The impact of relational co-creative research in service design practice

A co-creative case study with dementia family caregivers
in the Danish welfare system

MASTER THESIS BY
Nanna Dam Johansen & Rike Neuhoff

THESIS INFORMATION

University | Aalborg University

Master’s Programme | Service Systems Design

Project Type | Master Thesis (30 ECTS)

Project Period | Feb 2020 – May 2020

Hand In Date | May 28th 2020

Academic Supervisor | Luca Simeone

Title | The impact of relational co-creative research in service design practice. A co-creative case study with dementia family caregivers in the Danish welfare system.

Authors | Nanna Dam Johansen, Study no. 20181222 & Rike Neuhoff, Study no. 20180513

I. Abstract

This thesis investigates how a relational co-creative research approach impacts service design practice and thus aims to contribute to expand the understanding of service design and its value. The thesis draws conclusions from a case study, of which the design process explores the challenges of dementia family caregivers in the Danish welfare system. The case results in a report highlighting the insights and opportunity spaces on how to improve the support of dementia family caregivers. The case study employs an approach inspired by the Feed Forward methodology, and is structured in activities that ensure a relational and co-creative focus. The research suggests alternative methods, such as conversations, stories and a collective evaluation, as a way to extensively involve participants in a service design project. The approach reveals to challenge the role of service designers, stressing the need of resources and capabilities, such as the ability to support participants in emotionally difficult situations, that designers are not necessarily taught. Furthermore, the research shows that everyone involved in the service design process is to be understood as an expert – the participants as the experts of the theme, and the designers as the expert of supporting others in designing. The thesis reveals that relations between participants in a service design project that are characterised by trust, sensitivity and empathy are beneficial for a co-creative research process, as they ensure engagement and contribute to mobilise participants' reflections, making them think and act in ways that are more beneficial for them. These relations can be fostered by building safe, informal and authentic design environments. Thus, the thesis expands the understanding of service design as not only being a means to design services, but shows that the design process in itself is valuable, as it contains a transformative power. Based on the research, the thesis formulates assumptions about the approach and thus offers a foundation for future research.

Keywords: Service design, co-design, relational co-creation, welfare system design.

II. Acknowledgements

First of all we want to thank our supervisor. Luca, we are very grateful for the continued trust you have placed in us and our work. Your support pushed our work forward and gave us the necessary confidence to pursue our interests. We would also like to thank you for your thoughtful feedback regarding our academic work, which has greatly influenced our motivation and the level of the result.

Secondly, we would like to thank the dementia family caregivers who participated in the project. Thank you for your trust, your willingness to contribute and the dedication that you brought to the project. Without your participation the project could not have been realised. We promise that we will use our knowledge to further advance the awareness about dementia and to thereby hopefully contribute to creating a more dementia-friendly society.

Another big thank you we would like to give to the Designit Copenhagen team for selflessly welcoming us in your premises, providing us with everything we could possibly need – a great workplace, advice and help, materials, delicious food and drinks and last but not least a social environment. We wish Covid-19 had not forced us into the home office.

We would like to extend our thanks to our fellow students. Thank you for listening to us and for your feedback. We appreciate that we shared this experience together with you and are grateful for the exchange, which was highly made possible by Luca's super well organised supervision sessions.

And last but not least, we want to thank our family and friends. Thank you so much for your ongoing support from far and near. Thank you for encouraging us through words and opinions, through your genuine interest in our work and also for distracting us. Your support means a lot.

III. Table of figures

Figure 1: Double Diamond process model
Figure 2: Feed Forward methodology
Figure 3: Steps of Feed Forward integrated into Double Diamond
Figure 4: Overall research process
Figure 5: Stakeholder map
Figure 6: Facebook post to engage participants
Figure 7: Profiles of the participating dementia family caregivers
Figure 8: Conversation with a dementia family caregiver
Figure 9: Conversation guide template
Figure 10: Exemplary journey map
Figure 11: List of actors and initiatives within the context of dementia
Figure 12: List of feelings
Figure 13: Exemplary story
Figure 14: Clustering of quotes of dementia family caregivers
Figure 15: Research wall
Figure 16: Preliminary insights
Figure 17: Dinner with dementia family caregivers
Figure 18: Presenting and co-creating preliminary insights
Figure 19: Dementia family caregivers voting for their major issues
Figure 20: Relational mapping
Figure 21: Characteristics of positive and negative flows of communication
Figure 22: Key insights
Figure 23: Draft ideas developed with the Crazy 8 method
Figure 24: Exemplary scenario
Figure 25: Opportunity spaces of improvement
Figure 26: Project report

IV. Table of contents

I. Abstract 3
II. Acknowledgements 4
III. Table of figures 5
IV. Table of contents 6

1. INTRODUCTION 9
1.1 Introduction and motivation 10
1.2 Learning objectives 12
    1.2.1 Official learning objectives 12
    1.2.2 Personal learning objectives 13
1.3 Reading guide 14

2. LITERATURE REVIEW 16
2.1 Service design 18
    2.1.1 Evolution of service design 18
    2.1.2 Value of service design – from output to process 19
    2.1.3 The role of the service designers – From main actor to enabler 20
2.2 Co-design 21
    2.2.1 Co-design and user-centered design 21
    2.2.2 Benefits of co-design 22
    2.2.3 Criticism of co-design 23
2.3 Relations 25
    2.3.1 The relevance of relations in service design 25
    2.3.2 Relational services 25
2.4 Research focus 27
    2.4.1 Research question 28

3. PROJECT CONTEXT 29
3.1 Dementia 31
3.2 The importance of dementia family caregivers 32
3.3 Challenges of dementia family caregivers 32
3.4 Needs of dementia family caregivers 33
3.5 Problem statement 34

4. METHODOLOGY **35**
4.1 Double Diamond 37
4.2. Feed Forward 38
4.3 Overall research process 41
4.4 Ethics 42
4.5 Limitations related to Covid-19 42

5. CASE STUDY **43**
5.1 Discover 45
    5.1.1 Preparations 46
    5.1.2 Conversations 54
    5.1.3 Stories 62
    5.1.4 Conclusion of the Discover phase 68
5.2 Define 69
    5.2.1. Analysis and synthesis 70
    5.2.2 Collective evaluation 74
    5.2.4 Conclusion of the Define phase 78
5.3 Develop 79
    5.3.1 Relational mapping 80
    5.3.2 Key insights 83
    5.3.3 Crazy 8 87
    5.3.4 Design scenarios 89
    5.3.5 Co-constructing stories 91
    5.3.6 Conclusion of the Develop phase 92
5.4 Deliver 93
    5.4.1 Opportunity spaces for improvement 94
    5.4.2 Project report 96

6. DISCUSSION **97**
6.1 Reflections emerging from the design process 99
    6.1.1 Engaging participants 99
    6.1.2 The impact of conversations 102
    6.1.3 The impact of stories 103
    6.1.4 The impact of a collective evaluation 104

6.2 Further reflections on the research question 106
    - 6.2.1 Characteristics of beneficial relations 106
    - 6.2.2 Challenges related to the approach 108
    - 6.2.3 The role of the service designer 109
    - 6.2.4 The value of service design 112
    - 6.2.5 Relational co-creation in the context of welfare 113

6.3 Reflections on learning objectives 115
    - 6.3.1 Official learning objectives 115
    - 6.3.2 Personal learning objectives 115

7. CONCLUSION 117

7.1 Key findings related to the research question 119

7.2 Limitations & future research 121

8. REFERENCES 123

1

Introduction

1.1 Introduction and motivation

Service design is more and more being acknowledged as a discipline able to contribute to tackle society’s most pressing needs – wicked, ill-defined challenges evolving from very complex contexts such as for example welfare or healthcare (Polaine et al., 2013) and thus aids in fueling social innovation. Throughout our Master’s studies we have continuously reflected on the role and responsibility we have as service designers. This thesis stems from our deep wish to be service designers who use our tools, knowledge and gained competences to contribute to positive change and meaningful impact – to support people in creating desirable and sustainable futures and thus help to make this world a better place to live in. We believe that in order to have sustainable impact, to create change that is meaningful to people, we as designers have to design our own practices more inclusive, taking into account the various perspectives and needs of diverse stakeholders. We think, we have to open up our practices and design with people, fully acknowledging and starting with what their knowledge, capabilities and wishes are. With this in mind, co-creation seems to be an appropriate approach to be applied when practicing service design in the above mentioned complex contexts. However, even though there can be found many benefits and good intention of working co-creative, literature also highlights various challenges that practitioners risk to face when applying this approach, as further elaborated in the literature review (chapter 3.2).

In this thesis, we suggest that service designers have to more fully consider the important role and meaning of relations in their approaches, as relations seem to have a limiting or enabling impact on people’s participation, passion and engagement. Service design research has not yet revealed much information about the impact that the relations between participants in a co-creative service design process have on its success. The aim of this thesis therefore is to investigate more thoroughly how to design our own practices, so that we provide ideal environments for actors to fully make use of their personal, naturally inherited design capabilities. Thus, the aim of the thesis is to exactly explore this: The impact that co-creative research with a particular focus on relations can have on the service design practice.

By focusing on the research phase of the design process we intend to explore whether the reflections, insights and actions arising from co-creative research activities can be acknowledged as just as valuable and impactful as the final outcome of the design process. In other words, we investigate whether more emphasis should be given to the value and the transformative potential of the co-creative service design process itself, rather than seeing service design merely as a transitioning through phases of a design process, aiming to spawn a designed service (Vink et al., 2017). Our wish is to contribute to further expand the understanding of service design and our role as service designers, which might be shifting from being the main actor in service design projects to being an enabler that supports others to make use of their personal design capabilities (Manzini, 2015)– a new role that still requires to be profoundly defined (Pierri, 2017).

We dedicate the case study of the thesis to the theme of dementia and the challenges that dementia family caregivers face in the context of the Danish dementia welfare system. This decision stems from our motivation to contribute to exploring how to solve societal challenges. Dementia, its bitter progression and devastating consequences is a great challenge for individuals and society and requires action. In many cases, people who suffer from dementia receive care from their close relatives, which poses a great burden and an increased chance of developing physical and mental issues for the family caregivers. Therefore, we want to apply our service systems design skills to help dementia family caregivers – to contribute to retaining and strengthening their dignity and independence and to making them feel supported and cared for (Danish Health Authority, 2018).

1.2 Learning objectives

The learning objectives of the thesis are based on both official learning objectives defined by Aalborg University, as well as our personal learning goals. The purpose of the thesis is to demonstrate the competences, skills and knowledge that we are expected to possess as service system designers. The personal learning objectives reflect our personal areas of interest and where and how we as service designers wish to contribute to the field.

1.2.1 Official learning objectives

The official learning objectives (Aalborg University, 2020) are as follows:

Knowledge

Students who complete the module will obtain the following qualifications:

- Must have knowledge about the possibilities to apply appropriate methodological approaches to specific study areas.
- Must have knowledge about design theories and methods that focus on the design of advanced and complex product-service systems.

Skills

Students who complete the module will obtain the following qualifications:

- Must be able to work independently, to identify major problem areas (analysis) and adequately address problems and opportunities (synthesis).
- Must demonstrate the capability of analysing, designing and representing innovative solutions.
- Must demonstrate the ability to evaluate and address (synthesis) major organisational and business issues emerging in the design of a product-service system.

Competences

- Students who complete the module will obtain the following qualifications:
- Must be able to master design and development work in situations that are complex, unpredictable and require new solutions (synthesis).
- Must be able to independently initiate and implement discipline-specific and interdisciplinary cooperation and assume professional responsibility (synthesis).
- Must have the capability to independently take responsibility for own professional development and specialisation (synthesis).

1.2.2 *Personal learning objectives*

The personal learning objectives of the thesis are formulated according to our shared motivation:

- Gain more theoretical as well as practical knowledge about, and experience with, co-design. Engage participants as experts and inspire them with inclusive design approaches.
- Gain more knowledge about interactions and relations in the Danish welfare sector, in order to enhance our capability of working with complexity and systemic design.
- Make a research contribution that inspires others to use co-creative service design approaches as a way to challenge traditional practices.
- Contribute to further expand the understanding of service design and the role of service designers.
- Use the thesis as an opportunity to contribute with something meaningful for society.

1.3 Reading guide

This reading guide presents an overview of the thesis and its chapters.

Chapter 2: Literature review

Chapter 2 presents the theoretical foundation of the thesis, which leads towards the academic research question. The chapter presents various perspectives on service design – from how it evolved, over what the value of service design is, to the role of service designers in design processes. Further, it explores the difference between user-centered and co-creative design approaches, and discusses the benefits and challenges that involving people as participants in design processes entails. In addition, it provides perspectives on relational services and proposes that it may be beneficial for service designers to employ a more relational approach in their practice. The chapter lastly presents the academic research question, representing the core of this thesis that aims to contribute to filling a gap identified in the service design literature.

Chapter 3: Project context

Chapter 3 introduces the topic of dementia - the theme of the case study conducted to explore the research question. It initialises with a general introduction into the topic of dementia, presents data and knowledge, and states the important role, challenges and needs of dementia family caregivers. The chapter concludes with presenting the initial problem statement that is addressed within the design process of the case study: How can we use service design to discover the challenges of being a dementia family caregiver in the context of the Danish welfare system?

Chapter 4: Methodology

Chapter 4 presents the methodologies that are employed to explore the problem statement and the academic research question. First, we introduce the Double Diamond methodology, which provides the framework to structure the overall design process to address the problem statements of the case study. Thereupon, the Feed Forward methodology is presented, which we integrate as an inspirational methodology into the first two phases of the Double Diamond, in order to explore the academic research question of the thesis. In addition, the chapter gives on overview of the overall research process, presents some ethical considerations and addresses limitations related to the Covid-19 virus, that have affected the work.

Chapter 5: Case study

Chapter 5 documents the process of the case study, which serves as a lense to explore the academic research question of the thesis. The chapter is divided into sections defined by the four phases of the Double Diamond methodology – Discover, Define, Develop and Deliver – and documents the various activities conducted in the design process collaborating with dementia family caregivers. It reflects on the employed methods and presents the insights and outcomes developed from answering the problem statement of the case.

Chapter 6: Discussion

In Chapter 6 we discuss the academic research question of the thesis based on the key findings of the case study. It includes reflections on how the relational and co-creative research approach has affected the design process, as well as on its more overall impact on service design practice. Lastly, it discusses to which extent we have reached the official and personal learning objectives of the thesis.

Chapter 7: Conclusion

Chapter 7 concludes on the reflections on the research question, as well as elaborates on the overall limitations in the thesis and potential future research within the topic.

2

Literature review

Literature review

This chapter provides the theoretical foundation of the thesis, which leads towards the academic research question. The chapter presents various perspectives on service design – from how it evolved, over what the value of service design is, to the role of service designers. Further, it explores the difference between user-centered and co-creative design approaches, and discusses the benefits and challenges of involving participants. In addition, it provides perspectives on relational services and proposes that it may be beneficial for service designers to employ a more relational approach in their practices. The chapter concludes with the academic research question.

The chapter is divided into the following subchapters:
2.1 Service Design
2.2 Co-design
2.3 Relations

2.1 Service design

2.1.1 Evolution of service design

The emergence of service design can be understood by looking back to industrial design, a discipline defined in the 1920s. Industrial design evolved as an activity that aimed to use industrial technology to improve people's standard of living by meeting their fundamental material needs after World War I. The first industrial designers focused their efforts on exploring what kind of products would satisfy the needs of society, how they could contribute to an optimistic perspective about the future and how they could be produced in efficient ways. During the time of industrial design, the task of designers was primarily to design physical objects. However, over time human needs have changed. In Western industrialized countries material needs became saturated, the economy shifted into the service sector, and the design profession adapted from improving standard of living to increasing quality of life (Polaine et al., 2013).

Moving the focus from designing products to designing services, required a shift in the designers' practices. In the early 1980s service blueprinting (Lynn Shostack G., 1982) was introduced as a professional tool to design, manage and adjust services, which started the discussion on services as something that can be designed, indicating the starting point of service design (Vink et al., 2019). While initially service design was used as a means to redesign a firm's touchpoints to improve its customer experience (e.g. Zomerdijk & Voss, 2010), it has since been recognised as being valuable well outside of its initial boundaries and regularly applied to service systems (e.g. Patrício et al., 2018). Today, service design is for example embedded within governmental departments, public services and voluntary organisations (Pierri, 2017) and thereby deals with the most pressing and complex societal issues, such as an ageing population, chronic health, climate change, faltering education systems, and inner-city social problems, to name a few (Bason, 2018). According to Pierri (2017), this shift makes the scope of design become more broad and less clear. She reports that in this new landscape design can concern redesigning services, informing the strategy of an organisation, developing new campaigns, supporting organisational learning and new approaches to work with, or engaging and involving people in alternative ways.

Service design is often described as an user-centered, iterative and creative process that prompts service innovation (Stickdorn & Schneider, 2012). There are various ways service design is used for driving positive innovation forth, such as through hiring service designers around a specific brief (e.g. Stickdorn et al., 2018b, pp. 252–255), or building on and developing the diffuse design capabilities (Manzini, 2015) of non-designers who are embedded in the context, whereas the latter is often associated with the most long-term, sustainable changes (e.g. Pierri, 2017). While service design is already acknowledged as having a great transformative potential (e.g. Mager, 2009), there are service design researchers who recently criticised the prevailing understanding of service design for being too narrow still (Vink, 2019). To what extent the current understanding may be too narrow can be explained when looking at the historical transition from the design of physical objects to the design of services and systems. There it becomes apparent that the designers who were initially educated in graphic or product design, are the ones who first contributed to service design (Buchanan, 2001). Thus, service design was build on a set of general assumptions about design that are now "getting in the way of a more situated understanding of service design" (Vink, 2019, p.85). In the following we address two of these underlying assumptions – the value of service design and the role of service designers, to then highlight some alternative assumptions.

2.1.2 *Value of service design – from output to process*

One assumption that narrows the understanding of service design is the underlying idea that design is the output of an overall process. Vink (2019) claims that in the dominant narrative service design is often acknowledged as a means to develop new or improved services only. This perspective perceives the value of service design as something that is embedded in the output of the service design process – the developed service – as emphasised through statements like for example: "(T)he end result of this process across the different service design levels was a new football-watching service" (Teixeira et al., 2016, p. 248). Akama & Prendiville (2016) criticise this centering around the object as well. They stress that more emphasis should be given to the "active power of the process"(p. 31). Aligned with the understanding of design as a verb, Vink's (2019) work also suggests to put more focus on the value of the design process itself. She refers to a project in which a website was created to support youth in regards to mental health issues. A website like this is often presented as the outcome of the design process and perceived as where the value and contribution of service design lays. However, after interviewing the project participants "it became clear that much of the transformation happened in the process" (Vink, 2019 p.91). The participation in co-design activities for example transformed the way clinic staff perceived the youth – they started to recognise them as resourceful and capable, which in turn transformed the way the staff interacted with the youth at the clinic (Vink, 2019). Her example also exemplifies that relations established between actors participating in a design process can fuel positive transformation.

Dilnot (1982) also argues that the role and meaning of design goes well beyond the object that is supposed to be designed, but is a distinct form of socially significant activity – it is a way of thinking, communicating and giving. Vink et al. (2017) stress that service design methods should be acknowledged as a valuable means for transformation in themselves, rather than as a means to transition through the phases of the service design process working towards the final outcome only, as participating in them encourages actors to become aware and reflect on a certain situation and its constraints. This can in itself support them in realising more desirable futures. This perspective recognises service design as being "more than a practice for innovating services or a stage in the new service development process" (Kurtmollaiev et al., 2017, p. 70).

This novel perspective on service design differs from conventional ones as it expands the idea on service design to a more broad perspective that perceives the design process, regardless the output, as valuable.

2.1.3 The role of service designers – From main actor to enabler

This brings us to another assumption about design that challenges the understanding of service design – the idea that design is an activity carried out by professional designers (Vink, 2019; Manzini, 2015). If we acknowledge that the participation of actors in service design methods alone can support them in creating their desired futures, and thus the design process in itself is valuable, what does this then mean for the role of the designer? Who designs in this context? This dominant perspective where design is seen as an activity carried out by professionals is prevailing in service design too, however, is more and more criticised, as well. Opposed to the focus of literature about service design practice that often reports about the design activities carried out by companies and consultancies (Stickdorn et al., 2018a, pp. 262–263), Willis (2018) argues that design is "overdetermined by the model of professional design as the model of all designing" (p.2). Vink (2019) further elaborates that limiting the understanding of service design to time-limited activities carried out by professionals, reinforces the notion that service design is an exclusive activity, and Junginger (2015) argues it thus emphasises hierarchical power relations between designers and the people they design for. Manzini (2015) extends the idea of design by arguing that everyone designs since all people "consider a situation, imagine a better situation, and act to create that improved situation" (Series Foreword). This understanding of design is very much related to the often cited definition that design is to "device[] courses of action aimed at changing existing situations into preferred ones" from Simon (1969, p.111).

A perspective that acknowledges the design capabilities that are naturally inherited by all actors and which are supported by the means that information technology provides (Manzini, 2015), obviously contains an altered role for the 'expert designer' as well, as Manzini (2015) refers to people educated in design. Manzini (2015) stresses that those who are design experts have to "[distance] themselves from what has long been the figure of 'designer'"(Introduction). Thus, in this new realm, service designers rather act as enablers who support other actors and their individual and collective projects to design better, rather than being the main actor (Manzini, 2015). We would argue that this perspective on the role of designers is a more humble one, considering the fact that it more fully acknowledges the resources and capabilities of actors who are not educated in design.

This shift is an implication of changing relations between the designers and other actors, as the participants consequently hold more agency and ownership of the design process than previously, which moves the relation from more hierarchical to more equal and symbiotic relations (Pierri, 2017).

2.2 Co-design

In the view of how service design has evolved, co-creation has gained growing recognition as an approach and means to be applied to stay capable to constantly design in new, unknown and complex fields (Sevaldson, 2013) and as a key to ensure more sustainable and desirable solutions (Sanders & Stappers, 2008). Co-design can be defined as "the creativity of designers and people not trained in design working together in the design development process" (ibid. p. 6). Besides co-design, the term co-creation is often used, which Sanders and Stappers (2008) refer to as "any act of collective creativity" (p.6). As these definitions lie close to each other, we use them interchangeably in our work. The underlying belief that is driving co-creation as a popular approach forth is that people are the experts of their experiences and therefore should participate and be given a voice and agency in the design process (ibid.). This approach reframes the role of expertise within knowledge production and allows the participants to reclaim space for problem solving and creativity (Pierri, 2017).

2.2.1 Co-design and user-centered design

The practice of involving users in a design process comes in many different manifestations, with user-centered design and co-creation as examples of popular approaches within service design. Though these two practices differ in their purpose, they are often confused or treated synonymously (Sanders & Stappers, 2008). According to Sanders & Stappers (2008) however, it is important that we distinguish between user-centered design and co-design. Co-design involves participants in a hierarchically flat design process that perceives the participants as the experts. User-centered design on the other hand, considers the users (only) as a research subject. In the latter perspective, users may be observed or interviewed in the research, but beyond that hold a rather passive role (ibid.). When doing user-centered design one designs for people, whereas co-designing empathizes the idea of designing with people. Already in 2008 Sanders and Stappers (2008) predicted that service design practice would shift from working user-centered to working more co-creative, resulting in processes where people are considered as experts of their own needs. However, according to Steen et al. (2011) the term co-creation is still mostly used as a buzzword, and he claims that there is still a long way from theory to practice when it comes to ensuring co-creative processes. This may be a result of the lack of distinction between user-centred design and co-design.

Manzini (2015) states that within user-centered design "the design process is reduced to a polite conversation around the table of some participatory design exercise. In my view, the social conversation on which the co-design process is based is much more than that" (p.66). As design practice today centers around societal needs and is purpose-driven, user-centered design is not considered as an appropriate approach anymore: "The user centered approach cannot address the scale or the complexity of the challenges we face today. We are no longer simply designing products for users. We are designing for the future experiences of people, communities and cultures" (Sanders & Stappers, 2008, p. 10). Sanders & Stappers (2008) highlight that in regards to designing within highly increased complexity, user-centered design approaches are likely to fail. As design practice now centers around societal needs and is purpose-driven, it requires another approach. Co-creation on the other hand, is considered as being a suitable approach within service design (Akoglu, 2016). According to Sanders & Stappers (2008) the service design practice and society, will change if we apply co-creation to large scale problems as this approach ensures a strong link between people's needs and their environments. Akoglu (2016) concurs that in order to ensure a more sustainable future, we need people to take part in shaping it. We have to go from considering the user as a subject who we observe and try to understand, to considering them as collaborative partners of the project.

When comparing the above mentioned definitions of user-centered design (seeing the user as a research subject) to the definition of co-design (seeing the participant as the expert), it becomes clear that there is a great difference in the two approaches. Since the approaches differ in their intentions about how the design process is processed, who designs, for what purpose and with what outcome, we consider it to be important to properly distinguish the practices and to use the terms more considered.

2.2.2 *Benefits of co-design*

How do we then ensure a design process that is co-creative and not 'just' user centered? According to Akoglu (2016), it is essential when designing within the complexity of services and systems, to include relevant users early in the design process and to internally design the interactions (ibid.). She stresses that there is no correct answer on how to involve and collaborate with users in a co-creative process, as the approach can take many shapes varying in intensity, extent, timing and roles of the participants (ibid.). The importance however is that the value is created collaboratively with the involved people.

Sanders & Stappers (2008) stress that though the level of creativity of the stakeholders naturally varies and affects the process, a benefit of co-creation is that everyone can take part regardless of their creative competences. The approach is supposed to allow everyone to work together and communicate with each other regardless of their backgrounds (Akoglu, 2016). The result is that we end up working in much more diverse teams than earlier and in a good mix of various skills and knowledge from which designers can benefit (Sanders & Stappers, 2008).

As stressed by Akoglu (2016) co-creative research approaches do not only help designing for complex challenges, it furthermore has benefits that go beyond the actual service design project. Ideally, it will result in an increasement of creativity within traditional practices, by making people think outside the box and by developing innovative solutions in the future (Akoglu, 2016). From this perspective co-creation creates positive ripple effects on several levels – from the creative process, the service and the project management, to creating longer-term effects (Steen et al., 2011).

Steen et al. (2011) divide the benefits of working co-creative within service design into three categories – 1) benefits for the service design project, 2) benefits for the participants, and

3) benefits for the organizations involved. According to him, co-creation can help to gain a better understanding of the participants' needs and to collaboratively discuss and reflect on solutions to these. The users are therefore more likely to experience that the services they interact with are actually making a difference in their everyday life, and therefore they are expected to be of higher quality and sustainability. The involved organizations can benefit from getting inspired by an approach that might be new to them, resulting that they strengthen their competences within creativity and innovation (ibid.).

Furthermore, as co-creative processes involve the participating actors as practitioners of their own knowledge, the approach is supposed to be able to mobilize people's passion, reflections and thereby actions (Pierri, 2017). With this understanding the value and purpose of the design process shifts – it is no longer only about designing a fixed service as the outcome, but just as well about encouraging the participants' reflections and actions (Vink, 2019). Here, the value of service design is perceived as being embedded in the outcome and in the process.

2.2.3 Criticism of co-design

Besides arguments advocating for co-design as a promising approach, there are various scholars highlighting drawbacks, as well. Jørgensen et al. (2011) for example report from difficulties with getting actors interested in their design project, indicating that not only the co-design activity in itself can contain challenges but just as well the preparational process leading to the activity. They highlight the importance of preliminary knowledge creation by designers, to demonstrate other actors that they possess applicable knowledge and understanding about the addressed context and that they are able to speak the same language. Pierri (2017) emphasises that designers, when a project initialises, have to learn about the other actors' expectations and are the ones who have to negotiate their own role and articulate their own value to become involved in a project. Furthermore, Jørgensen et al. (2011) report that once interest is created, maintaining interestment and even engagement in order to keep the continuation of the project going, can be equally demanding. In a design project conducted by Jørgensen et al. (2011), the designers therefore had to have great power over the design process, since otherwise the project would have not been sustained. In this light one may ask whether co-design lives up to its name, when reality shows that the relations of power between the actors involved in the design process are not completely balanced. Furthermore, one can question whether or not the right actors were involved, as they might not have felt passionate enough about the topic. It might be worth reflecting upon, on the one hand, to what extent people's passion for the objective fuels sustainability and the transformative nature of a service design project and, on the other hand, whether the co-design perspective contains an overly idealised view of the power relations of the actors involved in the design process, if it assumes that they are equal, not hierarchical.
While co-design builds on the belief to expand the design team to include various, diverse actors, Trischler et al., (2018, p. 76) criticise that even if a co-design approach is employed

it still only “allows selected customers to become members of the service design team”, which gives them a more exclusive status opposed to those who have not been a part.

Pierri (2017) reports that giving and teaching co-design tools to people may not be sufficient to give them equal agency in the design process. She highlights that there are other, much more complex, factors that affect people’s participation, such as for example prolonged inequality, self-conception and relations between the participating actors. Being not aware of these influencing factors but assuming equal agency of the actors involved, can marginalise people during co-design activities, who are supposed to engage actively in them (ibid.). In this view, she claims that while co-design is generally recognised for being ethical and good, a serious analysis of the power relations and agency within a design process is long overdue (ibid.). Akama and Prendiville (2016) highlight that co-creative research processes are often very generic, with the purpose to reach an understanding of the needs of the involved. They stress that co-creative design processes need to go beyond the method focus that perceives the design process as a series of static events.

In this view, it becomes apparent that though a co-creative approach may contain many benefits, it seems to not necessarily live up to its intention to equally involve participants in a design process. The question is to what extent unequal relations among the participants in a design process can hinder their engagement and contribution. If we acknowledge that participation in itself can drive change forth and thus the value of service design may as well be embedded in the process, it is worthwhile to investigate how the right environments can help relationships emerge that enable actors to fully engage and contribute to the design process. The next chapter we will therefore dedicate to deeper investigate the role of relations in co-creative service design practice.

2.3 Relations

2.3.1 The relevance of relations in service design

When considering the relevance of relations in service design it is worthwhile to first define what a relation is. We understand a relation as “the way in which two people or groups of people feel and behave towards each other” (Cambridge English Dictionary, n.d.). When looking into relations in co-creative service design projects, two different focus areas arise. The first area focuses on the relations in the service system, whereas the second area concerns the relations between the participants in a design process. In the first mentioned focus, various actors interact with each other. This could for example be relations between patients and nurses, nurses and doctors, patients and doctors in a healthcare system. These relations are what the system is composed of (Vink, 2019). The second mentioned focus concerns how relations can affect the actors’ overall participation in the design team. This concerns relations between the designer and the other participants, as well as the relations among the participants in a design team themselves.

With this in mind, it becomes clear that our task as service designers is not only to co-design services with actors participating in a project, but just as well to develop processes and environments that support the possibility of individuals coming together – to design conditions where various forms of relations are likely to arise (Aguirre-Ulloa & Paulsen, 2017). Björgvinsson et. al (2010) as well argue that the purpose of working co-creative should be to foster long-term relationships, and to thereby ensure that the actions evolving from the process enter a real life context. This perspective Björgvinsson et. al. (2010) call ‘democratized innovation’, which is defined as “an open innovation milieu where new constellations, issues and ideas evolve from bottom-up long-term collaborations amongst diverse stakeholders” (p. 41). They highlight the importance of creating collaborative learning environments, where the process in itself brings new insights and knowledge to the participants through an open research process. The value then lies in the design process, the interactions and the relations, shifting the focus from project results to “creating arenas where different practices meet” (ibid. p. 49).

We believe that if we recognize that the relations in a design process – both in-between participants and between designers and participants – have an impact on the actors’ participation, we as service designers have to consider relations as a design material. We therefore need to consider how relational co-creation looks like in practice and what impact it has.

2.3.2 Relational services

As a starting point to explore and find answers to these questions it is worth reflecting about a statement by Manzini (2015): “Designers are engaged in a service profession”. Thus, we can consider our practice a service in itself – a service that supports actors in creating their desired futures. With this in mind, we would like to draw attention to a particular kind of service configuration – *relational services*, as defined by Cipolla and Manzini (2009), where we can find additional input to better understand how service design could potentially transition towards being more relation-focused and the impact this might have. Cipolla and Manzini (2009) define relational services as services that are "deeply based on interpersonal interactions" and that are "challenging the standard way of conceiving and offering services" (p.4). This means that these kind of services are deeply dependent on the relational qualities taking place in its operation (ibid.). They emphasise that designers should explore how these qualities of relational thinking can be applied and favored. If we as service designers manage to take on this responsibility, a relational service "improves or regenerates contexts of life, enabling and stimulating participants to collaborate with others. It means that relational services are able to promote a 'social learning process' towards sustainability, indicating a way of living based on sharing and collaboration" (ibid).

To further exemplify the characteristics of relational services, we would like to refer to *relational welfare* (Cottam, 2011) as an exemplary movement that focuses on relational services. Relational welfare values services that emotionally support users through relationship building and the fostering of social capital. It suggests new models that are more human and caring than the traditional welfare models – relational approaches that are collaborative and social. The radical approach suggests that professionals spend 80% of their time to focus on the users instead of on the system. The role of the professionals is then not "to intervene and solve problems", but to "listen, challenge and support a process of discovery and transformation" (ibid. p. 140). The approach thereby redefines the relations within the system, which among others can be done through storytelling and narratives. Cottam (2011) states that there is a need to "create the conditions for new forms of creative, developmental conversation", and to move away from traditional methods, such as for example focus groups. "It is through this new conversations that something shared, collective and relational will be grown" (p.144).

We think that the concept of relational services contains insightful and relevant aspects that can just as well be valuable for the service design practice, if we consider our practice as a service in itself. Looking at the challenges that service designers face when conducting co-creative processes, we see a potential that a more relational approach could aid practitioners to overcome these. Furthermore, by looking at the benefits of co-creative service design, we assume that a relational approach can even leverage these strengths.

2.4 *Research focus*

In the following we will summarise the insights gained through the literature review that lead towards the research question of this thesis.

By looking at the historical transition from product to service design, we became aware that service design evolved out of a set of general assumptions about design that are now limiting a more situated understanding of service design (chapter 1.1). One of these limitations concerns the perception about where the value of service design is embedded. Opposed the common understanding that the outcome at the end of a service design process is where the value lies, we learned that the design process can be considered as valuable as well, as research states that actors' participation in a design process is a means for transformation in itself (chapter 1.2).

This led to exploring other assumptions about design – that design is an activity carried out by people educated in design. However, learning that every person has naturally inherited design capabilities made us come to an understanding that professional designers should rather act as enablers – supporting others to fully make use of their design capabilities. This consequently implies an altered relation between designers and the people they design for (chapter 1.3).

In this regard co-design serves as an appropriate approach – an approach to be applied within service design where professional designers design with people not for them (chapter 2.0). We looked into how co-design differs from user-centered design and understood that it is important to distinguish the approaches more thoroughly, as they imply wholly different ideas, values and practices (chapter 2.1). We investigated the benefits that a co-design approach brings to the service design practice and became aware that it is a suitable approach in various ways: It aids designers in staying capable to design within complexity. It acknowledges and leverages the power of the design process. It builds on and fuels people's naturally inherited design capabilities (chapter 2.2).

However, the investigations also made us discover various challenges that service design practitioners face when following a co-creative approach. We recognised that there is a reciprocal link: On the one hand, co-design applied in practice seems to fail to fully live up to its intention – to establish equal relations. On the other hand, this seems to negatively affect actors in their participation (chapter 2.3).

This recognition induced us to try to understand the impact that relations between actors have for their participation in the design process. The research revealed that relations – "the way in which two people or groups of people feel and behave towards each other" (Cambridge English Dictionary, n.d.) – have only recently been recognized as fundamental design material within service design and their impact still lacks to be understood (chapter 3.1). While considering service design practice in itself as a service, we looked into the concept of relational services and examples in the field of welfare as a starting point to understand what a more relation-focused service design practice could imply. This research indicated that a more relational approach could potentially support service design practitioners to overcome the challenges and to leverage the benefits that the promising approach of co-creation contains (chapter 3.2).

Given this background, we wish to dedicate our academic research of the thesis to examine what impact a co-creative research approach with a particular focus on relations has on the service design practice. Thus we framed our research question as follows:

2.4.1 Research question

How does a relational co-creative research approach impact service design practice (in the context of welfare)?

3

Project context

Project context

As part of this thesis we conducted a case study that served as a lense to explore the academic research question. This initialises with a general introduction into the topic of dementia, which is the theme of the case study, presents data and knowledge, and states the important role, challenges and needs of dementia family caregivers. The chapter concludes with the presentation of the initial problem statement that is addressed in order to start the design process.

The chapter is divided into the following subchapters:
3.1 Dementia
3.2 The importance of dementia family caregivers
3.3 Challenges of dementia family caregivers
3.4 Needs of dementia family caregivers
3.5 Problem statement

3.1 Dementia

Dementia is a syndrome and an umbrella term for several diseases that damage the brain and affect a person's memory, decision-making, language, other cognitive abilities, mood, personality and behavior. The most common form of dementia is Alzheimer's disease, which makes up around 60–70% of all cases. Other forms include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Since dementia is mostly chronic and develops progressively, it often starts with small symptoms that are likely to then become inherently severe, so that they strongly interfere with a person's ability to perform everyday activities (World Health Organization, 2017).

Dementia represents a major, growing challenge for society. As a result of demographic ageing the number of people with dementia will rise within the next decades. According to the World Health Organisation (WHO) there are currently around 50 million people living with dementia worldwide, a number that is ten times higher than Denmark's total population and which is expected to triple by 2050 (World Health Organisation, 2019). In Denmark 36,000 elderlies above 65 years old are registered with a dementia diagnosis, however, as stated by the Danish Dementia Research Centre (DDRC) the number of unreported cases in Denmark is much higher (Danish Dementia Research Centre, n.d.). According to estimates, around 82.000 Danes over 65 years old suffer from dementia (Nationalt Videnscenter for Demens, 2020c), which means that only around 40% of the affected people are registered with a diagnosis (Nationalt Videnscenter for Demens, 2020a).

Although dementia mostly affects older people, with age as the strongest risk factor and though it is a major cause of disability and dependency among older people worldwide, it cannot be seen as a normal part of ageing (World Health Organization, 2017). In rare cases the first symptoms appear at the age of about 40 years (Nationalt Videnscenter for Demens, 2020c). This means that young people are not excluded from developing dementia. Of all cases, 9% are people who developed symptoms before the age of 65. This form of dementia is referred to as young onset dementia. Besides age and genetic factors there are factors, such as physical and cognitive inactivity, mid-life depression, social isolation, low educational attainment, unbalanced diets, tobacco and alcohol that can increase a person's risk to develop dementia (World Health Organization, 2017).

Dementia is wide-ranging in types, causes, symptoms and impacts. There is a lack of awareness and understanding of dementia in society, which leads to barriers in diagnosis and care, misconceptions and stigmatization (Blankman et al., 2012). For example, Alzheimer's Disease International states that there is little awareness in society that dementia develops and changes over time and that people with dementia are therefore often generalised and all put in the same undifferentiated category. This can lead to that their potential to contribute to conversations is being devalued, or that emphasis is mostly put on their impairments rather than on the remaining abilities and strengths. This lack of knowledge often leads to society avoiding interacting with people with dementia, and that people with dementia fear the reactions of others, feeling ashamed and inadequate. The stigma associated with dementia and the resulting social isolation and lack of stimulation can cause disabilities beyond those that are caused by the illness itself (Blankman et al., 2012).

3.2 The importance of dementia family caregivers

Family members are likely to become the primary caregivers of a person with dementia, thus they often hold a great responsibility that can be difficult to carry as a non-professional caregiver. In Denmark up to 300.000-400.000 people are an immediate relative and give care to a person with dementia (Nationalt Videnscenter for Demens, 2020c). The cost related to dementia is difficult to calculate, however it is estimated to be around 10 billion DKK yearly in Denmark (Nationalt Videnscenter for Demens, 2020c). This number however only includes the direct health and social cost, not including the lost earnings and the effort of the family caregivers. The cost of informal and unpaid care for people with dementia provided by caregiving relatives is estimated to be 7,4 billion DKK per year (Nationalt Videnscenter for Demens, 2020b). These numbers emphasise that informal family caregivers represent a major part of the Danish healthcare system.

As described by Haley (1997) the caregivers tasks in the early phases of the dementia disease primarily concern the management of finances and medications, whereas later they become increasingly responsible for fundamental physiological human needs, such as hygiene, clothing and food. Furthermore, the monitoring of the patient’s safety becomes increasingly relevant, since behavioural problems, such as depression, wandering and a lack of orientation may occur. According to Haley, all of this can imply a 24/7 responsibility. Furthermore, caregiving relatives are an indispensable key for formal healthcare providers to receive knowledge about the patient’s condition and to implement medical treatment. It is obvious that the work provided by dementia family caregivers is critically important for the healthcare system, however very fragile due to the various challenges they face. The following chapter will describe the challenges of being a dementia family caregiver.

3.3 Challenges of dementia family caregivers

Most people suffering from dementia receive care from their immediate family members, typically their spouses or children (Brodaty & Donkin, 2009). These family caregivers of people with dementia are often referred to as “the invisible second patients” (ibid. p. 217). The literature states that the risk and level of suffering from various psychological as well as physical health issues is significantly higher for caregivers of people with dementia than for caregivers of people with other disabilities (Brodaty & Donkin, 2009; McCabe et al., 2016). In fact, full-time family caregivers are twice as likely to be in a bad health condition than non-caregivers (Lord et al., 2014). The effects of being a dementia family caregiver are wide ranging and mostly negative.

Dementia family caregivers are facing an increased risk of mental health problems that can manifest for example as depression or stress. Recognising the changes in behavior of the person with dementia, witnessing a progressive deterioration of personality, experiencing the feeling of gradually losing a loved person, seeing them suffering and eventually witnessing their death, can be a stressful, sad and traumatic series of events (Haley, 1997). Moreover, caregivers run the risk of physical health problems as well. Constantly having to adapt to the needs of the person with dementia can result in poor sleep patterns, significantly more household chores, such as cleaning and laundry and physical strains through moving or lifting the person with dementia (Alzheimer's Research UK, 2015; Brodaty & Donkin, 2009).

Besides the strains directly related to caregiving, caregivers frequently experience secondary stress factors, such as the impact the disease has on the social life, as well. For example, as stated by Alzheimer's Research UK, a person's dementia has a major impact on the relationship between the caregiver and the other family members. According to them, people caring for a loved one may experience that their family is unaware of the challenges they face or feel left alone with the responsibility and duty of caring, which can lead to family conflicts, little social contact and support, and social isolation (Alzheimer's Research UK, 2015). Furthermore, many caregiver prioritise the needs of the person with dementia over their own wellbeing. They sacrifice time for themselves, for hobbies and for relationships with a partner or friends, due to feeling worried and guilty when leaving the person with dementia alone (ibid. 2015).

In addition to that, a relative's dementia can also have a great financial impact. According to Alzheimer Research UK (2015), there are several ways in which the financial situation of caregivers can be affected. Some people may experience it as a loss of income due to having to reduce working hours or even to give up employment because of the inability of leaving the person with dementia alone. Moreover, providing care to someone can imply an increase in the daily usage of utilities, since someone is at home most of the time, but also higher costs for transportation, special food, care products and equipment.

3.4 Needs of dementia family caregivers

The needs of dementia family caregivers can be divided into two major categories. The first category includes the caregiver's needs related to the management of the care recipient, whereas the second concerns the caregiver's personal needs (McCabe et. al., 2016). The first category deals with, among others, the need for information and knowledge – from knowledge about the diagnosis and progression of the disease, to behavioral challenges and methods to handle these, to information about possible support services (ibid.). Moreover, caregivers are in need of better care support, both formally and informally. Examples of needed formal support is help from care professionals and adequate and flexible service provision. Informal care support can be received through for example peer support groups to share experiences and knowledge, as well as help from family and friends. The second category deals with caregiving relatives' personal needs and stresses that relatives have a need to address their own health – both physical health, but even more importantly their psychological health. They often feel a lack of support in handling the stress and burden that being a caregiver causes. This support is essential to be received from both, formal care help, such as professionals and organisations, as well as informally from for example social support groups (ibid.).

Caregiving relatives express the need of having a strong communication with professionals in the healthcare sector as a way of ensuring that both relatives and the people diagnosed with dementia get the right information and knowledge (ibid.). They say that the communication should be routinely and ongoing as the dementia disease progresses and the needed information therefore continuously changes. These challenges show the need for improvement within policy and service provision. McCabe et al. (2016, p. 71) express that caregiving relatives' needs are not met by professionals, and that "studies have reported that there is a difference between caregivers' perceived needs and professionals' assessment of their needs".

3.5 Problem statement

Literature shows a wide range of challenges that family members of people with dementia face in their everyday life as informal caregivers. As we recognise what a responsible role dementia family caregivers have and how indispensable they are for our society, the healthcare system and the well-being of dementia patients, we think their own well-being should be supported and ensured as best as possible. Therefore, we want to dedicate the case study to this topic and contribute to improving the conditions for dementia family caregivers in the context of the welfare system, whose services may seem to have a great positive impact when targeted to the caregivers' needs. In addition to healthcare services, which contribute people's physiological and psychological health, we consider welfare services as the free support provided by the government to ensure people's wellbeing for all intents and purposes – including health, contentment, prosperity, equality and safety.

The case study conducted in this thesis is initialised by further exploring and identifying the challenges of dementia family caregivers from their own perspective and understanding how they experience their role. The initial problem statement of the design process is therefore formulated as follows:

How can we use service design to discover the challenges of being a dementia family caregiver in the context of the Danish welfare system?

4

Methodology

Methodology

This chapter presents the methodologies that are employed to explore the problem statement and the academic research question. First, we introduce the Double Diamond methodology, which provides the framework to structure the overall design process of the case study. Thereupon, the Feed Forward methodology is presented, which we integrate as an inspirational methodology into the Double Diamond to explore the academic research question. In addition, the chapter gives on overview of the overall research process.

The chapter is divided into the following subchapters:
4.1 Double Diamond
4.2 Feed Forward
4.3 Academic research process
4.4 Ethics
4.5 Limitations related to Covid-19

4.1 Double Diamond – to address the problem statement

To structure the overall design process, we employed the Double Diamond methodology. The Double Diamond is a design process model launched by the Design Council in 2004, which is often applied in service design. It helps to break down the design process into a sequence of phases to support comprehensibility and to enable design teams to plan and conduct the design process (Design Council, 2015). Figure 1 illustrates the Double Diamond, which suggests that a design process can be divided into the phases of discover (divergent process in which a problem is discovered), define (convergent process in which a problem is defined), develop (divergent process in which a solution is developed), and deliver (convergent process in which a solution is delivered). Design methods are used as a means to transition from one phase to the next, aiming to derive a solution (Design Council, 2015).

As described in the literature review, over time service design started to be used to solve more complex, multi-faceted and systemic challenges, which made design practitioners criticise the Double Diamond for being too simplified (Drew, 2019). One of the major criticisms on the Double Diamond is that it is illustrating a linear process, though design processes actually are known to be fluid and iterative (Drew, 2019). Another weakness is that the Double Diamond does not ensure a co-creative design process as it indeed suggests how to design – to go through divergent and convergent phases of designing – but not who designs. We assume that this can increase the risk of working user-centered instead of co-creative. In response to the criticism, the Design Council recently revised the model and the so-called Framework for Innovation was created (Design Council, 2019). The main component of this framework is still the Double Diamond model, but it has been expanded to include four principles to be adopted to ensure effective processes – 1) put people first, 2) communicate visually and inclusively, 3) collaborate and co-create and 4) iterate. In addition, a method bank is provided and the importance of a leadership and engagement culture highlighted (ibid.). However, we are in doubt whether mentioning design principles alone can ensure that they are taken into account. Therefore, and despite its weaknesses, we decided to apply the original Double Diamond in the thesis, as it brings simplicity and understandability into planning, structuring and thinking about the overall design process and as we have experience working with it.

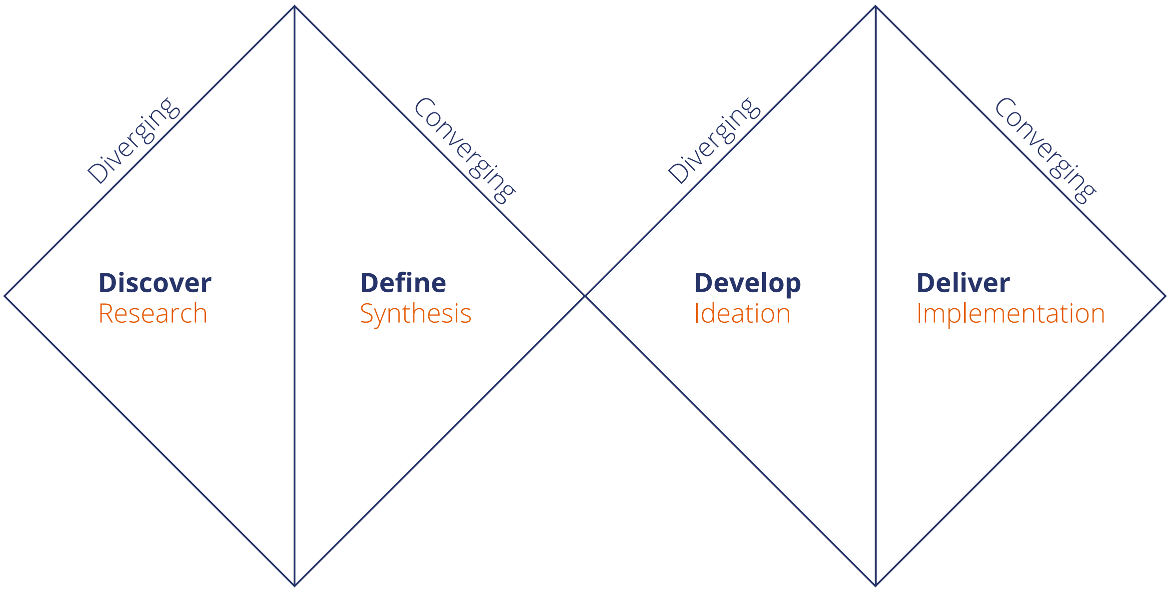


Figure 1: Double Diamond process model

4.2. Feed Forward – to explore the research question

To find answers to our academic research question about how relational co-creative research impacts service design practice when doing welfare projects, we decided to employ another methodology – the Feed Forward methodology (Kieboom et al., 2015). Opposed to the Double Diamond, Feed Forward suggests a framework and methods that are particularly developed to conduct co-creative research. Furthermore, the Feed Forward methodology stresses the importance of building relations to and between the participants of a design team and its methods are developed to exactly create these.

Feed Forward is a short form for 'Feedback to go Forward'(ibid.). The methodology (figure 2) was developed by Kennisland, a dutch organization that researches and designs social progress, and arose from their work and various experiments with Social Innovation Labs. These labs are temporary physical spaces located in a certain context and a means to collaboratively – with citizens, professionals, civil servants and policymakers – experiment and reflect on how to transform for example welfare by investigating what the current challenges are. Feed Forward provides a framework to "open up traditionally expert-driven practices like research, policymaking and innovation methodologies to people" (ibid. p.8). The aim of a lab is to create new relations and interactions among people and to make new perspectives on actions emerge (ibid.).

Feed Forward was developed as a methodology to run Social Innovation Labs and is commonly not applied in service design. For us as students with limited resources, for example financially, it was not realistic to conduct a Social Innovation Lab. However, as co-creation and interpersonal relationship building is the core of Feed Forward (ibid.), we think it is still worthwhile to employ the methodology to explore the research question of this thesis. In the following, we briefly outline the first three steps of the Feed Forward methodology, as defined by Kieboom et al. (2015) that we use as an inspiration to conduct our research process.

Step 1: Preparations

In step one, to begin the project, a research question has to be formulated to scope the social challenge, which will be the topic of the project. A multidisciplinary design team is set up that should reflect the social reality of the societal challenge. The design team becomes acquainted with the context and finds a space where to open up the lab (Kieboom et al., 2015).

Step 2: Collect, interpret and check stories

Central to the Feed Forward methodology are stories. In step two, the design team starts collecting stories from people by having conversations with them – stories about everyday challenges and what ideal solutions people are missing. Ideally, a story should be collected in a place that is familiar to the storyteller. Kieboom et al., (2015) stress that the more informal and authentic the setting is, the more comfortable a person is to share a story. It should be "an open, curious and equal conversation in which the distance between the story collector and the storyteller becomes as small as possible" (ibid. p. 47). The focus should be on getting people to open up about what they are engaged in and what their everyday life revolves around, rather than having answers to a list of specific questions. After the conversation the team interprets the information gathered, through writing a detailed story about the storyteller's challenges and ideas. Then, the team hands over the story to the storyteller again, to let them check its accuracy. This gives the storyteller a chance to edit and thereby makes them the owner of their story. Even though the storyteller might only give small corrections this is an important step, as it can start fruitful discussions and give in-depth insights to the story collectors (ibid.).

Step 3: Collective evaluation

The third step is to evaluate the stories and to identify opportunity spaces to tackle the mentioned challenges. First, the design team internally sift the material to then invite all storytellers to a collective evaluation, which is recommended to be organised in an informal environment, such as a barbecue.

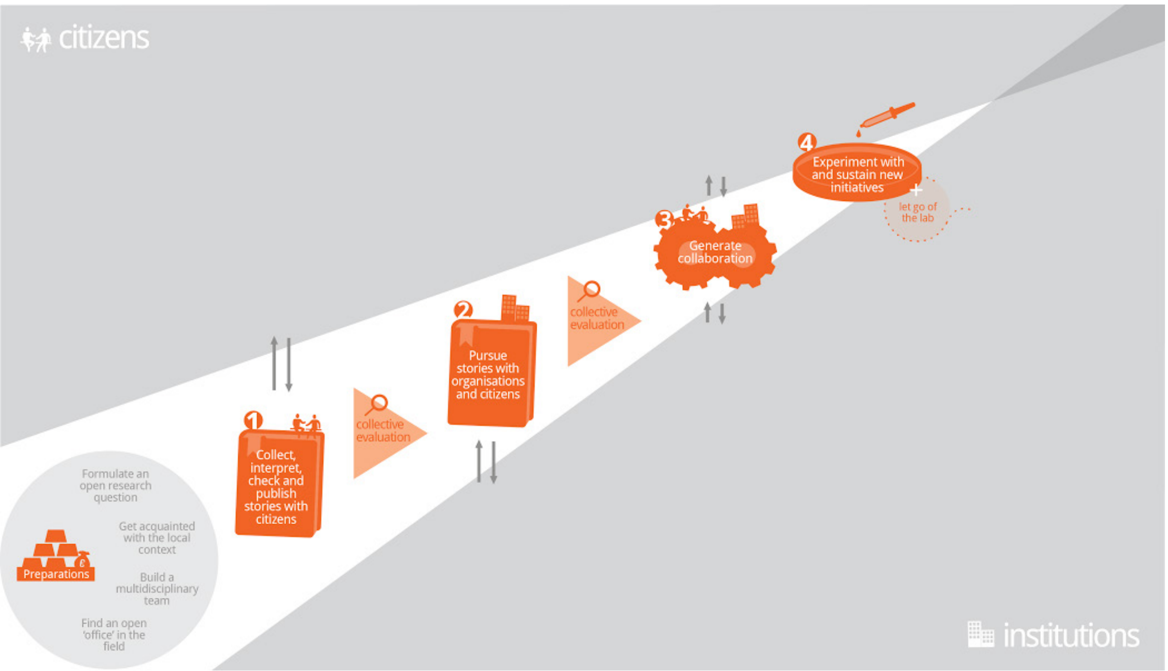


Figure 2: Feed Forward methodology

Since the methodology serves as an inspiration, we adjusted it according to our purposes. As our research question focuses on the research phase we integrated the first phases of the Feed Forward – those that focus on research and analysis – in the discover and define phase of the Double Diamond (figure 3). Furthermore, we did not follow the exact steps but rather got inspired by them and the suggested methods, and combined them with service design tools that we considered would meaningfully enrich the steps. Furthermore, we renamed the steps, as exemplified below (figure 3).

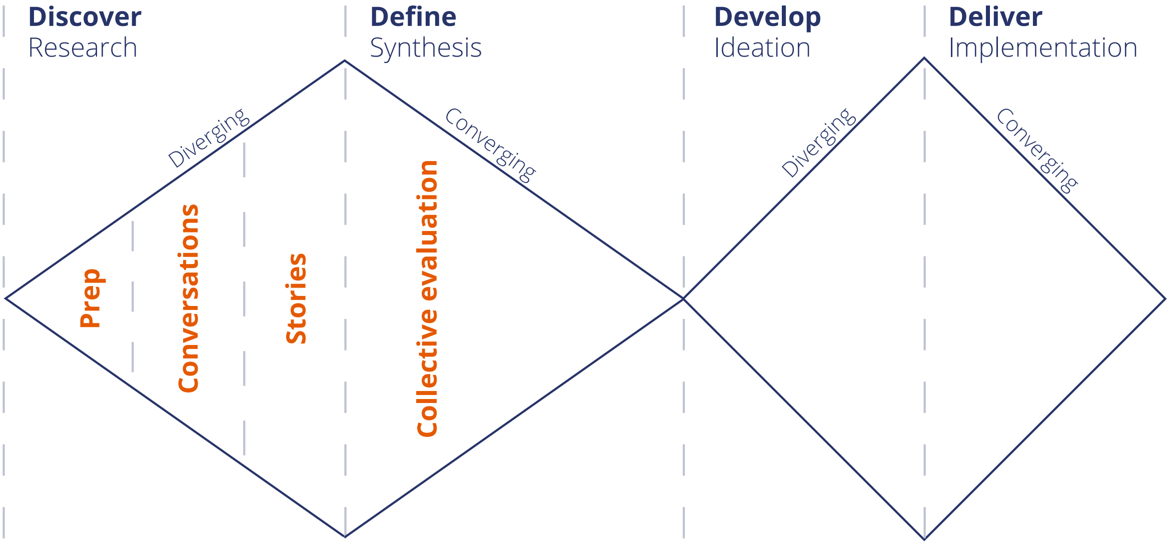
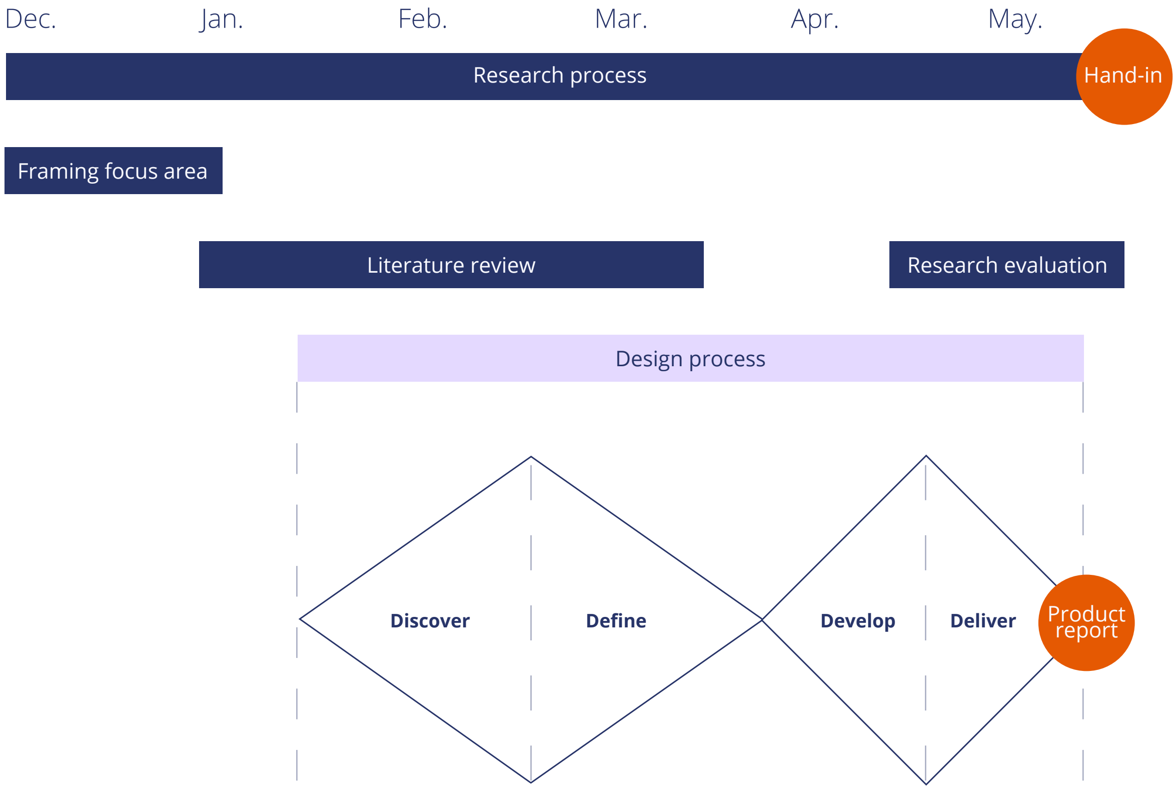


Figure 3: Steps of Feed Forward integrated into Double Diamond

4.3 Overall research process

Figure 4 visualises the overall research process of this thesis. It further shows how the two chosen methodologies will be integrated into the design process. The Double Diamond serves as a methodology to run the overall design process. The Feed Forward serves as a methodology to explore the academic research question.

This thesis has two outcomes. The first is the academic research contribution that evolved from exploring the academic research question. The second is our contribution to improving the quality of life of dementia family caregivers, which evolved from conducting the design project.



Methods employed

- + Desk research
- + Expert interview
- + Stakeholder map
- + Conversations
- + Journey maps
- + Stories

- + Transcribing
- + Clustering
- + Collective evaluation

- + Relational mapping
- + Key insights
- + Crazy 8
- + Scenarios
- + Co-constructing stories

Figure 4: Overall research process

4.4 Ethics

To complete the description of our approach we want to address the topic of ethics. As conducting qualitative research within the context of dementia implies collecting highly personal and sensitive data, we find it important to hold an ethical awareness in all phases of the process. Inspired by ethical principles outlined by Bjørner (2015), we are considerate about the fact that we work with a sensitive topic that affects the people we engage with. Therefore, we intend to be respectful, honest, truthful and legal towards the participants who are involved in the project. We avoid to make unnecessary demands on the participants and base our activities on informed consent (ibid.).

4.5 Limitations related to Covid-19

We would like to make the reader aware of some limitations related to the COVID-19 situation, which has affected the design of our study. Originally, the aim was to explore the impact of relational co-creative research throughout the all phases of the design process by collaborating with various stakeholders. Therefore, we had several co-creative activities scheduled in spring 2020 that involved dementia family caregivers, dementia patients, as well as healthcare and welfare professionals within the field of dementia. These activities aimed to take into account the diverse perspectives of various stakeholders to explore the impact of the chosen approach. However, in March 2020, halfway through the thesis project, the Corona virus started to spread in Denmark, resulting in the lockdown of society and the healthcare sector being in a state of emergency. The planned co-creative activities were therefore no longer possible to conduct and had to be cancelled, as it was not allowed to bring people together physically, and since the professionals naturally had more important things to deal with caused by the situation.

The academic research question of the thesis was therefore revised, resulting in a focus on the research and analysis phases only, rather than on the whole design process. While being a limitation somehow, this change of focus also made it possible to reflect on the impact of a relational co-creative approach on another level, as we got the opportunity to compare the co-creative process of the first two phases, to a rather user-centered process in the last two phases. This contrast enabled us to better reflect on where in a service design process the value is embedded and whether service design research creates more value than ‘just’ research insights.

Therefore, the participants of the project were solely dementia family caregivers, though scholars advocating for co-creative design approaches stress the value of collaborating with diverse stakeholders (Akoglu, 2016). Thus, our research would probably be more impactful and valid if it was conducted within a fully co-creative setting, incorporating the perspectives from other stakeholders as well. However, instead of feeling regretful of the circumstances we see the potential of exploring this in future projects.

5

Case study

Case study

This chapter documents the process of the case study, which serves as a lense to explore the academic research question of the thesis. As mentioned in chapter 3, the case study aims to contribute to the quality of life of dementia family caregivers. The chapter is divided into sections defined by the four phases of the Double Diamond methodology – Discover, Define, Develop and Deliver – and documents the various activities conducted in the design process. It reflects on the employed methods and presents the insights and outcomes of the case study.

As the academic research question aims to explore the impact of a relational co-creative research approach, the activities in the Discover and Define phases were crucial to explore both the research question and problem statement. The activities conducted in the Develop and Define phase of the design process were mainly conducted in order to address the problem statement. The activities conducted in the first two phases of the design process – Discover and Define – were therefore consciously more elaborate and in-depth than the last part of the design process to ensure profound insights related to the research question.

This chapter is divided into the following subchapters:

5.1 Discover
5.2 Define
5.3 Develop
5.3 Deliver

5.1 Discover

The Discover phase started with preparatory activities, as it is suggested in the Feed Forward methodology. Our preparations included formulating an initial problem statement, carrying out desk research to build up a foundation of knowledge about dementia and the Danish welfare sector, and conducting an expert interview to confirm and challenge the insights from the desk research. Following the methodology, we then worked with conversations and stories as a qualitative research tool to co-creatively generate insights with and about dementia family caregivers.

This subchapter will be divided into the following sections:
5.1.1 Preparations
5.1.2 Conversations
5.1.3 Stories
5.1.4 Conclusion of the discover phase

5.1.1 Preparations

Inspired by Feed Forward (Kieboom et al., 2015), we started the design process with preparatory activities to build a foundation for the field work. As mentioned in the project context chapter, the case study aimed to contribute to quality of life of dementia family caregivers and was therefore supposed to initialise with an investigation of their challenges. Thus, the problem statement for the design process to guide our work was formulated as follows:

How can we use service design to discover the challenges of being a dementia family caregiver in the context of the Danish welfare system?

The following preparations were supposed to build an initial foundation of knowledge about the theme, context and the realities of dementia family caregivers, who we wished to engage for the co-creative design process. This is aligned with findings from Jørgensen et al. (2011), who stress that preliminary knowledge creation about the realities of the people is a necessary first step in a co-creative design process, in order to be able to create people's interest and engage them in a project. In the following we will outline the preparatory activities conducted, their respective purpose and outcome.

Desk research

An important preparatory step in the design process was to gain a preliminary understanding about dementia and the challenges for dementia family caregivers. In order to collect information we conducted *desk research*. Desk research, as outlined by Stickdorn et al. (2018b) is often called secondary research and describes the collection, synthesis and summary of already existing research. As suggested by Stickdorn et al. (2018b), we used various sources, such as research papers, reports, websites, whitepapers, documentaries and other sources as a means to gain knowledge about the theme of dementia. The outcome of the desk research was synthesised and summarized in the text that is presented to the reader in chapter 3 of the thesis – the project context. The knowledge gained was seen as an appropriate starting point and as an enabler to have more informed conversations throughout the design process.

We conducted another round of desk research, focusing on exploring the formal and informal actors in the Danish welfare system that support, or intend to support, dementia patients and their family caregivers. We especially focused on the support services that are available around Copenhagen, as we expected this to be the main context in which we would work throughout the process. The findings were visualised in a *stakeholder map* (Stickdorn & Schneider, 2012). Generally, visualisations can aid service designers in many purposes, for example in capturing, understanding, analysing and communicating research or in imagining and designing new solutions (Giordano et al., 2018). Stakeholder maps are a fundamental tool within service design and give an overview of the actors involved in a given context (Stickdorn & Schneider, 2012). When creating a stakeholder map one usually first identifies all stakeholders involved, then maps them, to thereafter be able to analyse their relationship (Giordano et al., 2018). It is a good way to identify potential issues related to the various actors (Stickdorn & Schneider, 2012). In the stakeholder map we differentiated the formal and informal actors that dementia patients and their family caregivers might interact with (Figure 5).

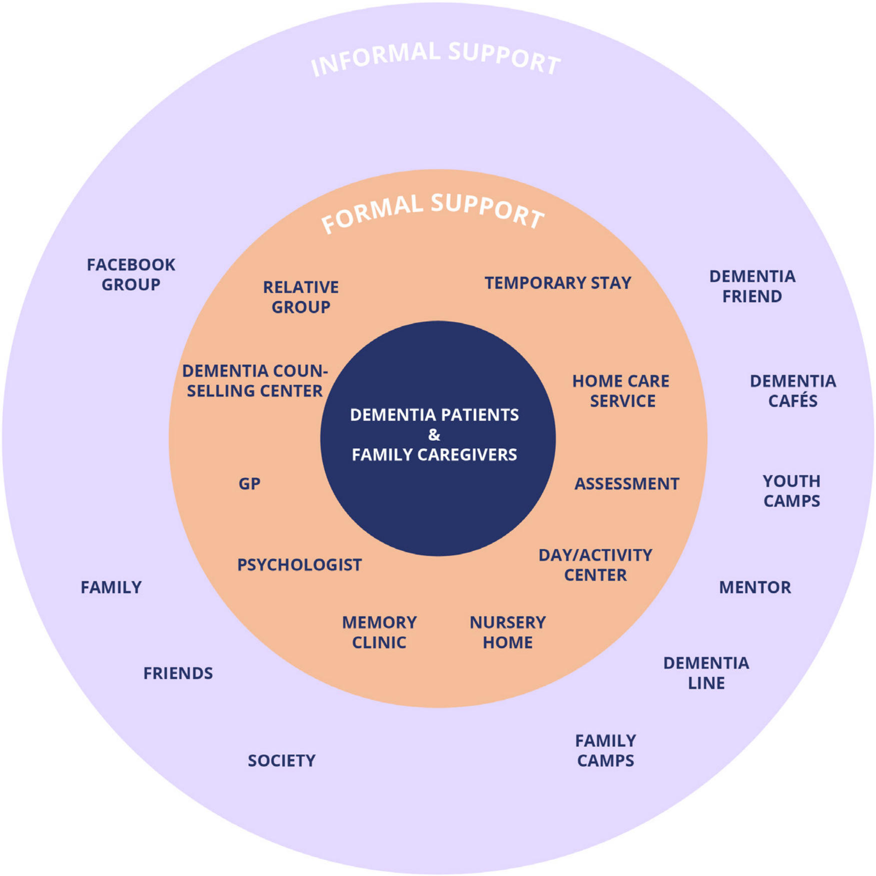


Figure 5: Stakeholder map

The stakeholder map visualises the desk research findings and gives an overview of the formal and informal stakeholders who offer services specifically focussed on providing support within the context of dementia. Some of them are solely focussed on supporting family caregivers, others are meant to support both – the person with dementia as well as the family caregiver. As the dementia patients and their family caregivers often are inseparable in the process, we placed them both in the center of the map. The inner circle closest to the family caregiver and dementia patient contains the formal support services offered through the public welfare and healthcare system. These are among others general practitioners, specialised memory clinic departments at hospitals, nursery homes, dementia coordinators, and supporting relative groups organised by municipalities. The outer circle represents the informal actors, such as the Alzheimer Association and their many supporting initiatives, Facebook groups, as well as family and friends. The stakeholder map was a help to not only identify the various actors in the system, but also to identify who might be a suitable stakeholder to conduct an expert interview with, which was planned as the next step. It furthermore was an important preliminary knowledge for us to possess before meeting the dementia family caregivers, as we wished to explore the quality of their interactions with actors in the system as well as outside the system. Besides the stakeholder map we created a more detailed table to capture all the preliminary research findings related to stakeholders in one place. This table can be found in the appendix (appendix A.01).

Expert interview

As a next step in our preparation phase we planned to conduct an in-depth interview with an expert in the Danish dementia context who holds knowledge about the challenges faced by dementia family caregivers. In-depth interviews are a fundamental qualitative research method within service design that allows researchers to understand a specific stakeholder's perspective and learn more about a certain topic (Stickdorn et al., 2018b). The interview was supposed to help find out whether or not the findings of the desk research about dementia family caregivers' challenges apply to caregivers in Denmark as well and to learn more about their challenges.

We decided to reach out to a counsellor of the dementia line of the Alzheimer Association, who was involved in the formation of the association. The Alzheimer's Association is an independent member organisation for people with dementia and their families. The association works to provide better conditions for people with dementia and their relatives (Alzheimerforeningen, n.d.). The dementia line is a telephone service offered by the Alzheimer Association, where affected people can get consultancy in all issues concerning dementia (Demenslinien, n.d.). By interviewing an expert and counselor we expected to receive both rich information about the challenges that family caregivers face and furthermore to learn about the holistic landscape of services available to dementia family caregivers. The interview, which took around one hour, was guided by a semi-structured interview guide concerning questions about her job as a counsellor, and challenges of dementia family caregivers (appendix A.02). Though it was a phone interview in which we expected to face challenges in establishing an atmosphere that allows a profound conversation, it was a valuable and in-depth conversation, which we assume was supported by the counsellor's professional experience in having in-depth conversations on the phone through her job as counselor on the dementia line. The interview recording can be found in the appendix (appendix A.03).

Through the expert interview we learned more about various challenges that family caregivers face and how they can be divided into different stages of the process that dementia patients and their family caregivers go through. The first stage is when the first symptoms arise and a dementia disease is suspected. The second stage is during and after a diagnosis is made. Though the counsellor described the diagnosis as a door opener to support services there apparently often is a lack of both formal and well as informal support, or dissatisfaction with the available services. Family conflicts as a result of differing opinions and expectations were mentioned as well. The next stage that was expressed as extremely difficult for family caregivers is when considerations about moving the relative with dementia into a nursery home become necessary. This move, according to the counsellor, is often made too late. However, if the person moves into a nursery home this often still represents a challenging time as caregivers may not feel that their relative receives appropriate care. Furthermore, she mentioned the time close to and after the person's death as a challenging period in which the dementia line is frequently approached.

The counsellor highlighted several other emotionally difficult issues: the feeling of being alone, of losing someone, the change in character and behavior, the denial of the diseased person (which is quite frequent), and grief. She stressed that a lack of knowledge and understanding of society often leads to feelings of shame and guilt. Further, she emphasised that the wellbeing of the caregiver is completely intertwined with the wellbeing of the sick person and that if the sick person is in a bad constitution, the caregiver often is as well. Another issue that she highlighted as problematic is the lack of knowledge of general practitioners (GPs), which apparently often leads to false diagnoses and a lack of support and understanding. In addition to that, we learned that the counsellors in most cases advise callers to get support from a psychologist and seek support in relative groups. Furthermore, she said that there is almost no conversation where they do not refer to a dementia coordinator. In Denmark each municipality has its own regulations and processes regarding dementia, however they all have a dementia coordinator who is educated within dementia and who represents a primary contact person for dementia family caregivers and the sick persons. She emphasised that the earlier the family caregivers receive support, the better for the wellbeing of the caregiver throughout the process of the disease.

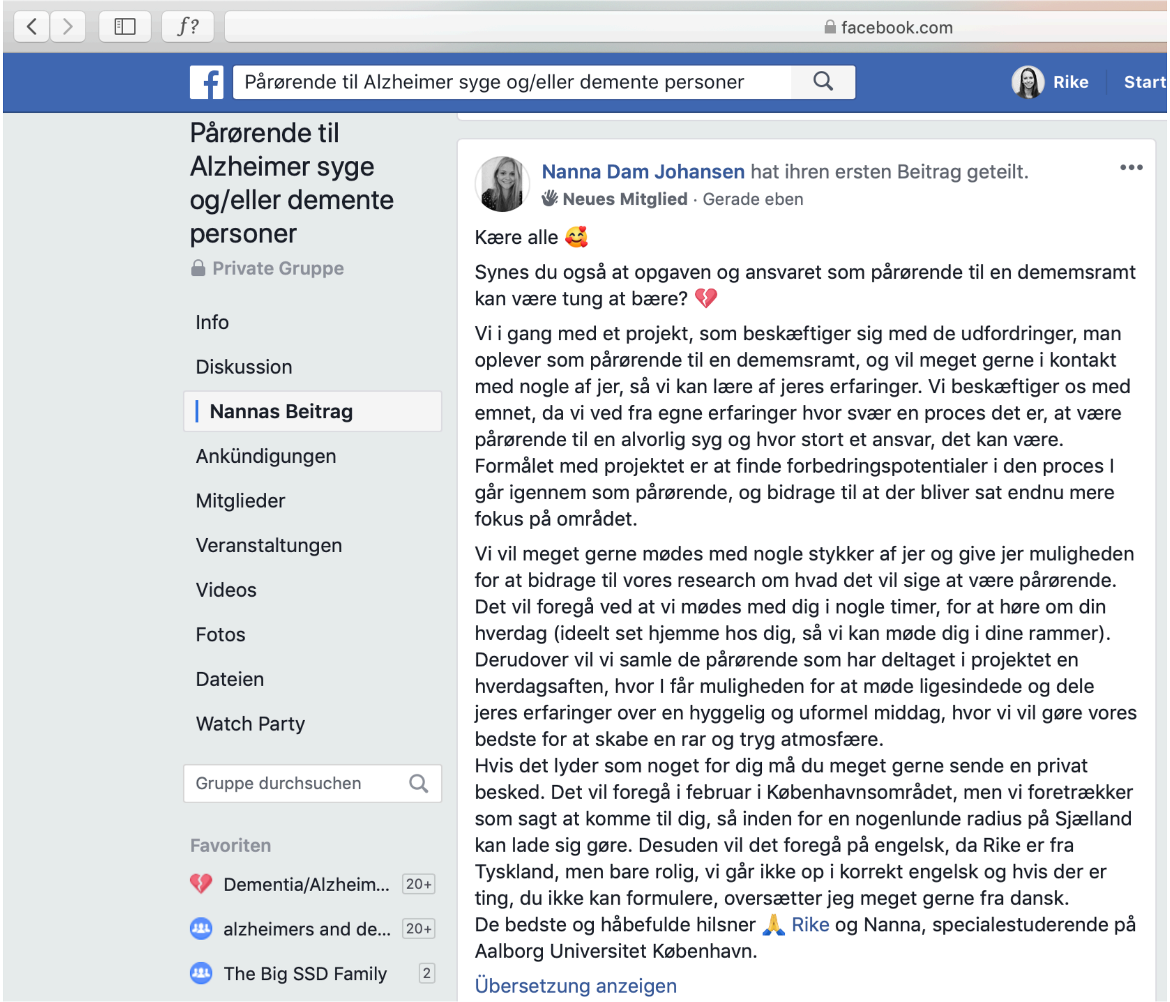
Through the detailed descriptions of the various problems that family caregivers face and by hearing from an expert that the family caregivers often are in a worse state of mind than the patient, we were able to confirm that there is a need to better support dementia family caregivers in the context of the Danish welfare system. Furthermore, we got more detailed information about the actors and services that we had earlier identified in the stakeholders map, and learned where difficulties in the interactions lay. We extended the stakeholder table, which can be found in appendix (appendix A.04) by one more column and added the newly received information about the respective actors.

Engaging people for the project

As the aim of the design project was to conduct a co-creative process with dementia family caregivers, the next step of the preparational work was to engage them as participants for the project. Therefore, we first needed to make them interested in the project. For this purpose we used Facebook as a platform to inform and invite family caregivers into the project. There exist several Facebook groups for dementia family caregivers in Denmark to support each other, where they share experiences, ask questions, give each other advice and emotional support. These groups were seen as a suitable place to engage people. These Facebook groups are also good examples of a general notion, where people are organising themselves in peer-to-peer networks or solidarity groups to solve urgent issues, independently from formal services by using their own capabilities to solve problems. This is aligned with Manzini's claim of people having naturally inherited design capabilities (Manzini, 2015).

The activity of inviting people to participate in a project is critical and should not be underestimated. Binder et al. (2015) for example point out that "(c)rafting an invitation to participate in a democratic design experiment is an active and delicate matter of proposing alternative possibilities just clearly enough to intrigue and prompt curiosity, and, on the other hand, to leave enough ambiguity and open-endedness to prompt the participants' desire to influence the particular articulation of the issue" (p. 162). When engaging people, it proved to be crucial for us to have preliminary knowledge and insights about dementia family caregiver's challenges, as it is also stressed by Jørgensen et al. (2011). It was our experience that it made the family caregivers realise that we were on their side and that we understood their difficulties, which encouraged their willingness to become a part. This was for example revealed through a message from a woman who became a participant in the project: *"Since I can hear that you know what you are talking about and if my/our situation can help just one person, then of course I will attend"* (translated from Danish).

We formulated a Facebook post (figure 6), which created interest from several people, who said they appreciate our willingness to contribute to improve the situation for dementia family caregivers. Several people considered the topic of the project as very relevant and started conversations with us through Facebook. Through these communications we were able to create the interest of ten people to take part in the project. However, due to the fact that some people's place of residence was far away from Copenhagen, we eventually ended up engaging six participants who live in or close to Copenhagen. We consciously chose to recruit a diverse group of participants for the project, as we wished to gain a wide range of insights into the various challenges family caregivers of people with dementia face, and to get a picture of the whole system around dementia patients and their family caregivers. We therefore strived to find both caregiving spouses and caregiving children of dementia patients. Further we aimed that the group represented both life situations with patients living at home and in nursery homes. This we succeeded in, as the profiles of the participants, which are shown below (figure 7), exemplify.



Nanna Dam Johansen hat ihren ersten Beitrag geteilt.
Neues Mitglied · Gerade eben

Kære alle 🥰

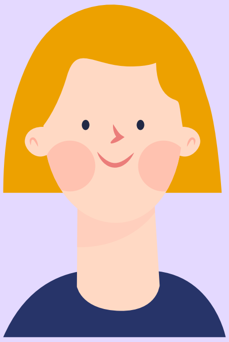
Synes du også at opgaven og ansvaret som pårørende til en dememsramt kan være tung at bære? 💔

Vi i gang med et projekt, som beskæftiger sig med de udfordringer, man oplever som pårørende til en dememsramt, og vil meget gerne i kontakt med nogle af jer, så vi kan lære af jeres erfaringer. Vi beskæftiger os med emnet, da vi ved fra egne erfaringer hvor svær en proces det er, at være pårørende til en alvorlig syg og hvor stort et ansvar, det kan være. Formålet med projektet er at finde forbedringspotentialer i den proces I går igennem som pårørende, og bidrage til at der bliver sat endnu mere fokus på området.

Vi vil meget gerne mødes med nogle stykker af jer og give jer muligheden for at bidrage til vores research om hvad det vil sige at være pårørende. Det vil foregå ved at vi mødes med dig i nogle timer, for at høre om din hverdag (ideelt set hjemme hos dig, så vi kan møde dig i dine rammer). Derudover vil vi samle de pårørende som har deltaget i projektet en hverdagsaften, hvor I får muligheden for at møde ligesindede og dele jeres erfaringer over en hyggelig og uformel middag, hvor vi vil gøre vores bedste for at skabe en rar og tryg atmosfære.
Hvis det lyder som noget for dig må du meget gerne sende en privat besked. Det vil foregå i februar i Københavnsområdet, men vi foretrækker som sagt at komme til dig, så inden for en nogenlunde radius på Sjælland kan lade sig gøre. Desuden vil det foregå på engelsk, da Rike er fra Tyskland, men bare rolig, vi går ikke op i korrekt engelsk og hvis der er ting, du ikke kan formulere, oversætter jeg meget gerne fra dansk.
De bedste og håbefulde hilsner 🙏 Rike og Nanna, specialestuderende på Aalborg Universitet København.

Übersetzung anzeigen

Figure 6: Facebook post to engage participants



ROSA (63)

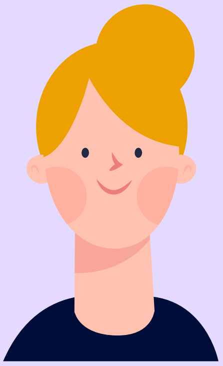
+ Gives care to her husband Hans (82)
+ Hans suffers from Alzheimer’s, Parkinson’s and Lewy Body dementia
+ Rosa noticed the first symptoms in 2010
+ Hans lives in a nursery home

Julie (30)

+ Gives care to her farther Sven (70)
+ Sven was diagnosed with Parkinson’s disease 25 years ago
+ Sven lives in a nursery home

Susanne (48)

+ Gives care to her mother Inge (78) and has been giving care to her father who passed away
+ Inge was diagnosed with Alzheimer’s disease in 2017
+ Inge lives in a nursery home



Lise (59)

+ Gives care to her mother Bente (84)
+ Bente was diagnosed with Alzheimer’s disease in 2012
+ Bente lives in a nursery home

Annie (65)

+ Gives care to her husband Oskar (75)
+ Oskar was diagnosed with Alzheimer’s in 2011
+ Annie and Oskar live together in a house

Figure 7: Profiles of the participating dementia family caregivers

Preliminary reflection on preparations

We quickly discovered that engaging family caregivers who found it relevant and giving to take part in such a project, was not as challenging as we initially thought. It seemed that some people even considered it as their duty to contribute to generate more knowledge about the theme of dementia and therefore gladly agreed to contribute. This might be due to the fact that we were inviting caregivers through Facebook groups, whose main function is to support each other, share knowledge and give advice. We therefore tapped into an already established group of people, who have unmet needs in their role as a dementia family caregiver, which might have made it less challenging for us to convince them about the relevance of the project and to engage them. As designers, we therefore experienced the benefits of entering a context in which people already acknowledge the importance of improving a situation and could through our project basically fuel and facilitate this process. However, even though we succeeded in engaging people, the process was not without challenges and limitations. Our initial idea about how to get in contact with potential participants was through relative groups for dementia family caregivers arranged by the Alzheimer Association and Copenhagen municipality. However, we were informed upon request that this was not possible, as it would require the prior consent of all caregivers present. We thus also experienced difficulties of getting immersed into a sensitive field. Although the approach through Facebook has eventually worked well, we also see advantages in engaging people through an organization or community.

5.1.2 Conversations

With the insights and knowledge gathered from the activities conducted in the preparation phase, the next step was to do the actual fieldwork and learn about the experiences from the dementia family caregivers' point of view. Inspired by the Feed Forward methodology, the actual fieldwork started by collecting stories from the dementia family caregivers' perspectives. The suggested means to collect these stories are conversations (Kieboom et al., 2015). In service design interviews can be seen as the methodical counterpart to conversations. There are several qualitative research methods used within service design with interviews being among the most popular ones (Stickdorn et al., 2018b; Stickdorn & Schneider, 2012). Conversations however, are only rarely explicitly mentioned as a research method. Some practitioners from the field of user experience design however, point out a difference between interviews and conversations (Motivate Design, 2019). They claim that interviews not only have "a structured formality that places limits on the discussion, they're also guided by someone who doesn't have a close personal relationship with the subject. The interviewee may seem like they're answering questions honestly, but what they're usually doing is filtering their answers based on assumptions about what the person asking questions expects to hear. They may worry about being judged for their responses, or they may simply not feel comfortable giving an honest answer" (ibid.). Conversations, on the other hand, they stress, are "organic, chaotic even. They follow a non-linear path informed by the previous history and relationship between the participants. There's less of a fear of being judged or concern that answers might be held against anyone. They can probe into personal information that wouldn't be appropriate for an interviewer to ask. While the results are unfiltered, messy, and sometimes inconsistent, it's a more honest representation of what a person thinks and feels" (ibid.). The difference between interviews and conversations highlighted, is interesting and relevant in the context of this thesis, as it describes interviews as an environment controlled by the researcher, whereas conversations are seen as a situation of equal control. It further is stressed that the challenge with conversations lies in establishing a genuinely trustful relation between the conversational partners, as only then people are completely open and honest (ibid.). This is aligned with what Kieboom et al. (2015) stress is important when having conversations. They claim that in order to make people feel comfortable the atmosphere should be as informal and natural as possible. The conversation should be "open, curious and equal" and the distance between the conversation partners "as small as possible" (ibid. p. 47). Pierri (2017) stresses that design is most transformative if it is "authentic to the lived experience" of people (p. 2954).

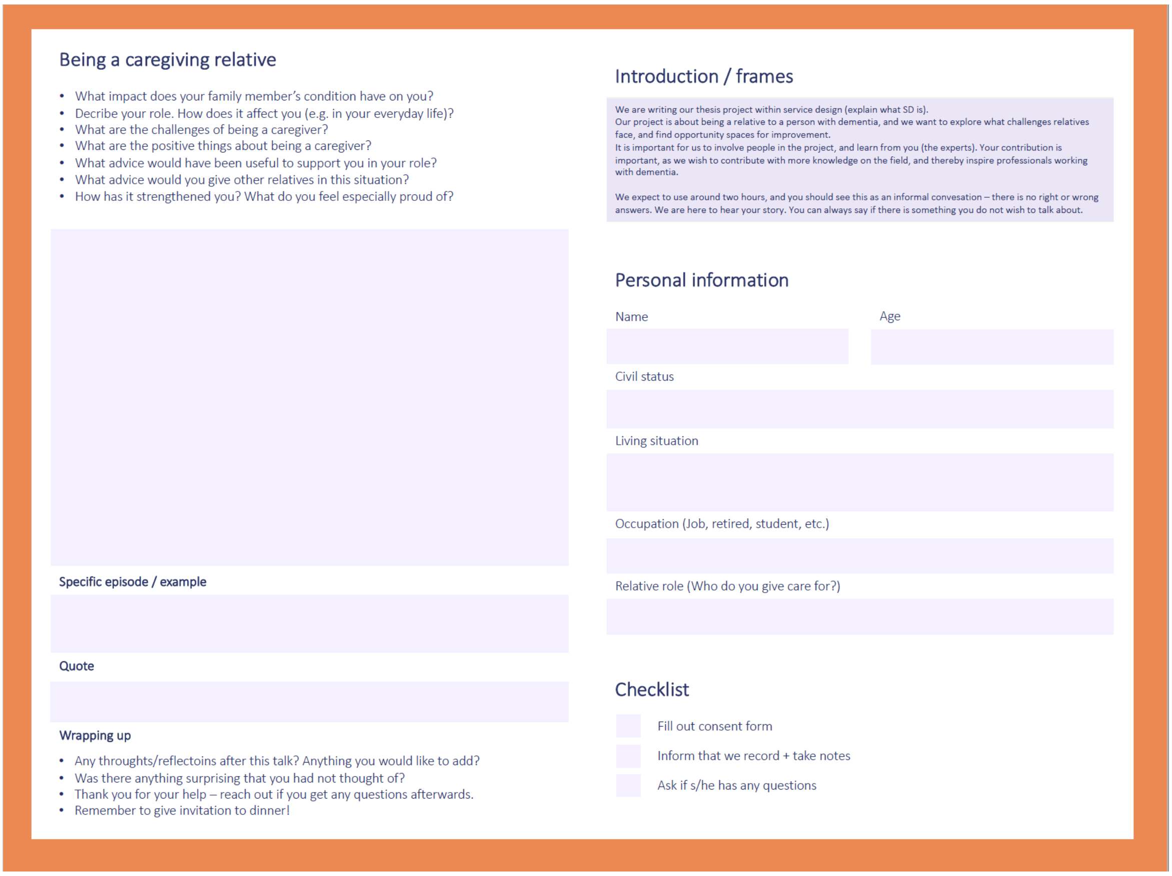
Inspired by these suggestions we aimed to meet the dementia family caregivers in their homes, as this is their natural environment and an informal setting where we expected people to be most comfortable to share their stories with us (figure 8). In addition, a meeting at their place meant less effort on their part, which is not to be neglected when taking the strenuous role of dementia family caregivers into account.

Figure 8: Conversation with a dementia family caregiver

We had five conversations each lasting between two to three hours. For the conversations we loosely defined roles between us, mainly in order to have one person responsible for the conversation and one responsible for taking notes. We did not bring a laptop to the meetings – a decision that was consciously taken to make the conversation feel as natural as possible. Instead, we had developed a conversation guide (figure 9) that provided space for notes and served as a means to have a loose structure for the conversation. The template in its full length can be found in the appendix (appendix A.05). Further, we recorded the conversations after consent was given. The interview recordings can be found in the appendix (appendix A.06).

As we aimed to make the distance between us and the storyteller as little as possible, we tried to have open, naturally flowing and curious conversations, rather than following the questions one by one. Thus, the conversation sometimes got off course, however often revealed a great amount of insights about the caregivers world of feelings and thoughts. Sometimes however, it became challenging to keep a balance between letting the caregiver tell everything she found relevant, while still ensuring to get insights about some concrete aspects we had in mind.

Often we started with a casual chat when meeting the participants before having a more contextual introduction from our side, where we gave information about us, the project and its purpose. We introduced the tools and emphasised that there were no right or wrong answers to our questions, and that if there was anything the person would not want to talk about we could just move on. The formalities, such as the consent form obviously also brought formality into the conversation but at the same time, explaining that it obligated us to protect their data, probably also contributed to a feeling of trust on the part of the caregivers. Throughout the conversations various service design tools were used. These will be explained in the following sections before presenting the findings from the conversations.



Being a caregiving relative

- What impact does your family member's condition have on you?
- Decribe your role. How does it affect you (e.g. in your everyday life)?
- What are the challenges of being a caregiver?
- What are the positive things about being a caregiver?
- What advice would have been useful to support you in your role?
- What advice would you give other relatives in this situation?
- How has it strengthened you? What do you feel especially proud of?

Specific episode / example

Quote

Wrapping up

- Any throughts/reflectoins after this talk? Anything you would like to add?
- Was there anything surprising that you had not thought of?
- Thank you for your help – reach out if you get any questions afterwards.
- Remember to give invitation to dinner!

Introduction / frames

We are writing our thesis project within service design (explain what SD is).
Our project is about being a relative to a person with dementia, and we want to explore what challenges relatives face, and find opportunity spaces for improvement.
It is important for us to involve people in the project, and learn from you (the experts). Your contribution is important, as we wish to contribute with more knowledge on the field, and thereby inspire professionals working with dementia.

We expect to use around two hours, and you should see this as an informal convesation – there is no right or wrong answers. We are here to hear your story. You can always say if there is something you do not wish to talk about.

Personal information

Name
Age
Civil status
Living situation
Occupation (Job, retired, student, etc.)
Relative role (Who do you give care for?)

Checklist

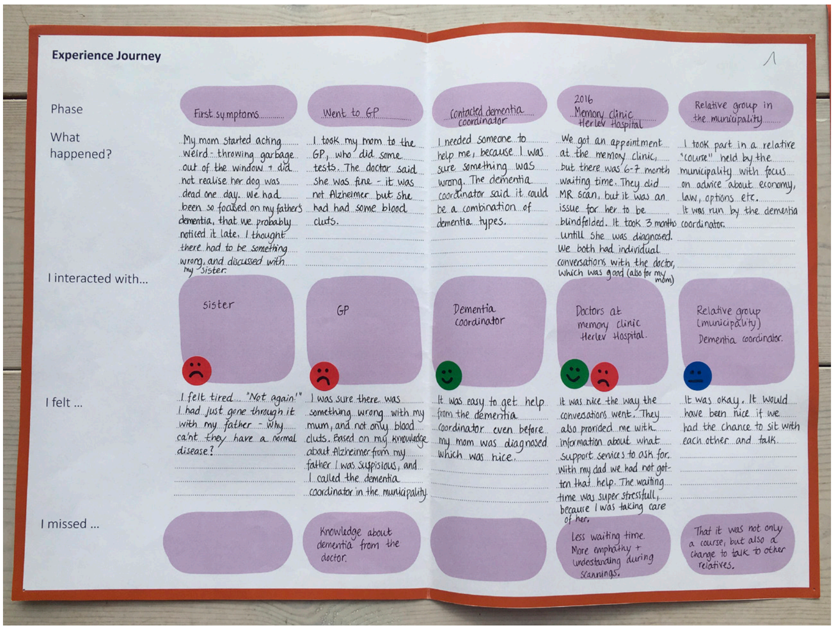
☐ Fill out consent form
☐ Inform that we record + take notes
☐ Ask if s/he has any questions

Figure 9: Conversation guide template

Journey map

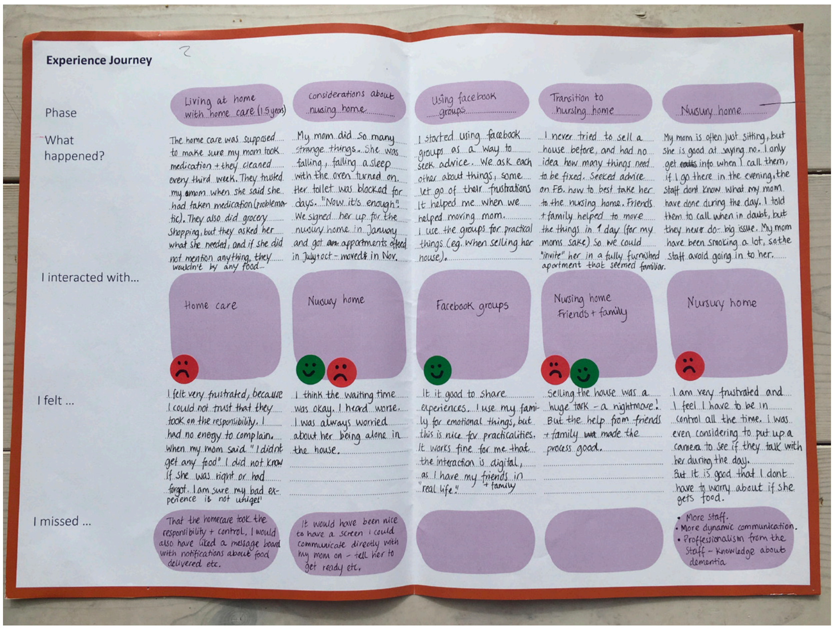
Through the conversations it was our aim to investigate, which existing services and actors of the Danish dementia welfare system the family caregivers had interacted and come into contact with already. We found it important to learn, which of the actors they perceived as helpful and supporting and which were lacking important aspects. In order to capture their experiences in a logical and chronological way, we created a journey map template (appendix A.07) and brought it as a tool to be used during the conversations. A journey map is a fundamental tool used in service design and aids in visualising, understanding and analysing someone's experience over time (Stickdorn et al., 2018b). Journey maps are structured in sequences of steps and can represent experiences on various levels. They are a flexible tool that can be adjusted to include diverse information, depending on its purpose (Stickdorn et al., 2018b).

The template helped to visualise and understand the intangible experiences of the dementia family caregivers and their interactions with various actors. Furthermore, the journey map proved to be a helpful communication tool in the course of the conversations. While talking, the family caregivers often used it to go back in their narrations by pointing on steps and thereby making it easier for us to follow and keep track. Initially, we thought it could be the storyteller filling out the template, however, during the first conversation we acknowledged that this would interrupt their flow of talking. Therefore, it was the notetaker who filled it out along the way. In the end of the conversation we used the map to confirm whether we had understood and captured the information correctly. Furthermore, each step was given a smiley sticker – green for a positive experience, blue for neutral, red for problematic. When we later put the journey maps on our research wall (Stickdorn et al., 2018a), the smileys were helpful as they clearly visualised the caregivers' feelings towards a certain interaction and thus made them more accessible for us. All of the journey maps can be found in the appendix (appendix A.08). Figure 10 exemplifies an exemplary journey as created during the course of a conversation.



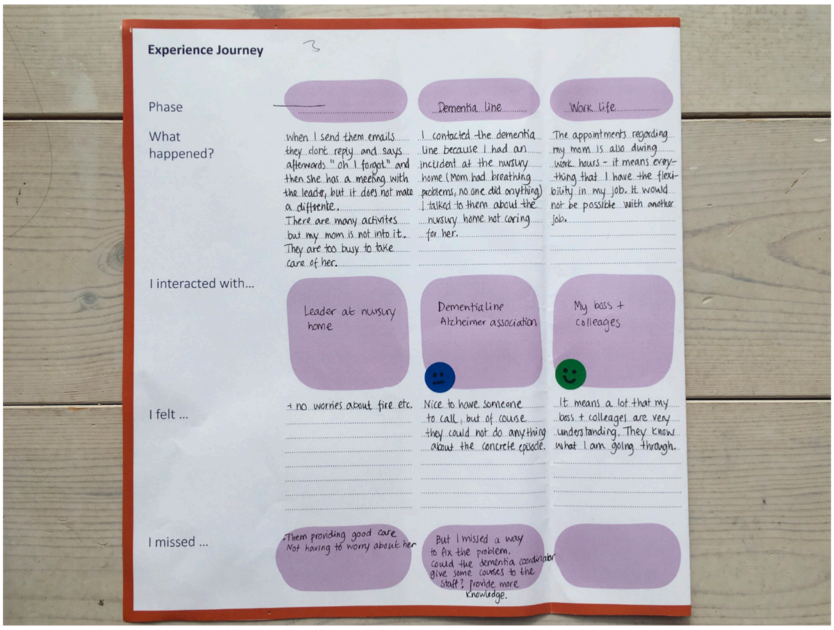
Experience Journey 1

Phase	First symptoms	Went to GP	Contacted dementia coordinator	2016 Memory clinic Herlev Hospital	Relative group in the municipality
What happened?	My mom started acting weird - throwing garbage out of the window + did not realise her dog was dead one day. We had been so focused on my fathers dementia, that we probably noticed it late. I thought there had to be something wrong, and discussed with my sister.	I took my mom to the GP, who did some tests. The doctor said she was fine - it was not Alzheimer but she had had some blood cluts.	I needed someone to help me, because I was sure something was wrong. The dementia coordinator said it could be a combination of dementia types.	We got an appointment at the memory clinic, but there was 6-7 month waiting time. They did MR scan, but it was an issue for her to be blindfolded. It took 3 months untill she was diagnosed. We both had individual conversations with the doctor, which was good (also for my mom)	I took part in a relative "course" held by the municipality with focus on advice about economy, law, options etc. It was run by the dementia coordinator.
I interacted with...	sister ☹	GP ☹	Dementia coordinator ☺	Doctors at memory clinic Herlev Hospital. ☺ ☹	Relative group (municipality) Dementia coordinator. 😐
I felt ...	I felt tired. "Not again!" I had just gone through it with my father - Why ca'nt they have a normal disease?	I was sure there was something wrong with my mum, and not only blood cluts. Based on my knowledge about Alzheimer from my father I was suspisious, and I called the dementia coordinator in the municipality.	It was easy to get help from the dementia coordinator even before my mom was diagnosed which was nice.	It was nice the way the conversations went. They also provided me with information about what support services to ask for. With my dad we had not gotten that help. The waiting time was super stressfull, because I was taking care of her.	It was okay. It would have been nice if we had the chance to sit with each other and talk.
I missed ...		Knowledge about dementia from the doctor.		Less waiting time. More emphathy + understanding during scannings.	That it was not only a course, but also a change to talk to other relatives.



Experience Journey 2

Phase	Living at home with home care (1.5 years)	Considerations about nusing home	Using facebook groups	Transition to nursing home	Nusury home
What happened?	The home care was supposed to make sure my mom took medication + they cleaned every third week. They trusted my mom when she said she had taken medication (problematic). They also did grocery shopping, but they asked her what she needed, and if she did not mention anything, they wouldn't by any food...	My mom did so many strange things. She was falling, falling a sleep with the oven turned on. Her toilet was blocked for days. "Now it's enough". We signed her up for the nusury home in January and got ~~an~~ appartments offerd in July + oct - moved in Nov.	I started using facebook groups as a way to seek advice. We ask each other about things, some let go of their frustrations. It helped me when we helped moving mom. I use the groups for practical things (eg. when selling her house).	I never tried to sell a house before, and had no idea how many things need to be fixed. Seeked advice on FB. how to best take her to the nursing home. Friends + family helped to move the things in 1 day (for my moms sake) so we could "invite" her in a fully furnished apartment that seemed familiar.	My mom is often just sitting, but she is good at saying no. I only get ~~calls~~ info when I call them, if I go there in the evening, the staff dont know what my mom have done during the day. I told them to call when in doubt, but they never do - big issue. My mom have been smoking a lot, so the staff avoid going in to her.
I interacted with...	Home care ☹	Nusury home ☺ ☹	Facebook groups ☺	Nursing home Friends + family ☹ ☺	Nursury home ☹
I felt ...	I felt very frustrated, because I could not trust that they took on the responsibility. I had no energy to complain. When my mom said "I didnt get any food" I did not know if she was right or had forgot. I am sure my bad experience is not uniqe!	I think the waiting time was okay. I heard worse. I was always worried about her being alone in the house.	It it good to share experiences. I use my family for emotional things, but this is nice for practicalities. It works fine for me that the interaction is digital, as I have my friends + family in "real life"!	Selling the house was a huge task - a nightmare! But the help from friends + family ~~wa~~ made the process good.	I am very frustrated and I feel I have to be in control all the time. I was even considering to put up a camera to see if they talk with her during the day. But it is good that I dont have to worry about if she gets food.
I missed ...	That the homecare took the responsibility + control. I would also have liked a message board with notifications about food delivered etc.	It would have been nice to have a screen I could communicate directly with my mom on - tell her to get ready etc.			• More staff. • More dynamic communication. • Proffessionalism from the Staff - knowledge about dementia



Experience Journey 3

Phase		Dementia line	Work life
What happened?	When I send them emails they dont reply and says afterwards "oh I forgot" and then she has a meeting with the leader, but it does not make a diffrence. There are many activites but my mom is not into it. They are too busy to take care of her.	I contacted the dementia line because I had an incident at the nursury home (Mom had breathing problems, no one did anything) I talked to them about the nursury home not caring for her.	The appointments regarding my mom is also during work hours - it means everything that I have the flexibility in my job. It would not be possible with another job.
I interacted with...	Leader at nursury home	Dementialine Alzheimer association 😐	My boss + colleages ☺
I felt ...	+ no worries about fire etc.	Nice to have someone to call, but of couse they could not do anything about the concrete episode.	It means a lot that my boss + colleages are very understanding. They know what I am going through.
I missed ...	Them providing good care Not having to worry about her	But I missed a way to fix the problem. Could the dementia coordinator give some courses to the staff? Provide more knowledge.	

Figure 10: Exemplary journey map

Triggers

Furthermore, we intended to use a list presenting various actors and initiatives within the context of dementia (figure 11) and a list of feelings (figure 12) as a means to trigger memories and past experiences on the parts of the caregivers. We imagined that the list of actors could support the storytellers in remembering which actors they had been interacting with, and thereby make it easier to fill out the journey. However, it became clear that most of them were able to clearly remember which steps their experiences consisted of and the list was therefore not needed. The list of feelings was also not used during the conversations as the storytellers were able to vividly express how they felt and what emotions they were going through.

Another important point regarding the triggers is that they to some extent seemed inappropriate. In several cases the storyteller was very emotional and sometimes cried while talking about her experiences. In such a case, obviously, it is important to show compassion instead of asking the participant to put a cross on a sheet of paper – something which could be perceived as insensitive and which may also destroy trust, as the storyteller might think we were only looking for information, rather than being genuinely interested in her fate. In some cases where the caregivers – who were certainly not less touched – spoke less emotional about the topic, we could have used the tools but did not find it necessary. In fact, in such conversations, in which deeply personal and moving issues are discussed, most likely such tools are not required, or should even be avoided. Instead, we found it important to be open, listen and ask profound questions.

I interacted with ...

- Praktiserende læge
- Hospital
- Alzheimerforeningen
- Besidder
- Demenskoordinator
- Dagcenter
- Hjemmehjælp
- Midlertidigt ophold
- Plejehjem
- Psykolog
- Demensrådgivning
- Rådgivnings- og aktivitetscenter
- Demensven
- Demenslinjen
- Familiecamp
- Demenscafé
- Pårørendegruppe
- Ungecamp
- Frivillige afdelinger

Figure 11: List of actors and initiatives within the context of dementia

Feelings

Afraid
Alone
Angry
Confused
Embarrased
Exhausted
Frustrated
Nervous
Sad
Scared
Shocked
Shy
Sick
Silly
Tired
Uncomfortable
Uninformed
Upset
Worries

Amused
Comfortable
Confident
Curious
Empathetic
Excited
Fantastic
Glad
Good
Grateful
Happy
Hopeful
Informed
Prepared
Proud
Relaxed
Repected
Taken care of
Thankful

Figure 12: List of feelings

Conversation findings

Through the conversations we learned rich details about the challenges of being a dementia family caregiver and the great responsibility they carry on their shoulders. We got several of the findings from the expert interview confirmed, but now learnt about them from the family caregivers' own point of view. We learned that the family caregivers' wellbeing is inevitably dependent on the wellbeing of their relative with dementia. The process of getting a diagnosis is often long and tiring, as the dementia patient and the family caregivers have to go through various complicated steps and meet many actors before the diagnosis is given. Often the interactions with these, for example with the GPs, are problematic, as these professionals do not always have the necessary knowledge about dementia in order to treat the patient with a holistic understanding. In some rare cases the family caregivers were offered individual meetings, but an identified issue was that family caregivers often feel that they are not provided with knowledge, information, guidance and support from professionals in order to be able to tackle and deal with the changes resulting from their relative's dementia disease. They therefore feel that they stand alone with too big of a responsibility, on the one hand, in regards to caring for their relatives and, on the other hand, in regards to learning and getting knowledge and information on how to do so. In general they feel that the system does not consider how affected they are by their relative's dementia disease and the wish to be better supported and to be more taken care of by the welfare system, was frequently expressed.

In addition, we learned that the dementia coordinators in the municipalities are crucial actors in the welfare system, whose support greatly contributes to the wellbeing of the family caregivers. They stressed to always experience great care and understanding from the dementia coordinator. The relative groups were as well highlighted as a forum that contributed to their wellbeing, as they got the opportunity to meet and exchange experiences with people in similar circumstances.

The conversations taught us that the family caregivers often are emotionally stressed, as they feel a big need of being in control. This is caused by a lack of trust to professional caregivers, such as homecare service and nursery home staff. It is the impression of the family caregivers that these professionals do not always have the necessary knowledge to take proper care of their relatives, which makes them feel worried. We found that this problem was often caused by a lack of communication and information provided by the professionals. However, we heard positive feedback from those dementia family caregivers, who stated to have a good relationship with the staff at their relative's nursery home. Through these cases we learned that, for the family caregivers' wellbeing, it is important to have a strong communication and a good relationship with the professionals taking care of their dementia relatives.

Preliminary reflection on the conversation method

While and after the participants told their stories various things were brought forth. One woman could for example suddenly remember experiences she had forgotten. Another woman expressed how good it felt that someone actually asks her how she feels about this disease, since normally everyone is mostly concerned about her father. Another woman highlighted how good it felt to talk and to get it out, because she never got the chance to do so. One woman expressed that she was emotionally very exhausted after having had the conversation with us. From the very beginning we were aware that we were demanding a lot by asking the participants to tell us their stories. Therefore, we always emphasised how grateful we were that they shared their experiences with us and that they took the time to meet us. As a sign of appreciation we always gave them a little thank you gift. To our surprise however, the women in most cases thanked us for devoting our thesis to this topic, as exemplified for example by the following exemplary message from a participant: *“Lots of wishes for your project and again thank you for choosing this subject, thus focusing on a matter that needs more focus and, dare I say: care”.*

5.1.3 Stories

The next step was, as suggested by the Feed Forward methodology, that we as designers wrote stories about the participants' experiences (Kieboom et al., 2015) and thus interpreted the findings mentioned above. The purpose of putting the findings into a narrative story was, on the one hand, for us to interpret and absorb the information through the writing, and on the other hand, to have a format that later on could be used to make others empathise with the caregiver's experiences.

Immediately after having had a conversation with a participant, we brought together our notes and revised the journey map. One of us then wrote down an anonymous story as a narrative. We aimed to do this at the same day, as the information would then still be fresh. Writing the stories was a valuable activity for us. It was a novel way to engage with research data that supported us in deeply internalising the new knowledge and emphasising with the storyteller. In addition, it revealed knowledge gaps, which was helpful too. However, it is a process that can easily bias the findings, as a story is a subjective interpretation. We were also aware that when writing the stories we dealt with emotional data, and that it is a very delicate matter to write another person's story and thereby 'take over', as we potentially could hurt the storyteller's feelings by showing how we interpreted and perceived their personal challenges. This made us carefully formulate the stories, which might have resulted in some information unconsciously being left out.

Kieboom et al. (2015) criticise that often people are only consulted by researchers, and rarely shown the results of the research activities, which prevents them from checking the results. Therefore they propose stories as a method to make the production and analysis of knowledge more inclusive and democratic (ibid.), which in turn challenges prevailing power structures with researchers being the experts and participants being the research subjects. For that, Feed Forward suggests that the written story is returned to the participant, so that she can read and check it, make corrections, and highlight concerns or misunderstandings. According to Kieboom et al. (2015) the stories are a powerful tool, for both the researcher and the participant, as working with them is a reflective activity that can prompt insight generation and in-depth exchange of knowledge and interpretation.

In service design stories can be found too, however are generally used for other purposes and in other phases of the design process. User stories (Stickdorn et al., 2018b) for example are essentially a tool to ensure a shared understanding between service designers and software developers about the user's goals. Storytelling (Stickdorn & Schneider, 2012) is a popular tool to narratively communicate ideas of service concepts from various perspectives and scenarios can be used to describe problems of current services as a foundation for ideating solutions or as "hypothetical stories" to explore ideas of new service offerings (Stickdorn & Schneider, 2012, p. 184). However, stories have not yet been introduced in service design as a research method to co-creatively produce knowledge, understanding and insights and were therefore seen as worthwhile to be explored within the context of this thesis.

Hence, we returned the stories to the dementia family caregivers, let them read it and make desired changes. It was an iterative and collaborative process aiming to capture the story in a way that fully aligned with the family caregiver's perspective. As the initial written story was only *our interpretation* of what was told, the iterative process of checking, making changes, rewriting, and checking again, made them own their story, and transformed them from what is normally seen as the research subject into the expert (Sanders & Stappers, 2008). For us, as designers, it was a valuable process as it generated a lot of added knowledge, empathy and an insightful story that represented the storyteller's experience in an appropriate way. In the following paragraphs two excerpts from emails are presented to exemplify the above mentioned:

"It was a wonderful meeting we had Wednesday and how wonderful it ended with this beautiful story, so beautifully written - I was very taken by it. Thank you so much!"

"Sorry to give you all these remarks, I truly loved your story of our story, but I find some things need to be corrected (I.e. titles etc), and I have to make sure that you really understand the reality of our living and everyday life and the background for my choices for my husband and me."

The outcome of the iterative process are five stories about the dementia family caregivers and their experiences and feelings regarding their role. In the following (figure 13) an exemplary story is presented while the remaining four can be found in the appendix (appendix A.09).

Susanne & Inge

» Why can’t my parents have a normal disease? Like cancer – something that I can relate to with my background as a nurse? «

48 years old Susanne lives in a suburb with her wife and two sons, and gives care to her mother Inge, who lives in a nursery home. Susanne has experienced dementia with both of her parents. First, her father got Alzheimer’s, who passed away five years ago, two years after they diagnosed him with dementia. During that time all the focus was on him and his disease, so that no one noticed, that also Inge was behaving differently.

However, one day when Susanne was visiting her, she found her mother’s dog laying dead on the floor. When she became aware that Inge didn’t realize that the dog was dead, she knew something was completely wrong. “Please, not again!”, she thought, acknowledging that this could be a symptom of dementia.

Susanne could convince her mum to go to the doctor, who found blood clots and said, apart from this, she were fine. However, Susanne was in doubt whether this diagnose was the only issue. Therefore, she took the matters into her own hands and contacted the dementia coordinator in the municipality to seek advice. Luckily, her municipality offers support from the dementia coordinator even before a diagnosis is made, which was

Susanne & Inge

very helpful. The dementia coordinator advised them to go to the memory clinic at Herlev hospital to get her mother checked. Unfortunately, they had to wait more than half a year for the first appointment, which was very frustrating.

At the memory clinic Inge was taken through different test. Among others, she had to do a CT scan, a procedure where she had to be blindfolded, which made her feel claustrophobia– something she had never felt before. "You can not blindfold a person with dementia!". Three months later she was diagnosed with Alzheimer's. Positive about the appointments at the memory clinic was the fact, that they gave Susanne and her sister advice on what kind of support they could ask for – a help that they had not experienced during the course of their father's illness.

Susanne got the opportunity to take part in a relative group held by the municipality, where they got advice on how to tackle the situation. However, Susanne would have liked to get the opportunity to talk to the other relatives about their experiences, as well.

The following time was a nightmare for Susanne. Inge was still living on her own and her condition got worse and worse. The home care did not do their job properly, and Susanne could not rely on them. They were supposed to make sure Inge took her medication, they would sometimes just leave the pills on the table or trust her when she said she already took it – resulting that she did not get her medication. Furthermore, they would ask her if she needed groceries. When Inge refused, they would just trust her without checking if this is actually true. "Don't ask the person with Alzheimer's, relief them from having to decide, guide them". This made Susanne very frustrated and especially worried. She had to always double check if her mother was good. Problematic was also that there was no communication between herself and the home care personnel. She only got information through her mother, and when Inge for example called and said she did not get any dinner, Susanne would not know if the food was not delivered or if her mother had just forgot.

» The worst part of this disease is that you get into a control mode, where it is very difficult to let go, because if you let go something will happen. «

At one point, after some critical episodes, Susanne thought: "Now it's enough!" and started the process of taking her mother to the nursery home. Susanne sought advice in various Facebook groups for relatives of people with dementia how to carry out the move to make it a easy as possible for her mother. With help from friends and family they managed to organize the move in one day, so that Inge could arrive to an apartment with her own furniture and pictures on the wall. These groups were and still are very helpful for her when she needs seeking practical advice. Here she asked for advice about how to make the best possible moving process for her mother. Selling her mother's house, however, was a nightmare, with so many things to be taken care of.

Susanne & Inge

Inge's life on the nursery home has been everything else than a fairytale. Susanne visits two to three times a week, which her sister does as well. Many issues have happened in the nursery home due to a lack of staff, their limited time, and especially, due to a lack of professionalism and knowledge from the care people.

There have been some critical episodes where Susanne experienced that the personnel did not react on serious health issues. She is also in doubt whether the staff actually talk much to her mother, which made her even consider to put up a camera. Susanne contacted the nursery home leader several times to discuss her concerns. However, often she does not get replies, and when approaching her at the nursery home she gets the same answer "Oh, I forgot", and nothing happens. In general, she misses a better flow of communication.

Susanne only gets information about her mother when she calls the nursery home. As she often visits in the evening, the staff who took care of her during the day is already off, which results that Susanne cannot get information about what activities her mother has been doing during the day.

Even though it is relieving for her no longer having to worry about whether her mother gets food or if there will be a fire in her house, it is clear that Susanne is frustrated about not being able to trust that the staff is doing their job professionally and responsibly. Recently, she contacted the dementia line at the Alzheimer Association to seek advice on how to tackle these issues at the nursery home.

Susanne expresses, that the responsibility of being a family caregiver has made her a person with a bigger need of having control, also in other areas of her life. Furthermore, she finds herself less tolerant and patient, and more aggressive than before. Luckily, Susanne seems to have a strong network when it comes to family and friends, who she uses to talk about emotions and struggles. Furthermore, Susanne has a very flexible job and tolerant boss that makes it possible to take part in meetings regarding her mother, which always happens during work hours. Her sister is a teacher, and therefore does not have the same opportunity as Susanne. She highlights the value of having a boss and colleagues, who understand the burden she goes through.

It is obvious that Susanne's effort has been very important for her mother's wellbeing, and one cannot help to worry about the ones with no such strong family caregivers around ...

» My mom went to a shower a week after she got in the nursery home, then they changed a lot of things, and then it took half a year until they showered her again, because they were too busy. «

Figure 13: Exemplary story

Preliminary reflection on the story method

For the participants, reading their stories was powerful, as it generated reflections, which prompted them to act differently than they would normally do. One participant stressed that the story was an eye opener for her. Reading a narrative about her own situation, written by someone else, made her realise that she went through an intense series of events and that she is allowed to take care of herself more without having to feel guilty. Another storyteller used her story as a means to communicate her experience to others. Another woman, who never had gotten any support as a caregiver, started reaching out for help from the system after having had the conversation with us. Of course this could have happened anyway, however we assume that the conversation contributed, as she got aware of various actors she could approach to be better supported. Here, the conducted preparatory research proved to be useful as we could pass our knowledge on to her.

The iterative story writing process therefore proved to be a valuable co-creative research method, as all parts got a lot out of the activity. On the one hand, we as designers got more rich details on the challenges and needs of the participants and ensured all misunderstandings to be corrected. On the other hand, the participants found it helpful to read their own experiences from another person's perspective, which resulted in valuable reflections and actions.

5.1.4 Conclusion of the Discover phase

In the Discover phase we first used various service design research tools to gain initial knowledge about dementia, the challenges that family caregivers face, as well as the services provided by the welfare system. The insights gathered through desk research and the expert interview built a foundation of knowledge that made us feel competent for the further steps. The initial knowledge helped us to develop an understanding and empathy for dementia family caregivers, which proved to be crucial for engaging potential participants for the project.

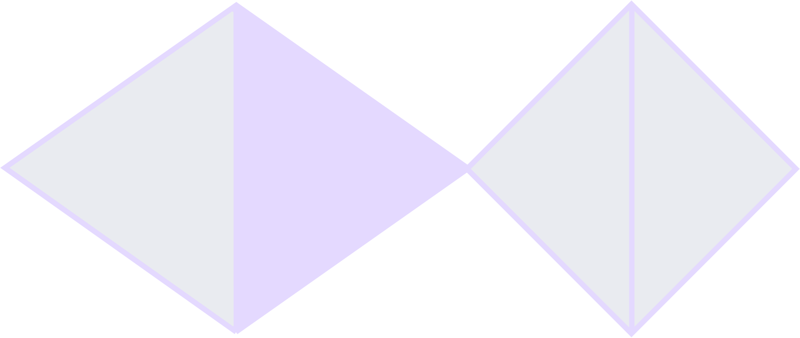
The process furthermore showed that conversations and stories can act as highly valuable methods to foster a relational co-creative research process. Both methods contributed to establishing relations between us and the participants, which can be described as trustful, authentic and mutual. The methods enabled a research process based on give and take, which authentically integrated into the participants lives. Furthermore, the approach resulted in an in-depth understanding of the caregivers' challenges and experiences with the welfare sector and thus provided us with valuable material to be analysed and synthesised in the Define phase.

Furthermore, we became aware that the approach made us have to take on many diverse roles. Besides what the role of a service designer naturally contains, for example being an interviewer, we suddenly found ourselves in highly emotional situations where we almost felt like consultants. This fact is worth questioning. Would it be more responsible to have this kind of conversation in the company of professional consultants, since very emotional and sensitive topics are the subject of the conversation? Whether this would be necessary and beneficial for the storyteller and for us would certainly be relevant to be investigated.

5.2 Define

In the Define phase we analysed and synthesised the research findings. We used a series of data synthesis methods, such as transcribing and clustering, in order to gradually bring forth the essence of the problems that dementia family caregivers face in the context of the Danish welfare system. This laid the ground for a collective evaluation with dementia family caregivers that served two purposes. On one hand, as it was situated in the context of a dinner, it gave us the possibility to bring together the caregivers and to provide them a platform to share and connect. On the other hand, it was a way to co-creatively define major caregiver challenges. By taking into account the key insights gained through the various activities, the problem statement was refined, which built the bridge into the Develop phase.

This subchapter is divided into the following sections:
5.2.1 Analysis and synthesis
5.2.2 Collective evaluation
5.2.3 Conclusion of the Define phase



5.2.1 Analysis and synthesis

We started the process of analysing and synthesising the research data by transcribing all conducted conversations. The transcribing process had two purposes for us. First, listening to the recording again and writing it down was valuable, as it made us get immersed in the data and helped us to memorise even small details of what the storytellers had said. Secondly, the consequent transcriptions, which can be found in the appendix (appendix A.10), enabled us to in the next step work further with the raw quotes of the participants. The quotes were a source of rich, unfiltered information, which revealed deep insights into the heads of the storyteller.

We color-coded each transcription in a different color to differentiate the conversations from each other. Afterwards we looked through the transcription to find relevant insights to help us answer the problem statement – to identify the challenges of being a dementia family caregiver in the Danish welfare system. We were especially looking for statements about challenges that the family caregivers face, the interactions with actors in the welfare system, expressions of feelings, as well as dreams and opportunity spaces. The quotes were cut out and paired up with quotes that addressed similar topics (figure 14). By doing so, clusters evolved. In this step the color coding paid off – when there was a cluster with many different colors it showed that this topic was addressed by multiple participants. The clusters that evolved were addressing the following themes: Nursery home, activity center, temporary homes, conflicts, caregivers' feelings, responsibility, law and formalities, dementia condition, surroundings and people, home care, (lack of) knowledge and information, informal support, municipality, GP, denial, memory clinic, family caregiver as a resource, dementia coordinator, relative groups, and giving support to others. Each of the above mentioned clusters we thoroughly looked into and summarised the overall challenges in descriptive notes. The text served as a means to faster grasp what kind of challenges a cluster addressed. By doing that, we could identify patterns in the data. For example, did the clusters of home care, nursery home and responsibility all address the issue of always feeling the need of being in control due to a lack of trust in professional caregivers.

Throughout the progression of the process we created a research wall (Stickdorn et al., 2018a) to make sure the generated data was stored and to visually arrange it (figure 15). Our research wall consisted of the stakeholder map including the findings from the expert interview, the caregivers' journey maps, the profiles of the caregivers participating in the project, and the clusters that emerged from transcribing and synthesising the conversations. The research wall was helpful as it enabled us to maintain an overview of the entirety of the findings.

Figure 14: Clustering of quotes of dementia family caregivers

Figure 15: Research wall

Preliminary insights

The patterns found in the data built the foundation for preliminary insights about the dementia family caregivers' challenges. As suggested by Stickdorn et al. (2018) we carefully formulated them, as they were supposed to serve as a point of reference for the collective evaluation whose validity had to be discussed and confirmed by the family caregivers.

The analysis identified seven issues across the participants' experiences that were found most challenging and most pressing to be tackled. The first issue was 1) "The need of being in control", which revealed that the family caregivers often do not trust the service providers, such as the home care staff, as they frequently experienced that they could not rely on them. This in turn means that the caregivers have to constantly check that their relative is okay, which does not relieve them in their role but rather causes a stressful responsibility. The second issue was 2) "Support", which showed that dementia family caregivers are very much dependent on informal support from people in similar situations who can relate, in order to not feel alone. Further it was revealed that it is essential that formal support is provided on a continuous basis to follow the progression of the disease. The third issue was 3) "Lack of info and knowledge", which showed that the necessary information often does not come to the family caregivers, but that they have to seek it out themselves, which they often either do not have the energy for or do not know whom to approach. The fourth issue dealt with 4) "Lack of professionalism" and revealed that the family caregivers think that the trained professional staff often do not have the needed knowledge, either to properly take care of their relatives or to answer the caregiver's questions. This causes problems up to dangerous situations and a bigger responsibility for the family caregivers. The fifth issue was 5) "Communication issues" and demonstrated the challenges related to a lack of a strong communication and information sharing between family caregivers and professional staff, as well as between the staff internally for example in a nursery home. This fact complicates the role of caregivers, as they are constantly busy trying to receive or pass on necessary information. The sixth issue was 6) "The wellbeing of family caregivers", highlighting challenges and factors affecting especially the mental health of the participants, such as uncertainties, stress, enormous responsibilities, family conflicts, lack of support, loneliness and grief. These factors are often a result caused by one or more of the other issues. The seventh and last issue was 7) "Public services", showing the problem of the public services in Denmark not being aligned across municipalities, as well as the lack of taking the family caregivers needs into account. Figure 16 shows the preliminary insights that were brought to the collective evaluation to be discussed with the participants.

① Need of being in control

- Home care is not reliable, so family caregivers feel they need to check and control, so that nothing bad happens.
- At nursery homes family caregivers often feel they need to have the responsibility (e.g. reminding staff what to take care of – food, medication, hygiene etc.)
- It is stressfull and overwhelming for family caregivers to have the responsibility to take care of the dementia stricken when they still live at home (e.g. physcically having to be there a lot).

② Support

- You feel alone as a family caregiver if you do not have people around you who can relate and whom you can share experiences with.
- The progression of the disease makes it important for family caregivers to always have someone to contact (ongoing support).
- The support services that are supposed to relive the family caregiver are not good enough (time and quality).

③ (Lack of) info & knowledge

- Often the information and knowledge does not come to you, but you have to seek it out yourself.
- Family caregivers often do not know where to seek out information and whom to call (or do not have the energy).
- Family caregivers miss training, advice and information (especially when the diagnose is given).

④ Lack of professionalism

- The GPs are often missing knowledge about dementia.
- The professional staff are often too poorly educated and miss knowledge about the disease.
- The professionals sometimes do not perceive the dementia stricken from a holistic perspective (e.g. being aware of other health issues).

⑤ Communication issues

- Family caregivers are not provided with many updates from the nursery homes and home care.
- There seems to be an issue with nursing homes' internal communication (across staff, shifts, etc.).
- The family caregivers are often not taken into account at formal meetings – are not asked what their needs are or offered meetings alone.

⑥ Wellbeing of family caregivers

- Too big of a responsibility leads to family caregivers being tired and frustrated.
- Family caregivers often feel guilt.
- Family caregivers deal with a lot of uncertainties which make them feel trapped with limited possibilities to plan.
- Family caregivers often feel alone/loney.
- It can create many challenges when the dementia strickens do not acknowledge their own disease or are in denial.
- Family conflicts are common, often because of disagreements related to the caregiving.

⑦ Public services

- The services are not aligned across municipalities, resulting that the support very much depends on where you live (e.g. waiting times)
- There are issues with borders between municipalities which can prevent family caregivers from getting the right support.
- The visitations' decisions are often not aligned with the expectations and needs of the family.

Figure 16: Preliminary insights

5.2.2 Collective evaluation

Once we had formulated preliminary insights a collective evaluation with all family caregivers who had been participating in the project was planned, as suggested by the Feed Forward methodology (Kieboom et al. 2015). The evaluation had several purposes. First, since we had learned that many of the caregivers had similar challenges and that an exchange with people who can relate is valuable, the event was intended to give the caregivers a chance to get to know each other, to share experiences, exchange ideas and ideally build relations. In addition, it was an opportunity to further strengthen the relation between us and the participants. Furthermore, the collective evaluation was important for the purpose of validating the preliminary insights, which would build the foundation for the next phase of the design process – the development of ideas about how to improve the situation for dementia family caregivers in the context of the Danish welfare system. Through the collective evaluation we strived to open up the activities of identifying major challenges, which is commonly known as an expert-driven activity (Kieboom et al., 2015), and to collaboratively discuss and refine the insights.

As we learned that the design process can be very valuable and transformative when it is authentic to the lives of people (Pierri, 2017) and as Kieboom et al. (2015) suggest to have the evaluation take place within the context of for example a barbecue in order to create an informal atmosphere, we invited the caregivers for a dinner (figure 17). To create an informal evening, the dinner started with welcome drinks and mingling. We were delighted to find that the caregivers were already using the chance to get to know each other by having lively conversations. Following up on that, while having dinner, we used the caregivers' written stories as a means to communicate their experiences to the others. Every participant read out her story to the others. Interesting conversations emerged, where the women related to each other's experiences, gave each other advice, and discussed the problematics of today's welfare system and aspects that need to be improved in order to better support family caregivers in their role.

Later on, we presented the preliminary insights and facilitated a shared discussion to get feedback on our analysis (figure 18). We could use the emerging discussions to refine the main topics, add more detailed insights, and explore which findings were most relevant to work further on. After the presentation and discussion we asked the participants to individually vote for the three topics that they found most pressing to be tackled (figure 19). Based on the distributed voting dots three issues stood out – 1) Lack of professionalism, 2) communication issues and 3) matters concerning the wellbeing of family caregivers.

The collective evaluation and voting revealed which challenges the participants found most relevant for us to work further on and thus gave us concrete insights on our initial problem statement about what the challenges of being a dementia family caregiver in the context of the Danish welfare system are. Since the lack of professionalism and the communication issues that the caregivers voted for as the major challenges were both related to a problematic flow of information and knowledge between dementia family caregivers and professional actors in the welfare system, we could in a next step refine the problem statement to scope the further course of the process. Finding answers to the new problem statement would also ultimately contribute to the wellbeing of caregivers, which was the third challenge that was among the top concerns faced by dementia family caregivers, which however did not describe the root of a problem but rather its results. The new problem statement, which scoped the further process was therefore formulated as follows:

How might we use service design to strengthen the flow of communication and knowledge between dementia family caregivers and professional actors in the Danish welfare system?

Figure 17: Dinner with dementia family caregivers

Figure 18: Presenting and co-creating preliminary insights

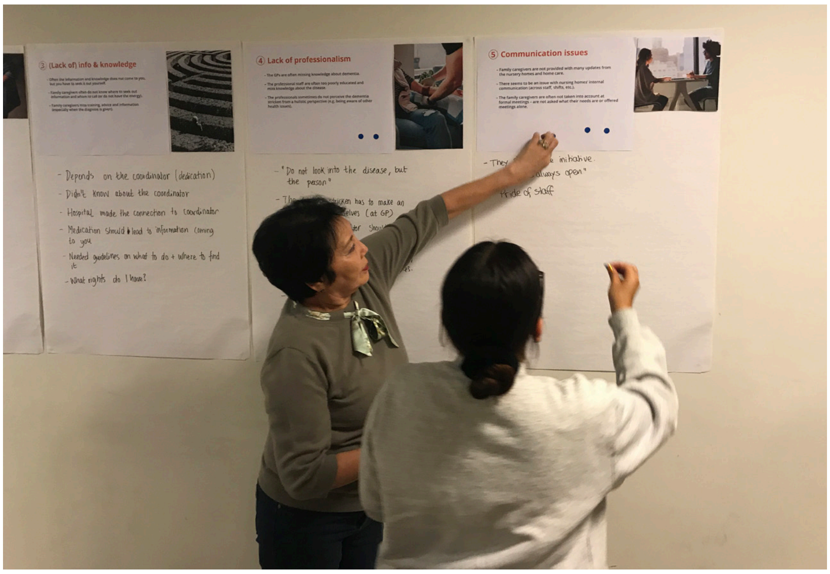


Figure 19: Dementia family caregivers voting for their major issues

Preliminary reflection on collective evaluation

As we approached the end of the evening we had a conversation with the family caregivers about how they experienced the project and their participation in it, serving as a methodological evaluation for us to reflect upon. One of the family caregivers thanked us for giving her the opportunity to connect with other family caregivers, which according to her, had given her the necessary information and energy to ask for help from the system. Another caregiver said that she had been involved in many projects about dementia, but she had never experienced a project that was done with so much care and warmth. She thanked us for involving her and for giving so much weight to their opinions, experiences and feelings and expressed the wish for more such co-creative projects. Another participant expressed how much she enjoyed the evening and the fact that no preparation or effort on their part was required which, according to her, was ideal and very relieving. Furthermore, the participants expressed the wish to connect digitally whereupon we created a joint Facebook group. There is still an exchange within this Facebook group, for example relevant information are shared, or the family caregivers inform each other about their well-being. From our perspective this is a great fact, as we were able to contribute to a sustainable exchange and mutual help among the participants through a single get-together. As the Covid-19 virus spread in Denmark shortly after this meeting, unfortunately no further physical meetings could take place within the project. However, as this single meeting had a lasting positive effect and helped to build relationships among the participants, we are positive that further meetings of a similar form would have further strengthened these positive effects. The informal and casual atmosphere of the evening contributed significantly to these effects, allowing the participants to get to know each other authentically. To our delight, the caregivers assured us that we could contact them at any time in the further course of the project.

5.2.3 Conclusion of the Define phase

In the Define phase we followed the methodological suggestions of the Feed Forward methodology (Kieboom et al., 2015) and combined them with methods and tools commonly used within service design. We first analysed and synthesised the research data with service design methods to then hold a collective evaluation in an informal context. The synthesis tools, such as transcribing, clustering, building a research wall and developing preliminary insights helped us to identify the challenges that dementia family caregivers face in the context of the Danish welfare system. The collective evaluation opened the expert-driven process up to the family caregivers and gave them the space and opportunity to challenge our work and contribute with their perspectives. The iterations and co-creation ensured the insights' validity, which is important as they are the foundation for ideas (Stickdorn et al., 2018). Furthermore, the collective evaluation was powerful, as it brought the project participants together and gave them a platform to share experiences and exchange perspectives, from which then new perspectives, reflections and actions could emerge. In addition, the collective evaluation further strengthened the relations between the participants and us. The activities conducted in the Define phase further enabled us to refine our problem statement to have a scope for the following Develop phase.

5.3 Develop

The overall goal of the Develop Phase was to find answers to the new problem statement about how to strengthen the flow of communication and knowledge between the dementia family caregivers and professional actors in the Danish welfare system. The activities conducted in this phase included mapping out the various communication flows and interactions, formulating key insight and developing ideas for improvement. The most desired ideas, from the perspective of the family caregivers, were described in scenarios, which were then discussed and further explored through the method called co-constructing stories. Lastly, an overview with suggestions on opportunity spaces for improvement was developed.

The activities in the develop phase were to a high extent affected by the circumstances related to Covid-19, and had to be conducted according to the formal guidelines. Several co-creative activities had therefore been cancelled or re-structured, such as activities with professionals in the welfare sector and ideation workshops.

This subchapter is divided into the following sections:
5.3.1 Relational mapping
5.3.2 Key insight cards
5.3.3 Crazy 8
5.3.4 Design scenarios
5.3.5 Co-constructing stories
5.3.6 Conclusion of the Develop phase

5.3.1 Relational mapping

As a preparation to develop ideas about how to strengthen the flow of communication and knowledge between dementia family caregivers and actors in the Danish welfare system, we first mapped out and thus visualised the currently problematic as well as the good communication flows. Mapping is a way to construct a simplified view on the complexity of the reality and aids in understanding and engaging in it (Aguirre-Ulloa & Paulsen, 2017). For the mapping we found inspiration in a relational mapping tool from systemic design that was developed to be used in co-creative workshops. It is supposed to help actors through the use of physical materials, for example yarn, and their properties understand the social relations that are at play in a particular context (Aguirre-Ulloa & Paulsen, 2017).

We started by representing all relevant stakeholders that are considered in the stakeholder map (figure 5), on a large board and arranged them in a circular array around the dementia family caregiver and the patient. Thereafter, we used different colored yarn to visualise existing flows of communications. As exemplified in figure 20, we then used red stickers to indicate problematic flows of communication and knowledge and green stickers to indicate positive flows. The assessment was done based on the knowledge generated through the research activities. Seen as positive were the dementia coordinator, the relative groups, the Facebook groups, family and friends, the initiatives from the Alzheimer Association as well as to some extent the nursery homes. The problematic flows of communication and knowledge were the GPs, the memory clinics, the home care services, the assessment (the professionals who assess the level of assistance that the person with dementia and the family caregiver receive), the temporary stays, as well as to some extent the nursery homes and family and friends. Thereafter, we reflected and analysed what characterises the positive flows and the problematic flows and summarised the result in a table (figure 21).

Figure 20: Relational mapping

What can we learn from the positive flows?	What can we learn from the problematic flows?
+ These interactions are personal and relational + The interactions happen between people with similar experiences + These actors have a big amount of knowledge + The actors are trustworthy + There is empathy, understanding & emotional support + Caregivers know what the purpose of the relation is and what to expect + The actors represent a place to seek advice + Give & take = equal relation	+ These actors hold important positions and represent key moments in the course of the disease. However, many of the family caregivers' questions remain unanswered. + There is a clash between expectations and offerings. + The caregivers are unsure about the actors' role and responsibility + There is a lack of guidance + There is a lack of trust, reliability, empathy and compassion + There is a lack of information and knowledge sharing

Figure 21: Characteristics of positive and negative flows of communication

Preliminary reflection on relational mapping

The mapping activity was valuable as it was a tactile, flexible and interactive way of visualising the intangible flows of communication and knowledge, which supported thinking and encouraged rich discussions. Through the hands-on activity analysis and ideation happened simultaneously. We became aware that the flows that are perceived as positive by the caregivers are characterised by strong interpersonal relations between the caregiver and the other actors. Interestingly, this is aligned with the findings from the literature review, which stress that the future of public services relies on relational services and welfare (Aguirre-Ulloa & Paulsen, 2017). This alignment made us ideate and reflect whether the problematic relations could be improved through applying the characteristics of the positive interpersonal relations.

However, we also became aware that the whole process of mapping, discussing and analysing would probably have been much more valuable and insightful if it was conducted in a co-creative session with the family caregivers and ideally the professionals from the welfare system, as originally planned. We for example became concerned whether our analysis was valid or whether we were biased from for example literature or personal values. Unfortunately, co-creation was not possible due to the societal circumstances of Covid-19, but would most likely have produced more insights and given less weight to our own personal ideas and perceptions.

5.3.2 Key insights

The relational mapping and the information and reflections arising from this exercise were captured in key insight (figure 22), which Stickdorn et al. (2018 p.131) describe as “concise and actionable format for communication within and across teams”. To make them most meaningful, we captured the essence of each insight in a headline, wrote a descriptive text for each, which we supported with a strong quote from the caregivers, which we extracted from the interview transcriptions. The purpose was to have a clear visual overview of the most problematic and positive flows of communication and knowledge between the family caregiver and actors in the welfare system.

Based on the insights, as shown below, we then discussed which of the negative communication flows were the most problematic ones and concluded that it was the communication between the family caregiver and 1) the GP, 2) the memory clinic, 3) the home care services and 4) the nursery homes, as a lack of communication and understanding from these actors causes serious problems for the dementia family caregivers. These interactions, which are characterised by a lack of trust and exchange of information, force caregivers to take on a great responsibility, which reinforces the need for control and thereby causes stress rather than relieving it. Therefore, we chose to focus on exploring how to strengthen these four problematic flows of communication and knowledge.

Key insights #01

01 General practitioners do not have enough knowledge and understanding about dementia

The general practitioners have a critical role in the journey of the dementia patient and the family caregivers. Many GPs do not have the necessary knowledge about the disease, which results that they do not meet people with the right understanding, or they in some cases giving wrong diagnosis. Furthermore, the interaction with the GP becomes problematic, as the patients and their family caregivers have too big a responsibility in e.g. remembering to make appointments. Family caregivers expect the GP´s to provide more information and support - a need that is often not met.

“Everytime I asked something he said: ‘Speak to the hospital.’ I feel he doesn’t know a lot about dementia and Alzheimer’s. And also they should remind the patients and caregivers for their appointments. Because how can a person with dementia remember to go to the doctor?” — Lise

Key insights #02

#02 The memory clinics do not provide enough information to family caregivers.

The memory clinics at the hospital need to take the whole family into account in the process of diagnosing the patient. The process is long, and the family caregivers need more support and guidance from the memory clinic, about the disease, behavioural changes, how to tackle these etc. Often the family caregivers find it necessary to seek out the information by themselves. It therefore has a positive impact when the memory clinic provides both oral and written information about the important factors to be aware of as a dementia family caregiver.

“It would have been nice if the memory cinic would have invited me from the beginning and taught me about how to behave and how to talk with this sick man. And how the treatment will be and how I can be a part of this. I wished for more information. And maybe also invite our children. I didn’t have this opportunity and I wonder why we haven’t been invited by the clinic, to get some training and advice. Without him. I miss this.” — Annie

Key insights #03

#03 Nursery homes & home care services do not communicate enough with caregivers and internally

The family caregivers have a need for more information about how their dementia relatives are being taken care of at the nursery homes. They need more consistent communication with the staff, e.g. through a communication tool, that could help them let go of the need of being in control. There is furthermore a need for better communication internally at the nursery homes, to ensure alignment between the staff, which would make it possible for the family caregivers to always get important information about their relatives, no matter what time of the day they visit.

“It’s always super confusing when they call, also because it’s always someone else. It would be nice if they had a more digitalised system because sometimes they call and talk for 20 minutes about things I have to do and remember and that is very difficult. ” — Julie

Key insights #04

#04 The nursery home and home care employees are not well enough trained within the field of dementia

The professional caregivers at nursery homes and home care service do not have enough knowledge about the dementia disease and how to tackle the behaviours. They need more specialization, e.g. through post-education, that guide them how to better give care to people with dementia. The lack of knowledge and understanding can result in problematic situations, e.g. lack of medical care, as the staff sometimes rely too much on the statements given by the person with dementia.

"My mom went to a shower a week after she moved into the nursery home. Then it took half a year until they could get her into a shower again. They said: 'But she says no'. And then they just gave up." — Susanne

Key insights #05

#05 Family caregivers need to be taken more into account at formal meetings

The family caregivers have a wish for being taken more into account at formal meetings. This is a need across the system - from meetings at the nursery home, to the hospital, as well as the assessment decisions. The family caregivers are not always seen as a person with a problem - even though they most often are. They need to be carried more by the system, and to be considered as someone who is also affected, and thereby need support.

"No one ever told me anything about it. Not even in the psychiatry. I never received any information or support group or anything. There is no one asking 'how are you'? I'm completely alone with all my things and thoughts. And it's super hard to stand with all this alone. I think it would be really nice if I would actually have someone who could explain me stuff." — Julie

Key insights #06

#06 The conditions at the temporary homes are bad, and thereby not relieving enough for the family caregivers

The family caregivers can be relieved in their responsibility of taking care of their relative with dementia by bringing them to a temporary home. However, the conditions at the homes are problematic, as there is a lack of activities, not enough staff, and the staff do not have the necessary knowledge. This occasionally results in accidents, which makes the family caregivers worried and not relieved, as intended.

"My dad went to these temporary stays, and sometimes when we came there in the evening it was all dark, because the light would only turn on if someone was moving. So they would all just sit there in dark rooms, and it was a nightmare. Or one time his catheter slipped out. And then they couldn't put it in themselves. And they didn't do anything, so he was just lying there, couldn't get rid of his urine." — Susanne

Key insights # 07

#07 The dementia coordinator is very valuable for the wellbeing of family caregivers.

The dementia coordinators are crucial actors for the wellbeing of family caregivers. The family caregivers perceive the dementia coordinator as someone they can always rely on. in the relationship to the coordinator, the family caregivers feel cared about and heard, and the coordinator often stand up for the family if there are issues in the communication with the system. They support and guide them on how to not only support their dementia relatives, but also how they can help themselves, and which actors they should be in contact with.

"The dementia coordinators know how it is to be a caregiver and they know what we're up against concerning the disease and they know the system. So very often I could call her crying and ask what I shall do and she would have ideas about how to solve problems because seven hundred thousand other people have been in the same situation. We had an expression in our relative group. We said they were our angels." — Rosa

Key insights #08

#08 Taken part in a relative group is crucial for the wellbeing of family caregivers

Relative groups contribute to the wellbeing of dementia family caregivers. It is important for them to be connected with people in the same situation, with who they can share and exchange experiences. In these forums they feel heard and understood. The teaching that the municipality provides through the relative groups is valuable as well. Many family caregivers continue in smaller self-arranged groups after the municipality relative groups end, which confirms the importance of these.

"In the group when we meet, there is always someone who knows how to help. If you don't come in a group, you don't have that opportunity to use others to help yourself." — Lise

Key insights #09

#09 The support provided through informal facebook groups is valuable

The informal support offered through caregivers facebook groups are a valuable forum for the family caregivers. The groups serve as platforms, where the family caregivers can seek immediate information and support from people with similar experiences. Due to the big number of members, the group function as one big brain, where the caregiver always gets replies quickly. This makes it a good tool for urgent questions in problematic situations, which can be both related to practical or emotional issues.

"Facebook is really useful. Sometimes we ask each other about different things. Sometimes it is just people letting go of frustrations. I seeked out advice in the facebook group on how, in the best way, move my mom into a nursery home. That is what you can get from facebook with all these different experiences." — Susanne

Figure 22: Key insights

5.3.3 Crazy 8

The next step was to develop ideas on how to strengthen the flow of communication and knowledge between family caregivers and GPs, memory clinics, home care services and nursery homes. For the ideation we chose the method Crazy 8's. The goal of this method is not to develop great ideas but to develop many quick draft ideas. It is an appropriate method to start thinking about possible solutions in a creative, action-oriented way (Crazy 8's, n.d.). For this ideation method, we placed the problem statement into the middle of a big paper, set a timer and tried to come up with eight ideas in eight minutes, addressing one problematic flow of communication and information each time. Hereby, all information – problems as well as their respective ideas – were captured in one big sheet of paper (figure 23).

As in the previous step, we again felt challenged by the fact that we could not co-create with the participants. We were not sure whether the ideas we developed were desirable from the perspective of the caregivers. Therefore, we decided to share the ideas with the family caregivers, let them comment on them and vote for the ones they found most desirable and promising to be implemented.

Figure 23: Draft ideas developed with the Crazy 8 method

In order to examine which of the ideas were the most desirable to dementia family caregivers, we used a quick voting technique (Stickdorn et al., 2018). This step is normally often included in a co-creative ideation workshop but had to be conducted digitally in our case. We used a Google questionnaire in which we categorized the ideas according to the particular flow of communication and knowledge they were concerned to improve – GPs, memory clinics, home care services or nursery homes. The questionnaire was then shared with and filled in by the members of the Facebook group with all the participating caregivers of the project. Through examining the results of the voting, we could conclude that the following ideas were the most promising to be further explored:

1. Some GPs get special training in the topic of dementia to ensure that patients and family caregivers receive the care and knowledge about dementia that they need. Those who are educated should be listed on borger.dk as a doctor educated in dementia, and patients and family caregivers are welcome to change their doctor according to this list for free.
2. Each dementia patient and his/her family caregiver is assigned a contact person at the memory clinic department at the hospital, who is available to answer questions, clarify uncertainties and give information throughout the diagnosis process.
3. Nursery homes use an interactive digital system where information about the patient is shared between the family caregiver and the professional staff, but as well across the various shifts in the nursery home to ensure that everyone is on the same page.
4. There exist home care services that are specifically trained in providing care to people suffering from dementia. They use an interactive digital system that allows the parties to share information about the patient.

These ideas served as the foundation for four design scenarios that were developed as a next step.

5.3.4 Design scenarios

After having identified the four most promising ideas, the goal was to explore and refine them in a more concrete manner. In order to do so we developed design scenarios that we afterwards co-creatively examined with the family caregivers through a method called co-constructing stories. Scenarios, as described by Stickdorn & Schneider (2012, p.184) are "hypothetical stories" that can add value at various phases of a service design process for example to meaningfully explore an idea. They prove to be an useful communication tool to describe particular aspects and key interactions of an imagined service offering (Stickdorn & Schneider, 2012). The goal was not to develop descriptions of finished detailed ideas ready for implementation, but rather to capture the aspects that could ultimately improve the flow of communication and knowledge between the respective actors, as addressed in the problem statement. After the scenarios were developed we asked the family caregivers to discuss and refine the ideas that were addressed in the scenarios with us. The following shows an example of one of the scenarios (figure 24). The three remaining scenarios can be found in appendix (appendix A.11).

Digital interactive system at nursery homes

Marianne is 48 years old and lives with her family in a suburb to Copenhagen. Her father is diagnosed with Alzheimer's and lives in a nursery home 30 minutes from her. She is his primary family caregiver, as her mother has passed, and her sister lives far away. Marianne works full time and has a hard time balancing work life with caring for her father, but she manages to visit him 2-3 times a week.

Luckily, she has a good communication with the nursery home as they have now implemented a digital platform in which she can get all the information needed. Before, she found it very hard to get information about her father, as the evening staff, who she met when she came to visit, had not been there during the day and therefore didn't know what activities her father had been a part of.

Now Marianne has an app, where the professional care personnel type in, which activities her father has taken part in, what they have had for lunch, what time he woke up, and when he got his medication. The staff also use the platform for internal communication, where they can choose what is visible for relatives and what is not. This gives Marianne the impression that all nurses and employees are on the same page and updated, which relieves her as a relative.

The platform makes Marianne feel less stressed out, as she knows she can always reach out to the staff. She especially likes the checklist function, where she types in things the staff needs to remember in regard to caring for her father. For instance, she often puts in when they have to remember to give him a special kind of medicine. The checklist function ensures her that the task is done, because she gets a notification about the task being completed by a staff member. This makes her let go of some of her worries and the constant feeling of having to be in control herself.

Figure 24: Exemplary scenario

5.3.5 Co-constructing stories

In order to elicit in-depth feedback from the caregivers we used, but slightly adjusted, a co-creative design method called co-constructing stories. The method is supposed to aid designers in obtaining deep insights into how people use and anticipate to use a particular service offering. Co-constructing stories work in two phases. A sensitization phase that encourages people to think about past experiences and an elaboration phase, in which they envision desired futures (Buskermolen & Terken, 2012). As we through the previous activities carried out in the project, such as the conversations, stories, and the collective evaluation, already had revealed in-depth information about past experiences, we used the scenarios to directly proceed to the elaboration phase. As suggested by Buskermolen & Terken (2012) we used the scenarios to present the ideas in a contextualised way. We digitally sent the scenarios to three family caregivers and asked them to reflect about the following questions while reading.

1) In what way does this scenario differ from the current situation?
2) What do you think about the interaction between the actors in the scenario?
3) What elements do you like? And what should be different?

Afterwards we individually invited them for a video call. Ideally, the feedback session would have been conducted co-creatively together with all of them at once, however this was not possible due to circumstances of not being allowed to meet physically. The feedback we received from the three participants was very different from each other, which is reasonable as individual contexts are affecting how people interact with and experience a service. While one participant said the service would definitely relieve her, the other caregiver could hardly identify with the scenarios.

The fact that the participant could not identify with the suggested ideas again stresses the value of co-creation. When co-creation is applied in ideation the emerging ideas might be more relevant, as various perspectives are taken into account. However, we are of course also aware that it is not doable to cover the needs of everyone participating in a project. The challenge of collaborating with a diverse group of caregivers (see caregiver profiles, presented in section 5.1.1.), which was a conscious choice in the beginning of the design process, became apparent at this point.

After the feedback, we chose to not develop final solutions, as these were primarily used as a tool to explore the various ideas and their characteristics. The purpose was instead to use our research and ideation to develop a list of suggestions on how to improve the interactions in the system, and have this as the outcome of the design process. These suggestions will be presented in the following Deliver chapter.

5.3.6 Conclusion of the Develop phase

In the Develop phase we continued our analysis of the flow of communication and knowledge between the actors in the system, and started ideating and reflecting on alternative solutions through various ideation tools. While trying to work co-creative to the extent possible despite the circumstances of Covid-19, the experience of being forced to take on the role of the design expert gave us insightful perspectives on how this affected the design process. We were quickly confirmed that it is difficult to develop solutions on other people's behalf without their involvement. We assume that it would have been most valuable to conduct a co-creative ideation workshop, ideally with professionals present as originally planned, in order to have the actors identify with the solutions. However, it is difficult to conclude if this would have been just as challenging as well, as the participants face different challenges after all, and despite the collectively defined challenges still wish for different solutions individually.

5.4 Deliver

The purpose of the Deliver phase was to summarise our insights and gained knowledge into a final deliverable - a project report. As our process has primarily focused on exploring the impact of a relational co-creative *research* process, and the value of the design process, it was consciously decided from the start of the project to not develop *one* final service solution as the outcome of the design process. Instead, we developed an overview with opportunities spaces on how to improve the problematic flows of communication and interactions. Furthermore, we developed a report that summarises all insights and suggestions on opportunity spaces to be shared with relevant stakeholders in the field of dementia in Denmark.

This subchapter is divided into the following sections:
5.4.1. Opportunity spaces for improvement
5.4.2 Project report

5.4.1 Opportunity spaces for improvement

We decided that the outcome of the design process should be a summary of the insights generated and a presentation of opportunity spaces for improvements, which relevant stakeholders working with dementia could get inspired by and learn from. The visual overview of opportunity spaces (figure 25) serves as a communication tool, presenting the suggestions and initiatives that could improve the current system.

The overview shows various suggestions and opportunity spaces on how to improve the communication and knowledge between the dementia family caregivers and professional actors in the welfare system. The four most problematic interactions are highlighted - the GP, memory clinic, home care service and nursery homes –, as well as the most positive ones - the dementia coordinator and the relative groups. In the bottom the characteristics of the positive and negative flows of communications are pointed out. It shows that the positive interactions are interpersonal and characterised by trust, empathy and understanding. These actors' roles are often clear and the family caregivers know what to approach them for. Moreover, it shows that these actors possess a great amount of knowledge about dementia, which is valuable for the patient as well as for the family caregiver. The negative interactions, on the other hand, are characterised by a lack of knowledge about dementia, which often leads to unanswered questions of the family caregivers. The roles of these actors are not always clear, which leads to a clash between the expectations and the provided offerings, resulting in unmet needs. Moreover, it shows that in general there is a lack of guidance, communication and empathy from these actors.

For each of the four problematic interactions a list of opportunity spaces on how to improve the communication and knowledge sharing is given. An example of a suggestion would be for some GPs to attend further training courses on dementia and to be found online as certified dementia doctors, so that patients and caregivers can change doctors as required and free of charge. It furthermore shows opportunity spaces in stronger support from the memory clinic, such as meetings for the whole family or a contact person, who the family can always ask questions in the diagnosis process. Furthermore, more training for home care staff and more consistency in staff is among the list of opportunity spaces, as well as a digital platform through which the nursery homes can communicate with the family caregivers.

As we did not have the opportunity to discuss these ideas with relevant professional actors, we would like to highlight that these suggestions are derived from the family caregivers point of view and may include aspects that are currently not feasible to be implemented in the Danish welfare system. However, we still see the potential of using them as an inspiration to relevant stakeholders and hope that they can contribute to make a positive difference for the family caregivers, which we through our project can see is highly needed.

Opportunity spaces for improving the support of dementia family caregivers

The following gives an overview of ideas of potential improvements to strengthen the communication between family caregivers and specific professional actors in the context of dementia in the Danish welfare system.

5

Nursery home

- The nurses get more ongoing education about dementia.
- The nursery home offers regularly meetings for family caregivers to ask questions (with the option to have a neutral third person present).
- The nursery home uses a digital interactive system, where nurses and family caregivers can share relevant information about the patient.
- The nursery home organises monthly info meetings for relatives.

4

Home care service

- There exist specialized dementia home care service.
- There is more consistency in care personnel.
- The home care service uses a digital interactive system, where nurses and family caregivers can share relevant information about the patient.
- The home care service can be tracked by the family caregivers (e.g. see if they have been there, when they come, what they did).

2

Memory clinic, hospital

- The memory clinic invites the whole family for a meeting when a diagnosis is given to provide information and answer questions.
- Each family is connected to a contact person who is available to answer questions.
- The memory clinic informs the family caregiver's doctor about the relative's diagnose (if everyone gives consent) so the family caregiver can receive better support.

1

General practitioner

- GPs get more training and gain more knowledge about dementia.
- Some GPs are specialy trained in dementia, and are visible as 'Dementia certificated doctors' for citizens on borger.dk.
- The GP reminds the patient and family caregiver when it is time for the next appointment.

What can we learn from the positive interactions ?
Dementia coordinator and relative groups organised by the municipality.

- The interactions are relational and interpersonal.
- It is beneficial to meet people with similar experiences.
- The actors have a big amount of knowledge about dementia.
- The interactions are characterized by trust, empathy and understanding.
- The services are emotionally supportive.
- The roles and purposes of the actors are clear (know what to expect).
- The interactions are more equal (give and take relations).

What can we learn from the problematic interactions?
General practitioners, memory clinics, home care service and nursery homes.

- There are critical situation occuring, and often unanswered questions.
- There is a clash between expectations and service offerings (unmet needs).
- The roles of the professionals are not clear.
- There is a lack of guidance + communication.
- There is a lack of trust to professionals.
- There is sometimes lack of empathy.

Figure 25: Opportunity spaces of improvement

5.4.2 Project report

In order to communicate our findings and suggestions to relevant stakeholders in the field of the Danish welfare system, we gathered all the learnings, insights and ideas derived from the design process into a report (figure 26). The report addresses the findings about dementia caregiver challenges, the most problematic issues as defined by the participating caregivers, the positive as well as the problematic flows of communication and knowledge in the system. Furthermore, it describes the characteristics of these in order to potentially inspire actors on how to improve their own interactions with dementia family caregivers. In addition, the report presents the key insights, as well as the above mentioned suggestions on how to improve the existing patterns. Besides the outcomes of the design process, the report briefly present the relational co-creative research approach, through which we have gained the presented knowledge. This serves as a means to inspire stakeholders in the Danish welfare system to involve citizens and service users to reflect and sparre on alternative solutions to existing services.

The intention is, as mentioned, that the report will inspire stakeholders within the area of dementia to either use our research and identified challenges for relevant projects, or to work further on the opportunity spaces presented in the report, and thereby improve the life of dementia family caregivers. The full report can be found in the appendix (appendix B).

Project report

Challenges of dementia family caregivers and opportunity spaces on how to improve the support

Background of the report

This report documents the outcome of our thesis for the Master's degree in Service Systems Design at Aalborg University Copenhagen, conducted from February until May 2020. Service design is a discipline that is used in many different ways from creating new service experiences to contributing to improving services and systems, for example within the healthcare and welfare sector. We dedicated the thesis to the theme of dementia, and explored the challenges that dementia family caregivers face in the context of dementia in the Danish welfare system. This decision stems from our motivation to contribute to exploring how to solve societal challenges. Dementia, its bitter progression and devastating consequences is a great challenge for individuals and society that requires action. In many cases, people who suffer from dementia receive care from their close relatives, which poses a great burden and an increased risk of developing physical and mental issues for relatives. For us it was crucial to conduct a collaborative design process in which we involved dementia family caregivers to a high extend, as we consider them as the experts of their experiences and challenges. Through the use of qualitative research methods and tools we aimed to understand the main challenges of caregivers, regarding existing support services. Based on this we collaboratively synthesised the challenges and came up with opportunity spaces that can contribute to tackle these – making family caregivers feel more supported and taken care of. In this report we share our process and the gained insights with the purpose to contribute to improving the wellbeing of dementia family caregivers.

Figure 26: Project report

6

Discussion

Discussion

This chapter discusses the academic research question based on the findings of the case study. The chapter elaborates on how the relational co-creative research approach impacted the design project, the potentials and challenges that were identified from exploring the approach, and how it affected the roles of us as service designers. The chapter furthermore addresses the potential of using the approach in a welfare context. Lastly, it is discussed how a more relational and co-creative focus can impact service design practice in general, and how it can broaden the perspective on service design, its outcomes and value contribution. Besides the discussion of the academic research question, the chapter considers to which extent the official and personal learning objectives have been reached.

The chapter is divided into the following subchapters:

6.1 Reflections emerging from the design process
6.2 Further reflections on the research question
6.3 Reflections on learning objectives

6.1 Reflections emerging from the design process

Since our academic research question examines the impact of relational co-creative research in service design practice, the focus of the key findings related to the research question mainly revolve around the outcomes of the research and analysis activities, or in other words the Discover and Define phase, of the design project. The reflections will be presented in a chronological order, appropriate to the design process, as many of them build on each other.

6.1.1 Engaging participants

The importance of a preparation phase

Before starting the actual fieldwork we conducted preliminary research through desk research and an expert interview. Though preliminary research is generally suggested as a starting point for service design projects we think it is an invaluable requirement when working relational co-creative in the context of welfare. It was noticeable that besides the fact that the knowledge gained in the preparation phase made us feel more knowledgeable and prepared, it also served us well when trying to engage dementia family caregivers for the project. Being able to empathise, relate, and through that show respect and understanding for their situation, was the reason why some caregivers became engaged in the project. We assume that our preparations significantly contributed to the fact that the caregivers trusted us and were convinced of the good intentions of the project. Thus, it laid the foundation for a relation and collaboration to be established in the first place.

Presenting the process: Step by step, or all at once?

When following a co-creative design approach the recruitment of participants is crucial and important, as the project is dependent on them. In the beginning of the project we therefore thoroughly considered how to best approach this task. More specifically we considered how much information about the co-creative process we should give to potential participants when engaging them for the project. Two approaches were considered – 1) engaging participants step by step by presenting one activity at a time, or 2) presenting them the entire process and planned activities from the beginning. As our process was initially not fully planned, and as we were concerned that the latter approach could potentially discourage people from participating, we chose the first approach – step by step. Our concerns regarding the second approach were about asking for too much, before even being able to fully convince people about the good intentions and the potential of the project and further, before being able to build up a relation to them, which we assume supported us in keeping them engaged later throughout the process. Although our strategy worked well, it raised ethical concerns. We frequently discussed whether or not it is ethically correct to continually ask the caregivers to take part in an additional activity. Do the participants say yes to further design activities because they do not want to disappoint or because they feel trapped in what they got into? Furthermore, the question is whether the difficulties to engage people for a project actually increase when they see the full extent of the "work". As we quickly experienced that people gladly contributed, our concerns about having less participants willing to contribute might have been unfounded worries. It therefore might have spared us designers for several concerns, as well as ensured that we were on the same page with the participants, which might as well have strengthened our relationship to them. Though finding the ultimate answer to these questions might not be possible, we feel that these considerations are important and should be taken into account.

Inclusion – exclusion

We believe that the chosen approach on how to engage participants always influences who feels addressed and who does not. We assume that our approach, asking for volunteering participants through a Facebook group, might have primarily addressed people who have some resources to give – for example time, energy, or emotional capacities to support others. Other people who might even be in a worse place regarding their caregiving responsibilities and challenges, probably have ruled out considerations about participation, as they might simply do not have the capacities to take on additional responsibilities, as the challenges they face are too big of a burden already. We acknowledge the fact that we could have made the process of engaging participants more inclusive by trying to, through different channels, give more family caregivers a chance to get involved in the project. We are aware that it might especially be important and meaningful to ensure that the voices of those who face the greatest challenges are heard. However, we also want to point out that we believe that being fully inclusive might not be possible, as there are many influencing factors that determine whether a person feels addressed by an invitation – with the platform where you stage your invitation and its formulation only being one of many.

One challenge that naturally excluded some people from the project was the geographical limited working field. When aiming to work co-creative with activities that strive to bring people together physically for various activities, one needs to find participants that are geographically relatively close to each other. This means that even though many people contacted us with the interest to contribute and participate in the project, we had to reject some of them, as they lived too far away. This unfortunately lowered the numbers of participants in the project. If we had conducted traditional interviews this would not have been as big of an issue, since we as designers could have met people where they are. However, we could not expect this mobilization from the participants, especially not when striving to invite people for various steps along the process. If this geographical limitation would not have been existent, our group of participants would as well have been more diverse, as some of the dementia family caregivers we had to reject were males. As our final group of participants ended up being only female family caregivers, the male perspectives would have been very interesting and valuable to involve.

Diversity among participants

This brings us to a limitation of our project - the lack of male participants. Of ten serious discussions about potential participation in the project only two were with men. Unfortunately, a collaboration did not evolve, as their places of residence were too far away. This of course resulted in the fact that we were unable to clarify whether the research results of the design process were cross-gender or gender-specific. It also raises the questions about the reasons for the low interessement of men. One explanation could be that:“ [a]ll over the world women are the predominant providers of informal care for family members with chronic medical conditions or disabilities, including the elderly and adults with mental illnesses” (Sharma et al., 2016, p. 1). Therefore it could be that the proportion of male family caregivers simply is significantly lower. It may however also be due to the fact that “women are more likely to be exposed to caregiving stressors, and are likely to perceive, report and cope with these stressors differently from men” (ibid.). This could mean that women may simply be more likely to do something about their situation, aiming to change it into a better, more desired one. Another assumption could be that women are more inclined to get involved in a project like ours, simply because of the fact that they like to help and offer support.

Although the project was not diverse in regards to gender representation, it was diverse in terms of the background of the participants. Although they all shared the experience of being a dementia family caregiver, they were in different situations regarding this role, as exemplified by the caregiver profiles (see chapter 5.1.1). Some of them were spouses, whereas others were the children of the sick person. Some dementia patients were living at home, whereas others lived in a nursery home, being in very different stages of the dementia disease. This diversity had both benefits and challenges. On one hand, it was very insightful as various perspectives were brought on the table when discussing issues and more desired futures. In addition, it was beneficial for the participants to be able to learn from the experiences of the other caregivers and ask them questions during the collective evaluation. However, this aspect would most likely have been reinforced if the caregivers had been exclusively spouses or children. In the course of the process we could see that it can be an important criterion in for example relative groups, as it enables participants to relate to each other even more. The diversity also created some difficulties within the process. When working with a democratic task like voting, as done during the collective evaluation, you risk to lose the ones, who are in another situation than the majority. Further, when developing ideas it is not possible to meet the whole variety of diverse needs to the same extent. Since it makes more sense to focus on a few similar needs than trying to satisfy the different needs of all actors – as this may result in satisfying no one – the developed ideas ended up being very relevant to some, whereas others could identify less with them. Therefore, in this regard, it might have been more beneficial to work with a group of participants that have more characteristics in common.

6.1.2 The impact of conversations

As suggested in the Feed Forward methodology, we worked with conversations as a research tool to generate knowledge in an informal, personal and authentic way (Kieboom et al., 2015). We recognized that an authentic conversation as a research method not only served as a means to collect insights, but seemed to be useful and valuable for the participants as well. Some expressed that it was helpful that someone took the time to listen, and even thanked us for the conversations. As we were still in the very beginning of the project, we were surprised by the fact that our activities were not just perceived as activities where they had to give, for example information, but just as well as activities they got something out of. The informal environment for example gave them the opportunity to talk openly about emotionally difficult issues. Sometimes however, the conversations became emotionally very intense, which very much affected our role that required some capabilities that are not necessarily common to designers. This we will go more into depth with in section 6.2.2 . We doubt that this would have happened to the same extent through a traditional interview, where the environment and relation is typically more formal and where the interview process is more controlled by the interviewer (Motivate Design, 2019).

The conversation method furthermore contributed to the fostering of a relation between us and the participants. Since we had enough time to show a real sincere interest in their fate and because the conversations took place in an informal setting, we were able to establish familiarity and trust between us. The roles were not as traditional and unequal as an interviewer and an interviewee, but rather characterised by partners in a more balanced conversation, talking on eye level. This we assume reduced their worries about being judged for what they were saying which certainly made them more open and honest in their narratives (Motivate Design, 2019). The fact that they seemed to feel comfortable in the situation, is something we assume greatly contributed to their willingness to continue participating in the project. Thus, the established relations assured the continuation of the project and therefore was really beneficial and important. From our experience with traditional interviews we did not experience a dynamic like this between the conversation partners yet. With this in mind, we advocate for conversations as a suitable method to be used when following a relational co-creative research approach.

In regards to the depth of the knowledge gained through conversations, it is worthwhile to consider if this method, which certainly requires more resources, such as for example time and emotional effort, is necessary. Surely, one can gain deep insights through an user-centered approach that interviews the user about challenges, however, it is our experience through the project that the method helped gaining a level of details and an understanding of complexity that we otherwise most likely would not have gained.

6.1.3 The impact of stories

The iterative story process, where the participants read the stories and gave feedback on our written interpretation, was a novel and intensive way to engage with research data, which contributed to an in-depth understanding of their realities and feelings, and made us deeply internalise the information. Furthermore, the iterative process ensured that most misunderstandings were cleared out.

In addition to this, the method was very suitable for a co-creative research process, as the caregivers were involved to a far greater extent than in a user-centered design process. The activity of producing and analysing knowledge was thereby done in a much more open and inclusive way, which emphasised the role of the participants as experts of their experiences (Sanders & Stapper, 2008; Kieboom et al., 2015), giving their voice and feelings a lot of weight. Thus, it was not just us as designers, who interpreted the stories and wrote a research report, as it is traditionally often done in user-centered processes (Sanders & Stapper, 2008), but instead the caregivers started feeling ownership about the research outcome – about the stories, which were iteratively refined together with them.

Another very interesting and important fact that emerged from the stories is that it made the caregivers see their own challenges from another person's perspective. It became clear that this made them reflect more on their own experiences and see these in a new light. In some cases this even resulted in that they could let go of some distressing feelings, which we perceive as a very valuable outcome. When asking the participants for feedback about the participation in such a research process, they expressed that the involvement had made them feel seen and heard.

Opposed to for example research reports that are common in user-centered design processes and which provide a summary of research insights to get the people of a design team on the same page (Sanders & Stapper, 2008), a story is a more relatable format, as the experiences someone went through are told, which makes the reader engage and feel empathy and compassion on a deeper and more personal level. To our surprise, some of the participants had even used their story as a tool to communicate their situation to friends and family outside the project, to make them more aware of their situation. Thereby the story contributed to tackle one of the identified challenges of family caregivers - that people around them, such as family, friends and the society often lack empathy, understanding, knowledge and awareness about their burden. This also confirms the usefulness of the story as a communication tool, which is seen as their major purpose in the Feed Forward methodology (Kieboom et al., 2015). It should be added that, as originally planned, the stories should later on in the process serve as a means to make the professional actors of the welfare system aware of the situation of dementia family caregivers and to make them feel empathy for them. Unfortunately, however, this could not be realised within the design process, due to the limitations mentioned in subchapter 4.5.

Though we see various benefits of the co-creative and iterative story method, it has to be pointed out that the approach required more effort than a traditional research process, where for example one hour, semi structured interviews are conducted and analysed.

Moreover, we acknowledge the fact that writing an engaging story is not a naturally inherited capability of every designer, and that some may find it difficult to write stories that live up to their full potential. Nor do we want to say that we are talented storytellers either, but what helped us was to iteratively write the story between the two of us before sending it out to the participants for the first time. One of us wrote the first version, whereafter the other one could make corrections and suggestions for improvement.

6.1.4 The impact of a collective evaluation

As we followed the first three steps of the Feed Forward methodology, the co-creative activities were not only conducted in the Discover phase but in the Define phase as well, which we consider to be a part of a research process. This means that we conducted the research insight evaluation as a co-creative activity. Therefore, after initially analysing and structuring the data ourselves, we invited the participants in for a dinner event that worked as an evaluation workshop, as described in section 5.2.2. This was done to ensure an informal environment with space for personal conversations and a focus on establishing and strengthening relations between all the participants.

It was our experience that the collective evaluation in the Define phase was highly relevant to ensure the insights' accuracy and validity and to reframe a problem statement whose exploration would meaningfully add value to the lives of the dementia family caregivers. Despite the iterative and co-creative writing of the story, we saw during the collective evaluation that there still were several misinterpretations on our part. This insight reveals that the more iterative and co-creative the evaluation is, the more precise your insights and data will become. The dinner was also a chance to involve the participants as the experts of their experiences (Sanders & Stappers, 2008) and to make them decide on the most relevant topics to work further on. It would not have reflected a co-creative mindset, if we had made this decision independently, without considering the participants' ideas and opinions.

The dinner evaluation was however not only an opportunity for us to discuss the insights, it was just as importantly an opportunity to bring the participants together and to provide them a platform to share experiences and connect. For the participants it seemed highly valuable to meet people in similar situations, who could relate to their experiences. We experienced that the process of them telling their story to others seemed to help them turn challenges into engagement and pride.

As the collective evaluation event was a success for us, we would like to raise awareness in regards to its planning process. There were some aspects that we handled very sensitively, which we assume played an important role in the success of the event. We for example believe that the participants may not have accepted the invitation if we had not managed to establish a relationship based on trust in advance and conveyed to them that we were genuinely interested in their well-being. In addition, we believe that the preliminary research contributed to the fact that the carers considered us as competent and that our project actually could contribute to making a positive difference in their lives. For the dinner itself, we very much reflected on how to create a safe and informal setting, as we had learned through the previous activities that this is a key to authenticity and to make the participants feel comfortable, which in turn contributes to creating relations. In regards to this, we were particularly careful to not only take, but also to give. For example, we planned the evaluation of the research insights for the last part of the evening, to make sure that we provided enough time for the participants to get to know each other. We also assumed that they were more open and confident to share their opinions, when they already knew each other. We think it was the right approach, as all caregivers eagerly contributed to the collective evaluation later during the evening. We also made a great effort to organize a nice and cosy dinner in itself. Later on, one of the participants expressed how relieving it was to just having to show up at such an event, without having to organize anything herself, as her own energy reserves are often scarce.

6.2 Further reflections on the research question

6.2.1 Characteristics of beneficial relations

As the research question of this thesis explores the impact of relational co-creative research in service design practice, it is important to discuss which kind of relations among the participants – or in other words, which kind of feelings and behaviours (Cambridge English Dictionary, n.d.) – have a positive impact on co-creative service design practices and which do not.

The initial inspiration for what could constitute a relational co-creative service design practice came from insights about relational services. We started by considering our own profession – service design – as a service in itself. By exploring characteristics of relational services and relational welfare (e.g. Aguirre-Ulloa & Paulsen, 2017; Cottam, 2011) and by investigating literature about the Feed Forward methodology (Kieboom et al., 2015), we had an initial idea of what characteristics might make up relational co-creation and how these could be achieved. Based on the activities conducted in the design process of the case study and the reflections that emerged from that, we derived various conclusions about which relational characteristics are beneficial for a co-creative service design practice.

One important characteristic is *trust*. Without trust in us designers and our good intentions to contribute to the field, the dementia family caregivers might not have gotten engaged in the project in the first place. Being able to establish initial trust required for example to conduct the preliminary research – in order to be able to show that we have a certain level of knowledge and understanding about the theme and the challenges that the dementia family caregivers face. This trust was further strengthened through the long conversations that we had and as a result, they confided us. If trust could not have been maintained or would have been disrupted, the participants would have probably dropped out of the project and the co-creation could not have been realised. To continuously maintain and strengthen this trust, we felt it was crucial to have a reliable, informal way of interacting with the caregivers from our side. This implied for example to be extremely reliable when it came to agreements or answering their messages, or to design the whole process in a way that was convenient from their perspective, not demanding too much. Furthermore, it implied being sensitive towards the environments in which we conducted the planned activities. We aimed for safe environments in which the participants felt comfortable, in which they could be themselves and where they felt no inhibitions about opening up. The conversations for example worked very well when being conducted in the family caregivers' homes. One conversation had to be conducted in a café, where we saw that the noisy surrounding and the passersby sometimes disturbed the participant in her narration and made her feel uncomfortable. Of course, whether or not one feels comfortable or uncomfortable, and seen and heard, has a great influence on a person's further participation and engagement

In this context, *sensitivity* – the ability to recognise the needs of the individual participant and to adapt to them, plays an important role. It was for example very individual how a caregiver appreciated to talk about her experiences related to her relative's dementia disease.

While some were very emotional and appreciated compassionate, emotional conversations, others spoke very rational and serene about their relative's disease. Being able to adapt felt crucial for having a pleasant conversation in which the participant is willing to open up and continue the conversation.

Empathy was another crucial characteristic of the relations among all participants. As service designers we gained initial empathy through the preliminary research activities, which was further expanded through the in-depth conversations and the iterative story writing process. When having the collective evaluation, where the participants first met each other, they certainly had empathy for each other just by the fact that they all shared the experience of being a dementia family caregiver. However, the fact that the participants had different roles as family caregivers, to relatives in different situations and stages of the dementia disease, still made them a diverse group of people. Here, we could see that the written stories, which were read out loud when each caregiver presented herself, created empathy and understanding among the participants. They started relating, giving advice or asking further questions. The stories were a convenient tool to get to know each other's experiences, feelings and struggles, and thereby gain empathy to each other, which provided a meaningful foundation for further conversations.

Furthermore, it was indeed noted that there is a great importance of *informality* (Kieboom et al., 2015) and authenticity (Pierri, 2017). This is understandable when one considers that the design project took place over a long period of time and that its core was about challenges – in this case related to the context of dementia in the welfare system – which have a big impact on the lived reality of the family caregivers and significantly determine their wellbeing. With this in mind, it makes sense that the design process should integrate authentically into their lived reality, so that there is as little additional stress and inconvenience as possible. Informality and authenticity were particularly evident in the way we communicated with the family caregivers. We for example used the communication means that they would use in their everyday lives, or left enough room during our interactions to talk about random topics, not only about matters directly connected to the project. In addition, the informality of for example the collective evaluation allowed the participants to have authentic conversations, making them share and exchange experiences and advice. Already after this evening they expressed the wish to stay connected through a Facebook group, which is a positive first step when considering that the long term goal of co-creation is to create sustainable relations among people (Kieboom et al., 2015). If we have had the chance to further continue the co-creation we consider it as likely that stronger relations could have emerged.

The relational approach fostered a process that authentically integrated into the participants' lives. It was time consuming to build up an authentic way of communicating and a trustful relationship, but in retrospect this has paid off. Through this novel relationship we connected with the participants on a deeper level than we would do when employing a user-centered design approach and got to know them and their lives well, which made our research and insights richer and wider. We also believe the relation to us, in combination with the activities conducted, made them become more open towards new insights and reflections on their part. The reflections and awareness mobilised them to intentionally act and think differently, in ways that are more desirable and beneficial for them. Furthermore, we assume that the approach significantly contributed to maintain the caregiver's engagement and thus sustain the project.

6.2.2 Challenges related to the approach

We also identify challenges that arose from the relational focus that need to be pointed out. For example, we discussed to what extent it was appropriate and needed for us designers to share our personal experiences and feelings with the caregivers when for example having conversations. On one hand, sharing is what constitutes authentic relations and conversations, which was desired, but on the other hand, it is difficult to assess to what extent these expressions bias the other person. Furthermore, you as the designer might not even wish to share your personal life in a professional work context. However, since it was important to us to have authentic and informal conversations and to build relations, as we considered them essential for the course of the project, we allowed ourselves to express our perspectives as often as it felt necessary and appropriate in order to establish authenticity and informality.

Furthermore, dealing with the personal lives and emotional issues of the participants can be difficult, since as a designer one is not necessarily trained in this. This will be elaborated further in the following subchapter, where the role of the designer is discussed. Moreover, it was our experience that the approach, to some extent, blurred the lines between professional and private life. In some cases this resulted in confusion on our part to what extent the nature of our relation to the participants is professional or private. Whether one likes this fact or not is probably very individual and varies from person to person, but it is certainly important to be aware of it at the beginning of a project, when an approach is chosen. There is also the question of whether the blurring borders can be prevented in any way, or are borders even desirable? Can the project be authentic and informal, despite the borders? We could not find answers to these questions within the context of this project, but it is certainly interesting to investigate them further through future research.

In addition, we consider to which extent the focus on relations in co-creative activities is resulting in the work automatically becoming biased. And, if we can even take it as far to say that the approach is a conscious choice to allow the work to be biased? When you as a designer involve yourself in a relational approach it might be naive to think that you can be completely neutral and not influence the project with your personality, values and beliefs, because these are inevitably involved in relations. Looking back on the project, we therefore find it interesting to consider whether, in choosing this approach, we have to some extent accepted to go against the traditional belief that research should be objective and unbiased.

6.2.3 The role of the service designer

The required competences and capabilities

When now being aware of the relational characteristics that are beneficial when conducting co-creative service design projects in the context of welfare, it makes sense to continue the discussion by considering what it implies for the designers. This subchapter will therefore look into the roles of the designer, and discuss what competences and capabilities are required when following a relational co-creative approach in the context of sensitive welfare projects.

When striving for creating relations and co-creative environments characterised by the properties mentioned above, it naturally requires more than just design capabilities from the designers. When working on a sensitive topic, such as dementia, one needs to possess a great amount of empathy and human understanding to deal with the emotional situations that can arise in the interactions with the participants. At certain moments, the conversations did not feel like research but rather like a private consultation. These experiences proved how challenging it can be to have sensitive conversations and support emotionally affected people, when one is not taught the methods and knowledge on how to do so, which designers usually are not. As we expected the participants feeling exhausted and emotionally affected from conducting the conversations, we saw it as our responsibility to leave them in a good place afterwards, which in some cases was not easy. As a designer you therefore need to possess capabilities in dealing with mental issues and talking to people about emotions, as this will most likely be a part of the conversations. It would have been useful to get professional advice beforehand, from someone who is experienced in conducting emotional difficult conversations.

Before conducting the conversations we had many considerations about the fact that it would require a lot from the participants to share their stories and 'revisit' old challenging memories. However, we forgot to consider and were surprised by the fact how exhaustive it was for *us* as well. Even though there certainly are benefits in conducting efficient research with one or more conversations each day, we would recommend having a day between each conversation, when being a team of a few designers. It simply requires a lot of energy to visit participants, who you have never met before, having hours-long conversations with them, being emotionally supportive, while listening for insightful details and trying to get an overview of the information. In addition to that, the approach requires to write the stories as soon as possible after the conversations, whose expenditure of time should also be taken into account.

Furthermore, another identified challenge when employing a relational co-creative approach in a sensitive area is that as a designer you need to be more flexible than usual due to the emotional strains of people. We experienced that there were occasional changes in the dates of our meetings, which required us to allocate enough time to carry out the research, so that the participants did not feel under any pressure but could make the activities in the project fit with their condition and responsibilities as a family caregiver.

This means that as a designer you need to let go of some control, as your project to a high extent relies on the participants and your relation to them. You often need to plan according to the participants' needs and capabilities, and the project therefore easily becomes fragile when working with participants who are in circumstances that are stressful and demanding to them. On a practical level, these experiences showed us that it can be beneficial for the design team to recruit enough participants, in order to be able to sustain the projects in case some of them cancel, as this is likely to happen. However, showing understanding in these situations aided us in establishing trustful, compassionate relations to the participants, which was revealed later on when people thanked us for being patient and empathetic to their situation. The trust and compassion we managed to establish from the beginning and throughout the process led to a very open communication and interaction between the participants and us as researchers.

We furthermore quickly became aware that being a designer in a relational co-creative process does imply letting go of what is normally seen as working hours. In order to establish an authentic relation and flow of communication, it was mostly during the evening hours we had to be reachable to communicate. Moreover, the conversations were often conducted in the afternoon or evening to make it fit the participants' everyday life. One should therefore be aware that when applying this approach to service design projects, the designer needs to adjust to another way of working that takes more time and changes the structure of a normal working day. For the participants the activities are not just a 'job', therefore, when stepping into their life and everyday settings, the designer should show respect by adjusting. It can be challenging, as it can feel as if the process becomes less efficient, when having to involve participants in most activities and decisions. It is therefore undeniable that this approach is more time consuming then others. However, we want to argue that it is worth it, looking at the outcomes, results and value created.

These experiences show that working with a relational co-creative research approach requires many resources from the designers, and thus is not the most easy and simple choice. It requires both time and emotional resources, and the project has proven that as a designer you will wear many different hats throughout the process. The shift between the various roles, which sometimes happens many times during a day, can be challenging and exhaustive in itself. Therefore, we find it important to be aware from the start of the project how much time and engagement you are able to put into the project. If you as a designer manage to show a big amount of engagement in the activities, it is our experience that this engagement pays off for the participants as well. By showing an effort, we experienced a gratefulness from the participants, who appreciated being able to contribute to the field. This naturally affected their participation, which they put a lot of effort, commitment and loyalty into.

Designers and participants – Who is the expert?

Additionally, we want to discuss the perspectives from the literature review presented in chapter 2 stating that within co-creation the designer should not act as the main actor (Manzini, 2015). We argue that it is beneficial for the designer to hold an expert mindset and expertise, and that it is more interesting and meaningful to discuss in which areas we as designers should act as experts and in which areas the participants should be considered as the experts.

We believe that when working co-creative the participants should be considered as the experts of the research topic – in this case what it is like to be a dementia family caregivers in the context of the Danish welfare system. Even though we found it useful and essential to have preliminary knowledge on the field before meeting the participants, the designers should not aim to become experts within the topic, as this is simply unrealistic and unnecessary, considering the fact that designers often switch the contexts they are working in and that the participants will always hold a higher level of expertise, since they have experienced their reality first-hand. The participants' role is therefore to be the experts providing knowledge and insights about their difficulties, needs, feelings and wishes related to a certain context. This however does not exclude the designers from being experts as well. Instead of claiming that by considering the participants as the experts, the designer cannot be one, it might be more relevant to ask in which other field the designer then is the expert. With the evolution of service design, we argue that the primary expertise of designers is no longer only to design objects and services. The service designers are now just as importantly becoming the experts when it comes to managing the activities and the overall process in the design project, as well as finding structure in complex material. Therefore we argue that the designers should not put aside their expert mindset. Without these expertises, the participants would have no professional guidance in how to best make use of their expert knowledge. This confirms the perspective presented in the literature review that the role of the service designer should be to support other actors (Manzini, 2015), which we argue that we do through our capabilities to find sense and structure complexity and processes. It is therefore more relevant to be aware of which competences to put aside, to make space for the participants and their knowledge, and which to put in the foreground. It is essential for a co-creative process to have designers, who manage to facilitate and enable the participants to contribute with their knowledge through various activities.

As a designer you moreover have the responsibility to plan the overall process, as this is what you are trained for. In a co-creative process this can be challenging, as you, on one hand, have to plan activities in advance to give people an overview of what kind of activities are going to be conducted and thus ensure their participation, on the other hand, you want to keep the process open to a certain extent, as you want to consider the inputs of the participants and as you have to be able to flexibly adjust to their condition, which may prevent you from sticking to the schedule.

We want to argue that the guidance through the process provided by designers, does not necessarily imply that power relations between them and participants are created. On the contrary, if the designers focus on fostering relations to the participants and creating informal and trustful environments, we would argue that more equal relations are built, in which each other's qualities are recognised and which thus mutually enrich each other. The designers therefore hold a rather humble role that acknowledges the resources of the participants, while still maintaining their own area of expertise. By showing respect to the fact that designers and participants enter the project with different roles, and by making these roles clear, we would argue that we also foster a more equal ownership of the project as well.

Through the project we have learned that designers can encourage participants' reflections about their realities, such as for example about challenges, feelings, relations, and interactions, by facilitating co-creative design methods. These reflections hold a great transformative potential for the individual actor that are likely to have sustainable impact beyond the boundaries and time frame of the project. This we will go more into depth with in the coming subchapter, in which we discuss where the value in service design projects is embedded.

6.2.4 The value of service design

In the following, we would like to share our considerations about what a relational co-creative research approach reveals about where the value of a service design project lies, as the design activities carried out in the context of this project have provided rich insights into this question.

As mentioned, we could see that the caregivers' participation in the co-creative design activities encouraged them to reflect and thus helped them to see their situations from a new, often very beneficial perspective. The participation became an opportunity for intensive exchange about their own situation and made them reflect on previous experiences and current interactions. The story method for example provided the participants with external perspectives on their experiences, which proved to have an impact in itself. For example, this external perspective helped one participant to let go of distressing feelings, and acknowledge and even feel proud about her achievements. Another person became aware of alternative, more beneficial perspectives and ways to act, which made her take action to seek the help she needed. Furthermore, the relations established among the participants proved to be impactful as well, as the participants have been able to continuously seek support from each other or share experiences, which they still do.

These findings enable us to critically reflect on the claims raised in the literature review (subchapter 2.1.2) about the value of service design. Our findings reveal an impact and value of service design methods that often remains to be overlooked. Commonly, service design methods are merely seen as a means to transition through the phases of a design process, working towards the output in form of a service at the end of the process. This output – the developed service – is also what is commonly considered as the value of service design (e.g. Mager, 2016). We however claim that we need to acknowledge that service design methods, when conducted in a co-creative manner, contribute to more than this. Through the project we noticed an embedded design process, happening on a meta-level, which was highly influenced by the participation and the interactions between the participants. The activities in themselves were driving positive change – change, which was particularly relevant to the individual participant. The participation in the co-creative service design activities encouraged the participants' own reflectiveness, made them build relations, and think and act in ways that had a positive impact on their own personal wellbeing.

These findings are very much aligned with recent perspectives on service design, presented in the literature review that advocate for acknowledging the transformative power of the design process (Akama & Prendiville, 2016; Vink et al. 2017; Vink, 2019, Kurtmollaiev et al., 2018). However, with this argument we do not want to claim that the end outcome – the developed or improved service – resulting from the service design process, is not as valuable and important. Instead, we think that the understanding of service design should be broadened to include both aspects. If we do not expand our understanding and recognize these positive aspects of the discipline, service design will not live up to its full potential, but be limited to rather narrow perspectives. Therefore, we see this research as a contribution to broaden the perspective into one that more fully acknowledges the value that service design can offer, and thereby expand the still fairly narrow understanding of our profession.

However, if we consider that the participation in co-creative service design activities contains a transformative potential, this also implies a certain limitation, which is that only the actors participating in a co-creative service design process are impacted and benefit from it. It is therefore interesting to reflect on how this value can be expanded beyond the boundaries of the design team and the project to have an impact to a greater extent. We suspect that we could have drawn conclusions on this question if we had had the opportunity to involve various other stakeholders into the co-creative design process. If we would have been able to make professionals and family caregivers come together to reflect on their interactions and current patterns, we can imagine that the impact of the participation could have been even greater. We for example imagine that the reflections emerging could have an impact beyond the boundaries of the project, impacting interactions within the system. As this is an assumption that we did not have the chance to validate in this project, it leaves us with some relevant questions that we will like to shed light on in subchapter 7.2, describing potential future research.

6.2.5 Relational co-creation in the context of welfare

In this thesis the impact of a relational co-creative research approach has been explored through a project conducted in the Danish welfare system, more precisely in the context of dementia. It is therefore relevant to lastly discuss in which other contexts the approach suitable may be suitable, and in which not.

Service design is increasingly applied to tackle the wicked, ill-defined problems of today's societies, such as for example chronic diseases, with dementia being only one example of many. Unfortunately, service design is still in its infancy regarding engaging in these contexts compared to for example policy makers, who remain to dominate these fields, yet it brings something valuable and new to the table (Polaine et al., 2013). As stated earlier in the thesis there is great potential in employing co-creative design approaches in these contexts.

Based on the insights generated through the explorations in the project, we see that relational co-creative research serves as a promising and impactful approach, when being applied in the context of sensitive welfare projects, such as the field of dementia. We realised that the approach helped leveraging various benefits that co-creation contains, such as creating an impact in the lives of the participants in itself, while at the same time lowering the challenges of co-creation, as it is able to ensure a higher level of engagement.

In order to sustain the interest of the participants in contributing to the project, it was important that their needs were given sufficient attention, that they did not feel in any way additionally burdened but that they felt comfortable with the activities carried out, and with the process in general. We claim that the approach significantly contributed to ensure that this was the case. This makes us assume that the approach may prove to be valuable in contexts where success is not measured in terms of competitive advantages or efficiency, but rather in terms of the level of value it provides to individual actors and society, or in other words, in terms of the level of social innovation. These contexts could for example be within welfare, healthcare, education (Polaine et al., 2013). We can also imagine that the approach would be suitable in any context where the presence of relational services is desirable. In the project we saw how the approach aided in establishing and sustaining relations among the team members that were characterised by trust, empathy, authenticity, compassion and give and take. As this kind of relation is aligned with the type of relation that is desired in relational services – services that are more human, caring, emotionally supportive, social, and collaborative (e.g. Aguirre-Ulloa & Paulsen, 2017; Cottam, 2011) – we believe that this approach could potentially support and contribute to the transformation of traditional services into more relational services. Considering Cottam's (2011 p.144) claim that the conditions for "new forms of creative, developmental conversation[s]" have to be created in which "something shared, collective and relational" can be grown, makes us think that relational co-creative research could contribute exactly to this.

However, we again emphasise that these assumptions are based on the insights generated from a single case study that unfortunately did not involve welfare service providers. Nevertheless, the observations and findings from this thesis let assumptions arise that a similar impact could emerge on a larger scale. Although the confirmation of these assumptions goes beyond the scope of this thesis, we find them worth to be presented as their further investigation may potentially be valuable for the service design field.

6.3 Reflections on learning objectives

6.3.1 Official learning objectives

The thesis was an unique opportunity for us to further strengthen the service design skills we had already acquired, to gain new ones and to demonstrate them in a context that truly matters to us. The context addressed in the case study – the Danish welfare system – was furthermore complex, and therefore considered as suitable to demonstrate our capabilities. The project allowed us to apply a methodological approach and methods commonly used within service design and to meaningfully enrich our practice with approaches and methods borrowed from other fields, such as from social innovation. The approach and methods from the service design field served us primarily to deal with the complexity of the context, through for example analysing and synthesising complex material, as well as in the guidance and facilitation that aimed at supporting the participants. The methods that were borrowed from the Feed Forward methodology, supported us in expanding and advancing the perspectives on service design. Through these activities we demonstrated an understanding of the service design field, that we can take advantage of its strengths, while being able to compensate for its weaknesses depending.

Another great learning were the constraints resulting from COVID-19 that challenged us to be flexible and adapt our approaches and the planned activities according to it. The situation taught us to work in unpredictable circumstances and develop alternatives, which is a valuable learning for future projects.

Another point worth highlighting is the initialisation and maintenance of the collaboration between us and the participants of the design project, as it taught us a lot about communication, the management of expectations and the facilitation of dialogues.

6.3.2 Personal learning objectives

An important goal that we have achieved by working on our thesis was to acquire theoretical as well as practical knowledge about co-creative approaches in service design. We gained experience in how to make our own professional practice more inclusive and ethical and thus how to make it better align with our own personal values. Co-creation has presented us with new challenges, such as engaging participants in a sustainable way, dealing with and adjusting to their diversity, facilitating ongoing communication and dialogues, and we are proud to have mastered these challenges effectively and satisfactorily. Nevertheless, as stated earlier, we initially wished for an even higher level of co-creation. Our goal was to collaborate with a group of diverse stakeholders, which was suddenly not possible anymore, resulting that this goal unfortunately was not fully fulfilled.

The work within the context of the Danish welfare system made us meet the goal to engage with complex, interconnected and societal problems, and train our skills in this direction. The work has confirmed our wish and motivation to continue using our service design skills to contribute to positive social change and to create meaningful value for people, and made us even better prepared for future projects in similar areas.

Last but not least, the project taught us that it is worthwhile to dare to experiment with new approaches and methods as these can meaningfully enrich service design. The experiments conducted in this thesis and their results inspire us and it is our impression that this is contagious. During the project we presented our findings to colleagues and friends, which has resulted in interesting and inspiring discussions about service design, inclusive design processes, alternative methods, and so forth. In this regard, we are happy that we have already been able to fulfill the goal of inspiring others and hope that our research contribution will continue to do so.

7

Conclusion

Conclusion

This chapter presents and summarises the key findings related to the academic research question. It furthermore presents the limitations of this study and possible areas of future research.

The chapter is divided into the following subchapters:
7.1 Key findings related to the research question
7.2 Limitations & future research

7.1 Key findings related to the research question

In this thesis it has been explored how a relational co-creative research process impacts the practice of service design. The research has been carried out through conducting a case study, which addressed the context of the Danish welfare system. In the case study the challenges of being a dementia family caregiver have been examined and conclusions about measures that would better support them in their responsible and demanding role have been derived.

To structure the design process and address the problem statements of the case study the Double Diamond methodology has been employed. In addition, elements of the Feed Forward methodology were integrated into the Discover and Define phases of the Double Diamond, to ensure co-creative and relational activities and thereby explore the research question. Alternative design methods such as conversations, stories and a collective evaluation have been applied throughout the process to ensure an iterative process and an extensive level of co-creation with a focus on relations. This experimentation left us with several reflections and findings on how the approach impacts service design projects, and service design practice in general.

First, the study proved that a co-creative project to a high extent relies on its participants and that the recruitment therefore is crucial. In relation to this, a conduction of preliminary research is beneficial in order to build trust, engagement and empathy to potential participants. The conversation method helped to build an informal environment in which we could collect rich insights and foster relations. The conversations showed to be valuable for the participants as well, proving that the method in itself is impactful. The story method, and the iterations arising from the use of the method, made us engage with the data in a novel and thorough way. The method made us co-creatively interpret research data, making the analysis open and inclusive, in which the participants became the experts of their own experiences and challenges. Furthermore, the usefulness of stories as a communication tool within the design team and to external stakeholders was revealed, as some participants used it to get understanding from their network, and as it worked well to create mutual empathy among the project participants. The use of co-creation in the analysis and synthesis phase enriched and validated the insights. Furthermore, the collective evaluation was an opportunity to bring the participants together, to make them co-create and provide them a platform to share and exchange, which proved to be impactful in itself, as they could guide and support each other, and see their own experiences from others' perspectives.

The research showed that relations that are characterised by trust, sensitivity and empathy are beneficial for a co-creative research process, as they ensure a higher level of engagement from participants, which thereby makes the project more likely to sustain. In addition to this, the relations can encourage participants' honesty, while making them more open towards the transformational impact of the design process, which adds additional value to the service design practice. Our study found out that these relations can be established by creating environments that are safe, informal and authentic, which make the participants open up and engage on a higher level.

However, the relational focus also left us with challenging dilemmas, such as to which extend we as designers should share personal experiences. What is the right dynamic in regards to the relationship among the designer and the participants in a project? In our project the lines between private and professional life frequently got blurred. It furthermore arose a question of how biased the project becomes when involving yourself in relations to the participants.

The approach proved to challenge the responsibilities of the designers, as the sensitive and emotional context required many different hats and competences, which are not necessarily taught to designers. The shift between various roles, which was frequently required several times a day, can be challenging and exhausting. The approach also required a lot of resources both emotionally and timewise, as it for example implied letting go of normal working hours.

Additionally, the findings support reflections about who is considered as the expert in a service design project. We conclude that designers and participants act as experts on each of their fields – the participants can be seen as the experts in the topic of the project, whereas the designers are the experts when it comes to facilitating the process and activities, as well as finding structure in the complex content. Thereby, the research aligns with perspectives who claim that the role of the designers is more that of an enabler (Manzini, 2015), whose task it is to support other actors who are not educated in design in creating their desired futures.

Through the co-creative activities we were able to mobilize the reflections of the participants, making them see new perspectives on their own realities. This proved to be a valuable outcome of the process in itself, as it made the participants take action in various ways – for example some were able to let go of distressing feelings such as guilt and others started seeking out for the help they needed. Thereby, the findings from the thesis revealed an impact and value of service design that often remains overlooked – that the participation in itself can drive positive change. We therefore argue that service designers should acknowledge the transformative power of the design process to a higher extend, and not only perceive the service outcome as the primary value in service design practice. This thesis can therefore be seen as a research contribution that supports broadening the perspective on the value the service design profession can offer.

7.2 Limitations & future research

In the following we outline the limitations that influenced the design process and thereby the academic research of the thesis. Following the limitations, we elaborate on future research that may be relevant and interesting to be carried out to further explore the assumptions and unanswered questions arising from the research.

Firstly, the conducted research is limited as it is a single case study in the context of dementia in the Danish welfare system. We therefore cannot say for sure that the approach and the generated insights are applicable to other contexts as well.

Secondly, though we thoroughly co-created with dementia family caregivers, we see a limitation in the fact that we did not involve other stakeholders in the project. An involvement of dementia patients would have been both valuable for the insights and, just as importantly, more ethical, as the project after all is based on their disease. We further see the lack of male family caregivers as a limitation as well, as the results cannot be generalised across genders. In addition, the lack of involvement of professional actors from the welfare system is a great limitation, as the thesis to a high extent is missing their perspectives on the challenges. This inevitably is a limitation to the outcome of the design process – the suggestions on how to strengthen the communication and information between the family caregivers and professionals. These suggestions are therefore meant as a foundation for further development that would require the professional perspective, in order to investigate their feasibility. As mentioned, the lack of involvement of other stakeholders was unfortunately to a high extent out of our control, due to the circumstances of COVID-19 in spring 2020. Furthermore, as we only gathered the participants once for the collective evaluation, it would have been valuable to conduct more shared co-creative activities to explore the established collaboration and relations between the participants even further.

We also see a limitation in the methods used throughout the project, as they certainly have affected the outcome. The use of conversations as a method can for example be seen as limiting, as it focuses on certain aspects, while leaving out others. Thereby our design process relied on the insights that were generated based on the told stories from the family caregivers, and their accuracy was not validated through additional research methods. A method like observations could potentially have revealed a discrepancy between what was told and what is the reality.

Another limitation that is important to be highlighted is our own personal bias, which cannot be considered as external to this thesis. As stated in the discussion, the approach made it difficult to balance between a neutral position and a personal involvement, resulting in our personal values and beliefs inevitably remaining to a certain degree in the project.

Lastly, we want to stress the fact that even though we experienced that the time frame for the thesis made it possible for us to thoroughly dig into a field of interest, the reflections and limitations emerging from the project still leave us with unanswered questions and assumptions that would be interesting and relevant to explore through future research. This would help us understand the implications and impact of our research more profoundly.

As stated in the discussion we assume that the approach could have contributed to transform the relations and interactions between the family caregivers and the professionals in the welfare system. We therefore suggest that future research focuses on further exploring how the participation in the design activities would have been affected by co-creating with various actors from the system. How would the participation of professionals have influenced not only the design process, but the relations between the actors in general? Would the involvement have encouraged awareness and reflections that could make a difference on a higher level? Since our research showed that the co-creative activities helped the participants to reflect and establish interpersonal relations, characterised by empathy, compassion, authenticity and informality, we wonder if the approach could be used to enable exactly this kind of relation between family caregivers and professionals as well. Therefore we see a great potential in investigating whether the approach can aid to transform the relations in the system into ones that are associated with more positive characteristics. In other words, we see a potential for future research to explore to what extent the relational co-creative approach can meaningfully contribute to transforming traditional services into relational services that are more emotionally supportive, humane and caring (Aguirre-Ulloa & Paulsen, 2017). When service design is able to make the relations, emerging from co-creative service design activities, enter the real life context (Björgvinsson et. al 2010), it could potentially contribute to relational systemic change.

Furthermore, it is our aim to develop a guide based on the reflections and methodological insights gained through the thesis. The guide will be targeted professionals working with service design projects, as well as professionals in the field of welfare, healthcare and social work, who wish to work more experimentally and involve people through co-creation. It should work a simple visual communication format that sums up and presens the various steps of the approach, suggestions to service design tools, guidelines and good advice, as well as challenges to be aware of. With this we hope to further inspire service designers to try out, and further explore, the relational co-creative approach when conducting research.

8

References

Aalborg University. (2020). Kandidatspeciale (2019/2020). Aalborg University, Kandidatspeciale. https://moduler.aau.dk/course/2019-2020/MSNSSDM4171?lang=da-DK

Aguirre-Ulloa, M., & Paulsen, A. (2017). Co-designing with relationships in mind. FormAkademisk - Forskningstidsskrift for Design Og Designdidaktikk, 10(1). https://doi.org/10.7577/formakademisk.1608

Akama, Y., & Prendiville, A. (2016). Embodying, enacting and entangling design: A phenomenological view to co-designing services. Swedish Design Research Journal, 9, 29–40. https://doi.org/10.3384/svid.2000-964X.13129

Akoglu, C. (2016). Co-Creation In Service Design Practice. 11th EAD Conference Proceedings: The Value Of Design Research. European Academy of Design Conference Proceedings 2015. https://doi.org/10.7190/ead/2015/32

Alzheimerforeningen. (n.d.). Alzheimerforeningen. Retrieved March 17, 2020, from http://www.alzheimer.dk/

Alzheimer’s Research UK. (2015). Dementia in the Family: The impact on carers. Alzheimer’s Research UK. https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/carers-report/

Bason, C. (2018). Leading Public Sector Innovation (Second Edition): Co-creating for a Better Society (3rd rev of 2 New ed). Policy Press.

Binder, T., Brandt, E., Ehn, P., & Halse, J. (2015). Democratic design experiments: Between parliament and laboratory. CoDesign, 11(3–4), 152–165. https://doi.org/10.1080/15710882.2015.1081248

Björgvinsson, E., Ehn, P., & Hillgren, P.-A. (2010). Participatory design and “democratizing innovation.” Proceedings of the 11th Biennial Participatory Design Conference on - PDC ’10, 41. https://doi.org/10.1145/1900441.1900448

Bjørner, T. (2015). Qualitative methods for Consumer Research. The value of the qualitative approach in theory and practice. Hans Reitzels Forlag. https://hansreitzel.dk/products/qualitative-methods-for-consumer-research-(i-bog)-i-bog-36789-9788741262321

Blankman, K., Ellenbogen, M., Graham, N., Hogg, L., Mittler, P., Piot, P., Splaine, M., Vernooij-Dassen, M., & Watt, A. (2012). World Alzheimer Report 2012: Overcoming the stigma of dementia—Executive Summary (p. 18).

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience, 11(2), 217–228.

Buchanan, R. (2001). Design Research and the New Learning. Design Issues, 17(4), 3–23. https://doi.org/10.1162/07479360152681056

Buskermolen, D., & Terken, J. (2012). Co-constructing stories: A participatory design technique to elicit in-depth user feedback and suggestions about design concepts. ACM International Conference Proceeding Series.

Cambridge English Dictionary. (n.d.). Retrieved April 29, 2020, from https://dictionary.cambridge.org/dictionary/english/relation

Cipolla, C., & Manzini, E. (2009). Relational Services. Knowledge, Technology & Policy, 22(1), 45–50. https://doi.org/10.1007/s12130-009-9066-z

Cottam, H. (2011). Relational welfare. Soundings, 48(48), 134–144. https://doi.org/10.3898/136266211797146855

Crazy 8's. (n.d.). Design Sprints. Retrieved April 27, 2020, from https://designsprintkit.withgoogle.com/methodology/phase3-sketch/crazy-8s

Danish Dementia Research Centre. (n.d.). Dementia in Denmark. Nationalt Videnscenter for Demens. Retrieved February 5, 2020, from http://uk.videnscenterfordemens.dk/dementia-in-denmark/

Danish Health Authority. (2018). National Research Strategy on Dementia 2025. Research for the benefit of people with dementia and their relatives. Danish Health Authority. https://www.sst.dk/-/media/Udgivelser/2018/National-Research-Strategy-on-Dementia-2025_Final.ashx

Demenslinien. (n.d.). Alzheimerforeningen. Retrieved April 19, 2020, from http://www.alzheimer.dk/her-faar-du-hjaelp/demenslinien/

Design Council. (2015). Design methods for developing services. https://www.designcouncil.org.uk/sites/default/files/asset/document/Design%20methods%20for%20developing%20services.pdf

Design Council. (2019). What is the framework for innovation? Design Council's evolved Double Diamond. Design Council. https://www.designcouncil.org.uk/news-opinion/what-framework-innovation-design-councils-evolved-double-diamond

Dilnot, C. (1982). Design as a socially significant activity: An introduction. Design Studies - DESIGN STUD, 3, 139–146. https://doi.org/10.1016/0142-694X(82)90006-0

Drew, C. (2019, September 3). The Double Diamond: 15 years on. Design Council. https://www.designcouncil.org.uk/news-opinion/double-diamond-15-years

Giordano, F., Morelli, N., Götzen, A. D., & Hunziker, J. (2018). The stakeholder map: A conversation tool for designing people-led public services. Service Design Proof of Concept, 16.

Haley, W. E. (1997). The family caregiver's role in Alzheimer's disease. Neurology, 48, S25-9. https://doi.org/10.1212/WNL.48.5_Suppl_6.25S

Jørgensen, U., Lindegaard, H., & Rosenqvist, T. (2011). Engaging actors in co-designing heterogeneous innovations. 13.

Junginger, S. (2015). "Organizational design legacies and service design". The Design Journal, 18(2), 209-226.

Kieboom, M., van Exel, T., & Sigaloff, C. (2015). Lab-Practice_publication_ENG.pdf. Kennisland.

Kurtmollaiev, S., Fjuk, A., Pedersen, P. E., Clatworthy, S., & Kvale, K. (2017). Organizational Transformation Through Service Design: The Institutional Logics Perspective. Journal of Service Research. https://doi.org/10.1177/1094670517738371

Lord, K., Livingston, G., Robertson, S., & Cooper, C. (2014). How people with dementia and their families decide about moving to a care home and support their needs: Development of a decision aid, a qualitative study. BMC Geriatrics, 16(1), 68. https://doi.org/10.1186/s12877-016-0242-1

Lynn Shostack G. (1982). How to Design a Service. European Journal of Marketing, 16(1), 49–63. https://doi.org/10.1108/EUM0000000004799

Mager, B. (2009). Service Design as an Emerging Field. In Designing Services with Innovative Methods (pp. 28–43). Keururu, Finland: Otava Book Printing.

Manzini, E. (2015). Design, When Everybody Designs: An Introduction to Design for Social Innovation (R. Coad, Trans.). The MIT Press.

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. The Gerontologist, 56(5), e70–e88. https://doi.org/10.1093/geront/gnw078

Motivate Design. (2019, March 14). What is the Difference Between Interviews & Conversations? Motivate Design. https://www.motivatedesign.com/what-is-the-difference-between-interviews-conversations/

Nationalt Videnscenter for Demens. (2020a). Nye landsdækkende tal for demens i Danmark. Nationalt Videnscenter for Demens. http://www.videnscenterfordemens.dk/forskning/forskningsnyheder/2018/05/nye-landsdaekkende-tal-for-demens-i-danmark/

Nationalt Videnscenter for Demens. (2020b). Omkostninger forbundet med demens. Nationalt Videnscenter for Demens. http://www.videnscenterfordemens.dk/statistik/omkostninger-forbundet-med-demens/

Nationalt Videnscenter for Demens. (2020c). Tal og statistik om demens—Nationalt Videnscenter for Demens. http://www.videnscenterfordemens.dk/statistik/

Patrício, L., de Pinho, N. F., Teixeira, J. G., & Fisk, R. P. (2018). Service Design for Value Networks: Enabling Value Cocreation Interactions in Healthcare. Service Science, 10(1), 76–97. https://doi.org/10.1287/serv.2017.0201

Pierri, P. (2017). Decentralising Design. Raising the Question of Agency in Emerging Design Practice. The Design Journal, 20(sup1), S2951–S2959. https://doi.org/10.1080/14606925.2017.1352805

Polaine, A., Løvlie, L., & Reason, B. (2013). Service Design: From Insight to Implementation (1st ed.). Rosenfeld Media.

Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. CoDesign, 4(1), 5–18. https://doi.org/10.1080/15710880701875068

Sanders, E., & Stappers, P. (2008). Co-creation and the New Landscapes of Design. CoDesign, 4, 5–18. https://doi.org/10.1080/15710880701875068

Sevaldson, B. (2013). Systems Oriented Design: The emergence and development of a designerly approach to address complexity. 22.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family—Caregivers of people with mental illnesses. World Journal of Psychiatry, 6(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Simon, H. A. (1969). The Sciences of the Artificial (1st ed.). MIT Press.

Steen, M., Manschot, M., & De Koning, N. (2011). Benefits of Co-design in Service Design Projects. International Journal of Dsign. http://www.ijdesign.org/index.php/IJDesign/article/view/890/346

Stickdorn, M., Hormess, M. E., Lawrence, A., & Schneider, J. (2018a). This Is Service Design Methods: A Companion to This Is Service Design Doing. O'Reilly Media, Inc.

Stickdorn, M., Hormess, M., Lawrence, A., & Schneider, J. (2018b). This Is Service Design Doing. O'Reilly Media.

Stickdorn, M., & Schneider, J. (2012). This Is Service Design Thinking: Basics, Tools, Cases (Reprint edizione). John Wiley & Sons Inc.

Teixeira, J. G., Patrício, L., Huang, K.-H., Fisk, R., Nóbrega, L., & Constantine, L. (2016). The MINDS Method: Integrating Management and Interaction Design Perspectives for Service Design. Journal of Service Research, 20. https://doi.org/10.1177/1094670516680033

Trischler, J., Pervan, S. J., Kelly, S. J., & Scott, D. R. (2018). The Value of Codesign: The Effect of Customer Involvement in Service Design Teams. Journal of Service Research, 21(1), 75–100. https://doi.org/10.1177/1094670517714060

Vink, J. (2019). In/visible—Conceptualizing Service Ecosystem Design [Karlstad University Studies]. http://urn.kb.se/resolve?urn=urn:nbn:se:kau:diva-71967

Zomerdijk, L. G., & Voss, C. A. (2010). Service Design for Experience-Centric Services. Journal of Service Research, 13(1), 67–82. https://doi.org/10.1177/1094670509351960

Vink, J., Tronvoll, B., Edvardsson, B., Wetter-Edman, K., & Aguirre, M. (2017, June 6). Service Ecosystem Design: Doing Institutional Work through Design.

Willis, A.-M. (2018). The Design Philosophy Reader. Journal of Design History. https://doi.org/10.1093/jdh/epz053

World Health Organisation. (2019, September). 10 facts on dementia. World Health Organisation. http://www.who.int/features/factfiles/dementia/en/

World Health Organization. (2017). Global action plan on the public health response to dementia 2017—2025. World Health Organization. https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

MASTER THESIS

Aalborg University | Service Systems Design
by Nanna Dam Johansen & Rike Neuhoff