergonomist's view, the capabilities of PwD and the affordance of the interventions should match for optimising the effect of the interventions and wellbeing of PwD. Capability is an umbrella term used in ergonomics to describe one's ability in sensory, cognition, and movement aspects when interacting with a system [31]. Even though PwD tend to have reduced capabilities in many aspects owing to ageing and the diseases they have, designers could take these capability declines into account and explore the remaining capabilities of PwD. With reference to the NDB model, studying these remaining capabilities could inform designers about the neurological factors, cognitive factors and general health factors of a person with dementia.

- **NDB model and Co-design**

Increasingly more designers involve PwD during Co-design by paying close attention not only to what they say but also to how they react towards a design [32-34]. In these studies, caregivers were usually invited to give explanations on the behaviours of PwD [32-34]. Referring back to the NDB model, the designers might get to know more about each person with dementia in terms of his/her psychosocial factors from the caregivers, such as one's education, occupation, personality type, history of psychosocial stress and personal behavioural response to stress.

- **NDB model and Data-enabled Design**

According to Data-enabled Design, Internet of Things (IoT) technology can enable designers to gather more types of continuous personal data about each person with dementia over a long period of time [30]. In addition, designers can combine quantitative data collected by sensors with qualitative data generated by the care teams (e.g., daily reports) to form a more comprehensive picture about the current state of each person with dementia and the context the person lives in, which corresponds to the proximal factors in the NDB model, i.e., personal needs, physical and social environments.

1.3 RESEARCH APPROACH

Throughout the doctorate, the author evaluated, adjusted and refined this preliminary answer to the main research question through a Research through Design (RtD) approach whereby "design activities play a formative role in the generation of knowledge" [35].

In answering the main research question, the author draws on the strength of RtD as a reflective practice. Through reflecting on the insights gathered along the process, the direction of the project will be adjusted iteratively and become more detailed. This phenomenon is referred to as “drifting”, an embedded way of arriving at relevant and high-quality work in design research [17]. Therefore, started from the main research question, the author evaluated this research question at each stage of the research process to generate detailed sub research questions that are relevant for each stage. There are seven sub research questions in total. From Chapter 2 to Chapter 8, each chapter is dedicated to illustrating the answer to each sub research question:

Chapter 2. What are the current non-pharmacological interventions for BPSD management, and if (and how) they incorporated ergonomics?

Chapter 3. If (and what) design recommendations for personalising non-pharmacological interventions for people with dementia could be generated from the literature on Ergonomics in Ageing?

Chapter 4. If (and what) design recommendations for co-designing with people with dementia could be generated from the design research studies that involved people with dementia as partners?

Chapter 5. If (and how) could recommendations on Co-design and Ergonomics in Ageing be applied in the field to facilitate non-pharmacological interventions for BPSD, and what does this imply on these recommendations in personalising dementia care? (Prototype De-light is developed)

Chapter 6. What types of data could be combined for personalised BPSD care in nursing homes, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team for analysis? (Prototype Data-care is developed)

Chapter 7. What are the values of Data-care after a longer implementation period in the field, and what does this imply for the Data-enabled Design approach in personalising dementia care?

Chapter 8. How could the learnings from Ergonomics in Ageing, Co-design and Data-enabled Design be integrated into a toolkit for personalising dementia care, and what is the perceived usefulness of the toolkit?

To understand the connections between these sub research questions, please see the cover page of each chapter where the sub research question is situated in.

The prototypes generated in the RtD process are not aimed to be developed into products on the market; rather, they act as instruments for the author to obtain answers to the research questions. The author hypothesised that this approach could guide her to a more general understanding of designing for personalised dementia care, which could lead to a broader application instead of an immediate commercial opportunity.

The prototypes developed in this doctorate played three roles. First, the prototypes act as a way to let users experience a future situation. Since design's common ground is about creating preferred future situations, it is vital for the users to experience them to give feedback on the designed situations easily. Secondly, these prototypes have the role of connecting abstract theories to concrete experiences. Users could better answer questions from the author by reflecting on their experiences enabled by the prototypes. Thirdly, these prototypes act as a carrier for interdisciplinary discussions. Since this research encompasses design, technology, and healthcare, the prototypes could connect professionals with different backgrounds by showcasing how these design approaches, recommendations, and tools could be used in real-life situations.

1.4 THE TECHNOLOGY INVOLVED

In Data-enabled Design, sensor data (mainly quantitative) needs to be collected together with qualitative data. The author hence applied an IoT technology for sensor data collection - Indoor Positioning System (IPS). IPS is a technology developed to collect the location data of people and moving object in real-time and can store the data for analysis afterwards [36]. The author has paid special attention to the ethics of involving PwD and the care team with this technology, which is described later on in the thesis.

IPS was selected because, among sensor data, location data has been used for monitoring BPSD and is also recognised as central to the context in BPSD management [37]. Specifically, not only movement patterns but also other relevant parameters (e.g., travelled distance, interaction time with others) could be derived from location data.

Linking back to the NDB model, the data collected could help designers to understand more about the current state of each person with dementia and the physical and social environments the person is in. For instance, walking distance can reflect how physically active a person is and could potentially inform designers on some behavioural and psychological symptoms, such as wandering, restlessness, and apathy. Moreover, after the initial field visit, the designers usually have developed an impression about the noise, lighting, temperature, crowdedness and decorations at different locations in the ward; hence the designers can, to some extent, deduce what kind of physical environment the person is in given the location data of the person. Last but not least, the number of

people that a person with dementia has contact with and the duration of these contacts could indicate the ward ambience and caregiver stability around the person, which constitute parts of the social environment around this person. In summary, location data collected by IPS could help one to generate insights on the proximal factors about each person with dementia, which coincides with what the author envisioned about the role of Data-enabled Design.

The IPS used in this doctorate was provided by PinXact, a start-up company in Delft. The author acknowledges that applying IPS only serves as a starting point and the first case in exploring the value of Data-enabled Design in personalising BPSD care. Moreover, since the location data constitute a big part of the understanding of BPSD, the author would argue the choice of IPS laid a solid foundation for future researchers who aim to explore other types of IoT technologies for personalising BPSD care.

1.5 THE RESEARCH FIELD

During this doctorate, the author focused on her field studies in the nursing home Zorggroep Elde Maasduinen, which is located near the city centre of Boxtel, the Netherlands. Zorggroep Elde Maasduinen is a large-scale nursing home with dedicated wards for PwD, among which there is a special ward (the Oleander) caring for residents exhibiting BPSD symptoms. The Oleander was chosen to be the main research field for this doctorate since it offers a typical case about BPSD care in an institutional care setting. In the Oleander, the care team studies the BPSD symptoms of each resident through observation, reporting and discussion to identify possible ways of managing these symptoms. The care team regards each resident as a unique individual. Contextual information concerning the culture of Zoreggroep Elde, the ward ambience of the Oleander, and the working structure of the care team is provided in Appendix C.

The author is aware that the knowledge generated from this doctorate is context-specific. To achieve a broad perspective about the living environment of PwD, she has visited a few nursing homes in the Netherlands, China and the United Kingdom in the first year of her doctorate. She noticed the differences in cultures across countries and also in organisational cultures among these nursing homes. Later on, she took these into considerations during her doctorate. The author does not argue that the knowledge in this thesis could be applicable to all the nursing homes; since the awareness of Person-Centred Care differs across nursing homes, and Person-Centred Care is not always feasible due to limited resources and different priorities for some nursing homes. Yet, her work in Zorggroep Elde Maasduinen offers a valuable starting point for investigating how to support personalised BPSD care with design and technology.

1.6 RELEVANCE OF THIS RESEARCH

The main contribution of this doctorate is the development of a design toolkit for personalising dementia care grounded in the findings of Ergonomics in Aging, Co-design, and Data-enabled Design from the literature and from the field. With this toolkit and the findings, designers and healthcare professionals could be empowered to design for personalised care to PwD.

In the healthcare field, the tools for facilitating care personalisation are becoming increasingly data-driven [38]. These tools are mainly digital and often applied in chronic condition management, such as cancer [39], physiotherapy [40], cardiovascular disease [41] and elderly care [42]. The patients are usually required to be cognitively able to set personalised goals and reflect on the data together with healthcare professionals. However, people in moderate to late stages of dementia usually have difficulties with goal setting and communication in general. As far as the author is aware, tools for personalising dementia care are lacking until now. Specifically, healthcare professionals in dementia care are mainly facilitated by training courses [43] and protocols [44] for delivering personalised care. The developed toolkit could be augmented with the current training and protocols and hence facilitate healthcare professionals to personalise care for PwD

In the design field, an increasing number of design tools have been created for dementia care. Yet, systematic toolkits for designing for dementia care are limited. To the author's knowledge, there are currently two projects that have developed toolkits for designing for dementia care, i.e., LAUGH [45] and MinD [46]. The toolkit developed by MinD focuses on design for PwD as a user group. Some tools are more focused on how to involve PwD in the design process [47][48], while others are guiding designers to consider the physical capabilities, and psychological and social needs of PwD [49]. The Compassionate Design Toolkit by LAUGH is the first and only toolkit so far to guide designers in creating personalised designs for PwD, which is focused on the senses and life history of PwD [50]. However, personalised designs have long been regarded as expensive and have low social impact. Thankfully, with the development of technology, personalised designs are becoming more prevalent, as exemplified by smart speakers, recommendation systems, fitness trackers and other products and services that can adapt to individual's preferences, behaviours, and experiences effortlessly [51]. These products and services point out a direction for the development of personalised designs for PwD to be more comprehensive, low-cost and, hence having a higher socioeconomic impact.

The Know-me toolkit was developed to further address the challenges faced by both healthcare professionals and professional designers. For healthcare professionals, this

toolkit could be augmented with current training and protocols and hence facilitate personalised care for PwD. For professional designers, this toolkit could introduce the data-driven direction for personalisation to help designers in designing personalised dementia care. In comparison to the toolkits by MinD and LAUGH, the Know-me toolkit adds the component of data-driven direction for personalisation and guides designers and healthcare professionals to work together for personalising dementia care. These features make the Know-me toolkit suitable to be applied in design scenarios where; both designers and healthcare professionals will be involved; sensor data can be collected from PwD under ethical considerations; the design outcome is to achieve personalised dementia care. We consider the “Know-me” toolkit as an addition to the toolkits developed by LAUGH and MinD.

1.7 DISSERTATION OUTLINE

The author implemented a series of steps in answering the main research question, which is structured as the chapters of this dissertation. The structure of the thesis and the relationships between the different chapters is shown in Figure 3. Several chapters are based on accepted publications (Chapters 2,3,4,5,6,7,8). Each chapter is preceded by a short introduction (i.e., the cover page) for ensuring a coherent and clear storyline throughout the dissertation.

Specifically, a systematic review was conducted first to comprehensively examine the status quo of managing BPSD with non-pharmacological interventions from an ergonomics perspective (Chapter 2, [52]). More theoretical research was then carried out in the directions of Ergonomics in Ageing and Co-design, which resulted in design recommendations on capability considerations (Chapter 3, [53]) and design recommendations on co-designing with PwD (Chapter 4, [54]). Afterwards, these design recommendations were applied and evaluated in the field, which leads to De-light, an interactive device for managing wandering behaviours exhibited by some PwD (Chapter 5, [55]). Later on, Data-enabled Design was being explored in the field. Guided by Data-enabled Design, a digital platform (named Data-care) was developed for facilitating personalised BPSD management in the nursing home (Chapter 6, [56]). The effect of Data-care on personalising BPSD management was then studied during a longer-term implementation in the nursing home, which helped the author to further reflect on the implication of Data-enabled Design in personalising dementia care (Chapter 7, [57]). De-light and Data-care are the design outcomes of the RtD approach, so they are prototypes for helping the author to obtain answers for the research questions and not aimed at the market. The learnings gained throughout the literature and field research enabled the integration of the three design approaches into Know-me, a design toolkit for

designing personalised dementia care, which was then evaluated in student projects for dementia care. The current landscape of designing for personalised dementia care was also drawn to situate this toolkit (Chapter 7, [58]). The author concludes this thesis with a reflection on the three design approaches and their relationships, thereafter with an envisage of the value of the Know-me toolkit. She ends with a reflection of the RtD approach and recommendations for future work (Chapter 9).

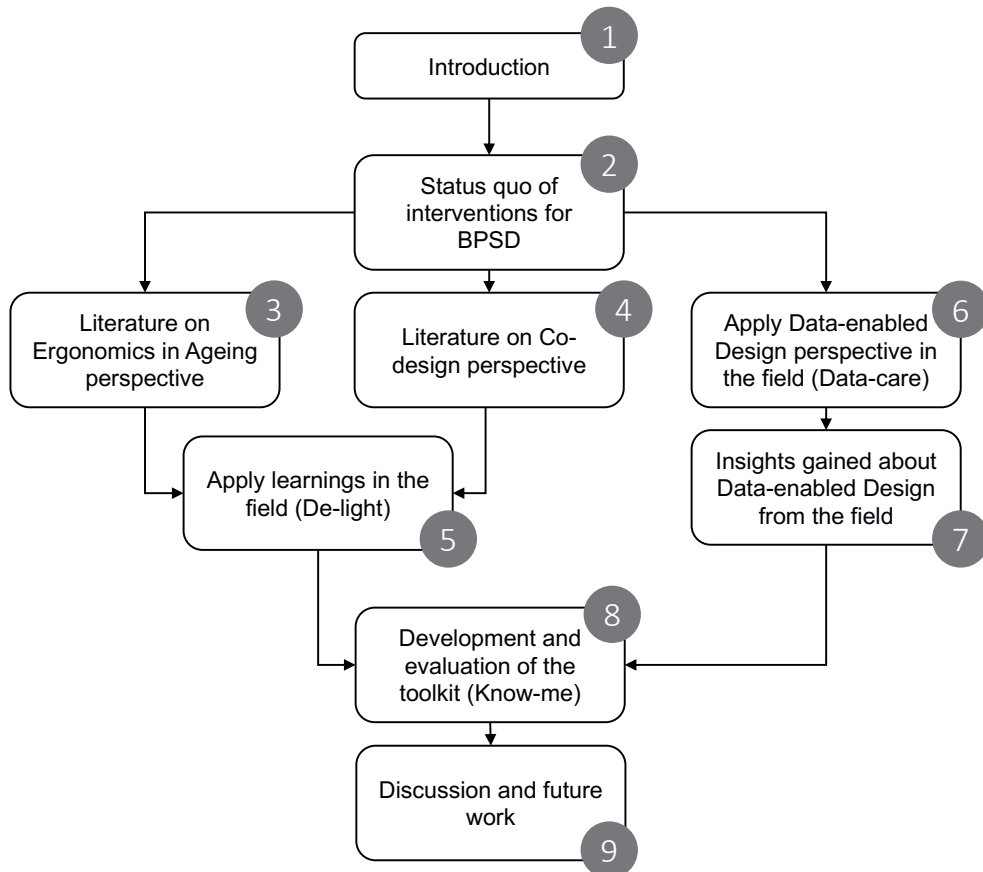


Figure 3. Dissertation outline.

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The status quo

The author first researched the status quo in the field of non-pharmacological interventions for BPSD management and engaged with ergonomics literature to answer the below sub research question:

What are the current non-pharmacological interventions for BPSD management, and if (and how) they incorporated ergonomics?

This chapter presents a systematic review of current non-pharmacological interventions for BPSD management in nursing homes. Based on ergonomics literature, the author categorised the reviewed interventions into sensory-, cognition-, and movement-oriented according to the main capabilities required for people with dementia to participate in these interventions. This review reveals that the evidence of the effectiveness of these interventions is low, and the consideration of ergonomics in these interventions is lacking, specifically in terms of capability considerations and the involvement of people with dementia. The supplementary files mentioned in this chapter can be accessed from the original publication online via the DOI provided.

ABSTRACT

Background: Non-pharmacological interventions for Behavioural and Psychological Symptoms of Dementia (BPSD) have been developed; however, a systematic review of the effectiveness of this type of intervention from a perspective of ergonomics is lacking. According to ergonomics, the capabilities of People with Dementia (PwD) should be considered in the interventions for the outcomes to be reliable. We aimed to systematically review the non-pharmacological interventions for BPSD in nursing home residents with an additional assessment criterion based on ergonomics, specifically, capability consideration.

Methods: The electronic databases MEDLINE, EMBASE, and PsycINFO were searched for non-pharmacological interventions treating BPSD in nursing homes. The interventions were categorised according to the capabilities of PwD required to participate. Study quality was assessed by the National Health and Medical Research Council (NHMRC) evidence hierarchy and the capability consideration.

Results: Sixty-four clinical trials met the inclusion criteria; 41 trials reported a significant reduction in at least one BPSD symptom; 20 trials reported no significant reduction in BPSD symptoms; three trials reported adverse effects after the intervention. Interventions were categorised into sensory-, cognition-, and movement-oriented. Capabilities of PwD were not considered in 28 trials, especially for sensory capabilities.

Conclusions: The majority of the clinical trials reported a significant reduction in BPSD. The quality of evidence for non-pharmacological interventions in these trials is low due to the lack of capability consideration, data inhomogeneity, and inadequate study design and reporting. Future studies should focus on improving the quality of evidence by including capability consideration and examining if a relationship between capability consideration and effectiveness of non-pharmacological interventions exists.

2.1 INTRODUCTION

Over 80% of People with Dementia (PwD) will develop Behavioural and Psychological Symptoms of Dementia (BPSD), also referred to as neuropsychiatric symptoms, during the course of their disease [1], with 97% of PwD developing at least one symptom over a five-year period [2]. BPSD is defined as “signs and symptoms of disturbed behaviour, mood, thought, or perception” [3]. The Neuropsychiatric Inventory–Questionnaire (NPI-Q) has categorised the reported signs and symptoms into delusions, agitation/aggression, depression/dysphoria, anxiety, hallucinations, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviours, and disturbance in appetite/eating [4]. BPSD could induce physical injuries and psychological distress in PwD and their caregivers, and it is identified as a predictor of nursing home placement [5]. In nursing homes, caregivers have reported responding to PwD exhibiting BPSD symptoms with verbal or physical abuse or to minimise contact with them, thus reducing the quality of care received by PwD [3]. Nursing home administrators could face increased financial costs due to increased medical and psychological care, security concerns, and staff turnover [3]. Therefore, effective management of BPSD needs to be identified and applied, especially in the nursing home setting.

Antipsychotic medication has been applied to manage BPSD, which has been shown to have low efficacy and serious side effects, such as increasing fall risk, mortality rate, and stroke occurrence [6,7]. As a result, non-pharmacological interventions have been developed to act as an alternative to antipsychotic medication. This study proposes a hypothesis that new insights could be gained if the non-pharmacological interventions and their clinical trials are also reviewed and assessed from a perspective of ergonomics. Ergonomics studies “the interactions between humans and other elements of a system, and applies theories, principles, data, and methods to design for optimising human well-being and system performance” [8]. Human performance depends on the person’s capabilities and limitations, while the system has its own requirements and affordances. These requirements and affordances need to match the capabilities and limitations of the target population for the outcome of the system to be reliable. From an ergonomist’s view, non-pharmacological interventions could be regarded as the system. The remaining capabilities of PwD and the requirements of the interventions should match for the outcome of the clinical trial to be reliable. Capability is an umbrella term used in ergonomics to describe one’s ability in sensory, cognition, and movement aspects when interacting with a system [9]. One needs certain levels of capabilities to be able to perform certain cognitive and functional activities, namely Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL).

Several systematic reviews have reviewed and assessed the quality of the clinical trials to conclude on the quality of evidence on the effectiveness of each intervention. Abraha et al. found that music therapy and behavioural management techniques are effective in managing BPSD, in general, while the evidence base is weak due to variations in the application of the interventions and measurements [1]. Brasure et al. reached the same conclusion on the weak evidence base after systematically reviewing non-pharmacological interventions in managing agitation and aggression in PwD [10]. Cohen-Mansfield identified that many non-pharmacological interventions have led to a statistically and clinically meaningful improvement in the management of behavioural problems and stated that the variation in criteria for success, screening procedures, and control procedures together with underreported treatment failures prevent further conclusions from being drawn [11]. A meta-analysis showed that non-pharmacological interventions delivered by family caregivers had an effect size in managing BPSD, at least equaling that of antipsychotic medication [12]. However, as the focus of the current review is on capability considerations of PwD when they are interacting with non-pharmacological interventions, caregiver interventions are not included in this review as caregiver interventions do not require the capabilities of PwD.

The systematic reviews currently available in the literature have evaluated neither the non-pharmacological interventions nor their clinical trials based on the abovementioned capability matching principle in ergonomics. Specifically, these reviews have not assessed if the capabilities of PwD were considered in the non-pharmacological interventions and their clinical trials [1,10,11]. In addition, the availability of resources, severity of cognitive impairment, and levels of comorbidity are different in community and nursing home settings. However, no systematic review of non-pharmacological interventions for BPSD has distinguished between interventions in community settings and nursing home settings. A systematic review of the effectiveness of non-pharmacological interventions for BPSD in nursing home residents is also lacking. Therefore, this study aims to systematically review the non-pharmacological interventions for BPSD in nursing home residents, with a special focus on capability considerations as recommended in ergonomics.

2.2 METHODS

Search strategy

The literature search was performed in three electronic databases: PsycINFO, EMBASE, and MEDLINE. For the searches, the following sets of search terms were used: (1) dementia, (2) BPSD, and (3) nursing home, with the searches limited to therapy (maximise sensitivity). The first set of terms included "dementia (exploded)", "dementia*", "Alzheimer*". The second set of terms consisted of "neuropsych*", "behav*", "behav*

problems (exploded)". The third set of terms involved "nursing home (exploded)", "nursing care". The date of the last search is January 8, 2018. The full search strategy is listed in the supplemental digital content (SDC) -1.

Inclusion criteria

Inclusion criteria for studies relevant for this review were: (1) studies that involved nursing home residents with a diagnosis of dementia; (2) studies that applied non-pharmacological interventions for BPSD which require capabilities of nursing home residents; (3) studies that reported on effects of the interventions on symptoms of BPSD; (4) studies with a pre-post, (quasi) experimental, cross-sectional, randomised controlled, or longitudinal design; and (5) studies written in English and published in a peer-reviewed journal between January 1, 1998, and January 1, 2018.

Intervention categorisation

The interventions were categorised according to the capabilities of PwD required to participate. Ergonomics has investigated human capabilities and how these capabilities change with age. The age-related capabilities investigated were in terms of the sensory, cognition, and movement aspects [13]. As the majority of PwD are over the age of 65, they suffer from capability declines in these three aspects, not only due to dementia but also age. Therefore, the interventions were categorised into sensory-, cognition-, and movement-oriented in this review.

Quality assessment

We evaluated the quality of each trial based on the National Health and Medical Research Council (NHMRC) evidence hierarchy [14]. In addition, each trial was judged for whether capabilities of PwD were considered. Two criteria were used in this review for rating "capability consideration." First, we assessed if the intervention investigated in the trial had been designed with the capabilities of PwD in mind; that is if design guidelines for PwD had been incorporated or PwD had been involved in the design process. When the first criterion was not satisfied, we assessed if the trial only included PwD with adequate capabilities required by the intervention. For example, if PwD with hearing impairments were excluded from a clinical trial on Music Therapy. The clinical trial was rated "Yes" for "capability consideration" if it satisfied either criterion and rated "No" when both criteria were not met.

2.3 RESULTS

The study selection process, guided by Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA), is shown in Figure 1.

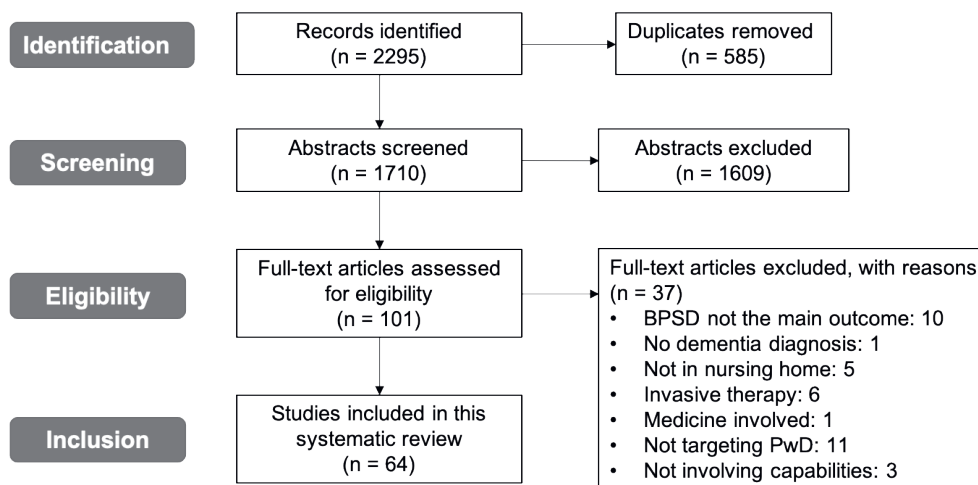


Figure 1. Flow diagram of the systematic review.

The search disclosed 2295 abstracts, of which 101 clinical trials were chosen as potentially relevant; of these, 64 trials met all the inclusion criteria. The summary of the three intervention categories is shown in Table 1. More intervention types were categorised as sensory-oriented rather than cognition- and movement-oriented. The summary of intervention outcomes is shown in Figure 2. Forty-one trials reported a significant reduction on at least one BPSD-symptom; 20 trials reported no significant reduction, while three trials reported that the BPSD symptoms worsened after the intervention. The “capability considerations” of the clinical trials are summarised and shown in Figure 3.

Table 1. Summary of the three intervention categories for BPSD in nursing home residents according to capabilities in ergonomics.

Intervention categories	Intervention types (number of trials)
Sensory-oriented	Music Therapy (21)
	Aromatherapy (9)
	Light Therapy (5)
	Technology-Assisted Therapy (5)
	Snoezelen Therapy (2)
	Positive Image Therapy (1)
Cognition-oriented	Reminiscence Therapy (5)
	Simulated Presence Therapy (3)
	Cognitive Stimulation Therapy (1)
	Storytelling Therapy (1)
Movement-oriented	Exercise Therapy (5)
	Outdoor Activity Therapy (4)

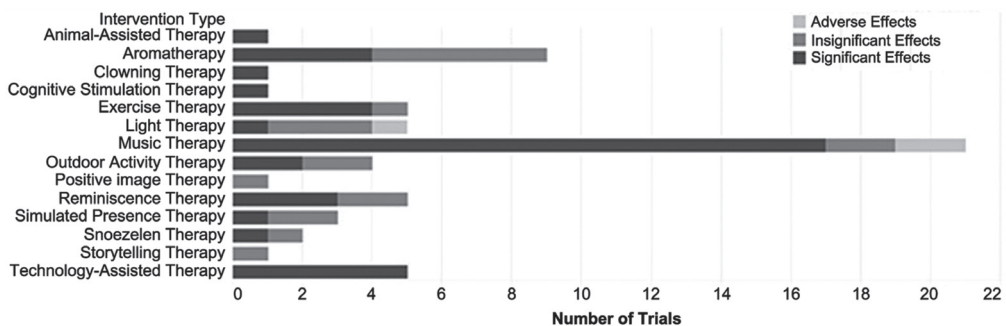


Figure 2. Summary of clinical outcomes of interventions for BPSD in nursing home residents.

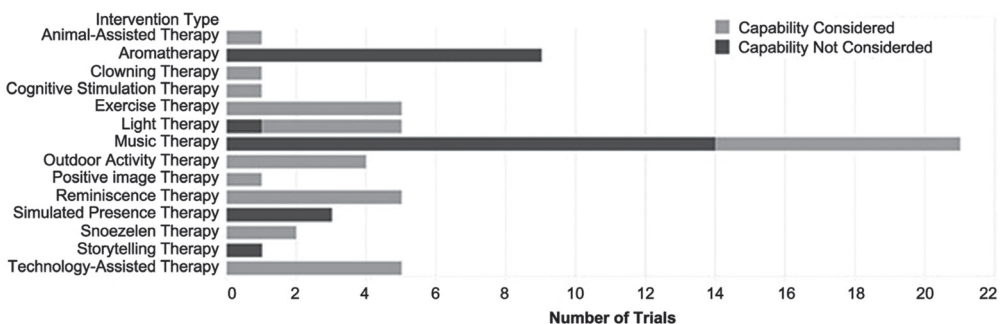


Figure 3. Summary of “capability consideration” of clinical trials on interventions for BPSD in nursing home residents.

As shown in Figure 3, 28 trials did not consider the capabilities of PwD. The details of each trial are listed in the supplemental digital content (SDC)-2. The details include trial type, patient type, intervention, scores in NHMRC and “capability consideration,” and outcomes. Each intervention type is described below in the sequence of sensory-oriented, cognition-oriented, and movement-oriented categories, with the intervention types that were investigated by only one trial described together as “other interventions” in each category. For trials satisfying the first “capability consideration” criterion (i.e. Snoezelen Therapy, Technology-Assisted Therapy, Animal-Assisted Therapy, Clowning Therapy, and Reminiscence Therapy), we included the specific design guidelines used or features of the intervention that had been modified based on preliminary field testing in the description below.

Sensory-oriented therapy

1. Music Therapy

Twenty-one trials investigated the effectiveness of Music Therapy; 10 trials are of NHMRC evidence hierarchy II [15-24], six trials are of hierarchy III-1 [25-30], two trials are of hierarchy III-2 [31-32], and three trials are of hierarchy IV [33-35]. The delivery approach, music type, content, session type, duration, frequency of application, and the total intervention time of Music Therapy vary across trials.

The delivery approach can be classified into receptive and active. The PwD only listened to the music in the receptive approach, while the PwD interacted with the music by singing or playing with instruments in the active approach. The music type can be divided into recorded and live. The contents of the music used were either generic music or music preferred by PwD. The session type was either an individual session or a group session. The duration of music ranged from 10 to 60 minutes in the trials, which reported duration. The reported frequency of application varied from once a week to every day, and the reported total intervention time spanned from two weeks to one year.

The outcomes of Music Therapy are mainly positive. Seventeen trials demonstrated that one or more BPSD symptoms had reduced significantly [16-26,29-30,32-35]. Two trials showed that the change in BPSD was insignificant [27,28], and two trials found that the BPSD symptoms deteriorated after the intervention [15,31]. Only seven trials considered the auditory capability of the PwD [20,22,23,25,29,33,34]. One trial mentioned the music was played “sufficient to be heard throughout the common area,” but it did not specify if the music was sufficient to be heard for the researchers or PwD [31]. Thus, the author decided this trial did not consider the hearing capabilities of PwD.

2. Aromatherapy

Nine trials have investigated the effectiveness of Aromatherapy; five trials were of NHMRC evidence hierarchy II [36-40], one trial was of hierarchy III-1 [41], and three trials were of hierarchy III-2 [42-44]. The delivery approach, formulation, concentration, frequency of application, duration, and total intervention time of Aromatherapy varied across trials.

The essential oil was delivered to the PwD through massage, spray, or diffuser. The formulation of essential oil used was either Lavender or *Melissa officinalis*, with concentrations varying from 2% to 100%. The reported frequency of application ranged from twice daily to three times a week, and the reported duration ranged from two hours to the whole night. The reported total intervention time spanned from ten days to four months.

The outcomes of Aromatherapy are mixed. Four trials showed the BPSD symptoms were significantly alleviated after the intervention, in which the essential oil was applied dermally or via a high-concentration spray [38,40,42,43]. The remaining five trials, in which the essential oil was delivered by spray in low concentration, found no significant reduction in BPSD [36,37,39,41,44]. None of the trials considered the olfactory capability of PwD.

3. Light Therapy

Five trials evaluated the effectiveness of Light Therapy; three trials were of NHMRC evidence hierarchy II [45-47], and the other two trials were of hierarchy III-1 [48-49]. The brightness, duration, and total intervention time of Light Therapy varied across trials.

The reported brightness of the light ranged from 1000 lux to 10,000 lux in the intervention groups and 100 lux to 300 lux in the control groups. The duration of the Light Therapy varied from 120 minutes to a whole day, and the total intervention time spanned from 10 days to 3.5 years.

The outcomes of Light Therapy are mixed. The clinical trial with the best experimental design found that agitation and depression were significantly reduced in a follow-up ranging from 0.5 to 3.5 years. In this trial, a bright light was applied for the whole day with or without melatonin in the intervention group and dim light with a placebo in the control group. This is a 2 x 2 factorial double-blind cluster-randomised trial comparing two light settings in several nursing homes, with a total of 189 participants, of whom 87% had dementia [46]. However, three trials found that Light Therapy had no significant effect in reducing BPSD [45,47,49], and one trial reported that the agitation in PwD was worsened [48]. One of the five trials did not consider the visual capability of PwD [47].

4. Snoezelen Therapy

Snoezelen Therapy, also referred to as Multisensory Therapy, was investigated by two trials, both with NHMRC evidence hierarchy IV [50,51]. One trial compared Snoezelen Therapy with Exercise Therapy for three weeks and found that the reduction in agitation was not significant under both intervention types [50]. The other trial integrated Snoezelen Therapy into 24-hour care for 18 months, with each resident having a personal care plan, and found a significant reduction in apathy, aggression, and depression after the intervention [51]. Snoezelen Therapy is designed with the sensory capabilities of PwD in mind. Declines in sensory capabilities (i.e. hearing, vision, taste, smell, touch) are common in elderly adults, with the rate of decline varying across senses for each person. By stimulating a few senses together in Snoezelen Therapy, a PwD with sensory impairments in less than five senses could still receive stimuli from the therapy via their remaining functional senses. According to the guidelines for designing perceptible information for PwD, different modes (pictorial, verbal, tactile) should be used together to present essential information [52]. Hence, all trials applying Snoezelen Therapy have considered the sensory capabilities of PwD.

5. Technology-Assisted Therapy

Technology-Assisted Therapy is the intervention type in which the roles of caregivers or therapists are replaced by technologies. Five trials were found for this intervention type. One trial explored the effectiveness of a personalised multimedia device [53]. The device can play music and display images, films, and messages that were selected or made by family members of the PwD. This trial was of NHMRC hierarchy level II and showed a significant reduction in agitation in PwD after the intervention. It also reported that assistance was needed and offered for PwD in late stages. This personalised multimedia device is designed with the touch capabilities of PwD in mind. Specifically, researchers found some PwD find touch-sensitive icons confusing in preliminary field testing; thus, they added traditional buttons affixed to the screen for those PwD with that preference.

Four trials examined the effectiveness of a therapeutic robot [54-57]. This robot, with the appearance of a baby seal, was placed on the lap of PwD. The robot generated movement and sound mimicking the baby seal to give somatosensory and auditory stimulations to PwD. The four trials were of NHMRC evidence hierarchy III-1 and reported that agitation and depression in PwD were significantly reduced with no reduction in antipsychotic medication after the intervention. One trial applied the robot in individual sessions [54], and the remaining three trials applied the robot in group sessions [55-57]. This robot is designed with the sensory capabilities of PwD in mind as it stimulates several senses in PwD, which is similar to Snoezelen Therapy. Therefore, all trials in this intervention type have considered the capabilities of PwD.

6. Other Sensory-Oriented Interventions

Three sensory-oriented interventions were evaluated by one trial only. Animal-Assisted Therapy was examined by a trial of NHMRC evidence hierarchy III-1 [58]. This therapy organised regular dog visits in a group session accompanied by a dog handler, which found depression in PwD was reduced significantly after the intervention. Positive Image Therapy was assessed by a trial of hierarchy II [59]. This therapy displayed images preferred by PwD with voice prompt during bathing time, which led to fewer behavioural problems. However, the sample size of this trial was too small to calculate the significance. Clowning Therapy was evaluated by a trial of hierarchy IV [60]. The elder clowns visited the nursing home regularly to entertain the PwD for 12 weeks and reported that BPSD was reduced significantly after the intervention. In the Animal-Assisted Therapy and Clowning Therapy, several senses of PwD were stimulated, which is similar to Snoezelen Therapy. In Positive Image Therapy, visual impairment was used as an exclusion criterion in the clinical trial. Therefore, all three trials have considered the sensory capabilities of PwD.

Cognition-oriented therapy

1. Reminiscence Therapy

Five trials examined the effectiveness of Reminiscence Therapy, which were all of NHMRC evidence hierarchy level II [61-65]. The session type, structure, duration, and total intervention time of Reminiscence Therapy varied across trials. The therapy has been conducted in group or individual sessions via unstructured, semi-structured, and structured activities. The reported duration of one session ranged from 30 to 60 minutes, and the reported total intervention time went from four to eight weeks.

Three trials showed the apathy, agitation, and depression of PwD were significantly reduced after the intervention [61-63], and the remaining two trials showed the reduction was insignificant [64,65]. This intervention is designed with the memory and attention capabilities of PwD in mind. In terms of memory, this intervention stimulates long-term memory, which is relatively intact in PwD, compared to other types of memories. In terms of attention, this intervention involves interactions between caregivers and PwD to keep PwD concentrated during the intervention. These interactions are essential as the capability of inhibiting irrelevant information is declined in PwD. According to the guidelines for designing for PwD, the design should remind PwD about their previous experiences and give feedback immediately, given the short attention span of the PwD [52]. Thus, the main cognitive capabilities of PwD were considered in the trials.

2. Simulated Presence Therapy

Three trials investigated Simulated Presence Therapy, with one trial of NHMRC evidence hierarchy III-1 [66] and two trials of hierarchy IV [67,68]. All trials applied audio recordings to simulate a phone call from a family member of the PwD to engage PwD in conversations.

One trial reported that the response of PwD varied widely from a dramatic reduction in distress to apparent indifference [67]. One trial found that some PwD recognised this phone call is a simulation and refused to listen again [68]. One trial reported that the “interest” subscale of the Positive Affect Rating Scale was significantly increased after the intervention; however, there was no change in BPSD [66].

The main cognitive capabilities of PwD were not fully considered in the intervention. In terms of memory, the phone call could trigger the long-term memory of the PwD by the familiar voices. However, in terms of attention, the interactions between PwD and the audio recordings were limited at the audial level, and this lack of sensory engagement could result in the PwD getting distracted easily during the therapy. Besides, it is difficult for caregivers to check if PwD are distracted. None of the trials has examined if PwD had the adequate capability to inhibit irrelevant information to ensure they can concentrate throughout the therapy. Therefore, these trials have not fully considered the main cognitive capabilities of PwD.

3. Other Cognition-Oriented Interventions

Two cognition-oriented interventions were examined by one trial only. Cognitive Stimulation Therapy was evaluated by a trial of NHMRC hierarchy II, which found apathy and depression in PwD were reduced significantly after the intervention [69]. Storytelling Therapy was assessed by a trial of hierarchy III-1, which found no significant reduction in BPSD [70]. Cognitive Stimulation Therapy provides cognitive games to stimulate PwD, and its clinical trial considered the cognitive capabilities of PwD by only including PwD in the early to moderate stages [69]. Storytelling Therapy prompts a group of PwD to give comments about a picture and uses these comments to form a story, and its clinical trial had no assessment on the cognitive capabilities of PwD participants.

Movement-oriented therapy

1. Exercise Therapy

Five trials examined the effectiveness of Exercise Therapy; four trials were of NHMRC evidence hierarchy II [71-74], and one trial was of hierarchy III-1 [75]. The content of the exercise varied across trials, from intensive strengthening to dance. Ranking the intensity of the exercise in these trials is difficult due to the lack of detailed exercise description in each trial. The total intervention time ranged from 12 weeks to 12 months in these trials.

Four trials found apathy and agitation in PwD reduced significantly [71-73,75], while one trial found no significant reduction in BPSD after the intervention [74]. All trials in this intervention type considered the movement capabilities of PwD by excluding PwD who were not capable of moving independently with or without an assistive device.

2. Outdoor Activity Therapy

Four trials examined the effectiveness of Outdoor Activity Therapy; three trials were of hierarchy IV [76-78], and one trial was of hierarchy II [79]. The content, duration, frequency of application, and total intervention time varied across trials. The reported content included gardening, horticultural therapy, and walking outdoors, and the duration ranged from 30 to 60 minutes. The reported frequency of application went from daily to twice a week, and the total intervention time spanned from 2 weeks to 12 months.

One trial found a significant reduction in verbal agitation in PwD [79], and one trial reported the physically non-aggressive behaviour in PwD reduced significantly after the intervention [78]. Two remaining trials found no significant reduction in BPSD [76,77]. All trials considered the movement capabilities of PwD by only including PwD who were capable of moving independently or with an assistive device.

2.4 DISCUSSION

As far as we are aware from the current literature, this is the first study to systematically examine the effectiveness of non-pharmacological interventions for BPSD in nursing homes, with an additional assessment criterion based on ergonomics, specifically, capability consideration. The current review investigated whether the capabilities of PwD were considered in the interventions and their clinical trials. The interventions were categorised according to the capabilities of PwD required to participate, which are sensory-, cognition-, and movement-oriented. The quality of evidence for the effectiveness of these interventions is found to be low in general. Sensory-oriented interventions have been explored and evaluated more than cognition- and movement-oriented interventions, with Music Therapy being investigated by the highest number of trials. In terms of capability consideration, sensory capabilities have been considered less than cognitive and movement capabilities, especially for auditory and olfactory capabilities.

To elaborate on the capability considerations in clinical trials, the trials that satisfied the first “capability consideration” criterion were on Snoezelen Therapy, Technology-Assisted Therapy, Animal-Assisted Therapy, Clowning Therapy, and Reminiscence Therapy. These interventions have accommodated capability considerations in them;

thus, the trials on these interventions have considered the capabilities in PwD. For interventions without capability considerations (i.e. Music Therapy, Aromatherapy, Light Therapy, Positive Image Therapy, Simulated Presence Therapy, Cognitive Stimulation Therapy, Storytelling Therapy, Exercise Therapy and Outdoor Activity Therapy), it is essential for trials to only include PwD with adequate capabilities for the intervention outcomes to be reliable. From this review, clinical trials on Positive Image Therapy, Cognitive Stimulation Therapy, and all movement-oriented interventions have assessed the capabilities of PwD for inclusion. Two-thirds of the clinical trials on Music Therapy, one-fifth of the clinical trials on Light Therapy, and all clinical trials on Aromatherapy, Simulated Presence Therapy, and Storytelling Therapy have not assessed the capabilities of PwD for inclusion. This lack of capability consideration implies that not all participants might have had the capabilities that the interventions required. For instance, not all participants can hear the music in a trial on Music Therapy. Consequently, the effectiveness of these interventions would have been underestimated, and, thus, a lack of capability consideration could reduce the quality of a trial and consequently lower the quality of evidence about the corresponding intervention type.

A few factors could cause sensory capabilities to be considered less than cognitive and movement capabilities. The sensory capabilities are more difficult to measure, and the PwD cannot actively communicate their sensory experiences due to their cognitive impairments. In contrast, the remaining cognitive capabilities of PwD are relatively well-tracked, as they are assessed regularly to monitor how their dementia progresses. The movement capabilities are crucial for the safety of PwD and, thus, were also assessed carefully in movement-oriented interventions.

To include the capabilities of PwD in designing interventions and clinical trials, three approaches should be considered. First, clinical trials should include capability requirements in their in- and exclusion criteria and indicate that the capabilities of PwD participants were adequate to participate in the interventions. This practice should be used as a criterion for evaluating the quality of a trial in systematic reviews. Second, a capability profile should be created for each PwD in terms of sensory, cognition, and movement aspects. The suitable interventions for a PwD can then be identified by matching the capability profile with the capability requirements of the interventions. The capabilities of PwD can be tracked over time with this profile to identify new interventions when the current interventions are no longer suitable due to capability decline. This profile also helps researchers to identify suitable PwD for clinical trials. Third, the interventions themselves should be designed with the capabilities of PwD in mind by incorporating design guidelines for PwD or involving PwD in the design process. An intervention with adequate capability consideration should be able to include as many capability impairments as possible or adapt to the remaining capabilities of PwD. For example, bed-bound exercises could be designed for PwD who are immobile. The

third approach is the most fundamental because some capabilities are difficult and costly to measure regularly. Moreover, by designing the interventions with capability considerations, more PwD with capability impairments will be able to participate and, thus, benefit from the interventions. With more participants, the clinical trials on non-pharmacological interventions for BPSD could have a larger sample size, which could improve the quality of evidence. Since ergonomics has a human-centred approach and has investigated age-related capability changes, it would facilitate the intervention design process.

A meta-analysis is impossible due to the following limitations of the clinical trials. Firstly, the outcomes have been measured by a broad range of validated scales and physiological parameters. Over 60 scales have been used, with some scales focusing on one aspect of BPSD (e.g., Cohen-Mansfield Agitation Inventory [80]) while other scales are measuring BPSD comprehensively (e.g., Neuropsychiatric Inventory [4]). The physiological parameters include heart rate, cortisol level, and skin conductance. Comparing the outcomes of these trials is difficult due to this wide variation in measurement methods. In addition, the design of control groups varies across trials. Some trials applied a placebo activity in the control group (e.g., reading activity as a placebo for Music Therapy [32]), while most trials applied “usual care” in the control group. “Usual care” was not clearly described in these trials and further hindered comparison. Moreover, some trials have not accounted for potential confounding factors. For instance, the social interactions between PwD might also contribute to reducing BPSD for Music Therapy conducted in a group session [22,29,30]. The current study demonstrates a lack of standardisation and heterogeneity in study designs of non-pharmacological interventions in clinical trials of BPSD. Therefore, improving data homogeneity, study designs, and reporting in future clinical trials is urgent, which is in accordance with previous systematic reviews [1,10,11].

The link between the effectiveness of non-pharmacological interventions and their capability considerations cannot be drawn due to the abovementioned limitations in clinical trials. These limitations make comparisons between intervention outcomes across clinical trials difficult. A hypothesis is that interventions that consider capabilities in PwD are more effective than interventions that do not. This hypothesis needs to be examined in future clinical trials, that is, by comparing the outcome measurements of the same intervention with and without capability considerations. This comparison can only be carried out when these clinical trials have overcome the limitations.

Apart from capability considerations, treatment parameters could also affect the effectiveness of the interventions, such as the dose, timing, and duration of intervention. Cohen-Mansfield stated that the effectiveness of intervention might depend on these parameters instead of the inherent applicability of the intervention type [11]. As treatment parameters were not commonly reported in clinical trials, together with

the abovementioned limitations in these trials, it is impossible to conclude how these parameters affected the effectiveness of an intervention, which is a remaining challenge for future studies.

A limitation of this review is that it is only focused on if the capabilities of the PwD are considered in the interventions and their clinical trials. We did not include caregiver interventions in the current study, as the focus of the current review is on capability considerations of PwD. The capabilities of caregivers are also vital for the interventions to be carried out reliably, thus ensuring high quality of evidence. For example, if a caregiver can accomplish the non-pharmacological intervention given the time constraints; and if the training is adequate for the caregiver to understand how to operate a device used for the intervention. However, it is not common for clinical trials to report these details; thus, the consideration of the capabilities of caregivers cannot be made in the current review. This review provides a starting point for considering human capabilities in non-pharmacological interventions and the subsequent clinical trials for BPSD in nursing homes. In future trials, it might be worthwhile to consider the capabilities of both PwD and caregivers. The fact that not all interventions were truly based on capabilities of PwD and that 28 out of 64 trials did not consider capabilities is also a limitation of the current review. It would be worthwhile for future studies to explore how to assess if the capabilities of PwD are truly considered.

Despite the fact that the current quality of evidence is low, the evidence indicates that a wide variety of non-pharmacological interventions for BPSD in nursing homes have been developed and carried out with a few reported adverse effects. The consideration of human capabilities for antipsychotic medications is not as vital as that of non-pharmacological interventions, which indicates that non-pharmacological interventions are more challenging to be implemented. Given their fewer adverse effects than that of medication, future studies focusing on non-pharmacological interventions for BPSD should include capability considerations for PwD to gather more high-quality evidence.

2.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The findings lead to the following five recommendations for future studies:

1. Capability requirements for PwD should be included in the in- and exclusion criteria of clinical trials on non-pharmacological interventions
2. Capability requirements should be included as a criterion for assessing the quality of clinical trials on non-pharmacological interventions in systematic reviews
3. The sensory, cognition and movement capabilities of each PwD should be assessed regularly over time and recorded in a profile to identify suitable interventions for each PwD and ease the selection process in clinical trials.

4. Non-pharmacological interventions should be designed with the capabilities of PwD in mind under the guidance of ergonomics.
5. Clinical trials should be conducted more systematically by establishing consensus on outcome measurements, refining study designs, developing reporting standards, and managing confounding factors.

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Insights from the Ergonomics in Ageing literature

The systematic review (Chapter 2) points out that non-pharmacological interventions should be designed with the capabilities of people with dementia in mind under the guidance of ergonomics; hence the author decided to generate a set of recommendations on capability considerations for personalising these interventions for people with dementia. At this stage, her sub research question is:

If (and what) design recommendations for personalising non-pharmacological interventions for people with dementia could be generated from the literature on Ergonomics in Ageing?

This chapter describes a review on the changes of age-related capabilities in the sensory, cognition and movement aspects in the field of Ergonomics in Ageing. As there is no ergonomics study about people with dementia specifically, and most people with dementia are over the age of 65, the design recommendations generated from this review are considered to be applicable to the majority of people with dementia.

ABSTRACT

Non-pharmacological interventions have been applied to manage Behavioural and Psychological Symptoms of Dementia (BPSD). However, it has been found that the capabilities of People with Dementia (PwD) have not been considered enough in these interventions. One domain of ergonomics (Ergonomics in Ageing) has investigated the age-related capability changes of humans, which could offer guidance for developing these interventions to fit with the capabilities of PwD. This study is based on a systematic review of non-pharmacological interventions for BPSD (Chapter 2) and aims to review literature in Ergonomics in Ageing and generate recommendations for both designers and healthcare professionals in facilitating and delivering these interventions to PwD. Most of the capabilities one would need to participate in these reviewed interventions have been found to decline with age except semantic memory, and the delivering of these interventions is advised to be personalised to fit the capabilities of each PwD given the heterogeneity of various capabilities is larger in older adults in comparison with that in young adults. This personalisation could be achieved with a combined effort of designers in developing facilitating objects and healthcare professionals in using these objects. The design recommendations stated in this paper could be evaluated and refined with multidisciplinary meetings or in case studies in the future.

3.1 INTRODUCTION

Antipsychotic medication is frequently prescribed to relieve Behavioural and Psychological Symptoms of Dementia (BPSD). However, they have low efficacy with serious side effects, such as increased mortality and stroke occurrence [1]. Consequently, non-pharmacological interventions have been developed in an attempt to reduce the use of antipsychotic medications in the management of BPSD. Several systematic reviews have investigated the effectiveness of these interventions and found the level of evidence for them is generally low [2-6].

From a Human-Centered Design perspective, the interventions are mainly delivered via the interaction of objects and humans [7]. The objects are designed artefacts to facilitate the delivery of the interventions, which are used by humans to fulfil their functions. For example, the music player is an artefact developed by designers, and it only becomes possible to generate a therapeutic effect (Music Therapy) on PwD when it is turned on by the caregivers.

There are a few nuances in both the design of the objects and in using the objects, and the capabilities of PwD should be carefully considered in both activities. For example, how could the music player be designed in a way that PwD can turn it on and change music by themselves? This could generate a positive feeling of “being in control” for PwD, who are constantly experiencing “loss of control”. How could the caregivers (or healthcare professionals in general) use this music player so that the music can be heard by PwD? This requires the caregivers to know if the PwD has a hearing impairment, and if so, at what volume should the music be played and where should the player be placed? These nuances point toward that the knowledge about the capabilities of PwD could benefit both designers and healthcare professionals in delivering non-pharmacological interventions to PwD. This might contribute to a higher level of evidence for these non-pharmacological interventions.

This study hypothesised that the knowledge in the capabilities of PwD could potentially be gained by reviewing the literature on Ergonomics in Ageing. This domain of ergonomics has investigated the capability changes of healthy individuals as they age [8]. We acknowledge that dementia does not only affect older adults; according to the statistics from the World Health Organisation (WHO), young-onset dementia accounts for up to 9% of cases [9]. This implies that changes in capabilities because of ageing is applicable for the majority of PwD and could offer guidance in the development of non-pharmacological interventions for BPSD.

Therefore, our study aims to first review the literature on non-pharmacological interventions for BPSD to identify the main capability they required from PwD and then review age-related capability changes reported in Ergonomics in Ageing. These findings will then lead to design recommendations for designers and healthcare professionals in facilitating these interventions.

3.2 METHOD

This study was conducted in several steps. Firstly, studies on interventions for BPSD from 1998 to 2018 were systematically reviewed. Only studies written in English and published in peer-reviewed journals were included. The literature search was implemented in three electronic databases: MEDLINE, PsycINFO and EMBASE. The intervention types were then identified from these studies. After that, the capabilities involved in each intervention type were identified. The interventions were then categorised into sensory-, cognition-, and movement-oriented according to the main capability they required from the PwD. Afterwards, the ergonomics literature on age-related capability changes was reviewed. The findings in age-related capability changes were then applied to generate design recommendations for the interventions. The steps are summarised in Figure 1.

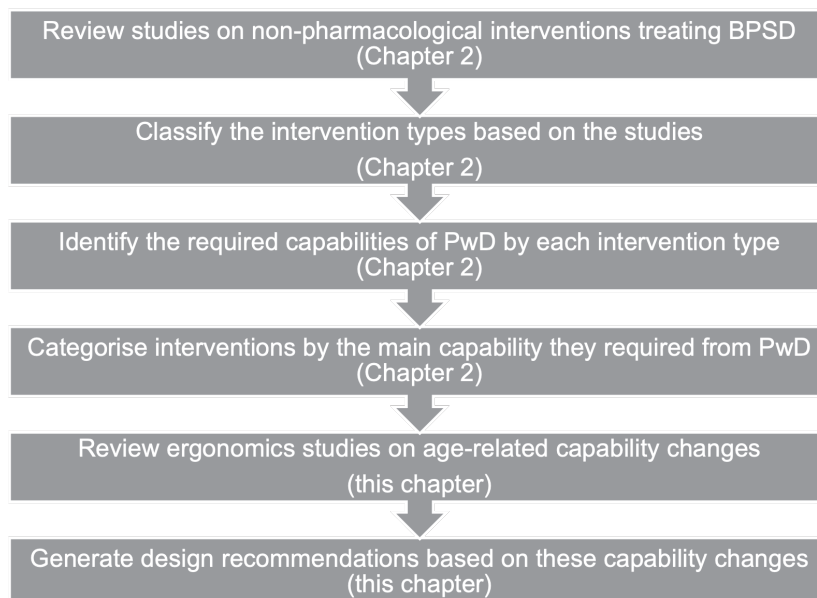


Figure 1. A flow diagram of this study.

3.3 RESULTS

The results of the systematic review are reported elsewhere [10] (Chapter 2). We dedicate the results section for the outcomes of the literature review on Ergonomics in Ageing. The age-related capabilities reviewed are classified into sensory, cognition and movement aspects according to the categorisation of the non-pharmacological interventions reviewed. Some capabilities were found to be reduced (e.g., vision, auditory, working memory) [11-14], while some were reported to be relatively intact in the older adults (e.g., semantic memory) [15]. These findings have been implemented into the adaptation of working place, products and services for the older adults with reported improvement in both their performance and well-being [16].

The age-related capability changes reported in the sensory aspect are auditory, olfactory, visual and somatosensory capabilities. The capability changes described in the cognition aspect are attention, memory, and executive control. The capability changes stated in the movement aspect are balance, muscular strength, movement speed, and locomotion. The changes in these capabilities with age and their according implications on non-pharmacological interventions are described in the Discussion section.

3.4 DISCUSSION

The design recommendations for non-pharmacological interventions are discussed below in terms of the three intervention categories (i.e., sensory-, cognition-, movement-oriented). A summary of these design recommendations is shown in Table 1. The possible applications of these recommendations are then discussed for each intervention category with reference to the findings from the previous systematic review (Chapter 2).

Table 1. Summary of design recommendations for non-pharmacological interventions.

Intervention categories	Involved capabilities	Recommendations
Sensory- oriented	Auditory	Locate sound sources closer and by the sides of PwD; use low-frequency sounds
	Olfactory	Apply aromatic components dermally or of high concentration; experiment with various aromatic components and compare their effects
	Visual	Reduce brightness gradually at the end of the intervention; diffuse emitted light; avoid reflecting surfaces; apply short-wavelength light carefully
	Somatosensory	Use objects to be easy-to-hold and drop-proof
Cognition- oriented	Attention	Conduct interventions in a dedicated room; embed prompts in the interventions
	Memory	Stimulate semantic memory; use short and simple sentences; use memory aid for PwD; avoid questions about future
	Executive control	Minimise activities involving planning, sequencing and multitasking
Movement- oriented	Balance	Carry out movement on hard flooring with protective clothing
	Muscular strength	Use movement with lower intensity
	Movement speed	Use movement with a slower rhythm
	Locomotion	Use movement mimicking the locomotion of the elderly

Sensory-oriented interventions

A sensory-oriented intervention could be enhanced by considering the change of auditory, olfactory, visual and somatosensory capabilities due to ageing. How the recommendations could be applied are given for a few interventions as examples below, which can be applied to other interventions involving these capabilities.

Music therapy mainly involves auditory capability. The two age-related auditory deteriorations are in auditory acuity and localisation. The auditory acuity is the ability to detect sound, which deteriorates the most for high-frequency sounds [14]. The auditory localisation is the ability to localise sound, which declines the most for high-frequency sounds [17], and the older adults are especially prone to front and back localisation errors (i.e., it is difficult for them to recognise where the sound comes from when the sound source is placed directly in the front or directly at the back of them) [18]. Therefore, the music therapy for PwD could be improved by locating the sound source close to the person to compensate for the reduced auditory acuity. The sound source could be placed at the sides of PwD to avoid issues with localising sound sources. In addition, music with low frequency should be selected.

In terms of aromatherapy, the olfactory system is the most involved. Olfactory impairment is common among older adults, and the impairment depends on the type of aromatic components, which varies from individual to individual [16]. Referring to the systematic review (Chapter 2), four reviewed studies applied the aromatic components dermally or of high concentration and showed the BPSD were significantly alleviated after the intervention [19-22]. The other five studies delivered the aromatic components by spray in low concentration and found there was no significant improvement in BPSD [23-27]. Only three types of aromatic components have been evaluated in all reviewed studies, which are: lavender, thyme and *Melissa officinalis*. Therefore, aromatherapy could be enhanced by applying the aromatic components dermally or of a high concentration and experimenting with a few more aromatic components. Due to the variation in olfactory impairment among PwD, a few aromatic components could be compared to identify the most effective one for each PwD.

For light therapy, the main sense involved is vision. Exposure to bright light could restore the circadian rhythm, and this rhythm is commonly disturbed in PwD [28]. Artificial light is usually used in interventions with a higher intensity than the standard light [29]. Visual deterioration of older adults means that more illumination is required for them to see adequately [16]. Therefore, besides circadian rhythm restoration, another possible benefit of this therapy would be that it allows PwD to see their surroundings more clearly. Moreover, the capability of older adults to adapt to darker conditions is reduced [11], and their susceptibility to glare is higher than that of young adults [30]. Thus, light therapy could be improved by reducing the brightness in the room gradually at the end of the intervention to allow PwD time to adapt to the standard light condition. In addition, the emitted light should be diffused to create ambient light and reflecting surfaces (e.g., mirrors) should be avoided to reduce glare in the therapeutic room.

Snoezelen therapy, also called multisensory therapy, gently stimulates the senses of sight, hearing, smell, and touch of the PwD [31]. In terms of sight, the recommendations of light therapy could be applied here. Besides, PwD are exposed to lighting conditions with a wider wavelength spectrum than that in light therapy since the variety of colours is used in Snoezelen therapy to engage the vision system of PwD [32]. It has been found that older adults have more difficulty discriminating and perceiving short-wavelength light [33]. Therefore, it is recommended that objects with short-wavelength lighting should be separated from backgrounds with similar lighting conditions even though their colours are different (e.g., blue and violet). Regarding touch, older adults have been found to have difficulty in sensing the weight of objects, which results in more variability in maintaining constant force when grasping an object [13]. This capability change could increase the number of dropping incidents which could disturb the therapy. Thus, the objects which are easy-to-hold and drop-proof are advised to be used in the therapy. Lastly, since Snoezelen therapy also employs the auditory and olfactory systems, the recommendations of music therapy and aromatherapy could also be applied here.

Cognition-oriented interventions

A cognition-oriented intervention could be improved by considering the changes in attention, memory, and executive control in PwD during ageing. The recommendations given in this section are applicable to all cognition-oriented interventions.

In terms of attention, older adults tend to have reduced capability to inhibit irrelevant information [34]; thus, it is important to remove distractors during the therapy. A dedicated room or space is advised to help PwD to concentrate during the therapy. Some prompts could be designed into the objects to redraw the attention of the PwD back to the intervention when healthcare professionals are not involved. For instance, in simulated presence therapy, the PwD is mainly guided by the audio or video recording instead of the therapist. The PwD could get distracted during the intervention, which might not be noticed immediately, thus affecting the outcome of the intervention. Even if a therapist notices and reminds the PwD, this reminder would disturb the flow of the therapy. Therefore, embedding some prompts in the audio or video recording would help PwD to stay focused on the therapy without disturbances.

There is a decline in working memory [13], episodic memory [34] and prospective memory [35] in the older adults except for semantic memory [15]. The reminiscence therapy and simulated presence therapy have already made use of this remaining capability and structured conversations with PwD based on their semantic memories. For example, old photos, nostalgic music, and voices of family members were applied to stimulate the semantic memory in these therapies. Due to the decline in the working memory [13], the older adults might have difficulty understanding long sentences because they could forget the beginning of a sentence by the time the sentence is finished. Similarly, as the ability of language comprehension depends on the interaction of working memory and semantic memory, it is also difficult for older adults to comprehend a sentence in which many words and clauses bisect the subject and verb [13]. Therefore, the instructions and questions to the PwD should be simplified and shortened during these interventions. Due to the decline in episodic memory [34], older adults could forget the topic of their talk during the conversation, which could trigger negative emotions in them. Hence, it is recommended to constantly remind PwD about what they have been talking about without interrupting the conversation. A memory aid could be developed based on the technology of real-time transcription, which could remind the PwD about what has been said in the conversation in a written form (this requires the PwD to have adequate vision). Due to the reduction in prospective memory [35], older adults might have difficulty with planning, retaining, or retrieving an intention as planned. Therefore, it is advisable to minimise conversations and tasks related to future planning for PwD during these interventions.

Lastly, a decline in executive control has been found in older adults [36]. Executive control encompasses a range of cognitive activities such as planning, sequencing and

multitasking. Thus, it is recommended that the activities in these interventions could be designed to involve short-term feedbacks, fewer steps, and one cognitive task at a time.

Movement-oriented interventions

A movement-oriented intervention could be enhanced by considering the age-related changes in balance, muscular strength, movement speed and locomotion. Movement-oriented interventions are more likely to cause physical injuries than sensory- and cognition- oriented interventions. As a result, it is important to consider these capability changes to avoid injuries. The recommendations given in this section are applicable to all movement-oriented interventions.

In terms of balance, postural sway increases with age [37]. Falls due to postural sway is a serious problem for older adults [38]. This age-related postural sway is greater when the person is standing on a more compliant flooring [39]. Consequently, these interventions are recommended to be carried out on hard flooring to minimise the risk of fall. Protective clothing and suitable shoes should be worn by the PwD in the meantime. The muscular strength drops with age [40]. It is essential to be aware of the lowered strength and endurance limits of PwD to design suitable and safe postures and movements for them. Water therapy, such as swimming pool exercises, could be incorporated for PwD whose muscular strength is inadequate for lifting their body weights. In addition, older adults are generally slower in movement than young adults [41]; hence, the therapists should demonstrate the postures and movements at a rhythm slow enough for PwD to follow. Regarding locomotion, older adults tend to have shorter steps and the time that both of their feet are on the ground is longer than that of young adults [42]. This gait change is the strategy of older adults to maintain balance. This strategy should be incorporated into the design of postures and movements in these interventions.

Personalising interventions

Literature in Ergonomics in Ageing also pointed out that the heterogeneity of various capabilities is larger in older adults in comparison with that in young adults [43], and different people can be affected by dementia differently [44]. Therefore, selecting suitable interventions for each PwD is also an essential component of delivering the intervention. In terms of managing BPSD in a nursing home, it is unlikely that one intervention could be suitable for all residents. For example, music therapy might not be suitable for PwD with auditory impairments or for PwD who are not sensitive to music. It is advised for healthcare professionals to create a capability profile for each PwD, and the suitable interventions for a PwD could be identified by matching the capabilities required in the intervention with the remaining capabilities of the PwD. The changes in capabilities over time for each PwD could also be tracked with the profile so that new suitable interventions could be identified as the disease progresses.

As mentioned above, the interventions are delivered via the interaction of objects and humans. In the “humans” part, healthcare professionals have developed their skills in differentiating the capability differences among PwD and in keeping track of the capability changes within a PwD. Their expertise could be augmented with the “objects” designed for these interventions, thus lowering their workload in personalising these interventions. To illustrate, the “objects” developed for delivering these interventions could be designed with a wide range of functional options for healthcare professionals to choose from. We will keep using a music player as an example: what if it also offers the possibility for family members of the PwD to send voice messages to him/her? Then the healthcare professionals could also use the music player for simulated presence therapy, which could have a stronger effect on some PwD than music therapy. What if the music player also offers the possibility of emitting calming lights? Then the healthcare professionals might use the music player for light therapy, which could be helpful for PwD with hearing impairment but with sufficient vision. We acknowledge that trade-offs such as production cost in designing these objects should be considered, and the design recommendations in this paper could help the developers of these “objects” and healthcare professionals to be more mindful about the capabilities of PwD than before.

3.5 CONCLUSION

This study provides an overview of important considerations for interventions treating BPSD from an ergonomics perspective. The interventions for BPSD from 1998 to 2018 were reviewed and categorised into sensory-, cognition- and movement-oriented. Most of the capabilities in these three aspects have been found to decline with age apart from semantic memory, and the interventions for BPSD could potentially be improved by aligning with the capabilities of PwD in view of these age-related changes. Not only could the design recommendations generated help designers with developing “objects” for facilitating these interventions, but also guide healthcare professionals with delivering the interventions. This study establishes a start point of utilising findings from Ergonomics in Ageing to design non-pharmacological interventions for BPSD. In the future, the design recommendations stated in this paper could be evaluated and refined with multidisciplinary meetings or in case studies.

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4



Based on: G. Wang, C. Marradi, A. Albayrak, and T. J. M. van der Cammen, "Co-designing with people with dementia: A scoping review of involving people with dementia in design research," *Maturitas*, vol. 127, pp. 55-63, Sep. 2019.

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Insights from the Co-design literature

The systematic review (Chapter 2) suggests that people with dementia should be involved in the design process of non-pharmacological interventions for these interventions to meet their needs. To get prepared for co-designing with them, the author reviewed design research studies that involved people with dementia as partners in the design process with the following sub research question:

If (and what) design recommendations for co-designing with people with dementia could be generated from the design research studies that involved people with dementia as partners?

This chapter demonstrates a scoping review of how to co-design with people with dementia. This review revealed that, despite a limited quantity, a growing number of studies had involved people with dementia in the moderate to late stages. This review also uncovered how designers involved this especially vulnerable group. Recommendations on guiding designers to co-design with people with dementia are generated together with the limitations of this approach. The supplementary files mentioned in this chapter can be accessed from the original publication online via the DOI provided.

ABSTRACT

Co-designing with People with Dementia (PwD) can uncover their needs and preferences, which have been often overlooked. It is difficult for PwD to understand designers and express themselves in a conventional co-design session. This study aims to evaluate the effects of involving PwD in design research on both PwD and the design process; to identify the trends of involving PwD in design research; to extract tools, recommendations, and limitations of involving PwD from reviewed studies to update the recommendations on how to co-design with PwD. A scoping review was carried out within the electronic databases PubMed and Scopus, and eight research questions were proposed in order to gain specific knowledge on the involvement of PwD in design research. Twenty-six studies met the inclusion criteria, and 32 sessions were evaluated. Beneficial effects on both PwD and the design process were reported. The number of studies involving PwD in the moderate to severe stages of dementia has increased. Based on the review, an update of the existing tools and recommendations for co-designing with PwD is provided, and a list of limitations about involving PwD is presented. The review shows that involving PwD in design research is beneficial for both the PwD and the design process, and there is a shift towards involving people who are in the moderate to severe stages of dementia. The authors propose that multidisciplinary meetings and case studies should be carried out to evaluate and refine the list of tools and recommendations as well as the list of limitations generated in this review.

4.1 INTRODUCTION

Fifty million people worldwide were living with dementia in 2018, and the numbers are expected to triple to 152 million by 2050 [1]. Dementia is the loss of cognitive functioning in a way that, most of the time, compromises the person's daily-life activities and social interactions [2]. Some of the main functions affected in People with Dementia (PwD) are memory, verbal skills, visual perception, and attention span [3]. These cognitive impairments hinder PwD from expressing what they want and how they feel, which makes caring for PwD different from caring for older adults who can communicate their needs and preferences. Therefore, PwD should be approached differently, and we believe a co-design approach with PwD could uncover their needs and preferences. Co-designing with PwD can offer novel ways of complementing existing approaches to care to improve their quality of life [4].

Co-design is a well-established approach in design practice [5]. Including users and other stakeholders in the design process can lead to designs that meet their needs and preferences [6]. Co-design refers to "the creativity of designers and people not trained in design working together in the design development process". Most people are creative and can contribute to design if provided with appropriate settings and tools [5]. The benefits of co-design have led to its application in designing for people with cognitive impairments, such as people with acquired brain injury (ABI) [7] and people living with dementia [4]. For ABI, co-design has been applied to generate an ecosystem of supports with the latest technology for people with ABI and their families [7]. For PwD, co-designing aids to create a common knowledge base among designers, users and other stakeholders about what living with dementia means, and helps to gain insight into what the remaining capabilities of PwD are; in fact, though, so far, most of the non-pharmacological interventions developed for PwD have failed to consider the remaining capabilities of PwD [8]. The process of co-design could also have a positive impact on the subjective well-being of PwD because it fosters social interaction and enhances empathic connections between participants [6]. As Kitwood states, "a person with dementia must be recognized as a person with thoughts, emotions, and wishes"; thus, PwD should be included in the design process [9].

Despite the above benefits, there are challenges when co-designing with PwD [10]. Due to their cognitive impairments, PwD cannot always verbally communicate their needs and preferences in a conventional co-design session [11]. Co-design activities often ask participants to describe previous situations or imagine future scenarios, and many PwD find these activities difficult [12]. The designers become the researchers as they start to modify a conventional co-design session to make it more suitable for PwD. Where applicable, we have elucidated this aspect in this review. In 2013, Span et al. reviewed studies that specifically involved PwD in the design of supportive information

technology applications [13]. In the same year, Hendriks et al. abstracted a list of guidelines for co-designing with PwD from previous studies on designing together with PwD, people with amnesia or aphasia, and older adults [11]. Though a starting point, that list of guidelines has not been updated since.

We propose that a wider perspective, that is, reviewing studies not only in the field of co-design with PwD but also studies that involved PwD in design research could inform researchers how to conduct more effective co-design sessions with PwD. By “involving PwD”, we mean PwD communicated their needs and preferences in the study rather than acting solely as test subjects, as in a clinical trial. Therefore, we reviewed the literature (a) to evaluate the effects of involving PwD in design research on PwD and on the design process; (b) to identify the trends over time of involving PwD in design research; and (c) to extract tools, recommendations and the limitations of involving PwD from the reviewed studies to update the recommendations for how to co-design with PwD.

4.2 METHODS

We conducted this study as a scoping literature review based on guidelines by Arksey and O’Malley [14]. Scoping reviews are defined as a process of mapping the existing literature or evidence base to identify trends and summarise research findings [15]. Compared with a systematic review, a scoping review answers broader research questions, does not regard study quality as the initial priority, and synthesizes findings more qualitatively than quantitatively [16]. We decided on a scoping review rather than a systematic review because our research questions are exploratory, and our goal is to map the current literature from a broad perspective.

Search terms

The search terms related to co-design were developed based on the current landscape of Human-Centered Design research visualized by Sanders and Stappers [5]. The inter-relationships between the set of search terms is illustrated in Figure 1. Co-design is the collective creativity of designers and people not trained in design as it is applied across the whole span of a design process [5]. In contrast, co-creation, defined as an act of collective creativity, is a broader term with applications “ranging from the physical to the metaphysical and from the material to the spiritual” [5]. The notions of co-creation and co-design originate from participatory design, which is an approach to participatory research [17]. In participatory research, the researchers work in partnership with participants throughout all stages of the research process to gather deeper insights into the world of the participants [18]. Participatory research has its roots in social science, and it supports socially marginalized people to investigate and analyze their reality so as to take

collective actions to change their current situation [17]. In Scandinavia, the participatory design dates back to the 1970s and is more research-oriented [19]. Recently, the notion of generative design research, which is more design-oriented, is proposed as an approach to bring stakeholders directly into the design process through design in order to ensure their needs and wishes can be met [20]. In generative design research, designers create tools for non-designers to let them look into possible futures and express themselves creatively.

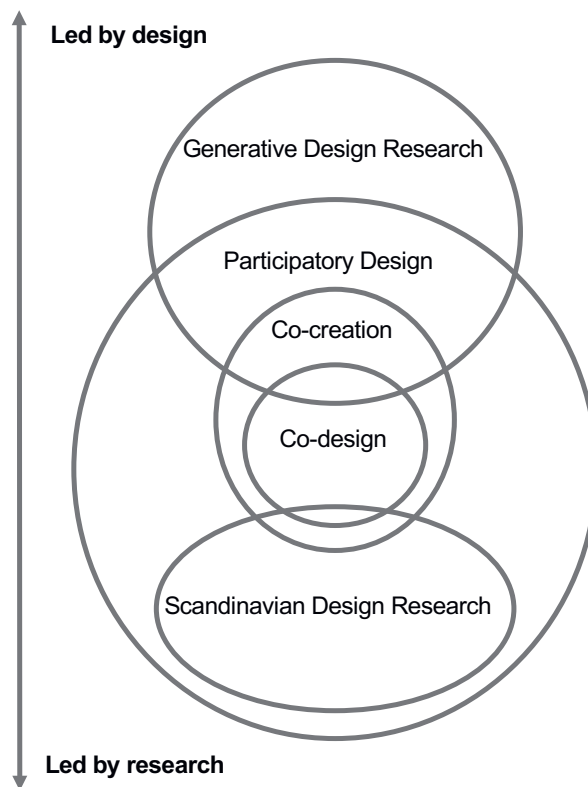


Figure 1. Inter-relationship between search-terms related to co-design (not in scale).

Therefore, the terms co-design, co-creation, participatory design, generative design research and Scandinavian design research are interconnected. To fully review the relevant literature, we decided to do a thorough search, thus absorbing the learning from a wider area than co-design. Accordingly, the first set of search terms consisted of "co-design", "co-creation", "participatory design", "generative design research", and "Scandinavian design research". The second set of search terms was related to dementia and included dement*, Alzheimer* and all other subtypes of dementia.

Inclusion criteria

The current review was conducted in two electronic databases: Scopus and PubMed. The search covered all studies published up to December 31, 2018. The inclusion criteria were: (1) studies that involved participants with a diagnosis of dementia; (2) studies that explicitly stated PwD were involved in the study process; (3) studies that reported outcomes; (4) studies written in English and published in a peer-reviewed journal.

Research questions

Each selected study was analyzed by the following eight research questions. We define a “session” as a period of time arranged for a particular activity involving PwD. Thus, some studies consist of a few sessions. Each session was analyzed individually for research questions 3 to 7.

1. What is/are the aim(s) of the study?

Since the studies included in our review are wider than the scope of design, we first distinguished if a study was a design study, that is, if the aims of the study involved delivering a product or service that could be used by a wider population.

2. What is/are the outcome(s) of the study?

The outcomes of the studies enable us to evaluate if involving PwD in design research has a positive effect on PwD and/or the design process.

3. Which dementia stage were PwD participants in for each session?

As dementia is progressive, the cognitive impairments of PwD will increase over time. The WHO has divided dementia into three stages according to the symptoms, namely, mild (early), moderate (middle) and severe (late), and the recommended caring practice for PwD in these three stages is different. Therefore, we recorded the dementia stage of the PwD involved in the studies reviewed and categorized the tools and recommendations based on the dementia stage.

4. If the study is a design study, in which stages of the design process and for how many stages were PwD involved for each session?

By answering this question, how PwD contributed to the design process could be identified. The whole design process in general consists of four stages, according to Sanders [21], as listed below.

- a. Pre-design stage: understand users’ experiences in the context of their lives, determine what is to be designed
- b. Generative stage: producing ideas, insights and concepts and developing them into designs
- c. Evaluative stage: assessing the effect or the effectiveness of the designs with users; users then give feedback on the design

d. Post-design stage: how the designs are experienced by the users

5. Who were the participants in each session?

We could get additional insights into how a session was organized by recording the participants in addition to the PwD and the researcher.

6. What was the setting of each session?

More insights into how a session was organized could be gained by recording where the session took place and whether it was an individual or group session, which in this review are referred to as “environmental setting” and “organizational setting”, respectively. In this review, an individual session is defined as a session involving only one PwD, although that person could be accompanied by informal or professional caregivers; and a group session as a session involving more than one PwD, again who could be accompanied by informal or professional caregivers or other participants.

7. How were PwD involved, and what were the tools and recommendations for involving PwD for each session?

The relevant information from the reviewed papers was extracted to form a list of tools and recommendations for co-designing with PwD.

8. What is/are the limitation(s) of the study?

The limitations mentioned in the studies were extracted and summarised into a list to help future researchers see the full picture for deciding whether or not to involve PwD in design research. The limitations identified could also be regarded as areas for improvement in future studies.

4.3 RESULTS

The search disclosed 137 records, from which 35 studies were selected as potentially relevant with regard to the scope of this paper; of these, 26 studies met all the inclusion criteria (see Figure 2).

All the studies showed that involving PwD has either a positive effect on PwD or the design process, or both. The benefits for PwD include: the imagination of PwD was positively affected; PwD expressed pride and felt valued; PwD engaged in activities; PwD made more social interactions than usual; PwD felt understood by others. The benefits of the design process include: PwD can give valuable feedback on the design; PwD can help with exploring design opportunities and defining creative solutions; preconceptions of the designers changed based on the insights gathered via designing with PwD; PwD can make useful remarks on the design details. Further information on each study can be found in the supplementary file.

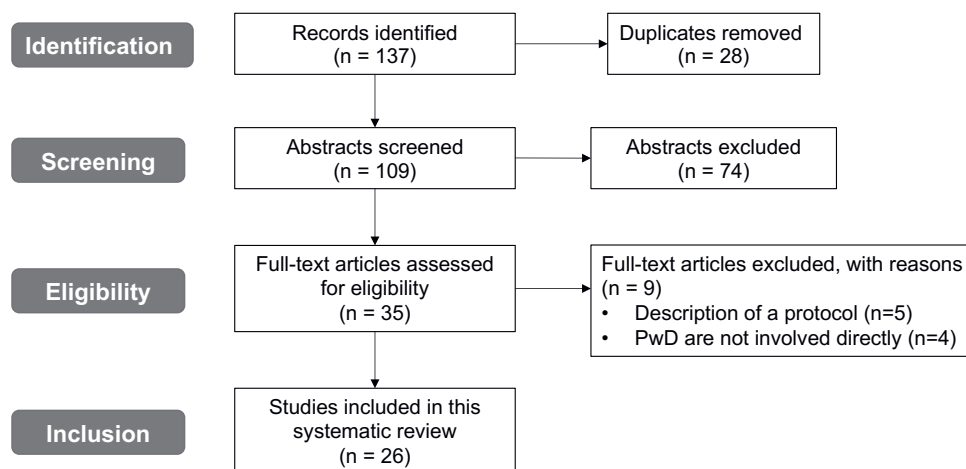


Figure 2. Flow diagram of the scoping review.

A summary of the included studies per year is shown in Table 1, which shows the trend in designing with PwD over time, with one study carried out in 2007 [22], three studies in 2009 [23–25], one study each in 2010 [26], 2012 [27] and 2013 [28], two studies in 2014 [29,30] and 2015 [19,31], four studies in 2016 [32–35], three studies in 2017 [36–38], and peaking at eight studies in 2018 [6,10,17,39–42]. Since some of the studies consist of more than one session, the total number of reviewed sessions is 32.

According to Table 1, for design studies, PwD were mainly involved in the pre-design and evaluative stages of the design process, and most of the sessions involved PwD only in one design stage; however, more recent sessions had begun to involve PwD in more than one design stage and sometimes in all stages of the design process.

The majority of sessions involved PwD in the mild stage of dementia, while more recent sessions had begun to involve PwD in moderate to severe stages. Most of the sessions involved a wide range of stakeholders in addition to PwD; interestingly, more recent sessions included PwD only, and these PwD were usually in the mild stage. There was also an increase over time in the number of sessions involving PwD together with professional caregivers. The majority of sessions were conducted in a group setting, and this remained stable over time. The majority of sessions were conducted in a community environment; however, more recent studies had started to conduct sessions in a nursing home environment.



Please see Table 1 on the next page.

Table 1 Summary of sessions from reviewed studies by year of publication (for each session, the answer to each research question is indicated by “v”; for each answer, the total number of sessions is summed per year).

First author, year	Number of design stages in which PwD are involved					Design stage(s) in which PwD are involved					Dementia stage of the involved PwD			
	one stage	two stages	three stages	four stages	not a design session	pre-design	generative	evaluative	post-design	not a design session	mild	moderate	severe	not mentioned
Hanson, 2007		v				v		v			v			
Year 2007 total	0	1	0	0	0	1	0	1	0	0	1	0	0	0
Faucounau, 2009	v							v				v		
Nomura, 2009	v								v		v			
Robinson, 2009	v					v					v	v		
	v					v					v	v		
	v							v			v	v		
Year 2009 total	5	0	0	0	0	2	0	2	1	0	4	4	0	0
van Rijn, 2010		v				v		v			v	v		
Year 2010 total	0	1	0	0	0	1	0	1	0	0	1	1	0	0
Meiland, 2012	v							v			v			
Year 2012 total	1	0	0	0	0	0	0	1	0	0	1	0	0	0
Martin, 2013	v					v					v			
	v							v			v			
Year 2013 total	2	0	0	0	0	1	0	1	0	0	2	0	0	0
Meiland, 2014	v					v					v			
	v							v			v			
	v							v			v			
Span, 2014	v					v					v	v		
Year 2014 total	4	0	0	0	0	2	0	2	0	0	4	1	0	0
Branco, 2015	v							v			v	v	v	
Tobiasson, 2015	v							v				v	v	
Year 2015 total	2	0	0	0	0	0	0	2	0	0	1	2	2	0
Lopes, 2016		v				v		v			v			
Subramaniam, 2016					v					v	v	v		
Treadaway, 2016					v					v			v	
Year 2016 total	0	1	0	0	2	1	0	1	0	2	2	1	1	0
Branco, 2017	v							v			v	v	v	
Goeman, 2017	v					v								v
Renehan, 2017	v					v								v
Tziraki, 2017	v							v				v	v	
Year 2017 total	4	0	0	0	0	2	0	2	0	0	1	2	2	2
Clarke, 2018	v					v								v
Hendriks, 2018				v		v	v	v	v				v	
Jamin, 2018	v					v					v			
	v							v					v	
Rodgers, 2018					v					v				v
Span, 2018				v		v	v	v	v		v	v		
Thoft, 2018					v					v	v			
Treadaway, 2018	v							v					v	
Tsekleves, 2018				v		v	v	v	v					v
Year 2018 total	4	0	0	3	2	5	3	5	3	2	3	1	3	3

Participants					Environmental setting					Organizational setting			
PwD only	PwD with informal caregivers only	PwD with professional caregivers only	PwD with informal and professional caregivers	PwD with informal and/or professional caregivers and other stakeholders	community	home	nursing home	combined	not mentioned	individual	group	combined	not mentioned
	v				v	v		v		v	v	v	
0	1	0	0	0	1	1	0	1	0	1	1	1	0
	v					v				v			
	v				v					v	v	v	
				v	v						v		
				v	v						v		
0	3	0	0	2	4	1	0	0	0	2	4	1	0
				v	v						v		
0	0	0	1	0	1	0	0	0	0	0	1	0	0
	v					v				v			
0	1	0	0	0	0	1	0	0	0	1	0	0	0
				v		v				v			
				v		v				v			
0	0	0	0	2	0	2	0	0	0	2	0	0	0
				v	v						v		
	v				v						v		
	v				v						v		
2	0	1	0	1	4	0	0	0	0	1	4	1	0
				v				v			v		
				v				v			v		
0	0	1	0	1	0	0	2	0	0	0	2	0	0
				v	v	v	v			v	v	v	
				v				v			v		
0	0	0	1	2	1	1	3	0	0	2	2	1	0
	v					v				v			
				v	v						v		
	v				v								v
2	1	0	0	1	3	1	0	0	0	2	1	0	1
	v				v						v		
	v						v						
	v						v						
				v		v					v		
				v	v	v		v		v	v	v	
	v				v						v		
				v	v		v				v		
5	0	0	1	3	5	3	2	1	0	4	6	1	0

The list of tools and recommendations is shown in Table 2. The tools and recommendations were categorized into “location”, “researcher”, “recruitment”, “structure”, “involvement methods”, and “specific tools and recommendations according to dementia stage”. In the last category, some tools and recommendations could be applied to all dementia stages, whereas others are more specific to one or two dementia stage(s).

Table 2. Tools and recommendations for co-designing with PwD based on the current review of the literature.

Location
<ul style="list-style-type: none"> • Offer a quiet environment • Offer a familiar environment • Offer an environment that suits the social status of PwD • Minimize travelling for PwD
Researcher
<ul style="list-style-type: none"> • Be flexible • Be empathetic • Be patient • Be well-informed about the daily life of PwD • Value different forms of participation • Present ethical concerns throughout the research
Recruitment
<ul style="list-style-type: none"> • Contact with the potential participants directly • Keep recruitment open throughout the project • Recruit people who have experience with caring for PwD to be present in the session
Structure
<ul style="list-style-type: none"> • Organize smaller groups than the usual focus groups for a group session • Allow informal breaks in the sessions
Involvement methods
<ul style="list-style-type: none"> • Doing daily activities together with PwD • Workshops <ul style="list-style-type: none"> ◦ with the purpose of creating ◦ with the purpose of giving feedback ◦ with the purpose of identifying needs • Interviews <ul style="list-style-type: none"> ◦ with the purpose of identifying needs ◦ with the purpose of providing feedback • Focus groups <ul style="list-style-type: none"> ◦ with the purpose of identifying needs ◦ with the purpose of providing feedback • Usability testing <ul style="list-style-type: none"> ◦ by observing how PwD interact with the prototype ◦ by PwD providing verbal feedback on the prototype
Specific tools and recommendations according to the dementia stage
<ul style="list-style-type: none"> • Mild <ul style="list-style-type: none"> ◦ Apply Think Aloud methods ◦ Create scenarios ◦ Make storyboards ◦ Apply visual prompts ◦ Let PwD build rapport with each other

- o Make vignettes
- o Use self-observation diary
- o Select PwD who know each other for group discussion
- o Separate PwD from their caregivers if PwD can express themselves independently so that PwD can give their opinions freely
- o Provide a few concepts instead of just one
- o Use a topic guide to make the session structure clear to PwD
- Mild to moderate
 - o Formulate questions in a way that PwD would not feel that they are being tested
 - o Acknowledge the contribution of PwD
 - o Use videos
 - o Recap the last session before every new session
 - o Ensure questions are not confronting
 - o Let PwD engage in one activity at a time
 - o Use external memory aids
 - o Use environmental cues and triggers
 - o Use subtle physical prompts
 - o Compartmentalize a main task into subtasks
 - o Create a routine for a specific task
 - o Plan tasks that are suitable for the educational level of PwD
 - o Plan tasks to have a purpose
- Mild, moderate to severe
 - o Use tangible materials
 - o Use functional prototype
 - o Apply the Wizard-of-Oz method
 - o Consider physical limitations (eyesight, hearing)
 - o Let PwD tell their story as they wish to tell it, no matter if it is true or not
 - o Use repetitions when necessary
 - o Use clear and short sentences
 - o Personalize the final design (e.g. with pictures of PwD)
- Moderate to severe
 - o Use auditory stimuli
 - o Pay attention to facial expressions and body language
 - o Encourage caregivers to support PwD
 - o Choose activities that PwD are familiar with (e.g., drawing, make collages, reminiscence)
 - o At least two persons (including the researcher) should be present in addition to PwD
 - o Give physical instructions by touching and supported physical movements
 - o Let caregivers act as interpreters of the behaviours of PwD and be aware of the opinions of the caregivers involved
 - o Talk along and help PwD like a caregiver would do instead of taking notes
 - o Bring probes and observe the reactions of PwD towards these probes
 - o Plan activities based on hands-on daily tasks
- Severe
 - o Apply Person-Centred Care principles

The list of limitations is summarised in Table 3. There are 12 limitations in total from the perspectives of researchers, PwD and caregivers. These limitations are inter-related; for example, the potential burden to the caregiver of participating in a study can cause caregivers to refuse to participate [41], and thus might lead to small and sometimes biased sample size in a study.

Table 3. Limitations of involving PwD in design research based on the current review of the literature.**Limitations of involving PwD in design research**

- Caregiver burden of participation
 - Potential stress in PwD
 - Feedback could be restricted to PwD who can express themselves verbally
 - Difficult to manage a continuity of information with PwD
 - Time-consuming for researcher
 - Expensive to execute
 - Difficult to generalize the findings
 - Small and sometimes biased sample size
 - The duration of sessions is usually short
 - Researchers could unknowingly influence what PwD say and do
 - Potentially high drop-out rate
 - PwD could be distressed if a prototype does not work
-

4.4 DISCUSSION

The current review demonstrates that involving PwD in design research is beneficial to both PwD and the design process, and as far as we are aware, it is the first review to analyze the trends in the field of involving PwD in this type of research. We identified that there was a shift towards involving PwD in the moderate to severe stages of dementia from 2014. Besides, tools and recommendations have been developed for involving PwD in the moderate to severe stages over the years. Last but not least, researchers have become more open-minded about the modes of PwD participation. Branco et al. explicitly state that it would be beneficial for researchers to be open about how PwD would like to participate, such as including non-verbal participation [36].

Some of the trends identified could be inter-related. Since PwD in the moderate to severe stages tend to reside in nursing homes, more recent studies were carried out in nursing homes. As informal caregivers are not always present in the nursing home environment, professional caregivers become the participants who accompany PwD in the sessions, which could explain the increase in the number of sessions involving PwD together with professional caregivers.

The other trend about involving PwD in the mild stage is organizing sessions with PwD as the sole participant(s) because researchers have noticed that the opinions of PwD could be interfered with by other stakeholders, and PwD in the mild stage can usually express themselves adequately without help from caregivers. One study which organized separate sessions for PwD and their informal caregivers found that the needs of PwD and informal caregivers could be conflicting [27]

On the basis of a comparison with the review by Span et al. [13], there appears to have been an improvement in involving PwD in design research. The current review demonstrates that before 2017, PwD were mainly involved in the pre-design and evaluative stages of the design process, which concurs with the findings by Span et al. [13]. The current review also found that researchers began to involve PwD in all stages of the design process in 2018. Span et al. [13] could find no study focusing exclusively on the involvement of PwD in the severe stages, and the current review adds that the first study involving PwD in the severe stages was published in 2015.

In general, the tools and recommendations generated by the current review coincide with the earlier guidelines proposed by Hendriks et al. [11]; the current review was able to add more detail to those earlier guidelines [11]. Due to an improvement in the reporting of the dementia stage in most of the studies, we were able to categorize recommendations according to the dementia stage of the PwD participants. An overview of the limitations of involving PwD in design research has not been addressed in previous studies, and a list of limitations was created based on the current review.

The current review has two limitations. First, since five reviewed studies did not mention the dementia stage of the PwD involved, the tools and recommendations of these studies were interpreted based on the experience of the authors to allocate them into the most suitable dementia stage(s) they could be applied to. We encourage future studies to mention the dementia stage of PwD. Second, because involving PwD in design research is a recent development, the number of studies included in this scoping review is limited.

4.5 CONCLUSION

The contribution of the current review is three-fold: 1) we demonstrated involving PwD in design research is beneficial for both PwD and the design process; 2) we found that more recent studies have begun to involve PwD in the moderate to severe dementia stages in design research; 3) we developed a list of tools and recommendations together with a list of limitations for co-design with PwD.

In the near future, the list of tools and recommendations together with the list of limitations should be evaluated and refined in multidisciplinary meetings; they could also be evaluated by case studies. The current review could help researchers to conduct more effective co-design sessions, which could better complement existing care approaches in order to improve the quality of life of PwD.

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Applying Ergonomics in Ageing and Co-design in the field

The author intended to first build empathetic connections with people with dementia before researching Data-enabled Design. Hence she went to the field and applied what she has learned from Ergonomics in Ageing and Co-design (Chapter 3 and 4) to answer the sub research question below:

If (and how) could recommendations on Co-design and Ergonomics in Ageing be applied in the field to facilitate non-pharmacological interventions for BPSD, and what does this imply on these recommendations in personalising dementia care?

This chapter describes a case study on evaluating the recommendations generated previously (Chapter 3 and 4) via the design of De-light, an interactive device for facilitating Snoezelen therapy (a type of non-pharmacological intervention for BPSD) with the aim of managing wandering behaviours in people with dementia. Through the design of De-light, the author evaluated and refined these recommendation lists while identified the wish of the care team in keeping track of the needs of people with dementia for delivering more personalised BPSD care.

ABSTRACT

Wandering behaviour can cause undesired consequences for People with Dementia (PwD), such as falling, getting lost or even fatalities. For caregivers, taking care of PwD with wandering behaviours is burdensome. If not intervened early, some wandering behaviours will escalate into crisis events. Inspired by Snoezelen therapy, this design research aims to explore how to convert the wandering behaviour to a guided activity with the minimum input from caregivers by intervening early, that is, engaging the senses of PwD, to avoid potential escalations. Based on Need-driven Dementia-compromised Behaviour (NDB) model, Crisis Development model, capability considerations for PwD and via a co-design approach, we developed De-light. De-light is a set of interactive sticks enhanced by light, audio and tactile experiences. Based on the degree of wandering behaviours of PwD, De-light can be placed by the caregiver in a safe and suitable area in the nursing home to provide a controlled setting for guiding PwD to perform physical activity. During developing De-light, the usefulness of the NDB model, Crisis Development model, and the recommendations on capability considerations and co-design for PwD have been evaluated.

5.1 INTRODUCTION

Wandering is a common Behavioural and Psychological Symptoms of Dementia (BPSD) that can cause a great risk for People with Dementia (PwD) and has been described as one of the most challenging behaviours to manage [1]. Moreover, wandering behaviour can cause undesired consequences, such as falling, and in the worst-case scenario, fatalities [2]. Professional caregivers in nursing homes (hereafter caregivers) have to take care of several PwD during their shifts and have reported burnouts when caring for PwD with wandering behaviours [3].

The Need-Driven Dementia-compromised Behaviour (NDB) model is the most-cited model for explaining BPSD. According to the NDB model [2], BPSD is a way for PwD to express their unmet needs and goals. Moreover, the factors contributing to BPSD in PwD can be divided into the background and proximal factors (see Figure. 1).

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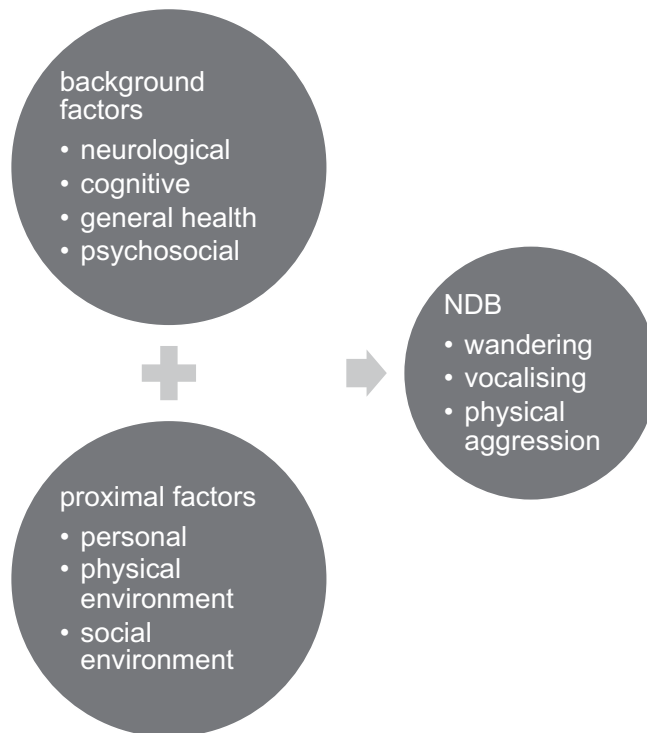


Figure 1. Need-driven Dementia-compromised Behaviour (NDB) model (reproduced based on [2]). The combination of background factors and proximal factors will generate Need-driven Dementia-compromised Behaviours (NDB).

Referring to Figure 1, the background factors mentioned in the model are relatively intrinsic, thus very difficult to change. Proximal factors, on the contrary, can be interfered with for managing BPSD and can be categorised into personal factors, factors in the physical environment and factors in the social environment. The personal factors include emotions, functional performances and physiological needs of the PwD. One common need for PwD with wandering behaviours is that they are constantly looking for stimulations from the environment [4]. The factors in the physical environment contain macro components, which are the overall settings, including layout and routines in the nursing home; and micro components, which are physical stimuli, such as light and sound. The factors in the social environment encompass all interactions with people, which include caregiver stability, ward ambience, and caregiver demeanours.

The current methods for dealing with PwD with wandering behaviours in the nursing home focus mainly on avoiding wandering behaviour, trying to control it with restrictions or applying precautions, for instance, putting warning signs on the door, hiding the doors or using monitoring systems to locate PwD and then interrupt the behaviour (see Figure. 2).

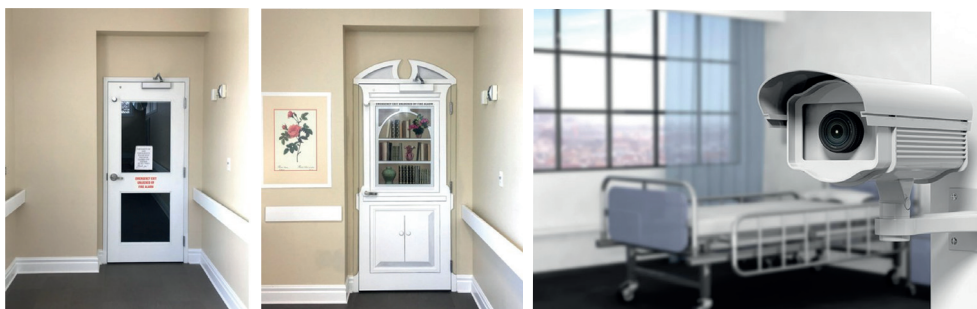


Figure 2. Current methods used in the nursing homes for managing wandering behaviours in PwD, which mainly discourage wandering.

According to the Crisis Development model (in Dutch: Crisisontwikkelingsmodel), wandering behaviour is a sign of increasing stress in PwD (see Figure. 3) [5]. This model divided the degree of stress in PwD into five stages along with time. Specifically, in Stage 0, PwD perform usual activities and do not exhibit BPSD. In Stage 1, as their stress levels increase, wandering behaviours are observed in some PwD. If there is no intervention at this stage, the stress in PwD will keep increasing to Stage 2, at which PwD is under high stress and not fully in control. If there is still no intervention applied, the stress in PwD will keep increasing to Stage 3, at which their control is completely gone, and crisis events arise (e.g., physical violence). It takes time and effort for caregivers to let the PwD at Stage 3 return to the relaxed stage (Stage 4). Simply limiting PwD from wandering could make their behaviours even worse. Instead, intervening early, that is, engaging PwD in activities, could

be helpful to prevent PwD and their caregivers from experiencing crisis events. However, the caregivers are usually occupied with several PwD during their shifts, so intervening to prevent escalation of wandering behaviours is not immediately possible most of the times. Inspired by Snoezelen therapy, PwD could be engaged by sensorial stimuli for avoiding potential escalations, which could also trigger them to carry out physical activities [6].

Several studies have shown that doing physical exercise is beneficial for the emotional and physical wellbeing of PwD [7-9]. As the duration of care received per PwD in the nursing home is expected to decrease in the future [10], there is a growing need for initiatives that stimulate physical activities that do not rely heavily on the caregivers.

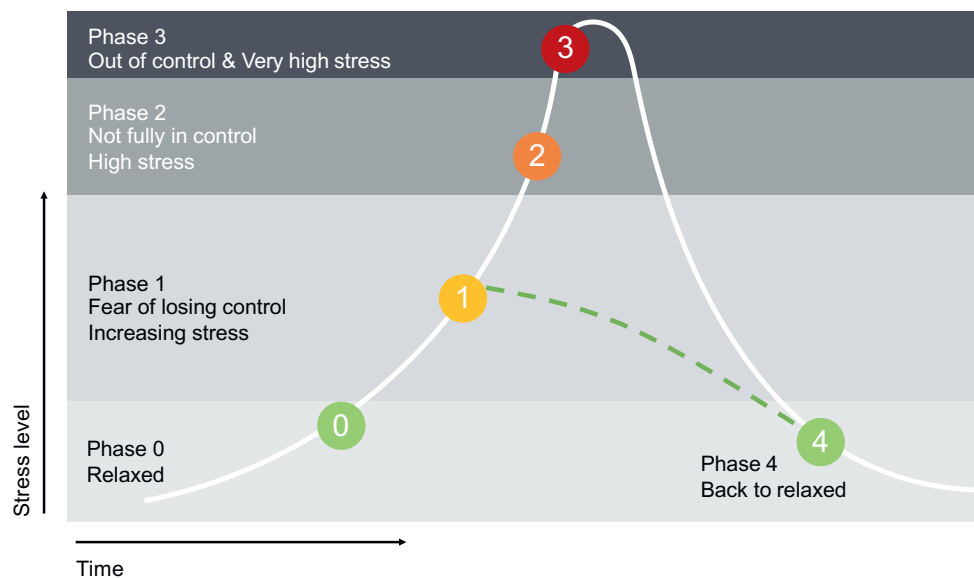


Figure 3. Crisis Development model (in Dutch: Crisisontwikkelingsmodel, reproduced based on [5]). Wandering behaviours are commonly seen in Stage 1. The dotted line indicates the ideal transition from wandering behaviours to the relaxed state for PwD.

5.2 OBJECTIVE

The aim of this design research is to investigate how to turn the wandering behaviour into a guided activity for PwD with minimal input from caregivers by intervening early. Referring to the Crisis Development model (see Figure. 3), the design intervention aims to create a smooth direct transition from Stage 1 to Stage 4 for the PwD; hence later stages of crisis (Stage 2 and 3) are avoided and thus it could take less time and effort for caregivers to calm PwD down. Both PwD with wandering behaviours and their caregivers are the users of our design intervention.

5.3 METHODS AND INSIGHTS

In the early research stage, we used video coding to analyse the wandering behaviours of PwD and the corresponding behaviours of the caregiver. It helped us to gain an understanding of the context quickly. In the design stage, we carried out a co-design session guided by the recommendations on co-design developed previously (Chapter 4) with two PwD and a caregiver. Through this session, we identified what PwD like and do not like, the needs and wishes of caregivers and gained real-life experience in interacting with PwD with wandering behaviours. In addition, we followed the recommendations on capability considerations for PwD (Chapter 3) to ensure the design intervention will fit with the capability levels of PwD. Since the insights of one design activity led to the set-up of the next activity, the methods and insights are presented together in chronological order in this section.

Video coding

Two videos were taken of one PwD in two different scenarios at the nursing home Zorggroep Elde Maasduinen in the Netherlands under ethics approval and informed consent from the caregivers and the legal representatives of the PwD. One video was taken when the PwD exhibited wandering behaviour in his own bedroom, and the other video was taken when the PwD was staying in the dining room, and the caregiver was making sure the PwD would not wander to the kitchen and to other PwD. Firstly, four Master students (Industrial Design Engineering, Delft University of Technology) coded these videos independently by recording behaviours of PwD and caregivers in a list with timestamps, then all these lists were compared and then summarised when a consensus was reached after a discussion with the first author GW.

From the video coding, we found that this person with dementia lost attention to the activity that he was currently doing easily, and there was no activity that could keep him engaged for over half a minute when he was staying alone in his bedroom. In contrast, he wandered less in the dining room, as the caregiver tried to attract his attention by using a soft football every time he wanted to wander off to the kitchen and to other PwD. Specifically, the caregiver played with the football in front of the PwD and invited him to touch the ball and play with her.

When the caregiver was playing the ball, the sound generated as the ball bounced on the floor and the movement of the ball attracted the attention from the PwD. When the PwD touched the ball, he began to squeeze and hold the ball close to him and examined it closely. He then threw the ball back to the caregiver, and the caregiver threw the ball back to him. This playful throwing lasted for seven to eight rounds, then the PwD lost attention and started to wander again. Then the caregiver tried to catch the attention of the PwD by having a “conversation” with him. Even though what the

PwD said was not comprehensible, the caregiver nodded and replied with simple words as if she understood what the PwD was talking about. In this way, the PwD engaged in this “conversation” for a while and then wandered again. Throughout the video, the caregiver was fully occupied in attracting the attention of this PwD by using these two methods (soft football and “conversation”) interchangeably, and she had no interactions with other residents.

We, therefore, came up with the following hypothesis: 1) physical stimulus (e.g., light, sound, and texture) can attract the attention of PwD; 2) interactive elements can prolong the attention time of PwD.

Co-design session

The co-design session was also carried out at the nursing home Zorggroep Elde Maasduinen in the Netherlands under ethics approval and informed consent from the caregivers and the legal representatives of the PwD. The co-design session started at 5 o'clock in the afternoon and lasted for one hour. Two other PwD and a caregiver participated in this session.

This session was organised by following the tools and recommendations for co-designing with PwD [11, 12]. Specifically, the location was selected to be the nursing home as it offers a quiet and familiar environment for PwD and minimises travelling for the PwD and the caregiver. The researchers (GW and Master students) were being flexible, empathic, patient throughout the session, valuing different forms of participation and presenting ethical concerns. In addition, the researchers were well-informed about the daily life of PwD before the session by the previous visit. The recruitment was done via direct contact with potential participants, and people who have experience with caring for PwD were also recruited (the caregiver). The recruitment was kept open throughout the project. The group size in the session was kept being smaller than a usual focus group session, and informal breaks were allowed in the session.

Since the PwD participants are in the moderate to severe stage of dementia, we also chose the co-design recommendations that suit these stages. Specifically, we brought probes and observed the reactions of PwD towards these probes; we used tangible materials and auditory stimuli; we considered the physical limitations (e.g. eyesight, hearing) of the PwD by asking the caregiver if they have any sensory impairments; we paid attention to their facial expressions and body language towards the probes, and also let the caregiver act as an interpreter for these non-verbal behaviours while being aware of the opinions of the caregiver involved; we encouraged the caregiver to support PwD by giving physical instructions such as touching and supported physical movements; we talked along and helped PwD like caregivers would do instead of taking notes; and in general, we applied Person-Centred Care principles throughout the session.

In the co-design session, we aimed to know what kind of physical stimuli and interactive elements PwD like and do not like and what are the needs and wishes of the caregiver. In terms of the stimuli, we placed them near the PwD to see if they could notice these stimuli. The stimuli included a Bluetooth speaker playing soothing music, a green LED chain with constant light, and another green LED chain with flashing light (both lights are regarded as calming according to the caregiver). As for the interactive element, we provided them with a ball (more interactive: lights up when being touched) and a small square speaker (less interactive: no reaction when being touched), then we observed the PwD and counted the time they spent on each object.

We have gained valuable insights from the co-design session. We found that the PwD had very narrow visual fields and were too focused on the area close-by to notice the outside stimuli without the guidance from caregivers; they did not have an observable response to the music, and there was no significant difference between the time they spent on the ball and the speaker. However: 1. PwD are more likely to respond to the human voice (e.g., instructions from caregivers). 2. PwD can notice things outside their visual field if guided by caregivers. As for the needs and wishes of the caregiver, she wanted the design intervention to be safe, easy-to-use, quick to set up, and can let her easily identify if it is broken.

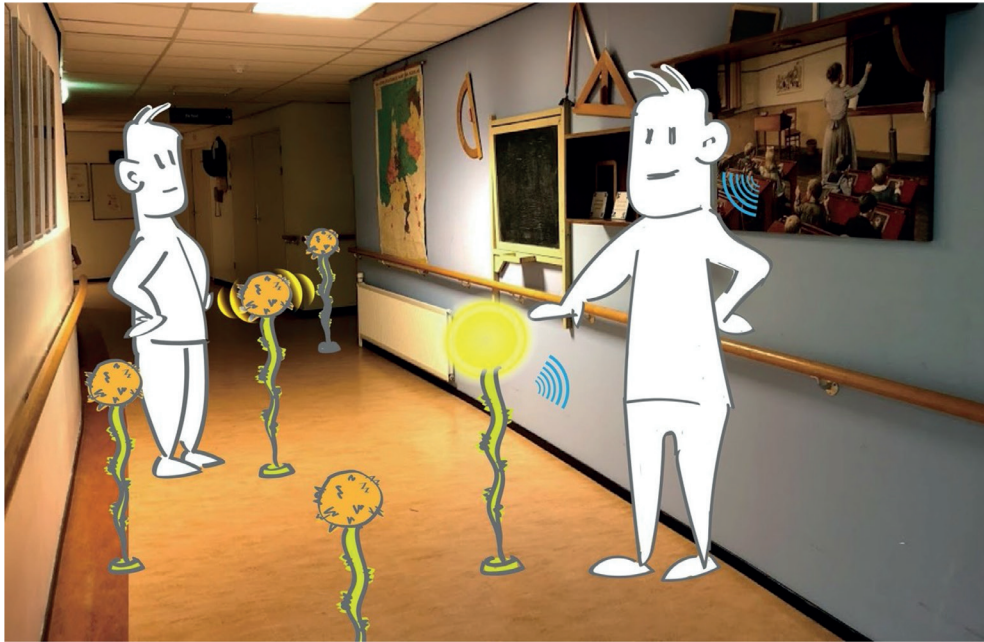
Capability considerations

Previous findings recommend that non-pharmacological interventions should be designed with the capabilities of PwD in mind under the guidance of ergonomics [13]; hence we followed the design recommendations on capability considerations for PwD [14]. For facilitating Snoezelen therapy, the design concept we envisioned will provide multisensorial stimulation to interact with PwD. The capability considerations applied are described below.

Specifically, in the sensory-oriented aspect, we ensured that the sound sources are located close and by the sides of PwD during the interaction; the low-frequency sound was used; the light source was determined to change its brightness gradually; the emitted light was designed to be diffused; reflecting surfaces were avoided; the wavelength of the light was chosen to be from 570 nm to 620 nm. Concerning the cognition-oriented aspect, we embedded auditory and visual prompts in the design intervention to attract attention from PwD; the guided activity that the design intervention intends to initiate was decided to involve no planning, sequencing and multitasking from the PwD. Regarding the movement-oriented aspect, the intended guided activity was designed to only involve movement with low intensity and slow rhythm from the PwD.

1.4 THE DESIGN

In light of the NDB model, Crisis Development model, video coding, and under the guidance of the recommendations on co-design and capability considerations, we came up with the final design concept – De-light (see Figure. 4).



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Figure 4. The design concept of De-light, which is designed to convert wandering behaviours into a guided physical activity.

The interaction details of De-light are demonstrated by the prototype (see Figure. 5), and the numbers in the figure correspond to the numbers in the text describing the interaction details. The details are as follows:

1. The De-light only has an On/Off button so that it is easy-to-use for caregivers. When turned on, the De-light automatically detect the proximity of people. The sphere will light up when it detects a person is in proximity to attract his/her attention, thereby triggers the subsequent interactions with the person. The caregiver immediately knows De-light is broken if it does not light up when switched on.
2. The glowing sphere on the top of the stick is soft and elastic to invite PwD to touch and cuddle it. By touching the sphere, De-light can automatically give verbal responses (e.g., “Hey, I like your warm hands!”). De-light also softly asks questions

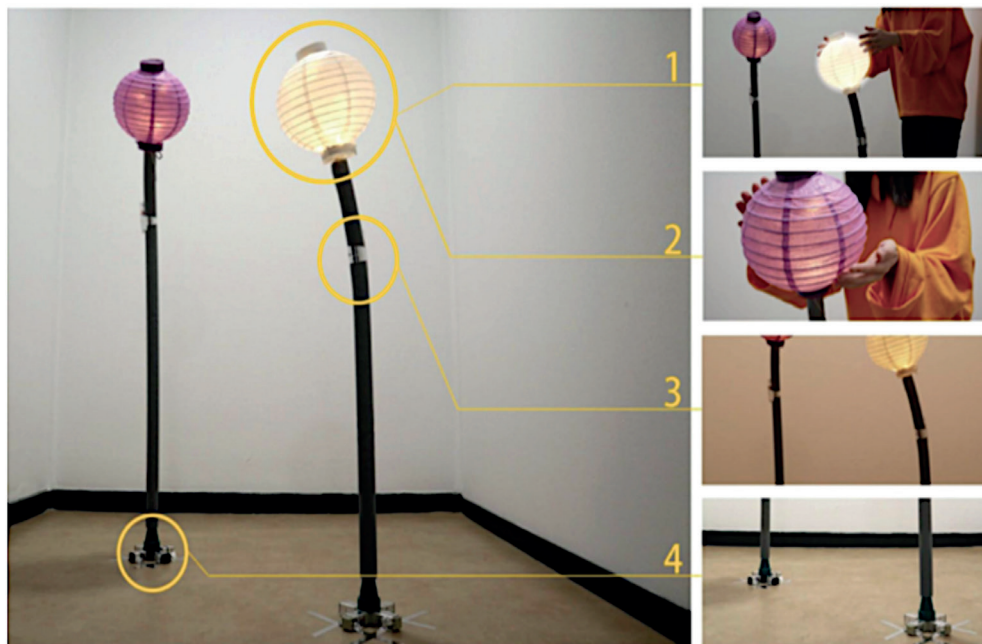


Figure 5. De-light prototypes and interaction details. The four small images illustrate the four enlarged interaction details of the prototype. The numbers on the image correspond to the numbers in the text.

(e.g., “Hello, how are you today?”) to maintain the attention of the PwD until the PwD stops touching it for five minutes. The light goes off when the PwD leaves.

3. The stick part is soft and flexible so that De-light behaves like a tilting doll when bent by the PwD, thereby creating a playful movement interaction with the PwD; this could also increase the number of ways that PwD interact with the De-light.
4. The bottom of De-light is moveable, and De-light is lightweight yet stable on the floor when pushed and pulled, so caregivers can place appropriate numbers of De-Lights quickly and easily in the corridor or other environments in the ward as needed.

Both physical and social environmental factors are modified by De-light. As mentioned in the NDB model, the physical environmental factors can be interfered with by the macro components and the micro components [2]. De-light takes both macro and micro components into consideration. For the macro components, De-light allows caregivers to personalise and customise the layout of the environment for the PwD; specifically, caregivers can place different numbers of De-lights in a safe and suitable area in the nursing home (e.g. corridors, living room, individual room of PwD) to form

an interactive environment for PwD as needed; for the micro components, De-light uses lights, sounds and tactile feedback as interactive means for PwD to satisfy their needs in seeking stimulation. Regarding social environmental factors, the guidance of caregivers on PwD is an essential part of using De-light; meanwhile, De-light is designed to encourage interactions while involving caregivers as little as possible.

De-light is designed to be easy to set up and only requires the caregiver to initiate and end the activity. This is achieved by setting a series of De-light in the environment. When the PwD loses interest in one De-light, he/she can be attracted to the next De-light. Once the activity is initiated, the interactive elements in De-light will keep PwD engaged. From the video coding and co-design session, we found the PwD participants easily lose attention to the same object or activity quickly, they respond to human voices better than music, and their attention can be guided by caregivers. Caregivers have to take care of several PwD at the same time; thus, they do not have full attention to guide one PwD throughout their shifts. According to the Crisis Development model, De-light is advised to be used when the PwD starts the wandering behaviour (Stage 1). Therefore, De-light allows PwD to vent their stress and energy in time by engaging them via a series of interactions without dramatically increasing the workload of caregivers.

In the intended use scenario, when a caregiver empirically judges that a PwD starts to wander around, the caregiver will set up a few De-lights in an area where he/she finds safe and suitable. Then he/she will guide the PwD to the De-lights environment and guide the PwD to interact with De-lights for a couple of minutes. After the activity is initiated, the interactive elements in the De-light will keep PwD engaged with minimal assistance from caregivers. When the energy and stress of PwD are fully vented by playing with De-lights (this is also judged by the caregiver), the caregiver will guide the PwD moving out of the De-lights environment to let PwD rest and relax.

The envisioned benefits of using De-light are summarised in Figure 6. The traditional methods for managing wandering behaviours discourage physical activities, require high workload for caregivers, lead PwD to have a high chance of escalation and cause safety concerns.. De-light encourages physical activities in PwD, and since the PwD will be around the De-light environment during the intervention, he/she will “wander” in the safe environment set by the caregiver. The caregivers do not have to constantly monitor the wandering of the PwD, thus can better divide attention to every PwD within his/her duties. The stress and energy in PwD are also vented in time so that potential crisis events could be avoided.



Figure 6. The envisioned benefits of De-light in the intended use scenario for wandering behaviour.

5.5 EVALUATION OF THE DESIGN

A focus group was organised to present the concept of De-light to a range of stakeholders, which consists of a person in mild to moderate stage of dementia and his wife, a psychologist, a geriatric doctor, a dietitian and two professional caregivers. The feedback given was noted down and clustered with the affinity diagramming method [15]. The analysed results are summarised in Table 1.

Table 1. Clustered feedback on De-light from the focus group.

Cluster	Code
Personal needs	<ul style="list-style-type: none"> Wandering behaviours could be triggered by different needs This design will only be effective for some PwD Whether PwD interact depends on their mood PwD have different thresholds for stimulation PwD have different reactions to unfamiliar objects
Context	<ul style="list-style-type: none"> De-light might attract other PwD PwD could be distracted if the background is chaotic The brightness of De-light might be affected by the lighting in the ward De-light should not obstruct the flow of people in space and cause trip hazards
Caregiver needs	<ul style="list-style-type: none"> Easy to clean A low frequency of charging or change of battery for the device Will not be broken down by some PwD

Specifically, the three clusters identified are personal needs, context, and caregiver needs. Regarding personal needs, the participants indicated that other unmet needs in PwD that could lead to wandering (e.g., look for someone, need the bathroom); thus, De-light might not work as intended if the need for PwD is not purely on seeking stimuli. This means that De-light is only suitable for some PwD, and even for these PwD, De-light does not work all the time. The participants also mention that the mood of the same PwD during wandering could be different, and different moods could affect whether the PwD find De-light interesting or not. Besides, different PwD have different thresholds for stimulation. For some PwD, the current stimuli provided by De-light could be too much for them to process. There is also a debate about whether familiarity is important for PwD. Some participants find the abstract shape of De-light could deter some PwD; some argue an unfamiliar shape could trigger curiosity in some PwD; while others maintain that a combination of familiarity and unfamiliarity yield the best results for some PwD. A caregiver made a nice summary: “you can only know if something has a positive effect, through trying it out for each resident, as you can never predict how someone will react. Even if it works for the first time, it might not work for the second time”.

Concerning context, in the nursing home setting, De-light might attract the attention of other PwD, so whether should De-light encourage multiple PwD play together or should it be used by only one PwD (in a dedicated room) is worth to be investigated. During interacting with De-light, PwD could be easily distracted by the movements and sounds in the surroundings. The lighting in the ward could affect whether the lights emitted from De-light can be perceived by PwD, since they tend to have vision decline. Lastly, De-light should not obstruct the flow of people in space and cause trip hazards.

As for caregiver needs, some specific issues have been raised regarding if De-light is easy-to-clean, how often does it need to be charged, and how robust can it be to withstand PwD from actively breaking it down.

5.6 DISCUSSION

De-light could potentially encourage PwD with wandering behaviours to vent their stress and energy in a controllable way by modifying the physical and social environments around them. Served as a set of interactive stimuli, De-light could possibly help the group of PwD who wander for seeking stimuli. Instead of restricting PwD in a closed room or preventing them from wandering, De-light encourages physical activeness in PwD, which will be beneficial for both the physical and emotional wellbeing of PwD in the long run.

Reflect on the NDB model

The NDB model has brought a new perspective for designers in understanding the wandering behaviours in PwD by depicting the background and proximal factors that could contribute to BPSD in PwD. However, this model only lists what factors could contribute to BPSD without indicating how one could make use of these factors in managing BPSD in PwD. Algase et al. found that the proximal factors have great potential for intervention, but they have not received enough conceptual development or usage in empirical studies [2]. Our research and design expand the NDB model by applying these factors to explore a way to convert wandering behaviours into a guided activity for PwD. De-light serves as a showcase for demonstrating a possible direction in modifying these factors in managing BPSD. Specifically, insights about the proximal factors were gained from the design process, and these insights guide the design of De-light. Starting from this model, our study made a step forward to investigate the impact of this way of working in managing BPSD in a real-life situation.

Reflect on recommendations of capability considerations

The recommendation list for capability considerations has been evaluated to be useful in designing De-light to fit with the capabilities of PwD in general. Since not all capabilities of PwD are involved in De-light, only some of the recommendations were evaluated; and additional recommendations are generated for some of the capability categories (see Table 2), which could be applicable when designing for people in moderate to severe stages of dementia.

Reflect on recommendations of co-design with PwD

We realised that although PwD have impaired cognitive capabilities, which means they have difficulty describing their previous experiences, articulating their feelings and needs, and imagining future scenarios, it is still insightful to conduct co-design session with them together with their caregivers. PwD can convey what they want and how they feel via their behaviours. The caregivers, who understand the PwD better than the design researchers, can provide more accurate interpretations for the behaviours of PwD. In addition, the caregivers are very likely to assist PwD with using the design intervention, so caregivers can express what they like and do not like about the design concept from a user's perspective. For example, we found that caregivers need to not only take care of PwD but also handle several devices during their shifts. Confusion could arise when handling multiple devices, so "easy to use" should be incorporated in every detail of the design. The caregivers can also talk with designers about the previous experiences in caring for PwD and imagine future scenarios in caring for PwD with the design intervention applied. Some caregivers could provide information on the life history of the PwD during co-design, which are useful handles for personalisation. The designers are also recommended to reach out to the family members and friends of PwD for this type of information.

Table 2. The added recommendations on capability considerations for people in moderate to severe stage of dementia.

Capabilities	Recommendations
Auditory	The tone and volume of the sound should be carefully chosen to avoid overstimulation
Visual	Contrast (colour and brightness) between “object of interest” and “background” should be large enough to be seen The intervention should be able to be placed close-by The frequency, brightness and colour should be carefully chosen to avoid overstimulation
Somatosensory	The size should be small enough to be hold with one hand (e.g., a football-size is too large) The size should be large enough to be manipulated with one hand (e.g., a pea-size is too small) No slippery surface
Attention	Movement could attract attention Human voices could attract attention (sometimes more than abstract sounds) A changing state could attract attention (e.g., turning off the light after it is on for a while) Provide timely physical feedback after an action by the PwD
Memory	The object should be big enough that it cannot be swallowed The object should be easy-to-clean
Executive control	The object should initiate the interaction The interaction should be open-ended
Muscular strength	The weight should be light enough to be hold with one hand

The recommendation list for co-designing with PwD has been evaluated to be useful in involving PwD in the design process. Since only people in moderate to severe stage of dementia were involved, the recommendations relevant to this specific user group were applied; and additional recommendations are generated and summarised (see Table 3). These recommendations could be used for co-designing with people in moderate to severe stage of dementia.

Table 3. The added recommendations on co-designing with people in moderate to severe stage of dementia.

Aspects of consideration	Recommendations
Probe selection	Vary in textures, forms, colours and other physical qualities Base on the past experiences and hobbies of the person Check with caregivers if the probes are suitable before the session
Structure	Inform caregivers about the co-design procedure beforehand
Researcher	Provide positive feedback to PwD

Reflect on both sets of recommendations

Some of the additional recommendations generated above for capability considerations and co-designing with PwD came from both the design process and the evaluation session. We noticed that some of the recommendations in capability considerations and in co-designing with PwD feed into each other. To illustrate, the selection of the probes (one aspect of the co-design recommendations) could be guided by the capability recommendations. For example, the probes should be large enough to avoid being swallowed during the co-design session. In turn, some learnings gathered during the co-design sessions could help with developing the recommendations for capability considerations. For instance, some PwD are observed to lack the initiative to start an interaction, which reflect the current cognitive-oriented capability of PwD; hence the product could be designed to be able to initiate the interaction.

Limitations and future development

Our research and design are still at an early stage. The evaluation and refinement of the recommendation lists on co-design and capability considerations are based on small sample size and need further validation. The feedback from the stakeholders indicates the potential values of De-light.

The evaluation session pointed out two main issues to be addressed in future studies. First, all stakeholders agree that the differences between PwD (or the uniqueness of each PwD) should be factored in for facilitating non-pharmacological interventions; moreover, the difference in the mood of the same PwD in the morning and in the afternoon could render an intervention from being effective to being not useful. More details need to be taken into consideration given the differences between PwD and the difference in the mood for the same PwD at different times. Secondly, caregivers expressed that they lack tools to keep track of the needs of all PwD in the ward given their busy working routine (e.g., caregivers do not remember if a PwD has been to the bathroom in the morning or not). Therefore, to support a personalised approach in BPSD management, the care team could be empowered with up-to-date information about each PwD.

5.7 CONCLUSION

In this study, De-light was developed and evaluated with the aim to facilitate caregivers with managing wandering behaviours of PwD in nursing homes via multisensorial stimulation. Specifically, De-light is envisioned to encourage physical activeness in PwD by converting wandering behaviours into a guided activity with minimal input from caregivers, which could reduce the incidence of crisis events and beneficial for the physical and emotional wellbeing of PwD. The recommendations on capability considerations and co-design have been evaluated and refined during the design process. Our research and design approaches suggest the possibilities of applying the NDB model and Crisis Development model in designing for PwD exhibiting BPSD. More research should be carried out on how to help the care team with personalising the use of De-light in the nursing homes.

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Based on: G. Wang, H. Gong, A. Albayrak, T. J. M. van der Cammen, and G. Kortuem, "Personalising management of behavioural and psychological symptoms of dementia in nursing homes: Exploring the synergy of quantitative and qualitative data," *BioMed Research International*, vol.2020, Article ID 3920284, 16 pages, 2020.

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Applying Data-enabled Design in the field

The previous field study (Chapter 5) found that the care team are lacking tools to keep track of the needs of all people with dementia in the ward, and the author hypothesised that Data-enabled Design could facilitate the care team in achieving this goal. She set the sub research question to be answered at this stage as:

What types of data could be combined for personalised BPSD care in nursing homes, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team for analysis?

This chapter describes the exploration process of how Data-enabled Design could be applied to facilitate the care team with personalising BPSD care, during which a digital platform (named Data-care) was developed. This digital platform could collect both quantitative and qualitative data about each person with dementia and visualise them integratively to facilitate the care team in analysing the data. In this way, up-to-date insights about each resident could be generated. The author involved the care team closely in the design process, and the interpretations of data made by the care team have helped her to understand more about each person with dementia and dementia care in general, in addition to what she has learned from Ergonomics in Ageing and Co-design. The supplementary files mentioned in this chapter can be accessed from the original publication online via the DOI provided.

ABSTRACT

Researchers have been exploring how to manage Behavioural and Psychological Symptoms of Dementia (BPSD) in a personalised way; meanwhile, assistive technologies have been developed to collect a variety of personal data. This urges more research in investigating the combination of data collected by the care team, which are mainly qualitative, and data collected by assistive technologies, the majority of which are quantitative. Previous studies, however, have yet to explore if and how a combination of quantitative and qualitative data could facilitate the care team to better understand each resident with dementia in the nursing home context for personalised BPSD management. Guided by a Research through Design approach, a prototype for collecting and visualising the quantitative and qualitative data towards personalised BPSD management was developed together with the care team. Via developing this prototype, knowledge was gained in what types of data could be combined for personalised BPSD management in nursing homes, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team for analysis. The main findings suggest that the types of data to be collected could be unique for each resident with dementia; the quantitative and qualitative data are of value to each other during data collection and analysis; data collection should be quick and standardised yet flexible for the care team; the overview page is vital for data presentation, and user scenarios could be created to nudge the care team to analyse the data at certain points of their working routine. In general, a combination of qualitative data and quantitative data could help the care team to discover more insights about each resident with dementia and thus improve the current practice of personalised BPSD management.

6.1 INTRODUCTION

Ninety-seven per cent of People with Dementia (PwD) will develop at least one behavioural or psychological symptom over a five-year period [1], which includes agitation, aggression, depression etc. [2]. The collective term for these symptoms is Behavioural and Psychological Symptoms of Dementia (BPSD), which has been identified as a predictor of nursing home placement [3]. BPSD is regarded as a type of communication for PwD to express their unmet needs and goals [4–6]. According to the Need-driven Dementia-compromised Behaviour (NDB) model (see Figure 1), the factors contributing to BPSD are divided into the background and proximal factors. Background factors consist of neurological status, cognitive status, general health, and psychosocial factors. These factors are inherent to the PwD, thus difficult to change. Proximal factors include personal needs, the physical environment and social environments. These factors could be modified for preventing or intervening BPSD. Each individual has his or her unique background and proximal factors; thus, the management of BPSD should be tailored to individual needs. However, the current personalised methods for managing BPSD are limited [7–9], which implies this field needs to be explored, especially in the nursing home setting.

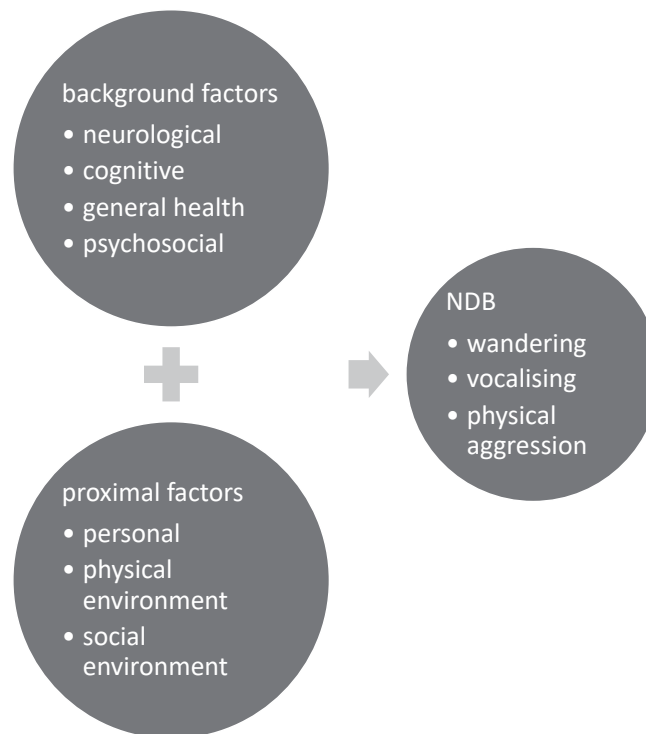


Figure 1. Need-driven Dementia-compromised Behaviour (NDB) model (modified based on [4]).

The recent research for personalised BPSD management in nursing homes is on facilitating the creation of a personal care plan for each resident. For instance, in the Behaviour Analytics & Support Enhancement programme, an individual care plan was created for each PwD participant based on a multidisciplinary meeting [10]. The creation of the care plan only relies on qualitative data generated by the care team so far.

A care team is usually composed of professional caregivers, e.g., nurses and care assistants, and other healthcare professionals, e.g., doctors, psychologists, dietitians, and managers. Professional caregivers are distinguished from other healthcare professionals in this study for the different roles they play in the creation of the care plan. This is because professional caregivers are involved in caring activities on a daily basis; accordingly, they are more involved with the data collection for care plan making. The involvement of other healthcare professionals is less than that of professional caregivers; they usually meet up with professional caregivers to get second-hand information about the current mental states and needs of PwD before collecting data themselves. In general, mainly the professional caregivers observe and remember the behaviours of each PwD and discuss them in the multidisciplinary meeting with other healthcare professionals so as to create the individual care plan. However, the qualitative data generated by the care team might not be accurate since human memory can be influenced by a variety of factors, can fade quickly, and can be inadequate in remembering details [11]. Moreover, it is challenging to collect and analyse data about care recipients like PwD, who cannot confirm if the data collected and the analyses are correct.

Concurrently, a range of assistive technologies has been developed to assist BPSD management in nursing homes [12]. The commonalities shared by them are that objective data about PwD are automatically tracked by sensors and stored and processed by algorithms quantitatively, and the analysed outcomes are then presented to healthcare professionals and professional caregivers via a network communication platform [13]. The types of data collected range from behavioural data, such as motion [14], acoustics [15], and location [16], which are used to monitor the behaviours of PwD; to physiological data, such as heart rate [17], skin conductance [18], and respiratory rate [19], which are used to evaluate the emotional state of PwD; to contextual data, such as location [20], temperature [21], and light level [21], which are used to assess the environments that the PwD is in. Researchers in Data-enabled Design stressed the importance of combining quantitative data (referred to as “sensor data” in Data-enabled Design) and qualitative data for designers to gain contextual, behavioural, and experiential insights in developing intelligent ecosystems [22]. A data framework on combining quantitative data and qualitative data for BPSD management has also been developed for researchers [21]. The researchers can use this framework to plan and organise data collection, extraction, and analysis to understand the context for dementia caregiver empowerment. More research is needed to explore if and how a

combination of quantitative and qualitative data could facilitate the care team, instead of designers or researchers, to better understand PwD in the nursing home context for managing BPSD in a personalised way.

In this study, the combination of qualitative data collected by the care team and quantitative data collected by the Indoor Positioning System (IPS) was explored. This is because, among the objective quantitative data collected by assistive technologies, location data has been used for monitoring BPSD and is also recognised as central to the context in BPSD management [12]. Not only movement patterns but also other relevant parameters (e.g., travelled distance, interaction time with others) could be derived from the location data. Therefore, combining location data and qualitative data for BPSD management can be the starting point of exploration. The IPS has been developed to monitor the locations of objects and people over space in real-time in the indoor environment [23], which is suitable for this study given the fact that PwD involved in this study usually stay indoors due to BPSD.

Our hypothesis is that a combination of qualitative data generated by the care team and quantitative data generated by the IPS could help the care team to discover more insights about a resident and thus improve the current practice of personalised BPSD management. This study is aimed at exploring what types of data can be combined for personalised BPSD management in nursing homes, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team for analysis.

6.2 MATERIALS AND METHODS

Study design

The Research through Design (RtD) approach was adopted, whereby “design activities play a formative role in the generation of knowledge” [24]. This approach has been used in codesigning ambient assisted living environments for informal dementia care and yielded concrete insights on the attitude of informal caregivers towards these assistive technologies [25]. In our study, a prototype of a digital platform was developed for combining the quantitative and qualitative data on personalised BPSD management through a series of design activities with the care team, e.g., interviews and evaluation sessions.

The function of this prototype is to “connect abstract theories to experience” [24]. The “abstract theory” is that a combination of quantitative and qualitative data could facilitate personalised BPSD management, and this prototype could then enable the care team to gain “experience” in collecting and analysing these data. The development

of this prototype helps to generate knowledge regarding the four research questions below:

- (1) What types of data can be combined for personalised BPSD management?
- (2) What are the values of these combinations for personalised BPSD management?
- (3) How to collect and present these data?
- (4) How to introduce these data in the working routine of the care team for analysis?

Ethics approval

The study was carried out in Zorggroep Elde Maasduinen nursing home in the Netherlands. In this nursing home, there is a special ward for PwD exhibiting BPSD symptoms. The study protocol was approved by the Human Research Ethics Committee of Delft University of Technology and Zorggroep Elde Maasduinen. Since this study involves collecting location data from the PwD and professional caregivers, written informed consent was obtained from professional caregivers and the legal representatives of PwD. In the end, the legal representatives of eight residents and all twelve professional caregivers have given consent to allow the IPS to collect their location data. The IPS requires each participant to carry a physical tag (in the shape of a thick ID card), and the location of the tag is tracked by the system for data collection. Three residents were excluded from the study later on because they showed signs of disliking the tags. The participants involved in the location data collection are shown in Table 1.

Table 1: Participants involved in location data collection.

Participant type	Number	Inclusion criteria
PwD	5	Diagnosed with dementia; residing in the BPSD ward
Professional caregivers	12	Working in the BPSD ward

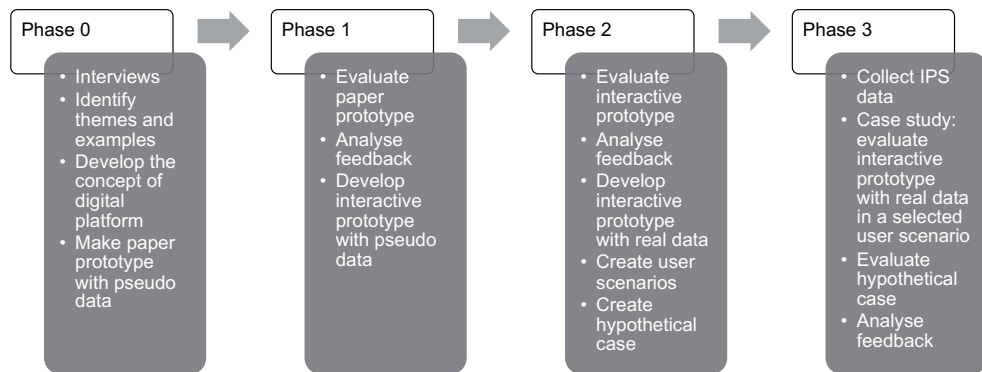
The Research through Design process

This process consists of four phases, and the learnings generated in the first phase act as the starting point of the next phase. Throughout the process, a prototype was developed and refined based on the feedback received from each phase. The participants involved in each phase of the RtD process are shown in Table 2. Specifically, the professional caregivers, doctor, psychologist and dietitian are directly involved with the care plan making; the manager is also involved in this study since she is in charge of the performance of the ward and participates in the multidisciplinary meetings.

Table 2: The number and professions of participants involved in the Research through Design process.

Profession	Phase 0	Phase 1	Phase 2	Phase 3
Professional caregivers	3	2	6	1
Doctor	1	1	1	0
Psychologist	1	1	1	1
Dietitian	1	1	1	0
Manager	1	1	1	0

Written informed consents were obtained from all participants. Some professional caregivers participated in both the location data collection and the RtD process. The aims of the four phases are to answer the four research questions above, and the activities carried out in each phase are described in detail below and are summarised in Figure 2.

**Figure 2.** Activities of each phase in the Research through Design process.

• Phase 0

Semi-structured interviews were conducted with professional caregivers and the responsible doctor, the responsible manager, the responsible psychologist, and the responsible dietitian of the ward. The interviews are aimed at discovering concrete themes and examples of the proximal factors since the NDB model has only provided abstract concepts about what proximal factors might be. The interview guide can be found in the supplementary files. In the interview guide, the NDB model (see Figure 1) was used as a conversation starter. Each interview lasted 45–60 min and was audiotaped and transcribed verbatim. Thematic analysis was undertaken and followed the six steps recommended by Braun and Clarke [26]. Specifically, the first and second authors (GW and HG) familiarised with the data, generated initial codes, searched for themes, reviewed the themes, then defined and named the themes, and finally produced a report on themes and examples identified for the proximal factors. The types of data that could be combined were initialised based on the report. The concept of a digital

platform was developed, and the interfaces of the digital platform were represented in a paper prototype to illustrate the concept. Some interface pages of the paper prototype are shown in Figure 3. Due to the time required for installing and adjusting the IPS, the data used for this prototype was pseudo data. The pseudo data were created based on the educated guess of the researchers via reading the reports in the ward.

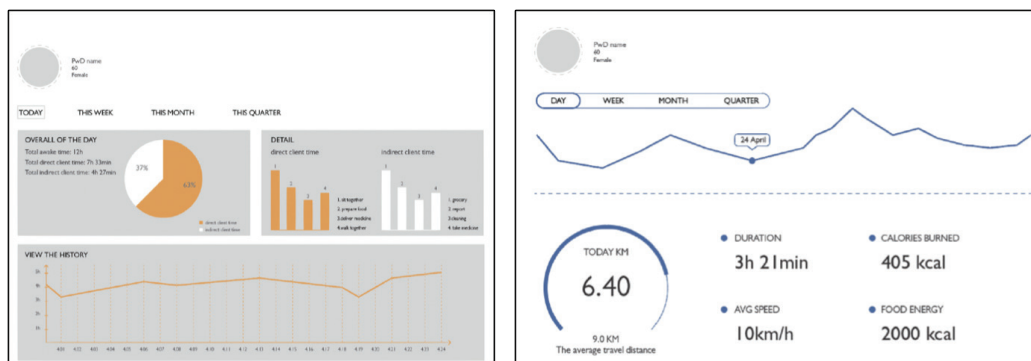


Figure 3. Interface pages of the paper prototype.

- **Phase 1**

The paper prototype was presented to participants for feedback on data visualisation and interface design via individual evaluation sessions, with each session lasting for 15 min. The sessions were recorded and transcribed verbatim. The transcripts were analysed using affinity diagramming [27]. Based on feedback from the evaluation session, the concept was further developed, and an interactive prototype was made accordingly. Some interface pages of the interactive prototype are shown in Figure 4. The data used for this prototype was the same pseudo data. Since the researchers were still exploring data visualisation and interface design, whether the data is real would not affect the user feedback gathered.

- **Phase 2**

The interactive prototype was evaluated on a tablet in the nursing home, as shown in Figure 5. Individual evaluation sessions were conducted, with each session lasting for 15 min. The task set out for the participants was to browse through the prototype and gather sufficient data, about a particular resident, that is relevant to their profession. This is because each profession has a unique role in personalised BPSD management. The participants stopped the task when they thought they had gathered sufficient data. The participants were then asked to think about when they would like to use the digital platform in their working routine, that is, when they would like to analyse the collected data. During the sessions, field notes were taken and analysed by an affinity



Figure 4. Interface pages of the interactive prototype.

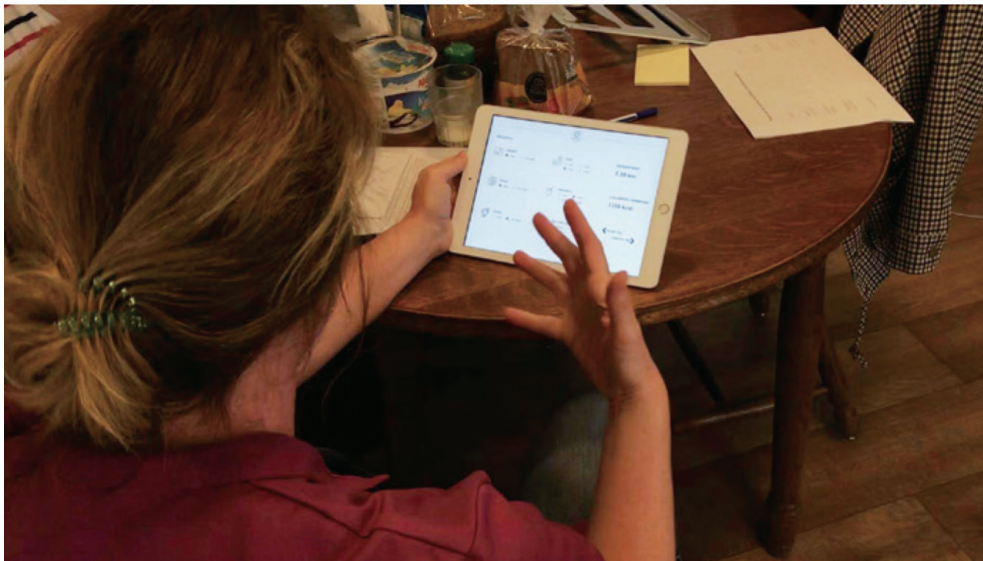


Figure 5. Evaluation of the interactive prototype with the end-user.

diagramming method specific for evaluating interactive prototypes [28]. Building on the feedback, the interactive prototype was improved in terms of data visualisation and interface design and incorporated with real data. A hypothetical case was created to help the care team imagine what the digital platform could do in the long term. User scenarios were created based on the answers regarding when one would like to analyse the data.

- **Phase 3**

A case study on data analysis was performed using the interactive prototype, and the hypothetical case was read to the care team for feedback. The care team was asked to select a resident and choose a user scenario, and the data was then collected about this resident for 15 days and provided to the care team. A data collection of 15 days was hypothesised to be able to allow the care team to have an experience of analysing real data. The care team was then asked to decide on the most suitable way to analyse these data. In the end, the responsible caregiver of the selected resident and the responsible psychologist analysed the data in a selected user scenario: care plan meeting. The meeting was observed, recorded, and translated from Dutch to English, and notes were taken and categorised using affinity diagramming [27].

6.3 RESULTS

In the following sections, the key findings to the research questions across successive research phases are described. In general, the findings become more detailed and concrete from Phase 0 to Phase 3. In Phases 0 and 1, only the first three research questions were touched upon because answering the last research question became only possible after the preliminary answers from the previous research questions were available. The relationships between the research questions and study phases are shown in Figure 6, and the readers may refer to Figure 2 for the activities carried out in each phase of the study.

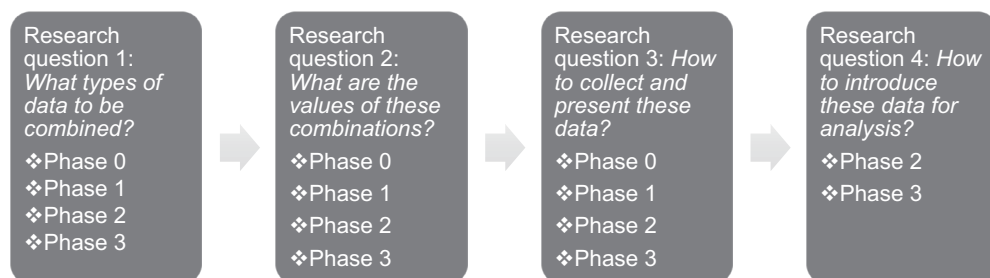


Figure 6. Relationships between the research questions and study phases.

What types of data

• Phase 0

For the quantitative data, concrete themes and examples of proximal factors were identified from the thematic analysis, which can be found in Table 3. In total, 13 themes were identified and supported by 29 examples. These themes and examples were discussed within the research team to develop a list of parameters that both reflect proximal factors and can be collected by the IPS. The parameters are, for each PwD, over the daytime, “movement distance,” “duration of stay in each room,” and “interaction time with others.” The data directly presenting these parameters are referred to as IPS data in this paper. The IPS data of each PwD are summarised and presented in a few periods, specifically, daily, weekly, and monthly for each member of the care team.

Table 3: Themes and examples identified for the proximal factors (the number in the brackets indicates the code number used in thematic analysis).

Three aspects of proximal factors	Themes identified for each aspect	Examples of each theme
Personal needs	Negative emotional state	Unfamiliarity (1, 4, 5) Stress (20) Confusion (7)
	Unmet physiological needs	Wrong diet (10, 11) Hunger and overeating (12) Lack of movement (13) Lack of sleep (14, 15) Toilet needs (17)
	A mismatch between functional ability and performance	Lack of freedom of movement (18, 19) Break of routine (21, 22)
Physical environment	Unsuitable light level	Not enough light to see clearly (31)
	Unsuitable sound level	Too low (23) Too high (24, 25, 26, 27) Echo (28, 29, 30)
	Unsuitable temperature	Too low or high (36)
	Number of people in the surroundings	Too many people walking in the surroundings (32, 33, 34) Staying by oneself in a room for too long (35)
	Smell	Unpleasant smell (37, 38)
	Weather	Lack of sunshine (3, 40) Bad weather has a negative influence (39)
	Interior decoration	Match personal identity (41)
Social environment	Caregiver demeanour	Lack of interaction with PwD (42)
	Family visit	The contrast during and after the family visit (6) Tiredness after a family visit (8, 51) A family member could give more rules to PwD (49, 52)
	Other staff visits	Normally do not interact with PwD (43)
	Fellow residents	Realising oneself is different from others (48) Disliking the behaviours of other residents (44, 45) Physical closeness and interactions are normally negative (46, 47)

For the qualitative data, the nursing home has a reporting system in place for recording the behaviours of residents. In this system, professional caregivers usually write a daily report of the behaviours of each PwD. In addition, the nursing home has created a plan (named signal plan) on behaviours for each resident based on the Crisis Development model (in Dutch: Crisisontwikkelingsmodel) (see Figure 7). For each signal plan, this model is used to guide professional caregivers to take appropriate actions based on the observed behaviours of the PwD [29]. The signal plan is developed based on the observations of the behaviours of a resident for three months, and it consists of five stages, which are colour-coded. In Stages 0 and 4, a PwD performs usual activities and does not exhibit BPSD (colour green). In Stage 1, as PwD's stress level increases, BPSD, such as wandering behaviours, is observed (colour yellow). In Stage 2, the PwD is under high stress and not fully in control (colour orange). In Stage 3, the control of PwD is completely gone, and crisis events such as physical violence arise (colour red). The daily reports and colour codes are of value to reflect the BPSD state of PwD quickly and reliably; thus, they were selected as the qualitative data to be collected. The daily reports, together with colour labels, are referred to as BPSD data in this paper.

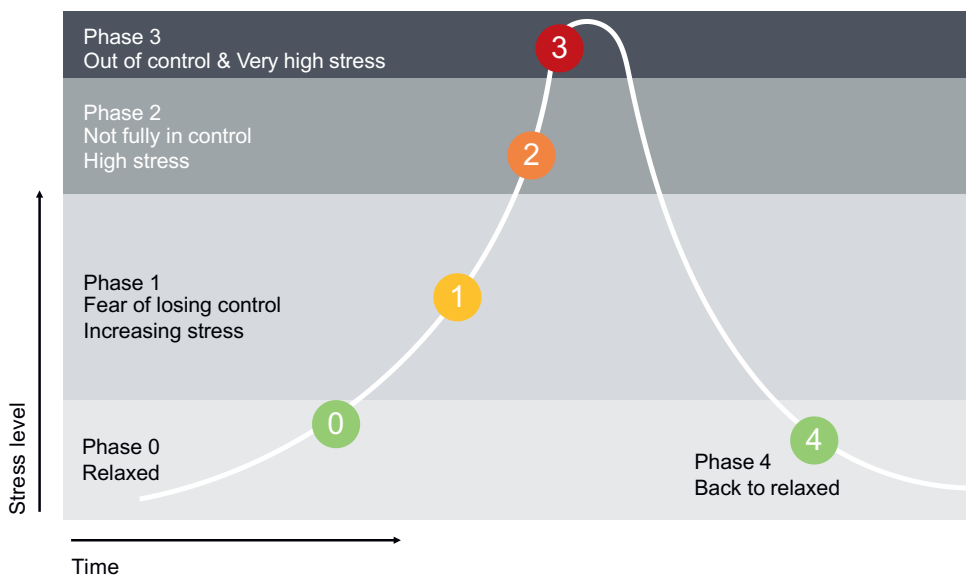


Figure 7. Crisis Development model (in Dutch: Crisisontwikkelingsmodel, based on [29]).

- **Phase 1**

During the evaluation of the paper prototype, the professional caregivers, doctor, and psychologist pointed out that they would also like to see the movement animations to identify possible movement patterns of the PwD. They gave examples such as “moving back and forth,” “suddenly accelerate,” and “suddenly stop,” which are insightful for

them to evaluate the behaviours of the PwD. Therefore, the animations for movement patterns were added in the interactive prototype for evaluation at the next stage.

- **Phase 2**

When evaluating the interactive prototype, the participants found it is time-consuming to watch through the animations for all the residents to identify movement patterns, so they suggested exploring half-hourly IPS data. Half-hourly IPS data is the sum of IPS data for every 30 minutes. Therefore, the animations for movement patterns were replaced with half-hourly IPS data for evaluation at the next stage. Real data was later incorporated into the interactive prototype.

- **Phase 3**

After analysing the real data on the interactive prototype, the professional caregiver indicated that she would like to know the sequence of events the resident has experienced over a day, which cannot be captured by the half-hourly IPS data:

"I also want to know the order of events that happened. Now I only know how long she stayed in each room every 30 minutes. But whether she goes to the living room before or after going to the bedroom, I do not know."

Values of these data

- **Phase 0**

During the interview, the care team mentioned that the IPS data collected could be used for detecting the onset of BPSD and effective ways of managing it. As the doctor put it:

"The walking distance. Does it give relaxation? ... Because sometimes when people are agitated, they get sort of rest by moving around, but sometimes they get more agitated (because of moving)."

Besides, the care team also thought that the daily reports they write could contextualise the IPS data. For example, the travelled distance of the tag could be due to the active movement of the PwD but could also be the result of passive movement, i.e., a professional caregiver pushing the wheelchair of a PwD to help the PwD move around. By reading the report, the professional caregiver was able to distinguish a passive from an active travelled distance by a PwD and thus provide a well-informed analysis of the physical activity of the PwD.

- **Phase 1**

During the evaluation of the paper prototype, the participants expressed the more

nuanced values of these data to their work, which were different for participants with different professions. The doctor and psychologist reported that they keep “detecting the onset of BPSD and effective ways of managing it” as the main value of data to them. In addition to this value, professional caregivers pointed out that they would also use IPS data as a reference when writing the daily report:

“I think that we can do better, and maybe there’s something we can do with the data. We see someone was high in stress. He’s walking a lot. We wrote down the distance he had walked instead of ‘he walks a lot’ because 200 meters is a lot to me, but 500 meters is a lot to my colleague.”

The manager would like to use data to evaluate the conditions of the residents and decide when they could leave the dedicated BPSD ward and go back to the regular ward, i.e., the ward for PwD without frequent BPSD:

“Because we are a special ward, only people with behavioural symptoms come here; the caregivers have more time for them (than caregivers from the normal wards). We try to understand their behaviours, and they will be sent back to the normal ward when we find a way to manage these behaviours. So, if we see the ‘interaction time with others’ of one resident has been low over some time, then maybe he could get used to life in the normal ward. We can then send him back to the normal ward and accommodate someone who needs more help.”

Whereas the dietitian stated:

“Only the walking distance per day is useful for me, so I can calculate the energy burned by the person.”

Moreover, for the same data type, participants with different professions value the data over different time periods; for example, the manager is only concerned about the monthly overview for each PwD, while professional caregivers are more concerned with daily data; the manager only wants to get an overview of the BPSD state of a PwD using colour codes, whereas professional caregivers need detailed information from the daily reports to know what happened to each PwD each day. The doctor and psychologist would like to decide whether or not to read the daily reports after reviewing the colour codes.

- **Phase 2**

When evaluating the interactive prototype, the participants saw the value of data as a reminder. They would like to be reminded to pay attention to a resident when there is a deviation or a sudden change of data collected about this resident. In the busy working environment of a nursing home, with residents who cannot fully express their needs, the care team thinks it is useful if the data can draw their attention to important issues that could be overlooked.

- **Phase 3**

After analysing the real data on the interactive prototype, the participants identified that the data had the value of understanding the day structure of the residents, which they had not thought about before:

"We intend to understand more about the behaviours of the resident, but the data is not insightful on that for now; instead, we find it is useful for day structure of the resident."

They then expanded:

"It is not the purpose (of data analysis), but it is also nice to know their day structure."

The insights they generated from the data led to modifications in the care plan. The insights and modifications in the care plan are shown in Table 4.

6

Table 4. The insights generated from data analysis and the subsequent modifications in the care plan from the care plan meeting.

Insights from data analysis (input of the care plan meeting, quotes from the professional caregiver)	Modifications in the care plan (output of the care plan meeting)
<i>"If she is not being invited to the living room, she will call somebody, and if she is then being invited to the living room, then the problem is solved. Maybe she is thinking I have finished morning care and eating; why am I still in my room? So, to prevent her from getting high in stress, we should invite her to the living room around 9:30 am."</i>	Invite the resident to the living room around 9:30 am
<i>"After activities, most of the time, she will be brought to her room. From the data, I can see sometimes she is brought to the living room. She tends to get high in stress when she is brought to the living room." "When she is high in stress and gets invited to the living room, sometimes she is fine, but sometimes she will have stress if she stays in the living room." "I will ask the physiotherapist to end the session in her room."</i>	Bring the resident to her room after activities
<i>"There is one day that she had both music therapy and physiotherapy; it is too many stimuli for her." "There is one time that she went to the activity room with the volunteers; that was too much for her." "one hour of activity is enough for the day and not too long."</i>	Limit the number of activities per day
<i>"If she had lots of activities in the day, like visits from the family, going to the church, music therapy, physio, it is better for her to eat in her own room." "If there are not so many things going on, she then eats in the living room."</i>	Choose dinner location based on the daily activities
<i>"Sometimes when she is shouting in the living room and being brought back to her room, after a while, she is invited to the living room again, she does not shout anymore, she just mumbles unhappily." "I will let her stay in her room after activities. It does not need to take long. After around 30 mins, I will check if she is OK. If she needs more time, I will go check after another 30 mins."</i>	Invite the resident to the living room as soon as she is calmed down

How to collect and present these data

- **Phase 0**

For collecting IPS data, each PwD participant had to wear a tag during the daytime. As each PwD had his or her own daily routine, daytime was defined as from the moment one is dressed in the morning until one is undressed to go to bed in the evening. This period of time is within the timeframe from 7 am to 10 pm. Each professional caregiver participant agreed to also wear a tag during his or her shift. The movement distance of each PwD per day was defined as the travelled distance of the tag per day. The duration of stay in each room of each PwD per day was defined as the duration of stay of the tag in each room per day. The interaction time with others of each PwD per day was defined as the duration of two or more tags being physically close per day. Physically close was defined as the distance between the tags being less than 0.5 m for more than one minute. We acknowledge that these definitions are by no means completely accurate in reflecting the activities of PwD; rather, they acted as starting points for the researchers and the care team to link IPS data with the activities of PwD which reflect proximal factors for BPSD.

The concept of a digital platform was developed at Phase 0 to collect BPSD data from professional caregivers and keep track of and present all the data. The digital platform was designed to be used on a type of tablet that is under current use in the nursing home. In terms of collecting qualitative data, this platform is envisioned to allow professional caregivers to write daily reports and save all the reports. Moreover, professional caregivers can give a colour label for each daily report (Figure 8). Specifically, they judge the stress level of the PwD according to the Crisis Development model by examining the behaviours of the PwD recorded in the daily reports (i.e., stress-rating). This is because that even though both daily reports and signal plans were part of the working practice of professional caregivers, there was no obvious link between the daily reports and colour codes used in the signal plans. This stress-rating feature links the daily reports and signal plans while minimising the workload of the professional caregivers.

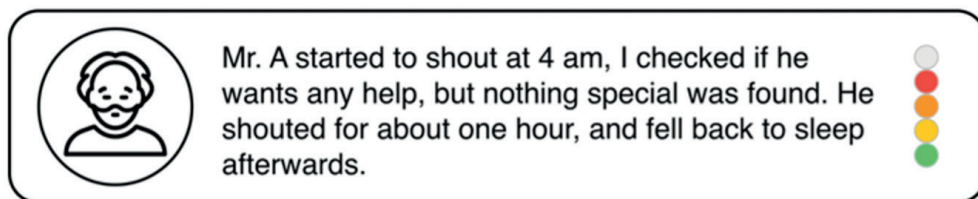


Figure 8. The interface page allows professional caregivers to colour-code daily reports by clicking on the drop-down list.

In terms of presenting data, familiar forms of data visualisation were chosen, such as bar charts, pie charts, and line charts. This is because some professional caregivers said they have difficulties with interpreting complex data visualisation (e.g., dashboard). The daily reports were gathered on an overview page and ordered based on when they were created. The paper prototype was later developed.

- **Phase 1**

While evaluating the paper prototype, all participants indicated that they would like to see IPS data and BPSD data being presented on the same page; in this way, it would be easier for them to draw inferences. For example, by looking at the combined data of BPSD state and walking distance for a PwD over a few weeks, they would be able to judge if there is a correlation between these two parameters. “Correlation” is used in a broader sense by the care team, i.e., the tendency for two parameters to change together in either the same or opposite direction, instead of the definition in statistics. All participants indicated that they would like to make some notes and highlights on the digital platform to record their insights when analysing the data and share the notes with other members of the care team.

At the end of Phase 1, an interactive prototype was developed. Considering the varied values of data expressed by different professionals when evaluating the paper prototype, the interactive prototype was developed to be able to prompt the participants to select their professions and then present the type and period of the data according to their professions. As the study progressed, the types and periods of data presented to each profession on the prototype were updated according to the findings in each phase (see Table 5).

A care team member can indicate his/her profession on the home page of the digital platform. The home page of the digital platform is shown in Figure 9, in which the five professions of the care team, i.e., professional caregiver, dietitian, manager, doctor, and psychologist, are presented. The IPS data and BPSD data were combined in the prototype. For example, the travelled distance data in a week are presented in a bar chart. The height of the bar presents the daily travelled distance, and the colour of the bar presents the colour label given to the PwD each day. This interface page is shown in Figure 10. On each page, professional caregivers and other healthcare professionals are encouraged to write short notes and make highlights. All the notes are then collected on an overview page that is accessible to the whole care team. The participants can click on the notes on the overview page to go back to the page on which the note was made. On this page, they can examine the original IPS data and BPSD data accompanying the note. In the interactive prototype, there are two overview pages for qualitative data, one for daily reports and the other for notes.

Table 5: The types and periods of data presented to participants on the prototype according to their professions (where D = daily data; W = weekly data; M = monthly data; HY = half-yearly data; HH = half-hourly data).

Profession	Paper prototype with pseudo data	Interactive prototype with pseudo data	Interactive prototype with real data
Professional caregiver	Movement distance [D, W, M] Interaction time with others [D, W, M] Duration of stay in each room [D, W, M] BPSD state (daily reports and colour labels) [D, W, M]	Movement distance [D, W] Interaction time with others [D, W] Duration of stay in each room [D, W] BPSD state (daily reports and colour labels) [D, W] Movement pattern [D]	Movement distance [HH, D, W] Interaction time with others [HH, D, W] Duration of stay in each room [HH, D, W] BPSD state (daily reports and colour labels) [D, W]
Doctor	Movement distance [D, W, M] Interaction time with others [D, W, M] Duration of stay in each room [D, W, M] BPSD state (daily reports and colour labels) [D, W, M]	Movement distance [W, M] Duration of stay in each room [W, M] BPSD state (colour labels then daily reports) [W, M] Movement pattern [D]	Movement distance [HH, D, W, M] Duration of stay in each room [HH, D, W, M] BPSD state (colour labels then daily reports) [W, M]
Psychologist	Movement distance [D, W, M] Interaction time with others [D, W, M] Duration of stay in each room [D, W, M] BPSD state (daily reports and colour labels) [D, W, M]	Movement distance [W, M] Interaction time with others [W, M] BPSD state (colour labels then daily reports) [W, M] Movement pattern [D]	Movement distance [HH, D, W, M] Interaction time with others [HH, D, W, M] BPSD state (colour labels then daily reports) [W, M]
Dietitian	Movement distance [D, W, M] Interaction time with others [D, W, M] Duration of stay in each room [D, W, M] BPSD state (daily reports and colour labels) [D, W, M]	Movement distance [W, M, HY]	Movement distance [W, M, HY]
Manager	Movement distance [D, W, M] Interaction time with others [D, W, M] Duration of stay in each room [D, W, M] BPSD state (daily reports and colour labels) [D, W, M]	Interaction time with others [M] BPSD state (colour labels only) [M]	Interaction time with others [M] BPSD state (colour labels only) [M]

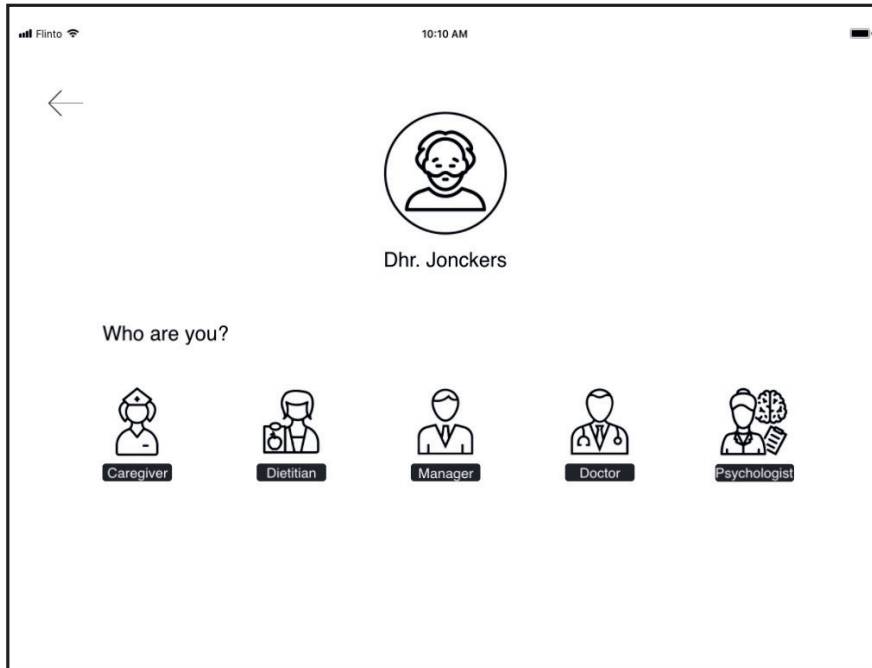


Figure 9. Home page of the digital platform prototype.

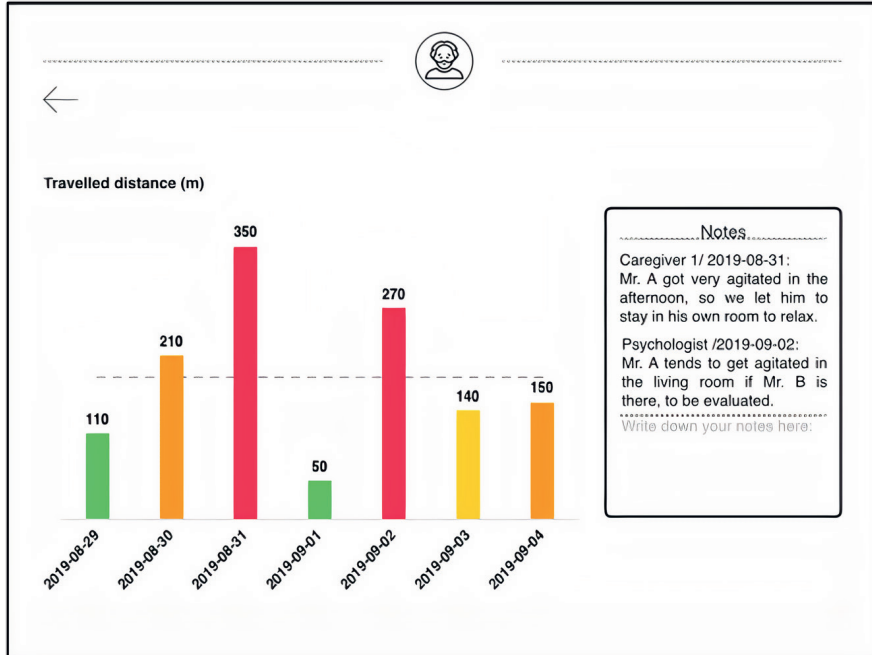


Figure 10. The interface page presenting the distance data and BPSD state of a PwD. The care team can write notes on the right.

- **Phase 2**

After evaluating the interactive prototype, all participants would like the digital platform to prioritise the presentation of the data according to the urgency of the events the data represents; for example, the data showing a PwD is in bad condition (e.g., suddenly reduced movement distance by half) is more urgent than showing a PwD is in a good state (e.g., the colour label stays green for a week). The participants stressed that they still would like to know both deterioration and improvement in BPSD for each PwD. All participants found push notifications would be helpful to remind them to use the digital platform, and the notifications should only show urgent events.

Based on their feedback, the interactive prototype was improved in terms of data visualisation and interface design. A hypothetical case was also created to help the care team imagine how the future digital platform could help with personalised BPSD management. The hypothetical case is shown in Table 6.

Table 6. The hypothetical case on how the future digital platform could help with personalised BPSD management (the hypothetical data collected are highlighted in bold).

Hypothetical case

Mr A has been diagnosed with Alzheimer's Disease (the main disease which causes dementia), and his data has been collected for one month in the nursing home. Through analysis, the care team identified that Mr A prefers to stay in the **dining room** in the **morning** but in his **bedroom** in the **afternoon**. His **average walking distance** is 200 meters per day. The **optimal duration of interaction** with him is around 30 minutes. If the duration is longer than optimal, Mr A **tends to be tired**; if the duration is shorter than optimal, he tends to **go to bed late**. However, one morning, Caregiver B noted Mr A **does not want to go to the dining room and gets agitated very often**. Since Caregiver B was also busy with other residents, s/ he reported this on the digital platform and carried on working.

The next morning, a notification was generated on the digital platform showing Mr A's **average walking distance** had decreased by half, and the **interaction duration** had dropped to 10 minutes. The digital platform suggested a multidisciplinary meeting within the care team. Because of working in shifts, Caregiver B was not in the nursing home, so Caregiver C organised the meeting to discuss the current state of Mr A. Based on the data from the digital platform, the care team decided to take Mr A for a health check and identified that he had a bruised leg. The care team then updated the care plan for Mr A, which included treatment for the bruised leg, serving food in his room, and informing family members about Mr A's situation; thus, they would adjust their visiting time. After the care plan update was made, the care team was able to evaluate the effectiveness of the updated plan with the new data from the digital platform. In summary, even though Mr A could not express what had happened to him, the digital platform sent out real-life notification based on the data collected by IPS and professional caregivers, and the other healthcare professionals used the data in the digital platform to identify the change in Mr A's behaviour and respond quickly without caregiver B's presence. In this way, the quality of care received by Mr A was ensured. Without the system, Mr A's change in behaviour might have been overlooked, which might have caused a delay in his treatment.

- **Phase 3**

While collecting real data, we found that the main difficulty of collecting data was the unestablished working routine for professional caregivers to use the tags. Out of the 15 days, three days of IPS data were completely missing because the professional caregivers forgot to give the tag to the resident, and four days of IPS data were partially missing because the tag was not fully charged the night before. This insight pinpoints

that there are several elements involved in data collection, and all elements, including tag usage, should be designed carefully to ensure high-quality data to be collected. Despite incomplete data, the professional caregivers have identified the value of the IPS in understanding the day structure of PwD, which informed the modifications of the care plan (see Table 4).

In terms of data visualisation, the half-hourly IPS data over the 12 days (excluding the three days with completely missing data: Nov 1, Nov 3, and Nov 6) is summarised on an overview page. The overview page for “duration of stay” is shown in Figure 11. The professional caregivers found the visualisation in the overview page is easy to understand and used it as the guide for reviewing BPSD data:

“First, I look at the overview page, and I find she has lots of time in the living room, then I check what happened in the daily report. Normally, if she is in a good mood, she stays in the living room; otherwise, she stays in her (bed) room.”

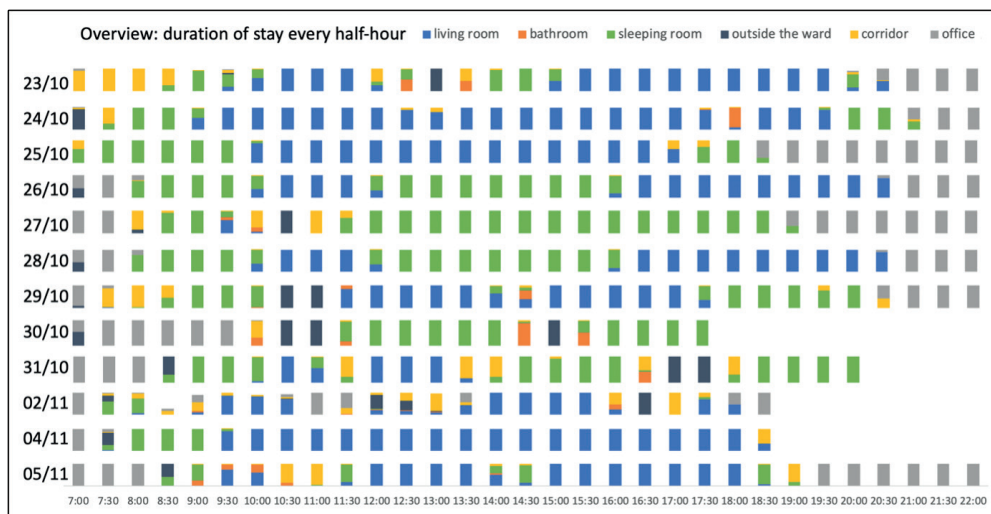


Figure 11. The overview page for “duration of stay” presented to the professional caregivers (since the tag was charged in the office each day, it has a long duration of stay in the office at the beginning and end of the day; the white space indicates data are partially missing on Oct 30, Oct 31, Nov 2, and Nov 4).

How to introduce these data for analysis

• Phase 2

As mentioned above, we only began to answer the last research question from Phase 2 after receiving sufficient input for the previous three research questions (see also Figure

6). Based on the feedback received previously, three user scenarios were identified for introducing data analysis into the working routine of the care team:

1. *Before a shift starts*

Before a professional caregiver starting a shift, she/he wants to know if she/he has missed something important in the days when she/he is not in the ward. She/he will then use the digital platform, and since her/his colleagues have highlighted the important things for each resident, she/he can quickly go through all the highlights. If there is a note she/he does not understand well, she/he will click into it to see the data and look up who wrote the note. The notes and data give more details to the professional caregiver on what has happened in the ward to keep her/him up to date.

2. *When a notification pops up*

A notification will pop up if there is a deviation or sudden change of the data collected for a resident. The notification is only seen by professional caregivers. The professional caregivers will then open the notification and examine the data. By looking at the data, professional caregivers can determine if anything urgent has happened to the resident based on her/his experience. If she/he thinks actions need to be taken by the care team to address this issue, she/he will organise a multidisciplinary meeting via email with the data file attached.

3. *Before a care plan meeting*

A care plan meeting is about evaluating the care plans of residents by the care team. Before the meeting, the professional caregivers and other healthcare professionals will review, independently, on the notes of the overview page and then on the data collected. They write down their insights to be discussed in the meeting. The notes and data could trigger the memories of professional caregivers and thus help them to better reflect on what has happened during their shifts. Moreover, the other healthcare professionals, who were mainly depended on the reports from professional caregivers before, could now get access to objective quantitative data to triangulate the information they obtained from the professional caregivers.

• **Phase 3**

User scenario "Before a care plan meeting" was chosen by the care team. The participants of the care plan meeting are a professional caregiver and the psychologist responsible for the ward. Only the professional caregiver examined the data before the meeting; the psychologist indicated she was too busy to look at the data beforehand. The professional caregiver wrote her insights from data analysis in the form of bullet points. During the meeting, the professional caregiver discussed her insights with the psychologist, and the psychologist looked at the data with guidance by the professional caregiver. They discussed what to change in the care plan, and the psychologist made

her notes (on modifications of the care plan) in a notebook (see Table 4). After the meeting, the professional caregiver took the notes made by the psychologist and modified the care plan for the resident in an electronic medical record system on the computer. The professional caregiver reported that it took her one hour to analyse the data, and she is not confident about her analysis:

“It is a lot of work for me to do. Maximum 30 minutes is ideal for me to prepare the meeting, and my interpretation of the data could be different from my colleagues.”

Therefore, to facilitate the next iteration of data exploration in the future, the aim is to allow users to extract useful information from the data as quickly as possible. Both the professional caregiver and psychologist found the hypothetical case was helpful for them to imagine how the digital platform could facilitate BPSD management in the long term.

6

6.4 DISCUSSION

This paper presents an exploration process of combining quantitative data from the IPS and qualitative data from the care team for facilitating personalised BPSD management in nursing homes. The RtD approach was adopted, and preliminary answers to the research questions were generated via developing and evaluating a digital platform. From the literature review, it has been found that the approach of combining quantitative and qualitative data have been used by researchers to understand BPSD, yet the user group of this approach has not been extended to the care team in the nursing home. In comparison to previous studies, our study led to detailed insights into how the care team would like to combine the quantitative and qualitative data in personalised BPSD management and how they might use these combined data to improve personalisation of care for PwD with BPSD. Specifically, what types of data can be combined, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team were investigated. The methods used and the findings generated in the study are discussed below.

Reflection on the methods

As to the methods, the prototypes enables different professionals in the nursing home to explore how might assistive technologies be designed and implemented in real-world conditions for personalised BPSD management. The value of an explorative prototype in the early design stage has been shown by a study in exploring parent-tracked baby data in interactions with healthcare professionals [30]. Babies cannot fully express their needs and are cared for by parents who need to communicate with healthcare professionals regarding the past and current state of their babies. Likewise, PwD are

mainly cared for by professional caregivers who communicate with other healthcare professionals about their BPSD state and interventions. Along with the development of the prototype, the preferred types and time periods of data become more specified for each profession of the care team (see Table 5).

The researchers also learned that real data could be introduced to the care team as early as possible in the research process. Despite the data collected being incomplete during the technology development, thus not rigorous in the researchers' opinion, they are still insightful for the care team. A previous study has found that discussions about the data become more detailed, personal, and concrete if the data is real and belongs to an individual [31]. When there is no real data available, we discovered that concrete examples of proximal factors could help the researchers to decide what parameters derived from the data would be relevant to BPSD management (see Table 3), and interviewing the care team is an effective method to gather these examples.

What types of data

Concerning what types of data to be combined, we found that there is a balance among "the insights that could be generated from the data", "the time required to collect and analyse these data", and "the feasibility of the technology". Besides, the types of data to be combined can be unique for each PwD. The European Rosetta project identified the usefulness of developing algorithms for monitoring the movement patterns of PwD to detect if there are significant changes in their day-to-day patterns of living at home [32]. Our study extends this finding by discovering that deviating from the daily patterns for a resident who likes wandering might be different from that for another resident who is immobile and constantly asking for help. The daily patterns for the first resident could be reflected by "walking distance", while "interaction time with others" might be more relevant to detect the daily patterns for the second resident. Therefore, this study serves as an important step in designing assistive technologies that can personalise what types of data to be combined and analysed for each PwD. The relations identified by the care team among the different data types are by no means statistically significant correlations or trends; instead, they serve as starting points for explorations. The care team can then explore these relations with the methods that they find suitable.

Values of these data

The data collected has been found to be valuable in five ways: 1) detection of BPSD symptoms, 2) reference for report writing, 3) evaluate the conditions of PwD for administration, 4) reminder for critical events, 5) understanding the day structure of PwD. These values, even when not shared by all members of the care team, are interrelated. This is because these values serve the common goal of the care team—managing BPSD in a personalised way. This study also discovered that different kinds of professionals find different types of data or the same type of data but in different

detailedness valuable for their work, which corroborates with the study on parent-tracked baby data [30]. The researchers also identified that the quantitative and qualitative data are of value to each other during data collection and analysis. It has been uncovered that quantitative data could improve the quality of qualitative data during the data collection phase. For example, the professional caregivers will write more objective daily reports, e.g., stating how long a person has walked, based on the IPS data. During data analysis, the qualitative data can be used to contextualise the quantitative data, which has been reported previously [22]. It has also been found that the participants tend to start from the overview of the quantitative data, which guide them to select the relevant qualitative data to analyse. The combination of the data could trigger deeper and more detailed insights that the care team is sometimes even unaware of themselves.

How to collect and present these data

This process needs to be quick and standardised yet flexible to engage professional caregivers and other healthcare professionals in data collection. It has been found that building the data collection process on the current working routines of professional caregivers and other healthcare professionals could minimise their workload when collecting data. By colour-coding the reports that the professional caregivers have already established a habit to write, the BPSD data collected are standardised. Yet, professional caregivers and other healthcare professionals still have the flexibility to write notes of any content that they find relevant to their work. Respecting the working routine of the care team has been shown to be essential in previous research projects in nursing homes [33, 34]. In the near future, the tag usage could also be built into the current working routine of professional caregivers to collect more reliable IPS data.

Regarding how to present the data, this study uncovered the importance of the overview page: the participants used the overview page as the reference page when analysing the data. With the current data visualisation, the participants preferred using the overview page of the quantitative data to that of the qualitative data. The data visualisation on the overview page is critical for the efficiency of data analysis. A low efficiency could lower the willingness for the care team to analyse the data, thus hindering collaboration. Similarly, a study supporting parents in recording and sharing the health information of their babies to the healthcare professionals found that a comprehensive yet clear data overview could make these communications more efficient [35]. More explorations are needed in improving the overview pages in the future. For the overview page of quantitative data, explanatory data visualisation techniques could be applied [36]; for the overview page of qualitative data, the researchers could explore natural language processing, word clouds, keyword searches, and more sorting methods, such as sorting against colour coding [37]. Previous studies found that the types of visualisation strongly influenced the discussion with the users [22]. We hence plan to also adopt exploratory

data visualisation techniques to enable the care team to explore the data from different perspectives in future studies. We acknowledge that it is inevitable for us to add our interpretations about the data during this process since the data were visualised by us before presenting it to the care team. As the data collected is of a large quantity, data visualisation by the research team is a vital step in the early research stage to make the data more understandable to the care team.

How to introduce these data for analysis

Introducing the data into the working routine of the care team for analysis means the care team can analyse and discuss the data collected effectively in their work. The importance of respecting the working routines of the care team is discussed in the data collection stage; similarly, in the data analysis stage, this process needs to be quick and standardised yet flexible. The researchers learned that data should be presented according to the level of urgency to let professional caregivers and other healthcare professionals focus on the most urgent issues in their work and be combined appropriately on one page to reduce the memory burden for them. User scenarios created based on when and where the care team would like to analyse the data nudge them to analyse the data at fixed occasions, for example, before a care plan meeting. Moreover, the care team should allow the outcome of the analysis to be able to deviate from the original aim of data analysis: as shown in the case study, the professional caregiver did not gain insights into the behaviours of the PwD but learned about the day structure of this PwD instead, which also contributes to personalised BPSD management. If the outcome of the analysis is aimed exclusively at uncovering behavioural insights, the care team might overlook the value of day structure for personalised BPSD management. Researchers in Data-enabled Design advocate that their research questions develop hand in hand with their understanding of the data and intelligent ecosystem [22]. In this study, the questions that the care team would like to answer with data also developed together with their understanding of the data; therefore, this openness is essential in effective data analysis.

Limitations and future work

In terms of limitations, the interviews and evaluation sessions were carried out in a one-to-one format in the current study; a potential drawback of this format is that discussions between participants are lacking, and these discussions might stimulate more ideas. However, in an individual setting, the participants can express their own needs and wishes instead of going along with what is expressed by the more dominant participants, which often happens in a group discussion. In addition, since this study adopted a qualitative approach, its findings are highly context-dependent. In another nursing home with different participants, the content and design of the prototype might be developed differently. The strengths of this study are that a wide range of professionals was included, and they participated in several phases of the RtD process, from contextual inquiry to prototype evaluation. The use of different professionals'

perspectives in the development phase of assistive technologies for PwD has been proven valuable [32, 38, 39].

In the near future, the digital platform will be improved based on the feedback in Phase 3 and will be implemented in the nursing home for a few months. In this way, the researchers can gain more insights into the long-term value of the data. This is because the most recent feedback obtained from the care team in Phase 3 was based on the first-time use of the digital platform by the care team, and factors affecting the data collection and analysis, e.g., patience, time investment, and intuitiveness of the interfaces, might change over time. After this, sufficient data will be gathered to form baselines for the behaviours of PwD participants, and algorithms will be developed for pushing notifications to the care team. Then, the researchers can evaluate the prioritisation of the data presentation and push notifications, e.g., does each profession have a preferred prioritisation? In the next step, with a large amount of data collected, the research team can develop machine learning algorithms to identify movement patterns of PwD in the animations, which could be a new data type to be explored with the care team.

6

6.5 CONCLUSIONS

A better understanding of how to combine qualitative data generated by the care team and quantitative data generated by assistive technologies for personalising BPSD management has been gained in this study. The types of data to be combined, their values, how to collect and present them, and how to introduce them for analysis should be carefully thought through when introducing assistive technologies for personalised BPSD management. A Research through Design approach has been effective in engaging the care team in reflecting on these questions together with the researchers. This study serves as a starting point for inspiring future researchers to investigate other types of data collected by assistive technologies and to explore other dementia care contexts to promote personalised BPSD management in the near future.

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7



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Insights gained about Data-enabled Design from the field

After the digital platform (Data-care) has been updated based on the feedback collected in the previous study (Chapter 6), it has been deployed over a longer period of time in the field. An accumulating amount of data enable the author to investigate more types of visualisations and explore the value of data when collected over a longer time span. The sub research question at this stage is:

What are the values of Data-care after a longer implementation period in the field, and what does this imply for the Data-enabled Design approach in personalising dementia care?

This chapter describes a formative study on exploring the values of Data-care in personalising BPSD management over a 7-week time period. During the evaluation, one of the three user scenarios developed in the previous study has been adopted and refined as “the caregiver analyse the visualisations and discuss his/her findings with healthcare professionals in a care plan meeting”. Hence the data visualisations have been developed for the caregivers while the feedback from the whole care team has been gathered. Evaluating Data-care informed the author further on how the Data-enabled Design approach could be adapted for personalising dementia care. The insights generated by the care team helped the author to develop a deeper understanding of the context of dementia care and the uniqueness of each person with dementia. The supplementary files mentioned in this chapter can be accessed from the original publication online via the DOI provided.

ABSTRACT

Background: Care personalisation is key to the wellbeing of People with Dementia (PwD), according to Person-Centred Care. With the development of the Internet of Things, a large quantity of personal data can be collected securely and reliably, which has the potential to facilitate care personalisation for PwD. Yet, there are limited assistive technologies developed for this purpose, and the user acceptance for assistive technologies is low in nursing homes. Therefore, through a Data-enabled Design approach, a digital platform was developed for helping the care team in a nursing home to personalise dementia care, specifically on the management of Behavioural and Psychological Symptoms of Dementia.

Objective: This study aims to evaluate the digital platform in a real-life context with potential users from two aspects: 1) to explore if the digital platform could help with generating insights on the current state of each PwD participant and 2) to gather feedback on the digital platform from the care team.

Methods: The digital platform was deployed in the nursing home for seven weeks, and the data collected were visualised and presented to the care team via the digital platform. The visualisations were analysed by the researchers for pattern detection. Meanwhile, the care team were asked to analyse the visualisations and were interviewed on 1) if any insights and actions are generated from the analysis; 2) the usefulness of the digital platform, and 3) what improvements they would like to see.

Results: The data collected in the digital platform demonstrated its potential for pattern detection. Insights were generated by the care team and categorised into “client level”, “ward level”, and “team level”. The corresponding actions taken by the care team were classified into “investigation” and “implementation”. The user acceptance varied across the care team, and three aspects of improvements for the digital platform were identified.

Conclusions: Via evaluating the digital platform, this study gained insights on applying Data-enabled Design in personalising dementia care; besides, it offers future researchers some recommendations on how to integrate assistive technologies in the nursing home context.

7.1 INTRODUCTION

Dementia has a physical, psychological, and social impact on People with Dementia (PwD), their caregivers, and families, as well as posing an economic burden to society at large [1]. The “person-centred” perspective on dementia care was introduced in the care practice by Kitwood [2], where “in addition to neurological impairments, the personality, past experiences, health, and other aspects of the person with dementia also influence how the person will behave”. Inspired by Kitwood’s theories, researchers in dementia care have been exploring how to manage Behavioural and Psychological Symptoms of Dementia (BPSD) in a person-centred manner [3–6].

Over 80% of PwD will develop BPSD during the course of their disease [7], and 90% of PwD living in nursing homes exhibit BPSD [8]. BPSD contributes to the most stressful, complex and costly aspects of dementia care, which commonly results in poor health outcomes for PwD [9]. Personalisation is a key element of the Person-Centred Care approach [10], and most current practices accommodate the past experiences, hobbies, capabilities, and preferences of PwD in developing personalised care plans [11,12]. However, some of these capabilities, behaviours, personalities and preferences of PwD could change over time as dementia progresses [13]. We propose that these changes should be monitored and considered for providing a holistic approach to personalised BPSD management. We argue a personalised care plan can only be helpful when it is up to date. Yet, it takes time and effort for care teams to notice and adapt to some of these changes given their high workload [14]. Recent research has been investigating the potential of data-driven assistive technologies in care personalisation.

Related work

Over the years, low-cost sensors, wearables, electronic health record, and artificial intelligence have been deployed in the healthcare setting to collect and analyse data about an individual in terms of his/her physical condition, living environment, lifestyle choices etc. [15]. Researchers hypothesise that these data could help healthcare professionals to make better and more timely decisions for each patient hence allow the care received by the patients to be personalised and continuous rather than general and episodic [16]. Collectively, data-driven care personalisation is made possible by assistive technologies which can integrate the data and best care practices for health service delivery [17]. A global agenda for personalised telehealth has been proposed [18].

Previous attempts have explored the application of data-driven assistive technologies in the field of cancer care [19], physiotherapy [20], cardiovascular disease [21], and elderly care at home [22]. Conversational agents [23] and data visualisations [19] are being developed for facilitating the interactions between the technologies and their users.

However, few studies have investigated this type of assistive technologies in personalising dementia care. The adoption rate of assistive technologies for dementia care in nursing homes has been low. A scenario-based survey study found that caregivers think assistive technologies have not been tailored to their needs and concerns [24]. Similarly, a systematic review identified that the acceptance of assistive technology is low without the users' input during its development process [25]. Therefore, one main reason for the low adoption rate is the lack of understanding regarding the interactions between the technology and the people involved.

Research context

In our prior work, we involved the care team in a Dutch nursing home and developed a digital platform for personalising BPSD management via a Data-enabled Design approach. Data-enabled Design is about using quantitative data from sensors and qualitative data from users in the field as a creative design material to inspire and inform the design process [26]. These data can be highly personalised for an individual. We, therefore, hypothesised that Data-enabled Design offers an approach to transform these personal data into valuable up-to-date insights about each person with dementia for the care team and hence can facilitate the care team in personalising BPSD management holistically. The digital platform was then developed for visualising and presenting the combination of quantitative and qualitative data to the care team and evaluated in the ward for 15 days. A detailed description of this digital platform can be found in Wang et al. [27].

We positioned this digital platform as an assistive technology to facilitate the care team with personalising BPSD management. Studies coming from the perspectives of care research [28,29], anthropology [30] and gerontology [31] have pointed out understanding the interplay between the technology and the context (e.g., environment, users) to which it is introduced early on could help the technology to be integrated for regular use in the future. Therefore, the current study was conducted to explore the effects of the digital platform as an assistive technology on facilitating personalised BPSD management in the daily care practice in this nursing home for a longer period of time. This is a qualitative study with the focus of researching the user experience of the care team in using the digital platform.

Goals

This study aims to 1) explore if the data visualisations of the digital platform could help with generating insights on the current state of each PwD participant and 2) gather the feedback on the digital platform from the care team after it was deployed in the nursing home for a longer period of time. In this way, it builds on our preceding work by investigating the interplay of the digital platform and the care team in a longer time frame to explore the opportunities and challenges for personalising BPSD care with assistive technologies in a real-life context among potential users.

7.2 METHODS

Study set-up

In our prior study, an Indoor Positioning System (IPS) was deployed in one of the nursing-home sites of Zorggroep Elde Maasduinen in the Netherlands to collect continuous location data from the residents and the professional caregivers (hereafter the caregivers). Zorggroep Elde Maasduinen is a large-scale organization for the care of older adults in the south of the Netherlands (www.zgem.nl) with multiple sites throughout the south of the Netherlands. The current study was performed in a nursing home site in Boxtel, which has a special ward (the Oleander) for caring for residents exhibiting BPSD symptoms. This ward is a specific ward for assessing the behaviours of people in the later stages of dementia (from moderate to late stages), who exhibit symptoms of BPSD, with the aim to find an intervention for these symptoms for each individual PwD so that, in time, the PwD can return to one of the regular dementia wards in the nursing home.

The Oleander was selected to be the development site of the digital platform since it offers a typical case about BPSD management in an institutional setting. The IPS was hence deployed in the Oleander with the consent of all the legal representatives of all the residents and all care team members. Contextual information concerning the culture of the nursing home, the ward ambience of the Oleander, and the working structure of the care team is provided in Multimedia Appendix 1 (accessible online). There are ten residents living in this ward, and the care team regards each resident as a unique individual. In order to understand the user experiences of the residents and the care team with using the digital platform in-depth, “three PwD participants” was decided to be the minimum sample size for this study given the budget limit.

The study protocol was approved by the Human Research Ethics Committee of Delft University of Technology and the Board of directors of Zorggroep Elde Maasduinen. The Ethics Approval Letters of Delft University of Technology and of Zorggroep Elde Maasduinen are provided in Multimedia Appendix 2 (accessible online). Since this study involved collecting location data from PwD and caregivers, written informed consent was obtained from the caregivers and from the legal representatives of the PwD.

Location data is collected because, among all types of sensor data, it has been used for monitoring BPSD and is also recognised as central to the context of BPSD management [32]. Specifically, not only movement patterns but also other relevant parameters (e.g., travelled distance, interaction time with others) could be derived from location data. Both caregivers and residents who participated were given tags since the digital platform was designed with the intention to record the interaction times between caregivers and PwD. This interaction time is defined as when and for how long the

caregivers are interacting with PwD per day. We programmed the IPS so that a physical distance of two tags less than half a meter lasting for more than one minute is registered as an interaction.

For each resident, several other parameters specific to the daily routine and behaviour of the resident were derived from the location data collected (e.g., travelled distance, travelled trajectory, duration of stay). Meanwhile, qualitative data about each resident (e.g., daily report) were collected to contextualise the location data. How might the digital platform help with personalised BPSD management is illustrated with a few envisioned scenarios in Figure 1.



Figure 1. Four envisioned scenarios where the digital platform could help with personalised BPSD management.

Study Design

In this study, a longitudinal study design was employed. As demonstrated in the previous section, evaluating the digital platform on BPSD management in the Oleander constituted the macro case study. Within the macro case study were nested micro case studies, and each micro case study is about one PwD participant. The sampling strategy of this study is a combination of typical case sampling and criterion sampling.

Regarding typical case sampling, a broad consensus about what is typical was achieved via a discussion of the research team and care team. All ten residents in the Oleander were identified as exhibiting typical BPSD symptoms. Within these residents, the legal representatives of eight residents with dementia signed the consent form. Three residents showed signs of dislike towards the tags, and they were excluded from the

study. Two participants dropped out later on because they showed signs of dislike towards the tags, and three participants completed the study, resulting in three micro case studies. In summary, the three PwD participants were two females and one male, one with Vascular Dementia, one with Lewy Body Dementia, and one with Alzheimer's Disease. Basic information about the three PwD participants can be found in Multimedia Appendix 3 (accessible online).

As for criterion sampling, "having a direct influence on the care plan of each PwD participant" was considered to be the inclusion criterion. For each PwD, the responsible caregiver of the PwD, the ward doctor (hereafter doctor), the ward psychologist (hereafter psychologist), and the ward dietitian (hereafter dietitian) have a direct influence on the care plan. Besides, the ward manager (hereafter manager) was also considered to have a direct influence on the care plans since she participates in multidisciplinary meetings for care plan updates. All members of the care team who meet the criterion were approached, and all of them consented to participate in the study.

Therefore, each micro case study included the PwD participant, his/her responsible caregiver, doctor, psychologist, dietitian, and manager. The sample size is considered to be adequate for this constructivist qualitative research, where a new, deep and nuanced understanding is aimed to be gained on personalising BPSD management with Data-enabled Design [33]. The study procedure is illustrated in Figure 2.

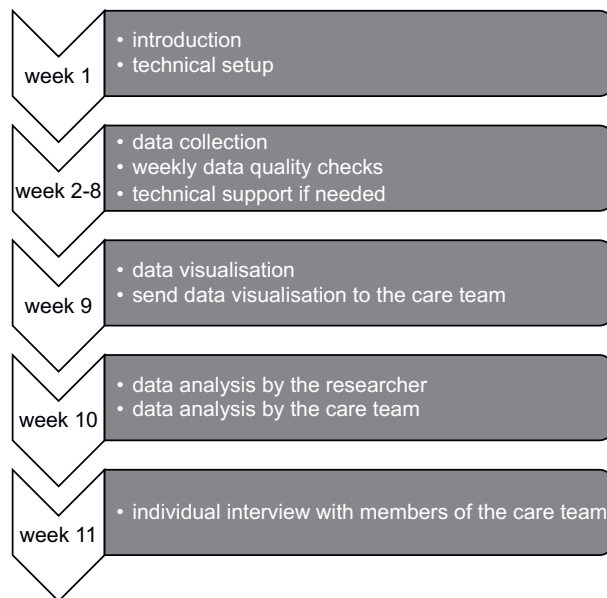


Figure 2. Study procedure.

Specifically, in week 1, an introduction was given to the participants, and the IPS was tested for its functionality. In week 2-8, the residents and caregivers wore the tag for collecting their location data in the ward in everyday life. The caregivers wrote daily reports and gave a colour code on the perceived stress level of the PwD participants (i.e., stress rating). In order to minimise the workload of the care team, these tasks were designed to be as close to the working routine of the care team as possible.

As for the daily report, it is part of the working routine of the care team. The daily reports usually record when and where the PwD participant got stressed, what did he/she do, what did the caregiver do to reduce his/her stress. Once a report is written, caregivers can select a category for the report (e.g., physical health; mental health) for it to be stored in the system. These reports are shared with other members of the care team, which could sometimes result in additional remarks and editing. The stress rating is done with the Crisis Development model (In Dutch: Crisisontwikkelingsmodel) [34], which is a standardized assessment tool used in several Dutch nursing homes for rating the stress levels of the residents, and each member of the care team has been trained to use it. This model divides the stress level of a person into green, yellow, orange and red, indicating no stress (green) to high stress (red). The care team records and categorises the effective measures carried out to help a resident relax at different stress levels on a so-called signal plan. Each resident has a personalised signal plan. Based on the signal plan, the behaviours of the residents' act as signals for their stress levels. The care team can then react by adjusting their interaction styles and environments for each resident according to the signal plan to reduce the stress for him/her. This way of working has been found to be helpful by the care team. Before the development of the digital platform, the care team did not explicitly record the stress of a resident over time using the Crisis Development model. During this study, the caregivers were instructed to conduct the stress rating. The frequency of stress rating has changed to every half-hour in this study (the previous frequency was once per day [27]) since the caregivers found the stress level of PwD usually change drastically over the day. The quality of data was checked weekly, and technical support was provided when needed.

In week 9, both quantitative and qualitative data were visualised in the digital platform. Since this study spans a longer period of time, new types of visualisations were created on the digital platform for conveying the large amount of collected data effectively. Once the visualisations were done, a notification was sent to the caregivers to start the data analysis. The user scenario for data analysis is:

The responsible caregiver analyses the visualisations and discusses his/her findings with other team members in a care plan meeting.

This user scenario was created based on the findings of the preceding study [27]. Hence the data visualisations were developed for caregivers to do the first round of data examination, and the feedback on the digital platform from the whole care team was gathered.

In week 10, both researchers and the care team analysed the visualisations with different goals. While the goal of the care team was on uncovering insights about the PwD participants via a combination of quantitative and qualitative data; the goal of researchers was to investigate if behavioural patterns of PwD could be identified with the quantitative data (i.e., the availability and utility of the data) and check with the care team about the identified patterns afterwards. In week 11, individual interviews were carried out with the responsible caregivers of each PwD participant, doctor, psychologist, dietitian and manager. The doctor, psychologist, dietitian and manager were interviewed three times, and each time specifically about each individual PwD participant. This leads to 15 interviews, i.e., five interviews per PwD participants. The participants involved in the study are shown in Table 1.

Table 1. Participants involved in the study.

Study phase	Participant type	Number of participants
Data collection	PwD	3
	Caregivers	12
Data analysis	Caregivers	3
	Doctor	1
	Psychologist	1
	Dietitian	1
	Manager	1

Data collection

The categories of data collected and their collection times in this study are summarised in Table 2. Precisely, some background information about each PwD participant was collected at the beginning of the study; the IPS data, daily reports, and stress rating about each PwD participant were collected from Week 2 to Week 8; lastly, the interviews were conducted at the end of this study and transcribed verbatim. The set-up of the location data collection in the ward is shown in Figure 3.

Table 2. Categories of data collected in the study.

Category of data	Collection time(s)	Description
Background information	At the beginning of the study	Age, gender, basic clinical background, typical behaviours of the PwD participants
IPS data	Continuous daytime collection from week 2 to week 8	Location of PwD participants and caregivers
Daily reports	Once or a few times per day from week 2 to week 8	Perception about when and where did the PwD participant get stressed, what did s/he do, what did the caregiver do to reduce his/her stress
Stress rating	Every half hour during the waking time of the resident daily from week 2 to week 8	Perception of caregivers about the level of stress expressed by PwD participant (the colour code used from low to high-stress level is: green, yellow, orange, red)
Feedback on digital platform	At the end of the study	Semi-structured interview on discovered insights and corresponding actions (if any), usefulness and desired improvements of the digital platform



Figure 3. The set-up of location data collection in the ward (the locations of the sensors are marked yellow on the map, and the data collected is sent to the server in the Office via Wi-Fi gateways).

Data analysis

• Overview

Three analyses were performed to fulfil the research goals outlined above. The first analysis examined the availability and utility of the data collected by the digital platform; the second analysis investigated what types of insights and actions, if any, could be generated by the care team via using the digital platform; and the third analysis studied the perceived usefulness and desired improvements regarding the digital platform.

Concerning the transferability of this study, we followed the strategies by Polit and Beck [35], which recommends that a sufficiently detailed description of the context is needed

for the study results to be meaningful to other researchers. Transferability is defined as “the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents” [36] and describing not just the study results, but their context as well could help the study results become meaningful to an outsider [36]. Hence, basic information about the nursing home where the research was conducted and a description of the three PwD participants is provided in Multimedia Appendix 1 and 3 (accessible online).

- **Analysis 1: Data availability and utility**

The aim of this analysis was to determine whether the digital platform could collect adequate data for the intended purpose of identifying behavioural patterns. With “adequate”, we imply the amount of data that could enable behavioural patterns to be revealed via visual inspection. Visual inspection, sometimes referred to as visual analysis, is the most widely used and recommended method for interpreting single-subject data [37,38]. This method involves the researcher analysing the data visually, which allows for a holistic evaluation for understanding the idiosyncrasies present in the data for each subject [39]. The amount of data collected depends both on the technical functioning of the IPS and the participants’ adherence (i.e., keeping the tags charged and connected, wearing the tags correctly).

The researchers examined the data availability by checking the proportion of the study period for which data were available for each PwD participant. Visual inspection was then applied to identify whether behavioural patterns could be revealed for each PwD participant. If behavioural patterns were found, these findings would then be validated with the care team. Three types of visualisations were created in the end, namely, tile plots (example in Figure 4), combined plots (example in Figure 5) and mapping plots (example in Figure 6). Only tile plots were used for the purpose of visual inspection. The guide for visual inspection and for the validation process with the care team can be found in Multimedia Appendix 4 (accessible online).

- **Analysis 2: Types of insights and actions**

The aim of this analysis was to explore what types of insights and actions, if any, could be generated by the care team from using the digital platform. To prepare the caregivers for the data analysis, we sent them an email with the link to the three types of visualisations and instructions. The caregivers were asked to analyse the data individually, and after that, they provided their insights to the care plan meetings. In this way, these insights were discussed within the care team, and the data visualisations will be revisited in the meeting if necessary. The caregivers were notified they could contact the research team if any questions arose during the analysis. Being involved in developing the digital platform previously, the care team has gained experience in this type of data analysis.

During the interview, each interviewee was asked if s/he had identified any insights from data analysis and, if so, whether s/he would take any actions based on the insights. The interview guide can be found in Multimedia Appendix 5 (accessible online). Based on the thematic analysis of the interview transcripts, GW and AA categorised the types of insights and actions into themes according to the six-step guidance by Braun and Clarke [40].

- **Analysis 3: Usefulness and future improvement**

The aim of the third analysis was to evaluate the perceived usefulness of the digital platform by the care team. During the interview, each interviewee was asked if this digital platform was useful to his/her work and what could be improved. The interview guide can be found in Multimedia Appendix 5 (accessible online). Thematic analysis was conducted by GW and AA following the same guidelines as in Analysis 2.

We acknowledge that PwD are among the key stakeholders in this project. Since the PwD participants were in the moderate to severe stages of dementia, we chose not to involve them in data analysis and interviews. Instead, we involved the care team because they evaluate and monitor the current physical and emotional states of the residents and respond to their needs daily. All this information contributes to the personal care plan. For the PwD participants, their data were collected and analysed; and the generated insights were shared with the care team and hence contributed to a timely update of their personal care plans. Given dementia is progressive, receiving up-to-date care is essential for the wellbeing of PwD. In this way, PwD can benefit from participating in this project.

7.3 RESULTS

Data availability and utility

The researchers examined whether location data collected over a longer period of time could reveal any behavioural patterns of PwD, such as trends and fluctuations of measured parameters within a day or over days. After the improvement of the tag design, the amount of missing data was reduced in comparison to the preceding study. However, there were still cases where no data was collected for a whole day; for example, two days of data are missing over the seven-week period for Participant 1, as shown in Figure 4 (14th May and 20th May). Four days and three days of data are missing for Participant 2 and 3, respectively. The missing data was mainly caused by the incorrect use of the tags by the caregivers. e.g., placing the tag on the wrong person or forgetting to charge or use the tags. Comparing with the preceding study, the amount of missing data has decreased. Specifically, three days out of seven weeks (on average) contain missing data in this study; in contrast, seven days out of 15 days contain missing data in the preceding study [27].

It seems that the missed data did not inhibit the potential for identifying behavioural patterns via visual inspection. To illustrate, we present a tile plot of the location data for Participant 1 from 1st April to 20th May in Figure 4. Specifically, this figure visualises the movement distance of this PwD in the corridor in the daytime each day, where the colour intensity corresponds to the movement distance (i.e., light colour: short distance; dark colour: long distance). From Figure 4, Participant 1 was found to have a longer movement distance in the corridor in April than in May and rarely moved in the corridor around 12:00 (which corresponds to lunchtime).

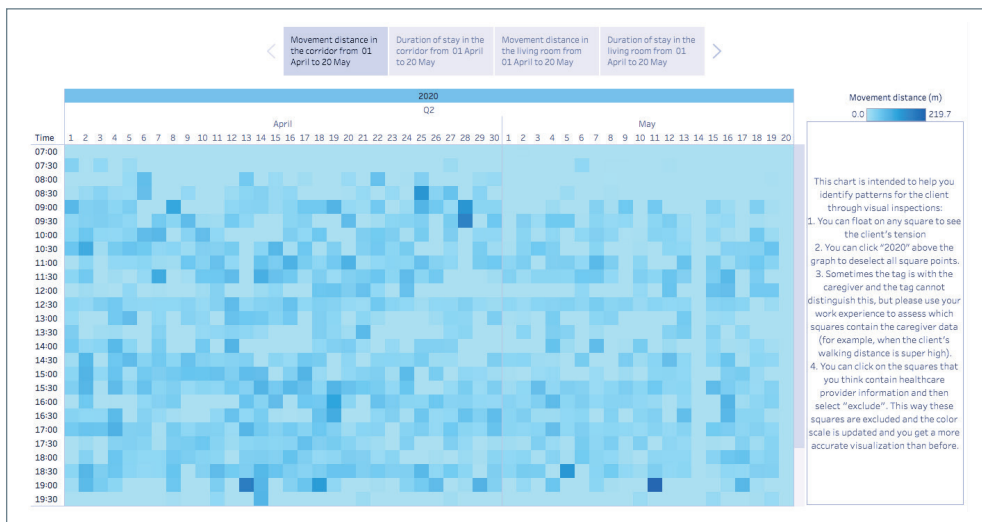


Figure 4. Movement distance in the corridor for Participant 1 each day during the daytime (tile plot).

In general, this visualisation in Figure 4 is representative of all three micro case studies in terms of availability and utility of the location data. More tile plot examples can be found in Multimedia Appendix 6 (accessible online). The data collected over this period of time is adequate for behavioural patterns to be identified via visual inspection despite some missing data. When discussing with the care team, we found that the daily patterns were usually within the expectations of the care team, mostly because they coincide with the daily routines of the participants (e.g., the care team expect Participant 1 to be in the living room at lunchtime). In a nutshell, the daily patterns uncovered about each PwD validate the experience and knowledge of the care team. Yet, the trends and periodic patterns over the days were usually new insights to the care team (e.g., the care team did not know the total movement distance of Participant 1 decreased over time).

In addition to tile plots, two more types of visualisations were also developed. The combined plot presents the daily reports and daily location data of the PwD participant side by side, as shown in Figure 5. Specifically, Figure 5 shows the duration of stay of

Participant 2 in all possible rooms in the ward each day and clicking a data point on the graph will bring the exact value of the duration of stay and the daily reports of this corresponding date. The main utility found of visualising duration of stay and daily reports together is to identify when the participants were under stress and what has been done to reduce their stress. From previous research, we know that PwD will be sent back to their bedrooms if they are showing symptoms of stress. Since there is a common belief within the care team that reducing the number of stimuli could help one to reduce stress, and the bedroom is regarded to have fewer stimuli than the rest of the ward. The daily reports usually record what happened and what has been done around the stressful moments for PwD.

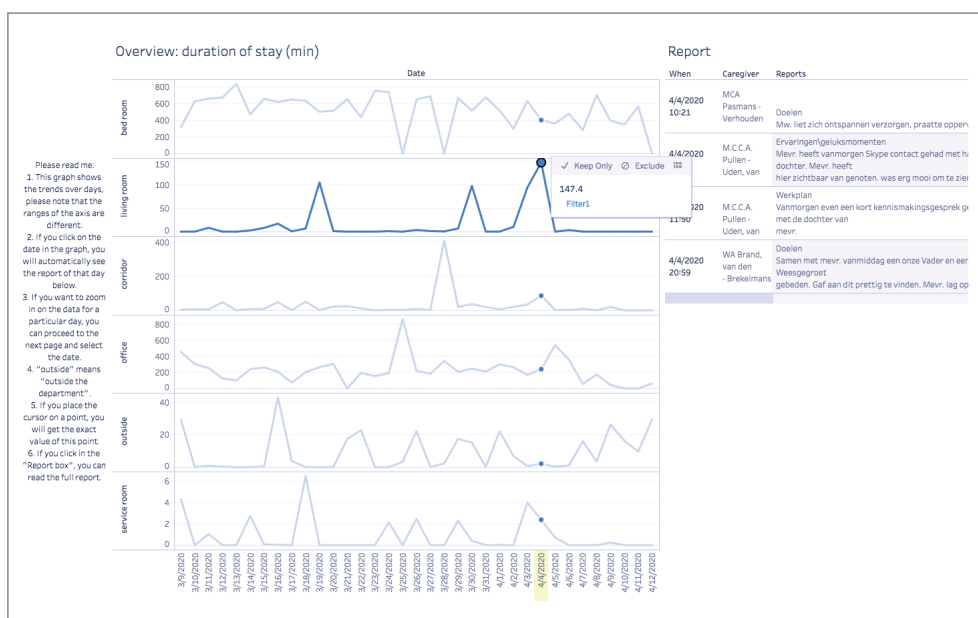


Figure 5. The duration of stay for Participant 2 in all possible rooms of the ward per day during the daytime and corresponding daily reports of her (combined plot).

The mapping plot presents the location data of all participants with their movement trajectories in the ward every hour in the daytime, as shown in Figure 6. For this visualisation, by selecting whose location trajectory one would like to look at, the trajectory of the selected person is highlighted, with all other participants' trajectories visible in the background. The main utility found of this visualisation is to identify if any PwD exhibits unique movement patterns spatially. From Figure 6, Participant 3 has been found to walk in circles when he is in his bedroom alone, which the care team indicated as insightful. The care team wonders if Participant 3 was looking for a way out. From past experience, they know that Participant 3 tends to walk when he is under stress, and this visualisation makes them realise that Participant 3 could walk in his room

for a while after he has been sent back to his own room for relieving stress. This type of visualisation is created because the care team expressed that they would like to know the exact locations (e.g., at which location within the room) and movement trajectories of the residents to uncover detailed movement patterns in our previous study [27].

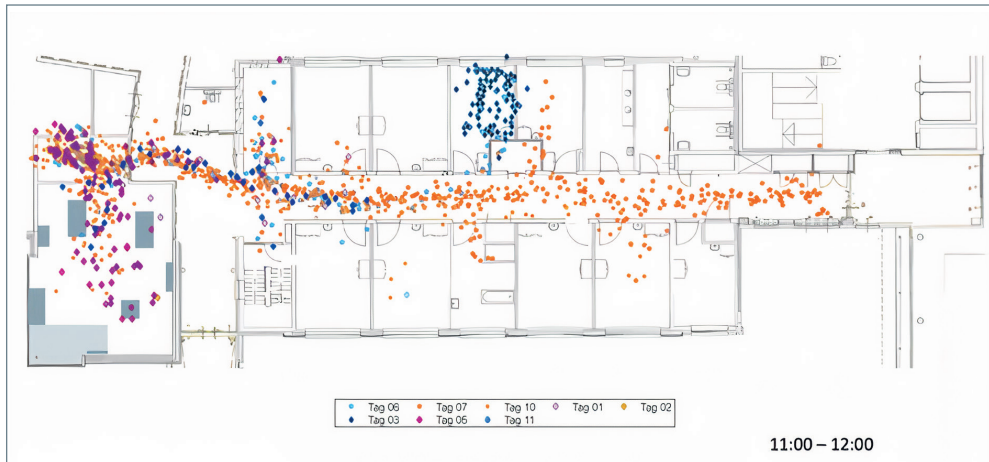


Figure 6. A snapshot of the movement trajectories of PwD participants (Tag 1-3) and caregivers (Tag 4-11) in the ward from 11:00 to 12:00 on 16-Apr-2020 (mapping plot).

Types of insights and actions

• Types of insights

The reported time spent on data analysis ranges from 0.5 to 1.5 hour. Twenty-nine insights were generated by the caregivers, the doctor, the psychologist, and the dietitian based on their interpretation of the data visualisations. The manager did not find any insights. These insights are grouped into 13 sub-themes which are under three broader themes. The first theme, client level (the care team refers to the residents as their clients), includes (1) day structure according to the care plan, (2) moments of unrest, (3) unusual movement trajectory, (4) behaviour change over time, (5) physical activity over time, and (6) effect of medication. The second theme, ward level, includes (7) interaction with caregivers, (8) interaction with other PwD, and (9) dining environment. The third theme, team level, includes (10) more detailed reports, (11) tag usage, (12) behaviours of caregivers, and (13) workflow. These themes and sub-themes of insights are presented in Table 3, with each theme illustrated by an example quote. The main data sources which these insights based on are presented in a square bracket after each example quote. The detailed analysis of all the interviews can be found in Multimedia Appendix 7 (accessible online).

Table 3. Types of insights generated from data analysis (the care team refer to the residents as their clients).

Theme	Sub-theme	Example quote
Client level	Day structure according to the care plan	"He has a day structure, in which he goes to the toilet two times a day around 11 am and 3 pm. From the data, sometimes he goes to the toilet once and sometimes he does not go to the toilet at all. Because of his agitation, he forgets to ask to go to the bathroom, and then we might forget about it too." (Caregiver 1) [Mapping plot + Stress rating]
	Moments of unrest	"He more often gets agitated in the afternoon than in the morning. I think maybe after lunch; he starts to think about the next step; he cannot wait to have something to eat. Sometimes he asks for food; sometimes, he asks what are we going to do next? He is a bit bored in the afternoon." (Caregiver 1) [Tile plot + Daily report]
	Unusual movement trajectory	"I see his usual pattern from his room to the living room and to the kitchen. There has been one time to the back of our ward. Why? I don't know, but that's not the route he usually takes. Yeah." (Caregiver 3) [Mapping plot + Daily report]
	Behaviour change over time	"It seems that the connection (between restlessness and stress) is no longer there ... perhaps his stress manifests itself less in movement and more in shouting. So, the restlessness has moved from motor to verbal. That is something I know from experience." (Doctor) [Tile plot + Stress rating]
	Physical activity over time	"You can see that in the morning he is more active. And during the day his walking distance gets less." (Caregiver 3) [Combined plot]
	Effect of medication	"He has medication at 8 am, 12 pm, 5 pm. When he is restless, he gets extra antipsychotic medicine. I sometimes noticed the medicine is effective and sometimes not." (Caregiver 1) [Combined plot]
Ward level	Interaction with caregivers	"It strikes me that he is relatively alone when he goes back and forth (in the corridor). Except at 5–6 pm when there is care routine, and he is (with somebody and) keep moving back and forth (in the corridor)." (Doctor) [Mapping plot]
	Interaction with other PwD	"Most of the time, I would like to see my clients only (in the digital platform), but sometimes when my clients interact a lot with other clients, then it's also sometimes useful to know what other clients are doing." (Dietitian) [Mapping plot]
	Dining environment	"I wonder what they have been doing during mealtime. Because I don't see some people in the living room (where the meal is served), it would also be nice if there is some quiet time around mealtime because when there's a lot of distraction, some people forget to eat or go walking." (Dietitian) [Mapping plot]
Team level	More detailed reports	"Sometimes even when a high-stress level is recorded for the client, there is no corresponding daily report to explain what happened" (Psychologist) [Combined plot]
	Tag usage	"If I look at 3rd May, yeah, I think he had his tag put on only at 11:30. Sometimes, on 14th May, he doesn't have it (the tag) with him at all." (Caregiver 3) [Tile plot]
	Behaviours of caregivers	"I am also impressed by the distance travelled by the care staff ... the staff is "more restless" than the residents. What's normal? I find it interesting to reflect on that with the team." (Doctor) [Mapping plot]
	Workflow	"It also gives me insight about all our daily things. And that's I think that my colleagues they are...that they are more interested to see this." (Caregiver 3) [Mapping plot + Daily report]

- **Types of actions**

Except for the manager, the rest of the care team participants would like to take some actions based on the insights they uncovered. Their intended actions are grouped into six sub-themes which are under two broader themes. The first theme, investigation, includes (1) discuss causes behind insights, (2) monitor day structure, and (3) evaluate changes in the care plan. The second theme, implementation, includes (4) change in care plan, (5) work practice, and (6) prediction. These themes and sub-themes of actions are presented in Table 4, with each theme illustrated by an example quote. The detailed analysis of all the interviews can be found in Multimedia Appendix 7 (accessible online).

Table 4. Types of actions based on the insights generated.

Theme	Sub-theme	Example quote
Investigation	Discuss causes behind insights	"I see this client moves a lot when he is in high-stress level around 3 pm; we don't know what is going on, maybe because he wants to go to the bathroom, or he has nothing to do. It is a signal that things are not OK for him; hopefully, we can find reasons for this" (Psychologist)
	Monitor day structure	"This allows us to see what has or has not already been offered in a day. This is easy to look back." (Caregiver 2)
	Evaluate changes in the care plan	"We decided...to let him go to bed earlier. And I hope when we see a new view (visualisation) then I can see a difference in that (stress rating). To get to know if it's helpful for him." (Caregiver 3)
Implementation	Change in the care plan	"We should bring him to the bathroom twice a day; this could help him to relax. I will discuss with my colleagues and update the care plan on this." (Caregiver 1)
	Work practice	"There should always be a caregiver in the living room when he is in the living room. He doesn't like to be alone." (Caregiver 1)
	Prediction	"From the data, I know when the client is more likely to get tense. Previously, I only observe their behaviours to get to know if he is tensed or not. It is predictive." (Caregiver 3)

Usefulness and future improvement

- **Usefulness**

The feedback of the care team participants on the usefulness of the digital platform for their work is categorised according to their professions. Their feedback is summarised in Table 5, illustrated with example quotes. The detailed analysis of all the interviews can be found in Multimedia Appendix 7 (accessible online).

Table 5. The perceived usefulness of the digital platform.

Professions	Perceived usefulness	Example quote
Caregiver (n=3)	Provide evidence for discussion and for confirming feelings	<p>"It is nice that we use the data as the evidence when we discuss what we see with the doctor and psychologist." (Caregiver 3)</p> <p>"The data are confirmations of our feelings towards the client." (Caregiver 2)</p> <p>"I feel they are a confirmation about what I already knew." (Caregiver 1)</p>
Doctor (n=1)	The insights are useful, but more scientific evidence is needed	"I think it is getting better and better. The clinical relevance is still complicated; for each client, we can do something with that, but for a scientific basis, not only a feasibility study but also a real clinical study is needed."
Psychologist (n=1)	Triangulate subjective report of the caregivers with collected data	"For me, since I am not in the ward myself, I normally talk with the caregivers; it is good to see how often he is in stress (from the visualisations)."
Dietitian (n=1)	Need more data related to food and dining	"It tells me where the person is, how long the person stays there. So, it gives some data for me. Yes. And stress. But it doesn't mean a lot for the dietitian. It doesn't say a lot about food; it is more about what's being done."
Manager (n=1)	The digital platform is not helpful for my work	"Is it helpful for my work? not so much, because if I must put a conclusion, I have to have more data, more in an overview ... I couldn't draw any conclusions from this data."

• Future Improvement

The care team participants formulated 23 key areas for developing the digital platform further. These are grouped into ten sub-themes which are under three broader themes. The first theme, data collection, includes (1) more types of data, (2) define whose data to collect, and (3) reliability of stress rating. The second theme, data visualisation, includes (4) personalised parameters, (5) filtering data by time, and (6) less clicking. Finally, the third theme, data analysis, includes (7) reduce analysis time, (8) who should analyse data, (9) develop an analysis workflow, and (10) automatic notifications. These themes and sub-themes of areas of improvements are presented in Table 6, with each theme illustrated by an example quote. The detailed analysis of all the interviews can be found in Multimedia Appendix 7 (accessible online).

Table 6. Areas of improvements for the digital platform.

Theme	Sub-theme	Example quote
Data collection	More types of data	"What I missed is the actions, the interventions that the team members have done and what the effect is on the behaviour of the clients; for me, it's hard to find any conclusion about analysing this data." (Manager)
	Define whose data to collect	"We have known him for a long time ... so we have done lots of analysis of his behaviours. I think these data will give much more information if it is someone new, who we don't know much about." (Psychologist)
	Reliability of stress rating	"Sometimes, stress-rating does not match the daily reports ... that is very unfortunate because you cannot see many things properly ... I don't know if there is any more convenient method for this (stress-rating)." (Doctor)
Data visualisation	Personalised parameters	"We only know the distance and how long he has been in the corridor. We would like to know how many times he moved back and forth in the corridor; this indicates his agitation." (Caregiver 1)
	Filtering data by time	"It would be helpful to see what the person is doing at a time they should eat ... that would tell me where the person is at mealtime or is he walking around? And that's interesting. If I can select the time, then that would be nice." (Dietitian)
	Less clicking	"If I can see the report of the day when I hover on the data of that day, that would be good, I don't have to select the date for the report, and it will make the process faster." (Psychologist)
Data analysis	Reduce analysis time	"This is new to me, I enjoyed doing it once. However, it is very difficult to look at the data when I have to care for clients." (Caregiver 2)
	Who should analyse data	"I noticed that caregivers have a lot of trouble in analysing the data. And I think that's... it has several reasons. But one of the most, I think the most important is that they are not used to analysing data." (Manager)
	Develop an analysis workflow	"We just talk about these in our regular meetings. It could be good if someone would first look at the data so that the data is not new for everybody ... and discuss with the team in the regular meetings. During the meeting, everyone can discuss if they see the same things and why or why not." (Psychologist)
	Automatic notifications	"It would be nice if the device can generate some insights automatically to help us with the analysis over time; for example, it can tell us when the data deviates from the baseline." (Caregiver 1)

7.4 DISCUSSION

Principal Results

Via evaluating the digital platform in a real-life context with potential users for seven weeks, this study gained insights on applying Data-enabled Design for personalising dementia care in a nursing home. Results demonstrated the potential for the data visualisations in the digital platform to reveal behavioural patterns despite the missing data. In addition, we identified three main types of insights generated from data analysis, two main types of corresponding actions, the perceived usefulness of the digital platform and three areas for its improvement.

- **Implications of Analysis 1**

The results show that integrating the digital platform into the nursing home environment might offer an opportunity for the care team to uncover the behaviour patterns of their residents and personalise the care plans accordingly.

A study on adapting mobile and wearable technology to support and monitor rehabilitation for PwD in the home environment has discussed that the monitoring approach could replace traditional methods for behaviour analysis (e.g., questionnaires) with four advantages [41]. The findings from the current study coincide with three of the four advantages identified, which are: the behavioural patterns identified by monitoring could be of higher resolution, data quality is independent of human recall, and collaborative care could be facilitated by sharing the data visualisations. The last advantage identified by this previous study is that the workload of the care team could be lowered by the monitoring approach [41]. In our case, the interplay of monitoring with assistive technology and the current practice of the care team was explored; hence the time spent by the care team in managing the tags and analysing the data was factored in. In this way, their overall workload was increased in the short term, which is the main pain point mentioned by the care team.

The workload of the care team might decrease in the long term as they gain experience with managing the tags and analysing the visualisations. Meanwhile, the future development of the digital platform should focus on autonomising some tasks for the care team. Moreover, BPSD management contributes to a high percentage of caring workload [42], and the insights generated from using the digital platform may offer novel and personalised ways for managing BPSD. Thus, using the digital platform would potentially enable BPSD management to be easier for the care team. In this study, most members of the care team have identified the potential added value of this digital platform to their care practice; besides, they have become more familiar with data collection and analysis. Higher familiarity and having perceived needs have been recognised as two contributing factors for better user adherence [41]. Hence, a longer-term evaluation is needed to examine if the effort and time invested by the care team in using the digital platform could be outweighed by the effort and time saved from using it.

- **Implications of Analysis 2**

The three main types of insights generated after data analysis are at the client level, ward level, and team level. Even though the initial aim of introducing the digital platform is to collect data that is unique to each individual, the care team generated insights that are not limited to the clients. This is because the context in which a PwD lives is also an important part to consider when personalising dementia care. This reveals the

importance of context in personalised dementia care, which we recommend future researchers and developers pay attention to.

Although the types of insights and the types of actions were categorised in the results section, they are interrelated in various ways. A tentative overview of the interrelations among them is shown in Figure 7. From the “Insight” section of this figure, some insights at the client level, ward level, and team level mutually influence one another. For example, when some caregivers increase awareness about their behaviours (team level), their interaction approach with the residents might change (ward level), and this may lead to a reduction in the frequency of BPSD moments for the residents (client level). Moreover, due to the interrelations between these insights, uncovering one insight may lead to the discovery of other insights. For example, realising the day structure of a resident is usually disrupted at certain times (client level) may trigger the care team to recall if there are any differences in this resident’s environment at these times (ward level) or to reflect if there are any difficulties in the workflow of the caregivers around these times (team level). Despite these overlaps, we feel that all the themes and sub-themes do provide a set of specific types and sub-types of insights, respectively. We find that discussing the various separated themes and sub-themes result in making sense of their interconnections naturally.

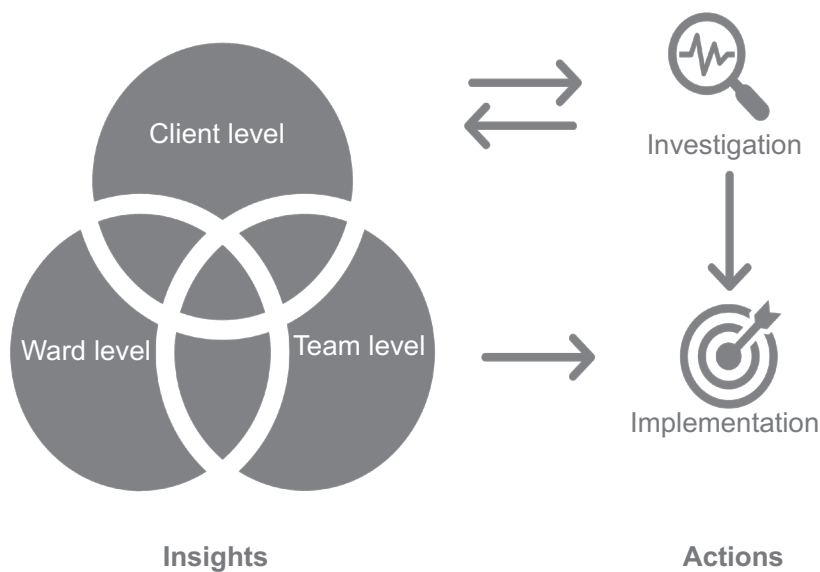


Figure 7. The tentative relations between the types of insights and types of actions generated in this study.

Zooming out from the “types of insights” in Figure 7, we postulate that these insights interact with the two types of actions identified, which are “investigation” and “implementation”. As illustrated by the arrows: when the insight is in the form of a statement (e.g. the client forgets to go to the bathroom when agitated), the care team will implement them in the care practice (e.g. we should bring him to the bathroom even though he did not ask for it); however, when the insight is in the form of a question (e.g. what has the client been doing during dinner time?), the care team will then inspect to find the answer by “investigation” (e.g. meeting, observation, collect and analyse more data), and this process will lead to more insights. When the care team is certain about their findings after the investigation, they will then implement them in the care practice.

We find these types of insights and actions, together with their interactions, could also be applied in evaluating assistive technologies in other contexts of personalising dementia care in nursing homes. We hence encourage future researchers and developers to use Figure 7 as a conversation guide when evaluating these assistive technologies with the care team and be open-minded about more types of insights and actions generated.

- **Implications of Analysis 3**

The PwD, caregivers, doctor, psychologist, dietitian and manager are among the key stakeholders for the digital platform. Previous studies have found caregivers’ acceptance of assistive technologies is vital for successful integration and usage of these technologies in nursing homes [24]. We would like to add that, in the case of managing BPSD with assistive technologies, all members of the care team should be involved. This is because a group effort is needed in incorporating insights from the data analysis into the current care practice for BPSD management. Different stakeholders tend to have different interests in a project. In our previous study, we identified the main value held by the care team is to provide better care to PwD. After the digital platform was implemented in the ward for a longer period of time, we noticed that, despite the main value, the different interests among stakeholders should be catered for. Specifically, most members of the care team identified the added value of this digital platform to their care practice. The manager, however, was mainly interested in the efficiency of care on the ward; therefore, she saw fewer benefits from the digital platform to her work.

To manage the competing needs stemming from different stakeholders, we recommend future studies to apply a multi-criteria analysis to prioritise the stakeholders involved [43]. For example, the manager might be interested in different aspects of care in comparison to other members of the care team and thus could be involved differently. Knowing the reasons behind the low acceptance of some stakeholders and prioritising the stakeholders early on could help with the development of future assistive technologies for dementia care in nursing homes.

Three main areas of improvement for the digital platform are identified, namely, data collection, data visualisation and data analysis. We postulate that these areas of improvement are interconnected to each other. Their tentative connections are shown in Figure 8. First, a change in data collection would affect both data visualisation and data analysis. For example, introducing data about non-verbal behaviours might lead to a change in data visualisations to accommodate this new data type, and the analysis process may have to be adapted accordingly. Secondly, an update in data visualisation tends to affect data analysis more than data collection. For instance, incorporating the hovering option for quick report reading can reduce the data analysis time directly, but data collection will not be affected. Thirdly, the data analysis process, in turn, tends to affect data visualisation more than data collection. Take including automatic notifications as an example; while data collection could be the same, additional visualisations might be needed for presenting the data based on which the algorithmic analysis is made. This is to ensure the transparency of algorithms to the users, which has found to be of paramount importance in decision-making [44]. The researchers and developers are advised to be aware of the mutual influences of these three areas when developing similar kinds of assistive technologies.

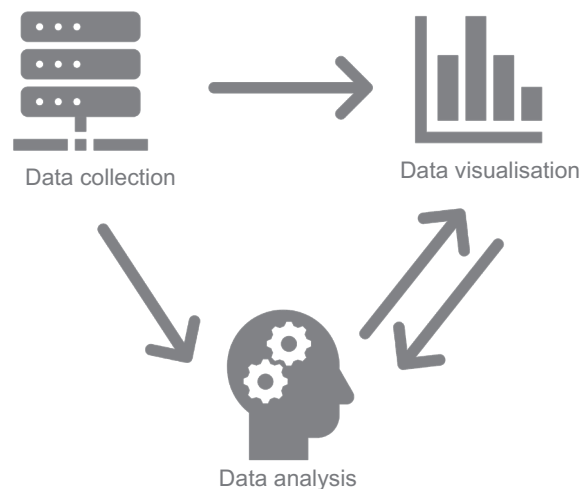


Figure 8. The tentative relations between the three improvement areas for the digital platform as identified in this study.

Reflection on Data-enabled Design

Through the evaluation of the digital platform, we have also learned about the value of Data-enabled Design in personalising BPSD management. First, we have experimented with the frequency and duration of collecting different types of data to explore the qualities and limitations of data as a type of design material, as suggested by Bogers and van Kollenburg [26]. In this way, the visualisations are perceived as relevant and meaningful to most members of the care team (e.g., by increasing the frequency of

stress rating). Secondly, after data has been collected over a longer period of time, the care team is able to gain insights from data visualisations that they otherwise will not gain via traditional methods (e.g., observation). The same results have been found in previous Data-enabled Design studies [46]. Moreover, the care team not only generated insights at the client level but also at the ward and team levels. This corresponds to the intention of Data-enabled Design: “gain detailed and nuanced contextual, behavioural and experiential insights” [26].

In addition, we have adapted Data-enabled Design in several aspects to fit it in the dementia care context. First, even though one of our key stakeholder groups, PwD, were not involved in the data analysis and interview sessions due to their cognitive impairments, we paid attention to their non-verbal behaviours when introducing the tags to them. For the residents who showed signs of dislike towards the tags, we excluded them from the study, although their family members have signed the consent forms. We then included “design the tags to be more dementia-friendly” on the to-do list. We found that more relevant design directions could be generated by combining Data-enabled Design with close observations of PwD (a way of co-designing with PwD [46]). In contrast, previous Data-enabled Design studies on developing a smart baby bottle have only involved the parents in the design research [47]. Similar to PwD, babies can communicate their needs non-verbally, and this implies that more insights could be generated when designers involve the babies during the design process in the future during Data-enabled Design.

Secondly, the Data-enabled Design approach was initially developed for designers to gain rich insights for their design projects. As stated by Bogers and van Kollenburg, “the aim of this approach is to, together with end-users, unravel the relevance, potential and pitfalls of data in a specific context to design concepts that resonate” [48]. In our study, we identified that the care team could also gain insights about PwD and their contexts using this approach to improve their care practice. Since the care team members are experts in understanding their clients and the care context, by involving the care team in the analysis, they can see things that designers cannot see. The designers can then learn from the insights generated by the care team and apply these insights into the design process. We, therefore, recommend the care team to be involved in the data analysis phase of the Data-enabled Design process: not only because the care team can gain more insights to improve their work but also because the designers can learn more from working with the care team.

Last but not least, if one would like to apply Data-enabled Design in the dementia care context, an evaluation of the designed product (assistive technology in our case) in the longer term is important. Both Figure 7 and 8 indicate there is an interplay between the technology introduced and the current BPSD care in the nursing home. There is a

growing body of studies on understanding how technology innovations change the dynamics between the people involved in healthcare, and these changes could, in turn, alter the role of the introduced technology in their daily practice over time [49]. This study adds to this body of work by gaining an understanding of the drivers and barriers of integrating assistive technology via a Data-enabled Design approach in the institutional dementia care setting.

Limitations and future work

The main limitation of this study is that all the interviews were conducted in a one-to-one format. This is because finding a time slot suitable for all the participants was difficult, given the fast pace and high uncertainty of the working environment in the nursing home. A potential shortcoming of this format is the lack of discussions within the care team, which might stimulate more ideas during the interviews. The benefit of this format is that each participant can express his/her own views and interpretations without being influenced by other participants. The strengths of this study are that the digital platform was deployed in a real-life context, and a wide range of stakeholders with different professional backgrounds was involved. Previous research has found that the use of different professionals' perspectives is valuable in developing assistive technologies for PwD [50–52].

For future work, the digital platform could be improved based on the feedback from the care team. For instance, regarding the analysis time, the manual process of data visualisation is planned to be automated by algorithms. In addition, further algorithms could be developed for pattern analysis (to replace visual inspection) and for making predictions. The results of the algorithmic analysis could then be presented in the form of pushing notifications, with which relevant visualisations will be provided.

Moreover, it would be interesting to investigate if combining different types of visualisations could generate more insights. Although all three types of visualisations were sent to the care team at the same time, all participants discussed the visuals one by one, which indicates combining visualisations had not been explored during data analysis. It could be that there is no explicit instruction in exploring visuals in a combined way, or all participants did not see the added value when combining these visuals; therefore, these explorations were not mentioned in the interviews.

In this study, we demonstrated an in-depth investigation with one care team in understanding the value of the digital platform and the application of Data-enabled Design in developing assistive technologies for BPSD management. The findings from this study are insightful at the theoretical level and in practice. We, therefore, suggest that researchers and developers could consider this case study approach in the development of future assistive technologies for dementia care.

The implication for dementia care during a pandemic

This study was carried out during the lockdown period in the Netherlands because of the COVID-19 pandemic. At the beginning of the project, the research team (GW, AA, and TvdC) went to the nursing home to introduce and discuss the study both at the management level and at the ward level. The principal researcher GW then spent a few months developing the digital platform with the care team. When the nursing home shut down because of COVID-19, the principal researcher stayed in touch with the care team via email, Skype and Zoom. In this way, the research team collected all the data without going to the nursing home and conducted the interviews online with the care team. With hindsight, this digital platform has the potential to help the care team and the researchers to gain insights about each PwD remotely, which might be valuable in the case of the current and future pandemics. In addition, the family members of PwD could be benefited by using the digital platform to stay updated about the situation of their loved ones in the nursing homes remotely, which could decrease the already-high communication workload of the care team during a pandemic.

7.5 CONCLUSIONS

Via evaluating the digital platform developed, this study gained insights on applying Data-enabled Design in personalising dementia care, specifically on BPSD management. The data collected demonstrated its potential use for pattern detection. The types of insights and actions generated from the care team by using the digital platform were identified and found to be interconnected. The perceived usefulness of the digital platform is found to vary across the care team, and we uncovered three aspects that the digital platform could be improved on. These findings could guide future researchers in investigating similar assistive technologies for personalising dementia care in nursing homes and beyond.

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8

Based on: G. Wang, A. Albayrak, E. Hogervorst, and T. J. M. van der Cammen, "Know-me: A toolkit for designing personalized dementia care," *International Journal of Environmental Research and Public Health*, accepted for publication on 23 May 2021.

A design toolkit for personalising dementia care

To sum up the research, the author developed Know-me, a toolkit that is concrete and hands-on for designers and healthcare professionals to use in designing for personalised dementia care. The sub research question at this stage is:

How could the learnings from Ergonomics in Ageing, Co-design and Data-enabled Design be integrated into a toolkit for personalising dementia care, and what is the perceived usefulness of the toolkit?

This chapter illustrates how the three design approaches were combined into the Know-me toolkit. First, the current landscape of designing for personalised dementia care was drawn to identify opportunities in this field. The Know-me toolkit was then introduced as a way of tapping into these opportunities. Afterwards, the development and evaluation of this toolkit were described. Specifically, the Know-me toolkit was evaluated in student projects on design for dementia care. Feedback regarding its perceived usefulness and desirable improvements were collected. A feature-by-feature comparison of the Know-me toolkit with similar state-of-the-art toolkits (mentioned in Chapter 1) was conducted and based upon this, the strengths and weaknesses of the Know-me toolkit are discussed. This preliminary study indicates that the Know-me toolkit is a helpful addition to the current pool of toolkits on designing for dementia care.

ABSTRACT

Personalisation is a crucial element in providing person-centred care for people with dementia. This paper presents the development and evaluation of a design toolkit to facilitate the work of designers and healthcare professionals in personalising dementia care. This toolkit, named Know-me, was grounded in the findings of Ergonomics in Aging, Co-design, and Data-enabled Design, derived from literature review and from the field during a four-year doctorate project. Know-me was designed to be easily accessible, flexible, and engaging, providing concrete and hands-on guidance for designers and healthcare professionals to use in designing for personalised dementia care. The Know-me toolkit was evaluated in student projects on design for dementia care. During this process, we found that Know-me could be adapted flexibly so that the care team could use some of the tools by themselves. A feature-by-feature comparison of the Know-me toolkit with similar state-of-the-art toolkits was conducted and based upon this, the strengths and weaknesses of the Know-me toolkit are discussed. This preliminary study indicates that the Know-me toolkit is a helpful addition to the current pool of toolkits on de-signing for dementia care.

8.1 THE CURRENT LANDSCAPE OF DESIGNING FOR PERSONALISED DEMENTIA CARE

Over the course of this doctorate, the author encountered a wide variety of designs for personalising dementia care (from the market, out of research projects and in the field). After clustering the collected designs and discussing within the supervisory team, she mapped out the designs for personalised dementia care in two dimensions (see Figure 1). This mapping was inspired and guided by the work of Sanders [1]. The resulted matrix is referred to as the current landscape of designing for personalised dementia care. This landscape serves as a benchmark for guiding the development of the Know-me toolkit later on.

The first dimension of the landscape is “who led the design”, and a spectrum is created from “Led by care team” to “Led by design team”. The second dimension is “how adaptable is the design”, and the spectrum associated with it goes from “Tailored to one PwD” to “Adaptable for more than one PwD”. Integrating these two dimensions leads to a matrix with four quadrants (as shown in Figure 1). To further explain these two dimensions, each quadrant will be discussed in detail with accompanying design examples below.

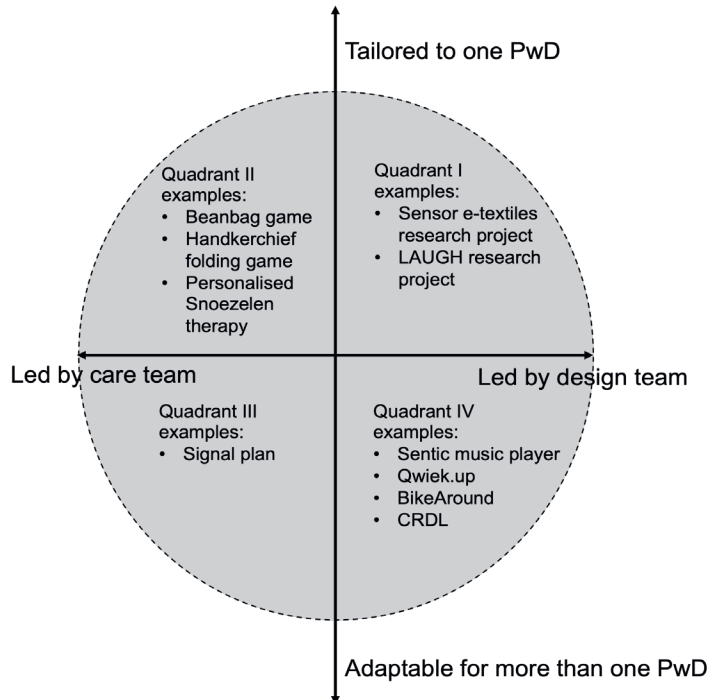


Figure 1. The current landscape of designing for personalised dementia care

- **Quadrant I**

In the first quadrant, the design team takes the lead in the design activities, and the outcome is usually a product/service/system that is “tailored to one PwD”. As exemplified by the Sensor e-Textiles research project, personalised textiles that provide sensory stimulation and encourage a “living in the moment” feeling for PwD have been developed. In this project, each textile is specific for a person with dementia [2]. In the LAUGH research project, highly personalised playful objects have been developed for a small group of residents in two dementia care nursing homes [3]. For example, an interactive steering wheel for a man who has been a driver and mechanical engineer; a retro telephone that plays Spanish conversations and songs for a woman who had lived in Spain; a soft toy with the outlook of a baby that can play music for a grandmother who has become withdrawn and unresponsive [3]. This toy has been developed into a scalable product for other PwD (where the music can be tailored by family members) after a positive evaluation with its targeted resident [4]. This case demonstrates that a design can move along the adaptability spectrum over time. Besides, the concept of designing for one person with dementia could be regarded as similar to the concept of Minimum Viable Product (MVP). An MVP is a version of a product with just enough features to be useable by early users who can then provide feedback for future product development [5]. This concept is helpful for the incremental development of a product. In the same light, designing for one early user until receiving the positive evaluation, then scaling the design to more users sharing the same unmet needs could be more effective than trying to satisfy the needs of a wide range of users at the start of the design process. However, as far as the author is aware, these designs are currently mainly driven by research projects, and the number of designers involved in this type of designs is low in practice.

- **Quadrant II**

In the second quadrant, the design outcomes are “tailored to one PwD” as well, and the difference with the first quadrant is that the design is led by the care team. This could be achieved by a collaborative effort within the care team or by one member of the care team. Since this doctorate draws on the definition of design by Herbert Simon (Chapter 1), where “design” is about changing existing situations into preferred ones, the design outcome can take many forms, and everyone can design. The beanbag game (Chapter 1) is an example of the many designs made by the care team. Another example is the “handkerchief folding game” for a person with dementia who used to enjoy doing housework before she had dementia. More examples can be found in Appendix B. However, these designs are often not reported, thus are not implemented at scale, and a systematic approach is lacking in creating them. A systematic approach would be helpful since creativity and resourcefulness are not uniformly distributed among healthcare professionals. As exemplified in the study on personalising Snoezelen therapy (Chapter 1), the perceived workload for implementing personalised interventions is high among most of the caregivers.

- **Quadrant III**

In the third quadrant, the care team leads the design, while these design outcomes are “adaptable for more than one PwD”. One example is the “signal plan” applied by the Oleander in the Zorggroep Elde Maasduinen nursing home (where the field study took place). A signal plan is a template for the care team to keep track of the behaviours of the residents when they are at different levels of stress and what have been the effective measures in managing the stress at these levels (e.g., adaption in interaction and environment). The signal plan is filled in for a resident after the behaviours of the resident are closely observed over weeks. Specifically, these behaviours are categorised into four groups, with each group corresponds to one stress level as defined in the Crisis Development model (In Dutch: Crisisontwikkelingsmodel) [6]. More information about this model can be found in Chapter 7. The effective measures carried out to help the resident relax at different stress levels are recorded and categorised in the same manner. Each resident has a personalised signal plan. Based on the signal plan, the behaviours of the residents act as signals for their stress levels, and the caregivers can then react by adjusting their interaction styles and environments according to the signal plan to reduce the stress in each resident. This adaptation has so far been achieved manually, and only a limited number of examples are available in this quadrant.

- **Quadrant IV**

In the fourth quadrant, the design outcomes are “adaptable for more than one PwD”, while the design team takes the lead this time. The design outcome is capable of adapting to its users, either automatically or manually. By “manually”, the author implies the caregivers or family members pay conscious attention and action to the adaptation; and in contrast, “automatically” means the adaption is achieved without either conscious attention or added workload of the caregivers and family members. The manual adaptation can be achieved in a few means:

- 1) by modular design (e.g., Sentic music player [7] provides three types of user interfaces for the listener so the caregivers can select the appropriate interface for the resident);
- 2) by letting family members add content to the design (e.g., Qwiek.up [8], an audio-visual projector, allows families to upload images and playlists for their loved ones remotely);
- 3) by providing a wide range of options to choose from (e.g., BikeAround [9], enabling residents to cycle within “Google street view” as the virtual scene, which offers the freedom for the resident to start the bike journey anywhere with Google Maps).

Regarding automatic adaptation, this is now only being fulfilled with designs that involve family members to play together with the resident (e.g., CRDL [10], a care instrument that translates physical contact between people into sound, allows the family to interact with the PwD playfully). The pure presence of the family members makes the design personalised for the resident. Yet, only a limited number of examples are available in this cluster.

To summarise, the author identified opportunities in each quadrant to be built on further, specifically:

- Quadrant I: How to encourage more designers to design for personalised dementia care that is “tailored to one PwD”.
- Quadrant II: How to provide a systematic approach for healthcare professionals to design for personalised dementia that is “tailored to one PwD” within their workload limit.
- Quadrant III: How to help healthcare professionals to find more ways to design for personalised dementia care that is “adaptable to more than one PwD” within their workload limit.
- Quadrant IV: How to help designers to find more ways to design for personalised dementia care that is “adaptable to more than one PwD” in an autonomous way.

The author would like to emphasise that the landscape as presented above is not complete; for example, sometimes it is debatable to quantify how adaptable one design is over another design. The intended function of this landscape is to serve as a scaffold to support the conversation about designing for personalised dementia care and spark future thinking and doing around this topic. This landscape is still taking shape and will be updated as more designs for personalised dementia care come into view. The author encourages future researchers and practitioners to contribute additional dimensions and clusters to this landscape.

8.2 THE KNOW-ME TOOLKIT

The author brought together the knowledge gained from the three design approaches (i.e., Ergonomics in Ageing, Co-design, Data-enabled Design) and integrated them to form a toolkit (name: Know-me) for personalising dementia care with design. The author envisions the toolkit can contribute to the identified opportunities in each quadrant of the current landscape for designing personalised dementia care. This Know-me toolkit consists of a user manual and four tools, which are a capability card set, a co-design

guide, a data exploration guide, and a person-centred canvas. The tentative relations between these four tools are illustrated in Figure 2. Specifically, the insights generated by the capability card set, co-design guide and data exploration guide feed into each other, and together, they contribute to the person-centred canvas. The envisioned users of this toolkit are designers and healthcare professionals (referred to as “users” below); specifically, it is envisaged that designers will co-design with healthcare professionals using the Know-me toolkit for designing personalised dementia care. How the toolkit contributes to the identified opportunities of the current landscape will be discussed in Chapter 9.

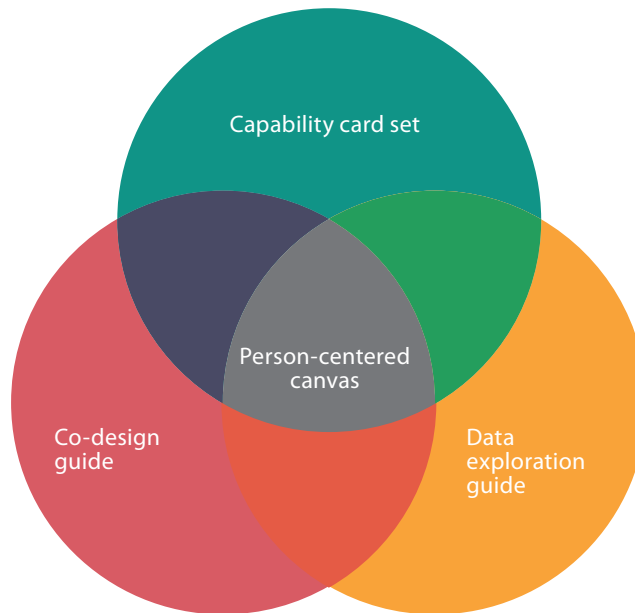


Figure 2. The relations between the four tools in the Know-me toolkit for personalising dementia care

Each tool of the Know-me toolkit will be introduced below. A website was developed for representing this toolkit and played a central role in disseminating this toolkit to potential users. The readers may look into the details of the toolkit via the website link below.

Know-me toolkit website link: www.designfordementia.squarespace.com

A. Capability card set

The aim of the capability card set is to help users to identify the remaining capabilities of PwD. The capability card set was created based on the exploration of the Ergonomics in Ageing approach in designing for personalised dementia care. The initial recommendation list was generated based on a literature review (Chapter 3) and refined in a field study (Chapter 5). There are 11 cards in total, and each corresponds to a

capability that is commonly different from older adults to younger adults. The capability cards were categorised according to their categories in ergonomics (i.e., cognition-, sensory-, and movement-oriented capabilities) and have their corresponding icons at the right bottom corner. On each card, a question is proposed to help users to identify possible capability limitations an older adult might have. Below the question, several suggestions are made about what could be done to allow one to still be able to interact with this older adult if s/he has certain capability limitations.

The cards for cognition-oriented capabilities (and the instruction card) can be found in Figure 3. The cards for sensory-oriented capabilities can be found in Figure 4. The cards for movement-oriented capabilities can be found in Figure 5. The full card set can be downloaded from the website www.designfordementia.squarespace.com.



Figure 3. The cards for cognition-oriented capabilities (and the instruction card).

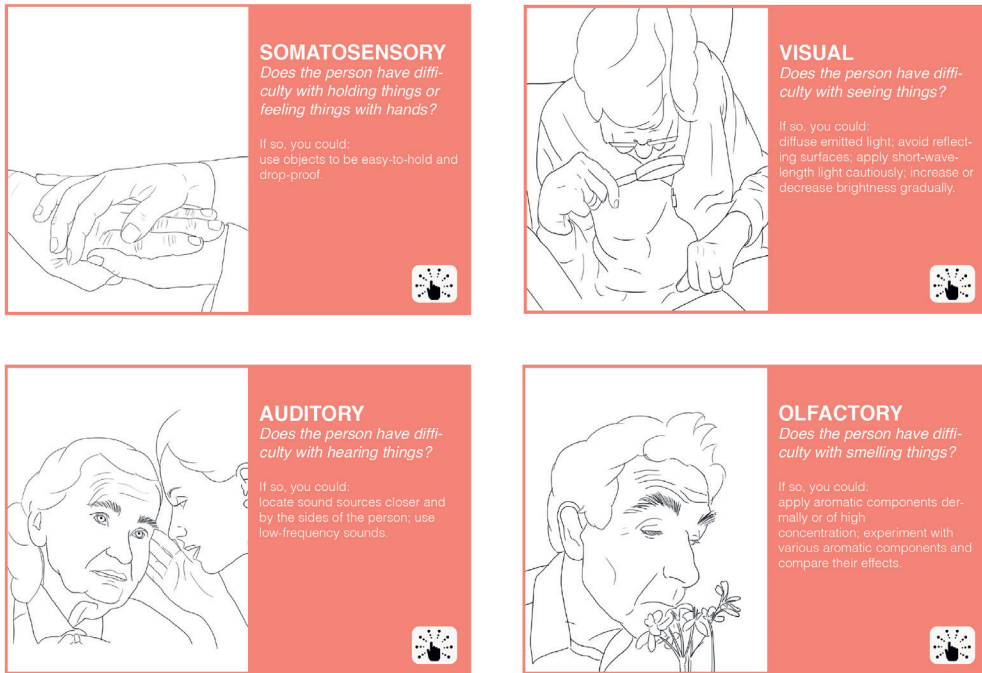


Figure 4. The cards for sensory-oriented capabilities.

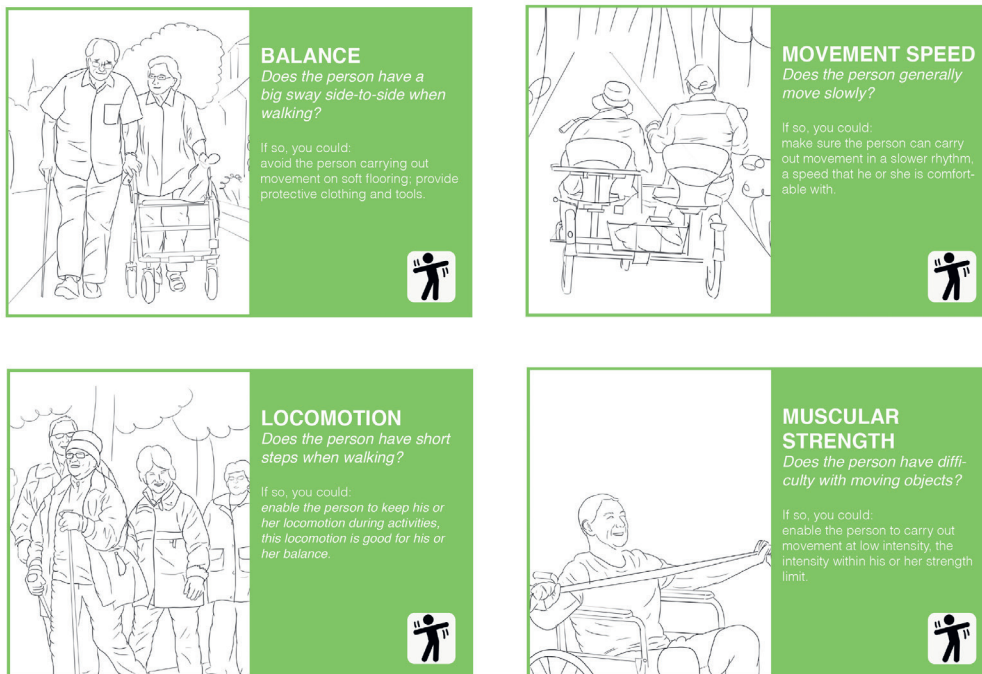


Figure 5. The cards for movement-oriented capabilities.

By using this card set, users can explore what the PwD can still do when their capability limitations are taken into account. The author advises the cards to be printed out so that they can be flexibly spread out, studied individually, placed together, and shared with other members if one is working within a team [11].

B. Co-design guide

The goal of this guide is to help users to uncover the needs of PwD via co-design. This guide is created based on the exploration of the Co-design approach in designing for personalised dementia care. The first part of the exploration has been done in a scoping review (Chapter 4), the outcome of which has been evaluated in a field study (Chapter 5). The co-design guide is visualised digitally in a way that is easy to navigate (zoom-in, zoom-out). It is interactive with a layered design and provides an overview to make the information more digestible for the users. The home page of the co-design guide is shown in Figure 6.



Figure 6. Home page of the co-design guide

On the home page, a “Read me” bubble is located at the centre to provide the background of the co-design guide. This guide is categorised into three bubbles, which are: “Decide”, “Prepare” and “Execute”, and they correspond to “decide on whether co-

design is suitable”, “how to prepare a co-design session”, and “how to execute the co-design session” respectively. The full guide can be accessed from the website www.designfordementia.squarespace.com.

C. Data exploration guide

The goal of this guide is to help the users to generate more insights about PwD by combining quantitative data and qualitative data. The data exploration guide is created from the exploration of the Data-enabled Design approach in designing for personalised dementia care. The concept of this guide was first formed during the design of the Data-care digital platform (Chapter 6) and then established in the evaluation of the digital platform (Chapter 7). This guide is visualised digitally in a way that is easy to navigate (zoom-in, zoom-out). It is interactive with a layered design and provides an overview to make the information more digestible for the users. The home page of the data exploration guide is shown in Figure 7.

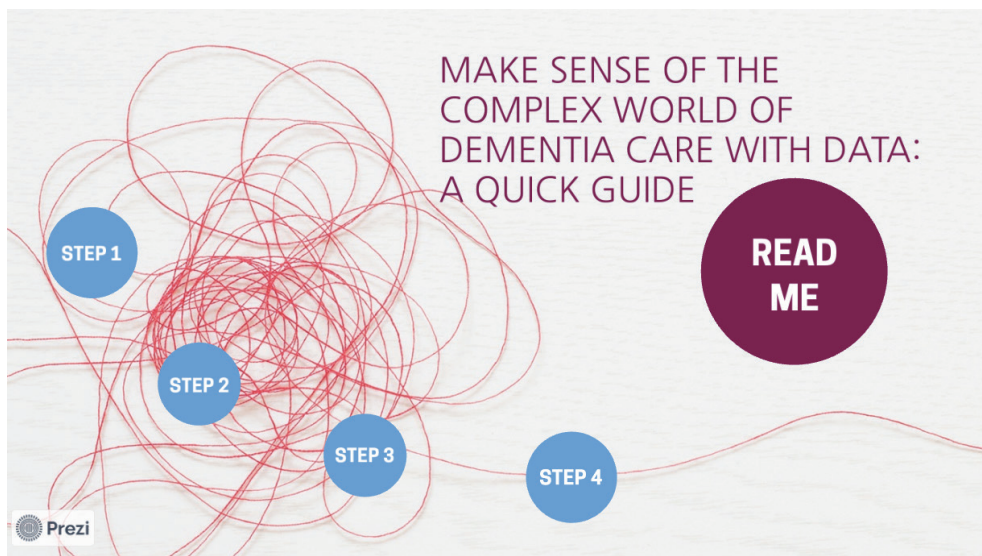


Figure 7. Home page of the data exploration guide

On the home page, a “Read me” section is located near the title to provide a background of this guide to the users. The guide is divided into four steps, which are “what data to be collected”, “the value of collected data”, “how to collect and visualise collected data”, and “how to facilitate data analysis”. Within each step, a description of the step is given and accompanied by some tips and more resources that the users can dig into. The full guide can be accessed from the website www.designfordementia.squarespace.com.

D. Person-centred canvas

The aim of this canvas is to help the users to have a clear overview of what aspects need to be considered when designing for a person with dementia. The person-centred canvas is developed based on the NDB model (Chapter 1), enriched by the explorations in non-pharmacological interventions for managing BPSD (Chapter 2), and established after the investigation of the three design approaches (i.e., Ergonomics in Aging, Co-design, Data-enabled Design). A template of the canvas is shown in Figure 8.

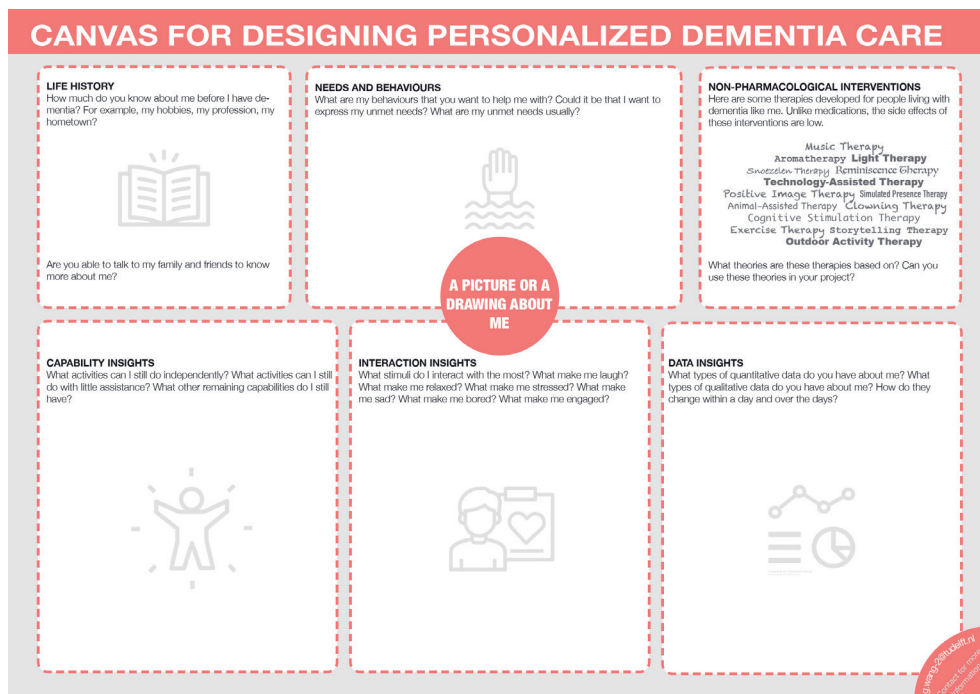


Figure 8. Template of person-centred canvas

The canvas is intended to guide the users to gather for designing personalised care; it also helps the users to map, manage, and keep track of all the information and insights they have gathered about a person with dementia in an integrative way. At the same time, this canvas is intended to inspire the users by presenting a summary of current non-pharmacological interventions for managing BPSD.

The canvas is divided into six sections, which are “life history”, “needs and behaviours”, “non-pharmacological interventions”, “capability insights”, “interaction insights”, and “data insights”. “Capability insights” corresponds to the findings of applying the capability card set; “life history” and “interaction insights” correspond to the discoveries of applying the co-design guide; “data insights” corresponds to the insights gained by

using the data exploration guide. At the centre of the canvas, users are encouraged to put a photo or a hand-drawing of the person with dementia since this method has been found to be helpful in stimulating person-centred empathy during design [12].

The envisioned connections of the six sections of the canvas are the following: the users are encouraged to involve caregivers, family members and friends of the person with dementia to collect past stories about the person (“life history”). This will help the users to zoom out from the current state of the person and see the person as a whole. Then the users are advised to frame the behaviours of the person (e.g., BPSD) as a way for expressing their unmet needs (“needs and behaviours”). This could be done through interviews with caregivers and/or careful observation of the person. To understand what the unmet needs could be, the users could combine the insights gathered about the current state of the person (“capability insights”, “interaction insights”, and “data insights”) and take into account the past of the person (“life history”) to form a comprehensive view of this person. In this way, all the background and proximal factors suggested by the NDB model will be covered, which helps the users to identify the possible unmet needs. After the unmet needs are identified, the users can then refer to the interventions (“non-pharmacological interventions”) for inspirations; and use all the insights presented in the canvas to design for the person. The summary of non-pharmacological interventions is intended to help the users to be aware of what interventions have been developed and evaluated in the medical field and thus dig into each intervention if needed (instead of performing a literature review from scratch). The users do not have to stick to one type of intervention; rather, they are encouraged to think about what the theories underneath these interventions are and how could these theories be applied for designing personalised dementia care.

In the end, this canvas could also help the users to share and reflect on the information and insights (basis of the design) with the important stakeholders in the design process. The author understands applying this canvas in real-life settings could be an iterative process and not as linear as what is suggested, yet this envisioned connection gives one a direction about how to use the canvas.

This canvas can be used in both a physical and digital format depending on the users’ preference. The author recommends the users to write the information and insights on post-its (could be physical or digital) and then position the post-its in the appropriate sections of the canvas. The canvas offers a structure for one to organise their post-its, and the post-its have the flexibility to be rearranged along the design process. The full-size canvas can be downloaded from the website www.designfordementia.squarespace.com.

E. User manual

The author encourages the users to explore their own ways of using the toolkit. Yet, a user manual is written to guide users who would like to have a structured approach in using these tools in the design process. The double diamond model [13]—the most-cited design process model—is used as a reference to inspire the users about how these tools might fit in the design process. According to the double diamond model, the design process can be divided into four phases, which are: discover, define, develop, and deliver. An illustration of how the tools contribute to the four phases is shown in Figure 9.

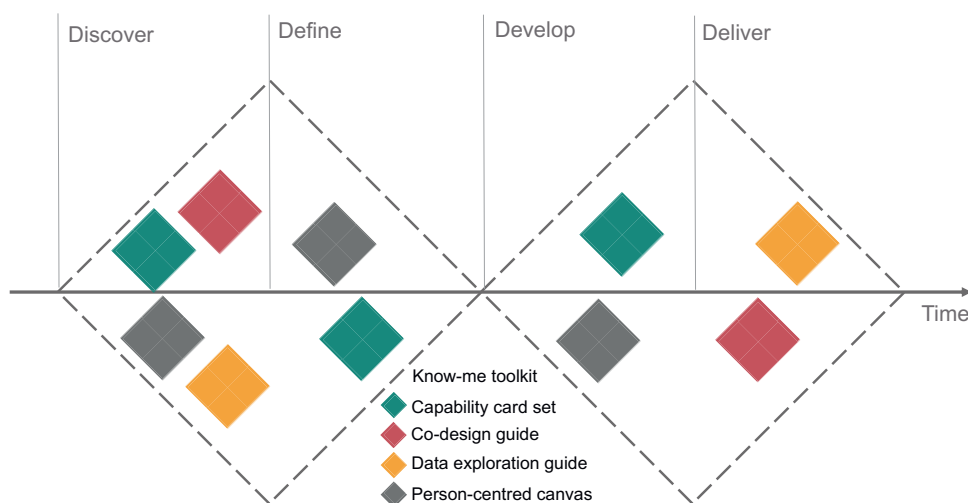


Figure 9. An illustration about how could the Know-me toolkit be applied in the design process (adapted from the double-diamond model [13])

Specifically, in the Discover phase, all tools are involved; in the phases of Define and Develop, the person-centred canvas and the capability card set are involved; in the Deliver phase, the co-design guide and data exploration guide are involved. The contribution of each tool at the different design phases is slightly different, and their intended roles are outlined in the user manual. The full user manual can be found on the website www.designfordementia.squarespace.com.

8.3 DEVELOPMENT OF THE KNOW-ME TOOLKIT

The Know-me toolkit was developed in three steps, and the process is illustrated in Figure 10.



Figure 10. The development process of the toolkit

First, the author visualised the research findings into the first version of the design toolkit under the inspirations of the tools developed for designers in the Delft Design Guide [14]. Secondly, four design students (Master students at the Delft University of Technology) who have experience with designing for PwD were involved in providing feedback on the form and layout of the tools and then on the language and content of the tools. Based on the feedback of each round, the author redesigned the toolkit. To name just a few modifications, the language used in all the tools was adapted from an academic tone to a designer-friendly tone. An academic tone aims to be all-encompassing, which results in detailed explanations and argumentations. The design students commented they were sometimes “lost in the language” while reading the toolkit, and this led to a refinement of the language in this toolkit. In addition, the design students found some advice given by the toolkit were abstract, and the advice was subsequently made more concrete and practical based on a follow-up discussion with the students. Two design students raised the question that they found guidance on how to use the toolkit is lacking; hence a user manual was developed.

During the development of the user manual, the students provided feedback on its language and content and then the layout. The author then redesigned the user manual according to the feedback. During this process, two design students indicated that it would be convenient to keep all the tools and the user manual in one place online, and this led to the development of the website. In addition, the website is also helpful for: 1. Increase the accessibility of the toolkit; 2. Remove the burden of sending the toolkit to the users manually after each update. The website was then refined based on the students’ comments on its language, content and layout. For instance, the background image of the webpage of each tool is changed from a picture of PwD to a screenshot of the tool. This is because design students commented that they would like to see how the tool looks like briefly before clicking the “download” or “open” button.

The home page of the website is shown in Figure 11. The author sees the website as the platform for disseminating the toolkit. This platform was designed to be inviting and concise with the purpose to introduce the toolkit to the users effectively.

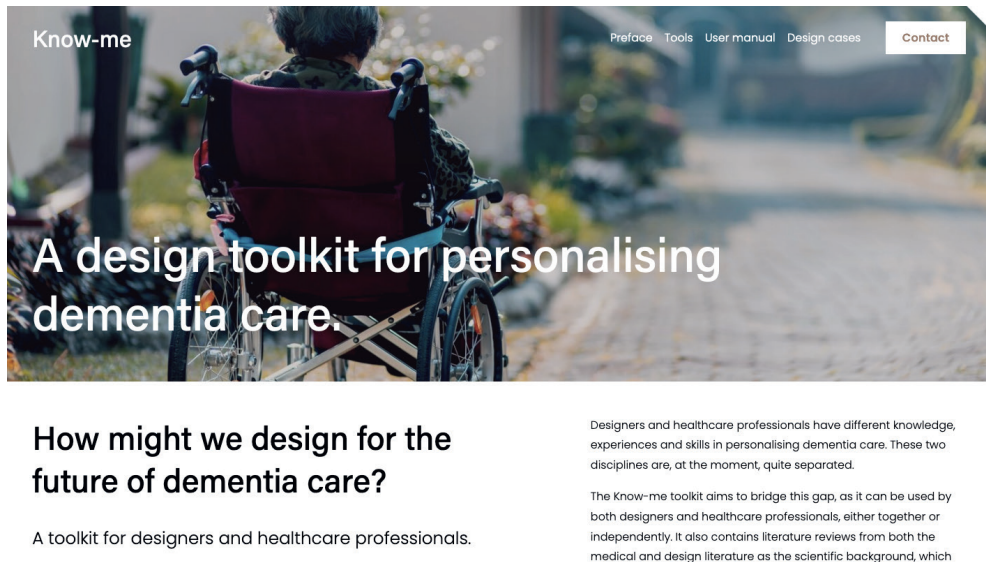


Figure 11. Home page of the website for the Know-me Toolkit

Specifically, the “Preface” button leads the users to a page where the background and aims of developing the toolkit are explained. All the tools are listed under the “Tools” button, the user manual can be accessed with the “User manual” button, and the design examples can be accessed with the “Design cases” button. A “Contact” button was introduced for the users to ask questions and give feedback. Scrolling down the page, the users can see a survey to leave their feedback about the toolkit. At the bottom of the home page, relevant information sources were listed for users who would like to learn more about the research in general.

For the webpage of each tool, underneath an overview image of the tool, the rationale behind developing this tool was summarised into an introductory paragraph. The users can access the tool by clicking the “download” or “open” button listed below the introductory paragraph. This website enables the author to update the toolkit seamlessly based on the feedback of the users. While the author keeps track of the updates in each version of the toolkit, the users use the most up-to-date version of the toolkit without worrying about the detailed changes.

8.4 EVALUATION OF THE KNOW-ME TOOLKIT

The Know-me toolkit was evaluated with the following research questions:

1. **What is the perceived usefulness of this toolkit?**
2. **What are the desired improvements for this toolkit?**

To answer the research questions, the toolkit was evaluated by student projects focusing on dementia care design at the Faculty of Industrial Design Engineering (IDE), Delft University of Technology, during the Advanced Concept Design course. The below section explains the context, methods, and outcomes of this evaluation.

Context

Advanced Concept Design is a compulsory course for the Master students majoring in Integrated Product Design at IDE. This course focuses on the conceptualisation phase of product development and starts from a real-life design challenge and ends with the concept of a product or a product-service system. The design challenge was co-created with RespectZorg nursing home, a non-profit care organisation in the Netherlands. RespectZorg then teamed up with Vegro, a wholesale company of care aids in the Netherlands, to provide students with information and support during the assignment. The design challenge was related to BPSD management in nursing homes, and the specific assignment was:

Design a product/product-service system in the nursing home that can engage people with dementia in meaningful activities (alone, with family members, or as a group) for 30 minutes a day.

In total, 16 students participated in this course. The students were divided into three subgroups with three sub assignments: 1) reduce apathy during the morning coffee break; 2) reduce restlessness in the afternoon; 3) reduce wandering behaviours. Students worked on the project for 20 weeks. In the first ten weeks, the students worked in subgroups to understand the design context and received guidance from experts in the field of culture, ergonomics, and technology. In the last ten weeks, each student came up with his/her own design direction, developed concepts and prototypes, and delivered an animation and report about their final designs.

Due to COVID-19, the students were not able to access the nursing home, which made the research phase especially difficult for them. Specifically, they received limited support from healthcare professionals and were not able to meet PwD in person. Some students were not able to test their design concepts in the nursing home, while other

students sent their prototypes to the nursing home and tested them remotely. The author acted as an expert in the field of dementia care design and provided relevant information and insights to the students who reached out.

Methods

The author introduced the toolkit to the students in Week 15 via an online lecture. After the toolkit was introduced, the students were able to ask questions about the toolkit in a personal Q&A with the author. All 16 students asked questions about the toolkit and other questions related to their designs. The author was also present in future meetings to give advice on how to use the toolkit and other questions related to dementia care design.

In Week 16, the author was approached by the course coordinator, who is a professional designer herself, suggesting the possibility of creating a care team version of the person-centred canvas. The course coordinator postulated that the care team could fill in the canvas by themselves with the information of the residents they are taking care of. In this way, the students could receive some real data about the PwD that they were designing for without adding too much workload to the care team. Together with the course coordinator, a care team version of the person-centred canvas was created by adapting the original person-centred canvas. The person-centred canvas template of this care team version is shown in Figure 12.

The person-centred canvas was adapted to be more accessible to the care team in a few ways. First, the design terminologies were replaced with everyday language (e.g., “capability” is replaced with “what one can do”). Secondly, the layout was adapted from A3 to A4 since most of the offices in the nursing home can only print A4 papers. Thirdly, the capabilities mentioned in the capability card set were added to the canvas to help the care team reflect on the remaining capabilities of each resident. Moreover, some short answer questions were changed into a checklist since the care team have limited time, and they are more familiar with a structured way of working. Lastly, the language changed from English to Dutch since this canvas was deployed in the Netherlands, where all caregiver participants are native Dutch speakers.

In Week 17, the care team filled in six person-centred canvases, each representing a resident in the nursing home. These canvases were sent to the students immediately via email. In addition to these meetings and materials, the students were free to choose other design methods and tools during the design process.

In Week 20, the students were asked to reflect on their design process and the Know-me toolkit via an online questionnaire. The questionnaire consists of open questions and

PERSOONSGERICHT CANVAS VOOR DEMENTIEZORG



Tekening van de persoon

LEVENS GESCHIEDENIS

Hoeveel weet u over mij?

-Van de tijd voordat ik dementie kreeg-

hobby's

beroep

geboorteplaats

woonplaats

Wat zeggen mijn familie en vrienden over mij?

BEHOEFTE EN GEDRAG

Wat zijn gedragingen waarmee u mij wilt helpen?

Zou het kunnen dat ik mijn onvervulde behoeften wil uiten? Zo ja wat

Wat zijn meestal mijn onvervulde behoeften?

DATA OVER MIJ

Welke metingen en gegevens van mij, zoals lichaamsgewicht, bloeddruk en andere data (uit dagrapporten, zorgplannen, dieetplan) zijn mogelijk van belang om te begrijpen welke aanpakken of benaderingen / prikkels wel of niet goed voor mij zijn?

MIJN MOGELIJKHEDEN

Welke activiteiten kan ik nog **zelfstandig** doen?

Welke activiteiten kan ik nog doen **met weinig hulp**?

Welke andere mogelijkheden heb ik nog?

Ik heb moeite met (kruis aan aub)

- dingen zien
- dingen horen
- dingen ruiken
- dingen vasthouden
- dingen voelen met mijn handen
- bewegende objecten
- planningstaken
- herinneren van recente gebeurtenissen
- filteren van prikkels / irrelevante stimuli

Dit is op mij van toepassing

- ik beweeg over het algemeen langzaam
- ik zwaai van links naar rechts als ik loop
- ik maak korte passen als ik loop

Is er iets anders dat u wilt noemen?

THERAPIEËN

Welke van de onderstaande therapieën werken voor mij? (kruis aan aub)

- Muziektherapie
- Aromatherapie
- Lichttherapie
- Snoezelen-therapie
- Herinneringstherapie
- Robot therapie
- Positieve beeldtherapie
- Gesimuleerde aanwezigheidstherapie
- Dierondersteunde therapie
- Cognitieve stimulatietherapie
- Oefentherapie
- Verhalenverteltherapie
- Outdoor activiteitstherapie
- Clown therapie
- Anders, namelijk _____

HIERMEE ZIJN WE ERG GEHOLPEN - DANK U WEL!

Figure 12. The person-centred canvas template for the care team (in Dutch)

multiple-choice questions with a single choice option. In the questionnaire, six items are evaluated, which are: the user manual, the co-design guide, the data exploration guide, the capability card set, the original person-centred canvas and the filled-in canvas by the care team. Each student was asked to select the tools that they found the most and the least useful in the toolkit. If none of the options applied, the students could select “others” and write their answers. The students were then asked to give the reasons behind their choices by the open-ended questions. The questionnaire can be accessed via the link <https://forms.gle/UEbEdjgFfJnjMPzi7>. It is explicitly mentioned in the questionnaire that the answers will not be taken into account during grading, and the author is not involved in the grading process to allay concerns about social desirability bias.

The author then conducted a thematic analysis of the collected data together with a student assistant. Following the guidance of Braun and Clarke [15], both researchers got familiarised with the data independently first, and three discussion sessions were conducted for generating initial codes and searching for themes, reviewing themes and defining themes until consensus was reached. All discussions were facilitated by a Miro board.

Results

Ten out of 16 students responded to the questionnaire. Only one participant has previous experience with designing for PwD. Five students rated their satisfaction with their designs at six, and five other students rated at five on a seven-point Likert scale (1: not satisfied; 7: very satisfied). All students have indicated that they would appreciate direct interactions with PwD and more involvement of caregivers. Each tool has been perceived as the most useful by some students and the least useful by some other students. The outcomes of the thematic analysis are summarised in Table 1 and Table 2, respectively. Table 1 sums up how the toolkit is perceived by the students in contributing to their design process, while Table 2 encapsulates the desired improvements of the toolkit.

In Table 1, four themes were identified that the toolkit could help to “understand the context and users”, “initiate the ideation”, “develop the concept”, and “test the prototype”. In order to understand the context and users, the toolkit is perceived to be able to provide knowledge about the PwD before field study, as well as help designers to gain insights from the care team and narrow down the design brief. The capability card set was mentioned by a few students to help them understand the capabilities of PwD. In terms of initiating the ideation process, the toolkit was reported to offer design directions and to help designers with understanding the needs and wishes of PwD. As for developing the concept, the toolkit was used as a knowledge source and could provide criteria for improving the design. Regarding prototype testing, some design

students found the toolkit helped them to answer user testing questions and to predict the reactions of PwD to their prototypes.

Table 1. Themes and sub-themes on how the Know-me toolkit is perceived to contribute to the design process with example quotes.

Theme	Sub-theme	Example quote
Understand the context and users	Provide knowledge about the end-users before field study	"Allow for you to get information about PwD without needing to be there in person."
	Gain insights from the caregivers	"I do believe that I could have used the person-centred canvas to gain better insights from the caregivers."
	Narrow down the design brief	"Design for dementia is an elaborate topic, so the toolkit gives you hands-on tips on where to start."
	Understand the capabilities of PwD	"Capability cards helped me when designing my product that is multi-sensory and how to adjust it so that people with dementia can enjoy the product."
Initiate the ideation	Understand the needs and wishes of PwD	"I think these tools are helpful during the ideation phase to understand the needs and wishes of the users better."
	Offer a design direction	"In the first period, I didn't know what to do; it gave me helpful instructions, like which direction I could think about (for instance, music therapy)."
Develop the concept	Use as a knowledge source	"I needed to design something the size of an image that PwD could still see. Therefore, I checked the capability cards."
	Provide criteria for improving the design	"The capability cards helped to think of what you need to still improve the concept."
Test the prototype	Answer some user testing questions	"For me, it could answer some of the questions that I wanted to determine in user testing."
	Predict the reactions of PwD	"Give insight into the way the end-user handles certain things/products."

In Table 2, three themes were identified for desired improvements of the Know-me toolkit, which are: "elaborate the tools", "add more elements to the toolkit", and "make the toolkit more accessible". Specifically, the students commented that the tools could be elaborated in three ways, which were: provide more examples about how each tool could be used; increase the details of the capability cards; include how the toolkit could be used with the care team. In addition, the students would like to see the toolkit to include three elements in addition to the current scope, which were: literature resources about dementia; methods for remote testing; methods for evaluating responses of PwD. As for the accessibility of the toolkit, the students indicated the toolkit would be more helpful if: the visibility of the website were higher in the Google search; the user manual was easier to find on the website; hard copies of the toolkit were given with templates; and the toolkit was provided at an earlier stage of the design process.

Table 2. Themes and sub-themes on the desired improvement of the toolkit with example quotes.

Theme	Sub-theme	Example quote
Elaborate the tools	Provide more examples of how each tool could be used	"Maybe examples of how they are used in a design process, how they come back in a final design."
	The capability cards could be more detailed	"I think it will be better if there are more classification of different stages and types of dementia in the cards."
	Include how to use the toolkit with the caregivers	"The canvas would also have helped if the caregivers had time to fill them in."
Add more elements to the toolkit	Add literature resources about dementia	"I think that's "more literature resources for further explanation of dementia" which means making this tool becomes a literature searching tool for designers to use."
	Include methods for evaluating responses of PwD	"I used the positive response schedule by introducing an activity between the caregiver and the person with Dementia. It helped me understand, observe and mark the behaviour of both the PwD and the caregiver."
	Include methods for remote testing	"I would like to see the reactions of PwD themselves. So maybe more technological support with cameras etc."
Make the toolkit more accessible	Visibility of the website	"More a practical thing; it is a bit difficult to find the website and also to find different sections of the website."
	The user manual should be more visible	"Not really sure which manual you're referring to."
	Hardcopy and templates to make it more accessible	"Maybe these tools could be made into one booklet with templates so researchers could use it on the fly."
	Provide the toolkit at an earlier stage of the design process	"It gave me inspiration. But these cards were shown to me at a late stage, so, unfortunately, I could not use them as much as I wanted."

Discussion

• Main findings

This evaluation was aimed to identify the perceived usefulness of the Know-me toolkit and desired improvements about it. The toolkit has been found to be able to contribute to each stage of the design process, which are contextual inquiry, ideation, concept development and prototype testing. Letting the care team fill in the person-centred canvas by themselves was an activity not as planned, and some students found these filled-in canvases are helpful for their designs. The person-centred canvas played a different role when being introduced to the care team, that is, a sensitising material for designers to gain insights about PwD and their living contexts. This coincides with previous studies on design toolkit development that a tool could play different roles depending on whom it is introduced to [16]. Meanwhile, three areas for improvements have been identified for the toolkit, each of which will be discussed in detail below.

1) Elaborate the tools

The Know-me toolkit as an early-stage toolkit needs to accumulate design examples. The toolkits developed previously for designing for PwD usually provide this kind of examples on their website [17–20]. The designs developed by the students in the Advanced Concept Design course were selected and added to the website of the Know-me toolkit as the first batch of examples to help users who would like to use the toolkit in the future. Next, the capability card set could adopt a layered design since some students prefer an overview of all the capabilities while other students would like more detailed information about these capabilities. A capability card set with multiple layers could help the designers to retrieve detailed information when needed while maintaining an overview. Lastly, advice will be given to designers on how to use the toolkit with the care team. Although some students found the filled-in canvas informative, others found the filled-in canvas contains too little information to be useful. Therefore, this type of guidance is needed to help designers to engage and gather relevant information from the care team without increasing their workload significantly.

2) Add more elements to the toolkit

As for the elements that were indicated by the students as worth being added to the Know-me toolkit, one of them is mainly related to the lack of direct interactions with PwD due to the COVID-19 pandemic. Specifically, some students would like to receive advice on how to do remote testing with PwD. The other two elements are generic, one is on providing more literature resources about PwD, and the other is on how to evaluate the responses of PwD towards a prototype. Whether these elements should be added and to what extent ought to be considered further as the Know-me toolkit is designed not to be all-encompassing and should be used with other tools and resources. The Know-me toolkit could, however, point out some other tools and resources that might be helpful for the users.

3) Make the toolkit more accessible

The accessibility of the Know-me toolkit could be optimised. The website of this toolkit should ideally be distributed more so that more designers can find this toolkit. The website should be designed in a way to make the user manual more visible. It is important for the users to know about the existence of the user manual before they decide to use it or not. Based on this insight, the “User manual” button was added to the top of the home page (of the toolkit website). Since the toolkit was under development in the first half of the Advanced Concept Design course, it was provided to the students at a later stage. In future use, the toolkit should be introduced to users at the beginning of the design process. The toolkit is currently digital, and not all parts are printer-friendly. A printer-friendly version of the toolkit will be created so that it can be printed with an A4 format by users themselves. This

will help not only designers but also other people who would like to be involved (e.g., PwD, care team, families).

- **Comparisons with state-of-the-art toolkits**

To triangulate with the preliminary evaluation of the Know-me toolkit by the student projects, we compared the Know-me toolkit with similar state-of-the-art toolkits on design for dementia care. This offers another basis for us to discuss the strengths and weaknesses of the Know-me toolkit. Specifically, the Know-me toolkit was compared with the toolkits developed by the MinD project and the LAUGH project (introduced in Chapter 1) in a feature-by-feature manner (Table 3).

From Table 3, the main strengths of the Know-me toolkit are the explicit involvement of healthcare professionals as co-designers in the design process, the added component in the Data-enabled Design, and the usage of layered design in some of the tools that can interact with users in the digital format. The tools that adopted the layered design are the co-design guide and data exploration guide. In comparison to the evaluation findings earlier, the students did not comment explicitly on the interactivity of some of the tools, yet some students indicated that the capability card set would be easier to use if it had a layered design. The weaknesses of the Know-me toolkit are that: it is less visible on search engines (i.e., Google), and not all components of the toolkit can be printed easily. These weaknesses are the areas for improvement of the Know-me toolkit in the future, which also coincide with the feedback by the students. We think the tension between “layered design” and “printer-friendliness” could be solved by developing two versions of the Know-me toolkit: one version is interactive with layered design; the other version is printer-friendly. The users can choose which version they prefer during the design process.

Table 3. Feature-by-feature comparison of the Know-me toolkit with similar state-of-the-art toolkits on design for dementia care

Features	Know-me toolkit	Toolkit by MinD	Toolkit by LAUGH
Target users	Designers and healthcare professionals	Designers	Designers
Components	Ergonomics in Ageing; Co-design; Data-enabled Design	Ergonomics in Ageing; Co-design;	Ergonomics in Ageing; Co-design;
Design goal	Personalised design	Generic design	Personalised design
Stages of dementia that are applicable	All stages	All stages	Moderate to late stages
Design examples on how to use the toolkit	Design examples available online (no design examples were available when evaluating with the students)	Design examples available online	Design examples available online
Format	Cards, interactive tools, canvas	Cards, canvas	Booklet
Detailedness of instructions	Step-by-step instructions	Step-by-step instructions	Only design elements are explained
Interactivity and layered design	Some tools are interactive digitally with a layered design	None of the tools is interactive digitally or with layered design	None of the tools is interactive digitally or with layered design
Accessibility	Does not yet appear on the first page of Google search with the search term "design toolkit dementia"	Appears on the first page of Google search with the search term "design toolkit dementia"	Appears on the first page of Google search with the search term "design toolkit dementia"
Hardcopy availability	The interactive tools cannot be easily printed	Can be easily printed	Can be easily printed
User manual availability	Available on the website (was not as visible when evaluating with the students)	The rationale of each tool is explained on the website	No user manual
Design stages that are applicable	For the whole design process (introduced the toolkit at a later stage when evaluating with the students)	For the whole design process	For the whole design process

Limitations

The author is aware of the selection bias in this study. Specifically, the students involved have relatively homogenous education backgrounds. In addition, the toolkit was introduced to the students at a later stage, so the students were not able to apply the toolkit in the whole design process in order to evaluate it. Moreover, the answers of the students to the open questions were short in the questionnaire, mostly about 1 to 2 sentences. Considering the students have other study activities to finish, the author only followed up on the answers which were ambiguous and received enough clarifications for the data analysis. Not being able to interact with PwD directly is another limitation of this evaluation study. Since this caused some tools in the toolkit to be used less than others by the students (e.g., co-design guide) due to a lack of direct contact with PwD, however, it is ethical to prioritise the health of PwD during the pandemic. Triangulating the feedback of the students by a comparison of the Know-me toolkit with similar state-

of-the-art toolkits on design for dementia care, i.e., toolkits by LAUGH and MinD, helps with improving the validity and reliability of our findings.

Future work

The Know-me toolkit will first be improved based on the findings of this study and be evaluated again when it is possible to visit nursing homes. During the next evaluation round, a few research activities could be done to address some limitations mentioned above. First, designers with varied educational backgrounds and working experiences should be recruited to design for personalised dementia care with the Know-me toolkit. Secondly, a few workshops could be organised along the design process to help the designers reflect on how they have used the toolkit, which might result in richer information with less recall bias. The care teams should also be involved to give their feedback on the usefulness and desired improvements of the toolkit.

The Know-me toolkit was initially developed for designers to co-design with healthcare professionals, and the evaluation study found that it was quick and easy to adapt the language and format of some parts of the toolkit to let the care team use it by themselves. This opens up the opportunities provided by the toolkit further: 1) What insights, if any, could be gained by the care team when using the toolkit by themselves? 2) What actions, if any, could the care team take based on these insights? Any actions that can change the current living situations of PwD into preferred ones is regarded as a design activity (Chapter 1). Can healthcare professionals be empowered by the toolkit to design for personalised dementia care? To answer this question, a thorough evaluation of the adapted Know-me toolkit should be conducted with the care team beforehand in the future.

8.5 CONCLUSION

In this paper, we showcased Know-me, a toolkit for designing personalised dementia care. We envisaged that designers would co-design with healthcare professionals using the Know-me toolkit to support designing for personalised dementia care. Via evaluating this toolkit, we identified that Know-me could be adapted flexibly in a way that healthcare professionals can use some of the tools by themselves. Together with a feature-by-feature comparison of the Know-me toolkit with similar state-of-the-art toolkits, this preliminary study indicates that the Know-me toolkit is a helpful addition to the current pool of toolkits on designing for dementia care and worth to be developed and evaluated further.

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9



Discussion and future work

This last chapter summarises and reflects on the research approach and outcomes of this doctorate and returns to the main research question introduced at the beginning of the thesis:

What are the design approaches, recommendations, and tools that could facilitate personalised dementia care?

In this chapter, the author first discusses the contributions of the three design approaches from Human-Centered Design (i.e., Ergonomics in Ageing, Co-design and Data-enabled Design) in the context of personalising BPSD care in the nursing home setting and of personalising dementia care in general. To do so, she captures the most important insights obtained from each design approach with reference to the Need-driven Dementia-comprised Behaviour (NDB) model (introduced in Chapter 1). She thereafter highlights their implications in practice by illustrating how the Know-me toolkit could expand the current landscape of designing for personalised dementia care. After that, she reflects on the doctorate in terms of the research approach and general limitations. Lastly, she presents future directions and opportunities for disseminating, evaluating and extending the knowledge generated in this doctorate for designing personalised dementia care.

9.1 REFLECTIONS ON THE THREE DESIGN APPROACHES

Referring back to the preliminary answer from Human-Centered Design (HCD) on personalising dementia care (Chapter 1), the three design approaches (i.e., Ergonomics in Ageing, Co-design and Data-enabled Design) were selected to be investigated in this doctorate owing to the potential insights they might generate for the NDB model. Each design approach offers a unique perspective on personalising dementia care; thus, it is worth finding the synergy of these three design approaches. This doctorate shows a way to integrate these three design approaches into a design toolkit for personalising dementia care. As mentioned in Chapter 1, a design approach describes ways for how to go about a design activity and offers a comprehensive process across design phases [1]. These three design approaches not only have implications for many aspects of the design process but also for ways of working and for the mindset of the designers. The author deliberately chose not to develop a specific action plan in which professional designers and healthcare professionals are expected to follow but developed a toolkit that offers them a scope and hands-on tools to get started with designing for personalised dementia care; this also allows professional designers and healthcare professionals to make their contexts, own ideas and skills part of the design process.

Ergonomics in Ageing

Researchers in Ergonomics in Ageing have been studying the capabilities of older adults to design products and environments that help with their autonomy [2]. Even though traditionally, it is not focused on a particular human being, it offers an instrumental lens for designing personalised dementia care. The author found that reframing “what an older adult is not able to do” into “the remaining capabilities of the older adult” could inspire creativity in the design process, which coincides with previous findings [3]. Since this is an exact question, it can open up possible directions for a personalised design.

Even though not all PwD are older adults (over the age of 65), and there are capability changes due to dementia that is different from normal ageing, as ergonomics studies on PwD are lacking at the start of this doctorate, the literature in “Ergonomics in Aging” offers a solid starting point in considering the capabilities in the majority of PwD. In addition, this design approach could make designers and healthcare professionals aware of what types of remaining capabilities a person with dementia might have by providing a structured overview of the capabilities (i.e., sensory-, cognition-, and movement-oriented capabilities). This allows for a comprehensive view of the capabilities of a person with dementia, which is crucial when designing for personalised dementia care.

The recommendation list on capability considerations (Chapter 3) generated in this doctorate is not all-encompassing. For example, while this doctorate was underway,

some researchers have investigated how the cognitive decline in dementia could affect the environmental visual literacy of PwD and have formulated design guidelines on colour use in care environments [4]. Besides, intuitive interaction research, a field on non-conscious interface interactions, has found that physical affordance can make interfaces more intuitive for PwD [5]. This research on intuitive interaction research has informed the design of an interactive device for PwD to help with their social engagement [6]. In general, the body of work that applies the ergonomics approach in dementia care and design has been increasing. Moreover, more insights from practice could provide valuable feedback to this recommendation list. The author has evaluated and refined this recommendation list in a field study (Chapter 5), and this updated list should be evaluated in different contexts in the future.

Another finding from Ergonomics in Ageing is that the age-related capability differences between two older adults are usually bigger than that between two younger adults, and thus it is vital to pay attention to individual capability differences among PwD during the design process (Chapter 3). This ergonomics approach is vital in designing for personalised BPSD care and personalised dementia care in general since meeting the remaining capabilities of the person is the prerequisite for a design to be usable. Meanwhile, the rate of capability decline is faster in older adults than in young adults, and this rate also varies from person to person and with the progression of dementia, so it is key to keep track of the capability levels of PwD regularly (Chapter 3). In this way, the designs could be timely adapted to suit one's changing remaining capabilities.

Co-design

Co-design has been increasingly adopted in HCD as an approach for designers to engage directly with users [7]. In the context of dementia care, the author found that co-design needs to be conducted with careful consideration and preparation. This is because articulation and abstract thinking are usually required for traditional co-design sessions, while PwD might not be able to express their opinions and imagine the future due to their cognitive decline. In addition, they are most of the time emotionally and physically fragile; and the care burden of caregivers is high, so they have limited time to contribute to the process.

The scoping review (Chapter 4) has uncovered that there is a growing body of work on co-designing with PwD, and a recommendation list was developed by summarising the considerations and preparations used in these studies. An increasing number of studies have also started to explore co-designing with people in the moderate to late stages of dementia. This trend is influenced by Person-Centred Care; that is, acknowledging PwD can express themselves with non-verbal behaviours, and BPSD could be a way for them to express their unmet needs. The author then evaluated this recommendation list by co-designing with PwD (in the moderate to late stages) in the field study (Chapter 5);

this is because PwD exhibiting BPSD symptoms in the nursing home are usually in the moderate to late stages of dementia. The professional caregivers in the collaborating nursing home were invited to the co-design sessions since they are involved intensively in the care of the residents. The insights generated helped the author to evaluate and refine the recommendation list further.

The recommendations generated in this doctorate offer a preliminary overview of how to organise a co-design session with PwD. While this doctorate was underway, several researchers elsewhere developed knowledge on how to co-design with people in the moderate and late stages of dementia along the same line: specifically, around open-mindedness, compassion, sensorial-orientation, and capability considerations.

For instance, Kenning has developed a reciprocal design approach where the co-design session was planned in a way that participating by itself was beneficial for PwD and their caregivers [8]. This is an ethical act since if PwD cannot envision the long-term benefit of the design anymore, they can still have an in-the-moment joy when participating in the session. Hendriks and colleagues started from a universal approach to find a set of tools and techniques to involve PwD, and they found out that a more individualised way of working is needed, and a personal relationship between the person with dementia and the designer is crucial for the success of the design [9]. Treadaway and colleagues have been exploring how to stimulate the implicit memories of PwD through senses since implicit memories such as emotional and procedural memories can be retained in the moderate to late stages of dementia [10]. These memories make each person unique even when the explicit memories are faded away. In the same direction, Kenning conducted a co-design session in which each participant was given a personalised fiddle bag [8]. Each bag contained multi-sensorial objects that had been tailored to each person. The researchers observed the actions of the participants, assessed the likes and dislikes of each person towards the objects in his/her bag, and stimulated interactions and laughter.

The author is aware that some studies were also conducted in exploring how to co-design with PwD as a group. For example, Branco and colleagues expanded on the ten types of person-centred interactions with PwD into ten insight cards on how to co-design with PwD in general [11]. Fennell found that reflection-in-action, embracing uncertainty, and appropriate language use are important for designers to co-design well with PwD [12].

In summary, the involvement of PwD in the design process has become more person-centred, and most of the time, more personalised. The recommendations on co-design (Chapter 4) and the co-design guide (Chapter 8) generated from this doctorate are generic and emphasise the flexibility that designers can use to adapt them in different

contexts and with different participants. The author argues that the amount of time and attention the designers invest in each person during the co-design process makes co-designing an indispensable part of the process for designing personalised dementia care. This will then contribute to Person-Centred Care for PwD.

Data-enabled Design

Since “Data-enabled Design” was coined by Bogers and van Kollenburg in 2016 [13], this design approach has increasingly been applied in practice along with the development of IoT, Artificial Intelligence (AI) and big data. In this design approach, both quantitative data collected by sensors and qualitative data collected by users are used as creative materials to inspire designers (Chapter 1). In applying Data-enabled Design for personalising BPSD care, the author found that analysing qualitative and quantitative data together are insightful for both the designers and the care team (Chapter 6). Hence the author adopted a modified version of Data-enabled Design based on the goal and context of this doctorate. First, guided by the “participatory data analysis” approach [14], the author involved the care team in the data analysis phase more closely than that in the original Data-enabled Design approach, and this is because the tacit knowledge within the care team about the residents in the ward and their BPSD is easier to be uncovered in data analysis than in interviews or co-design workshops. This tacit knowledge is so valuable that the care team frequently discovered more insights than the author during participatory data analysis.

The findings during the development of the Data-care digital platform centre at the different kinds of synergies between quantitative and qualitative data (Chapter 6). For example, the author found that the qualitative data helps with contextualising the quantitative data, and the stories people tell based on the quantitative data enrich the qualitative data, which coincides with the findings of Bogers and van Kollenburg [13]. In addition to what has been found by Bogers and van Kollenburg, the author identified a few more synergies between quantitative and qualitative data in the dementia care context (Chapter 6). For instance, the caregivers indicated that they would like to see the quantitative data collected before writing their reports, and these reports are used as qualitative data for the research. This implies that the caregivers find the quantitative data collected by sensors could help them improve the quality of their reports (the qualitative data). Within the care team, quantitative data is perceived as more objective than qualitative data and being objective is regarded as better than being subjective. This perception is insightful for the author. It is worth mentioning that although analysing quantitative data is a subjective process, the caregivers find it is reassuring to compare their subjective feelings with the collected quantitative data when reporting their findings to other members of the care team. To some extent, the quantitative data collected improves the quality of the qualitative data collected. More types of synergies between qualitative and quantitative data can be found in Chapter 6.

Another modification of the Data-enabled Design the author made is to make use of the data that the care team has been collecting as much as possible before devising new data collection tasks for the team (Chapter 6). This is because, in the dementia care context, the care team has already had a high workload. Daily reports, care plans, discussion notes are the carriers of the qualitative data in this research. The reasons behind using these documents are that these documents have almost covered all the relevant contextual information, and they are produced as part of the working routine of the care team. Due to the heavy workload of the care team, the author aimed to minimise the conscious efforts of the care team at the data collection stage. The only additional tasks that caregivers had were to distribute tags to the residents and give a stress rating for each resident. Throughout the research, the number of mistakes in these tasks (e.g., forgetting the tags, distributing the tag to the wrong person, forgetting the stress rating) was reduced but still existed (Chapter 7). The caregivers reflected that their busy working schedule made them forget about these tasks sometimes or carry out these tasks hastily. These data collection tasks could be refined to be more intuitive for caregivers in the future, and one can imagine that the cases of incorrect use might increase if more data collection tasks were asked of the caregivers.

This modified Data-enabled Design approach also reflects the value of care personalisation. First, regarding what types of data to be collected, it has been found that this varies from person to person (Chapter 6). For a resident who is immobile, the “walking distance” parameter is not relevant; yet the “duration of stay in each room” could be insightful if one is usually sent to the bedroom when agitated. This is because the bedroom has fewer stimuli than the outside, and agitation is usually regarded as a result of over-stimulation, according to the care team. In addition, the duration and frequency of data that need to be collected vary from person to person. Moreover, who analyses the data is critical. In the Oleander, each resident has a responsible caregiver and shares the same doctor, psychologist, and dietitian. Since the responsible caregiver of a resident knows the most about this resident compared to other caregivers, it is most insightful and effective to involve the responsible caregiver of each resident in data analysis. Moreover, quantitative data allows for not only a detailed but also a long-term perspective into the behavioural patterns and daily routines of PwD. This type of data can be collected unobtrusively and continuously, thus could generate insights into the behaviours of each resident that the care team are not yet aware of.

Care personalisation is only a facet of Data-enabled Design. Bogers and van Kollenburg argue that insights at both the personal and contextual level could be obtained with this design approach [13], which is further ascertained in this doctorate. During data analysis, in addition to personal insights, the care team generated insights on the ward level (e.g., dining environment) and team level (e.g., the workflow of caregivers). The insights at the team and ward level feed into the context (physical and social

environment) in which a person with dementia is in (Chapter 7). Referring to the NDB model, the context is also an important aspect to be understood when designing for personalised dementia care.

The author is aware that Data-enabled Design is first developed as an approach for designing intelligent ecosystems. The term ecosystems refer to compositions of interrelated products, services and people, the relationships among which are dynamically formed and evolve over time [15]. “Intelligent” implies that the ecosystems can learn about the users and contexts over time and adapt their interactions with the users based on contexts accordingly. This is especially instrumental for dementia care since the progression of dementia varies from person to person, and it is critical to provide up-to-date care to PwD for their well-being. Yet, the heavy burden of dementia care could lead to some changes in the person (e.g., physical, psychological, or cognitive aspect) being overlooked. The Data-care digital platform developed (Chapter 6 and 7) serves the purpose of providing timely insights to the care team for personalised BPSD care; however, it is only a starting point towards an intelligent ecosystem for personalised dementia care. At the moment, the author and the care team are acting as the main part of the intelligent ecosystem: some parts of the data are collected manually, the data are visualised and analysed manually, and all the actions that are taken (based on the insights) manually (Chapter 7). Products and services could be developed in the future to add to this intelligent ecosystem to make this process more autonomous and efficient. The learnings from applying Data-enabled Design in personalising BPSD care and the data exploration guide developed (Chapter 8) during this doctorate could inspire future researchers in developing this intelligent ecosystem further.

9.2 RELATIONSHIPS BETWEEN THE THREE DESIGN APPROACHES

The three design approaches explored in personalising BPSD care are interconnected rather than isolated. A tentative overview of their interrelations is shown in Figure 1, where designing for personalised dementia care sits at the intersection of these three approaches. The insights obtained from these three approaches feed into each other, and these insights mutually influence one another. In addition, they complement each other since they offer different perspectives to look at personalised dementia care.

To illustrate, it is sometimes difficult to evaluate the capabilities of a person with dementia according to the methods in Ergonomics in Ageing. Since these methods requires the participants to actively communicate their sensory, cognitive and movement experiences, and PwD may have difficulty with this. By co-designing with them, designers will be able to uncover the remaining capabilities of each person with

dementia through interactions, observations, and reflections. In turn, the literature from Ergonomics in Ageing could prepare the designers for the co-design sessions. For example, the designers will be more aware of possible capability differences among PwD when organising and conducting co-design sessions.

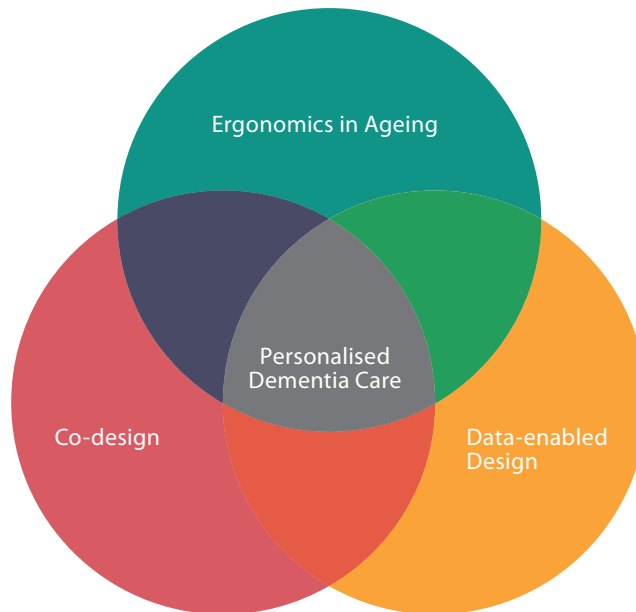


Figure 1. The relationships between the three design approaches and design for personalised dementia care.

These identified differences in capabilities and preferences among PwD from Ergonomics in Ageing and Co-design also shed light on Data-enabled Design. Specifically, the designers could have a sense about what types of data should be collected, how often and for how long, for the insights generated to be helpful for each person. These variations in the data collection phase for each person with dementia could then affect data visualisation and analysis later on (Chapter 7). This means that the collection, visualisation, and analysis of the data are personalised for each person to some extent. The insights generated from data analysis could, in turn, reveal the current capabilities and preferences of the person with dementia. For instance, a decline in the daily walking distance could reflect the mobility of the person decreases; a longer duration of stay in the bedroom could indicate the person finds staying in the bedroom more comfortable. Indeed, staying longer in one's room does not necessarily mean the person prefers this room to other places. The qualitative data (e.g., daily reports) are needed to identify a possible explanation (e.g., whether the person prefers staying in the bedroom or there might be a medical reason for the person to be in the bedroom). If there is no recorded qualitative data that can explain this, the care team could set up an investigation by starting to record relevant quantitative and qualitative data.

Together, these three design approaches can help designers to gain insights into the proximal and background factors that contribute to BPSD, as mentioned in the NDB model (Chapter 1). In this way, the BPSD exhibited by each person with dementia will be managed in a person-centred manner. The author emphasises that the understanding gained about each person with dementia using a combination of these design approaches is never all-encompassing. Only a limited part of the richness, complexity and versatility of the person and the context s/he lives in are revealed. That being said, in comparison to previous studies on dementia care, this combined approach has uncovered many more individual insights. The author argues that these insights are sufficient to offer a starting point to design for personalised dementia care. While applying these design approaches in the design process, the privacy of PwD and their caregivers should be respected, and one should apply these design approaches only to generate insights that contribute to the well-being of PwD.

All three design approaches direct the designers and healthcare professionals to give personal attention to each person with dementia, which enables them to gain a highly detailed and nuanced understanding of each person and the interpersonal differences among PwD. Together, Ergonomics in Ageing, Co-design and Data-enabled Design form the three pillars for designing personalised dementia care, based on which the toolkit Know-me was developed. The envisioned value of the Know-me toolkit in personalising dementia care will be discussed in the next section.

9.3 ENVISIONED VALUE OF THE KNOW-ME TOOLKIT IN PERSONALISING DEMENTIA CARE

The Know-me toolkit is envisaged to contribute to the opportunities identified in the current landscape of designing personalised dementia care. Applying this toolkit will lead to an expansion of the current landscape, which will be explained in detail below. The identified opportunities can be found in Chapter 8. An illustration of the expanded landscape is shown in Figure 2.

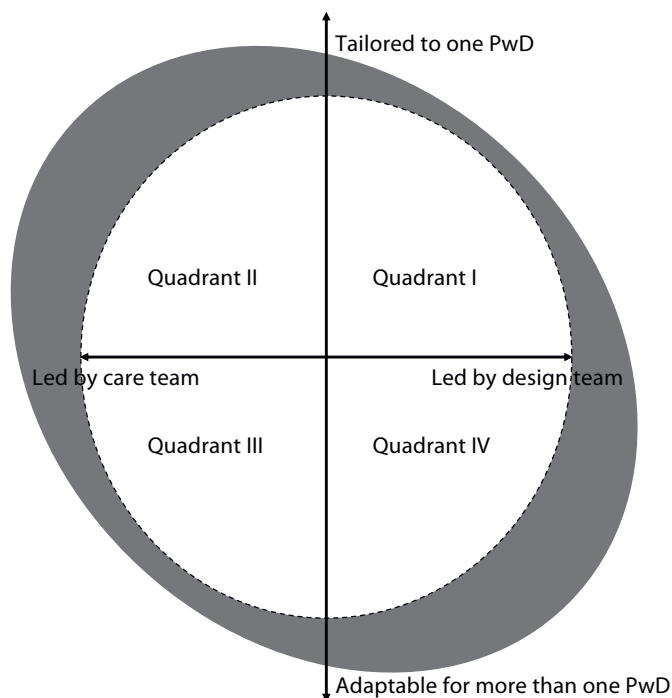


Figure 2. The expanded landscape of designing for personalised dementia care (the grey areas indicate the expansions, where the expansions of Quadrant II and IV are envisioned to be larger than that of Quadrant I and III).

- **Quadrant I**

The opportunity identified in Quadrant I is on how to encourage more designers to design for personalised dementia care that is “tailored to one PwD”.

The Know-me toolkit can be used in design education to encourage more designers to design for personalised dementia care that is “tailored to one PwD”. The author plans to partner with educational institutions and non-profit organisations to reach out to people who would like to contribute to personalising dementia care. Anyone interested in helping PwD could sign up, and they will then learn about the toolkit, build on their design skills, and help a person with dementia around them. This type of learning programme for personalised design has a successful precedent. Fixperts is a learning programme that challenges young people to use their creativity and skills to solve everyday problems for a real person; it has delivered more than 400 projects since it was established in 2016 [16]. The outcome of a Fixperts project is a personalised design for a specific person. A Fixperts project offers students the opportunity to solve problems taken from the world around them and work in teams to research and develop solutions, sketch out ideas, model prototypes, and make a final product. Similarly, via applying the Know-me toolkit in a real-life context, the students will develop a host of valuable transferable skills from empathy to collaboration.

- **Quadrant II**

The opportunity identified in Quadrant II is on how to provide a systematic approach for healthcare professionals to design for personalised dementia that is “tailored to one PwD” within their workload limit.

The Know-me toolkit can be used by the care team to design personalised dementia care that is “tailored to one PwD” within their workload limit. The author acknowledges that some healthcare professionals are creative and resourceful without the help of the toolkit; however, the channels for sharing their tips and tricks are limited. This toolkit offers a systematic creative approach for any healthcare professionals to create personalised designs for PwD. This toolkit has been shown to be flexible and can be adapted to the care team, who usually do not have training in design (Chapter 8). Besides, it can be used individually or within a team. The current training courses and protocols of Person-Centred Care for healthcare professionals are helpful yet lengthy and of a prescriptive tone. The Know-me toolkit offers hands-on guidance for the care team to reflect and act. In an engaging and user-friendly manner, it presents that personalised design is a way towards Person-Centred Care and shows what elements could help with the personalised design. It is also easily accessible and encourages one to approach personalising dementia care in a creative way. Via reflecting, gathering information, writing and drawing, the care team could reach some insights and design ideas that are specific to a person with dementia that cannot be found in the generic guidelines and protocols. The Know-me toolkit could thus be a hands-on systematic augmentation of the current training courses and protocols for healthcare professionals to deliver Person-Centred Care. This doctorate has shown that a tailored design for PwD could be simple yet effective (see Appendix B for some examples). In addition, powerful and low-cost prototyping tools such as 3D-printers and laser cutters have become more accessible to the public than before. Therefore, design for personalised dementia care is not limited to the available time and resource of professional designers anymore.

- **Quadrant III**

The opportunity identified in Quadrant III is on how to help healthcare professionals to find more ways to design for personalised dementia care that is “adaptable to more than one PwD” within their workload limit.

The Know-me toolkit can be used by the care team for finding more ways to design for personalised dementia care that is “adaptable to more than one PwD”. Specifically, with the development of IoT, AI and big data, more tools for collecting, exploring, and analysing data will be available to the care team. The care team can apply these technologies for understanding each person with dementia more comprehensively during their care practice. Take AI as an example; it can discover interesting patterns and predict coming events automatically. Healthcare professionals might consider

including AI as a partner to facilitate them in personalising dementia care. Despite the convenience and power offered by these technologies, the ethical issues that come with them should be addressed in advance. The Know-me toolkit could guide healthcare professionals to reflect on their work, and to be aware of the personhood of PwD, so as to help them make ethical decisions when working with these technologies.

- **Quadrant IV**

The opportunity identified in Quadrant IV is on how to help designers to find more ways to design for personalised dementia care that is “adaptable to more than one PwD” in an autonomous way.

The toolkit can be used by the design team to develop intelligent agents that can “adapt to more than one PwD” in an autonomous way. This prediction is also supported by recent developments in technology. Thanks to IoT, big data and AI, designers can develop intelligent agents that can adapt and learn new things over time [17]. These intelligent agents could dynamically fit with the needs of a person with dementia over time which can enable a continuum of personalised care, hence contributing to the quality of life of PwD and their caregivers. Besides, these intelligent agents could be context-aware when they receive proper and correct inputs. Specifically, it can adapt its interactions with people based on with whom it interacts, the time of the day, as well as the physical and social environment. In this way, the care team are supported in the process of personalising dementia care. The care team will not be replaced by intelligent agents; rather, they still play their role in personalising dementia care by deciding when and to whom the intelligent agents should be introduced, among other tasks. The Know-me toolkit offers guidance to future designers and technology developers in shaping these intelligent agents. For example, it inspires designers to reflect on what data to be collected to train the algorithms and what metrics to look for when evaluating the intelligent agents. Most importantly, by guiding the designers and developers to co-design with PwD, this toolkit will ensure PwD to be approached as persons instead of data source for intelligent agents.

9.4 REFLECTIONS ON THE RESEARCH APPROACH

The author adopted a Research through Design (RtD) approach in this doctorate (Chapter 1). In summary, she started with the main research question and evaluated this research question at each stage of the research process to generate detailed sub research questions that are relevant to each stage. The knowledge gained from the literature and from the field fed into the development of two prototypes: De-light (Chapter 5) and Data-care (Chapter 6). In turn, these prototypes helped the author to answer the research questions. More details about the RtD process and the limitations of this doctorate are outlined below.

The author first reviewed the literature on non-pharmacological interventions for BPSD management to identify opportunities for improvement in this field (Chapter 2). The author emphasised that this review is done with an ergonomics perspective so as to distinguish it from traditional systematic reviews focusing on the clinical evidence of the non-pharmacological interventions. The author explored whether the capabilities of PwD were considered during the design and implementation of these interventions. These considerations were found to be limited, which led the author to review the literature on Ergonomics in Ageing (Chapter 3). The systematic review of non-pharmacological interventions also highlighted that the active involvement of PwD is lacking in developing these interventions. In this light, the author reviewed the literature from design research to learn how PwD have been involved as partners in the design process (Chapter 4).

In the next stage, the author applied the learnings from Ergonomics in Ageing and Co-design in developing the De-light prototype; in this way, the recommendations generated from desktop research were evaluated in the field (Chapter 5). During the development of De-light, the care team indicated that they would like to keep track of the needs of each resident for delivering more personalised BPSD care. This led to the development of the Data-care digital platform prototype guided by the Data-enabled Design approach (Chapter 6). During this process, new knowledge about the application of Data-enabled Design, which is more context-dependent, was generated. The Data-care digital platform prototype has been updated in a few iterations based on the knowledge gained over time (Chapter 6).

The intention at the final stage was to integrate the three design approaches by combining De-light with Data-care in the nursing home so as to develop a design that can facilitate personalised Snoezelen therapy for PwD exhibiting BPSD symptoms. The author planned to personalise the De-light according to the capabilities and preferences of each person with dementia as monitored by the Data-care digital platform. The author envisioned the De-light could be an intelligent agent that can learn about each PwD and the context and adapt its behaviour (e.g., voice feedback, light feedback) based on with whom it is interacting, its surroundings and time.

However, due to the COVID-19 pandemic, the author was not able to install the De-light in the nursing home. After consultation with the supervisory team and the nursing home, the author shifted the focus to evaluating Data-care in the nursing home for a longer period of time. From this evaluation, more insights about applying Data-enabled Design in personalising BPSD care were generated (Chapter 7). The author then developed and evaluated the Know-me toolkit combining the three design approaches (i.e., Ergonomics in Ageing, Co-design, Data-enabled Design) for designing personalised dementia care. Interestingly, this workaround contributed to the challenge of how to

gain insights about PwD remotely (Chapter 7), which could be of value in the current and in future pandemics.

Regarding general limitations, the author was not able to develop the De-light further due to the COVID-19 pandemic. Besides, this doctorate was mainly carried out in one nursing home in the Netherlands as a typical case with given time and budget constraints. Whether the Oleander offers a typical setting in BPSD care varies across organisations and countries. This could limit the transferability of the results. Being able to evaluate the Know-me toolkit within the context of the RespectZorg nursing home (Chapter 8) increases the transferability of the research findings. Since the management and organisational culture for dementia care could vary among nursing homes (e.g., the resident to caregiver ratio, the vision of the nursing home, the training received by the caregivers), applying the Know-me toolkit in more dementia care contexts would increase the transferability of the research outcomes further. Besides, the experiences of PwD and the care team may be different when outside the Netherlands. Since the majority of participants have a similar cultural background (native Dutch), this might restrict the knowledge to be transferred across cultures. For example, in some other cultures, the physical well-being of PwD is valued more than their emotional well-being. As for the credibility of the results, in all qualitative studies carried out in this project, there are possible recall biases of participants despite the use of quantitative data as triggers for the discussions, which has been acknowledged in previous doctoral research [18].

In summary, this doctorate generated knowledge on how to personalise dementia care with HCD approaches in the context of institutional BPSD care on multiple levels of abstraction (approaches, recommendations, and tools). The knowledge presented on multiple levels of abstraction has been found to be helpful in the design process [19]. The three design approaches and their interrelations provide more abstract guidance, while the Know-me toolkit offers more concrete design directions within the solution space. The combination of abstract and concrete knowledge makes designing for personalised dementia care more actionable for designers and healthcare professionals while allowing for flexibility. Their learnings from using the toolkit could then inform the further development of the toolkit itself and the more abstract knowledge associated with it.

9.5 FUTURE WORK

In this section, the author lists the opportunities for future work on developing the knowledge gained in this doctorate and the Know-me toolkit. These opportunities are divided into three parts, which are dissemination, evaluation and extension.

Dissemination

Throughout the research, the author has been to several conferences and nursing homes to disseminate and discuss her work. In the meantime, she wrote blogs, attended podcasts and created videos online to enable her work to reach a wider audience. The toolkit developed in this doctorate (and the website associated with it) also communicate with designers and healthcare professionals about how to design for personalised dementia care. Moreover, with this dissertation, the author sets out to inspire and guide more design researchers on exploring how to facilitate personalised dementia care with design.

In the near future, the author aims to further disseminate this work to academia and to the healthcare and design practice communities in the approaches mentioned above. The author would like to inform management teams in nursing homes that “personalising dementia care” is one aspect that should always be considered during decision making. It is ethical and desirable to design for personalised dementia care since each person with dementia is unique and personalising dementia care is the core of Person-Centred Care for PwD; it is also increasingly feasible and viable to do so thanks to the development of IoT, AI and big data. Last but not least, disseminating methods and tools (such as in this thesis) for personalised dementia care could make the personalisation process more efficient and engaging than before.

Evaluation

The field studies conducted in this doctorate have led to the generation of insights, exemplary prototypes and tools from a methodological perspective. Yet, the outcomes are still in their early phases and have not been tested with large user groups. Even though the usefulness of the Know-me toolkit offers a reasonable indication about the value of the three design approaches in personalising dementia care, more designs should be developed with this toolkit, and whether these designs contribute to Person-Centred Care for PwD should be evaluated. This evaluation would verify the usefulness of the toolkit, hence a justification of the knowledge gained in this doctorate and thereby a contribution to the value of dissemination.

At the time of writing, the author is mentoring two Master graduation projects where the students are applying the toolkit on personalising dementia care (in the Netherlands and in China, respectively). The feedback of both students will be gathered, their design concepts will be evaluated, and the author will observe some of their design activities to see how the students are using the toolkit.

The advance in technology and learnings from Data-enabled Design also allow future design concepts to be evaluated remotely. The author found that the presence of the researchers in the field could affect the evaluation. For instance, when the researchers

are in the ward, the caregivers might be more aware of the introduced intervention by the researchers and offer it to PwD more often; and PwD might become agitated when they see the researchers as strangers in the ward. A myriad of sensors can keep track of the times when and for how long a design intervention is introduced to the resident by the caregiver when the designers are not there, and if there are any changes in the behaviours of the resident after the design is introduced. The author acknowledges that not all effects of the designs could be captured by sensors currently, and ethical issues need to be addressed in advance. This emphasises the value of qualitative data in contextualising the quantitative data. The designers can triangulate the feedback from the caregivers together with the data collected by sensors to evaluate the effect of the designs on the residents more accurately. This is because caregivers have to take care of several residents in nursing homes at a given time; thus, it is difficult for them to focus on the change in behaviours of each resident over time. Besides, as mentioned before, human memory could be influenced by a variety of factors, fade quickly and not be good at details [20] (Chapter 6). Therefore, this Data-enabled Design approach could lead to a less biased evaluation of the design outcomes.

Extension

The author aims to regularly update the Know-me toolkit along with the developments in the fields of Ergonomics in Ageing, Co-design and Data-enabled Design. As discussed before, while this doctorate was ongoing, more knowledge has been generated in these fields. For Ergonomics in Ageing, some researchers started to explore the capability differences between PwD and healthy older adults [4]. Regarding Co-design, researchers began to wonder how such an individual way of working for designers could be adapted for a larger user group, and the associated ethical issues were aimed to be explored (e.g., how deep should a designer step into the relationship with PwD) [9]. As for Data-enabled Design, the technological landscape has changed significantly while this research was underway. Many IoT devices can store the data over a longer period of time, and more powerful algorithms have been developed with lower cost for data analysis. These advancements enable the long-term evaluation of a design. This long-term evaluation is important because a design that is effective for a week might not be effective in the long term. One reason is that dementia is progressive in nature, which implies the preferences and symptoms of the person with dementia might change over time. In the field visits, the author has noticed some design products are left unused in the nursing homes for this reason (Chapter 1). Therefore, it is important to avoid the illusion of first-time use, and the products and services should be timely updated based on the insights generated from both quantitative and qualitative data. The intelligent agents, who can learn and adapt to the interaction preferences of PwD over time, could contribute to this solution space too. Along with the development of technology, the know-me toolkit could be expanded to offer more guidance to the design team on developing these intelligent agents.

The author also envisions that the accessibility of the Know-me toolkit could be expanded to the general public (e.g., family members of PwD). In this way, she hypothesises that more people will be able to help with developing personalised designs for PwD. This is because the Know-me toolkit has been found to be easily adaptable to the care team – who usually do not have training in design (Chapter 8). Evaluation studies with these user groups should also be carried out in the future to evaluate this hypothesis. After adequate evaluations and adaptations, the author endeavours to embed this toolkit into the websites of non-profit organisations for PwD and their caregivers (e.g., Alzheimer Nederland). In this way, more people in different contexts might be inspired to design for personalised dementia care. It is important to evaluate the Know-me toolkit in a wide range of contexts for generalising this toolkit and the knowledge associated with it. It would be insightful to see if the design outcomes vary in different contexts and what users have done to adapt the toolkit to different contexts.

9.6 CONCLUSION

In this thesis, coming from a Person-Centred Care perspective, the author has described the exploration process of designing for personalised dementia care with three design approaches originated from HCD under the context of personalised BPSD care in nursing homes. The author is aware of the great new opportunities and responsibilities for future designers and healthcare professionals in designing for personalised dementia care. With the Know-me toolkit and the knowledge associated with it, this doctorate has laid a foundation for integrating Ergonomics in Ageing, Co-design and Data-enabled Design to expand the current landscape of designing for personalised dementia care.

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Summary

SUMMARY

Research context and main research question

In 2017, the World Health Organisation initiated the global action plan on public response to improve the physical, mental, and social wellbeing of people with dementia, their caregivers and families. This plan highlighted that the gap between the care needed by people with dementia and the care provided to them is wide. Around the 1990s, there was a movement in the field of dementia care, suggesting that people with dementia should be cared for in a person-centred manner. Specifically, as far as possible, people with dementia should be cared for in a way that takes into account their personality, life experiences and preferences. Personalisation is a key element in providing Person-Centred Care to people with dementia.

Yet, the approaches, recommendations and tools for personalising dementia care are limited. Therefore, this thesis investigated how this personalisation could be facilitated by design. Specifically, the author explored how to personalise the care for Behavioural and Psychosocial Symptoms of Dementia (BPSD). This is because BPSD contributes to the most stressful, complex, and costly aspects of dementia care. As dementia progresses, impairments of cognitive function are commonly accompanied and occasionally preceded by a deterioration in emotional control, social behaviour, or motivation, which adds an extra challenge and burden to dementia care. BPSD has also been identified as a predictor of nursing home placement. Non-pharmacological interventions for BPSD care have been developed, which offers ample room for personalisation.

Therefore, the author aimed to answer the below main research question within the context of designing for personalised BPSD care in nursing homes:

What are the design approaches, recommendations, and tools that could facilitate personalised dementia care?

In answering this research question, this thesis initially explored the field of healthcare and the field of design to form a preliminary answer. From the field of healthcare, the author drew on Person-Centred Care, and from there, she looked at BPSD from the lens of the Need-driven Dementia-compromised Behaviour (NDB) model, where BPSD is interpreted as a way for people with dementia to express their unmet needs. Factors contributing to BPSD have been categorised by this model, which could be unique for each person with dementia. From the field of design, she approached the research question from the lens of Human-Centered Design and explored three design approaches that are most relevant in designing for personalised BPSD care, namely, Ergonomics in Ageing, Co-design and Data-enabled Design. Specifically, the author

hypothesised that applying these three design approaches in an integrative way could reveal insights into the factors contributing to BPSD, as mentioned in the NDB model, for each person with dementia. She further hypothesised that gaining insights about these factors could facilitate the design of personalised dementia care.

Research approach and methods

The author implemented a series of steps in evaluating these hypotheses from the literature and from the field via a Research through Design (RtD) approach whereby “design activities play a formative role in the generation of knowledge”. The fieldwork was done in close collaboration with the Zorggroep Elde Maasduinen nursing home in Boxtel, the Netherlands. The facilitating technology was provided by PinXact company in Delft, the Netherlands.

In answering the main research question, the author draws on the strength of RtD as a reflective practice. Through reflecting on the insights gathered along the process, the direction of the project was adjusted iteratively and became more detailed. Therefore, starting from the main research question, the author evaluated this research question at each stage of the research process to generate detailed sub research questions that are relevant for each stage. A combination of research and design methods such as systematic review, scoping review, interviews, observations, questionnaires, document analysis, and prototyping were used to answer these sub research questions. The seven sub research questions and the findings associated with them are summarised below.

Sub research questions and their findings

[1] To start off the doctorate, the author first conducted a systematic review (Chapter 2) to explore the status quo of non-pharmacological interventions for BPSD management. She reviewed the studies from an ergonomics perspective to answer the below sub research question:

What are the current non-pharmacological interventions for BPSD management, and if (and how) they incorporated ergonomics?

This review reveals that a variety of non-pharmacological interventions have been developed for BPSD management, and they were categorised into sensory-, cognition-, and movement-oriented according to the main capabilities required for people with dementia to participate in them. It has also been found that the evidence of the effectiveness of these interventions is low, and the consideration of ergonomics in these interventions is insufficient, specifically in terms of capability considerations and the involvement of people with dementia in the design process.

- [2] Guided by the findings of the systematic review (Chapter 2), the author investigated the literature on Ergonomics in Ageing to explore how to personalise non-pharmacological interventions to fit the capabilities of each person with dementia (Chapter 3) with the sub research question:

If (and what) design recommendations for personalising non-pharmacological interventions for people with dementia could be generated from the literature on Ergonomics in Ageing?

A set of design recommendations on capability considerations for personalising non-pharmacological interventions were generated based on capabilities in the sensory, cognition and movement aspects as described in the Ergonomics in Ageing literature. Examples of how these design recommendations could be applied in personalising non-pharmacological interventions were then introduced.

- [3] The systematic review of non-pharmacological interventions for BPSD management (Chapter 2) also indicates that involving people with dementia as partners in the design process is a way for developing non-pharmacological interventions that meet their needs. To get prepared for co-designing with people with dementia, the author conducted a scoping review (Chapter 4) on studies that involved people with dementia as partners with the sub research question:

If (and what) design recommendations for co-designing with people with dementia could be generated from the design research studies that involved people with dementia as partners?

Recommendations on how to co-design with people with dementia were generated based on the reviewed studies. A list of limitations on this involvement approach was summarised. This review also discovered that, although still a limited quantity, a growing number of studies had involved people in the moderate to late stages of dementia in the design process.

- [4] With the learnings from Ergonomics in Ageing (Chapter 3) and Co-design (Chapter 4), the author conducted a design case study (Chapter 5) in the field to first build empathetic connections with people with dementia before Data-enabled Design and evaluated the design recommendations generated previously with the sub research question:

If (and how) could recommendations on Co-design and Ergonomics in Ageing be applied in the field to facilitate non-pharmacological interventions for BPSD, and what does this imply on these recommendations in personalising dementia care?

An interactive device (named De-light) was developed for facilitating Snoezelen therapy (a type of non-pharmacological intervention for BPSD) with the aim of managing wandering behaviours in people with dementia. Through the design of the De-light, the author evaluated and refined the design recommendations, and she also identified the wish of the care team in keeping track of the needs of people with dementia in the ward for delivering more personalised BPSD care.

- [5] The author hypothesised that Data-enabled Design could facilitate the care team in achieving their wish (as described in Chapter 5). She explored this hypothesis by a design case study (Chapter 6) in the field with the sub research question:

What types of data could be combined for personalised BPSD care in nursing homes, what are their values, how to collect and present them, and how to introduce them in the working routine of the care team for analysis?

A digital platform (named Data-care) was developed. This digital platform combined quantitative data collected by an Indoor Positioning System with qualitative data collected by caregivers. Five values of this combination were identified by the care team. The types of data to be combined should be personalised to the needs of each resident. The data collection process should involve a minimal effort by the care team, and the data should be visualised in an integrative way to facilitate data analysis. User scenarios were created to build the data analysis process into the working routine of the care team.

- [6] After the digital platform (Data-care) had been updated based on the feedback collected in the previous study (Chapter 6), it has been deployed over a longer period of time in the field. The author conducted a formative study (Chapter 7) on exploring the values of Data-care in personalising BPSD management over a 7-week time period with the sub research question:

What are the values of Data-care after a longer implementation period in the field, and what does this imply for the Data-enabled Design approach in personalising dementia care?

An accumulating amount of data enabled the trends and patterns in the behaviours of the residents to be revealed. Insights were gained on the client level, ward level and team level by the care team. Some insights led to direct implementation, while others led to further investigation. The majority of the care team found the digital platform (Data-care) useful for their work and commented on how the digital platform (Data-care) could be improved for data collection, visualisation and analysis. Three aspects were identified for adapting Data-enabled Design to the context of personalising dementia care.

[7] To integrate the learnings of the three design approaches for designers and healthcare professionals, the author aimed to develop and evaluate a toolkit for personalising dementia care (Chapter 8) with the sub research question:

How could the learnings from Ergonomics in Ageing, Co-design and Data-enabled Design be integrated into a toolkit for personalising dementia care, and what is the perceived usefulness of the toolkit?

A toolkit (named Know-me) was developed and evaluated. Know-me was designed to be easily accessible, flexible and engaging, providing concrete and hands-on guidance for designers and healthcare professionals to use in designing for personalised dementia care. A website was developed to disseminate the Know-me toolkit (see: <http://designfordementia.squarespace.com>). This toolkit was evaluated in student projects on design for dementia care and compared with similar state-of-the-art toolkits. Three aspects of improvements for the Know-me toolkit were identified.

Answer to the main research question and its implications

The learnings gained throughout the literature and field research enabled the author to evaluate the two hypotheses proposed at the beginning of the doctorate and to refine the preliminary answer formulated at the beginning of this doctorate. Specifically, the three design **approaches** from Human-Centered Design (i.e., Ergonomics in Ageing, Co-design and Data-enabled Design) could be applied to help designers and healthcare professionals to gain insights into the factors contributing to BPSD, as mentioned in the NDB model, for each person with dementia. In addition, while each design approach offers a unique perspective, the insights gained from these three approaches feed into each other and mutually influence one another in contributing to design for personalised dementia care.

Together, these design approaches form the three pillars of designing for personalised dementia care. The **recommendations** generated guide designers and healthcare professionals to give attention to each person with dementia, which enables them to gain a highly detailed and nuanced understanding of each person and the interpersonal differences among people with dementia. The Know-me toolkit was developed to provide concrete and hands-on guidance for designers and healthcare professionals to get started with designing for personalised dementia care. These **tools** are flexible and engaging, allowing designers and healthcare professionals to make their contexts, own ideas and skills part of the design process. The Know-me toolkit is envisaged to be able to expand the current landscape of designing for personalised dementia care.

The **approaches** and the set of **recommendations** and **tools** generated could be used by both the creative industries and healthcare providers for personalising BPSD care

and for personalising dementia care in general. For instance, the designers could, by co-designing with the care teams, develop products, services, and product-service systems for offering personalised dementia care. Through this process, care teams could learn about the role of design in personalising dementia care, gain insights about their residents, and realise their important roles in the design process. The care teams could then use these insights themselves for developing and adapting their working procedures, interaction strategies, and interior environments for delivering personalised dementia care.





Samenvatting

Onderzoekscontext en belangrijkste onderzoeksvraag

In 2017 heeft de Wereldgezondheidsorganisatie het wereldwijde actieplan voor een publieke respons op dementie geïnitieerd, dat tot doel heeft het fysieke, mentale en sociale welzijn van mensen met dementie, hun verzorgers en families te verbeteren. Dit plan onderstreepte dat de huidige kloof tussen de zorg die mensen met dementie nodig hebben en de zorg die hen geboden wordt, groot is. Rond de jaren negentig was er een beweging op het gebied van dementiezorg, die voorstelde dat mensen met dementie persoonsgericht zouden moeten worden verzorgd. In het bijzonder zou er in de zorg voor mensen met dementie zoveel mogelijk rekening gehouden moeten worden met hun persoonlijkheid, levenservaringen en voorkeuren. Personalisatie is een sleutelement bij het bieden van persoonsgerichte zorg aan mensen met dementie.

Toch zijn de benaderingen, aanbevelingen en instrumenten voor het personaliseren van dementiezorg beperkt. Daarom is in dit proefschrift onderzocht hoe deze personalisatie kan worden vergemakkelijkt door ontwerp. Specifiek heeft de auteur onderzocht hoe de zorg voor mensen met gedrags- en psychosociale symptomen bij dementie (BPSD) kan worden gepersonaliseerd. De reden hiervoor is dat BPSD bijdraagt aan de meest stressvolle, complexe en kostbare aspecten van dementiezorg. Naarmate de dementie voortschrijdt, gaan de cognitieve functiestoornissen vaker gepaard met en worden soms voorafgegaan door een verslechtering van de emotionele controle, het sociale gedrag of de motivatie, wat een extra uitdaging vormt in de dementiezorg zorg en de zorgzwaarte meestal vergroot. BPSD is geïdentificeerd als een voorspeller van plaatsing in een verpleeghuis. Er zijn niet-farmacologische interventies voor BPSD-zorg ontwikkeld, die veel ruimte bieden voor personalisatie.

Daarom wilde de auteur de onderstaande hoofdonderzoeksvraag beantwoorden in de context van het ontwerpen voor gepersonaliseerde BPSD-zorg in verpleeghuizen:

Wat zijn de ontwerpbenaderingen, aanbevelingen en hulpmiddelen die gepersonaliseerde zorg voor dementie kunnen vergemakkelijken?

Bij het beantwoorden van deze onderzoeksvraag verkende de auteur aanvankelijk het gebied van de gezondheidszorg en het gebied van design om een voorlopig antwoord te vormen. Vanuit het veld van de gezondheidszorg putte de auteur uit de literatuur over persoonsgerichte zorg, en van daaruit bekeek ze BPSD vanuit de focus van het Need-driven Dementia-compromised Behavior (NDB) model, waarbij BPSD wordt geïnterpreteerd als een manier voor mensen met dementie om hun onvervulde behoeften te uiten. Factoren die bijdragen aan symptomen van BPSD zijn in dit model in categorieën ondergebracht, wat een unieke uitkomst kan geven voor iedere individuele persoon met dementie. Vanuit het ontwerpveld benaderde de auteur de uitdaging vanuit

het focus van Human-Centered Design en onderzocht ze drie ontwerpbenaderingen die het meest relevant zijn bij het ontwerpen voor gepersonaliseerde BPSD-zorg, namelijk Ergonomics in Ageing (Ergonomische aspecten van veroudering), Co-design (Het "samen ontwerpen", een manier van ontwerpen, waarbij de eindgebruiker en belangrijke anderen nauw betrokken worden bij het gehele ontwerpproces van een nieuw product, systeem of dienst). En Data-enabled Design (gegevens-gestuurd ontwerpen, dit stelt ontwerpers in staat om de verzamelde gegevens en bijbehorende inzichten als input te gebruiken tijdens het ontwerpproces) Meer specifiek veronderstelde de auteur dat een combinatie van deze drie ontwerpbenaderingen inzichten zou kunnen opleveren in de factoren die bijdragen aan BPSD, zoals vermeld in het NDB-model, voor ieder persoon met dementie die BPSD-symptomen vertoont. Ze stelde verder de hypothese op dat het verkrijgen van inzicht in deze factoren het ontwerp van gepersonaliseerde dementiezorg zou kunnen vergemakkelijken.

Onderzoeksaanpak en methoden

De auteur heeft een reeks stappen geïmplementeerd om deze hypothesen uit de literatuur en uit het veld te evalueren via een Research through Design (RtD) -benadering waarbij "ontwerpactiviteiten een vormende rol spelen bij het genereren van kennis". Het veldwerk is uitgevoerd in nauwe samenwerking met verpleeghuis Zorggroep Elde Maasduinen in Boxtel. De faciliterende technologie werd geleverd door het bedrijf PinXact in Delft, Nederland.

Bij het beantwoorden van de centrale onderzoeksvraag putte de auteur uit de kracht van RtD als reflectieve praktijk. Door steeds weer na te denken over de inzichten die tijdens het proces werden verzameld, werd de richting van het project iteratief bijgesteld en nader uitgewerkt. Zodoende heeft de auteur, uitgaande van de hoofdonderzoeksvraag, deze onderzoeksvraag in elke fase van het onderzoeksproces geëvalueerd om gedetailleerde deelonderzoeksvragen te kunnen genereren die relevant zijn voor elke fase van het proces. Een combinatie van onderzoeks- en ontwerpmethoden zoals systematische review, scoping review, interviews, observaties, vragenlijsten, documentanalyse en prototyping werden gebruikt om deze deelonderzoeksvragen te beantwoorden. De zeven deelonderzoeksvragen en de daarbij behorende bevindingen worden hieronder samengevat.

Deelonderzoeksvragen en hun bevindingen

[1] Om te beginnen met het doctoraat, voerde de auteur eerst een systematische review van de literatuur uit (Hoofdstuk 2) om de status quo van niet-farmacologische interventies voor BPSD-management te inventariseren. Ze beoordeelde de onderzoeken vanuit een ergonomisch perspectief om de onderstaande deelonderzoeksvraag te beantwoorden:

Wat zijn de huidige niet-farmacologische interventies voor BPSD-management en hebben ze ergonomische aspecten geïntegreerd? Zo ja, hoe?

Deze review laat zien dat er een grote verscheidenheid bestaat aan niet-farmacologische interventies voor de behandeling van BPSD, die zijn onderverdeeld in sensorisch-, cognitief- en bewegings-gericht volgens de belangrijkste capaciteiten die nodig zijn voor mensen met dementie om eraan deel te kunnen nemen. Ook bleek dat het bewijs van effectiviteit van deze interventies laag is, en dat de aandacht voor ergonomische aspecten bij deze interventies meestal ontbreekt, met name voor wat betreft overwegingen van de capaciteit van mensen met dementie op het gebied van sensorisch-, cognitief- en bewegings-gerichte functies, en de betrokkenheid van mensen met dementie bij het ontwerpproces.

- [2] Geleid door de bevindingen van de systematische review (Hoofdstuk 2), onderzocht de auteur de literatuur over ergonomie bij veroudering om te onderzoeken hoe niet-farmacologische interventies kunnen worden aangepast aan de mogelijkheden van iedere persoon met dementie (Hoofdstuk 3) met de deelonderzoeksvraag:

Kunnen ontwerpaanbevelingen voor het personaliseren van niet-farmacologische interventies voor mensen met dementie worden gegenereerd uit de literatuur over ergonomie bij veroudering; en zo ja welke?

Een reeks ontwerpaanbevelingen voor capaciteitsoverwegingen voor het personaliseren van niet-farmacologische interventies werd gegenereerd op basis van vermogens op het gebied van sensorische, cognitief- en bewegingsaspecten zoals beschreven in de Ergonomics in Ageing literatuur. Vervolgens werden voorbeelden geïntroduceerd van hoe deze ontwerpaanbevelingen konden worden toegepast bij het personaliseren van niet-farmacologische interventies.

- [3] De systematische review van niet-farmacologische interventies voor BPSD-management (Hoofdstuk 2) geeft ook aan dat het betrekken van mensen met dementie als partners in het ontwerpproces een manier is om niet-farmacologische interventies te ontwikkelen die aan hun behoeften voldoen.

Om de toekomstige co-design sessies met mensen met dementie zo optimaal mogelijk uit te kunnen voeren, voerde de auteur een scoping review (Hoofdstuk 4) uit van design research studies waarbij mensen met dementie betrokken waren als partners met de deelonderzoeksvraag:

Kunnen ontwerpaanbevelingen voor co-design met mensen met dementie worden gegenereerd uit de ontwerpstudies waarbij mensen met dementie als partners betrokken waren; en zo ja, welke?

Op basis van de onderzoeken uit de scoping review (Hoofdstuk 4) werden aanbevelingen gedaan over hoe mensen met dementie te betrekken in het ontwerp (design)-proces. Er werd een lijst met beperkingen van deze benadering van betrokkenheid opgesteld. Uit deze review bleek ook dat, hoewel nog steeds in een beperkte hoeveelheid, een groeiend aantal onderzoeken mensen met matig ernstige tot ernstige dementie in het ontwerpproces betrok.

- [4] Met de lessen van Ergonomics in Aging (Hoofdstuk 3) en Co-design (Hoofdstuk 4), voerde de auteur een design case study (Hoofdstuk 5) in het veld uit om eerst empathische connecties op te bouwen met mensen met dementie en evalueerde de ontwerpaanbevelingen die eerder waren gegenereerd met de deelonderzoeksvraag:

Kunnen aanbevelingen over co-design en ergonomie bij veroudering in het veld worden toegepast om niet-farmacologische interventies voor BPSD te vergemakkelijken, zo ja, hoe; en wat betekent dit voor het personaliseren van dementiezorg?

Een interactief apparaat (genaamd De-light) werd ontwikkeld voor het faciliteren van Snoezelentherapie (een niet-farmacologische interventie voor BPSD) met als doel het dwaalgedrag van mensen met dementie te beïnvloeden. Door middel van de gegevens van het ontwerp van de De-light evalueerde en verfijnde de auteur de ontwerpaanbevelingen voor het personaliseren van dementiezorg, en identificeerde ze ook de wens van het zorgteam om de behoeften van mensen met dementie op de afdeling te volgen met als inzet het leveren van meer gepersonaliseerde BPSD-zorg.

- [5] De auteur stelde de hypothese dat Data-enabled Design het zorgteam zou kunnen helpen bij het vervullen van hun wens die in het vorige onderzoek is geïdentificeerd (Hoofdstuk 5), namelijk het in kaart brengen en volgen van de behoefte van de personen met dementie aan meer gepersonaliseerde BPSD-zorg. Ze onderzocht deze hypothese door middel van een design case study (Hoofdstuk 6) in het veld met de deelonderzoeksvraag:

Welke soorten gegevens kunnen worden gecombineerd voor gepersonaliseerde BPSD-zorg in verpleeghuizen, wat is de waarde van deze gegevens, hoe kunnen ze worden verzameld en gepresenteerd, en hoe kunnen ze voor analyse worden geïntroduceerd in de werkroutine van het zorgteam?

Er werd een digitaal platform ontwikkeld (genaamd Data-care). Dit digitale platform combineerde kwantitatieve gegevens verzameld door een Indoor Positioning System met kwalitatieve gegevens verzameld door de zorgverleners. Het zorgteam identificeerde vijf combinaties als belangrijk. De gegevens die moeten worden gecombineerd, moeten worden aangepast aan de persoonlijke behoeften van iedere bewoner. Het gegevensverzamelingsproces moet een minimale inspanning van het zorgteam vergen, en de gegevens moeten integraal worden gevisualiseerd om gegevensanalyse te vergemakkelijken. Er zijn gebruikersscenario's gemaakt voor de analyse van de gegevens, en om het proces van gegevensanalyse in de werkroutine van het zorgteam te introduceren.

- [6] Nadat het digitale platform (Data-care) was geactualiseerd op basis van de feedback die werd verzameld in de vorige studie (Hoofdstuk 6), is het gedurende een langere periode in het veld ingezet. De auteur voerde een formatieve studie uit (Hoofdstuk 7) naar het verkennen van de waarden van Data-care bij het personaliseren van BPSD-management gedurende een periode van 7 weken met de deelonderzoeksvraag:

Wat zijn de waarden van Data-care na een langere implementatieperiode in het veld en wat betekent dit voor de Data-enabled Design-aanpak bij het personaliseren van dementiezorg?

Door een opeenstapeling van gegevens konden renden en patronen in het gedrag van de bewoners worden vastgesteld. Door het zorgteam is inzicht verkregen op cliëntniveau, afdelingsniveau en teamniveau. Sommige van de verkregen inzichten leidden tot directe implementatie, andere leidden tot nader onderzoek. De meerderheid van het zorgteam vond het digitale platform (Data-care) nuttig voor hun werk en gaf commentaar op hoe het digitale platform (Data-care) verbeterd zou kunnen worden voor dataverzameling, visualisatie en analyse. Er werden drie aspecten geïdentificeerd voor het aanpassen van Data-enabled Design aan de context van het personaliseren van dementiezorg.

- [7] Om de lessen van de drie ontwerpbenaderingen voor ontwerpers en zorgprofessionals te integreren, wilde de auteur een toolkit ontwikkelen en evalueren voor het personaliseren van dementiezorg (Hoofdstuk 8) met de volgende onderzoeksvraag:

Hoe kunnen de lessen van Ergonomics in Aging, Co-design en Data-enabled Design worden geïntegreerd in een toolkit voor het personaliseren van dementiezorg, en wat is het gepercipieerde nut van de toolkit?

Er is een toolkit (genaamd Know-me) ontwikkeld en geëvalueerd. Know-me is ontworpen om gemakkelijk toegankelijk, flexibel en boeiend te zijn en biedt concrete

en praktische begeleiding aan ontwerpers en zorgprofessionals om te gebruiken bij het ontwerpen van gepersonaliseerde zorg voor dementie. Er is een website ontwikkeld om de Know-me toolkit te verspreiden (zie: <http://designfordementia.squarespace.com>). Deze toolkit werd geëvalueerd in projecten van studenten over ontwerp voor dementiezorg. Er werden drie aspecten van verbetering voor de Know-me-toolkit geïdentificeerd.

Antwoord op de belangrijkste onderzoeksvraag en de implicaties ervan

De lessen die tijdens het literatuuronderzoek en het veldonderzoek werden opgedaan, stelden de auteur in staat de twee hypothesen te evalueren en het voorlopige antwoord dat aan het begin van dit doctoraat werd geformuleerd, te verfijnen. Specifiek zouden de drie ontwerpbenaderingen van Human-Centered Design (dwz Ergonomics in Ageing, Co-design en Data-enabled Design) kunnen worden toegepast om ontwerpers en zorgprofessionals te helpen inzicht te krijgen in de factoren die bijdragen aan BPSD, zoals vermeld in het NDB-model, voor iedere persoon met dementie die BPSD-symptomen vertoont. Hoewel elke ontwerpbenadering een uniek perspectief biedt, beïnvloeden en voeden de inzichten die uit deze drie benaderingen worden opgedaan, elkaar bij het ontwerpen van gepersonaliseerde zorg voor dementie.

Samen vormen deze ontwerpbenaderingen de drie pijlers van het ontwerpen voor gepersonaliseerde dementiezorg. De gegenereerde aanbevelingen zijn een leidraad voor ontwerpers en zorgprofessionals om aandacht te schenken aan iedere persoon met dementie, waardoor ze een zeer gedetailleerd en genuanceerd inzicht krijgen in iedere persoon en in de interpersoonlijke verschillen tussen mensen met dementie. De Know-me toolkit is ontwikkeld om ontwerpers en zorgprofessionals concrete en praktische begeleiding te bieden bij het ontwerpen voor gepersonaliseerde zorg voor dementie. Deze tools zijn flexibel en boeiend, waardoor ontwerpers en zorgprofessionals hun context, eigen ideeën en vaardigheden onderdeel kunnen maken van het ontwerpproces. De Know-me toolkit is bedoeld om het huidige landschap van ontwerpen voor gepersonaliseerde dementiezorg uit te breiden.

De benaderingen en de reeks aanbevelingen en instrumenten die worden gegenereerd, zouden door zowel de creatieve industrie als de zorgverleners kunnen worden gebruikt voor het personaliseren van de zorg voor BPSD en voor het personaliseren van de zorg voor dementie in het algemeen. Zo zouden de ontwerpers, door samen met de zorgteams te ontwerpen, producten, diensten en productservicesystemen kunnen ontwikkelen voor het aanbieden van gepersonaliseerde BPSD-zorg. Door dit proces zouden zorgteams kunnen leren over de rol van design bij het personaliseren van dementiezorg, inzicht verkrijgen in hun bewoners en in hun dagelijkse zorgroutine en interactiestrategieën, en een belangrijke bijdrage in het ontwerpproces voor het leveren van gepersonaliseerde BPSD-zorg kunnen leveren.



Appendices

APPENDIX A PRODUCTS AND SERVICES ON BPSD CARE

In total, there are 37 products and services targeting BPSD on the website: dementie-winkel.nl. These products and services are categorised according to the non-pharmacological intervention they facilitate.

Intervention	Products/services	Description	Functions in the intervention
Music therapy	Easy-to-use music player and radio	Music player or radio that has minimal buttons	Enable PwD to play music by themselves
	Music-vibrate waterbed	A waterbed vibrating with music	Adding haptics/massage elements
	Music pillow	Pillow with build-in loudspeakers	Music source is close to ears without contact
	CRDL	A music player only plays when there is physical contact between two people	Adding therapeutic touch and interactions between music and touch
	Bands that play in nursing homes	Live music	Introduce live music
Positive image therapy	Experience-oriented projections	Positive images are projected on the ceiling	Immersive effect
	Glittering tube	A tube with slowly-moving eye-catching particles	Constantly moving images
	Old photoset	A set of old photos	Adding reminiscence
	UV mat	Change sunlight to a range of lights	No electricity needed
	Aquapaint	Paint with water	Adding fine motor control, occupational therapy elements, reminiscence
	Jigsaw puzzle	Designed for dementia	Adding fine motor control, occupational therapy elements, reminiscence
Animal therapy	Stuffed animal and dolls	Self-explanatory product name	Adding reminiscence
	Paro	A robotic seal interacts with PwD by sound and movement	Interaction
	Robot Zora	Humanoid robot	Interaction
Reminiscence therapy	The chitchatter	a set of equipment which can play music and video, showing objects	Adding sensory elements
	Communication football	A football with a question on each panel	Interaction between caregiver and PwD
	Call to mind	A set of cards having questions	Help caregivers to think of questions
	Creative scene	A puzzle for locating daily objects	Adding sensory elements and fine motor control
	Talking photo album	Self-explanatory product name	Adding sensory elements
	Food table	A table of food full of things people used to eat in the 40s/50s	Encourage people to reminisce through taste

Nature therapy	Bird tree	An artificial tree with bird sounds	Adding natural elements to an indoor environment
	Decoration company	Decorate the indoor environment with a poster of nature, making the indoor environment look like outdoor	An indoor garden
Snoezelen therapy	Spray and CD relaxation	Smell combined with the music of the same theme	Facilitate the therapy
	Tovertafel	Positive interactive images are projected on a table	Interaction with the images
Aromatherapy	Fragrance box	Familiar smell	Adding reminiscence
Tactile therapy	Sensory snap	Touch and match textures with pictures	Cognitive stimulating
	Weighting blanket	Provide snugly heavy feeling which increases body awareness	Deep pressure therapy activates the parasympathetic nervous system
	Fiddle blanket	Blanket attached by objects with different shapes and materials	PwD can play with the objects everywhere, with all objects organised on the blanket
	Doebook/lock suitcase	Contains familiar objects – zip, button/ a variety of locks	Adding reminiscence, occupational therapy, organised in the book/ suitcase
	Tactile disks	Disks with different patterns that put under the PwD feet	Cognitive stimulating, feeling at a unique part of the human body
	Kinetic sand	A type of sand	A type of pleasant feeling
	Fiddle ball	A ball with different extrusions	A type of pleasant feeling, acupressure effect (a type of massage)
	Playform	Works like playdough	A type of pleasant feeling, reminiscence
Acupressure/ massage therapy	Neck massage pillow	A pillow that can massage the neck	Relieve the burden of caregivers
Exercise therapy	BikeAround	Google Street View with a stationary bike to help dementia patients remember	Adding sensory stimulation, positive feedback, reminiscence
	Experience Table	Games and activities with interactive screen	Encouraging interactions among PwD, intuitive touch screen
	Parallel bicycle	Two bicycles combined into a four-wheel bicycle	Allow PwD to ride safely

APPENDIX B PERSONALISED DESIGNS BY HEALTHCARE PROFESSIONALS

	This PwD as a person... (handles for personalisation)	Personalised designs
PwD 1	Like gardening	Decorate her room with flowers (plastic, so it cannot be eaten), and mention the flowers to her when she is agitated
	Used to be athletic	Play the bean bag game with her when she is apathetic
PwD 2	Used to be an accountant	Provide papers to her as money to count when she is apathetic
	Like Beijing opera	Play TV programmes with Beijing opera when she is depressed
PwD 3	Used to enjoy housework	Provide her with a stack of handkerchiefs to fold when she is apathetic
PwD 4	Used to be an officer in the government	Call him "Officer xx" and show him the prizes that he has won during his career when he is depressed
PwD 5	Like outdoor activities previously, but cannot stand up due to the stroke	Bring him close to the window and open the window in his room regularly to prevent him from being agitated
PwD 6	Used to be a teacher, and loves Chinese Calligraphy	Ask him a favour to write something in Chinese Calligraphy when he is restless
PwD 7	Experienced a period of poverty in his youth	Remind her the prepared bathwater would be wasted when she resists going for a shower
PwD 8	Used to enjoy sewing	Present the sewing work she has done before and praise her when she is apathetic
PwD 9	Has once lost a child in a market	Accompany her to the bus stop and back to seek for her son when she is wandering and trying to find her son
PwD 10	Used to be a manager and a rigorous mother	Let her choose between two dishes during a meal and give a positive and affirmative response to what she says to prevent her from agitation
PwD 11	Used to be a wall painter	Bring him a brush (without paint) when he is restless and let him "paint" his own bedroom
PwD 12	Has a quiet and introverted personality	Sitting by her side for a moment and ask her what she's looking at, then start the chatting when she is apathetic
PwD 13	Has been a loving mum	Brought her a doll and allowed her to keep it as her kid. Ask "how is your kid?" to start the conversation when she is apathetic
PwD 14	Like birds and had raised a few before	Show him videos of birds and play bird songs to him when he is depressed
PwD 15	Had experience of staying in a prison	Created a certificate stating that he is released when he shows wandering behaviours and says: out of the prison
PwD 16	Worked as a shepherd when he is young	Provide a box of beans and invite him to count them, which calms him down when he is agitated
PwD 17	Used to be an English teacher	Ask her about simple English words when she is apathetic

APPENDIX C CONTEXTUAL INFORMATION ABOUT THE RESEARCH FIELD

Care culture in the nursing home	Ward ambience	Working structure of the care team
<p>Zorggroep Elde Maasduinen has 2,000 employees and 1,400 volunteers and cares for around 3,500 elderly people. In managing BPSD, the nursing home adopts the Dementie-model [1]. Besides, the nursing home has used a standardised signal plan for the residents based on the Crisis Development model [2]. This model divides the stress level of a person into green, yellow, orange and red, indicating no stress (green) to high stress (red). The effective measures carried out to help the resident relax at different stress levels are recorded and categorised on the signal plan. Based on the signal plan, the behaviours of the residents' act as signals for their stress levels, and the caregivers can then react by adjusting the interaction style and environment for each resident according to the signal plan to reduce the stress for each resident.</p>	<p>In the ward where the IPS is installed, there are ten bedrooms available, and each resident has his or her own bedroom, which they can decorate with their personal belongings. The bedrooms open onto the main hallway, to which the living room is also connected. The living room is composed of an open kitchen and a dining room. The dining room is shared by these ten residents, and the decoration presents a home-like nostalgic atmosphere. This is where daily activities take place, such as watching television, chatting, singing, reading, or playing games. Most of the time, caregivers facilitate the residents with these activities in the living room. Three bathrooms are located on the two sides of the hallway.</p>	<p>There are four caregivers in the morning, three in the afternoon, and one in the night shift. Each day, depending on the state of the residents, the caregivers write one or more or no daily report(s) for each resident. In this study, their extra tasks are wearing the tags, help residents wearing the tags and record a stress rating for the residents following the Crisis Development model. Each resident has a responsible caregiver, and all the residents share the responsible doctor, psychologist and dietitian. The manager is mainly in charge of the performance of the ward and the wellbeing of the employees. The responsible caregiver is accountable for updating the care plans of the resident. Caregivers have a weekly meeting with the doctor and the psychologist, and occasional meetings with the dietitian when the dietary plan needs to be changed.</p>

[1] "Methodology - D-ZEP Oleander." <https://dzep-oleander.nl/methodiek/> (accessed Mar. 30, 2021).

[2] R. Geelen, "Agressie en ontregeld gedrag: het Crisis Ontwikkelings Model (COM)," in *Dementiezorg in de praktijk - deel 2*, Bohn Stafleu van Loghum, 2015, pp. 167–184.

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Gubing Wang was born in Chifeng, China. She started her PhD in 2017 at Delft University of Technology, at the Department of Human-centred Design within the Faculty of Industrial Design Engineering. Her research centres on the intersection of digital technology, healthcare and design; she has been exploring the values of the Internet of Things and Artificial Intelligence to the healthcare systems and how could they be integrated effectively. This covers design methods, ethical issues and the study of real-world cases as sociotechnical systems.

Prior to her PhD research, Gubing studied Biomedical Engineering at Imperial College London for her Master and Bachelor's degrees with the centenary prize, where she has developed an aptitude for technology and design in healthcare. After a one-year experience in developing drug delivery devices as an intern in GlaxoSmithKline, she further discovered her interest in the front-end of the design process. Hence, she embarked on design research and selected a topic that is close to her heart: dementia care. This is because her grandma developed vascular dementia when Gubing was studying abroad, and Gubing hopes she could do something for her grandparents with whom she grew up in Chifeng.



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