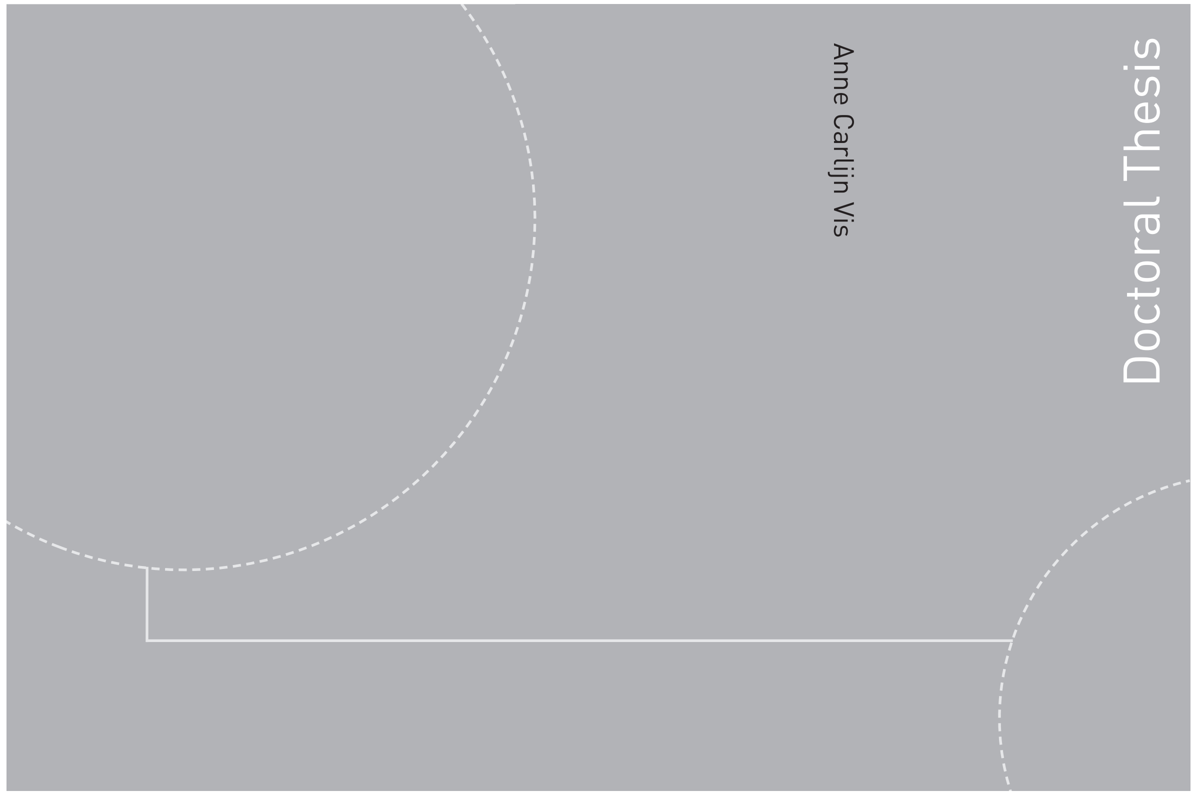
ISBN 978-82-326-3554-2 (printed version)
ISBN 978-82-326-3555-9 (electronic version)
ISSN 1503-8181



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Anne Carlijn Vis

Matching Intentions with Experience

A human-centred service design approach to shared decision making

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Thesis for the degree of Philosophiae Doctor

Trondheim, December 2018

Norwegian University of Science and Technology
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Doctoral theses at NTNU, 2018:383

Printed by Skipnes Kommunikasjon as
MILJØMERKET
241 TRYKKSAK 731

Tell me and I will forget,
Show me and I may remember,
Involve me and I will understand.

- Confucius, 450 B.C.

Abstract

Demographic change towards an older population and increasing prevalence of life-style related diseases lead to changing needs for medical care. Simultaneously, medical practice is moving away from paternalistic decision making. Patients and their next-of-kin are increasingly invited to become active agents in treatment decisions. This practice is called Shared Decision Making (SDM).

Chronic Kidney Failure (CKF) is used as an example to investigate the implementation of SDM practice in chronic care. SDM is being promoted among others in Norway (Leivestad, 2013) and the United States. However, a systematic review that covered studies from various countries, conveyed that patients with CKF and their next-of-kin have frequently reported a lack of choice. Moreover, others have claimed that best practices on effective approaches to information dissemination and knowledge acquisition for patients with CKF are lacking. Furthermore, regarding SDM in general, there is a need to investigate how patients and their next-of-kin are best supported in making a choice, as only providing information is not enough.

The aim of this thesis is to reach a better understanding of aspects that can support the (re)design of pre-treatment education and decision-support programs for chronic patients and their next-of-kin. This is done by investigating existing interventions that provide pre-treatment education and/or decision support to patients and their next-of-kin from a human-centred design perspective. Emphasis is placed on the situation in Norway.

Sub-goals of the thesis are to:

- Provide insight into information needs of adults with CKF pre-treatment start and their motivations behind treatment preferences.
- Establish an overview of pre-treatment education programs for adults with CKF from an international perspective.
- Contribute to knowledge on how to apply participatory design methods in hospital care contexts.
- Investigate the potential introduction of “serious games” as a supplementary strategy to support SDM.

The thesis builds on design theory, constructivist learning theory, and insights from studies that were conducted for this thesis. The thesis contributes to the field of Design for Health, which embraces all kinds of design practice and design research that has the intention to contribute to health and wellbeing. Human-centred service design stands at the core of this thesis. Service design has close links to other design disciplines, such as product, interaction and graphic design. The thesis is therefore relevant for all kinds of design practitioners and design researchers who work with health. The survey, opinion, and empirical research contributions that this thesis provides are specifically relevant for designers whose work concerns patient education programs.

The thesis provides insights into the information needs of patients' pre-treatment choice. This knowledge aids designers in determining what information to include in a holistic service offer and in specific interventions of such a service, such as pre-treatment education programs. Furthermore, insights regarding the barriers to SDM that patients and their next-of-kin have reported are provided. Designers can use this knowledge to develop solutions that meet these barriers. Practical examples of how education services may be organized are provided additionally. Designers can use this knowledge when (re)designing akin service offers. However, more empiric research that allows cross-case comparison is needed to clarify which aspects of contemporary programs support or constrain SDM. As programs vary greatly in set-up, and are evaluated through various measure, evidence for the effectiveness of program components is lacking. Designers should critically reflect upon using them.

The findings of the thesis indicate that designers should carefully consider the timing of information and how information is presented and formulated, accounting for people with various learning styles and knowledge levels. Designers are also recommended to better account for universal design guidelines to support people with cognitive disabilities.
The thesis presents a theoretical argument for the use of serious games as a supplement to face-to-face and website-based programs. This argument is relevant because, serious games might contribute to stimulating reflection and discussions concerning treatment alternatives.

Designers are recommended to apply a service design approach and to use education and decision support programs as part of a more extensive service offer. Medical practitioners and designers should be aware that gaps may occur between intentions of service providers, expectations of participants and experiences in practice. Designers can use the knowledge that this thesis contributes with when (re)designing patient education programs; It can help them develop propositions that bridge these gaps. Qualitative evaluations can help uncover constrains. Designers can use such insights when redesigning patient education programs; It can help them develop propositions that overcome these constrains. Co-design sessions that facilitate collaboration across medical disciplines can benefit the (re)design of healthcare services. The development of evaluation schemes that patients fill out can support medical practitioners to continue the introduction of iterations, without the further involvement of designers.

The methodological contributions inform human-centred design practice and research in healthcare settings. It presents approaches that are relevant for designers whose work concerns service design or participant involvement in healthcare settings. The thesis specifically contributes knowledge regarding the organization of co-design events in this context.

This thesis adds to the discussion on participation in design, by proposing that in healthcare, and in other settings that involve long-lasting participant relationships that build on trust (e.g. schools, public welfare agencies), a specific ethical consideration has to be made; Designers should reflect upon the possible long-term effects of participation on relationships between participants *after the workshop.* This is important as trust is established over time through successive interactions. Concerning participant selection, designers are additionally recommended to reflect upon the vulnerability of potential participants and the costs versus benefits of their participation.

Furthermore, the thesis illustrates that within a healthcare setting, the inclusion of external experts as workshop participants can be valuable for idea generation. Designers are recommended to consider both the inclusion of practitioners that work with similar healthcare services and the inclusion of designers as participants. Both parties bring in new perspectives, and are able to question current practices. Additionally, the thesis demonstrates the value of involving practitioners that are familiar with the healthcare context to facilitate the workshop. Although they are not designers, they have a thorough understanding of the context and the problems that needs to be addressed. Organizing a trial workshop can help such facilitators gain confidence in the application of design tools. Furthermore, designers are recommended to anticipate if specific aspects of healthcare contexts (hierarchy, working in disciplines and unfamiliarity with co-creative tools) may have an effect during the workshop, and to adopt the assignments accordingly.

Pre-treatment education and decision support programs for patients and their next-of-kin are important elements in chronic care services. Moreover, they are important supports for the SDM process. The knowledge that this thesis generates, supports designers in the (re)design of such programs to better meet the information and support needs of patients and their next-of-kin.

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List of Acronyms and abbreviations

CKF	Chronic kidney failure
HD	Haemodialysis
SDM	Shared Decision-Making

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Preface

The vacancy for this PhD project stated the Department of Design's wish to expand research that would support *'a sustainable health care system and ensure good living conditions for a growing and aging population.'* Furthermore, the vacancy specified the department's aim to expand knowledge on *'the opportunities and challenges associated with how design and design thinking can contribute to this goal, especially in a Nordic context.'* Being given the freedom to find a specific topic of personal interest within these boundaries was very exciting, but also difficult. I spend the first months formulating a more precise objective. The choice to work with chronic kidney failure was motivated by the fast numbers of people that suffer from this chronic condition over a relatively long period and by the growing prevalence of chronic kidney failure in the Nordic countries due to lifestyle changes. Within the field of care for chronic kidney failure, one specific topic caught my interest: The possibility to move haemodialysis treatment out of the hospital into the homes of patients (Home-HD). I wondered if the machines were too difficult to operate for patients or their caregivers, and if this caused the low number of people on Home-HD. In 2014, most machines for Home-HD that lay-people had to operate themselves had the same interface as the machines that were used in healthcare clinics and were operated by specialized dialysis nurses. Initial literature research and discussions with medical professionals showed however that the low number of patients on Home-HD might have other causes, rather related to both medical practitioners and patients being unfamiliar with Home-HD as a treatment option. I therefore changed my objective from optimizing the interface of haemodialysis machines for use by patients and caregivers, to stimulating the uptake of Home-HD by reducing knowledge barriers. Around the same time, I first read about the concept of shared decision-making (SDM). This made me realize that from an ethical perspective it would be more just to stimulate SDM than to focus on the stimulation of Home-HD specifically. My objective became therefore to stimulate SDM with help of design approaches.

During my studies and work as a professional designer, I had gained some experience with conducting and analysing interviews. However, before I started with this PhD project, I had never consciously used an academic approach to the analysis of qualitative data. First, learning about various analysis methods, next determining which methods to use, and then moving from theory to the actual application of these methods in practice was a struggle for me at first. With help of the instructions from my supervisors, I was able to improve my analysis skills. My supervisors have helped me understand that data analysis is about developing a higher-level interpretation of data; After conducting the research and transcribing the data you have a general impression of the data, but once you start investigating the text sentence for sentence, you start to discover patterns. Working back and forward through the texts, gradually an image starts to form on how different themes connect and form overarching categories. By really working with the text, sentence for sentence and going back to texts when you formulate a new theme, you build a deeper level of understanding of the meaning of what was said or what was observed. Your understanding becomes richer. Although data analysis is a time-consuming activity, I found it very interesting and inspiring to work on the analyses. *Strauss and Corbin (1998) have stringently formulated it: "Doing research is hard work. It also is fun and exciting. In fact, nothing can compare to the joy that comes from discovery." (p.14).* I found the discussions with my supervisors very enriching. Their different backgrounds, personalities, and research experience made that they viewed the data from different perspectives, leading to richer insights. The discussions uncovered how our pre-understanding, which is inherent to our backgrounds, influenced our interpretations of the data.

Furthermore, I had to learn that doing research is not a linear process that starts with a literature review, leading to the identification of gaps and the formulation of research questions, followed by data collection and analysis. Instead, I found out that the research process can be partly cyclic, resembling a design project with a fussy front-end, diverging and converging phases. Or, as my supervisor Marikken Høiseth once described it during one of our conversations: *'It is like a jungle, where you sometimes just have to jump into to a liana to see where it takes you.'*

Even though I enjoyed having the freedom to formulate my own project and to find my own subjects for investigation as the project was independent from any research group, I sometimes experienced this independence as challenging. I sometimes felt that I was superimposing a problem to the healthcare practitioners that I approached. Who was I to come from a university, to approach their organization, to do some research and then to propose that things might be improved? In future, I therefore really hope to get the opportunity work on projects that are based on a need that is expressed by healthcare practitioners or people who receive care instead. Despite these feelings of being the outsider who superimposes a problem, I really enjoyed the collaborations with the healthcare practitioners I have had during the project. The interesting conversations with them, have deepened my understanding of healthcare practices and have enlarged my appreciation of their work. Seeing their passion for caring for others has been a strong motivation for me to continue with my project.

Acknowledgements

First of all, I would like to express my gratitude to my supervisors for their guidance and the many interesting discussions we have had on our interpretations of interview transcripts and observations notes. Martina, I appreciate the challenges you have given me the past years and greatly value your positive and constructive support. Sigrid, thank you for always making time for me when I needed support and your thorough feedback. I greatly appreciate your effort to help me succeed and your enthusiasm for the project. It has helped me to keep going. I enjoyed attending the IEEE SeGAH 2016 conference in Orlando together. Marikken, thank you for investing time and energy to familiarize yourself with my project and your constructive and detailed feedback on the many drafts I send you.

Furthermore, I would like to express my gratitude to the two nurses that organize the Kidney School for allowing me to research their program. I appreciate their willingness to participation in the expert interview, their help in getting permission to do observations and interview patients, and their help in obtaining permission from their department head and recruiting colleagues for participation in the co-design workshop. My appreciation goes to the presenters and participants of the Kidney School who allowed us to observe the group session. I would like to thank the three participants that allowed us to interview them and Maria Kristine Bækkelie for her support during these interviews. I greatly appreciate the workshop participants' enthusiasm and their willingness to contribute to the project and their efforts to change their practices.

Additionally, I would like to thank Anne Regine Lager and Jürgen Kasper for the many interesting discussions on shared decision making and its implementation in practice. Meeting you always energized me and I always went home with many new thoughts and insights.

I would further like to express my gratitude to the two practitioners at the Dialysis Network, for making time to talk to me and inform me about their organization and the education program they offer. Thank you to Dr. G.W.J. Bruinsma and L. Collou, MSc. whom organized the Serious gaming course and gave me permission to write my own assignment. Thank you to the students that participated in the course and helped to develop the game, C. Barreira, V.C. Maduro, I. de Vent. Your dedication and creativeness was inspiring. Marianne Kleveland, I would like to thank you for taking on the assignment for D7 and your dedication.

Dear fellow PhD candidates in Design and Architecture. Thank you for making the past 1.5 years so much more enjoyable to be in office. It was great to be part of such a social group. Good luck with your projects. I look forward to read your theses!

Thank you Martha, for your positivity. It has helped my more than you migth realize.

Lieve Maarten, het is zo fijn dat je zo goed op me past. Zonder jou was ik niet zo ver gekomen. Het leven is zo veel leuker samen. Op naar nieuwe avonturen!

1. Introduction to the topic

This chapter presents a brief introduction to the research topic, objectives and research questions that are addressed in this thesis. More detailed information is presented in chapter 2. This thesis contributes to the field of Design for Health. Design for Health embraces all kinds of design practices as well as all strings of design research that have the intention to contribute to health and wellbeing (Wildevuur, 2017). Human-centred service design stands at the core of this thesis. Service design has close links to other design disciplines, such as product, interaction and graphic design. The thesis therefore contributes with knowledge that is relevant for all kinds of design practitioners and design researchers who work with health. As the thesis aims to support the improvement of health services, it also contributes to this field.

My background and how it influenced the selection of the topic for this thesis
As a high school student, I considered studying medicine. However, the outlook on having to operate on people withheld me. Instead, I chose to study industrial design engineering. Both fields are about helping people and improving their lives. During my studies, I realised how important it is to have a thorough understanding of the people for whom you are developing. One can design the most excellent products, but if they do not bring value to the stakeholders, the product is unlikely to become successful. For that reason, my interest in user insight studies has grown. User insight studies can help a product development team to construct an in-depth understanding of behaviour, values, needs and demands. Furthermore, I believe that stakeholder participation in the design process leads to better solutions. My first job after graduation was at Royal Philips in the department of pain relief, where we worked on projects for people with chronic pain. It made me realise the huge potential for improvements in the healthcare sector and the positive impact such improvements can have on one’s life, especially for those with a chronic condition. My desire to work with design in healthcare projects that aim to improve the situation of chronically ill people is reflected in this thesis.

1.1 Defining research area and topics

Changing demographics
The demographic shift towards an older population (United Nations, 2015) and the increasing prevalence of lifestyle-related diseases (World Health Organization, 2013), due to increasing age, unhealthy lifestyles and longer survival on treatment, puts stress on healthcare systems worldwide. Although the demand for healthcare services is rising, the portion of people of working age is diminishing. With proportionally fewer people working in the healthcare sector in the future and a growing demand for care, reconsideration of where and how patients are cared for is necessary to ensure the sustainability and quality of healthcare systems. One of the options to reduce the pressure on specialised hospital services is to move non-critical care out of hospitals by supporting patients to be cared for at home. People will have to rely more on their own resources and help of their relatives and friends. The development of new welfare technologies, such as telecare, enables more treatment, rehabilitation and care to take place where people live.

Shared Decision Making

Along with the growing awareness of a need for change to ensure the sustainability and quality of healthcare systems, a paradigm shift in medical practice is gaining traction. Medical practitioners are no longer recognised as the sole authority when it comes to decision making regarding medical care. More often, patients and their next-of-kin are recognised as knowledgeable parties, as well. This cultural shift away from paternalism is a phenomenon that is supported by changes in medical legislations. Nowadays, informing patients on treatment options and involving them in treatment decisions are legally mandated practises in many western countries. Norway and the United States, for example, have included statements in their patient right laws that express that patients have a right to be informed about examination and treatment options, procedures, possible risks and side effects. Furthermore, these laws state that patients should be given the opportunity to ask questions and are allowed to participate in treatment discussions (American Cancer Society, 2014; Helse- og omsorgsdepartementet, 1999). Such medical practice is referred to as shared decision making (SDM).

SDM has been promoted, as from a medical perspective it can be unclear which treatment option is best for an individual patient. Each treatment modality can have dissimilar effects on a person's life and his or her family. Some treatments are commonly performed at home, whereas others are performed in a hospital or care clinic, either as self-care or assisted by a nurse. Some might require surgery, whilst others do not. Furthermore, there are differences between treatment during daytime and night time. Moreover, some treatments require a strict treatment schedule and diet, whereas others allow more freedom. Furthermore, the medical outcome of treatments can differ, as associated risks, benefits and side effects are treatment-specific and individual. For patients in Norway, economic consequences of treatments are similar, as care is fully compensated by funding from tax revenues (Mossialos, Wenz, Osborn, & Anderson, 2015). In cases where none of the treatment options have clear medical advantages over other options, it is considered especially desirable that the patient is part of the treatment selection process and offered the full range of relevant options (Charles, Gafni, & Whelan, 1997; Elwyn et al., 2010). The thought behind SDM is that medical practitioners are specialised in the medical aspects of treatments, whilst patients are the experts on their lives, values and beliefs. The latter can, thus, provide insight in personal considerations towards treatment aspects, such as the risks and side effects they would prefer to avoid, the benefits they value most or the treatment schedule would suit them best.

Elwyn et al. (2012) defined SDM as a process in which the patient is first explained that there is a choice to be made, and why it is relevant for the patient to be involved. Next, the treatment options and related pros and cons are explained. Finally, the patient is supported in exploring preferences, and a discussion takes place in which both the patient's and the medical practitioner's perspectives are articulated to come to a decision together. Decision aids are tools that are developed with the intention of helping people deliberate on the options to form preferences related to their personal values (Elwyn & Miron-Shatz, 2009). Some are intended to be used during a consult, whilst others are intended to be used by patients in the privacy of their home. The concept of SDM is discussed more thoroughly in section 2.2.2 of this thesis.

Chronic kidney failure

In this thesis, chronic kidney failure (CKF) is used as an example to investigate the status quo of SDM practice in specialised hospital care. Although the focus in this thesis lies on the specific case of supporting SDM for people with CKF, it is expected that some of the findings will be generic and transferable to other medical conditions. CKF was chosen as an example, as it is one of the lifestyle-related chronic conditions that is increasing in prevalence. Furthermore, the available treatment options are rather diverse, as will be explained later.

People that suffer from CKF have a reduced kidney function. The function of the kidneys is to filter waste products and excess fluid from the blood, as well as produce specific hormones (National Kidney Foundation, 2017). CKF is a progressive condition, meaning that the function of the kidneys further diminishes over time. Eventually, some form of renal replacement therapy is needed to survive. Internationally, several guidelines for clinical practice exist that give advice on how to decide between renal replacement therapy options (Atai & Johnson, 2012; Covic et al., 2010; Levin et al., 2008; National Kidney Foundation, 2015; Warwick et al., 2014). Due to limited clinical evidence, these documents contain advice and suggestions for care, rather than guidelines for best practice. Although the documents include some statements on what information should be provided, they do not describe how patient education can be practically realised. Furthermore, different nuances imply different views on how a decision should be made. Unanimity on best practices for patient education on renal replacement therapy is, thus, lacking. Pierratos (2013) urged for the formulation of a systemised approach to patient education that individual centres can adopt and in which the interactions between healthcare practitioners, patients and their next-of-kin are central.

Studies on treatment selection for people with CKF have indicated that, when patients are involved in the decision, a form of home care is more often selected than when medical practitioners make the decision for the patient (Goovaerts, Jadoul, & Goffin, 2005; Jager, Korevaar, Dekker, Krediet, & Boeschoten, 2004; Manns et al., 2005). It has been suggested that pre-treatment patient education plays an important part in this preference (Chanouzas, Ng, Fallouh, & Baharani, 2012; Lacson et al., 2011; Moran & Kraus, 2007; Pipkin et al., 2010). In addition to educated patients preferring different treatment modalities, some medical benefits have been suggested to be associated with pre-treatment education. Unplanned dialysis starts seems to be less common for educated patients, and there is more time between the referral and the beginning of dialysis (Marrón et al., 2006). More information on CKF and the most commonly used treatment methods can be found in chapter 3.

Challenges related to shared decision making and chronic kidney failure

Although SDM is promoted for CKF in countries like Norway (Leivestad, 2013) and the United States (National Kidney Foundation, 2015), it can be debated whether or not current programs supporting SDM are sufficient, as patients and their next-of-kin report a lack of choice (Morton, Tong, Howard, Snelling, & Webster, 2010). Timely provision of sufficient information appears to be problematic in many cases (Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005). Furthermore, paternalistic handling, the lack of experience of medical practitioners with specific treatments, and the availability of resources have been mentioned as barriers (Goovaerts et al., 2005). In addition, the strong focus on clinical needs, rather than lifestyle and quality of life aspects, has been suggested to be problematic (Hope, 2013). In addition to being insufficiently informed, patients' attitudes and skills might hinder their participation in SDM. People can lack self-efficacy in performing treatment, might hold beliefs concerning how patients should be involved in care, have fears or suffer from cognitive difficulties (McLaughlin, Manns, Mortis, Hons, & Taub, 2003). Furthermore, low health literacy can be a barrier for participation (McCaffery et al., 2013). An additional hurdle can be the required reading level of written materials, which is often higher than the recommended level (Morony, Flynn, McCaffery, Jansen, & Webster, 2015).

Best practices on effective approaches to information dissemination and knowledge acquisition for patients with CKF are lacking (Finkelstein et al., 2008; Liebman, Bushinsky, Dolan, & Veazie, 2012; Pierratos, 2013). Furthermore, there is a need to investigate how patients prefer to be informed (Havas, Bonner, & Douglas, 2016) and how they can best be supported in making a choice, as only providing information is not enough (Elwyn & Miron-Shatz, 2009). Supporting SDM is important, as the choice for a specific treatment will influence the patient's life and his or her family.

1.2 Objective of the thesis

Based on the above-described situation and problem identification, the aim of this thesis is to acquire a better understanding of aspects that can support the (re)design of pre-treatment education and decision support programs for chronic patients and their next-of-kin. This will be realised by investigating existing interventions that provide pre-treatment education and/or decision support to patients and their next-of-kin from a human-centred design perspective[1].

Sub-goals of this thesis are to:

- Provide insight into information needs of adults with CKF pre-treatment start and their motivations behind treatment preferences by conducting a scoping literature review.
- Establish an overview of pre-treatment education programs for adults with CKF from an international perspective by conducting a literature review and by analysing publicly accessible online platforms regarding their content and information mediation strategies.
- Contribute to knowledge on how to apply participatory design methods in hospital care contexts by conducting co-design workshops with medical practitioners and patients.
- Investigate the potential introduction of "serious games" as a supplementary strategy to support SDM by providing a theoretical discussion and the development of a prototype.[2]

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[1] Human-centred design is elaborated upon in section 2.1.1.

[2] This fourth sub-goal is added because the healthcare sector is showing a growing interest in gamified solutions. Annual conferences, such as Serious Games for Health and Games for Health Europe, attract growing numbers of participants from both the game and healthcare industries. Although many health-related gamified applications and games are being developed with multiple purposes, an example of a

The results of this thesis are meant to contribute to the development of programs that support patients and their next-of-kin in SDM. The findings will support designers in the development of relevant designs and give healthcare providers insight into why and how their program could be improved. This thesis thereby contributes to the field of Design for Health (Lab4Living). The thesis contributes with knowledge that is relevant for various kinds of design practitioners and design researchers who work with health. As the thesis aims to support the improvement of health services, it also contributes to this field.

Emphasis is placed on the situation in Norway, where Bent Høie, the Minister of Health and Care Services, has appointed the introduction of free treatment choice as a spearhead for action, stating that 'No decision about me, without me' should become a prerequisite for treatment decisions (Høie, 2015). Pre-treatment education and decision support for people with CKF is used as an example, although findings are expected to be transferrable to other conditions where several treatment modalities are available, such as prostate cancer and obesity. The project does not include research about training of persons to prepare for treatment start after they have selected a treatment modality, nor does it consider the training of medical practitioners to facilitate SDM. Although these are important aspects for the quality of care, it was decided to focus first and foremost on the design of supports for patients in the SDM process.

1.3 Research Questions

In order to meet the objectives of this thesis, the following research questions, with corresponding sub-questions, have been formulated:

1. What information needs do people with chronic kidney failure and their next-of-kin have when they need to consider renal replacement therapy?
2. What are the factors that might enable or constrain the realisation and enactment of shared decision making in practice?
    a. How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organised? Which of their aspects support or constrain shared decision making?
    b. How are current information websites and web-based decision aids on renal replacement therapy designed and structured? Which of their aspects support or constrain shared decision making?
3. How can serious games support shared decision making processes?
4. How can design approaches contribute to the (re)design of programs that support shared decision making?
5. To what degree can the findings from this thesis contribute to improving programs for medical conditions other than chronic kidney failure?

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game that educates patients about treatment options and/or supports them in deliberating on the options has not been found.

1.4 Thesis outline

This thesis builds upon several studies. Chapter 2 first introduces the underlying theoretical perspectives that lie at the basis of the thesis. Section 2.1 presents related design theories, whilst section 2.2. goes deeper into decision-making models in healthcare. Chapter 3 presents CKF in more detail to give the reader a better understanding of the situation people with CKF that face the start of renal replacement therapy experience, and which treatment options exist. Chapter 4 presents the higher-level research approach, discussing epistemology and used methodologies. Chapter 5 provides two literature reviews that formed the basis for further empiric research. Section 5.1 focussed on obtaining insight into the information needs of patients and their next-of-kin who phase treatment choice. Section 5.2 provides a review of education programs that intent to meet these information needs. The empiric studies that were conducted successively follow two tracks. Chapter 6 presents the studies that were done on technology-mediated education and decision support programs. It provides insights on how current information websites and web-based decision aids on renal replacement therapy are designed and structured. Furthermore, it discusses which of their aspects support or constrain SDM. Additionally, it provides insights on how serious games may be applied to support SDM. Chapter 7 presents the studies that were done on face-to-face education programs. It discusses how current face-to-face education programs for people with CKF and their next-of-kin are organised, and how these programs may support or constrain SDM. Additionally, it provides knowledge on how human-centred methods may be applied to re(design) specialist healthcare programs. Chapter 8 forms the concluding chapter. It provides a discussion of the strengths and weaknesses of this thesis, it presents the thesis' contributions, and it offers suggestions for further research.

2. Theoretical perspectives

This chapter presents the theoretical background for the thesis, places the thesis in context and explains the stance of the researcher. A brief introduction into the theoretical perspectives that stand at the basis of the thesis are given, starting with a discussion on human-centred design, continuing with shared decision making as a model for decision making in healthcare and ending with a presentation of the constructivist learning theory as an approach to education.

2.1 Design and design research

The author – A designer and researcher
Pre-understanding plays a role in the problem selection and leaves its imprint on the research process (Alvesson & Sköldberg, 2009). In the following, I will briefly discuss my background and the standpoints I had at the start of this thesis.

I am educated as an industrial design engineer and have worked in a company that develops consumer products. This experience has formed my manner of working, looking at things and interpreting things. I like to describe myself as a *human-centred designer*, being interested in people's meaning making when interacting with products in their daily lives. Thereby, I am perhaps interested in different topics than other designers are. My background also influences the angle of investigation in which I engage. Qualitative techniques are important measures for obtaining insight into what is meaningful to people and building an understanding of their motivations and behaviours. Empathy helps to ensure that ideas are relevant, fit for purpose and desirable (Design Council & Technology Strategy Board, 2011). As a designer, my goal is to create a better future situation for the people surrounding me. This is initiated by looking for things that could be improved and questioning current practices and function of products and services.

Before discussing human-centred design, the meaning of the verb designing is discussed, as this is inherent to the concepts for design research that are applied in this thesis. Briefly, designing is a process that consists of imagining possible futures, deciding on what is desired and finding a way to realise these objectives (Krippendorff, 2006). This worldview influences how designers are inclined to work and how they frame problems or challenges and search for and communicate solutions. In their search for solutions, designers collect, reassemble and integrate knowledge from different fields and adapt this information to the specific needs and context of the problem that is addressed (Buchanan, 1992). These specific needs and context relate to the particular situation in which the problem or challenge occurs, including the stakeholders and (future) users that are involved. First, the designer maps the current situation and the stakeholders' needs and concerns (Buchanan, 1992). The designer then formulates a working hypothesis for a preferred outcome, based on these insights. Creative acts of making constitute an important part of the design process (E. B.-N. Sanders & Stappers, 2014). Designers, for example, make sketches and develop prototypes. They may also use probes and toolkits to actively involve others in the design process. In their search for desired solutions, designers are constantly reframing the problem. When they experiment, designers reflect on envisioned effects of the designed intervention for the different stakeholders. The knowledge that designers use for reflection is partly implicit or tacit (Schön, 1983). Prototypes enable the designer to check their hypothesis to improve the current situation.

Design research is a relatively new research field, compared to traditional fields such as science and chemistry. There is a need for the development of a ‘science for design’: bringing together effective design practices and successful methods to develop theories on design (Krippendorff, 2006). These theories help to improve design methods and their application in projects, leading to better problem-solving approaches. Designers can contribute to theories on design by reflecting on how to apply methods and what is learned from the application of familiar methods in new situations (Steen, 2011). The goals and approaches of design research are usually closer to applied research than to fundamental research (Horváth, 2007).

This thesis contributes to the science of design in the healthcare domain by contributing with knowledge about how design methods can support the (re)design of pre-treatment patient education and decision support programs. This thesis is positioned as a *socially sensitive* project, where the major challenge is to select fit technologies and to adapt them sensitively, considering factors such as experience, well-being and sustainability, rather than the development of new technologies (Horváth, 2007). Below, human-centred design is explained as a specific position towards design and the role of the designer. As will be explained, a focus on social contextual factors is inherent to the design approach of human-centred designers.

2.1.1 Human-Centred Design

In the design field, two views prevail concerning the role of the designer: the designer as the expert who designs for people and the designer who actively involves people in the process and designs with them (E. Sanders & Stappers, 2008). In the first view, people are seen as users and act as study subjects that inform the design process. They are not directly involved in the design project, but are rather consulted to inform iterations, at most. This position regarding the designer as the expert who places users at the centre of the design process, but does not directly involve them, can be referred to as User-Centred Design. This approach is typical for projects that are technology-driven. A broad scope of design approaches is applied by designers that adhere to this view (E. B. N. Sanders, 2008a). In some cases, the user is involved during parts of the process (e.g. usability testing); in others, the designer aims to build an understanding of the user indirectly by developing guidelines that inform the design process (e.g. applied ethnography and ergonomics). In brief, user-centred design is about designing for people.

Design has traditionally been user-centred, but the position of designers towards design and the involvement of users has been changing over the past decades. In the new position that has emerged, called Human-Centred Design or Participatory Design, people are regarded as knowledgeable, intelligent agents with their own understanding of the world around them.

They are seen as experts on their own lives and experiences and are, therefore, actively involved in the design process as partners in design. This is regarded as necessary to meet people's needs (Lucero, Vaajakallio, & Dalsgaard, 2012; E. B. N. Sanders, 2008a). In short, human-centred design is about designing with people.

In human-centred design, human needs form the drivers for design, instead of technological functionality (Krippendorff, 2006). As human needs form the drivers for design, building empathy is an important task at the start of any human-centred design process. Within the field of human-centred design, a large variety of methods and tools exist that help designers build empathy. Some of these tools enable the inclusion of human actors as active participants in the design process, such as co-design sessions and generative toolkits. The large variety in methods and tools allows designers to adapt their approach for each project, based on the project's specific context and aim. An important decision that human-centred designers need to make is when, how and to what extent to work in a human-centred manner; this means that designers need to decide when and how to involve external parties, and how to balance the ideas and suggestions of involved parties with their own creativity and expertise as designers (Steen, 2011).

In this thesis, the perspective on human-centred design as proposed by Krippendorff (2006) is followed. The meaning that people attach to products is of great significance. It is a designer's task to find solutions that *"make sense to us, remain useful, and enable us to feel at home with them"* (Krippendorff, 2006, p.39). The meaning of a product is constructed upon its possible imagined uses, which stem from previous experiences, culturally related conceptions, habits and motivations. People base their actions on these possible imagined uses. The meaning of a product is individual, context-dependent and can change over time, as people continuously reconstruct the meanings of products in their lives as they gain experience. Furthermore, Krippendorff (2006) explained how language plays a central part in how an object is perceived. "It is the use of language that distinguishes forms, materials, functions, and problems". (Krippendorff, 2006, p.20) How people speak of a product can change one's perception of it. Due to individuality and changing perceptions over times, there is no single truth. Krippendorff (2006) explanation of developing individual understanding is compatible with the ontology of social constructivism, which is the basic ontology applied in this thesis. A discussion on social constructivism can be found in section 4.1.

In human-centred design, the meaning and imaginable uses of a product form the starting point of the design process. During the design process, the focus lies on the different roles a product can assume in society and assigning meaning to them. Building an understanding of the different prevailing perceptions of a specific contextual experience, i.e. building empathy, at the start of a design project is important for human-centred designers. Such empathic insights into perceptions of an experience, personal values, habits, motivations and goals can inform suggestions for change. Krippendorff (2006) suggested asking questions about the meaning and use of objects, such as 'What does this X mean to you?' 'Why do you use this X the way you do?' and 'What did you think when using this X?' to build empathy. Such questions allow people to tell the story of the meaning of an artefact in their life. By listening to what people say and interpreting their comments, a designer develops an empathic understanding of the meaning of the product to different individuals. This enables the designer to develop different ideas for change and assess the desirability of these ideas.

The challenge with building empathy, however, is that the designer's understanding is second-order. Krippendorff (2006) explained the concept of second-order understanding in a figure, which is depicted below (Figure 1). The figure shows that the person on the left has a certain understanding of a bike. When she explains this to the person on the right, he forms an understanding of a bike. However, his understanding is influenced by personal experience and cultural conceptions. There is, therefore, a risk for distortion (Alvesson & Sköldberg, 2009). Second-order understanding and the risk for distortion is encapsulated in this quote: *"I can never be sure what the meaning is that you read into my words, because what moves from me to you are signals and not the meaning of signals".* (Pitasi A, von Glasersfeld E., 2001, cited in Kasper, Légaré, Scheibler, and Geiger (2010). Methods such as co-design can help diminish the effects of distortion, as people are given an active role in the design process.

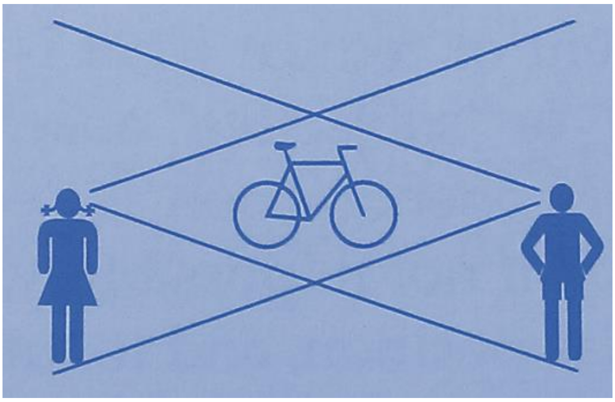

Figure 1 – Second-order interpretation by Krippendorff (2006, p.67)

Krippendorff (2006) specifically focused on the origination of meaning from a human's interactions with products. The author considers Krippendorff's view to be applicable to the design of services, as well. Summarising, the role of the human-centred designer is to build empathy towards people's perceptions of a specific experience, actively involve them in the design process and create meaningful products. The role of people is to act as partners in design, contributing with personal insights on experiences.

2.1.2 Designing for Services

Over the past centuries, companies in industrialised countries have focused on the sales of products. A shift in focus to the delivery of services was stimulated by a need to differentiate from competitors. Around the millennium shift, companies started to increasingly diversify, moving from the delivery of standard services to focusing on the delivery of customised services that provide the service receiver with a memorable experience (B. J. Pine & Gilmore, 1998). For many companies, services are now their main sales product. The main difference between buying a product versus making use of a service is the frequency of contact between people and providers. When a product is sold, there usually is a one-time contact between a client and a supplier. The delivery of services, however, evolves over several contact points between service receivers and service providers that are spread over time. Designers have followed the shift from product focus to service focus. Service design is now an established specialisation.

Service design is a relatively new discipline. As a consequence of the immaturity of the field, consensus of the concept of service design has not yet been established (Stickdorn & Schneider, 2011). Consequently, several definitions of service design can be found that each lay significance on slightly different aspects. An example of three different definitions of the concept of service design are:

- “Service design is the shaping of service experiences so that they really work for people. Removing the lumps and bumps that make them frustrating, and then adding some magic to make them compelling”. - Mat Hunter, Chief Design Officer at the Design Council (Hunter, 2015)
- The service design approach brings a human focus to the development of services. It helps organisations see the big picture as customers see it, and offers tools to design every little interaction between customers and the entire organisation. – (LiveWork)
- “Service design is the design of the overall experience of a service, as well as the design of the process and strategy to provide that service”. – (Moritz, 2005)

The differences between the three definitions of the concept of service design signify the lack of consensus in the field. This lack of consensus is related to the multidisciplinary background of the discipline. The discipline has close connections to psychology, ethnography, anthropology, sociology, product and interface design, information management and marketing. Coming from various fields, service designers do not necessarily take a human-centred position. Nevertheless, qualitative tools that involve the analysis of data from individuals rather than statistics are commonly used. Due to the lack of consensus on the concept of service design, the author presents her personal view on how to design for services, building on a more human-centred position towards service design.

Whilst only the last definition specifically refers to the development of a strategy that service providers can use, all three definitions emphasise the experience of the service receiver. Experience can be defined as ‘the mental impact felt and remembered by an individual caused by the personal perception of external stimuli’ (Sundbo & Sørensen, 2013). Such stimuli could address any of the senses. Experiences are remembered because something extraordinary, out of the daily routine happened, whether it is positive or negative. Experiences are individual and influenced by previous incidents and personal background. Therefore, these experiences are time-related: People can have another experience of a similar event later in their life. This understanding of experiences being individual and time-related is in line with the social constructivist paradigm (section 4.1). Even though experiences are intangible, experiencing and the memory of positive events is valuable to people (J. B. Pine & Gimore, 2013). Experiences can vary widely and may have longer lasting educational and informative effects.

Services can be individualised by breaking them up into small packages that can be rearranged to meet an individual's exact needs. When done well, this can create a 'wow feeling': an exceptional experience (J. B. Pine & Gimore, 2013). Starbucks and Apple are perhaps the best-known companies that turned a standard service into an experience: Starbucks not only offers a coffee serving service, they create a setting where people enjoy spending their time. Apple has created a special shopping experience in their stores by focusing on hospitality that was inspired by the services in chic hotels. Although the main aim of these companies is to sell products and deliver services, they include stimuli to create an experience around their products or services (J. B. Pine & Gimore, 2013).

A note on the meaning of 'experience' in the context of service design
The word 'experience' has a dual meaning in English. It can refer to 1) 'knowledge, skill or wisdom gained through practice', and 2) 'an event that affects or involves a person' (Slot Webcommerce bv., 2017). Other European languages differentiate between these meanings. In Dutch, Norwegian and German, the words *ervaring, erfaring* and *Erfahrung* denote the first meaning, which is related to learning, whilst *belevenis, opplevelse* and *Erlebniss* denote the second meaning. In service design, the focus is on the latter.

The service design approach

Service design is a holistic approach to the development of services. When designing for services, the focus lies on the design of coherent processes to guide interactions between stakeholders. The process is human-focused, paying attention to both the service providers and service receivers. Although the direct interactions between service provider and service receiver receive the main focus, the larger system of relations between other stakeholders and physical and non-physical elements is also taken into account (Stickdorn & Schneider, 2011). The development of a coherent service experience is important, as every individual interaction that takes place during service delivery contributes to the overall service experience. The goal of service design projects is not only to design service experiences that appeal to the service receivers, on both the rational and emotional levels, but also to develop services that are resource-effective and economical for the service provider (Bechmann, 2010). The outcome of a service design project can have various forms, from an organisational structure to physical objects (Stickdorn & Schneider, 2011) or a combination of the two. Service design projects can be small or large scale and concern the improvement of existing services or the development of new services.

A large diversity of methods and tools have been applied in different service design projects. Some of these tools have been specifically developed by service designers, whilst others have been taken over from related disciplines (Bechmann, 2010). Hardly any service design project is similar to another, as the tools are adapted to fit the context of a project. Although the methods and tools that are applied in service design projects do not necessarily include service providers and service receivers as active partners in the design process, the use of participatory techniques, such as co-design, is not uncommon, either. Bechmann (2010) is one of the scholars who regarded the involvement of stakeholders in the design process as an important pillar of service design. He claimed that all stakeholders should be seen as resources for development, as the people who use, maintain or own a service are considered to be experts on their needs and preferences (Bechmann, 2010).

Empathy and the focus on experiences and processes are key to service design. Instead of designing for a generalised target group, perspectives and interests of individuals are used during the design process. The intention is to minimise risks for failure through developing a deep understanding of the stakeholders. By involving them directly in the design process, this risk is further diminished, and a feeling of ownership is built amongst the involved parties. This feeling of ownership supports the implementation of changes in practice. A challenge with the design of services is that the process does not have a clear ending. When changes have been realised, new problems and possibilities can often be found during the evaluation of the service. There is constantly the possibility to further improve the service experience (Bechmann, 2010).

Information visualisation is an important part of the service design process. Several tools exist to support visualisation. The User Journey Map and the Service Blueprint are two of such visualisation tools. A User Journey Map provides an overview of the series of direct interactions that take place during a specific timeslot between a service provider and a service receiver, from the receiver's perspective. Such interactions are referred to as Touchpoints. User Journey Maps are often used to display an existing service and enable the evaluation of this service. Direct touchpoints between service provider and service receiver are called front-stage interactions. Often, supporting interactions take place in the background to realise these front-stage interactions. Actions that are indirect and invisible to the service receiver are referred to as back-stage interactions. A Service Blueprint is a visualisation of the collection of front stage and back stage interactions that take place. Service blueprints are commonly used to visualise and communicate the outcome of the design phase in order to support the implementation of changes (Stickdorn & Schneider, 2011).

To summarise, the role of the designer, when designing for services, builds empathy towards people's perceptions of a specific experience to obtain a holistic overview of the current service offering; this is accomplished by mapping the interactions that take place and redesigning the service such that both the service provider and service receiver benefit from it. Due to the disciplinary background of the field, different views on the role of people prevail. The author has presented a human-centred perspective on the design of services. Clatworthy (2014) is an example of a scholar who promoted a more profound expert approach in which interviews, observations and methods such as role-playing support the design team in building empathy and developing relevant solutions.

Service design in healthcare
Service design can be used to improve the efficiency and effectivity of healthcare services and may, thus, help to reduce the costs and pressure on healthcare practitioners. The goal when designing for services in healthcare is to deliver better care to the patient whilst providing healthcare practitioners with a satisfying work experience (Hans, 2015). Service design tools can be used to map the sometimes-disparate patient pathways and redesign the system's interactions.

Healthcare services take place in a complex context. In professional healthcare settings, strong hierarchies exist based on profession. Due to specialisation, working in silos can occur, and risk aversion is one of the main criteria (Bowen et al., 2013). Service design projects have been administered to innovate public healthcare services. The NHS Institute for Innovation and Improvement (2009) have even developed a guide on workshop facilitation to support the advancement of care services. In healthcare, a hospital or medical professionals are often the service provider, whilst patients and their relatives are the service receivers. Relationships between patients and healthcare practitioners are changing, with patients being more often involved in decision related to their care more often than before (see section 2.2 on Shared Decision Making). This requires changes to the services that are provided to patients.

2.1.3 Co-design

As mentioned above, co-design is a method that human-centred designers can apply to actively involve people as participants in the design process. Although it is not necessarily applied when designing for services, the method can be applied in service design projects that utilise a human-centred design approach.

Co-design is used to refer to acts of collective creativity between designers and non-designers that occur during the design process. It includes processes of collectively creating and evaluating ideas in various phases of the design process, such as brainstorming, sketching and prototyping. In co-design sessions, designers and non-designers are considered equal. Kensing and Greenbaum (2013) defined four guiding principles for co-design. Co-design should: equalise power relations, support democratic practices and situation-based actions, and provide tools and techniques to support these objectives.

In co-design workshops, designers can take the role of facilitator, not actively contributing to the discussions in the workshop. Alternatively, designers can be part of the creative team and collaborate with non-designers in the workshop as participants. Involving stakeholders actively and directly in the design process ensures that ideas are reviewed early and anchored amongst the stakeholders, creating a feeling of ownership; this ensures that the project will meet the needs of the people involved (Yang & Sung, 2016). Furthermore, design-by-doing engages people, results in resourceful dialogues by offering alternative ways of communicating (Björgvinsson, 2008) and fosters shared learning (Simonsen & Robertson, 2013). It allows designers to build empathy for people, whilst people experience what it is to be a designer. Bringing together stakeholders with dissimilar needs fosters and strengthens the

innovation process. As co-design gives people space for self-determination, it builds commitment to change (Buur & Larsen, 2010).
For projects in the public sphere, it can be difficult to identify all stakeholders, due to the complex context (Garde, 2013). Another challenge with co-design is that the outcome of the project is unknown. Therefore, it is uncertain at the start of a project which actors and resources will be needed to realise the outcome of the co-design sessions. Some outcomes might not be realisable when the involvement or participation of external actors is needed. This might be frustrating for the participants in the design project, and they might even come to doubt the effectiveness of the outcome of the design process. It is, therefore, recommended to communicate these challenges early (Bowen et al., 2013).

To summarise, co-design sessions are a method that human-centred designers can use to actively involve stakeholders in the design process. The designers themselves can either take on the role of facilitator or participant. The role of individuals in co-design workshops is to actively contribute with personal insights, ideas and opinions.

2.2. Shared Decision Making

Several conceptual models exist that explain decision making in healthcare contexts. The following four models are most prominent in contemporary discussions: shared, informed, interpretive and paternalism. Paternalism is the traditional model for decision making in healthcare. Regarding a patient's authority in decision making, paternalism and informed decision making are at different ends of the scale, whilst shared decision making (SDM) and interpretive decision making are in-between (Wirtz, Cribb, & Barber, 2006). Figure 2 depicts the relation between the four models. It must be noted that there are grey zones; there are no definite boarders between the different models and their characteristics partly overlap. Furthermore, universal agreement on the concepts of these four decision-making models is lacking.

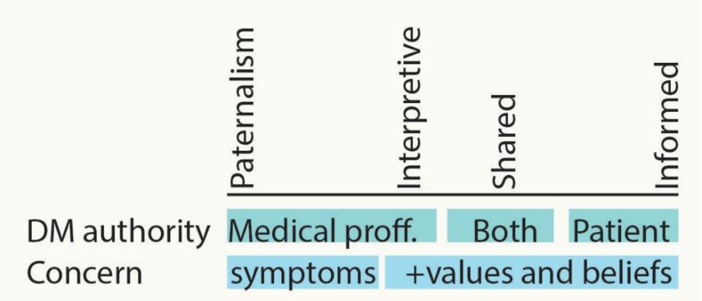

Figure 2 - Decision making authority and concerns in four decision making models (adapted from Wirtz et al. (2006, p.117))

Healthcare in Europe has a mainly paternalistic tradition, meaning that medical practitioners are accustomed to selecting the treatment that they considered best for the patient, basing their decision on medical insights. This decision-making tradition goes back as far as the Ancient Egyptian period. Although the Greek Enlightenment brought some change in the doctor-patient relationship, the medieval period in Europe saw a restoration of paternalism.

When the first hospitals for common people were built in the 18th century, new knowledge led to a shift in focus from symptom treatment to understanding the cause of symptoms. As doctors possessed clinical knowledge, patients were dependent on their expertise (Kaba & Sooriakumaran, 2007).

Since the 20th century, other decision-making models have been proposed. The most commonly discussed are the interpretive, shared and informed decision-making models. In the interpretive decision-making model, the medical practitioner selects the treatment, as in the paternalistic model. However, in this model, the medical practitioner bases the decision on not only medical insights, but also the values and preferences expressed by the patient. In contrast to the paternalistic and interpretive models, the SDM and the informed decision-making models give the patient agency over the treatment decision. The difference between the SDM and the informed decision-making models lies in the role of the medical practitioner in the decision-making process. In the interpretive model, the medical practitioner shares medical insights to allow the patient to make a decision based on this information and personal values and beliefs. When it comes to making the decision, the medical practitioner takes a passive role. In the SDM model, however, the medical practitioner is actively involved in the decision-making process, contributing with both medical insights and personal views. In the SDM model, both parties aim to come to a consensus on which treatment fits best for the individual patient through a dialogue (Wirtz et al., 2006). In SDM, patients and medical practitioners are, thus, regarded as partners in the treatment decision-making process. Whereas the role of the patient in the paternalistic and interpretive decision-making models is more-or-less passive, the role of the patient in the SDM and informed decision-making models is that of an active agent.

This thesis focuses on SDM as a model for treatment selection in the case of potentially life-threatening medical conditions for which several treatment options exist, while there is uncertainty at play. This uncertainty can be related to several aspects, such as: how effective a treatment option will be for the individual, which side effects a treatment option will cause and to what degree these side effects will appear (Charles et al., 1997).

2.2.1 Motivation for shared decision making

A culture shift is taking place in healthcare, as increasingly more individuals are advocating for SDM[3]. Self-determination by patients is increasingly considered to be desirable, and changing social beliefs stand at the basis of this change. In the 1970s, discussion arose on the need for an ethically just relationship between medical professionals and patients. Paternalism was critiqued for being positivistic, focusing on facts and leaving out any value-based considerations. Instead, medical practitioners should have considered a person's right to control over his or her own life. This should be realised through the sharing of decision-

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[3] This culture shift is related to a bigger sociologic change in healthcare. Traditionally, healthcare has been focused on delivering acute care, eliminating factors that cause disease (pathogenesis). In salutogenesis, the focus rather lies on promoting health and quality of life (Eriksson & Lindström, 2008). It incorporates the development of coping strategies to positively affect health (Ageborg, Allenius, & Cederfjäll, 2005). Salutogenesis is regarded as especially relevant for chronic care.

making authority and responsibility on the basis of trust and confidence in each other's competence (Veatch, 1972). Another stimulus for the growing interest in SDM has been the changing need for medical care, with a growing share of care being dedicated to the management of chronic conditions, instead of acute care. Chronic disease management is long-lasting, contrary to acute care. Treatment options might have dissimilar effects on a person's life, requiring different knowledge, skills and behaviour from patients to be effective. For example, various treatment schedules, treatment effects and side effects may need to be considered. It has become more important to consider a patient's values and beliefs, as the effects of the treatment on lifestyle are lifelong. As patients are experts on their lives, values and beliefs, and are the ones that will need to live with the consequences of a treatment, advocates of SDM argue that patients should be actively involved in the decision-making process to ensure the best quality of life (O'Connor et al., 2005). Realising this active involvement of the patient in the decision-making process requires a shift from linear communication to a dialogue that enables the exchange of knowledge and experience. In addition to medical information, the personal circumstances and values of the individual patient are considered. The goal is to select the treatment method that fits best for the patient. The intention is that this approach positively affects the quality of life of the patients, as they receive the treatment that fits best with their preferred lifestyle and important values and beliefs. Furthermore, SDM matches with ethical ideals, such as respecting a person's freedom of choice over their own body.

As mentioned in chapter 1, the change from paternalistic decision making to SDM has been supported by changes in legislations concerning patient rights in various western countries, such as Norway (Helse- og omsorgsdepartementet, 1999), as well as by politic debate (Høie, 2015).

2.2.2 The concept of shared decision making

When searching for definitions of SDM, one finds various conceptual models. Variations relate to the roles and responsibility that are assigned to the patient and the medical practitioner. Furthermore, the term is used inconsistently, and few definitions build on the work of others (Makoul & Clayman, 2006). The article by Charles et al. (1997) is utilised here as a starting point to explain the basics of SDM, followed by a discussion on how the concept has been later redefined by others. The article by Charles et al. (1997) is used, as their article is a common reference and it best matches the author's understanding of SDM.

Charles et al. (1997) defined that for a decision-making process to be labelled SDM, at minimum, the following four key elements need to be present:

- At least one medical practitioner and a patient are involved;
- A two-way exchange of information takes place between them, regarding treatment options and personal preferences;
- The medical practitioner and a patient work together; and
- They reach a consensus concerning treatment type together.

SDM is defined here as a process – although the term is also used to refer to the outcome of a decision-making process. It is recognised that the situation can be more complicated in practice, as more parties are involved (Charles et al., 1997). The influence of spouses and other family members is an example, as well as the interests of other medical practitioners, especially in cases of patients with comorbidity. Charles et al. (1997) assigned responsibility for the facilitation of SDM to the medical professional, who needs to:

- Create the right setting for an open dialogue;
- Elicit preferences concerning lifestyle and values from the patient;
- Present unbiased medical information;
- Help the patient in weighing the information and formulate preferences; and
- Give a treatment recommendation.

This last step is acknowledged as being tricky, as patients are accustomed to paternalistic handling and might be tempted to agree with the medical professional in hope for better care (Charles et al., 1997).

Changing definitions and advancements

A practical challenge with the conceptual model of SDM by Charles et al. (1997) is that it only explains key elements that need to be in place, but not a description of the behaviour that supports SDM. Guidance about how to realise SDM in clinical practice is needed (Elwyn et al. (2012); Wirtz et al. (2006). Elwyn et al. (2012) therefore presented a three-step model that provides practical guidance to medical practitioners. The building of a supporting relationship stands at the basis of their model. Furthermore, the medical specialist's most important tasks are explained as providing agency through offering information and supporting decision making (Elwyn et al., 2012).

Elwyn et al. (2012) explained that, first, the patient should be informed that there is a choice and why he or she is involved, which is referred to as "choice talk". This is an addition to the conceptual model by Charles et al. (1997), which does not mention this component. Second, the treatment options should be explained in detail, or "option talk". This is similar to the model by Charles et al. (1997), which explains that the responsibility for the presentation of unbiased medical information lies with the medical practitioner. Third, the medical specialist and patient should exchange their thoughts and collaboratively select a treatment, which is referred to as "decision talk" (Elwyn et al., 2012). This step is sometimes referred to as deliberation. It embraces the description by Charles et al. (1997) of a medical professional's responsibility to help the patient in weighing the information and formulating preferences, and offer a treatment recommendation.

Elwyn et al. (2012) explained that supporting patients in deliberating on options and exploring what the patient values most together are both intended to help the patient in developing informed preferences. The notion of informed preferences is another addition to the conceptual model of Charles et al. (1997). Elwyn et al. (2012) recognised that people will have initial preferences towards treatment options. However, they pointed to the importance of deliberating on options to ensure that preferences are informed and rooted in a sound understanding of the different options (Elwyn et al., 2012). A critique on this three-step model is that it is not grounded in theory, but solely based on their own experience with implementing SDM in practice.

Kasper et al. (2010) also built on the Charles et al. (1997) conceptual model of SDM. They used communication theory to evaluate deliberation from an interpersonal perspective, arguing that people do not base their decision on the original information that is provided by the other party, but rather on their personal interpretation of it, as people selectively attend to the information they receive. Thus, the understanding of the information is individual (Kasper et al., 2010). Information should, therefore, not be regarded as a static entity, but as an understanding created through communication (Kasper et al., 2010). Kasper et al. (2010) based this argument on the effect of second-order understanding[4], and argued that patients and medical professionals should be supported in communicating with each other. It is suggested that decision aids could provide such support (Kasper et al., 2010). The Kasper et al. (2010) explanation of the difficulty of communication gives extra complexity to the Elwyn et al. (2012) notion of informed preferences: How can be it ensured that both parties understand each other and really build their decision on informed preferences?
Charles et al. (1997) already mentioned this concept, but an important point that Kasper et al. (2010) additionally stressed is that both medical professionals and patients contribute with medical insights as well as preferences. This recognition affects the dyad in the deliberation process.

Makoul and Clayman (2006) presented a model that integrates different definitions of SDM, including aspects that are frequently mentioned in the various definitions of SDM. The model distinguishes between elements that are essential for SDM to take place, and additional elements that ideally should be in place, as well. One element in particular that Makoul and Clayman (2006) considered to be essential, but which is not covered explicitly by the definitions that they integrated into theirs, is the importance of discussing a patient's self-efficacy[5] regarding the different options. Discussing self-efficacy in addition to values provides a supplementary perspective on the acceptability of the various treatment options (Makoul & Clayman, 2006).

Decision aids

The formation of treatment preferences entails more than becoming informed (Charles et al., 1997). People need to reflect on their personal situation, values and beliefs. Decision aids are tools that can support the patient in structuring information and evaluating options (Elwyn et al., 2012). Furthermore, decision aids can support the communication about preferences between the medical practitioner and patient (Kasper et al., 2010). Some decision aids are

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[4] Sections 2.1.1 on human-centred design and section 4.1 on social constructivism explain the concept of second-order understanding further.

[5] Self-efficacy is a concept that belongs to the social cognitive theory paradigm. It denotes a person's belief in being able to perform a specific behaviour. According to SCT, behaviour is rooted in a person's expectations of self-efficacy and the obtained outcome (Makoul & Clayman, 2006).

intended to be used in a consult, whilst others are intended to be used at home. The latter are often longer and more detailed.

In their systematic review of Decision Aids, Stacey et al. (2014) found that the use of decision aids for patients leads to knowledge increase, a feeling of being better informed and more aware of personal values, more active involvement in the decision-making process and fewer people being undecided, compared to standard care. They further found that decision aids have a positive effect on communication between medical practitioners and patients. In addition, their study showed that the use of decision aids affects people's treatment choices, with less invasive options being selected more often (Stacey et al., 2014). However, other effects remain to be further studied, such as cost-effectiveness, treatment adherence, the effects on people with lower literacy levels and the required detail of the included information (Stacey et al., 2014). Although the effects on costs remain to be further examined, it has been suggested that the selection of conservative options over more invasive techniques can result in reduced costs (Marla L Clayman, Bylund, Chewning, & Makoul, 2016).

2.2.3 Contemporary challenges in shared decision making processes

Although political drivers are stimulating the culture shift from decision making by medical specialists to SDM, current practice does not seem to have fully made the transition yet. Some challenges remain to be overcome. Patients should realise that there is a choice and understand the importance of taking part in a decision. This awareness should make them willing to participate in treatment decisions. However, patients have been found to be reluctant to take part in such decisions (Harwood & Clark, 2013; Morton et al., 2010). Patients' attitudes might hinder participation, as SDM is often new to them. Medical specialists are still commonly considered to be the experts, by both patients and medical professionals (Kienlin, 2015). Unfamiliarity with individual decision making in certain cultures can further hinder SDM (Elwyn et al., 2012). Overcoming this challenge requires a culture change that affects both parties. However, realising such a culture change is not easy. Optimisation of education programs and decision aids might be a first step to enhance motivation amongst patients and meet knowledge deficiencies. However, as indicated by Charles et al. (1997), medical practitioners are required to guide the process of SDM. This means that they must become supportive of the SDM concept, as well, which requires an ethical and political discussion.
A second challenge for SDM in practice is that the models lack clarity about how to select treatment options to discuss, i.e. "framing of the option set" (Wirtz et al., 2006). As will be discussed in chapter 5, practitioners globally make different choices regarding the scope of options to present. This has ethical consequences related to the degree of autonomy of the patient in selecting a treatment. It is known that non-medical factors, such as the experience of a centre (Covic et al., 2010), physician preference and reimbursement policies can influence usage of different treatments (Goovaerts et al., 2005). For care providers in publicly funded healthcare systems, such as in Norway, cost-effectiveness might be an additional factor that is at play. In Norway, this challenge is partly overcome by the involvement of the Norwegian Directorate of eHealth, a government institution that owns the website helsenorge.no. This website is one of the main channels through which SDM is encouraged. On the website, the

concept of SDM is explained, and treatment options are presented for various common medical conditions. For these conditions, the option set is, thus, determined on a national level. However, the experience of a centre with diverse treatment options and physician preferences might still influence the final decision.

A third challenge is the lack of clarity around accountability in relation to professional ethics (Wirtz et al., 2006). According to the above-proposed models of SDM, the final decision lies with the patient, whilst medical practitioners will need to endorse this decision (Charles et al., 1997; Kasper et al., 2010). This can be challenging for medical practitioners, as they are traditionally held responsible for the medical outcome of a patient. As mentioned above, SDM depends on the support of medical professionals, as they are the ones that should guide the process. Without their support, SDM cannot take place (Charles et al., 1997; Elwyn et al., 2012).
A fourth challenge for SDM is that past studies on SDM and its effects vary widely in the measurement methods used and the effects that were measured. Due to the large diversity in studies, the relationship between SDM and positive effects remain unclear (Marla L Clayman et al., 2016). This challenge can be overcome when the scientific community agrees on which methods to use to evaluate SDM and its effects.
Despite these challenges, the benefits that SDM can bring are worth the effort. As will be discussed in chapter 3, not only do political policymakers and patient associations promote SDM, but medical boards are promoting the practice, as well. This is reflected in various guidelines for clinical practice that have been published internationally (Atai & Johnson, 2012; Covic et al., 2010; National Kidney Foundation, 2015; Warwick et al., 2014).

2.3 Constructivist approaches to learning

Learning theory is considered relevant for this thesis, as parts of the SDM process comprise learning tasks, e.g. patients and their next-of-kin should be informed about this ‘new’ way of taking medical decisions, and gain understanding of why their involvement is important. Furthermore, they will need to be informed about the options they have and supported in formulating informed preferences (Elwyn et al., 2012). SDM requires active participation from both the patient and the practitioner, something many people currently are not accustomed to in a healthcare setting. Patients and practitioners will have to learn about ‘factual data’ on the available treatment options and be supported in communicating with each other (Kasper et al., 2010). Various kinds of educational interventions exist to educate patients about treatment options, such as information websites, brochures and one-on-one instruction during consults. Decision aids are another example of a type of educational intervention that is used to educate and support patients and medical practitioners (Charles et al., 1997; Kasper et al., 2010).

In this thesis, the author follows a constructivist view on learning. Constructivist approaches to learning are the most prevalent in contemporary conceptions of learning (Mayer, 2004). Various approaches to learning fall under constructivism, such as problem-based learning (Savery & Duffy, 2001) and experiential learning (Kolb, 1984). Constructivist approaches to learning all regard learning as an active process in which learners construct new concepts based on reflecting upon their experiences. Experiences are people's observations: what they do, see, hear, feel. Learning can be regarded as "a holistic process of adaptation to the world", as new and unfamiliar observations trigger learning (Kolb, 1984). From these observations, people select what is viable within their mental world (Savery & Duffy, 2001). The relevant incoming information is organised, structured and integrated with previous knowledge. People do not passively absorb information, but rather actively reflect upon it. Learning is, therefore, not a process over linear information exchange. Consequently, the same information can mean different things to different individuals (Kasper et al., 2010). Constructivist learning can be described as "learning by thinking" (Mayer, 2004). Learning is an active and individual process, involving cognitive processing.

In constructivism, learning is regarded as an ongoing process. Learners construct new knowledge based on their previous understanding and experiences. With new related experiences being interpreted, people further develop their knowledge. To make sense of external knowledge, learners need to have the appropriate cognitive structure (Kasper et al., 2010), meaning that how much an individual learns from a specific educational intervention depends on the individual's previous knowledge of the topic, the ability to learn and the compatibility between the individual's preferred learning style and the program's teaching style (Hjelsvold, 2017). If a program is situated too far from the individual, he or she can become bored, distracted, frustrated or even discouraged (Hjelsvold, 2017; Wilson et al., 2009).

Guided learning

Vygotsky's concept of the Zone of Proximal Development (ZPD) brings the level of difficulty of a program in relation to a person's current level of knowledge and learning abilities. The ZPD is defined as the range of learning that an individual can achieve with guidance. It is the bandwidth through which an individual can be moved from what he or she can already do or knows, to what the individual can achieve with new skills or insights with the help of guidance. This guidance is provided by a more knowledgeable resource through cooperative social interactions. The range of the ZPD is individual, so even though various individuals start from a similar knowledge base and receive the same guidance, they might not achieve the same amount of learning; some individuals learn quicker than others (Vygotsky, 1978) and some learn better through specific method than some of their peers might (Kolb, 1981).

According to Mayer (2004), a constructivist understanding of learning is often wrongly translated into activity-based teaching with too little guidance. As it is reflection that motivates learning, the goals should, therefore, be to stimulate cognitive activity through providing learners with guidance (Mayer, 2004). Learners require a certain amount of instructional guidance to achieve optimal learning outcomes; too little guidance may result in learners not obtaining insights into the general rule behind a solution or building incorrect conceptions, whilst too much guidance may result in students being discouraged to actively reflect over the material. Active reflection is needed to make sense of the material and integrate new insights with their previous knowledge to reach a higher level of generalised knowledge that can be applied to other tasks (Mayer, 2004).

Experiential learning and learning styles

Experiential learning is a specific concept of learning that falls under the constructivist paradigm. Kolb's model of experiential learning describes a four-stage cyclic model for learning in which experiencing, perception, cognition and behaviour are combined (Kolb, 1981). The model explains how learners first translate an experience into a concept by reflecting upon it and bringing it in relation to their previous knowledge. Later, the learner generalises the concept and tests to see if it is applicable in new situations as well. In doing so, the learner develops new knowledge (Kolb, 1984). The process of learning includes phases of thinking, feeling, perceiving and behaving (Kolb, 1984).

Kolb (1981) further recognised that people have different preferred learning styles, meaning the learning activities that are most efficient are dependent on the individual learner. Although the learning process is cyclical, due to individual learning styles, individuals have different strengths and weaknesses. *Accommodators* are enactive learners who are good at carrying out experiments and are more prone to taking risks. They are able to adapt quickly to new circumstances, using intuition and trial-and-error. *Divergers* are iconic learners whose strength is their imaginative abilities. They are good at formulating and analysing a concrete situation from various perspectives and sculpting a network of relationships. Brainstorming sessions are well-suited for divergers. *Assimilators* are inductive learners whose strength lies in their ability to formulate theoretical models. Through inductive reasoning, they find relationships between different observations. *Convergers* are hypothetic-deductive learners who are good at the practical application of ideas. Their strength lies in applying hypothetic deductive reasoning to specific problems (Kolb, 1981, 1984).

When someone's learning style does not fit with the accommodated learning activities, this student experiences the task to be more difficult, which might lead to a lesser performance. Incongruity between the preferred learning style and offered learning approach might further lead to incompatibility and alienation, whilst a match might lead to more involvement. The motivation to learn might, thus, be related to the match between the preferred learning style and accommodated learning activities (Kolb, 1981).

From theory to practical advice

The main challenge for teachers is to give students enough freedom to stimulate active reflection whilst giving them enough guidance to ensure that their reflections lead to useful knowledge (Mayer, 2004). Teaching is, thus, a challenge of finding the right balance between freedom and guidance, and providing guidance that directs students in obtaining the right knowledge. Alignment between learning objectives and learning activities in a program is vital for learning outcomes (Biggs, 1999). Learning objectives should clearly state the knowledge or skills the learner is expected to develop, whilst the teaching methods should encourage learners to undertake the right learning activities (Biggs, 1999; Mayer, 2004). This concept of alignment implies that learning objectives should be clear, and that it is important to check whether the set-up of an educational intervention supports its learning objectives.

The nature of the subject matter directs the learning that is best suited to stimulate learning. Developing specific skills is different from teaching fundamental theory (Kolb, 1984). Traditional direct instruction might be sufficient to meet certain learning objectives in students with specific learning styles, whilst students with different preferred learning styles would benefit from a different approach. In many cases, some level of guidance and freedom to explore is needed to meet the learning objectives (Mayer, 2004). To match the needs of a diverse group of learners with varying learning styles, it is best to accommodate for several learning activities to enable people to learn through their preferred learning style. Accommodating various learning styles makes it more likely that individuals become engaged. Furthermore, when the same message is provided through different techniques, it is more likely that it is remembered (Hjelsvold, 2017). Instead of regarding an educational intervention as a 'source of knowledge', thinking of it as a tool to engage, connect and foster different kinds of learners opens up a different approach to learning. The intervention then becomes a way to guide students on a learning path (Dougiamas, 2009).

For constructivists, the goal of educational interventions is to stimulate active reflection by the learner. Hands-on activities and group discussions can promote active reflection as long as learners receive structured guidance that directs them towards the learning objectives (Mayer, 2004). Additional examples of teaching methods to provide guidance are: giving hints about a general rule behind a concept, giving directions on what aspects are important to address, describing a theoretic model that applies to the case and providing coaching or feedback (Mayer, 2004). Listening carefully and asking questions to provoke thoughts can also stimulate thinking amongst learners. Furthermore, asking learners to present their opinions, ideas or projects to peers encourages them to actively reflect over their argumentation, which stimulates learning (Dougiamas, 2009). These teaching activities can take place both in a group setting and in a one-on-one setting.

2.4 Serious games and gamification to support education

As stated in the preceding section on learning theory, providing several learning activities to a diverse group of learners can foster their engagement and positively affect learning effectively. A part of the thesis focuses on the use of game-based learning activities as an addition to the learning activities that are contemporarily offered to patients. The main argument for why serious games and gamification might support educational interventions relates to how games can address people's motivation to learn. Games can stimulate intrinsic motivation for learning as the playfulness that is inherent in games is associated with inherent satisfaction (Ryan & Deci, 2000). Furthermore, well-designed games are engaging and can, therefore, maintain a learner's attention over a longer period of time. For example, mystery can be used to arouse curiosity and keep players eager to learn more (Wilson et al., 2009). Multiplayer games also offer social interaction with other players (McCallum, 2012).

Serious games vs gamification

Although they are related, there is a difference between serious games and gamification. Gamification is the design strategy of introducing game elements in a non-game context

(Deterding, Dixon, Khaled, & Nacke, 2011). Examples of game elements that are found in gamified solutions are challenges, levels, themes, badges and leader boards (Hamari, Koivisto, & Sarsa, 2014). Although these are also common elements in games, a gamified platform is not a game. A serious game, on the other hand, is a game that has intentions beyond merely being entertaining, such as training or educating players (Susi, Johannesson, & Backlund, 2007). The playful activity of playing a game is used to encourage players to train or learn (Rego, Moreira, & Reis, 2010; Sicart, 2013). Serious games, for example, have been used to facilitate knowledge acquisition, skill development and behaviour change (Ritterfeld, Cody, & Vorderer, 2009).

The term "serious games" is commonly used to refer to interactive games with a digital format. Digital games are available on various platforms such as desktops, the Internet, mobile apps or VR labs. One of the benefits of digital games is that they can combine different media into a multimedia experience, which fosters knowledge uptake, engagement and comprehension (Fox, 2009). However, more traditional formats, such as card or board games, can also be applied for serious purposes. Games can be intended to be played by a single player or have a multiplayer format.

Serious games and gamified platforms in healthcare

The main advantage of creating playful experiences over providing plain information is that playful activities can engage users and motivate participation and use (Fox, 2009; Hamari et al., 2014; Wilson et al., 2009). In addition, experiencing a situation in an alternative world can help externalise a problem. When the player overcomes the problem in the alternative world, the player can gain the confidence and skills to similarly approach the real-world problem (Cheek et al., 2015). Another benefit is that games provide a safe environment that can give players insights into different scenarios of what could happen, which is key for the understanding of procedures (Barthel, 2013). Furthermore, with games it is possible to give specific and timely feedback, as they usually work with levels. Relevant and rightly timed feedback can increase learning effectiveness (Wilson et al., 2009). The engagement of the player with the game motivates continued play, enhancing learning potential (Wilson et al., 2009).

Several advantages have been associated with the use of gamified computer-based programs for patient information platforms, compared to traditional products as folders, leaflets and consults with nurses. Gamified platforms provide freedom of use; they can be played at home, at any time, can adjust to the knowledge level of the player and allow a certain freedom to navigate and follow personal interests. Furthermore, multimedia techniques can be used to represent the same data in different formats. In addition, such platforms provide the opportunity for repetition, stimulating recall and knowledge uptake. Finally, such platforms can be used to present relevant information in a structured way and reduce consultation time needed to explain options, leaving more space for questions and discussions (Fox, 2009; Hamari et al., 2014). Serious games directed to patients have also been shown to be able to increase self-care and disease-related knowledge (Kato, 2010) and advance skills and change behaviour (Baranowski, Buday, Thompson, & Baranowski, 2008; DeSmet et al., 2014), thereby positively affecting people's health. A meta-analysis of games for healthy lifestyle promotion showed that games can be attractive to people of all ages and genders (DeSmet et al., 2014).

Furthermore, patients have indicated that a game can be a valid intervention, considering them to be fun, challenging and relevant (Forsberg, Nilsagård, & Boström, 2015; Fox, 2009). However, there might be a bias to publish positive results; sample sizes in many of the published studies are small, and some are based on self-reported data rather than objective measurements (Kato, 2010).

Examples of recent developments within the healthcare context

In recent years, a vast amount of health-related serious games and gamified applications have been developed that address various phases of patient journeys. The Games for Health Taxonomy categorises serious games in five health-related activities: preventive, therapeutic, assessing, educational and informative (Sawyer, 2008). Serious games for health have also been categorised according to the type of health the game addresses: physical, cognitive or social health (McCallum, 2012). The games vary widely, not only regarding their intentions and content, but also regarding the media platform through which they are available (Kato, 2010), their format as single or multiplayer games and the audience for which they are developed. Some serious games have been developed as stand-alone interventions, whilst others are part of multifaceted programs (DeSmet et al., 2014).

Serious games for health have been developed for people of all ages, for numerous medical conditions, and make use of various formats and techniques. To name a few:

- Gryphon Rider: A multi-player videogame that provides balance exercises to support rehabilitation of children with acquired brain injury by use to the Kinect (Grendel Games, 2015)
- Balance-it: A mobile app that aims to prevent overweight amongst adolescents by motivating them to eat fewer snacks and be more active (Spook et al., 2015)
- Re-Mission: An older, well-known game that helps adolescents understand cancer and adjust their behaviour to treatment requirements (Kato, Cole, Bradlyn, & Pollock, 2008)
- Super Better: An online game to decrease symptoms of depression in adults by focusing on increasing resilience (Roepke et al., 2015)
- Actief op Jacht (Active hunting): A digital board game to help elderly individuals maintain their mobility by use to the Kinect. It facilitates socialisation, as well (Grendel Games, 2014)
- Virtual environment: A game to stimulate rehabilitation of and exercise by elderly individuals in a nursing home (Bruun-Pedersen, Serafin, & Kofoed, 2016)
- Cystic Fibrosis Game: A physical board game to educate families about cystic fibrosis (Focus Games Ltd, 2017)

In the case of chronic kidney failure (CKF), there are opportunities for the introduction of serious games or game elements in all five categories, as listed in the Games for Health Taxonomy: preventive, therapeutic, assessing, educational and informative (Sawyer, 2008). There are available examples to be found in some of these categories. People diagnosed with CKF that have sufficient remaining kidney function can postpone treatment if they are following the right diet and exercise plan (PreventieConsult, 2011b). The Dutch Kidney Organisation has just developed a game to keep such individuals motivated to adhere to their diet and training schedules, called Coach4Life (Nierstichting, 2014a). To create awareness about lifestyle-related diseases, preventive applications have been developed. Furthermore, a decision aid in the form of a serious game has been developed to support patients with prostate cancer. The formative evaluation study of this game showed that serious games might be used as a decision aid. Based on insights from the constructivist learning theory, a serious game might be used as an alternative learning method that is especially suitable for accommodative learners.

3. An introduction to chronic kidney failure

This chapter introduces chronic kidney failure (CKF) to provide readers without a medical background with some context for the cases that are presented in this thesis. Although the studies in this thesis focus on the situation for CKF, CKF is regarded as an example of a medical condition for which the realisation of shared decision making (SDM) is relevant. Some of the insights that are presented in this thesis will be specific to the context of CKF, whilst others will be transferable to other medical conditions. In this chapter, CKF as a medical condition is explained first, followed by a brief introduction into the most commonly used treatment methods. Next, guidelines for clinical practice are discussed.

3.1 Chronic kidney failure

CKF is a condition in which the function of the kidneys is strongly reduced. As a result, harmful particles remain in the blood, 'poisoning' the body. Additionally, the fluid balance becomes destabilised, leading to too little precipitation of water.[6] CKF is classified into different stages, according to the remaining level of kidney function. Commonly, the kidney function slowly degrades over time (Mayo Clinic Staff, 2015). A healthy diet and physical exercise can help slow down the degradation of the kidney function, sometimes even postponing intensive treatment for years. However, CKF is often discovered rather late, as symptoms regularly only start to appear when the kidney function drops below 15%. Eventually, in the end stage, the kidneys filter less than 10 litres of blood a day, compared to the 180 litres of blood that healthy kidneys filter. When the kidney function is this low, renal replacement therapy is needed to survive (Landsforeningen for Nyrepasienter og Transplanterte, 2006; Nierstichting, 2014c; PreventieConsult, 2011b).

The number of people suffering from CKF is increasing, due to the increase of the elderly population (United Nations, 2015), longer life expectancy and a growing number of people suffering from lifestyle- related diseases like diabetes mellitus and cardiovascular diseases (World Health Organization, 2013). These demographic changes increase the chance of developing CKF. As diabetes mellitus, cardiovascular diseases and CKF are related, it is not uncommon for people to suffer from a combination of these conditions (PreventieConsult, 2011a). Smoking, overweight, an unhealthy diet and too little physical activity are additional risk factors for developing CKF. Hereditary factors can also play a role (PreventieConsult, 2011a). The improvement of treatment methods has led to people surviving longer on treatment, despite their severe condition. All these factors together result in a vastly growing population of people with CKF that are dependent on renal replacement therapy.

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[6] Several different terms are used to indicate the same medical condition. In this thesis, I use chronic kidney failure, as this is defined in PubMed as a MeSH term. Other terms in use are: chronic kidney disease, chronic renal disease and uraemia. In cases where one refers specifically to the final stage of CKF in which treatment is needed to survive, the condition is sometimes referred to as end-stage renal disease (ESDR), end-stage renal failure, end-stage kidney disease, end-stage kidney failure, stage 5 kidney disease and stage 5 renal disease. The words dysfunction, impairment and insufficiency are also sometimes used instead of the words failure or disease.

In Norway, the dialysis population has doubled over the last decade (Pike et al., 2013). In 2012, 515 new individuals were diagnosed with end-stage CKF in Norway (Saran et al., 2015; Statistisk Sentralbyrå, 2014). By the end of 2012, 4448 people in Norway were on treatment for CKF, of which 72% had a functioning transplanted kidney. The other 28% (1245 individuals) underwent dialysis therapy. Most of the population was male, 65%. The median age of the population was 60 years, with a range of 1 to 95 years. In addition, 40% of the population was aged 65+, and 40% of these patients were aged 75+ (Leivestad, 2013).

3.1.1. Treatment options

Several treatment methods exist for people with end-stage CKF. These treatments cannot cure the condition, but are life-sustaining. People with end-stage CKF, thus, require life-long treatment. Figure 3 displays the different treatment methods that are commonly used today: a kidney transplant, peritoneal dialysis (PD), haemodialysis (HD) and conservative treatment.

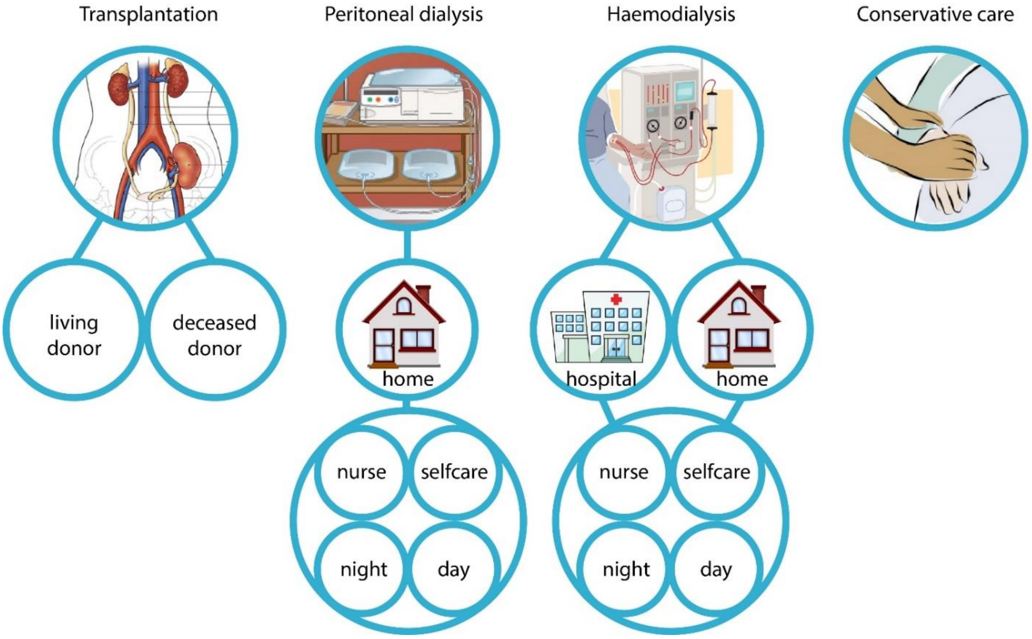


Figure 3 - Renal replacement therapy, overview of treatment methods

As people can live with 50% of kidney function, it is possible for people with two healthy kidneys to donate one of them. A kidney from a living donor usually comes from someone that is known to the patient. It is also possible, though less preferred, to receive a kidney from a diseased donor after having been waitlisted. PD uses the peritoneum as a filter. Dialysis fluid is transported from a bag into the abdominal cavity via a catheter and is kept there for some hours to allow the particles to be exchanged with the blood (Nierstichting, 2014c). PD is usually undergone at home, whilst HD can be undergone at a clinic or at home (Landsforeningen for Nyrepasienter og Transplanterte, 2006; Nierstichting, 2014c; PreventieConsult, 2011b). HD uses a dialyser machine to filter the blood externally. The patient is connected to the dialyser via two needles, usually placed in a fistula or graft in the forearm. A pump ensures that blood flows through the machine via tubing (Nierstichting, 2014b). Both dialysis techniques (HD/PD) can be undergone during the day or during the night, and can be performed by the patient or by a nurse or a caretaker. Conservative care is an option for people that do not want to start renal replacement therapy. In this case, a patient receives medication to suppress the symptoms of kidney failure, and eventually follows a strict diet. This can postpone death, but is not a life-sustaining therapy. Elderly individuals, in particular, who suffer from other medical conditions might not benefit enough to justify the intensive treatment programs that transplantation and dialysis entail.

According to the Norwegian Knowledge Centre for the Health Services, all treatment modalities for CKF are rather costly. Transplantation is the most economical, even though it is an expensive surgical intervention and patients will need to take life-long medication afterwards to prevent repulsion of the kidney by the body. HD at home is more economical and effective, compared to HD in the hospital. However, PD is the least costly dialysis modality (Pike et al., 2013). The cost for the different dialysis modalities consists of different costs related to aspects such as home refurbishment, training facilities, medical equipment and staff.

People are often eligible for several treatment methods and comparable medical outcomes might be expected of the different techniques (Little, Irwin, Marshall, Rayner, & Smith, 2001), except in the case of conservative treatment, where only symptoms are treated. Although medical outcomes are comparable, in general, effects of treatment on the daily life of the person undergoing treatment and their next-of-kin differ significantly.
In many countries, a kidney transplant is the most preferred treatment method, as it is associated with a better quality of life and lower costs (Saran et al., 2015). This is also the case in Norway (Leivestad, 2013). Although the kidney transplant rate in Norway is the highest worldwide (USRDS ESRD Database, 2016a), the waiting list for new patients is increasing (Stiftelsen Organdonasjon, 2017). People on the waiting list can become dependent on dialysis in the meantime, when the function of their own kidneys becomes too low. Furthermore, not everyone is eligible for a kidney transplant. These people will need to undergo a form of dialysis to survive or opt for conservative care.

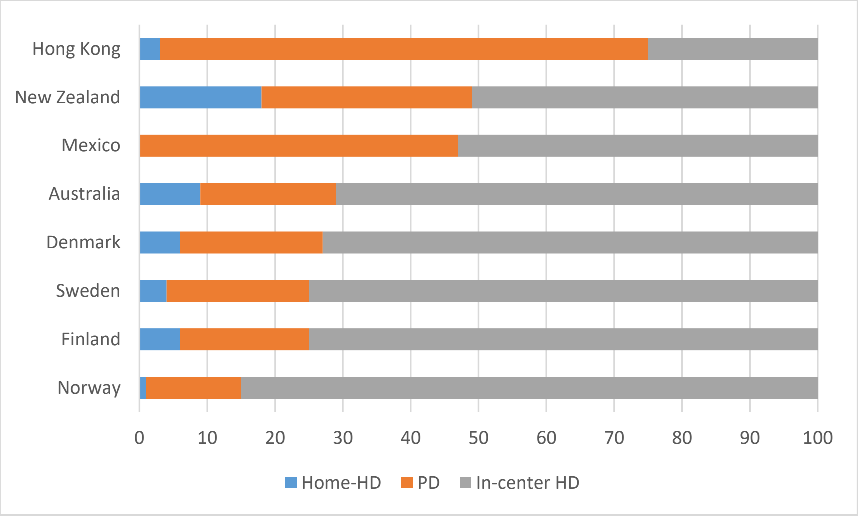
HD in the hospital is by far the most commonly used form of dialysis globally (Saran et al., 2015). HD can also be undergone at home, i.e. home-HD. In this case, a HD machine is placed in the home of the patient. One can choose to engage in full self-care, meaning that the patient takes full responsibility for the dialysis sessions, the set-up and operation of the dialyser, as well as the cannulation of the vein. It is also possible to receive help from a nurse or partner during this process (Dianet, 2014b). Home HD treatment sessions can be undergone more frequently and may take longer compared to HD in the hospital. As a result, fluctuations in the composition of the blood are smaller, leading to fewer physical complaints (Nierstichting, 2014b). Furthermore, the treatment schedule allows for some flexibility. Before one can start on home-HD, the person with CKF and, eventually, his or her caregiver receive training at the hospital. These trainings are organised by the individual institutions that offer home-HD. Consequently, they differ in set-up and duration (Hilbers & Geertsma, 2010).

Several benefits for both the medical profession as the patient have been associated with home-HD compared to other dialysis methods. Patients have reported a higher quality of life (Chanouzas et al., 2012); this method has been found to empower patients (Ageborg et al., 2005) and has been associated with longer life expectancy and fewer hospitalisations (Curtin, Sitter, Schatell, & Chewning, 2004; MacGregor, Agar, & Blagg, 2006; Pauly et al., 2009). For healthcare providers, moving HD from the hospital to the home relieves the pressure on professional caregivers, since individuals take on self-care, eventually assisted by a caregiver (Chanouzas et al., 2012). In addition, more hospital beds are available for acute care (Lehoux, Saint-Arnaud, & Richard, 2004). Furthermore, for society, home HD is cheaper than dialysis at the hospital (Pike et al., 2013). Although these studies have found positive effects, they are relatively few. To build a stronger argument for the facilitation of home HD, more clinical studies are needed.

Despite these suggested advantages, the use of home-HD has been diminishing worldwide (MacGregor et al., 2006). It is suggested that home-HD is underused (Goovaerts et al., 2005), and that 25% or more of people with CKF could undergo home-HD if they had access to effective regional training and support programmes (Moran & Kraus, 2007). Nevertheless, home-HD is not fit for everyone. There might be some physical, social and practical circumstances that make treatment at home difficult (Nierstichting, 2014b). Examples of barriers for home HD are: the condition of the patient needs to be stable, the home might need to be refurbished and there needs to be sufficient space for the machine and supplies (Dianet, 2014b). However, self-dialysis does not require special skills or mental capacity, as is sometimes perceived. Age is not an obstacle, either, but older people might need a longer training period. Barriers for home HD from the patient perspective also exist. Some patients have stated that it turns their home into a hospital (Kilbourn & Buur, 2007). In addition, others have expressed appreciating meeting peers at the hospital ward, lacking self-efficacy towards performing self-care or considering it inappropriate to perform treatment unattended by a medical specialist (substandard care) (McLaughlin et al., 2003; Pipkin et al., 2010). The motivation to perform self-care is, therefore, considered to be most important, as well as a fit with a person's health and lifestyle (Muroma- Karttunen, 2013).

Substantial differences in distribution of treatment methods exist between and within countries (Saran et al., 2015). Non-medical factors such as physician preference, reimbursement policies and the availability of healthcare services were found to play a role in the distribution of treatment options, whilst no correlation was found between home-HD rates and the use of other treatment modalities, population density and national wealth (Goovaerts et al., 2005). Hong Kong, New Zealand and Mexico are the countries with the highest rates of home dialysis worldwide (USRDS ESRD Database, 2016b). Comparing rates of home dialysis in Norway with Scandinavian neighbours, Denmark, Sweden and Finland, Norway is lacking behind, especially regarding the prevalence of home-HD. Graph 1 presents an overview of distribution of dialysis types per country in 2014 (USRDS ESRD Database, 2016b).

Since the rates for home dialysis in other Scandinavian countries are higher, the author assumes that there is potential to increase the rates of people with CRF on home treatment in Norway. Considering the benefits associated with home treatment of people with CRF, in general, and, the long distance to hospitals in some areas in Norway, in particular, supporting an increase in home treatment seems relevant. However, reimbursement policies for hospitals might need to be updated, as it is currently economically more favourable for hospitals to treat dialysis patients in-centre. For patients in Norway, economic consequences of treatments are similar, as care is fully compensated by funding from tax revenues (Mossialos et al., 2015).



Graph 1 - Rates of people of total dialysis community on home dialysis per country in 2014

3.2. Guidelines for practice

Considering the large array of treatment options for people with CKF, deciding which treatment the patient will start is not easy. Several guidelines for clinical practice give advice on how to make treatment decisions related to renal replacement therapy options (Atai & Johnson, 2012; Covic et al., 2010; Levin et al., 2008; National Kidney Foundation, 2015; Warwick et al., 2014). Table 1 gives an overview of the guideline documents that are discussed here. Due to limited clinical evidence, these documents contain advice and suggestions for care, rather than guidelines for best practice. Nevertheless, to give practitioners insight into the rationale behind the suggestions, references to literature on conducted studies are usually included. All five associations advocate for more randomised controlled trials to increase evidence on best practices, as at present most of the data is qualitative and compares outcomes of intervention groups with historical controls.

Nuances suggest different views on how a decision should arise. Most guideline documents recommend informed decision making by the patients and their next-of-kin. The Canadian Society of Nephrology, on the other hand, states that it is the role of the pre-dialysis team to select the most suitable form of renal replacement therapy (Levin et al., 2008). The author reads this as a paternalistic implication. However, the National Kidney Foundation of the US

Organisation	Name	Reference
European Renal Association – European Dialysis and Transplant Association	European Renal Best Practice (ERBP)	(Covic et al., 2010)
UK Renal Association	Clinical Practice Guidelines for Planning, Initiating and Withdrawal of Renal Replacement Therapy	(Warwick et al., 2014)
National Kidney Foundation (USA)	Kidney Disease Outcomes Quality Initiative (KDOQI)	(National Kidney Foundation, 2015)
Kidney Health Australia	Caring for Australians with Renal Impairment Guidelines (CARI)	(Atai & Johnson, 2012)
Canadian Society of Nephrology (CSN/SCN)	Guidelines for the management of chronic kidney disease	(Levin et al., 2008)

Table 1 - Overview of guidelines documents on the treatment of chronic kidney failure

recommends an SDM process in which patients, relatives, caregivers and physicians are included (National Kidney Foundation, 2015). Unanimity on best practices for patient education on renal replacement therapy is, thus, lacking. This was also found by Liebman et al. (2012) and Pierratos (2013), and the latter urges the field to formulate a systemised approach.

The guidelines all stress the importance of a well-timed referral to a nephrologist and a timely choice in order to prepare for treatment start. However, ‘timely’ is a vague description. This is a consequence of the difficulty in forecasting the progression of the disease.
The guidelines state that patients who need to start treatment urgently, without prior referral to the hospital, should be educated as soon as their condition allows. Furthermore, the guidelines recommend education including all (available) renal replacement therapy options, the content of care, implications for lifestyle and preparations for treatment start. In some programs, conservative care is considered as an option, whilst others state that it should be discussed when appropriate. These two suggestions exemplify the framing problem: Although some guidelines advise informing on all renal replacement therapy options, others suggest only mentioning the available ones; some consider conservative care as a renal replacement therapy option, whilst others do not. This leads to patients being offered a different number of options, depending on which guidelines a hospital follows.

Four of the five guideline documents suggest that multidisciplinary care teams are a good arena for providing education through a structured education program. Three of the five guidelines also suggest including the function of the kidneys, causes and effects of the condition, medication and dietary advice. Furthermore, the guidelines advise standardising the secondary care path (Atai & Johnson, 2012; Covic et al., 2010; Levin et al., 2008; National Kidney Foundation, 2015; Warwick et al., 2014).

Unique points for each guideline

What is unique for the European Renal Best Practice guidelines (Covic et al., 2010) is that a ‘PD first’ strategy is suggested, meaning that they advise informing patients first about PD, but also discussing all other renal replacement therapy options. The guidelines advise to always inform patients and relatives about all treatment options, as the possibility of needing to switch to another alternative may later emerge. The guidelines further suggest ensuring that all renal replacement therapy options are supported either by the clinic itself or by the clinic in collaboration with other clinics. Furthermore, the documents include guidelines for offering assisted PD, a treatment option not mentioned in any of the other documents.

What is unique for the guidelines from the UK Renal Organisation (Warwick et al., 2014) is that treatments in which the patient is actively involved (self-management) are encouraged, such as dialysis at home, self-care and pre-emptive kidney transplantation. Furthermore, the organisation advises including effects of renal replacement therapy options on lifestyle, in addition to medical information. The guidelines from the UK Renal Organisation are further unique in suggesting the continuation of the education program when patients are on treatment, re-evaluating the decision and fostering adherence and self-management. Finally, it is advised to build and individualise the education program on adult learning techniques, taking into account learning style, capacity and preferences.

The KDOQI guidelines (National Kidney Foundation, 2015) are unique in that they recommend an SDM approach in which ‘promotion of living’ should be the focus, rather than prolongation of life. This concept further stresses the importance of discussing the effects of renal replacement therapy options on lifestyle, as is advised by the UK Renal Organisation. The guidelines state that there should be room to discuss the patient’s goals and lifestyle preferences in relation to the renal replacement therapy options. The document includes a statement on the need for research concerning how to best structure patient education and facilitate SDM.

What is unique for the CARI guidelines (Atai & Johnson, 2012) is that they advise supporting patients prior to treatment start in managing their disease thought pharmacological and dietary support. Furthermore, this stresses the importance of adjusting the program to the individual and considering the individual’s cultural and social background.
The guidelines by the Canadian Society of Nephrology (Levin et al., 2008) are the only ones to include advice on the configuration of the educational team. Additionally, the guidelines include suggestions for media to use and offer information about where to obtain relevant teaching materials. As with the guidelines from the UK Renal Organisation and the KDOQI, these guidelines also suggest discussing the effects of treatments on lifestyle.

Although all guidelines include some statements about the information to provide, they generally provide little guidance on how to realise an education program in practice. Many of them indicate the importance of individualising the information to the patient, but provide little advice on how this can be accomplished. The UK Renal Organisation and the Canadian Society of Nephrology are the only two to offer hands-on advice about what kind of educational materials to use. They suggest using: individual instruction, group sessions and both written and digital materials, such as DVDs, CDs and websites (Levin et al., 2008; Warwick et al., 2014). The UK Renal Organisation further advises basing the education program on adult learning techniques, and suggests "using a range of teaching methods within one session in order to allow learning to take place whatever the learning style" (Warwick et al., 2014). The Canadian Society of Nephrology advices using decision aids and expert patients who have been trained, in addition to the aforementioned materials (Levin et al., 2008).

The Norwegian patient law

As the focus of this thesis lies on the situation in Norway, not only internationally available clinical guidelines provide relevant insights. The Norwegian patient rights law (Helse- og omsorgsdepartementet, 1999) also needs to be taken into account. This law is not specific to the case of CKF, but also provides regulations for medical practice, in general. It includes some sections that prescribe SDM as a practice. Section 3.1 states that patients have a right to participate in the selection of methods of examination and treatment. Furthermore, section 3.2 requires that patients are made aware of the treatment procedures, risks and adverse effects, unless the patient indicates not wanting this information. Section 3.5 addresses individualisation of the information. It explains that the information should be adapted to the individual patient, accounting for age, maturity, experience and cultural and language background. This is more specific than the references to individualisation that the clinical guideline documents on CKF advise. Furthermore, the law requires medical practitioners to check if the patient understands the information. Additionally, the law states that patients should be given the opportunity to ask questions. This points to the importance of the interaction between patients and practitioners.

4. Research approach

In this chapter, a justification is given for the use of various methods that were applied for this thesis. A brief discussion of the epistemological stance, the related methodological considerations, brief presentations of the methods applied and ethical considerations are provided. Detailed method descriptions are presented in the next chapter together with the presentation of findings.

My background

In addition to being a female industrial designer from Northwest Europe, I am biased through my life experiences. This influences my worldview, the questions I ask and the approach I choose to take. Following the human-centred design philosophy (Krippendorff, 2006), I chose to rely on inquiry to gain understanding of the experiences of those who organise and those who participate in pre-treatment education and decision aid programs in order to be able to design for or with them.

4.1 Epistemology

The thesis is built on the framework of social constructivism, which corresponds with the author's intention to gain understanding of people's experience of specific phenomena, i.e. pre-treatment education and decision support platforms.
Guba and Lincoln (1994) explained constructivism as one of four scientific paradigms in qualitative research. Positivism, post-positivism and critical theory are the other three. One could say that positivism and constructivism are at different ends of the spectrum. In constructivism, reality is seen as a construct that is valid for a specific person in a certain context, at a specific time. Interactions between the researcher and informant form the basis for knowledge creation. As multiple persons can take part in an event, multiple realities of that event exist, which can be conflicting. Reality is, thus, relative. Constructivist researchers aim at building an understanding of people's perception of an event through reconstructing individual constructs (Guba & Lincoln, 1994), which reveals the 'complexity of views', i.e. variations in meaning (Creswell, 2013). Positivism has a very different worldview, as reality is seen as something fixed that can be objectively measured. In post-positivism, reality is regarded as fixed, but humans' understanding of reality is imperfect; thus, findings are considered to be probably true. In critical theory, reality is regarded as transactional, based on historic influence. Knowledge is regarded as more or less negotiated; the creation of knowledge is a political process (Guba & Lincoln, 1994).

The constructivist worldview is reflected in this thesis in the search for individual experiences of the same event at a specific point in time. The events that are central in this thesis are pre-treatment education and decision aid programs for people with CRF and their next-of-kin. Both events can support shared decision making (SDM), which is the central topic of this thesis. Views from various individuals are collected through qualitative inquiry. The aim is to come to an understanding of both events through interpreting the different personal views. In constructivism, findings are considered to be 'created' by the researcher through a hermeneutic interpretation process of the collected data. To give the reader a better understanding of how the author's background influenced this thesis, the introductions of some chapters contain blue text blocks that present personal notes and reflections. These parts show that the author is not just working as a researcher, but is also a person who is truly involved in the creation of the thesis.

Social constructivists define reality (ontology) as local and socially co-constructed factors through previous experiences, historical and cultural norms and social interactions with others. The subject of investigation in social constructivism is people's understanding of the world (Creswell, 2013). The goal is the "production of reconstructed understandings of the social world" (Denzin & Lincoln, 2011) in order to explain how a specific event is perceived in a specific social context. In this thesis, the researcher recognises that each individual's experience of pre-treatment education or a decision aid is influenced be his or her personal background. For example, interactions between a person with CRF and medical practitioners preceding the studied event influence a person's experience of the event. Having an understanding of medical practice and its culture in Norway is, therefore, valuable, as well as being familiar with the standardised care pathways for people with CRF. This knowledge helped me place the informants' stories in relation to their social and cultural context.

The epistemological stand in social constructivism is that evidence is subjective and influenced by interpretation. Multiple realties exist: those of each individual respondent and that of the researcher. Methodologies that belong to social constructivism can be described as hermeneutical and dialectical. Hermeneutics is a methodology of interpretation. Individual experiences are elicited through interactions between the individual informants and researcher (Guba & Lincoln, 1994). Both language and action is studied (Schwandt, 1994). In this thesis, interviews and observations were very important methods for insight collection (see section 4.2.4. on case studies). The informants present their perceptions of an event. The researcher collects and interprets these perceptions; through a dialectical interchange, stories are compared and contrasted (Guba & Lincoln, 1994).

Each individual's personal background influences their perception. Therefore, findings are created during data analysis and reflection. The perception of the informant and the interpretation of the researcher together lead to knowledge construction (Guba & Lincoln, 1994). Krippendorff (2006) described this as second-order understanding and explained it through a figure (Figure 4). As the findings of qualitative, social constructivist methods rely on second-order understanding, assuring that the trustworthiness of the findings can be problematic. To reduce the risk of misinterpretation and strengthen the trustworthiness of the presented findings of the thesis, three researchers were involved in the data collection and interpretation. Through various discussion rounds, a consensus on the interpretation of the data was formed. Moreover, the author chose to add notes on her personal background, reflecting on her experience, motivation and perception of the research topic.

Figure 4 - Second-order understanding exemplified as a medical practitioner explaining to a researcher the experience of prescribing medication to a patient (adapted from Krippendorff (2006, p.67))

Some of the methodologies that are applied in this thesis could be associated with social constructionism instead of social constructivism. In social constructionism, the focus lies on the creation of experiences in relation to social context or on the discovery of the meaning that is associated with an event or object by a society, and how language and interactions can change the meaning that a society designates to an event or object. During design workshops, people collaborate on ideating possible new solutions. Through group discussions, ideas are formed and evaluated. A common understanding arises regarding which ideas would be possible, relevant and achievable for the context in which they are developed. Despite that, two types of design workshops were organised during this thesis (section 4.2.3 and 4.2.4). The thesis rather belongs to the social constructivist paradigm, as the focus lies mainly on the discovery of individual meanings that people attach to specific events and how such insights can be used to optimise the experience of pre-treatment education and decision aids as events that support the SDM phenomenon.

4.2 Methodological and ethical considerations

Methodologies belonging to social constructivism evolve around open-ended questioning of individual respondents and observations in the field. The intention is to display the variety of meanings attached to a certain event (Holloway, 2005). This is done through the interpretation of expressed language and people's actions. Researchers in the constructivist paradigm tent to watch, listen, ask, record and examine to build understanding through interpretation (Schwandt, 1994). The goal is not to theorise, but rather to explain (Alvesson & Sköldberg, 2009). In this thesis, the focus lies on the comparison of individual experiences in relation to pre-treatment education and decision aids as events that can support SDM, explaining how specific design aspects can affect people's experiences positively or negatively, and how such insights can contribute to the improvement of programs to make them more beneficial for people with CRF, their families and medical practitioners.

The methods applied in this thesis are mainly qualitative. Qualitative methods can provide insights into the meanings people attach to events or products and motivations behind their behaviour, whereas quantitative methods are more suited to uncovering the frequency of an event or the relation between specific variables. Table 2 presents an overview of the applied methodologies and states in which sections they are discussed.

Ethical considerations influenced the study designs (Robson, 2011). Ethical considerations are, therefore, presented in addition to the methodological considerations. Patients who have just been diagnosed with a serious condition are in a very vulnerable position, as their situation is new and their future is uncertain. These concerns especially need to be taken into account for those who do not yet know the treatment that they will start. Therefore, as researchers, we should be careful not to burden patients more than necessary. In this project, I tried to find a balance between obtaining relevant insights whilst trying to act in the least intrusive manner as possible for newly diagnosed patients and their relatives.

Methodology	Described in	Applied in
Literature reviews	Section 4.2.1	Section 5.1
Desk research	Section 4.2.2	Section 6.1
Design workshop	Section 4.2.3	Section 6.2
Case study (interviews, observations, co-design)	Section 4.2.4	Section 5.3

Table 2 – Overviews of applied methodologies

4.2.1 Literature review

Methodological considerations

In a literature review, one collects and analyses scientifically documented reports, such as journal articles, dissertations and research reports (Robson, 2011). A literature review can be used to identify similarities and differences between studies that have been realised in an area. Furthermore, it can offer insights into knowledge gaps and disputed parts (Robson, 2011). Literature reviews for design projects usually aim at combining insights from various previous projects to inform the current project (Hanington & Martin, 2012). When conducting a literature review, it is necessary to thoughtfully select the databases to include in the search, as differences occur between databases where articles are retrieved (Robson, 2011). Furthermore, checking the credibility of the source before inclusion is important (Hanington & Martin, 2012).

Method application

Two literature reviews were conducted with the goal of finding general patterns as well as knowledge gaps. A scoping review was conducted to build understanding of information needs of adults with CRF pre-treatment start and their motivations behind treatment preferences. A scoping strategy was used, as the intention was to identify relevant articles to obtain an impression of contemporary knowledge of the topic, rather than aiming to be fully exhaustive (Robson, 2011). A more detailed method description can be found in section 5.1.1.
A systematic literature review was conducted to develop an overview of existing pre-treatment education programs on renal replacement therapy options for adults with CRF worldwide, as well as information about the pros and cons of different approaches. Due to resource constraints, only one researcher was involved in selecting and evaluating the studies.

Three literature reviews covering the same topic were found during the search for articles. Twelve additional studies were found that had not been covered in any of these reviews. A more detailed method description can be found in section 5.1.2.

Ethical considerations
Following ethical research practice, these literature reviews were executed to obtain an overview of what research has been executed, what is known about the topic and to identify knowledge gaps. This prevents double work being realised and informants from being burdened unnecessarily. An additional consideration when including articles on empirical studies in a review article is whether your secondary use of the data might be against the initial consent from the subjects in the studies you are including (Boddy et al.). The researcher reflected on this question and considered that the purpose and set-up for the literature reviews did not induce any risk for the initial subjects.

4.2.2 Desk research

Methodological considerations
Desk research constitutes the collection and analysis of existing data from various sources. In contrast to empirical research, the data does not come directly from a human source (Hanington & Martin, 2012). Desk research can help in identifying gaps by mapping what has been done previously. It is relatively inexpensive and allows for the comparison of data from various sources. Nevertheless, one has to be cautious and check the sources' credibility (Hanington & Martin, 2012). Internet-based research is a specific instance of desk research. One of the benefits of Internet-based research is that the Internet provides a large, international data pool (Robson, 2011).

Conventional qualitative content analysis (Hsieh & Shannon, 2005) was used to analyse the collected data. Content analysis helps reveal recurring themes and issues that need further exploration (Edmondson & McManus, 2007). Conventional content analysis is appropriate for obtaining knowledge and understanding and describing an event. However, it could fail in recognition of key categories, which can result in findings that do not accurately represent the data (Hsieh and Shannon, 2005). In conventional qualitative content analysis, categories for coding are formulated directly upon interpretation of the data. Attention is paid to the content as well as the contextual meaning of the content (Tesch, 1990, cited in Hsieh and Shannon (2005).

Method application
Two desk research studies were conducted. In both studies, credibility of the source was included as an inclusion criterion to ensure that analysed data was of sufficient quality. A list of relevant subjects was prepared beforehand to ensure that key categories were considered during analysis.
The first study focused on the analysis of online information mediation platforms. The aim of the first desk research study was to gain knowledge on how existing information websites present information concerning CRF, specifically what information they present and how it is

presented. Three websites matched the selection criteria. The second study focused on the analysis of publicly accessible decision aids. The aim of the second desk research study was to learn how existing decision-making aids are set up, what information they present and what support they provide to people with CRF. Similarly to the first desk research study, gamification was one of the aspects that was analysed to see if there was a potential to introduce serious games as a supplementary strategy. Four online available decision aids were analysed. An online search led to the identification of several decision aids. A selection was made based on the aforementioned selection criteria, with some additional criteria. Four decision aids matched the selection criteria.
Both studies aimed at exploring the status quo of contemporary practices that contribute to the development of better patient information platforms that present relevant information and facilitate treatment decision making. A more detailed method description focusing on the practical execution of both desk searches can be found in section 6.1.

Ethical considerations
Only publicly accessible websites were included, for practical reasons, but also because the creators of these websites have made a deliberate choice for their information to be available for the public to use. Furthermore, the included websites were all created by reliable companies. The content of these pages is, therefore, considered to be trustworthy. Both studies focus on the form of communication (design and linguistics), centring on the differences and communalities between the websites, rather than being a value evaluation on the correctness of the content. Therefore, the risks for the creators of the websites are considered to be low. It was deemed unnecessary to obtain informed consent for both primarily explorative studies.

As the desk research studies aimed at obtaining a general overview of what online tools are available and how they are designed, not on what design is preferred, it was considered unnecessary to involve research subjects from the public. Furthermore, the researchers deemed it difficult to include patients on ethical grounds, as not all hospitals offer all the different treatment methods to their patients. This leads to variations in the treatment options that are presented to patients. There is a risk that subjects are not given a (similar) choice. Presenting them with a choice that is not given to them in practice is considered unethical.

4.2.3 Design workshop

Methodological considerations
Design workshops are creative sessions during which participants collaboratively ideate solutions for a specific challenge. Design workshops can be applied during various phases in the middle of the design process: exploration, concept generation and evaluation. It is a form of activity-based research, which can help build trust of stakeholders and elicit relevant insights (Hanington & Martin, 2012). Although participants in such workshops are not necessarily designers, there are usually some designers amongst the participants. Design workshops need to be carefully planned and prepared, and can provide in-depth qualitative insights. Facilitators need to be able to anticipate the dynamics between the participants and the progression of the assignments (NHS Institute for Innovation and Improvement, 2009).

Method application

A scrum-based workshop was organised with the goal of developing a concept for a serious game that could support people with CRF in the formulation of preferences concerning renal replacement therapy options. Scrum is a project management framework used to structure the development process of products (Schwaber & Sutherland, 2013). It is a rather flexible approach to the design process, in which the developers for each step prioritise the actions to improve.[7] A designer further developed the game concept that was created during the design workshop through several iterations. It is a designer's task to develop solutions that make sense to people (Krippendorff, 2006). Involving other experts in the development process through design workshops and evaluative studies helps ensure the relevance of the concept. However, when an expert design approach (E. Sanders & Stappers, 2008) is taken, there is a risk for distortion, as the designer's understanding is second-order. A more detailed method description of the design workshop can be found in section 6.2.

Ethical considerations

It was decided to take an expert approach to the game concept development, instead of trying to find stakeholders that could take part in the process, for both ethical and practical reasons. As SDM is not yet common practice in all hospitals, variations exist between the number of treatment options that are presented to patients and the nature of the decision-making process (paternalistic versus shared). Consequently, patients might not be offered a treatment choice. Ethically, it is not justifiable to interfere with current medical practice and expose them to the idea of SDM, which it is not achievable for them. Furthermore, people who have just been diagnosed but have not yet started treatment are in an uncertain situation and are, therefore, vulnerable. Practically, there was limited time to develop the game concept (due to the structure of the course), which would have made participant recruitment difficult. Further ethical and practical challenges with the design of a serious game for SDM are discussed at the end of section 5.2.

4.2.4 Case study

Methodological considerations

In a case study, one studies a specific event in depth by collecting data from multiple sources. The event is usually studied in its physical and social context. The belief is that studying the event holistically provides more relevant insights than analysing the datasets seperately (Hanington & Martin, 2012). Case studies commonly include direct observation of the event and interviews witht the actors involved (Yin, 2003). Case studies can be used to explore an event to inspire the design project or study the effects of innovations (Hanington & Martin, 2012). A case study is a suitable approach for studying complex contemporary social events when one wants to find answers to research questions that start with 'why' or 'how'. Case studies are unsuitable when one wants to obtain insights into the prevalence similar interpretations of an

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[7] I was allowed to formulate an assignment for students in a course on serious game development. However, the teacher decided on the development approach (Scrum). From my previous work as a design professional, I was familiar with this method.

event (Yin, 2003). A unique characteristic of case studies is that they allow the inclusion of all kinds of materials as evidence, including documents and artefacts (Yin, 2003). Case studies allow for triangulation. Four types of triangulation exist: data triangulation, observer triangulation, methodological triangulation and theory triangulation (Robson, 2011). The first two types of triangulation have been applied in the case study that was conducted for this thesis. Data triangulation is the collection of data through different empirical techniques and from different sources. When observations are conducted, observer triangulation can be applied when different observers observe the same event. However, triangulation introduces a risk for discrepancies and disagreements, and direct comparison between datasets is problematic (Robson, 2011).

Face-to-face interviewing was applied, as it is a form of a dedicated conversation, enabling in-depth investigation of experiences and motivations (Robson, 2011). Open-ended questioning of individual respondents in the field enables the display of the complexity of meanings. Using a semi-structured interview guide allows the emergence of a natural conversation. However, one of the disadvantages is however that it is difficult to repeat the study (Robson, 2011). The interviews were transcribed verbatim. This provides a detailed overview of the collected data and supports its intensive analysis. The disadvantage of transcribing a tape record verbatim is that some of the authenticity of the conversation is lost, like intonation (Denscombe, 1998). The audio tapes were, therefore, saved so that the researchers could refer to the recordings, if needed.

Non-participatory direct observation was applied to collect real-life, first-hand data (Denscombe, 1998). This means that the observers did not participate in the event, but observed it from a distance, like ‘a fly on the wall’. One cannot ask the informant for an explanation, but the risk of ‘going native’ is low, as it is easier to keep a birds-eye perspective (Gold, 1958). Observations allow a focus on language use, attitude and behaviour (Robson, 2011). Observations further allow the study of a natural setting (Gold, 1958).

For the data analysis of the first case, which included interviews and observations, the Constant Comparative Method as described by Boeije (2002) was applied. This method provides a systematic approach to analysis of qualitative data from various sources. The Constant Comparative Method is as a five-step approach using different analysis activities per step: 1) open coding, 2) axial coding, 3) triangulation of data sources, 4) consensus building on the interpretations and 5) hypotising how the different interpretations relate to each other (Boeije, 2002). Figure 5 presents a visualisation of the Constant Comparative Method that I made to display the analysis proces. As second-order understanding[8] introduces a risk for misinterpretation, group discussions amongst researchers were organised. Through exchanging individual interpretation of the data, each researcher’s individual understanding was deepend. The findings represent the consensus of the researchers, supporting the trustworthiness of the interpretation.

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[8] A further explanation of second-order understanding can be found in section 4.1.

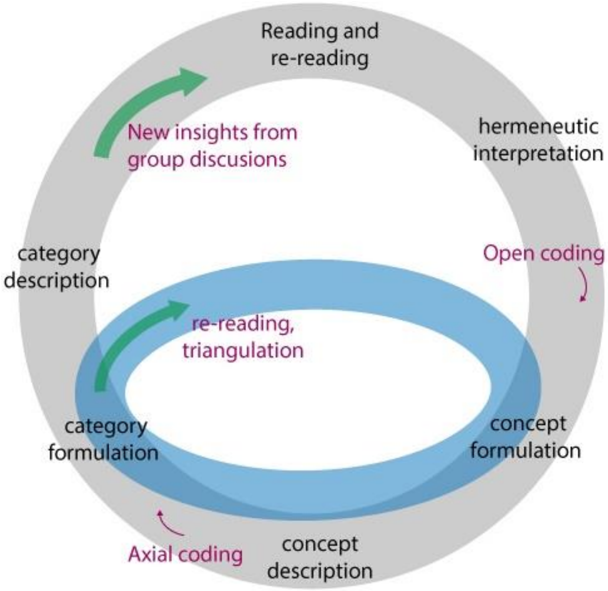

Figure 5 – Visualisation of the Constant Comparative Method, including group discussions.

For the data analysis of the second case, which included interviews, directed qualitative content analysis (Hsieh & Shannon, 2005) was applied. This method was chosen, as it supports the validation or extension of conceptual frameworks that were formulated in prior research (Case 1), supporting the refinement, extension and enrichment of the insights (Hsieh & Shannon, 2005). New insights are obtained to benefit the further description of the phenomenon (pre-treatment patient education programs). Deductive reasoning, guided by the conceptual framework that was the result of a prior study, leads to insights on similarities and differences between the cases. Data that did not fit under the initial conceptual framework were inductively analysed and structured under new codes. One of the downsides of this method is that a researcher is informed by the findings of the first study, introducing a risk for bias. Consequently, researchers are more prone to look for data that is supportive of the initial findings. To reduce this risk for bias, peer debriefing can be applied (Guba & Lincoln, 1994).

A co-design workshop was organised additionally. Co-design workshops are a way to bring designers and non-designers together in making. It is a form of activity-based research (Hanington & Martin, 2012) and helps to ensure that the project will meet the needs of the people involved (Yang & Sung, 2016). Design-by-doing engages stakeholders, facilitates effective dialogues by offering alternative ways of communicating (Björgvinsson, 2008) and supports the discussion of possible future scenarios (E. B.-N. Sanders & Stappers, 2014). Furthermore, co-design workshops allow the creation of many relevant ideas and create ownership amongst the participants (Hanington & Martin, 2012). In a service context, the goal of a workshop will usually be to generate ideas for a new or improved service (Engine Service Design, 2008). The difficulty with service design, however, is that you design for a practice, but the practice itself cannot be designed (Björgvinsson, 2008), as practices are dependent upon human interactions and changing contexts.

Method application

For this thesis, an explorative, comparative case study (Yin, 2003) was performed to study patient education practices in its context. The findings of this kind of case study are indicative rather than constitutive. The aim of the case study was to collect in-depth insights on how patient education is organised in practice, what kind of experiences such programs prompt in both medical practitioners and patients and to evaluate if a service design approach could support the (re)design of pre-treatment education programs. The study takes an inductive approach, applying qualitative research methods. The insight phase of the study builds on two cases. The first case consists of three sets of data: an expert interview with two nurses, observations of group education sessions and three interviews with patients. The second case consists of two expert interviews. The ideation phase consists of a co-design workshop with medical practitioners and aimed at reducing the gaps that were found during the insight phase. The evaluation phase consists of an expert interview with two nurses and observations of group education sessions. This was done to evaluate if the implemented changes that were the result of the co-design workshop helped to improve the program. More detailed method descriptions can be found in section 5.3.

Furthermore, an expert interview was conducted with the development team of 'My Treatment Choice'. Rather than being a case study, this interview provided a case illustration of the development of a decision aid. The aim of this study was to learn about the development of a decision aid: the motivation for the team to develop one, the considerations they made regarding the content and its representation and their experiences with the development of the decision aid. The intention of this study was to provide relevant insights to future development teams that will work on the development of a decision aid. A more detailed method description can be found in section 6.1.

Ethical considerations

The Norwegian Social Science Data Service has approved the study protocol for the case studies (case number: 44537). The ethical principles on ensuring anonymity and confidentiality, as described in the Declaration of Helsinki, were followed. Before the start of each interview, the researchers explained the goal of the research, the set-up of the study and the intended use of the data for article publication. It was made clear that participation was voluntary, and that the participant could ask to terminate the interview without argumentation. The participants signed a form of informed consent before the start of the interview. Data were anonymised directly during the transcription process. The audio file and transcript were stored separately from the participant data to prevent the information from being linked to a specific person.

All interviews were audio-recorded, as this is less intrusive than video recording (Denscombe, 1998). Furthermore, making audio recordings allows the researchers to concentrate on the conversation in the interview, and provides a record that can be transcribed afterwards (Robson, 2011).

Changes of plans

The approach presented above represents the final approach to the project. The original project plan was different. Due to challenges encountered during the project, the project plan had to be changed. Originally, the intention was to do a comparative case study (Yin, 2003) between three actors that organised patient education on treatment options for people with chronic renal failure. Although these three parties have a similar goal (to help patients make a choice between treatments), their approaches to patient education differ. Additionally, these actors have diverse backgrounds (long history versus newly formed group) and cultures (academic environment versus patient organisation). Comparing the three cases would have been informative. The idea was to follow a similar approach for the three parties: 1) conducting expert interviews with those responsible for the program, 2) performing observations of the program and 3) interviewing participants in the program.

Three parties had been approached and agreed to participation. However, one party cancelled the group sessions that would be observed after the expert interview had been conducted. The study of another program was discontinued, as the patients that were involved in the development of this program were few and were already involved in user testing and reference groups. We did not want to burden them with an additional study. A fourth party that was approached did not want to participate in the study, as this part did not want the participants to be contacted. This thesis consequently builds mainly on one single case, supplemented by the insights of some additional expert interviews. However, a multiple case study would have led to more generalizable results, as the findings from the various cases could be compared (Yin, 2003).

Conducted studies – Methods, findings and discussion

The following three chapters (chapter 5-7) present the studies that were conducted for this thesis. For each study, the applied method, findings and a discussion of the findings are presented. Chapter 5 comprises two literature studies. The goal was to obtain insights into state-of-the-art research on patient education and decision support programs, and how these interventions meet patients' information needs.

The insights from the literature studies formed the background for the empiric studies described in chapter 6 and 7. These studies follow two tracks that were conducted in parallel. One track focusses on technology-mediated information and decision support programs, while the other track focusses on and face-to-face information and decision support programs.

In chapter 6, technology-mediated patient education programs are analysed. The chapter comprises various studies that were conducted to obtain insight into contemporary service offers that apply technology to mediate information and provide decision support to patients. The studies in chapter 6 have mainly an international scope.

In chapter 7, face-to-face programs are investigated. In this chapter, contemporary face-to-face education practices are studied qualitatively. The was done to obtain insights into how contemporary patient education programs are organized and structured, and how design methods may be applied to (re)design them.

Note: This thesis contributes to the field of Design for Health, which embraces all kinds of design practices as well as all strings of design research that have the intention to contribute to health and wellbeing (Wildevuur, 2017). Human-centred service design stands at the core of this thesis. Service design has close links to other design disciplines, such as product, interaction and graphic design. The thesis therefore contributes with knowledge that is relevant for the various kinds of design practitioners and design researchers who work with health. Each study concludes with a paragraph called 'relevance for design'. 'Design' is used in general as the findings from the studies contribute with insights that are relevant for various design disciplines. Nevertheless, this does not mean that the contributions have similar implications for the designers in each of these disciplines. For example, regarding the provision of information to patients, service-, interaction- and graphic designers might have a different focus:

- Service designer are concerned that the right information is delivered in time, without overload.
- Interaction designers aim to make information accessible to patients and ensure that patients can find the information that they need.
- Graphic designers work with how the information is visually presented, ensuring that images are relevant and not disturbing the patient.

5. Setting the stage

The following chapter presents two literature review studies that were conducted to obtain insight into state-of-the-art research on patient education and decision support programs, and how these interventions meet patients' information needs. Section 5.1 comprises a scoping literature review in which the considerations of patients with chronic kidney failure (CKF) regarding treatment choice and their experience of the information mediation trajectory were investigated. Section 5.2 comprises a systematic literature review in which the structure of existing interventions that provide pre-treatment education to patients with CKF and their next-of-kin were investigated.

5.1. Patients' considerations regarding treatment options and their experience of the information mediation trajectory – A literature review of qualitative studies

Abstract

Shared decision making (SDM) is increasingly promoted by both politicians and medical practitioners who want to give patients more agency over the healthcare services they receive. In order to realize SDM, patients need to become better informed about their options and supported in making a choice. In order to be able to develop adequate interventions, designers will need to what information the intervention should provide.

The goal of this literature study was to gain insight into the information needs of people with CKF prior to treatment decision making. This study therefore aimed to identify which subjects patients report to consider when they are offered to take part in treatment decisions. Further, the study aimed to investigate patient's experience of becoming informed and taking part in treatment decisions.

This study provides insights into the information needs of adults with CKF pre-treatment decisions. An overview of themes that patients have reported to consider regarding treatment choice and the relationships between these themes is presented (figure 6). Patients mentioned the effects of treatment on daily life most often. The study furthermore presents an overview of barriers to participation in treatment decisions that patients have expressed to have experienced. These barriers relate to 1) communication problems, 2) their own emotions, and 3) lacking resources at some medical clinics.

Insights from this study can support designers in deciding which topics to cover in pre-treatment information services. Furthermore, awareness of the possible barriers to becoming informed that patients may experience, may help designers to develop solutions that overcome these barriers. The insights of this study are more specific and detailed than current clinical guideline documents.

Aim of the study

The overall aim of this thesis is to acquire a better understanding of aspects that can support the (re)design of pre-treatment education and decision support programs for chronically ill patients and their next-of-kin. This particular study aimed at contributing to this goal by collecting knowledge on subjects that patients with CKF might consider regarding treatment options and their experience of the information mediation trajectory. The main research question for this study was: What information needs do people with CKF and their next-of-kin have when they need to consider renal replacement therapy?

This knowledge provides insights into the information demands of adults with CKF pre-treatment choice and can support developers of interventions in deciding the information that needs to be included in the intervention. Knowledge of patients' experiences with current practices can help developers decide how to mediate the information, supporting the improvement of future interventions.

Method

A scoping review was conducted to construct an understanding of information needs of adults with CKF pre-treatment start and their motivations behind treatment preferences. A scoping strategy was used, as the intention was to identify relevant articles to get an impression of contemporary knowledge of the topic, rather than aiming to be fully exhaustive (Robson, 2011).

Literature reviews for design projects usually aim at combining insights from various previous projects to inform the current project (Hanington & Martin, 2012). As described under the aim of this study, that is also what this study intends to do. A literature review can be further used to identify similarities and differences between studies that have been realised in an area (Robson, 2011). This study made use of mind mapping (Hanington & Martin, 2012) to display the findings of previously conducted qualitative studies regarding patients' considerations concerning treatment choice. By mapping the findings in a mind map, allows the indication of overlapping findings between various studies, thus providing insights into which factors patients mentioned most frequently across studies.

Initial search terms were listed during a brainstorming session, based on my knowledge of the topic. The applied search terms were: 'qualitative', 'Chronic Kidney Failure', 'CKF' (and other variants of the diverse medical terms for CKF, both full terms and abbreviated versions), 'dialysis', 'transplantation', 'conservative care', 'decision making' and 'choice'. Inclusion criteria were: a) perspectives from adult patients (18+) with CKF, not medical practitioners, b) who were offered more than one renal replacement therapy option, c) published in 2000 or later (initial search conducted in May 2015, repeated in December 2017), and d) written in English. Snowball sampling (Johnson, 2014) was used as a secondary search strategy, meaning that the reference lists of relevant articles were searched to identify additional articles on the topic (backward snowballing). In addition, for the articles that were included, the titles of the articles that cited the included articles were checked (forward snowballing). Articles that were included in one of the four systematic reviews were excluded from this review to avoid double report. The search yielded four systematic reviews of qualitative studies, and three additional qualitative studies that had not been included in any of the reviews. Thematic analysis (V. Braun & Clarke, 2006) was used to identify recurring themes in the different datasets. Themes were formulated inductively. One of the benefits of thematic analysis is that it results in a higher abstraction level by carefully examining which elements diverse studies have in common. This enabled me to collect the findings in a mind map.

Findings

To acquire insight into the information needs of people with CKF prior to treatment choice, a literature search was conducted a) to identify which subjects patients might consider when deciding on treatment options, and b) to learn how they experience becoming informed.

The literature search yielded four systematic reviews on treatment decision making by adults with CKF, published between 2009 and 2015. All four reviews described their search strategy, including the databases that were searched and timeframes. For two studies, the specific search terms were listed (Harwood & Clark, 2013; Murray et al., 2009), whilst the other two provided a more general description of the topics that were included in the search (Hussain, Flemming, Murtagh, & Johnson, 2015; Morton et al., 2010). For the study by Murray et al. (2009), a multidisciplinary team was involved to determine search terms. In all four review studies, the selection criteria were clearly formulated, and the article selection was executed by two researchers independently and then compared. Included articles were quality appraised, yet it is unclear how this affected the findings for all four studies. The analysis process is clearly described in two studies. In these two studies, two researchers collaborated in data analysis, strengthening the validity of the findings (Harwood & Clark, 2013; Morton et al., 2010). The other two studies merely mentioned the analysis method. It is, therefore, unclear how codes were constructed and validated (Hussain et al., 2015; Murray et al., 2009). All four reviews presented descriptive quotes to illustrate the codes and reflect upon implications for practice. A limitation of these reviews is that they only included studies published in English from mainly western countries. Patients who opted for kidney transplantation or conservative management are underrepresented in the studies, as well as patients with non-western ethnicities or with cognitive difficulties. Socio-demographic characteristics are generally poorly described, so little is known about how these characteristics influence decision making. For example, although the effects of literacy were mentioned, they were insufficiently studied in this setting. Some reviews included studies that were conducted more than a decade ago. Care practices and cultures might have changed over the past years, which may lead to different considerations amongst patients today. Furthermore, many studies present retrospective accounts of the decision-making process. Consequently, recall as well as the experience with the current treatment may have influenced the respondents' replies.

Three additional qualitative studies that had not been included in any of the four previously conducted systematic reviews were included in this study. These studies were published between 2013 and 2016 and were conducted in various countries: New Zealand (Walker et al., 2016), Singapore (Griva, Li, Lai, Choong, & Foo, 2013) and the Netherlands (Van Rooijen et al., 2013). Respondents were selected based on variety in age, gender, disease progression and treatment type, including respondents in the pre-treatment phase, reducing effects of recall and living with a treatment. Respondents of non-native ethnicities were underrepresented in two studies (Griva et al., 2013; Van Rooijen et al., 2013). Two studies focused on dialysis options only, excluding decisions related to kidney transplantation or conservative care (Griva et al., 2013; Walker et al., 2016). Interview guides were well-informed. For two studies, the interview guide was informed by previously published studies on the topic (Van Rooijen et al., 2013; Walker et al., 2016). For the third study, the interview guide was informed by discussions with medical professionals and a pilot study (Griva et al., 2013). All three studies made use of investigator triangulation to validate the findings and present illustrative quotes together with codes. In the study by Van Rooijen et al. (2013), additional validation measures were applied. Experienced patients were involved in data analysis of the interviews, respondents were given the opportunity to comment on the findings and the findings were further validated through a focus group and forum discussion.

The goal of this literature study was to gain insight into the information needs of patients with CKF prior to treatment decision making, One sub-goal of this study was therefore to identify which subjects patients might consider when deciding on treatment options. A mind-map was made to visually present the accumulated findings of the articles that were found in the literature search (figure 6). The mind-map presents an overview of the themes that were identified during each study on patients' considerations regarding treatment choice. The mind-map furthermore depicts the relationships between the different themes and portrays the studies in which these themes were identified to visualize the how often each aspect was mentioned across studies. As shown in figure 6, aspects that patients mentioned most frequently across studies were: a) Having a normal life, b) the effect of treatment on their family, and c) the benefits and risks of treatment options. Additionally, patients frequently reported concerns related to self-efficacy and the effect of treatment on their autonomy. Personal experience with a specific treatment, either by patients themselves, or from relatives and friends were also frequently mentioned as being considered when deliberating on treatment options. The text below further explains the figure.

Considerations concerning treatment choice

Pursuing a normal life

Patients expressed the wish to live a life that is as close to normal as possible. They aim to have a good quality of life. Patients try to anticipate what their future life will be like and want to minimise intrusiveness (Griva et al., 2013; Harwood & Clark, 2013; Hussain et al., 2015; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013; Walker et al., 2016). This is illustrated by the following quote: *"If you can't have some semblance of a normal life, then why would you want to live?"* (Tweed & Ceaser, 2005, cited in (Hussain et al., 2015). Important considerations for patients, in the context of this topic, relate to the time and place where the treatment will take place. Aspects that they considered in relation to time were: the time of the day when the treatment takes place (day or night) (Griva et al., 2013; Van Rooijen et al., 2013; Walker et al., 2016), the frequency and duration of the treatment (Griva et al., 2013; Harwood & Clark, 2013; Van Rooijen et al., 2013) and flexibility in scheduling treatments (Griva et al., 2013; Walker et al., 2016). Aspects related to place were: having support from next-of-kin (Harwood & Clark, 2013; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013), privacy, physical space at home and at work (Van Rooijen et al., 2013), the distance to the clinic (Griva et al., 2013; Harwood & Clark, 2013; Van Rooijen et al., 2013; Walker et al., 2016), feeling safe (Griva et al., 2013; Van Rooijen et al., 2013; Walker et al., 2016), contact with peers (Van Rooijen et al., 2013; Walker et al., 2016) and time spent with family (Griva et al., 2013; Walker et al., 2016). Furthermore, the effects on the lives of family members and not wanting to be a burden

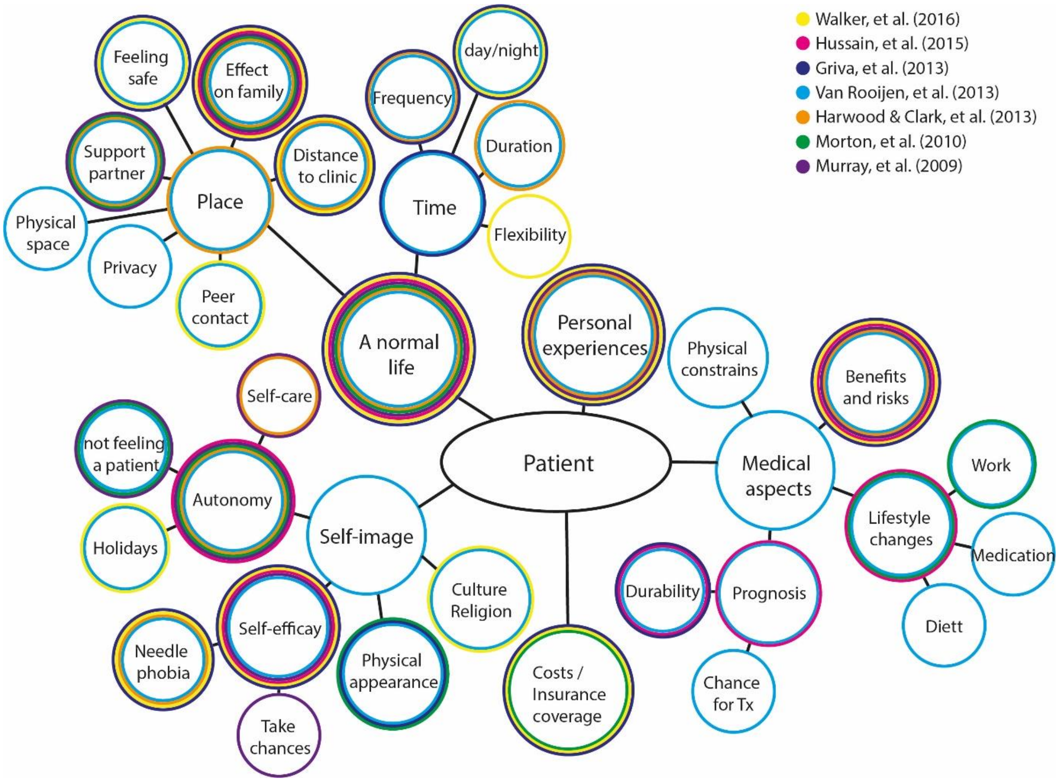

Figure 6 – Overview of themes displaying patients' considerations regarding treatment choice.

(Harwood & Clark, 2013; Hussain et al., 2015; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013) are aspects related to the place where the treatment is conducted. This is illustrated by the following quote: *"Well I couldn't see that it was really going to achieve anything apart from disrupting everybody's life"* (Ashby et al., 2005, cited in (Hussain et al., 2015). For some patients, mostly the elderly, the hassle of preparing for and undergoing treatment was not worth the effort. For others, there was no doubt that they wanted to live and, thus, needed to undergo treatment (Morton et al., 2010).

Self-image

Patients expressed considerations that relate to their self-image. Autonomy was mentioned (Harwood & Clark, 2013; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013). Aspects that were mentioned in relation to autonomy were going on holidays, (Van Rooijen et al., 2013; Walker et al., 2016) maintaining personal interests to not feel like a patient all the time (Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013), and self-care. Furthermore, to some, self-care and being personally responsible for carrying out the treatment sessions were important (Harwood & Clark, 2013; Murray et al., 2009), as illustrated by this quote: "*I like taking responsibility for my own care"* (Bass et al., 1999, cited in (Morton et al., 2010). They also expressed concerns that point to their self-efficacy (Griva et al., 2013; Harwood & Clark, 2013; Murray et al., 2009; Van Rooijen et al., 2013; Walker et al., 2016). Needle phobia is a specific concern that is mentioned in relation to this theme (Griva et al., 2013; Harwood & Clark, 2013;

Van Rooijen et al., 2013; Walker et al., 2016), as well as a fear that things will go wrong (Murray et al., 2009; Walker et al., 2016). However, the willingness to take chances was mentioned by some patients (Murray et al., 2009). Furthermore, patients expressed considering the effects on their physical appearance and sexual appeal (Griva et al., 2013; Morton et al., 2010; Van Rooijen et al., 2013), as exemplified by this quote: "*Having a fistula on the arm would show I was a patient. However, with an abdominal catheter on the belly, people would not know"* (Chen, M., 2007, cited in (Morton et al., 2010). Additionally, religion and cultural norms can play a role in the decision-making process (Van Rooijen et al., 2013; Walker et al., 2016). *"Our culture is our life [...] that is what makes us us, that is a huge consideration when we were thinking about dialysis"* (Walker et al., 2016).

Medical aspects

In addition to personal values and beliefs, patients expressed considering certain medical aspects. They considered aspects related to the prognosis of the length of treatment, specifically the estimated durability of effective treatment (possible need to switch) (Griva et al., 2013; Hussain et al., 2015; Van Rooijen et al., 2013), and in the case of dialysis choice, the potential to receive a kidney transplantation in the future affects their choice (Van Rooijen et al., 2013). Possible complications, risks and benefits are considered (Griva et al., 2013; Harwood & Clark, 2013; Murray et al., 2009; Van Rooijen et al., 2013), as well as the required changes in diet, medication and their work (Van Rooijen et al., 2013). Furthermore, if they have any physical constraints, they consider how this could affect the treatment (Van Rooijen et al., 2013). Although medical aspects do play a role in the decision, this role was found to be less prominent than life values and patients' beliefs related to their self-image (Harwood & Clark, 2013; Hussain et al., 2015; Walker et al., 2016). This is especially considered for the quality of life versus longevity (Hussain et al., 2015; Morton et al., 2010), as is illustrated by this quote: *"If you are supposed to really follow that regime, I would rather cut a couple of years off my lifespan".* (Aasen et al., 2012, cited in (Hussain et al., 2015). Nevertheless, to other patients short- and long-term health benefits weighed most (Van Rooijen et al., 2013; Walker et al., 2016) *"I wanted to know which one would work better and make me feel better, in the long term what is going to make me as well as possible for as long as possible"* (Walker et al., 2016).

The factors above provide an overview of aspects that patients may consider when taking treatment decisions. However, the aspects that a patient considers are individual (Hussain et al., 2015). Furthermore, the statements of patients in the study by Van Rooijen et al. (2013) indicated that some of the abovementioned values and beliefs can be interpreted in various ways, such as considerations related to independence, living a normal life and not feeling like a patient. As an example, for some people, independence was associated with being responsible for one's own treatment, while other patients expressed the importance of not having to rely on support from their families, and others expressed independence as not being dependent on treatment every day, or not having to think of treatment during the day (Van Rooijen et al., 2013). Due to the individuality of values and beliefs, a 'good quality of life' is an individual concept. Therefore, there is no single best treatment (Harwood & Clark, 2013).

Furthermore, personal experiences with a treatment, or those of acquaintances, influenced the choice (Griva et al., 2013; Harwood & Clark, 2013; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013; Walker et al., 2016), as this quote illustrates: *"My brother... he was doing that for five years and I realise how hard it was for him to do it"* (Tweed & Ceaser, 2005, cited in (Hussain et al., 2015). Patients also considered the opinions of family members (Morton et al., 2010; Murray et al., 2009). Furthermore, a factor that was mentioned by respondents outside the EU were the costs and the coverage by their insurance (Griva et al., 2013; Morton et al., 2010; Walker et al., 2016).

Experiences regarding becoming informed and taking part in treatment decisions

The goal of this literature study was to gain insight into the information needs of patients with CKF prior to treatment decision making. A sub-goal of this study was therefore to obtain insight into how patients experience becoming informed The analysis of the literature shows that many patients indicated that they were offered a choice and were supported in taking part in a treatment decision (Harwood & Clark, 2013; Van Rooijen et al., 2013). They collected information from family, medical professionals and experienced patients (Griva et al., 2013; Harwood & Clark, 2013; Hussain et al., 2015; Morton et al., 2010; Murray et al., 2009; Van Rooijen et al., 2013; Walker et al., 2016). However, some did report to have experienced barriers that affected the possibility to partake in the decision.

Communication

Patients expressed experiencing barriers related to communication in the pre-treatment phase. Some expressed having experienced consults with biased professionals who pushed for a specific treatment (Morton et al., 2010; Van Rooijen et al., 2013), as illustrated by this quote: *"Since [the nephrologist] owned four haemodialysis units, his suggestion was that I go on haemo"* (Whittaker & Albee, 1996, cited in (Morton et al., 2010). Other medical professionals seemed to hold pre-assumptions regarding the patient's preferences (Van Rooijen et al., 2013; Walker et al., 2016) or sometimes lacked the knowledge of lesser known treatment options (Van Rooijen et al., 2013). The way information is formulated can also affect a person's choice (Hussain et al., 2015; Morton et al., 2010; Walker et al., 2016). In addition, patients expressed that medical specialists sometimes misunderstood their knowledge level, overestimating what the patient knows and understands (Van Rooijen et al., 2013). Patients reported that trusting their medical practitioner makes it easier for them to accept the information that is offered (Harwood & Clark, 2013; Hussain et al., 2015; Murray et al., 2009; Walker et al., 2016), as this quote illustrates: *"I know them, they know me, that's what will work"* (Walker et al., 2016). Furthermore, they expressed experiencing the information mediation process to be mostly linear from medical specialist to patient, whilst they would prefer an exchange. Some felt that they were not given the chance to ask questions or were unsure about what to ask (Hussain et al., 2015; Walker et al., 2016). Some expressed finding it difficult that the information was mostly mediated through text and conversations, as they preferred more visual ways of learning (Van Rooijen et al., 2013; Walker et al., 2016). Some illiterate and non-native speakers had difficulty understanding the information and felt embarrassed and lost, but refrained from indicating this to their medical specialist (Walker et al., 2016). In addition, the use of medical jargon overwhelmed some patients (Walker et al., 2016). A person's attitude can also become a barrier. Some patients indicated not being interested in all the information (Van Rooijen et al., 2013). Others experienced lacking the energy and having difficulty concentrating due to their illness (Morton et al., 2010; Van Rooijen et al., 2013), as exemplified by this quote: *"I was so sick at the time I didn't catch on to it"* (Breckenridge, D., 1997, cited in (Morton et al., 2010).

Lacking information on specific topics

Patients expressed experiencing the lack of information on certain topics to be a barrier for treatment choice. Some stated that not all options were discussed (Harwood & Clark, 2013; Morton et al., 2010; Van Rooijen et al., 2013), and that attention was mostly paid to positive aspects, but the negative aspects were neglected (Van Rooijen et al., 2013). Some indicated lacking information of practical aspects on daily life (Griva et al., 2013; Morton et al., 2010; Van Rooijen et al., 2013; Walker et al., 2016). Others expressed that the information was too theoretical and desired contact with 'experienced peers' – patients in treatment (Griva et al., 2013; Van Rooijen et al., 2013; Walker et al., 2016). Additionally, they would have liked more information about options for extra support, specifically financial support (Van Rooijen et al., 2013). Furthermore, they indicated that too little attention was paid to the motivations behind treatment preferences, from both the patient side as well as the medical specialist side (Van Rooijen et al., 2013). The researchers in two studies reported that they experienced some instances in which the statements from patients indicated that they had misunderstood the information (Hussain et al., 2015; Van Rooijen et al., 2013). Medical practitioners are still commonly regarded as the one that has the knowledge. Therefore, patients rely on their medical team to share relevant information with them (Hussain et al., 2015).

Timing

Some patients expressed having experienced the timing of the information to be problematic. This has two components: information being mediated either too early or too late (Harwood & Clark, 2013; Morton et al., 2010; Van Rooijen et al., 2013) and receiving too much information in a short time, i.e. information overload (Van Rooijen et al., 2013). In the case of information being offered too late, some patients reported that their next-of-kin or physician had to make the decision for them, as they were too ill themselves (Harwood & Clark, 2013; Hussain et al., 2015; Morton et al., 2010). Some indicated that they would have liked some time to re-evaluate their choice, especially as they needed to get used to the idea of dialysis at home (Walker et al., 2016). This is illustrated by the following quote: *"Maybe with time I'd get better and be able to take them [the needles] out, that is the only thing stopping me from going home"* (Walker et al., 2016).

Emotions

Patients expressed that they experienced the treatment decision as a choice between life or death and, thus, not a real choice (Harwood & Clark, 2013; Hussain et al., 2015; Morton et al., 2010), as this quote illustrates: *"I had no choice… I wanted to live"* (Kaufman et al., 2006, cited in (Hussain et al., 2015). Consequently, facing and making a choice is experienced as stressful (Harwood & Clark, 2013). Patients also expressed experiencing fear about things going wrong (Murray et al., 2009), death and physical limitations (Hussain et al., 2015). Additionally, some experienced inertia, as it is uncertain how fast their disease will progress and, thus, when they would need to start treatment or how long they will live, regarding choosing palliative care (Hussain et al., 2015; Morton et al., 2010), as illustrated by the following quote: *"They can't tell you, you know, how long you have to go. You see this is [very] true, they don't know"* (Bass et al., 1999, cited in (Morton et al., 2010). At the same time, some patients regarded this phase as a chance to re-evaluate life and their priorities (Morton et al., 2010). People indicated generally being reluctant to discuss living donor kidney donations with their acquaintances (Morton et al., 2010).

Lack of resources

Some patients indicated that a lack of resources has limited their choice or hampered them from starting their preferred treatment. This has practical causes, as there can be waiting lists, or the treatment is not available in their area (Morton et al., 2010; Van Rooijen et al., 2013). Physiological contraindications can reduce the number of options (Morton et al., 2010; Van Rooijen et al., 2013), although differences exist between the strictness and support of medical centres (Van Rooijen et al., 2013).

Discussion

The findings of this study show that patients strive to minimise the effects of treatment on their daily lives. The fact that patients in every qualitative study that was included in this review mentioned this concern signifies the importance of this topic for patients. It might explain why patients expressed wanting more information on practical aspects of treatments and possibilities for extra support, another finding of this review study. The fact that the concern for the effects on daily life is rather important to patients might further explain why patients were additionally found to request more contact with 'experienced peers'; they might expect these experienced peers to be able to inform them about how a treatment has affected their personal lives. However, this is exactly the reason why the involvement of experienced peers during information programs has been debated (Warwick et al., 2014), as their stories are individual. Many uncertainties exist around how an individual will react to a treatment, and the daily lives and values of people differ. Statistics could be used to explain the chances for an individual to benefit from a treatment or to develop side effects. The problem with statistics, however, is that patients might have difficulties understanding them (Elwyn et al., 2012).

The findings show that some patients regarded the effects of treatment on daily life and the congruence with their self-image as more important than the medical effects of a treatment. Furthermore, the findings show that a patient's reasoning is individual. This signifies the importance and relevance of a change of practice to SDM; medical practitioners are used to dealing with acute medical conditions that can be cured. In the case of chronic diseases, however, care cannot cure the medical condition, and lifelong treatment is needed. Instead of focusing on the medical effects of treatment, the quality of life of the patient has becomes more important (Eriksson & Lindström, 2008). Yet, prolonging life and the physical condition of the patient traditionally are weighed the most in considerations by medical practitioners (Hussain et al., 2015) As patient's values and beliefs play a role, it becomes difficult for a medical practitioner to decide which treatment is best for the individual patient.

The review showed that patients in diverse studies mentioned having experienced barriers towards SDM. Some referred to being constrained by biased medical practitioners, whilst others were not informed about all treatment options. This shows the necessity of obtaining commitment from medical practitioners as a first step towards SDM (Charles et al., 1997); without their support and according behaviour, SDM will not be achieved in practice. In addition, information about all treatment options will have to be made available to patients. Another barrier that some patients described was a lack of resources at the hospital where they were treated. Consequently, they could not choose a specific type of treatment. Another barrier to SDM is that differences exist between medical centres regarding which conditions they consider to be contraindicative for specific treatments (Van Rooijen et al., 2013). If a specific condition is considered to be a contraindication for a treatment at one hospital whilst it is not at another, the number of options a patient is offered will differ, depending on the hospital. For these reasons, it would make sense to develop a national strategy for SDM practice to allow every patient to receive the same options, no matter where they are treated. This has also practical consequences, as treatment options would need to be made available nationwide. Furthermore, it might be necessary to set up a training program for medical practitioners, as they can affect a patient's preferences through framing information differently (Epstein & Peters, 2009).

This review showed that patients reported expecting medical practitioners to provide them with relevant information to participate in the treatment decision. The review also found many considerations that are related to personal values and beliefs. For the medical industry, it is difficult to provide patients with information about such personal concerns. Patients should be informed about specific value- and belief-related topics that they may want to reflect upon regarding their treatment options.

Two other influences on treatment preferences were mentioned regularly by patients in this study: not wanting to be a burden and feeling supported by their next-of-kin. This shows the importance of patients discussing the treatment options with their next-of-kin and expressing preferences with each other. However, the theory on SDM does not display the complexity of reality (Charles et al., 1997), where more than two actors influence the treatment decision. To give patients a positive service experience, it might, therefore, be necessary to develop interventions that provide space for a patient's next-of-kin to participate.

The findings of this review further show that patients in various studies mentioned the role of family members in formulating their preferences. The fact that family members play a role might explain why patients change their opinion after a consultation in which the medical practitioner thought they had come to an agreement (Epstein & Peters, 2009). It shows that the decision is made in a complex context, and that this context can affect the outcome of a decision. As (Epstein & Peters, 2009) explained, when uncertainty is at play, it can be difficult to imagine the outcome; when a situation is unfamiliar, and when the stakes are high, people are more likely to change their mind. Therefore, it might be necessary to check whether a patient still supports a decision that was made during a preceding consultation. In a study by Walker et al. (2016), patients explicitly expressed a need to re-evaluate their choices. Re-evaluation of choices is especially relevant, as considerations may change when a disease progresses and a patient starts to feel sicker (Epstein & Peters, 2009).

This study found that a patient's concerns related to self-efficacy might influence his or her preferences. Basing preferences on fears is unfavourable. In the case of needle phobia, it has been shown that patients can overcome their initial fear and thrive on haemodialysis treatment (Hope, 2013; Muroma- Karttunen, 2013). Therefore, a patient's fear of needles does not necessarily need to be a reason to eliminate haemodialysis as a treatment option. The fear of things going wrong might also be mediated through providing additional information on the security measures around a treatment. The fact that fear might affect a patient's preferences underlines the importance of discussing a patient's self-efficacy, as suggested by (Makoul & Clayman, 2006). It is important to support an open dialogue between the medical practitioner and the patient on treatment preferences and the motivations behind these preferences, as this will help misunderstandings and fears to be mediated by providing individualised information.

The finding that patients' reasoning about certain topics is individual underlines the importance of discussing motivations behind preferences. When someone states that autonomy is important for him or her, a medical practitioner will have to go more into depth to understand the individual's motivation behind this statement. Discussing a patient's motivations behind preferences will further help to ensure that a preference is not based on a misunderstanding of information. However, this does happen, as the researchers in two of the studies found (Hussain et al., 2015; Van Rooijen et al., 2013). Furthermore, such discussions can support a patient's understanding, as patients may oversimplify complex situations (Epstein & Peters, 2009).

The findings show that patients might need information regarding any of the topics listed in the mind-map (Figure 6). Nevertheless, individual differences exist regarding the information a patient will consider when formulating informed preferences. The study shows that some patients experienced an information overload, and that other patients reported having difficulties taking in all the information as the lacked the energy and had difficulty concentrating due to their illness. This shows that an information service that can be individualised and paced according to an individual patient's needs will benefit the patient. Patients do not necessarily have to know everything about each topic.

This review shows that various patients reported a lack of information. However, this does not necessarily mean that they were not offered the information. It could be that the information was offered to them, but that it was not mediated effectively, causing patients not to register it. Patients also reported that they were influenced by how information was presented to them. The findings show that patients in various studies expressed that information was too theoretical, and that they had a need for more dialogue and possibilities to ask questions, as well as a need for alternative information sources that presented information visually, rather than through text and talks. This indicates that information mediation processes might need to be optimised.

Education programs and decision aids may be further improved once more insights into how patients process information and cope with the decision-making process are obtained (Hussain et al., 2015). A service design approach may help to secure continuity of patient-centred communication throughout the healthcare service (Hussain et al., 2015), supporting interdisciplinary care teams to deliver patient-centred care (Harwood & Clark, 2013), and supporting patients in starting a treatment that is best aligned with their preferences (Morton et al., 2010).

Relevance for medical practitioners

This literature review shows that pursuing a normal life is the most commonly described consideration by patients regarding treatment options. As patients want to minimize intrusiveness, they pay attention to practicalities of the treatment, such as where and when the treatment is performed. Maintaining autonomy and not feeling like a patient all the time are two other considerations that patients frequently described in the studies. These considerations relate to a person's self-image. These themes are subjective and individual, supporting the recommendation in the KDOQI guidelines to focus foremost on individual's values and beliefs and on what quality of life means to a patient (National Kidney Foundation, 2015). The findings that different patients may give different meanings to the same theme and that not every patient considers the same themes further supports the importance of focusing on the individual, as does the finding that cultural norms and religion may for some patients influence their treatment decision-making.

This study additionally supports the European Renal Best Practice guidelines (Covic et al., 2010) and the UK Renal organisation's guidelines (Warwick et al., 2014) in their advice to inform patients with CKF about the possible necessity to change treatment modality in future. This study shows that some people with CKF have reported to take the prognosis of the durability of effective treatment into consideration when deliberating on treatment options. This is an aspect that is addressed in the European Renal Best Practice guidelines (Covic et al., 2010), which advise practitioners to always inform patients and relatives about all treatment options, as patients might need to switch to an alternative after trying their first choice. The guidelines from the UK Renal organisation go one step further, specifically advising practitioners to re-evaluate treatment decisions with patients after treatment start (Warwick et al., 2014).

The reality of being on treatment was a topic of interest in the literature review on information needs, as well. Patients not only want general information on the practicalities of treatments, but they also want to consider aspects that relate to the day-to-day reality of being dependent on treatment, such as being able to spend time with family, receiving support from a next-of-kin, and flexibility in the scheduling of treatments. However, these themes are not mentioned in contemporary clinical guideline documents as topics to address.

Relevance for design

This literature review provides insights into the information needs of adults with CKF prior to treatment decisions. An overview of subjects that adults with CKF have indicated to consider

when deliberating on treatment options is presented. The study furthermore clarifies how the various subjects relate to each other. This knowledge aids designers in determining what information to include in a holistic service offer and in a specific intervention of such a service. The fact that patients report to expect to be informed by medical practitioners, underlines the importance of integrating information interventions in care services.
The insight that patients are very focussed on the effects of treatment on daily life, might be transferable to other chronic diseases. In contrary to acute care, which is given in a short time-frame, chronic care is lifelong. This means that patients will have to live with a treatment for a much longer period of time. Consequently, their quality of life while on treatment becomes a more important aspect to consider. For designers this signifies the importance of helping patients understand the possible effects of treatments on a patient's daily life.

This study furthermore provides designers with insights into patient-reported experiences of becoming informed and taking part in treatment decisions. Having knowledge of the various barriers that patients may experience aids designers in developing solutions that meet these barriers. Specifically, this study shows that designers should carefully consider how information is formulated; Designers should be aware that bias, underling pre-assumptions of patient preferences, and neglecting to present negative aspects of treatments, may negatively affect patients' ability to partake in treatment decision making. Furthermore, the timing of information in reference to the patient journey should be considered: Information should be delivered at the right time and in the right pace to avoid overload. Additionally, this study shows that designers, when working on the development of an intervention, should account for patients' knowledge and language levels, as well as preferred learning styles. More visual and interactive ways of learning may be required.
This literature study furthermore uncovers some political challenges that may form a barrier to SDM. Although it will usually not be a designer's task to deal with these, knowing that these challenges may occur will help them to better facilitate discussions with stakeholders. Designers should be aware that medical specialists may hold different views on the desirability of SDM and on the contraindications for specific treatments. Furthermore, not every medical centre may have the same resources. Differences between medical centres might therefore occur regarding which treatment options they can offer and what additional support they can offer to their patients.

Next step This study provides insights in the information needs of patients with CKF and their next-of-kin when facing a treatment choice. In particular, the study provides insights into the themes that patients consider when deliberating on treatment options, and the barriers that some patients have experienced to becoming informed and involved in SDM.

The insights of this study raised the question what information programs are available to patients. More specifically, I was interested to learn: What information is presented and how is this information is mediated to patients? Additionally, I wondered if these programs meet the information needs that were identified in the above-described literature review study.

5.2 A review of educational interventions on renal replacement therapy for people with chronic kidney failure

Abstract

An important requirement for SDM is the education of patients regarding their treatment options. To acquire a better understanding of aspects that can support the (re)design of pre-treatment education and decision support programs, this study aimed at establishing an overview of pre-treatment education programs for adults with CKF that are practiced internationally to learn more about how they are structured and the information mediation strategies they apply. A systematic literature review was conducted. The literature review covers three systematic reviews and twelve original research articles. Interventions were found to vary greatly in structure and content. They were delivered by medical practitioners in various roles, had various scopes and made use of different types of materials. Educational interventions were often compared to standard care, using quantitative measures. The methodological quality of the studies is a concern, as socio-demographic characteristics of patients groups frequently are not described, and measures commonly had not been validated previously. Cross-case comparison between studies was not possible due to the diversity of measures that were applied, and the large variation in structure and content of the programs. This inhibits drawing conclusions regarding the effectiveness of the various components that are applied in contemporary education programs. Many of the published studies did however report significant positive changes of education programs, indicating that investing time and energy in the education of patients is beneficial and may support SDM.

Aim of the study

The overall goal of this thesis is to acquire a better understanding of aspects that can support the (re)design of pre-treatment education and decision support programs for patients and their next-of-kin to better support them in making a treatment choice. This sub-study aimed at establishing an overview of pre-treatment education programs for adults with CKF that are practiced internationally to learn more about how they are structured and the information mediation strategies they apply. The study focused specifically on the following two research questions: 1) How are current education programs for people with chronic kidney failure and their next-of-kin designed and organized? And 2) Which aspects of these education programs may support or constrain shared decision making?

Patients have frequently reported being under-informed when asked to make a treatment choice (Morton et al., 2010). One of the problems is that education appears not to be part of common practice (Isom & Chertow, 2015). Medical practitioners who want to develop an education program for CKF patients in order to promote their involvement in treatment choice may refer to clinical guideline documentation. Pre-treatment education and topics that need to be covered are discussed in various clinical guideline documents. However, these documents include little practical information on how medical practitioners can organise such an education program (Gordon & Lash, 2011). For example, the clinical guidelines from the European Renal Best Practice (ERBP) Advisory Board only state that “all patients and their families should receive well-balanced information about the different renal replacement therapy options, by means of a structured education programme" (Covic et al., 2010). Additional information about how such a program should be organised and what topics it should address is not given.

The preceding section (5.1.1) provided insights into patients' considerations regarding treatment options and showed that there are indications that few substantial differences exist globally between the factors that influence treatment choice by patients and their next-of-kin. As education is most effective when it addresses the needs of the patients and their next-of-kin (Davis & Zuber, 2013), obtaining insights into how current education programs are structured provides an overview of the techniques currently used in practice. Such an evaluation will demonstrate what these programs have in common and where they differ. Evaluation studies concerning their effects may provide an understanding of the strengths and weaknesses of these programs and indications for how they might be improved.

Methods

A systematic literature review was done, as this allows the formation of a thorough overview of the research that has been conducted on a specific topic. One challenge with applying a systematic search strategy is that the search commonly yields 'false positives' (Robson, 2011). Therefore, the search protocol included a list of inclusion and exclusion criteria. These criteria were used to evaluate the titles and abstracts of articles that had been found in search.

Search protocol

The literature search included the following databases: PubMed, EMBASE, Web of Science and Scopus. These four databases were selected after a discussion with a librarian of the university's medical library and my supervisors. The search for articles in the databases followed a systematic approach. Initial search terms were listed during a brainstorm session. PubMed was subsequently used to identify MeSH terms and MeSH-related entry terms related to the words that had been listed during the brainstorm session[9]. The same was done in EMBASE. The collection of terms was used to search each database. The time frame for the search was set to articles published in the preceding five years (2011 – May 2016). The search was repeated in December 2017 to identify any new articles.

Table 3 displays the words included in the search. In each database, an individual search was first conducted for each term. Then, the search terms in each box were combined with OR. Afterward, a search combining the two search strings was conducted with AND. The searches were then limited to publication in the English language. Ultimately, the titles of the articles that matched the search were reviewed for relevance.

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[9] Medical Subject Headings (MeSH) are terms indexed by the National Library of Medicine for the MEDLINE®/PubMED® library (Georgia State University Library, 2018).

Search terms related to CKF	Search terms related to patient education
Chronic Kidney Failure, End-Stage Kidney Disease, End Stage Kidney Disease, End-Stage Renal Disease, End Stage Renal Disease, End-Stage Renal Failure, End Stage Renal Failure, end stage renal dysfunction, end stage renal impairment, end stage renal insufficiency, end-stage kidney failure, end-stage renal disease, Chronic Renal Failure, ESRD, Kidney failure, kidney insufficiency, renal failure, renal insufficiency, chronic kidney insufficiency, chronic renal failure, chronic renal insufficiency, stage 5 kidney disease, stage 5 renal disease	Patient education as Topic, Patient Education, Education of Patients

Table 3 - Overview of search terms

The search was conducted like a waterfall, meaning that after executing a search in a new database, the titles of the relevant articles were matched with findings from the previous searches in the other databases to exclude double findings. Figure 7 displays the search strategy and the total number of articles from the search, as well as the relevant articles in each database.

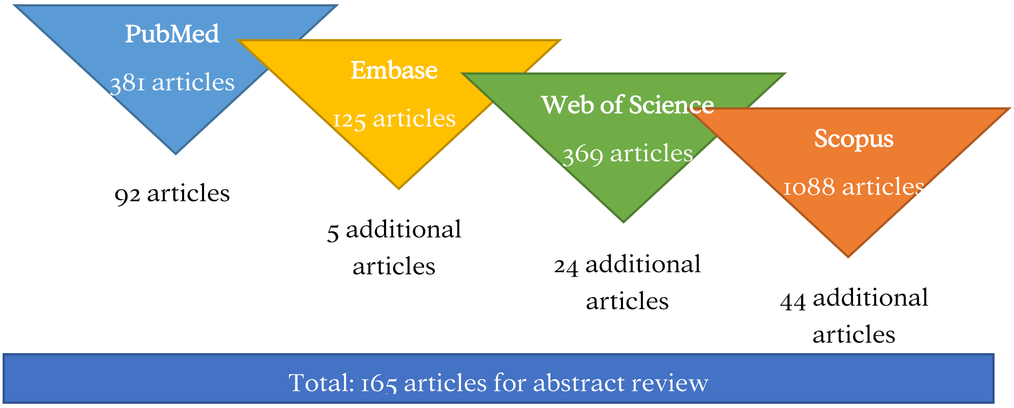

Figure 7 - Search strategy and results

Selection process

The 165 articles that were identified during the search were reviewed on the following inclusion criteria: 1) aimed at adult patients with stage 3-5 CKF and their families, 2) included information on more than one renal replacement therapy option, 3) included a description of the intervention, not mere general pros and cons of patient education. Exclusion criteria were: a) concerning education after choice of treatment, b) focused on end-of-life decision making, c) described a decision aid, not an education program. Articles about decision aids were excluded, as the main objective of a decision aid is not to inform the patient about renal replacement therapy options, but rather to help them make a choice between renal replacement therapy options. Book chapters and editorials were excluded. Articles were quality appraised based on the credibility of the publication channel. Articles were excluded when they had not been subject to peer review. After reviewing the abstracts and the full text, when necessary, seventeen articles were deemed relevant. Three of these articles were systematic reviews of educational interventions for adult patients with CKF on renal replacement therapy options. Two of the original articles were covered in these reviews (Hanko et al., 2011; Lacson et al., 2011). To avoid double representation, these two articles were excluded from the analysis. Thus, twelve original studies and three systematic reviews remained for analysis.

Findings

The goal of this literature review was to establish an overview of pre-treatment education programs for adults with CKF that are practiced internationally to learn more about how they are structured and the information mediation strategies they apply. The study focused specifically on the following two research questions: 1) How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organized? And 2) Which aspects of face-to-face education programs may support or constrain shared decision making?

The search yielded three systematic review articles on the topic of pre-treatment patient education on renal replacement therapy options for patients with CKF. The three systematic reviews each have a different focus, but share an interest in collecting evidence on the aspects of education programs that effectively contribute to patient learning. Van den Bosch, Warren, and Rutherford (2015) focused on aspects that support making a modality choice, whilst Devoe et al. (2016) searched for components that stimulate the choice for PD treatment specifically. Both studies discussed education programs aimed at patients in later stages of CKF and included interventions for people that had to start dialysis acutely. Lopez-Vargas, Tong, Howell, and Craig (2016) aimed to identify effective components for preventing CKF progression, evaluating interventions for patients with both early and later stages of CKF and excluding interventions for people who suffered from an acute onset of CKF.

Table 4 presents the main characteristics of the twelve articles that matched the inclusion criteria. The studies described practices in various countries worldwide. Ten of these twelve articles encompassed the practice at a single centre, whilst the other two were multi-centre studies. One of these multi-centre studies was conducted on a national level, whilst the other described a care practice that is practiced in 26 centres throughout six European countries. Nine of the twelve articles described a study in which an educational intervention was evaluated in comparison to standard care. Some studies made direct comparisons with a control group, whilst other studies used historic data from before the intervention to compare outcomes. Three articles rather presented the educational approach at a specific hospital or clinic, but did not include a study on its effects in comparison to standard care. Two of these three studies described how they had developed and implemented a new education program

Author (year)	Country	Study design	Control intervention	Patient number (standard care / intervention)
Cankaya et al. (2013)	Turkey	Retrospective, single centre	Standard care	N=88 (27 / 61)
Chiang et al. (2016)	Taiwan	Retrospective, single centre	Standard care (regular education program)	N = 656 (620 / 36)
Chiou and Chung (2012)	Taiwan	Prospective, single centre	Standard care (a handout)	N= 60 (30 / 30)
Davis and Zuber (2013)	US	Narrative description	n.a.	n.a.
Enworom and Tabi (2015)	US	1) Retrospective and 2) Prospective survey	Standard care	1) N=49 (24 / 25) 2) N= 98 (not indicated)
De Maar, De Groot, Luik, Mui, and Hagen (2016)	Netherlands	Retrospective	Standard care	N = 153 (51 / 102)
Maaroufi et al. (2013)	France	Prospective, narrative description	n.a.	N = 228
Machowska et al. (2015)	26 centres in AT, DK, FR, SE, UK, DE.	Prospective	Standard care	N = ? (? /270)
Massey et al. (2016)	Netherlands	Prospective, multi-centre, randomised controlled trial	Standard care (consultations, group sessions)	n= 80 (40 / 40)
Mollicone, Pulliam, and Lacson (2013)	US	Retrospective	Standard care	N = 30217 (27052/ 3165)
Watson (2013)	Canada	Retrospective, narrative description	n.a.	N = 100
Yu et al. (2014)	Taiwan	Prospective, single-centre randomised trial	Standard care (written instructions, consult with specialised dialysis nurse)	N = 425 (213 /232)

Table 4 – Main characteristics of included articles

for their practice (Davis & Zuber, 2013; Watson, 2013), whilst the other study investigated the characteristics of patients who chose different treatment options (Maaroufi et al., 2013). Five of the studies had a retrospective design, whilst the seven other studies had prospective designs, two of which were randomised controlled trials. As can be seen from the table, patient numbers varied greatly between the studies.

Many of the retrospective studies relied on medical data abstracted from patients' medical journals (historical data). Some included survey data that was self-reported by patients. Qualitative methods were not applied to evaluate the intervention in any of the studies. Quantitative data can provide insights in numbers and shares, but provides little support for the why-questions.

The survey that Enworom and Tabi (2015) performed to measure CKF knowledge levels amongst the patient population did not measure how many of these patients had previously participated in an educational intervention. Therefore, it is unclear if education improved knowledge levels in this population. Machowska et al. (2015) compared the demographic data of the 270 participants in their study with the historic demographic data of patient records in the European Renal Association—European Dialysis and Transplant Association (ERA-EDTA) Registry in 2012. It is unclear how many patient records this registry encompassed at the time. Two studies (Cankaya et al., 2013; Yu et al., 2014) focused specifically on how the intervention had affected patients that eventually started with a specific treatment, whilst it would have been interesting to study the effects for patients that choose other treatment options, as well. The studies that compared an intervention with standard care commonly compared socio-demographic characteristics of the patients in both groups. None of the studies reported significant differences between characteristics of the groups. However, only two studies indicated that the characteristics of the participants did not differ significantly from the general CKF patient population (De Maar et al., 2016; Machowska et al., 2015). Reporting this is relevant, as discrepancies may occur due to participant selection. For example, Chiou and Chung (2012) excluded people with visual, hearing or cognitive disabilities. However, patients with advanced CKF may suffer from such disabilities (Berger et al., 2016). Other examples are the studies by Enworom and Tabi (2015) and Massey et al. (2016), in which people who did not speak the official national language were excluded. Consequently, minority groups might be underrepresented in these studies. In the study by Cankaya et al. (2013), a gender difference was present between the non-intervention and intervention group. The cause of this difference is not further discussed, although it may have indicated that the intervention had a stronger positive effect on male participants. Another concern for many of the studies is that they applied measures that had not been previously validated. Exceptions are the studies by Chiang et al. (2016) and (Massey et al., 2016), which made use of an established index. The authors of the three systematic reviews all critique the studies that report on patient education for CKF. They found the studies to be of poor quality: few randomized controlled trials were conducted and many studies were observational, lacked case comparisons and had a low number of participants. Van den Bosch et al. (2015) and Lopez-Vargas et al. (2016) further articulated a need for more homogeneity in the descriptions of studies and the standardisation of outcome measures to support case comparisons.

Many studies compared the intervention to standard care. However, descriptions of what standard care entailed were often lacking. This made it difficult to understand which services the patients in the intervention groups received in addition to standard care. Information is given about the intervention's effect, but little information is provided about the additional effort that was invested to deliver the intervention. Furthermore, interventions varied greatly in structure and content. They were delivered by professionals in different roles and made use of various types of materials. Each clinic seemed to have developed its own program. Often there was little explanation of the reasoning for why the program was set up as such. Only in two studies did the authors refer to learning theory. Massey et al. (2016) referred to the Theory of Planned Behaviour, and Watson (2013) referred to nosogogy, which combines principles from pedagogy (child teaching) and andragogy (adult teaching). Van den Bosch et al. (2015) and Lopez-Vargas et al. (2016) also found programs that were based on a theoretical framework. Similarly to the two studies that were found in this review, it was unclear if these theories contributed to the programs' effectiveness. The frameworks included the adult learning theory (Van den Bosch et al., 2015), trans-theoretical model, health belief model and self-regulation theory (Lopez-Vargas et al., 2016).

The main research question for this study was: How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organized? The analysis of the literature shows that education programs vary significantly in structure and content.

An analysis of the design of the programs that are described in the twelve additional articles showed that these programs have rather diverse designs. Ten of the twelve programs were taught at the hospital during office hours, though there were a few exceptions. The program that is described by Massey et al. (2016) took place at the patient's home during the evening or weekends, whilst the program that is described by De Maar et al. (2016) started with a home visit by a social worker, followed by an individual consult at the hospital. As shown in Table 5, seven programs focused solely on the individual patient and consisted of consults to which the patient and relatives were invited. The program that is described by Davis and Zuber (2013) was an exception. This program only consisted of group sessions with other patients and their relatives. Four other programs consisted of both individual consults and group sessions. For each of the three systematic reviews, the researchers came to the same conclusion that there is a large variety in patient education practices. Yet they also identified aspects that were common for many of the education programs. Many of the programs were found to be multifaceted; they included different education formats, consisted of multiple sessions and involved a team of educators. The duration and frequency of the sessions was found to be diverse (Devoe et al., 2016; Lopez-Vargas et al., 2016; Van den Bosch et al., 2015). The programs were taught by different medical professionals. In six programs, the renal nurse was the main educator. A multidisciplinary care team consisting of specialised renal nurses, nephrologists, dieticians and social workers were the educators in three programs. For one program, the main educator was a social worker (Massey et al., 2016). Experienced patients were additionally involved in five of the programs. For two programs, it is unclear who the educator was (Cankaya et al., 2013; Enworom & Tabi, 2015). Two of the systematic reviews presented similar findings. They found that nurses and nephrologists played an important role in the programs, often supported by nutritionists and social workers and, sometimes, patients who have started treatment (Lopez & Willis, 2004; Van den Bosch et al., 2015).

	Format			Educator				Topics						Materials		
	Individual	Group	Combined	Renal nurse	Multidisciplinary team	Social worker	Experienced patient	Kidney function	Causes of CKF	Lifestyle	Treatment options	Treatment preparations	Long-term survival	Printed information	Visit dialysis unit	Video
For non-acute patients																
Cankaya et al. (2013)	x							x	x	x	x			x		
Chiang et al. (2016)			x		x		x		x	x	x	x		x	x	
Chiou and Chung (2012)	x			x							x					x
Davis and Zuber (2013)		x		x			x							x		
Enworom and Tabi (2015)								x	x	x	x	x	x			
De Maar et al. (2016)	x			x			x				x			x		x
Maaroufi et al. (2013)	x			x							x			x	x	
Massey et al. (2016)	x					x		x	x	x	x		x	x		
Mollicone et al. (2013)			x		x			x	x		x	x		x		x
Yu et al. (2014)	x				x		x	x	x	x	x	x				
For acute patients																
Machowska et al. (2015)	x			x							x	x		x		x
Watson (2013)			x	x			x	x	x		x			x		x

Table 5- Characteristics of education programs

Some of the programs had a narrow scope, focusing on treatment options (Chiou & Chung, 2012; De Maar et al., 2016; Maaroufi et al., 2013; Machowska et al., 2015), whilst the focus of other programs included a much broader range of topics. Machowska et al. (2015) explained that they deliberately decided to focus specifically on renal replacement therapy, as their main goal is to start as quickly as possible with the patient's preferred treatment after the patient has experienced an acute onset of CKF. However, the other four programs with a narrow scope were aimed at patients who have been diagnosed in time. These patients do not need to start treatment quickly, but usually have a few months' time to prepare themselves. Nevertheless, why their programs also had a narrow scope is unclear. Clinical guideline documents advise including a broader scope of topics (see section 3.2). Cankaya et al. (2013) indicated that their program consisted of a broader range of topics, but that they had divided the program into two sections, and that those who are diagnosed in time receive the first three sessions to support coping. Patients receive detailed information about treatment options in three follow-up sessions when their kidney function has further declined.

In contrast to the other eleven programs, the program that is described by De Maar et al. (2016) is the only program that does not promote SDM. Not each program presents all the treatment options, as some focus specifically on the choice between dialysis types. All programs, except one, indicated to be careful that information concerning renal replacement therapy options is presented without bias. De Maar et al. (2016) described how their program specifically aims to promote home treatment, with patients only being presented with the option of in-centre treatment when all other options are deemed irrelevant.

The program that is described by Enworom and Tabi (2015) specifically addressed measures to slow down the progression of CKF. Including this topic appears relevant, both from an economic as a psychological perspective. The costs of care for patients who do not yet require renal replacement therapy are lower than the costs of renal replacement therapy, and undergoing renal replacement therapy requires significant lifestyle changes, affecting patients' quality of life (L. Braun, Sood, Hogue, Lieberman, & Copley-Merriman, 2012). The literature review on patients' considerations regarding treatment options (section 5.1.1) showed that patients pursue a life that is as close to normal as possible. This indicates that slowing the progression of CKF is a relevant topic to discuss with patients, as treatment might be postponed. Two programs addressed the psychological effects that the diagnosis and becoming dependent on renal replacement therapy may have on patients (Enworom & Tabi, 2015; Massey et al., 2016). Watson (2013) pointed to the importance of assessing a patient's readiness to learn prior to starting with education, arguing that a patient's state of mind can be a barrier for learning. They further explained how their education program focuses on an individual's needs, values and beliefs, and which options for support can be offered. The program described by De Maar et al. (2016) had a similar focus. They started with a questionnaire to acquire insight into the patient's lifestyle and values, which allowed the rest of the program to be adapted to the individual's information needs. The article by Yu et al. (2014) comprised a very detailed description of the topics that the program addressed. The authors used medical terminology to describe the program. This raises the concern of whether they use similar terminology when educating patients.

During most of the programs, patients were presented with printed information. This information commonly consisted of a combination of visual and written information. Chiang et al. (2016) and Watson (2013) specifically indicated that the printed information they offered is available in several languages. In one program, decision aids are used to support patients in making a treatment choice (Machowska et al., 2015). The program described by Davis and Zuber (2013) is unique in that patients were provided with a newsletter four times a year, and props such as dialysis materials were brought to the group sessions. The article by Enworom and Tabi (2015) lacks information about the materials they used.

The second research questions for this study was: Which aspects of face-to-face education programs may support or constrain shared decision making? As the education programs differed significantly and were commonly analysed with various measures that had not been validated previously, it is difficult to answer this question based on the findings from this study. However, the analysis of the twelve articles that described original studies did commonly find positive effects of education. This indicates that education programs can support SDM.

Six studies reported that their education program resulted in significant changes regarding treatment choice (Cankaya et al., 2013; Chiou & Chung, 2012; De Maar et al., 2016; Massey et al., 2016; Mollicone et al., 2013; Watson, 2013). Furthermore, four studies reported significant health benefits (Cankaya et al., 2013; Enworom & Tabi, 2015; Mollicone et al., 2013; Yu et al., 2014). Additionally, two studies reported significant positive changes related to knowledge gain (Chiou & Chung, 2012; Massey et al., 2016) . Table 6 lists the significant benefits of educational interventions that were found in the studies that compared standard care to an intervention. The systematic reviews found similar benefits. Two reviews found that patient education supports a choice for home treatment (Devoe et al., 2016; Van den Bosch et al., 2015). Furthermore, two reviews found that patient education improves knowledge and lowers mortality and morbidity risks (Lopez-Vargas et al., 2016; Van den Bosch et al., 2015). Lopez-Vargas et al. (2016) also found that patient education improved quality of life, supported self-management and led to better clinical outcomes.

Theme	Reported significant benefits of education intervention	Study
Treatment choice	More patients chose a kidney transplantation from a living donor. Donors were recruited from a broader network and donors were younger.	(Cankaya et al., 2013)
	Educated patients more often chose a form of home care therapy.	(De Maar et al., 2016; Mollicone et al., 2013; Watson, 2013)
	Educated patients more often choice a form of self-care therapy.	(De Maar et al., 2016)
	Participants became more positive towards living with a kidney transplant or HD treatment.	(Massey et al., 2016)
	Patients were less uncertain prior to treatment start and had less decision regret after treatment start.	(Chiou & Chung, 2012)
	Patients and people in their social network talked more about the disease and treatment options.	(Massey et al., 2016)
Health	Patients had a higher remaining kidney function at treatment start.	(Cankaya et al., 2013)
	Kidney function declined at a slower rate in educated patients, leading to improved clinic outcomes.	(Enworom & Tabi, 2015)
	Patients had a higher rate of prepared vascular access for dialysis.	(Mollicone et al., 2013; Yu et al., 2014)
	Fewer and shorter hospitalisations. Patients suffering from less severe conditions reduced the total medical costs in the first 6 months on HD.	(Yu et al., 2014)
Knowledge	Patients had higher knowledge levels after education.	Chiou and Chung (2012); (Massey et al., 2016)

Table 6 – Identified significant benefits of educational interventions

Despite these positive reports, there are some concerns regarding the studies. The evaluative studies generally compared the non-intervention groups with intervention groups. By doing so, it is little surprising that the intervention groups showed more benefits, as considerably more time and effort have been invested, in general, in educating them. Additionally, publication bias may play a role, as it is possible that only the studies that showed a positive effect of an intervention have been reported and published. In only two cases did the standard care program seem to already include an education program (Chiang et al., 2016; Massey et al., 2016). Chiang et al. (2016) found that patients who received additional group sessions more often chose home treatment and were better prepared for dialysis. However, they reported that these differences were not significant. As the number of patients in the intervention group is relatively small, a more extensive study is needed to evaluate if these indications for positive effects indeed are significant for the patient population at large. However, Massey et al. (2016) found that their intervention significantly increased knowledge levels and led to significantly more communication between patients and other attendees of the program (members from the patient's social network). The nine evaluation studies had different aims and, therefore, used different evaluation methods. Consequently, their results are difficult to accumulate. However, they all reported positive effects of the education interventions compared to standard care programs. Unfortunately, the studies provided little insight into which education methods were most efficient, as it was not possible to make cross-case comparisons due to the diversity of set-up and evaluation measures.

Discussion

As the design of the educational interventions, the design of the standard care programs and the primary outcome measures evaluated varied, comparison between the studies is difficult. Lack of comparability across the studies precluded the accumulation of findings. Consequently, it is difficult to say which specific aspects of the education programs are the most effective. Campbell and Witten (2011) suggested measuring knowledge before and after the course, as well as patients' satisfaction with the program, and measuring treatment regret after a patient has started treatment. Furthermore, important subgroups appear to be underrepresented in the participant sample. People with cognitive disabilities, low (health) literacy and immigrants who do not master the main language well might not benefit as much from the programs as relatively healthy, higher educated, native people.

For SDM to take place, patients should not only possess relevant knowledge of treatment options, but they should also possess the skills to evaluate this knowledge in relation to their personal concerns and the skills to communicate their preferences to their physician. Traditionally, medical specialists have made decisions without the direct involvement of the patient. To become active participants in medical discussions concerning their health, patients will need to change their behaviour and should be helped to obtain the appropriate skills (section 2.2). Many of the described interventions appear to focus on mediation of medically relevant information, but seem to pay little attention to how this connects with people's lifestyles, values and beliefs. The programs described by Watson (2013) and De Maar et al. (2016) appear to be an exception.

Although more research is needed on the effectivity of various designs of education programs, education seems worth the effort. Education interventions were found to result in various health benefits. Although the causality between the various health benefits cannot be determined on the basis of these findings, one could speculate that the benefits may be related. When the kidney function reduces at a slower rate (Enworom & Tabi, 2015), treatment start may be postponed. This enables the planning of and preparation for treatment start. Consequently, patients are healthier at treatment start (Cankaya et al., 2013) and might experience fewer complications (Yu et al., 2014).

Chiou and Chung (2012) found that patients in the intervention group had less decision regret after treatment start and had higher knowledge levels. Reducing decision regret is important, as patients who agree with their treatment choice and are aware of its importance might be better compliant with their treatment regimes.

The studies additionally showed that patients in intervention groups more often choose a form of home treatment or self-care. This is important, as the number of people in need for care is growing. Non-critical care needs to be moved out of the hospital to keep the healthcare system sustainable (De Maar et al., 2016; Mollicone et al., 2013; Watson, 2013). Furthermore, patients who received an intervention more often considered living kidney donation and talked more about this with others (Cankaya et al., 2013; Massey et al., 2016). Compared to being waitlisted for a kidney from a deceased donor, living kidney donation provides additional health benefits for the patient, as treatment can be planned and may be started earlier (Warwick et al., 2014).

The program that is described by Massey et al. (2016) is unique in that it takes place at the home of the patient, outside of typical working hours. Although the authors speculated that this is key to its success, delivering such a service requires additional effort form the medical team. To determine whether it is worth the extra effort from healthcare providers, it would be interesting to investigate if these factors indeed support the success of the program, and how much these factors contribute to the program's success. This study shows that further research into the design of education programs is needed, as questions remain on the effectiveness of the diverse components that are applied in patient education programs (Devoe et al., 2016; Lopez-Vargas et al., 2016; Van den Bosch et al., 2015).

Relevance for medical practitioners

Medical practitioners who want to develop an education program for adults with CKF in order to promote involvement in treatment choice, may refer to clinical guideline documentation. Pre-treatment education and topics that need to be covered are discussed in various clinical guideline documents. However, these documents include little practical information on how medical practitioners can organise such an education program (section 3.2 and (Gordon & Lash, 2011).

The literature review in this section contributes with knowledge on how various programs are structured and which information mediation strategies they apply, presenting an overview of education programs that have been introduced in various medical clinics around the world. The overview provides aspects that developers of programs may consider when developing a program. Examples of formats, educators, topics and materials used by other programs are presented. Moreover, a distinction has been made between programs for acute patients and non-acute patients.

Some of the clinical guidelines recommend presenting conservative care as a treatment option, while others only recommend discussing it when the medical practitioner deems it relevant. This literature review of education programs showed that this reflects in medical practice: Differences exist between clinics regarding whether or not conservative care is presented to patients as a treatment option. The scoping review on patients' information needs provides indications that some patients, most of whom are elderly, feel that starting treatment is not worth the effort. The number of elderly patients with CKF will continue to grow due to higher life expectancy, and a growing number of patients will suffer from comorbid conditions. Therefore, including conservative care as a treatment option or not is a specific subject medical practitioners are recommended to consider.

The findings additionally show that investing time to educate patients can have significant benefits, such as patients more often choosing a form of home-care, patients more often discussing their options with their next-of-kin and education programs reducing uncertainty. This indicates that educated patients make better informed choices. However, due to the lack of cross-case comparisons, the large diversity in structures of programs and variety in measures of the effects of programs, it is impossible to draw any conclusions on which aspects of these programs contribute to these positive effects. The overview presented here therefore merely presents alternatives for the setup of such programs.

Relevance for designers

The overview of education programs in this study gives designers insight into how other medical practices have structured their programs. This may form the basis for a new program. Unfortunately this study turned out the be of little further relevance for designers, due to various reasons: 1) The quality if the individual studies is debatable, 2) cross-case comparison was not possible due to the diversity in measures that have been applied, and 3) the programs vary significantly in structure and content.

Despite the shared critique on the quality of studies, the three systematic reviews were found to include suggestions for potentially effective components of education programs. Suggested components are: 1) education being given by a multidisciplinary team (Lopez-Vargas et al., 2016; Van den Bosch et al., 2015), 2) involving both patients and their families, 3) dividing the program over multiple days (Devoe et al., 2016; Lopez-Vargas et al., 2016), 4) including problem-solving group sessions (Van den Bosch et al., 2015), 5) small group size (Devoe et al., 2016), 6) stimulating interactivity and 7) including telephone follow-up (Lopez-Vargas et al., 2016). Evidence that these components really are effective is however lacking, so designers should critically reflect upon them.

Next steps The first literature review, presented in section 5.1, provided insights in the information needs of patients with CKF and their next-of-kin when facing a treatment choice. The second literature review, presented in section 5.2, contributed with insights on how contemporary education programs are structured, but provided little evidence on which aspects of these programs contribute to their effect.

Insights from both literature studies formed the basis for further research. From this point the research is divided into two tracks that were developed in parallel; In one track, described in chapter 6, technology-mediated education and decision support programs were analysed. Findings from the second literature review (section 5.2) showed that many education programs apply mainly face-to-face education formats. Nowadays patients can also find much information on the Internet. It seemed therefore relevant to investigate how the Internet and other interactive media are used to educate patients on treatment options.

In the other track, described in chapter 7, face-to-face education programs were further investigated. The studies that were analysed for the second literature review (section 5.2), mainly made use of quantitative assessment measures to evaluate the effect of a program. However, qualitative studies may provide another kind of relevant data, which can help in answering why and how questions concerning a program's effect. The studies in chapter 7 investigated specifically how participants and healthcare practitioners experience such programs. Such insights can provide indications for which aspects of education programs are effective and appreciated, and which components might be improved.

6. Technology-mediated pre-treatment patient education and decision support programs

This chapter focuses on technology-mediated pre-treatment patient education and decision support programs. Section 6.1 presents a study in which I examined the current offer of online, publicly available programs for people with CKF and their next-of-kin and studied a program that is under development to describe their approach and experiences. Section 6.2 presents a theoretic discussion and an explorative study in which I investigated the potential of introducing a serious game as an additional, alternative learning activity to extend the current service offerings.

6.1 Analysing current practice – Review of online, publicly available information websites and decision aids for people with chronic kidney failure and their next-of-kin[10]

Abstract

Patients can nowadays find much information on the Internet. In addition to offers for participation in face-to-face education programs at individual clinics, which were investigated in section 5.2 and chapter 7, the Internet has become another resource that may be used to educate patients about treatment options. The following chapter presents two desk research studies that were conducted to investigate how the Internet is used to inform and educate patients on treatment options, and how contemporary online solutions support or constrain SDM. The studies had an international scope and focused on the content of the platforms and information mediation strategies that are used. Additionally, websites were reviewed regarding which mediation strategies they apply, to analyse if the content of the websites is in alignment with clinical guidelines on patient education. This was also done to evaluate if the websites make use of the additional mediation strategies that the Internet offers compared to traditional printed brochures. Three information websites and four online decision aids were analysed with help of conventional content analysis.

The review showed that information on the Internet generally is quite general, indicating that these websites should function as a part of a more extensive service offer. Differences exist between websites regarding which topics they present in addition to information about treatment options. The websites mainly use text to mediate information. Some include videos, links to further reading, or the option to write in personal remarks. The graphic styles of websites differ considerably, with websites using various colour schemes.

The insights from both desk review studies provide medical practitioners with an overview of aspects that they should reflect over, prior to developing a website. Designers may use the

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[10] The text in this section is partly based on the article 'Home Haemodialysis and Gamification – A new approach to information mediation' that was published in the Proceedings of the Third European Conference on Design4Health 2015 (Vis & Keitsch, 2015). The original article can be found in Appendix A.

insights from this study as the starting point for a new project. Insights into the constrains and support for SDM of current solutions aids designers in developing better solutions.

Aim of the study

This study had as an overall goal to investigate which aspects of the current offer of online, publicly available information websites and decision aids for adults with CKF and their next-of-kin support or constrain the realisation of SDM in practice.

This study aimed to contribute to this goal by mapping the current offer of online, publicly available information websites and decision aids for adults with CKF and their next-of-kin. The objective of this study was to gain an understanding of how contemporary information websites and decision aids present information concerning CKF, what information they present and how this information is presented. The research question that this study aims to answer were: 1) How are current information websites and decision aids on renal replacement therapy structured? And 2) Which of their aspects support or constrain SDM?

The interactivity of websites was reviewed, in addition to evaluating if the websites and online decision aids meet the requirements that clinical guidelines provide on patient education. This was included in the analysis, to evaluate if websites make use of the additional mediation strategies that the Internet offers compared to traditional printed brochures. The literature review on patients' information needs (section 5.1), found that patients have reported that it was problematic for them that information was mostly mediated through text and conversations. Some patients indicated to prefer more visual ways of learning (Van Rooijen et al., 2013; Walker et al., 2016). As people have different learning styles, text-based materials are not effective for everyone. Some people learn better through more visual or interactive ways of presenting information (Kolb, 1981).

Method

Two desk research studies were conducted (Hanington & Martin, 2012) in spring 2015. In the first desk research study, the status quo of information websites for people with CKF and their relatives was explored, while the second desk research study investigated the status quo of web-based treatment decision aids for people in the same patient group. Conventional content analysis (Hsieh & Shannon, 2005) was applied to analyse the websites. Section 4.2.2. provides more insight into the rationale behind conducting desk research and applying conventional content analysis for the specific purpose of this study.

Data collection

For both desk studies, Google was used to search for websites. Search terms were the various English names for CKF, as well as their Dutch and Scandinavian counterparts (Danish, Swedish and Norwegian). For the second desk research study, the online search via Google was extended with the search terms 'decision aid' and 'decision support'. Furthermore, decision aids that were described in articles that the PhD candidate had come across during preceding literature reviews were retrieved.

Both desk searches had an international scope, including websites from various geographic areas and in various languages. The selection of platforms to include in the study was chosen on the basis of the pre-defined selection criteria. Inclusion criteria for both studies were: 1) accessible online, 2) open to use by everyone, 3) offered by a trustworthy source (an official healthcare or patient organisation), 4) directed to people with CKF and their relatives and 5) available in a language that is mastered by the researcher (English, Dutch, Scandinavian). The third criterion, credibility of the source, was included to ensure that the selected platforms would be of sufficient quality. For the second desk research study, two additional inclusion criteria were used: 6) focus on treatment choice for renal replacement therapy and 7) having interactive aspects.

For the second desk research study, some decision aids were excluded, even though they matched the inclusion criteria. The first exclusion criterion was the focus of the decision aid. Decision aids that focused on end-of-life care or when to start dialysis were excluded, as they did not include a choice between renal replacement therapy options. An example of such a decision aid is 'Kidney Failure: Should I Start Dialysis?' (Healthwise, 2014). This decision aid intends to support patients in deciding whether to start with a life-sustaining therapy. To patients who have decided that they want to start treatment, Healthwise offers a second decision aid to support them in deciding which type of dialysis treatment they prefer. This second decision aid is called 'Kidney Failure: What Type of Dialysis Should I Have?' (Healthwise, 2015). The second decision aid was the format of the decision aids. Only interactive websites were included. Books, videos and information leaflets such as 'You have a choice' (Ameling et al., 2012) were excluded, as these are not directly available to any patient at any time, but need to be ordered. Downloadable PDFs were excluded as well, as their content is static, whilst the intention was to explore how interactivity is used and if game elements are applied. An example of such a downloadable booklet is the 'Yorkshire Dialysis Decision Aid' (Bekker HL et al., 2015). This booklet contains information as well as assignments to be filled out by the patient.

Data analysis

The platforms that met the inclusion criteria were evaluated with help of conventional content analysis (Hsieh & Shannon, 2005). The PhD candidate prepared a list of key topics to look for during the analyses of the platforms that were included in both studies. This list was based on the analysis from clinical guidelines documents, as presented in section 3.2. Subjects included on the list were: a) Explanation of the disease, b) Discussion of all renal replacement therapy options, and associated risks and benefits, c) Implications for lifestyle (including medication and dietary advice) and d) Preparations for treatment start. One additional element was added to the list of analysis topics; e) information mediation strategies. This was done to evaluate which different media websites apply, to evaluate if the websites meet the needs of patients who prefer more visual ways of learning (section 5.1).

Some websites were excluded from the first desk research study, as none of the pre-defined topics for data analysis were addressed on the website. These websites had a different objective than educating patients on their disease and possible treatment options. Three information websites and four decision aids matched the selection criteria.

Findings

The objective of this study was to gain an understanding of how contemporary information websites and decision aids present information concerning CKF, what information they present and how this information is presented. The findings are presented per sub-study.

Findings on Information websites

This part of the study aimed at mapping the current offer of online, publicly available information websites for adults with CKF and their next-of-kin. The following three information websites met the inclusion criteria:

1. **Dianet** is a non-profit expertise centre for renal replacement therapies in the Netherlands. The organisation strives to deliver optimal care that matches the lifestyle of the patient by taking a personal approach in promoting health and quality of life for kidney patients. Via their website, Dianet intends to provide freedom of choice on treatment method by communicating 'medical, social and technical possibilities' (Dianet, 2014a).

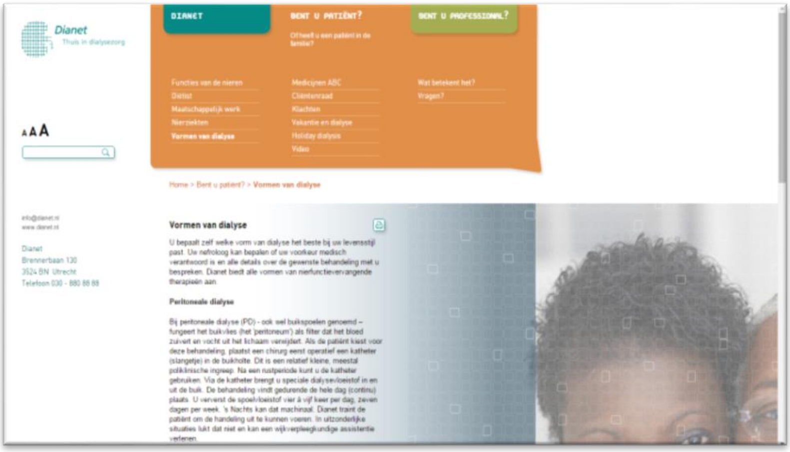
2. **Mine Behandlingsvalg** "My Treatment Choice" is a website that focuses on enabling patient participation in treatment choice. The website is developed by the University Hospital of North Norway and Takepart Media & Science. The website is intended to build an understanding of treatment options and support assessment in relation to the patient's lifestyle (University hospital of North Norway, 2014).

3. **Njurdagboken**, "The Kidney Diary" is a website facilitated by the Swedish Kidney Association and produced in collaboration with the Karolinska University Hospital and the University Hospital in Linköping. The website is intended for kidney patients and their relatives. The goal of the website is to make people feel more informed, capable, confident and motivated, and to encourage people to be involved in their care (Pagels, Wång, Eriksson, Magnusson, & Melander, 2014).

The objective of this study was to gain an understanding of how contemporary information websites present information concerning CKF, what information they present and how this information is presented. Below, the findings related to the first research question 'How are current information websites on renal replacement therapy structured?' are presented.

The most notable differences between the websites relate to diversity in how information is presented on each website, both graphically and content-wise. To exemplify this, Figure 8 shows the page with information about home HD on each of the three platforms. The screenshots show that the sites vary considerable in graphic appearance, using different colour pallets, fonts and dissimilar types of illustrative images.

On Dianet, the treatment methods are explained in text and the language is directed towards the patient, addressing the patient with 'you'. For example: "You can choose if you want to



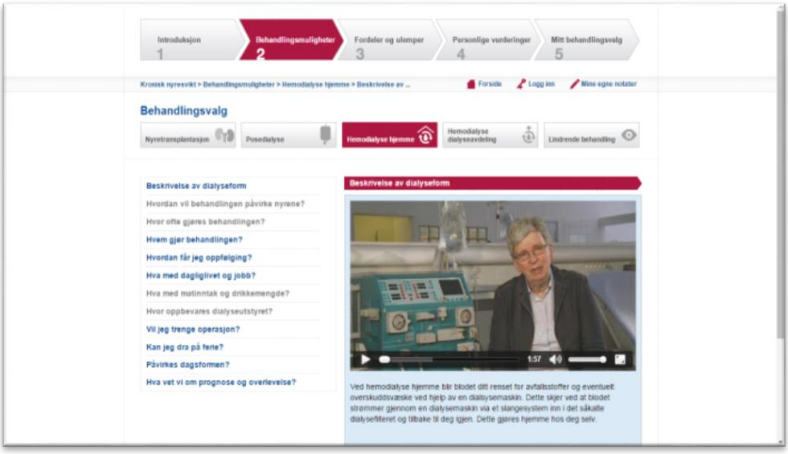
Vormen van dialyse

U bepaalt zelf welke vorm van dialyse het beste bij uw levensstijl past. Uw nefroloog kan bepalen of uw voorkeur medisch verantwoord is en alle details over de gewenste behandeling met u bespreken. Dianet biedt alle vormen van nierfunctievervangende therapieën aan.

Peritoneale dialyse

Bij peritoneale dialyse (PD) - ook wel buikspoelen genoemd – fungeert het buikvlies (het 'peritoneum') als filter dat het bloed zuivert en vocht uit het lichaam verwijdert. Als de patiënt kiest voor deze behandeling, plaatst een chirurg eerst operatief een katheter (slangetje) in de buikholte. Dit is een relatief kleine, meestal poliklinische ingreep. Na een rustperiode kunt u de katheter gebruiken. Via de katheter brengt u speciale dialysevloeistof in en uit de buik. De behandeling vindt gedurende de hele dag (continu) plaats. U ververst de spoelvloeistof vier à vijf keer per dag, zeven dagen per week. 's Nachts kan dat machinaal. Dianet traint de patiënt om de handeling uit te kunnen voeren. In uitzonderlijke situaties lukt dat niet en kan een wijkverpleegkundige assistentie verlenen.

A. Dianet - Screenshot of page on home HD



Ved hemodialyse hjemme blir blodet ditt renset for avfallsstoffer og eventuelt overskuddsvæske ved hjelp av en dialysemaskin. Dette skjer ved at blodet strømmer gjennom en dialysemaskin via et slangesystem inn i det såkalte dialysefilteret og tilbake til deg igjen. Dette gjøres hjemme hos deg selv.

B. Mine Behandlingsvalg - Screenshot of page on home HD

Mats har hemhemodialys

Mats är 56 år gammal. Han bor tillsammans med hustrun Marianne och hunden Bella. Mats grundsjukdom är polycystisk njursjukdom, en ärftlig njursjukdom där njurvävnaden successivt omvandlas till blåsor (cystor).

Mats var tidigt medveten om sin njursjukdom, men han klarade sig länge utan dialys. När Mats var 40 år hade dock hans njurfunktion sjunkit så pass mycket att han började känna sig trött och hade visst illamående. Vid denna tid arbetade han som personalchef på ett stort svenskt företag.

Eftersom det inte fanns någon nära anhörig som kunde donera en njure, sattes Mats upp på väntelistan för att få en avliden persons njure, s.k. nekronjure. Mats hade symtom på njursvikt men symtomen kunde hållas på en acceptabel nivå genom att han i väntan på transplantation fick äta specialkost med mindre äggviteinnehåll. Mats hade tur och behövde inte vänta särskilt länge innan han blev transplanterad. Tiden som transplanterad var bra och mestadels bekymmersfri. Efter ca 12 år visade en röntgenundersökning av den transplanterade njuren att det tyvärr fanns en tumörförändring i transplantatet. Man var tvungen att operera bort njuren och Mats blev därefter dialyspatient.

Eftersom funktionen hos de egna njurarna var mycket låg och Mats är lång med stor kroppsvolym, var peritonealdialys inte en gångbar behandlingsform. Redan i samband med att transplantatet opererades bort påbörjades bloddialys via en tillfällig dialyskateter. En kort tid härefter fick han en AV-fistel på vänster underarm.

Siktet var tidigt inställt på att kunna börja med bloddialys hemma (hem-hemodialys). Mats fick träna på hemdialysenheten på sjukhuset i ca åtta veckor och under träningen fick han lära sig hur man klär dialysmaskinen, sticker sig själv och hur man tar hand om eventuella komplikationer.

Tiden har gått fort och Mats har nu sedan ett par år tillbaka sin behandling hemma. Han sköter det mesta själv men hustrun Marianne ger honom handräckning när så behövs. Ungefär var åttonde vecka träffar han sin doktor på sjukhuset. De går då igenom provsvar och medicinering. Mats

Foto : Stefan Melander

C. Njurdagboken - Screenshot of page on home HD

Figure 8 - Screenshots of pages about home HD from the three websites

dialyse during day or night time". The medical condition itself, CKF, is not further explained. The various dialysis options are presented, but transplantation and conservative care are not mentioned as treatment options. The texts about the treatment options are relatively short, but concise. The website has a separate section with videos in which patients talk about their motivation to choose a specific treatment method or about their experiences with the treatment. Furthermore, the website contains links to brochures that can be ordered. Dianet is the only platform that provides information about dialysis for children. The videos on this topic are directed towards the parents, not the child patients.

The first section of Njurdagboken consists of links to downloadable PDF files that patients can use to keep track of their personal health, covering aspects such as weight, blood pressure, medicine intake, personal goals and exercise. The site additionally covers symptoms that can occur, CKF as a medical condition and treatment alternatives. These sections are rather detailed and have a formal, distanced writing style. For example: "Usually one manages his treatment himself". The section on treatment alternatives is an exception. This section includes patient personas[11] and is written as a narrative in the third person. For example: "At this time, Mats was working as an HR manager at a large Swedish company". In these personas, the personal motivation for selecting a specific treatment is mentioned. This personal story is followed by a brief, formally written explanation of the treatment itself. All renal replacement therapy options are presented, including conservative care. Links to external webpages for further reading are included in some sections of the webpage.

The first section of Mine Behandlingsvalg forms the introduction to the second part on treatment options. The introduction explains CKF as a medical condition and briefly introduces the three main treatment options (dialysis, transplantation and conservative care). The next section goes deeper into the treatment options, followed by a section on pros and cons for each treatment option. Information is presented with a combination of videos issuing medical professionals and patients and short texts with a personal style of writing. For example: "Here you get help to understand what form of treatment suits you best". In the videos, the patients speak about their experiences with the treatment. Mine Behandlingsvalg is the only platform of the three that has an interactive part with gamified elements.

Comparing the amount of information and the level of detail of the information, Mine Behandlingsvalg is in-between. Dianet is more general and brief. Njurdagboken is very detailed when it comes to explaining the medical condition and related effects, whilst the information on treatment options is relatively brief and informal.

The second research question for this desk review study asked 'Which aspects of Internet-based information and education platforms for patients support or constrain SDM?'. The following findings of the analysis of information websites relate to this question.

Two of the three websites mainly make use of text to mediate information. This can be a barrier for certain people who learn better through more visual or interactive media. On

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[11] Written personal stories of patients (Hanington & Martin, 2012).

Dianet and Njurdagboken, text forms the main information source. The text is only occasionally supported by an illustrative image. On Mine Behandlingsvalg, video and text are used in combination. Concerning the information on treatment options specifically, the analysis shows that the texts on Dianet and Njurdagboken are short and relatively general, although both sites include references for further reading.
Two websites include a section that aims to support patients in making a treatment decision. Njurdagboken includes a page that covers topics that patients may consider when making a treatment choice. Mine Behandlingsvalg has a section where one can evaluate the information about the treatment methods in relation to one's personal values and lifestyle. This section includes the possibility to take notes. It can, however, only be accessed by users that are logged into the website.

Findings on Online decision aids

This part of the study aimed at mapping the current offer of online, publicly available decision aids for adults with CKF and their next-of-kin regarding renal replacement therapy options. The following four decision aids met the inclusion criteria:

1. **My Kidneys, My Choice** (Kidney Health Australia, 2012) was developed by a multidisciplinary team of healthcare professionals. Baxter Healthcare Australia and New Zealand funded the project. The project is endorsed by Home Dialysis, Kidney Health New Zealand and Kidney Health Australia. This decision aid is available in clinics in printed format, as a downloadable PDF and as an interactive version on the websites of the three organisations that endorse the project.

2. **My Life, My Dialysis Choice** (Medical Education Institute, 2016) was developed by the Medical Education Institute (MEI), an American non-profit organisation. The decision aid is endorsed by the American Association of Kidney Patients (AAKP) and Home Dialyzors United (HDU). It is the only platform that is available in more than one language (English and Spanish).

3. **Option Grid, Chronic Kidney Disease: Treatment options** (Elwyn G et al., 2015) was developed by the Option Grid Collaborative, an independent association of individuals supported by the Dartmouth Institute for Health Policy and Clinical Practice in Hanover, New Hampshire, US. This decision aid is available as an interactive tool and as a downloadable PDF.

4. **Kidney Failure: What Type of Dialysis Should I Have?** (Healthwise, 2015) was developed by Healthwise, an American non-profit association with a mission to help people make better health decisions in order to receive the best care for themselves individually. This decision aid is an interactive website, but the home page includes a link to a non-interactive version of the information.

The objective of the second desk review study was to gain an understanding of how contemporary online decision aids present information concerning CKF, what information

MY CHOICE

Use the section below to write down your thoughts on the different treatment options available for kidney failure. Remember, your feelings and preferences may change over time.

MY THOUGHTS

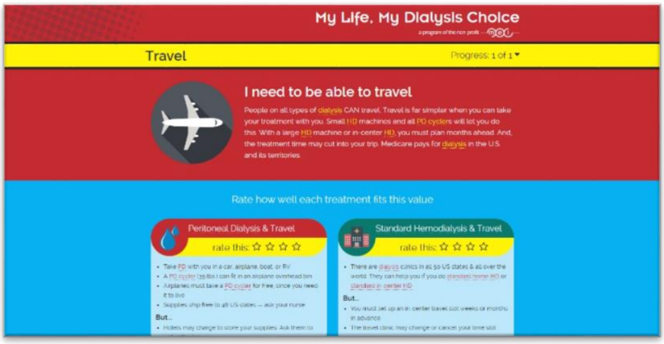
Am I considering a transplant? [✓ YES] NO

Am I considering dialysis? [✓ YES] NO

Am I considering conservative care? YES [✓ NO]

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

A. My Life, My Choice



I need to be able to travel

People on all types of dialysis CAN travel. Travel is far simpler when you can take your treatment with you. Small HD machines and all PD cyclers will let you do this. With a large HD machine or in-center HD, you must plan months ahead. And, the treatment time may cut into your trip. Medicare pays for dialysis in the U.S and its territories.

Rate how well each treatment fits this value

Peritoneal Dialysis & Travel

- Take PD with you in a car, airplane, boat, or RV
- A PD cycler (35 lbs) can fit in an airplane overhead bin
- Airplanes must take a PD cycler for free, since you need it to live
- Supplies ship free to 48 US states — ask your nurse

But...

- Hotels may charge to store your supplies. Ask them to

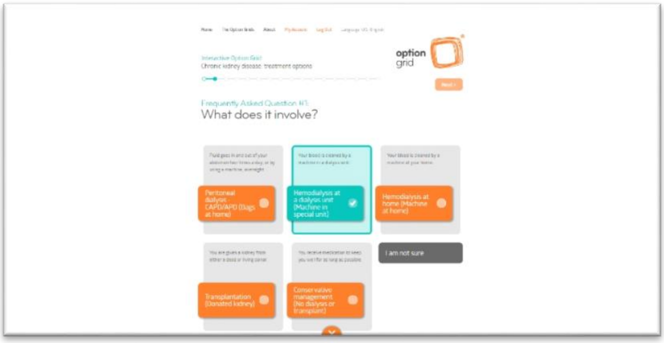
Standard Hemodialysis & Travel

- There are dialysis clinics in all 50 US states & all over the world. They can help you if you do standard home HD or standard in-center HD

But...

- You must set up an in-center travel slot weeks or months in advance
- The travel clinic may change or cancel your time slot

B. My Life, My Dialysis Choice



Interactive Option Grid

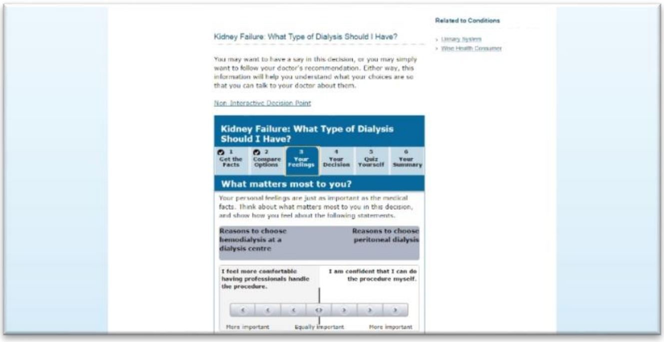
Chronic kidney disease: treatment options

Frequently Asked Question #1:

What does it involve?

- Peritoneal dialysis CAPD/APD (Bags at home)
- Hemodialysis at a dialysis unit (Machine in special unit) ✓
- Hemodialysis at home (Machine at home)
- Transplantation (Donated kidney)
- Conservative management (No dialysis or transplant)

C. Option Grid, Chronic Kidney Disease: Treatment options



Kidney Failure: What Type of Dialysis Should I Have?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

Kidney Failure: What Type of Dialysis Should I Have?

What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to choose hemodialysis at a dialysis centre	Reasons to choose peritoneal dialysis
I feel more comfortable having professionals handle the procedure.	I am confident that I can do the procedure myself.

D. Kidney Failure: What Type of Dialysis Should I Have?

Figure 9 - Screenshots of the four decision aid websites

they present and how this information is presented. Below, the findings related to the first research question 'How are current online decision aids on renal replacement therapy structured?' are presented.

The four decision aids that were analysed explain their goal with the tool on their homepage. The goals are similar and come down to helping patients understand the effects of the different treatments on their lives and formulate a preference based on this knowledge. This study shows that each decision aid takes a different approach to realise this aim. The decision aids have simple graphic profiles and include few visual elements, such as icons, drawings, pictures or animations. Figure 9 shows that the pages use very different ways of presenting information. Two sites use bright background colours, whilst the two others have white backgrounds. Objects such as tabs and text blocks are arranged differently. 'My Life, My Dialysis Choice' uses icons in flat design and star ratings, whilst 'Kidney Failure: What Type of Dialysis Should I Have?' includes Likert scales.

All four decision aids are text-based and use a personal style of writing, addressing the user with 'you'. Out of these four decision aids, the decision aid from Healthwise (Kidney Failure: What Type of Dialysis Should I Have?) is the only decision aid to include an explanation of CKF as a medical condition. The information that is presented here is very brief. Comparing the four decision aids regarding the renal replacement therapy options that are included, two of them cover all options (My Kidneys, My Choice and Option Grid), whilst the other two focus on dialysis only.

All four decision aids focus on effects of the treatments on lifestyle, e.g. time spent on dialysis, diet and how to adjust to holidays. However, topics covered differ between decision aids. In the "Kidney Failure: What Type of Dialysis Should I Have?" decision aid, stories from other patients are included about their motivation for choosing one of the dialysis types. An example of such a story is: *"'I am on the waiting list for a kidney transplant. In the meantime, I chose PD so I could be home with my kids as much as possible. I like taking care of the treatments myself. It makes me feel less like a patient all the time.' Georgia, age 34"* (Healthwise, 2015).

The tools are interactive, to a varying extent. Nevertheless, their interactivity is limited. Users have restricted freedom in navigating through the decision aids. The user often needs to follow a linear path. The information stream is directed by 'Next' button clicks. "My Kidneys, My Choice" is an exception. In this decision aid, the user can navigate to the different tabs whenever he or she likes. In "My Life, My Dialysis Choice", information is presented according to the values the user has marked as important. The Option Grid (Elwyn G et al., 2015) starts with questions on the individual user's background. It is, however, unclear if and how this information affects the information that is provided by the tool.

The decision aids include a few gamified elements. Three of the tools have a progress bar on the top that shows how far the user has come. Two have a knowledge quiz at the end. It is clearly indicated that these are not to test the user, but rather to help the user evaluate his or her personal knowledge. Three decision aids present ratings at the end. These are rather to present the user's considerations of options than his or her achievements.

The second research question that this desk review aimed to answer was: 'Which aspects of Internet-based information and education platforms for patients support or constrain SDM?'. The following findings of the analysis of online decision aids relate to this question.

My Life, My Dialysis Choice is the only platform that offers users the option to change the language of the information. Users can choose between English to Spanish, the two main languages that are spoken in the United States, where it is used. Another form of individualisation of information that is found in this decision aid is that the information is presented according to values that are selected by the user. The user is presented with various pre-defined values, divided over three areas; Lifestyle, Health and Partner & Family. With this approach, however, it becomes more difficult to get an overview of the practical aspects of the various treatment options. Whether the Option Grids support individualisation of information is a bit unclear. The decision aid starts with background questions about the user. It is, however, unclear if and how this information affects the information that is provided by the decision aid.

None of the decision aids contain statistic numbers or data on, for example, probability of developing side effects or average survival time to indicate uncertainty related to how individuals may react to a treatment. Neither graphs nor other graphic representations of information were present. The information that is provided about the treatments is a summary only. However, the decision aids provide links to further reading to support the user in obtaining more information. Differences can be found regarding the level of detail of the options that are presented in the decision aids, e.g. whether they differentiate between different types of PD and types of kidney transplantation.

Three out of the four offer the option to access a non-interactive version of the content. Two decision aids allowed users to download the information as a PDF and print it, which may support SDM for people who are not accustomed to computers or those who prefer reading from paper. These decision aids allowed users to note comments and personal questions, which could then be printed and taken to a consultation. This may help to support patients and medical practitioners in discussing treatment options. In the 'My Kidneys, My Choice' decision aid, the user is additionally urged to write down personal thoughts on pros and cons of the treatments, instead of being provided with fixed answers. Furthermore, they provide the user with different types of tasks. Table 7 displays examples of typical tasks per decision aid. The 'Kidney Failure: What Type of Dialysis Should I Have?' decision aid specifically addresses self-efficacy, as the assignment below shows, and fear of needles. The other decision aids ask for preferences regarding the treatment options, but do not ask for the reasoning behind these preferences.

The desk research showed that all four decision aids focused on the treatments' effects on lifestyle. However, the topics that are covered differ between the decision aids. Comparing the topics with the findings from the scoping literature review on patient's considerations regarding treatment choice (section 5.1) shows that not all themes that patients tend to consider were addressed. Although three decision aids addressed several practical aspects of

Program	Examples of tasks
My Kidneys, My Choice	Write down your thoughts on the different treatment options available for kidney failure. *Example:* Home Haemodialysis Add PROS, Add CONS, Add Thoughts (buttons, text boxes appear on mouse click)
My Life, My Dialysis Choice	Check the values that matter most to you. For each value you select, you'll be able to rate how each treatment option fits your life. *Examples of values:* I don't want to be a burden on my family, I need to be able to work or go to school
Option Grid, Chronic Kidney Disease: Treatment options	Frequently Asked Question #3: How often will I need this treatment? *Example of an answer:* Usually you need to go to the dialysis centre three times per week for a minimum of four hours. How important is this question to you? *Answer:* 6-point scale: Not important at all – Extremely important
Kidney Failure: What Type of Dialysis Should I Have?	Think about what matters most to you in this decision and show how you feel about the following statements. *Example of a dilemma:* a) I feel more comfortable having professionals handle the procedure. – versus – b) I am confident that I can do the procedure myself. *Answer:* 7-point scale: a: More important – a+b: equally important – b: More important

Table 7 - Examples of typical tasks per decision aid

treatment options, more subjective topics, such as self-efficacy, cultural beliefs, and the effect on lives of family members were not addressed.

In all decision aids, results are presented in a table format. The table can either be printed as a PDF or sent to the user by email. The decision aid from Healthwise (2015) also includes the opportunity to takes notes to print and take to a consult. Three decision aids include a recommendation to share the results with a medical professional and to use them as an input for a discussion on treatment choice. Two of the tools additionally advise the user to talk to family members about the choice. "Talking to family and loved ones may help you make the best decision" (Kidney Health Australia, 2012).

Comparing information websites and online decision aids

The desk research studies on information websites and web-based decision aids revealed a grey area between information websites and web-based decision aids. Some websites included some form of decision support in addition to providing disease-related information, while some decision aids included background information on the medical condition in addition to treatment information. No cross-references were found from one medium to the other.

Two decision aids had a generic format that was also used for other medical conditions, while the information websites and other decision aids were specific to CKF. Differences were found regarding the type of treatment options that are presented. Some platforms were developed by non-profit organisations, while others were developed by for-profit organisations. However, no relation was found between the options set and the profit system of the organisations. Rather, the option set seemed to depend on the treatment options that are offered by the clinics themselves.

Upon comparing the graphic design styles of the three information websites on CKF to the decision aids on renal replacement therapy, the differences in style become notable. While the information websites had basic coloured backgrounds, mostly white, some decision aids made use of bright colour schemes. In general, the graphic design of both information websites and decision aids was simple. However, the information websites included pictures that portrayed humans, while decision aids rather made use of more abstract imaging, such as icons. Additionally, information websites generally had longer sections of text and included links to further reading. Such links were not found in any of the decision aids. Regarding language use, most websites had a personal style of writing, addressing the user with ‘you’. These differences in design give the website a different character. The author would describe them as medical, formal and serious, versus a bit more playful, informal and ‘young’, respectively.

Discussion

The information websites and decision aids were analysed to see whether they provided information on topics that are recommended in clinical guideline documents. These guidelines recommend including all available renal replacement therapy options, the content of care, implications for lifestyle and preparations for treatment start. Some of the guideline documents recommend to also explain the function of the kidneys, causes and effects of the condition, as well as medication and dietary advice (section 3.2). The analysis showed that these topics are generally covered on digital platforms. However, the analysis also showed that considerable differences exist concerning: 1) The level of detail of the information; often, only a summary is given. 2) The emphasis that is given to the different topics; some go deeper into certain topics, whilst other topics are only briefly addressed. 3) How the information is presented, specifically the media that are used and the style in which the text is written.

There are two platforms that provide an argument on why patients should participate in the treatment decision, specifying effects on lifestyle. The other platforms just inform the user that the platform provides information on treatment options. Explaining the reasoning behind SDM is, thus, not a topic that is generally included on digital platforms. Informing patients that there is a choice to make and why their involvement is important is the first step in the SDM process (Elwyn et al., 2012).

One of the tasks of a medical practitioner in the SDM process is to support the patient in decision making by helping in reflecting upon the information in relation to their values and beliefs (Charles et al., 1997; Elwyn et al., 2012). The medical practitioner, thus, provides guidance to the patient in formulating informed preferences. A teaching method that provides guidance gives directions on the aspects that are important to consider (Mayer, 2004). As patients and their relatives have indicated focusing on maintaining a lifestyle that is as close to normal as possible (section 5.1), medical practitioners can guide patients in considering how the different treatments would affect their lifestyle. The findings indicate that a digital platform could support medical practitioners in this aim. Three of the digital platforms specifically urged users to consider their lifestyle and values in relation to the treatment options. Makoul and Clayman (2006) suggested discussing a patient's self-efficacy towards the different options, in addition to discussing his or her values. The findings of this study show that one of the decision aids included questions to address this matter. The other digital platforms focused on people's preferences. For these tools, the medical practitioner could debate the reasoning behind the preferences, also addressing self-efficacy. This would be a way to ensure that preferences are informed and not driven by fear or a lack of self-efficacy.

An important aspect related to individualisation of information is the aspect of uncertainty. The medical outcome of a treatment can differ from person to person, as associated risks, benefits and side effects are individual (Charles et al., 1997). Uncertainty is a complex factor in treatment decision making. Patients with low numeracy, in particular, might have difficulty understanding statistics in relation to their own condition (Elwyn et al., 2012). The analysis showed that none of the platforms account for this issue. It might, therefore, be beneficial to address the aspect of uncertainty on medical information websites and decision aids, such as explaining what uncertainty is, how it affects the information that is presented and that this concern is something to discuss with a medical practitioner. Coming back to a difficult topic during a consult allows people to ask questions about it.

The findings from the desk research studies showed that the information that is provided on decision aids often are short summaries only. This implies that patients and their next-of-kin are expected to obtain more thorough knowledge from other sources, such as information brochures, consultations and education sessions in hospitals. Although links for further reading are occasionally presented, little information is generally available about where patients can obtain more information. A service design approach (Moritz, 2005) may help map the available offer and set up a network of connections and interactions between various information sources and actors. This can ensure the development of a process that coherently supports SDM. From a service design perspective, development teams should, for example, consider the requirements that the digital platform that they are going to develop will meet, and the requirements that will be met by parts of the system around the platform and the actors involved. Awareness of the platform's context will help to assess the information that needs to be presented on the platform and the information that will be mediated in other ways.

Meeting patients needs

Some of the digital platforms that were studied partly support the additional requirements related to individualisation of information and offer the opportunity to ask questions concerning the Norwegian patient law (Ministry of Health and Care Services, 1999). One information website and one decision aid specifically support patients in asking questions, as they include the possibility to take and print notes to take to a consult. An example of individualisation that was found in this study was the option to change the language of the information on the platform from English to Spanish. Not all patients benefit equally from the provided information if it is only available in one language. Other forms of support might be needed to offer these patients the same information. Allowing users to change the language on the platform can be seen as an option for individualisation that promotes understanding. Another example of possible individualisation is the inclusion of background questions about the user in one of the decision aid starts. These questions might be used to individualise the content. It is, however, unclear if and how this information affects the information that is provided by the decision aid. Another decision aid provides some form of individualisation in presenting information according to user-indicated values. Despite these examples of individualisation, the findings indicate that the platforms overall hardly account for individualisation regarding age, maturity, experience, physical abilities and cultural and language background. Developers of new digital platforms could, therefore, benefit from applying guidelines for universal design as additional requirements for the platform. Some guidelines, for example, recommend enabling navigation on the webpage with help of a keyboard instead of a mouse, the use of contrast and colours and offering text or subtitles for video and sound fragments (Direktoratet for forvaltning og IKT, 2015). Developing a digital platform in accordance with these guidelines will help to ensure user-friendliness for a broad public.

When developing digital platforms to support learning, it is very important to know your audience. In contrast to face-to-face teaching, a platform cannot respond to any cues from learners that indicate that they are struggling (Dougiamas, 2009). Considering that the users of medical information websites and decision aids can be extremely ill, they may have problems concentrating for a long period of time. Furthermore, as patient populations are diverse, it is likely that some users will suffer from cognitive difficulties. The prevalence of cognitive difficulties is partly related to the medical conditions themselves. In the case of CKF, people are more likely to suffer from cognitive difficulties. A decline in global cognitive functioning, abstract reasoning and verbal memory is associated with a declining kidney function (Davey, Elias, Robbins, Seliger, & Dore, 2013). Cognitive difficulties are also more prevalent amongst the elderly. The will to participate in SDM is unrelated to age (Elwyn, Gray, & Clarke, 2000). As the majority of the CKF population is elderly, designing to include this group is relevant. Considering the audience of medical information websites and decision aids, accounting for universal design guidelines becomes extra relevant to ensure inclusion.

The study in patients' information needs (section 5.1) showed that patients are concerned about the effects of treatment on their daily life and the lifestyle changes that are necessary. Some websites address this information need by including patient stories, either in the form of personas or in the form of videos where they talk about their motivation to choose a specific treatment method or their experience with it. The IPDAS criteria for decision aids (O'Connor et al., 2005) recommend that if patient stories are included in a decision aid that these stories should present a range of positive and negative experiences. The study of information needs (section 5.1) showed additionally that concerns for lifestyle changes are related to different topics for different individuals. The review of the content of websites shows that differences exist between which topics related to lifestyle the websites address.

Use of text and media

The findings indicate that there is a wide variation in the way the materials are displayed and the amount of detail involved in the information. The required detail of information that is offered to patients and their next-of-kin on digital platforms needs further investigation (Stacey et al., 2014). As the developers in the interview indicated, it is a balancing act between offering sufficient information and avoiding redundant information. Furthermore, a balance needs to be found in presenting complex medical information and maintaining the user's attention. It was found that the platforms were mainly text-based, occasionally supported by other media such as images and movie clips. Text can be problematic for less literate people (Elwyn et al., 2012), and considering that patients might be profoundly ill when they use the platform, it is likely that some people will have problems concentrating for a long period of time. The IPDAS collaboration has developed a checklist to evaluate the quality of a decision aid for developers and medical practitioners. One of the criteria that is included in this checklist is to "provide ways to help patients understand the information other than reading" (O'Connor et al., 2005). The UK Renal Organisation also advises the use of various education methods to stimulate learning amongst people with different preferred learning styles (Warwick et al., 2014). The findings in this study show that not all digital platforms meet this criterion.

The clinical guidelines from the UK Renal Organisation and the Canadian Society of Nephrology include advice on the kinds of educational materials to use. They suggest using individual instruction, group sessions and written and digital materials, such as DVDs, CDs and websites (Levin et al., 2008; Warwick et al., 2014). This advice shows that a digital platform can be one of a variety of approaches to inform patients. According to the learning theory, offering a collection of educational approaches can stimulate learning in different types of learners (Hjelsvold, 2017). It is important for developers of learning platforms to know their audience. As explained above, they should know not only what knowledge level patients and their next-of-kin bring to the digital platform, but also what kind of guidance can help them understand the information (Vygotsky, 1978). All human senses can be used for learning (Kolb, 1984). With digital platforms being mainly text-based and static, their potential to facilitate learning through hearing and doing is neglected. From a universal design and constructivist learning theory perspective, determining the best way to mediate information is difficult to say. However, developers should ensure that the education methods facilitate the needs and skills of different types of learners by applying designs that account for its use by people with impairments.

Three of the **decision aids** present ratings for treatment options at the end of the decision aid. Although these ratings are only intended as an indication for which treatment option might be preferred, my personal concern is that patients may follow them too strictly. Additionally, these decision aids does not include measures to weigh the importance of specific aspects against other aspects in these ratings. Consequently, the decision aids' representation of patient preferences is incomplete.

Although the reading level of the text that was presented on the websites and decision aids was not measured, differences in the amount of text, the writing style, the length of sentences and frequency of use of terminology were noted. These differences make it plausible that some of the platforms require a higher reading level than other platforms. The IPDAS criteria stipulate that developers check that the decision aid is "understood by those with limited reading skills". The maximum reading level that the IPDAS criteria advise using is grade 8 (O'Connor et al., 2005). Regarding the importance of the information and the potential diversity of education level amongst the readers, it is vital for development teams to ensure that a platform meets this requirement.

Relevance for medical practitioners

This review of information websites and online decision aids contributes with an overview of how others have structured their websites, which information they present and the mediation strategies that they use. The study shows that, similar to the review of face-to-face education programs, there is a spread in how information is presented and which information is presented. This spread gives indications for which aspects medical practitioners should reflect over when developing a new website; which topics they want to address on the website, the level of detail of the information and the language use; formal or personal.

Clinical guideline documents provide an overview of topics to address in education programs for patients (section 3.2). The analysis shows that some websites do not address all these topics, this counts especially for the decision aids, who focus on treatment options and include very little background information. On some websites additional topics are addressed, but with one exception, only very general information is provided. Links to further reading are included in some websites. These findings indicate that these websites should be used as part of a larger service to meet the education criteria that are listed in guideline documents; patients will need to receive additional information from other sources to become fully informed about their options.

Similar to the findings of the review of face-to-face education programs (section 5.2), this study shows that there is diversity in which options are presented to patients. This may be caused by the difference between various guideline documents (section 3.2). Before developing a website, medical practitioners should however make a deliberate choice for which options to present, being aware of the consequences of their choice for patients.

Relevance for designers

This overview gives indications for aspects that designers may reflect over when developing a new website; colour pallets, fonts, types of illustrative images and other media to support the text. Examples were found of personas, videos and links to other websites. The review of the websites furthermore shows that designers may better account for universal design guidelines; Information was mainly mediated through text and very few options were found to change the settings of the websites to help patients to better understand the information. Designers may consider language settings, font size, contrasting colour use, and options to view the content in other formats. The latter is important for people with cognitive disabilities. For people with CKF this is extra relevant as the prevalence of cognitive disabilities for this patient group is higher than in the average population. Displaying information in various formats is also recommended in the IPDAS criteria for decision aids (O'Connor et al., 2005), though rather for the purpose of supporting people in understanding the information. The criteria recommend to use multiple methods to display probabilities, such as text, numbers and diagrams, and to allow patients to select how they are displayed to support understanding. Regarding the support that websites provide to stimulate understanding, this review showed that websites make limited use of alternative media and rely mostly on static content. Designers can make more use of the additional information mediation strategies that the Internet offers compared to traditional printed brochures.

The study shows that websites, with some exceptions, generally present information at a limited level of detail. This indicates the importance for service designers to develop holistic service offers that ensure that the information that patients need is made available to them through a combination of interventions.

Next step The findings from this study indicate that current information platforms and online decision aids are mainly text-based, not very interactive and make limited use of other media to offer information in an alternative format. However, text can be problematic for less literate people (Elwyn et al., 2012) and for individuals with other preferred learning styles (Hjelsvold, 2017). The IPDAS criteria, as well as documents with clinical guidelines, advise presenting information in various formats to facilitate learning (Levin et al., 2008; O'Connor et al., 2005; Warwick, Mooney, Russon, & Hardy, 2014). Websites currently make too little use of their potential to foster learning through other senses, as (Kolb, 1984) suggests to be effective.

The literature review of people's considerations of treatment options (section 5.1) showed that family members' opinions were often very important for patients to consider. The tasks in the decision aids to help patients reflect upon preferences provide however little support to patients to have such conversations, although two of them advised users to talk to family members. These insights led me to question if there is a potential for serious games to support SDM.

6.2 Exploring the potential for serious games to support shared decision making processes[12]

Abstract

Findings from section 6.1 indicate that information websites and decision aids rely mostly on text to mediate information. They make limited use of the possibilities for offering alternative ways of learning. This can be problematic for some patients. Furthermore, they offer limited support to patients in discussing treatment options with their family. Patients have reported that the opinions of their family members were an important consideration for their treatment decision (section 5.1). This section aimed at investigating how serious games could be used as an alternative support for the SDM process. It presents a theoretical discussion on how serious games may support the SDM process focuses on. The discussion addresses: 1) how serious games could change patients' attitudes towards treatment decision making, 2) how serious games could potentially support patients in evaluating and reflecting on treatment options and 3) how serious games could teach people to communicate their preferences and actively participate in decision making. By including examples of serious games that have been proofed successful in similar healthcare contexts, this discussion shows that there is potential for serious games to support the SDM process in various stages. Serious games may be used as an alternative for other healthcare services. Some challenges for the use of serious games in healthcare were found. The discussion of these challenges can help medical practitioners evaluate if they want to invest resources for developing a serious games.

Aim of the study

Pursuing a normal life is the most frequently mentioned concern by patients when in it comes to treatment decisions for CKF. Patients are therefore interested in learning about the reality of being on treatment. Which aspects patients deem important for their quality of life is individual and subjective (section 5.1). Education programs that are offered at clinics include the use of various materials, such as information brochures, DVDs and dialysis materials (section 5.2). Contemporary information websites and online decision aids are mainly text-based, and make limited use of other media to offer information in an alternative format. Decision aids include assignments that help patients to reflect upon their preferences, but provide little support to patients to discuss their treatment options with family members (section 6.1). Websites currently make little use of their potential to foster learning through other senses, as Kolb (1984) suggests to be effective. While text can be problematic for less literate people (Elwyn et al., 2012) and for individuals with other preferred learning styles (Hjelsvold, 2017). Moreover, patients have expressed the need for more visual and interactive ways of learning (section 5.1).

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[12] The text below is partly based on an article that was published in the proceedings of the 2016 IEEE International Conference on Serious Games and Applications for Health (SeGAH), called 'Kid-Ney's Journey: A Game to Support Treatment Selection for People with Chronic Kidney Failure' (Vis, 2016). The original article can be found in Appendix B.

The aim of this study was to investigate the potential for serious games to support shared decision making (SDM) processes in order to present an alternative to current practice. The aim of the first part of this study was to theoretically evaluate if there is a potential for serious games to support SDM. The research question that this part aimed to answer was: How can serious games support the SDM process? . The aim of the second part of this study was to develop a prototype for a serious game that could provide people with CKF and their family with insights into the effects of the various treatment types on daily life, as well as to help them to formulate preferences towards the treatment options. The goal of the game was to stimulate patients to discuss treatment options with family members, as that patients have indicated that their family members' opinions were very important for them to consider (section 5.1).

Method

For the first part, the literature on SDM was reviewed first to identify contemporary challenges with SDM. The three-step model for SDM by Elwyn et al. (2012) was used to link the challenges to the different phases of the decision-making process. This model divides the SDM process into the following three phases: choice talk, option talk and decision talk (section 2.2.2). Second, a theoretic discussion on how contemporary challenges with SDM might be mediated through solutions that apply serious gaming was developed by reviewing scientific literature on serious games for healthcare to identify potential solutions from related areas. Solutions that apply serious gaming have been developed and evaluated for related challenges. The findings from both literature reviews were then juxtaposed to develop a theoretic evaluation on the potential use of serious games to support SDM processes.

For the second part, a design workshop was organised to develop a first concept for a serious game. This design workshop was part of a course on serious gaming that was organised at the University of Twente in August 2015. During the course, the Game of Games (Bruinsma & Spil, 2015) was used to guide the game design process. The Game of Games is a game that is based on scrum (Schwaber & Sutherland, 2013). Figure 10 displays a picture that was taken during one of the creative sessions.

In between creative sessions, the course participants were presented with a theory on game design, such as player types, game mechanics and dynamics. The lecturers gave me the opportunity to formulate an assignment related to my PhD project preceding the course. During the course, a team of four students (including myself) worked on this assignment, which was formulated as follows: *"Develop a game concept in which people with chronic kidney failure (CKF) are encouraged and helped to make a choice between available treatment methods. As a team, you should decide who will be playing the game, in which context the game will be played and how much time the game will take to play, and describe which benefits the patient gets from playing the game".*

The students were given information about the treatment methods and the identified potential for the use of serious games as a support for SDM processes, but were not informed about existing decision aids to avoid guiding them in a similar direction. The students were further

Figure 10 - Playing the Game of Games. Photo by Gijs van Ouwerkerk - www.gijsvofoto.nl

informed about the main insights from the studies that were conducted during the insight phase (sections 5.1 and 5.2). A human-centred design approach (Krippendorff, 2006) was applied. The needs, skills and behaviours of people that would interact with the product were placed in the centre during ideation.

Four students from the product design department at the Norwegian University of Science and Technology evaluated the resulting game concept. Involving others in the development process through evaluative studies helps to ensure the relevance of the concept (Hanington & Martin, 2012). These four students had just taken part in a course on game design, in addition to having experience with human-centred design. Furthermore, they were of the same age as the target group for which the game was developed. To give the students some insight into the context in which the game is played, I briefly explained the situation for people with CKF in Norway and the motivation for this project. Next, I explained the goal of the game to the students. The students received a manual with instructions and were asked to play the game whilst thinking aloud (Hanington & Martin, 2012). Meanwhile, I observed them playing (Denscombe, 1998). Afterwards, the students and I had a group discussion (Denscombe, 1998) during which the students were asked for feedback. Additionally, an expert review (Hanington & Martin, 2012) was conducted by a nurse (RN) specialised in working with people with CKF. The expert review mainly focused on the content of the dilemma cards and how this could be optimised. Both evaluative studies iteratively informed the design process.

Findings Part I - The potential of serious games to overcome certain SDM challenges

Below, the potential for serious games to support SDM processes is explored. Suggestions are presented on how serious games could help in overcoming some of the challenges that SDM faces. The discussion focuses on: 1) how serious games could change patients' attitudes towards treatment decision making, 2) how serious games could potentially support patients in evaluating and reflecting on treatment options and 3) how serious games could teach people to communicate their preferences and actively participate in decision making.

1 Choice talk – Realising an attitude change towards SDM

SDM is a relatively new concept. Its practice calls for a culture change for medical professionals as well as patients. Patients need to become willing to actively participate in decision making concerning their care. A challenge, however, is that medical specialists are still commonly considered to be the experts by both patients and medical professionals (Kienlin, 2015). A mind-set for SDM needs to be established before people are presented with information on options to ensure effective learning. Guidance in this first phase is needed to direct patients' interest to the information on all options in the second phase. Serious games have been shown to support an attitude change in people. Brown-Johnson, Berrean, and Cataldo (2015) demonstrated that their game supports lung cancer patients in adopting assertive communication strategies in consultations.

Providing people with a sense of relatedness to other people who are significant to them can facilitate the motivation to learn. In a healthcare setting, this means that patients who feel respected and cared for by their team of medical professionals might be more likely to make an effort to study. Motivation to learn about SDM can be further strengthened with the help of serious games. A serious game can be used to gradually introduce a patient to the concept and construct an understanding of the importance of SDM during gameplay. One of the benefits of serious games over other media is that serious games can be adapted to the motivational stage of the player in order to slowly change a player's mind-set towards SDM. Mystery can be used to arouse curiosity and, thus, keep players engaged and eager to learn more (Wilson et al., 2009). Furthermore, increasing the number of contacts can increase effect size of an intervention (Krebs, Prochaska, & Rossi, 2010).

The biggest challenge in this first phase might be to motivate people to learn about this new attitude towards treatment decision making. According to the self-determination theory (Ryan & Deci, 2000), it is important to focus on personal endorsement. People should experience making a choice to explore and learn, rather than being forced to study. One of the benefits of serious games over other media is that games can facilitate intrinsic motivation for learning, as the playfulness that is inherent in games is associated with satisfaction (Ryan & Deci, 2000). According to the constructivist learning theory, people actively reflect upon information; they do not passively absorb it. Increasing personal commitment leads to stronger persistence, a growing positive perception of one's self and increased engagement (Ryan & Deci, 2000). Clearly communicating the personal value that SDM provides may help to raise people's interest. Crutzen et al. (2011) presented an overview of strategies that have been used to foster exposure to online health-related behaviour change interventions for adolescents. They found among others that interventions that were interactive resulted in higher exposure than those with non-interactive context, as people spent more time on the page and revisited the page more often. Furthermore, they found that communication adapted to the specific target group increased exposure (Crutzen et al., 2011).

2 Option talk – Informing patients about treatment options

SDM aims to foster self-determination by giving patients agency. Agency is afforded by providing patients with medical information and supporting them in reflecting upon options

(Elwyn et al., 2012). A challenge, however, is that contemporary information sources often are mainly text-based. This is especially problematic for people with low literacy and numeracy (Elwyn et al., 2012) and reduced cognitive capabilities due to their illness. Additionally, the current information sources are rather structured and appear to lack a focus on fostering a patient's feeling of competence for evaluating choices. According to the constructivist learning theory, tasks in the learning environment should reflect the complexity of reality to ensure that learners can also apply their knowledge in practice (Savery & Duffy, 2001). One of the benefits of games is that they can gradually introduce more complexity and provide the opportunity to practice as many times as the user wants. Furthermore, games provide a safe environment where one can make mistakes and learn from them. Games can, thus, be used to build a feeling of competence through practice. A feeling of competence is important to motivate people to continue to learn and explore (Ryan & Deci, 2000).

Serious games might be a more suitable medium to stimulate knowledge acquisition and option evaluation by patients for various reasons than alternative media that provide little possibilities for interaction. A meta-analysis of games for healthy lifestyle promotion showed that serious games can increase knowledge levels (DeSmet et al., 2016). Serious games commonly make use of various media to mediate information, making them less reliant on text. Furthermore, interactivity is more engaging that reading an information leaflet or website with static content (Fox, 2009; Hamari et al., 2014). Games are well-suited for learning, as they provide players with agency inside a defined system of rules (Sicart, 2013). Games provide players with control. Individuals are able to influence how the game evolves through their actions (McCallum, 2012; Wilson et al., 2009), thus fostering a feeling of competence.

The constructivist learning theory describes learning as an active process in which learners construct new concepts based on their experiences (Kolb, 1984; Savery & Duffy, 2001). Individualised learning based on the player's characteristics is important to optimise learning. Games can offer individualised learning experiences, as they can make use of levels that can be adapted to the individual's zone of proximal development (Vygotsky, 1978). Adaptability of serious games through levels helps players at different stages to feel competent and able perform the requested activities. In-game rewards and feedback can also be used to strengthen a player's feelings of competence. Generally, one needs to be careful with extrinsic motivators, such as points and rewards (Hamari et al., 2014). 'Option games' will, however, mainly be played during a short timeframe, making the fact that extrinsic motivators can undermine intrinsic motivation less important than it is for games that support rehabilitation or prevention (McCallum, 2012). Such games commonly need to be played over a longer period of time to be effective. As patients are in a stressful situation and need to process a lot of information, repetition and pacing are important (Elwyn et al., 2012). Serious games are a well-suited medium to provide pacing in accordance with their level structure.

It is recognised that patients might want to discuss their situation with family. Therefore, family members also need to have access to the same information (Elwyn et al., 2012). Games can give players a sense of relatedness by offering players the option to cooperate with other players and by providing in-game opportunities for conversation (McCallum, 2012). Games can be played by several people at a time, thus fostering interaction between people through a shared activity, lowering the barrier for conversation. Conversing with others encourages reflection, as one needs to think over how to clearly formulate thoughts and feelings. Phrasing creates meaning, and interactions with others helps people build understanding (Rapley, 2008). Such in-games conversations with family members can help patients find out what quality of life means for them. Furthermore, it can help patients to formulate preferences, first in conversations with family, and later in discussions with their medical specialist. Serious games also offer players new experiences and practice (Kolb, 1984). Game mechanics can be used to optimise the setting for collaborative learning and facilitate interaction and collaborative activities (Oksanen & Hämäläinen, 2014). More specifically, games can be used to create an arena for discussion of treatment options between the patient and his or her next-of-kin. It can make it easier for people to start a discussion with relatives. Social networking sites and massively multiplayer online games are types of games that are particularly strong in this aspect. Pandemic is an example of a cooperative board game that fosters strategic discussions (Leacock, 2007).

If serious games are to be used as ‘option talk’, then game play should be kept simple. The serious game is most likely played for only a few times in the phase between diagnoses and treatment decision – although patients often have the opportunity to later switch to another treatment. Furthermore, patients might be cognitively affected by their illness. Learning to play the games should, thus, require little time and effort. Although similar game mechanics and concepts might be used, the content of a game will need to be disease-specific and might even need to distinguish between different stages of a disease, as treatment options might change as a disease progresses. Yet, there is a risk with serious games, which is that players might play strategically to win, rather than to make in-game choices based on their personal values (Sicart, 2013).

3 Decision talk – Exchanging considerations and collaboratively make a decision

The first phase of the SDM process ‘choice talk’ focuses on patients’ attitude towards taking part in treatment decisions. However, providing information alone is insufficient to promote behaviour change. To establish behaviour change, people should not only be motivated to take part in SDM and be aware of their options, but they should also possess the skills and feel competent to perform the new behaviour (Ryan & Deci, 2000). Effective education is comprehensible and actionable for patients (Young, Chan, Yevzlin, & Becker, 2011). To allow patients to actively contribute in discussions concerning treatment decisions, practicing the necessary communication skills might be beneficial. One of the benefits of serious games is that people can practice at home, without the need for a medical practitioner to guide them. Studies have shown that serious games for behaviour change related to personal health can lead to better knowledge, attitude changes and behaviour changes (Baranowski et al., 2008).

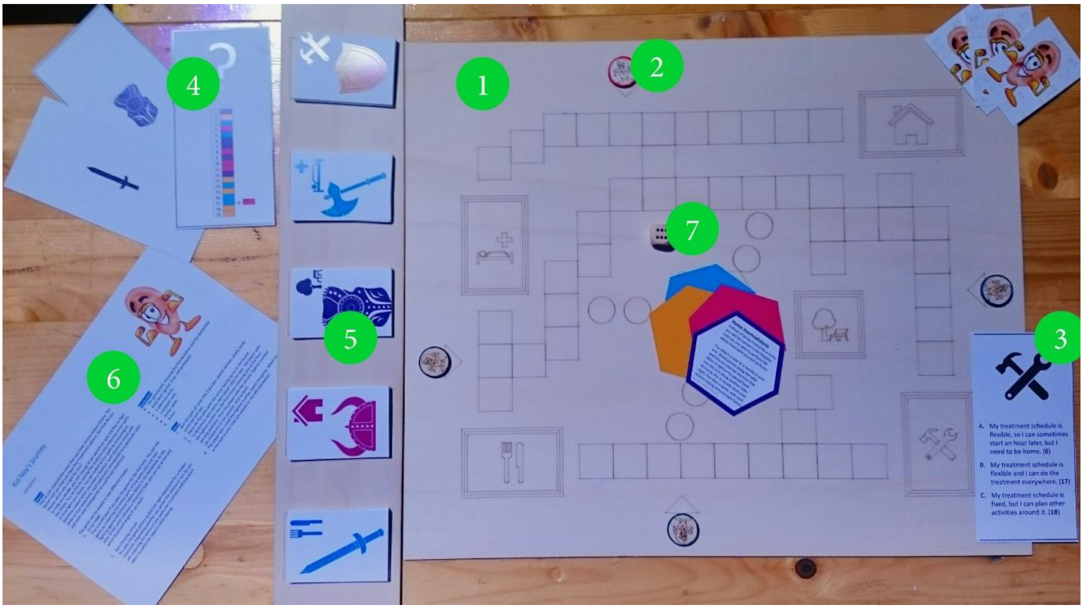
Games provide active learning activities, or experiencing, as it is called in constructivist learning theory (Kolb, 1984). Experience is central to learning and forms part of a holistic process that also includes perception, cognition and behaviour. The learner develops concepts through the transactions that occur between subjective experience and objective environmental conditions. When transactions take place, personal concepts are changed (Kolb, 1984). Furthermore, it is important to let players feel competent in performing the new behaviour (Ryan & Deci, 2000). Games as health interventions have been found to be effective in providing a sense of competence and to prompt behaviour change (Kato, 2010; Shelton & Scoresby, 2011). The level of the tasks can be adapted to the skills of the player to gradually build feelings of competence. Through playful actions, players learn new behaviours that they can use in real-life situations (Graafland et al., 2014). In the context of fostering SDM, games can support patients in developing and practicing communication skills that can help them in consults with their physician.

As behaviour is influenced by personal characteristics as well as environmental influences (Kolb, 1984), representation is important to ensure that patients go through the same cognitive processes as they would in real life (Wilson et al., 2009). A transfer from in-game skills to external tasks only takes place when the cognitive processes are similar (Tobias & Fletcher, 2012). Serious games can be used to simulate real-life situations, allowing the player to practice skills in a safe environment and giving players insight into different scenarios of what could happen, which is key to understanding procedures (Barthel, 2013). Transfer of knowledge from an alternative world to real life is thought to be better supported by gameplay than face-to-face or traditional classroom teaching (Cheek et al., 2015). Furthermore, experiencing a situation in an alternative world can help externalise a problem. When the player overcomes the problem in the alternative world, the player can gain the confidence and skills to similarly approach the real-world problem (Cheek et al., 2015). Scenario-based games are, for example, an appropriate tool for learning new skills (Sina, Kraus, & Rosenfeld, 2014). One of the benefits of serious games is that they can provide specific and timely feedback, which increases learning effectives (Wilson et al., 2009). Rewards can distract players when they are used to reward ‘correct’ behaviour (Shelton & Scoresby, 2011). Therefore, in games that focus on behaviour change, rewards need to be used with care.

As attitude change and skill development collaboratively contribute to behaviour change. It makes sense to include both goals in one intervention. Perhaps the best timing for such a behaviour change intervention is to instigate it before people become ill, as ill people might have many other things towards which they need to adjust, such as less energy or muscle power, shorter attention spans and new lifestyles. Furthermore, to establish a culture change towards SDM, much of the population will need to adopt a new attitude towards medical decision making. Programs for adolescents might be most effective to gradually establish this cultural change, as adolescents are still developing their self-image, which includes trying new behaviours to become more independent. Furthermore, adolescents are on the verge of becoming independent from their parents for medical encounters. One of the benefits for game developers will be the ability to learn from many other games that have been previously developed for adolescents, such as Re-Mission and Kaledo (Kato et al., 2008; Viggiano et al., 2015).

Findings Part II – Developing a game concept

During the course in serious gaming, the students developed a concept for a board game called Kid-Ney's Journey. An image of the prototype they made is displayed in Figure 11. The image shows the (1) playing board, (2) pawns, (3) dilemma cards, (4) answer cards, (5) armour cards, (6) manual and (7) dice.



A. My treatment schedule is flexible, so I can sometimes start an hour later, but I need to be home. (6)

B. My treatment schedule is flexible and I can do the treatment everywhere. (17)

C. My treatment schedule is fixed, but I can plan other activities around it. (18)

Figure 11 - Kid-Ney's Journey board game

The game is targeted at people 21 to 40 years old who need to start treatment soon and their families. The goal of the game is to give these people insight into the effects of a treatment on their daily lives and to help them weighting the advantages and disadvantages of each treatment method. The intention of the game is to encourage a dialogue between the people that will be living with the consequences of the treatment daily, i.e. both the patient and the close family. The game that can be played by two to four players is intended to last for 20 to 30 minutes and can be played at home, or in the waiting room in the hospital's out-patient clinic. The design of the board games is inspired by the popular games Cluedo and the Game of the Goose. The storyline of the games is that each player needs to collect armour to defend their Kid-Ney (an anagram for the player's renal function) against the disease.

The goal in the game is to collect a complete armour in one colour for their Kid-Ney in order to be able to be strongest when fighting the disease. Each colour represents a specific treatment method. A player collects pieces of armour by visiting the five locations on the board by throwing the dice. In each location, the player is presented with a set of four dilemmas, which have been formulated according to possibilities and constraints that come with each treatment. An example of such a dilemma is: "My treatment schedule is fixed, but I can plan other activities around it". By choosing one of the options, the player receives an armour card in a specific colour. Once a player has collected five different pieces of armour in the same colour, the player goes to the "Battlefield" in the middle of the board. Here, the player needs to answer the final question: “Which treatment method represents your colour of armour: A kidney transplant, HD in the hospital, PD or HD at home?” The game is won by answering this question correctly.

It was decided to develop a board game and not a mobile application or interactive website, as the team wanted to design a multi-player game that allowed for interaction and discussion between the players. A board game gathers people around a table and, therefore, has a low barrier for direct conversation. Several ideas for games and game concepts were developed by the student group. Each idea was inspired by existing, well-known and easy-to-play games. This was a deliberate choice, as the group wanted to develop a game that has a low threshold to start playing with rules that are easily and quickly understood. Thus, players would avoid spending time on reading a long manual or discussing uncertainties about how to play the game. The game will probably be played once or, at most, a few times during the short period in which a decision on treatment method needs to be made.

Redesign of the game concept

From the group discussion with the design students who evaluated the game and the expert review with the nurse, the following points for improvement were identified:

1. Reconsider which treatment methods are presented, i.e. consider omitting transplantation dilemma in the game. Transplantation is often the preferred treatment method, as it is considered to result in the best quality of life. The choices that represent the option kidney transplantation frequently stand out as the best choice. The differences between the dialysis options might, therefore, become neglected.
2. Layout of the board: How to move from the start position to the playfield and between the tiles of the field and the five locations was not clear. Additionally, to avoid people needing several turns to reach a location, distances between the five locations might be shortened to speed up the game.
3. Icons: The meaning of icons to indicate the five locations appeared to be ambiguous. Therefore, some icons could be redesigned, and text could be added.
4. Dilemmas: Not all dilemmas on the cards were clear, as some formulations are long. Furthermore, different tenses were used in the statements. These dilemmas should be reformulated and shortened. Additionally, changing the card design might be beneficial to allow each player to see which dilemma they have previously selected.

These points will guide further development of the game concept and the redesign of the game.

Discussion

Despite the potential of serious games to support SDM, the development of a good serious game is challenging, for two reasons: 1) designing games that are fun is difficult, 2) developing good education material is difficult. Combining this makes it even harder, as neither can be compromised (Cheek et al., 2015; Hjelsvold, 2017). Currently, making games motivational is ‘more of an art than a science’ (Frost & Eden, 2014). Although theoretic concepts from psychology are used, questions remain on what aspects of a serious game makes them attractive and motivational (Cheek et al., 2015; Frost & Eden, 2014). Nevertheless, the combination of game theories with behaviour theories appears to be most beneficial (DeSmet et al., 2014). Furthermore, it is important to meet the specific health-related needs of the target group, accounting for their demographic aspects (Cheek et al., 2015). Behavioural scientists, game professionals and medical specialists will, thus, need to collaborate to design effective games and invest in substantial user-centred research during game development (Baranowski et al., 2008).

The learning goal determines what learning approach is most effective. Developing behavioural skills is different from learning facts (Kolb, 1984). The design of a serious game for SDM will, thus, depend on which challenge the game will address. Digital solutions can support patient education (Fox, 2009) and have a large reach, especially when they are internet-based (Cheek et al., 2015). However they take more time and investment to develop than board or card games. Commercial games are often developed on larger budgets than those available for the development of serious games. This is a challenge, as people that play commercial games might have similarly high expectations for a serious game (Cheek et al., 2015). The game concept presented in this article is a board game. The students that developed it were free to decide the kind of media through which they would develop a serious game. Their decision to develop a board game was based on their considerations of the needs of patients and the context in which the game will be used. This reminds us that technology is a means to an end, not an end in itself. Nevertheless, there are clear benefits of online solutions that a board game does not provide. For example, the content of online solutions can easily be updated; users can be motivated to take notes on their thoughts and questions, which can be saved digitally. The My Kidneys, My Choice decision aid (Kidney Health Australia, 2012) includes the latter and also focuses on encouraging the user to formulate personal pros and cons for treatment types. Ideally, a benchmarking test is executed to compare advantages and disadvantages of both technologies. Developing online games has the additional advantages that digital games can be adapted to eventual physical and cognitive hindrances of players, and that multimedia techniques can be used to stimulate knowledge uptake and engagement (Fox, 2009). However, interaction between players will be different, and one main goal of the game was to create an arena for discussion of treatment options between the patient and their family.

A multiplayer board game gathers people around a table and, therefore, has a low barrier for direct conversation than a game that is played digitally. Playing a game with people is more engaging than reading an information leaflet or website individually (Fox, 2009; Hamari et al., 2014). The game could be played at home as an alternative to playing at the hospital's outpatient clinic. The benefits of a serious game that people can play at home are twofold. People can learn in a safe environment at any time and re-play the game several times. As time is scarce in healthcare, patients can play a game in preparation of a consult. This ensures efficiency during consults.

Learning through a game will not be everyone's preferred learning style (Hamari et al., 2014), yet for those who prefer more active or visual ways of learning, games can be motivating (Kolb, 1981). Others might prefer face-to-face education instead, or be hesitant to use digital media (Cheek et al., 2015). A serious game for SDM that focuses on knowledge acquisition and reflection on treatment options should, thus, be offered as a supplement to the existing care service. As people are ill, they should always be offered the opportunity to discuss questions concerning their illness and treatment methods with a medical specialist. Patients who feel very sick need and desire , and patients and caregivers might rather interact with a health professional. Therefore, despite their advantages, decision aids or games can and should not replace the entire information provision for patients. People who are dealing with a serious illness should have the opportunity to discuss questions concerning their illness and treatment methods with a healthcare professional, especially since gamification does not work for everyone in every situation (Hamari et al., 2014). Consequently, the game should be used as an additional information source, not as a replacement for current information sources.

As the information in the game often needs to be simplified, there is a risk of trivialising the problem or over simplifying it. Another challenge is that the intended learning goal often is different from the game goal. In such cases, the learning goal may be reached indirectly. For skill development, alignment between the activities that are performed in the game and the goal of the game supports effective learning (Shelton & Scoresby, 2011). Activities must have an appropriate level of difficulty for the player to be engaged and feel competent (Cheek et al., 2015). The engagement of the player with the game motivates continued play, enhancing learning potential (Wilson et al., 2009). At the same time, the cognitive effort that the game requires may compromise learning effects (Schrader & Bastiaens, 2012).

The game concept presented in this article is targeted at patients who are 21 to 40 years of age. This was a choice made by the students who developed the game concept, and was based on the fact that the students are in this age group. With no possibilities to involve patients or obtain user insights during the course, this choice allowed them to rely on their own insights about the aspects that play a role in this period of one's life. Furthermore, the students thought this age group would be especially exposed to the effects on social life when needing to start treatment. The storyline of the game is a bit ironic, with Kid-Ney collecting a harness to defend himself for the disease. The group expected that gallows humour could be appreciated by the target group, but were also aware that such irony might not be appreciated by people outside the target group. Older people might prefer a more serious storyline. Regardless of age, people should be given the opportunity to choose their treatment method (Little et al., 2001). With the majority of the patient population being elderly, a design including this group is relevant. Therefore, more research and development would be beneficial to adapt the game concept to diverse user groups.

Having a thorough implementation plan that is endorsed by health professionals is essential in ensuring an intervention's use in practice. It is necessary to reflect on how a program can be implemented and integrated into current practice to ensure its use and effectiveness (Fox, 2009). A lack of technical support might, for example, obstruct the successful introduction of a new game (McCallum, 2012). Involving a medical professional in the development process is seen as beneficial, as they are experts on the practicalities of treatment and know what concerns and questions patients often have. In collaboration with medical experts who frequently are in contact with patients, it is possible to phrase the dilemmas, such that they represent dilemmas that patients indicate struggling with language with which they are familiar (e.g. food not nutrition, sport not physical activity). Involving a medical professional directly in the concept generation process, as a co-designer, can even be more beneficiary, as expert knowledge can directly be implemented during the process of co-creation in the idea generation and concept development phase. The same goes for involving patients and caregivers who have experienced the treatment selection process in the design process. They are experts on their experiences and struggles, as well as the aspects that they considered and the support that they wished they had during the process.

The game concept presented here is intended to increase knowledge on effects of treatments on lifestyle and tries to encourage people to discuss these concerns with their relatives. Although the content of the game is based on medical information, and is informed by studies concerning which effects on lifestyle are important in the decision-making process by patients (section 5.1), whether or not this game really meets the needs of the patients and spouses sufficiently needs to be tested with actual patients. Before this is done, the iterative development process should be continued to adapt the storyline to the specific user groups (Allam, Kostova, Nakamoto, & Schulz, 2015) and optimise the content. Next steps in the development process are to evaluate and redesign the game concept with people within the same age group as the target group. This will ensure that the concept is playable, interesting and meaningful. To ensure that the content is correct, medical specialists should be asked to review the concept, and methods for implementation in their practice should be discussed.

Decision to discontinue the game concept development process

The PhD candidate believes that a serious game can be a valuable addition to contemporary patient education practices and can support treatment decision making. Serious games mediate information through more interactive and visual methods. Text-based materials are not effective for everyone. Serious games might support these persons in understanding the information that is offered to them. Nonetheless, the PhD candidate decided not to continue with the development of game concepts for this thesis. This decision was made for several reasons.

First, testing an early concept with a vulnerable target group might not beneficial enough to justify the burden for these individuals. People who have just been diagnosed with a chronic condition and have not yet started treatment are in a vulnerable position. They have to learn to accept and cope with their diagnosis, and as treatment has not started yet, they might feel extremely sick and be unsure what their future life on treatment will be like.

Second, SDM is not common practice in hospitals in Norway today. There are few patients who are being offered to participate in treatment decisions by their physician, and who are informed on the full range of treatment options. Many of these patients have already been involved as informants in other projects that aim to promote SDM. Including them in this study, as well, could mean that they become over-burdened.

For these two ethical reasons, it would be preferable to further develop the concept with people outside of the specific target group, even though this is not in line with the human-centred, co-design approach of this project. One of the benefits of such an approach in which other informants are used would be that the target group is not burdened unnecessarily. A possibility could be to involve people who have already started treatment and have adapted to their new way of living. This however raises a similar, ethical problem. The problem of involving such patients is that SDM is not current practice today. These people might therefore not have been given a choice by their medical team. Informing them about SDM and all available treatment options could be confronting and upsetting for them and disturb the relationship with their medical team.

It was considered to involve people who have a similar age as the target group as everyone could potentially be diagnosed with CKF and end up in the same situation as patients. It was however decided not to do this for several reasons:
First, a disadvantage of involving people other than the patient group is that people who are not chronically ill will not be familiar with the patient journey, and will not experience the same needs or emotions, even if tools are used to build empathy. The setting thereby becomes artificial, and the trustworthiness of the findings is reduced.

Second, it was also expected to be difficult to test and evaluate the developed game concept in actual medical practice. Medical regulations for testing new interventions are strict. Gaining permission from an ethical committee would take time, and was expected to be difficult due to the lack of a research partner with a medical background. This project was initiated by the PhD candidate herself, without any prior connections to medical practitioners. Although contacts have been established with parties that work with this patient group, no party was identified that articulated a need for anything more radical than incremental changes to their existing program. I wanted to avoid that this project became a university-pushed project. It might have been possible to deliver a ‘proof of concept’ outside the healthcare context. Testing and evaluation of any mid-term concepts and prototypes outside the actual intended use context would however raise questions concerning the transferability of the findings to medical practice.

Third, no opportunities for an eventual product to become implemented in medical practice had been identified. I wanted to avoid disappointment amongst participants who would eventually have been involved in the design process. Participants invest energy and develop expectations toward the project’s outcome and application in practice, especially if they are satisfied with the achieved results. As there was no platform available for introducing a game concept, and as there was no need from the service provider’s side, the outcome of the project was unlikely to become implemented in actual practice. Furthermore, I realized that even if the project would succeed and the game would be implemented in practice, there would not be any support for maintaining and managing the game when this PhD project was finished, unless efforts would be made to receive funding for this.

Fourth, contact had been established with a party that was working with a similar project that aimed to promote SDM through an interactive platform in Norway (section 6.3). This development team has already created their own platform for testing and has established a strong support group over the past several years. Recently, their project was identified as an example case by the Norwegian Directorate of Health and received extra support to realise the project and to introduce it into healthcare practices in Norway. This party was interested in gaining feedback from a design perspective.

Taken together, it was decided that the results that this serious game project would deliver, would not justify the effort and time of both participants and the researcher.

The game-concept has been presented to a company that develops serious games for healthcare services. This company considers developing the game-concept further, if they find a healthcare partner that is interested in developing the game collaboratively.

Contribution to medical practice

This study contributes with a theoretical discussion on how serious games may be used to meet specific challenges of the SDM process. The discussion focusses on how serious games potentially can 1) change patients' attitudes towards treatment decision making, 2) support patients in evaluating and reflecting on treatment options, and 3) teach people to communicate their preferences and actively participate in decision making. By including examples of serious games that have been successful in similar healthcare contexts, this discussion shows that there is potential for serious games to support the SDM process in various stages. Serious games may thus be used as an alternative for other healthcare services. The discussion also presents challenges for the use of serious games in healthcare. This discussion can help medical practitioners evaluate if they want to invest the time and money for the benefit that serious games can bring.

Relevance for designers

The study presents examples of serious games that have been developed in healthcare for similar purposes. Designers might use these examples as inspiration for their own project. The discussion on discontinuing the development of a serious game concept on the ground of a) lacking an implementation platform and support for maintenance, and b) the difficulty of involving targeted patients in the study, contributes to the discussion of participant involvement and ethics in the participatory design field.

Next step The analysis of information websites and online decision aids (section 6.1) showed that considerable differences exist concerning how the information is presented on these websites, specifically the media that are used and the style in which the texts are written. The study showed that contemporary information websites and online decision aids are mainly text-based, and make limited use of other media to offer information in an alternative format. I wanted to obtain some understanding of where the differences in design come from and especially to learn what motivations may lie behind these differences.

6.3 Analysing current practice – An expert interview with two developers of a decision aid

Abstract

The review of information websites and decision aids (section 6.1) showed that considerable differences exist between websites concerning: 1) The level of detail of the information they provide, 2) The emphasis that is given to the different topics. 3) How the information is presented, specifically the media that are used and the style in which the text is written. The goal of this study was to investigate what motivations may lie behind these differences in representation. A semi-structured interview was held with two members of a development team to obtain an in-depth insight into how a decision aid is developed.

The main insight for the development team was that the importance of fitting the intervention into patient care pathway and developing supporting strategies to ensure its intended uses in practice. The development of the content was a balancing act between delivering sufficient information and avoiding information overload, between empowering patients and keeping the text understandable, and between visual simplicity and attractiveness of the design.

The main contribution of this study for medical practice is that only designing an intervention is insufficient. Interventions need to be implemented in patient care pathways. This shows the relevance of applying a service design approach when developing patient education programs. The study contributes additionally with experienced-based insights that aid designers in their projects,

Aim of the study

The findings from section 6.1 highlighted that considerable differences exist between what information is presented in decision aids, how decision aids present information and the support they provide to patients in reflecting upon their treatment options. The goal of this study is was to investigate how an online decision aids is developed. The research questions that this study aimed to answer were: Which motivations lie behind the project, how is the content and format of the decision aid determined and developed and who is involved during the development process? The intention was not to theorise, but rather to explain. The insights from this study are intended to support developers of new platforms by enabling them to learn from the considerations and experiences of another development team.

Method

A semi-structured interview (Robson, 2011) was conducted with two members of the development team of one of the online decision aids that had been included in the desk research studies (section 6.1). This interview aimed to obtain in-depth insights into the team's motivations, considerations and experiences with developing the decision aid. Section 4.2.4 provides more insight into the rationale behind conducting a semi-structured interview and the approach to data analysis for the specific purpose of this study.

Case selection

The decision aid that was selected as study case for this study is a decision aid that is developed by a dedicated team within an academic hospital in Norway. I had met two members of the team at a conference on implementing SDM in Norway at the University of Oslo, Institute of Health and society, on February 5, 2015. During a break we had an interesting discussion about our projects and our understanding of SDM. At the time of the interview (October 2016), the decision aid that they were developing had been released online, but the team was still developing it further. Originally, the platform was developed for CKF specifically. Over time, the scope of the project has broadened. At the time of the interview, the team was working on the development of a generic approach that could be applied to multiple medical conditions. As the platform is developed for use in Norway, the information on the platform is provided in Norwegian and follows the clinical guidelines that practitioners follow in Norway.

Study Participants

The participants for the interview were selected based on purposeful sampling (Patton, 2002). The two participants were selected based on their expertise and role in the development team. They form part of the core of the development team. The PhD candidate had met both participants and some of their colleagues during a conference and contacted the two later by telephone to ask if they were willing to participate in an interview.

Data collection

The face-to-face interview took place at the department of the development team. The face-to-face setting supported the creation of a dedicated conversation on motivations and experiences (Robson, 2011). The two experts were interviewed at the same time to enable them to supplement each other's statements, thereby generating richer responses and enhancing the reliability of the responses (Denscombe, 1998). Open questions addressing pre-defined topics were posed during the flow of the interview. The pre-defined topics concerned the goal, target group, motivation and development process (Table 8). The interview was conducted by me in October 2016 and lasted 1 hour and 20 minutes. During the interview, I took short notes, noting down key words and crossing off the pre-defined topics that had been addressed.

Data analysis

Afterwards, the interview was transcribed verbatim and anonymised. As some of the authenticity of the conversation is lost in transcription, like intonation (Denscombe, 1998), the tape records were kept to enable the author to listen to specific parts of the interview.

Introduction	intro + informed consent
Background	(Start recording) Responsibility / role interviewees?
Main topics	Can you say what you are developing? • Goal? And for whom? • Definition of a decision aid • Motivation to start the project • History of the project • Practical information on organisation (project team, cooperation, user testing) • What information was included? Which techniques were used? How was the site's structure determined?
Conclusion	Anything not discussed? Thank you.

Table 8 - Interview guide of expert interview with developers

The Constant Comparative Method, as described by Boeije (2002), was applied for data analysis. Supports such as memo writing, close reading and re-reading were applied throughout the analysis, which relied on hermeneutic interpretation of the transcribed texts. NVivo10 (QSR-International, 2015), a program specifically intended for the categorisation and coding of data, was used to structure the data transcripts and notes. As second-order understanding introduces a risk for misinterpretation, my second supervisor, who has a background in nursing, made her own interpretation of the data based on the interview transcript. Afterwards, we met twice to discuss our interpretations of the data. These discussions deepened each researcher's individual understanding of the data. In between the two discussion rounds, I went back to the data to analyse it from my deepened understanding and changed perspective. The discussions support the trustworthiness of the interpretation. The findings represent the consensus of the researchers. To ensure that no misunderstandings had occurred, the two experts who had been interviewed were given the opportunity to review the text on the findings. No comments were received within three months.

Findings

The aim of this study was to investigate how an online decision aid is developed. The research questions that this study aimed to answer were: Which motivations lie behind the project, how is the content and format of the decision aid determined and developed and who is involved during the development process? The following findings provide an answer to these questions.

Background of the project

In 2009, a medical practitioner raised the idea of advocating for SDM for the first time formally at the management level of the academic hospital in northern Norway where he was employed. In December 2013, Norway's minister of health visited the hospital to officially release the first beta version of a publicly available information platform focused on CKF, which was delivered after a year of content development. With extra financing from governmental parties becoming available, the project commenced with the development of a more generic format that could be applied to other diagnoses. The first version of this new platform was released as an independent website in 2015. One year later, the content of this website was moved to helsenorge.no, a public government-owned website. Meanwhile, the team continued developing the content. At the time of the interview, the team was still developing the website. During that time, the core development team consisted of the two members that were interviewed, three additional team members and the medical practitioner who had originally initiated the project. One of the interviewees was the project leader. The other interviewee was responsible for the development of the implementation strategy and supporting strategies from a research perspective. Two of the other project members shared responsibility for contact with medical practitioners, patients and user testing, whilst the third was responsible for the film snaps and animation, as well as user testing. As the core team is small, their tasks were relatively broad, and they were all very aware of the status of the project overall.

The team's intentions

The interviewees explained that the goal of the project is to realise a practice change from paternalism to SDM in Norway. *"If we are successful, the project leads to more shared decisions and better-informed choices".* The interviewees' statements showed that the motivation for the project has ethical grounds, related to the right to have a say in decisions that concern oneself and be well-informed. *"This (SDM) will be good for the patient. This form of involvement or ownership over one's own disease".* From the start, the goal of the project has been to develop a platform to support medical practitioners in providing comprehensive information for their patients. The intention was to realise this by developing an information platform that can be used by the patient at home and by patients and medical practitioners during consults. Furthermore, the platform is intended to support relatives, who could support the patient in making a choice. Trustworthiness of the information and the neutrality of the platform, in particular, were core concerns for the team. As the platform focuses on medical expertise, the team members continuously paid careful attention to how the information was presented to avoid steering the patient in an unintended direction. *"To provide balanced information... so that you get the feeling that there is someone who knows everything about each treatment".*

The interviewees explained that from the start, the goal has been to develop an open, online platform for anyone to access at any time. This has been a deliberate decision, as the platform becomes a means to promote awareness about SDM in the general population. Due to its open online format, patients that perhaps were not informed about SDM by their own doctor can access the platform. *"Everyone should have free access to it. Since it is available on the* *internet, everyone can find it and take advantage of it".* The interviewees expressed that they regard the transfer to helsenorge.no as an opportunity to further strengthen awareness about SDM. Although the platform is publicly available, the interviewees indicated that the correct timing to inform patients about SDM and treatment options has previously been and continues to be of great concern. Therefore, the team developed strategies to anchor the platform to patient care pathways.

The interviewees specified that, even though the realisation of SDM is the goal of the project, not every patient will want to make use of this opportunity. Furthermore, they expressed that they consider the will to participate in SDM to be unrelated to age. The platform is, therefore, designed for adults of all ages with various diagnoses. *"Our goal is that each patient gets the opportunity, if they want it".* User-friendliness has been an important driver for the platform's design. The interviewees explained that this is reflected in the architecture of the platform, which has been kept basic to enhance user-friendliness and avoid distractions from what they considered to be the main enabler of SDM: open communication during a consult. In addition, the interviewees indicated that adolescents need to be addressed differently; this concern was not in the scope of the project at the time of the interview, but may be assessed in the future. The interviewees explained that the team regards the platform as a tool that can be used in combination with other tools and strategies to promote SDM.

Expanding the project's scope

Different nuances could be noted between the statements from the two interviewees concerning the platform. These differences relate to the progressing insights that the team has obtained during the development of the platform, as well as the members' varying expertise. The team member who had been involved in the project from the start focused more on the platform's content and architecture. Initially, the main goal of the project was to develop a platform that provided relevant information to patients with CKF to enable them take part in the selection of a treatment method. The focus was on the selection of relevant information and providing that information in a clear and understandable way. Over time, the scope of the project has broadened and become more complex. This was partly due to the team gaining a better understanding of the concept of SDM and partly enabled through the growing budget that became available as the project obtained support from external parties. " *We have all learned along the way. But that only means that our understanding of SDM has grown".* This broader scope is reflected in statements from the other team member, who described the platform as a measure for supporting SDM that is part of a system of supporting strategies.

The interviewees pointed to an insight that has led them to change the platform's structure. During the development of the project, they realised that the patients needed to be informed via the platform that there is a choice to make, and that the platform needs to motivate them to participate in this choice. Establishing a mind-set towards SDM is needed to encourage patients to reflect upon the information about the treatment in relation to their own values and beliefs. "*It is the framework around the information that motivates participation in SDM... It is not just about telling [the patients] about treatment options, then the patient still does not realise that he or she has a choice".* To encourage the platform's use and support a change of practice from paternalism to SDM, the development of supportive systems around the platform became key. *"To develop a structure around the consult and the decision, to enable patients to answer the question ['What do I want?'] together with medical specialists".* The use of the platform is now promoted on several levels: a) inside the platform by focusing on motivation and involving medical practitioners in the development of the information section, b) outside the platform by developing routines around the platform to implement it in patient care pathways and c) through the development of supporting strategies in the form of training for medical practitioners. Figure 12 depicts this layered strategy. These shifts in focus show that the team's understanding of SDM has deepened, realising that only providing a platform with information about treatment options was insufficient to support SDM. The interviewees pointed out that tight collaboration with healthcare practitioners during the development phase has been an important strategy to ensure the platform's use in practice. Consideration of the patient care pathway has been key in steering the implementation strategy regarding when and how patients are introduced to the platform.

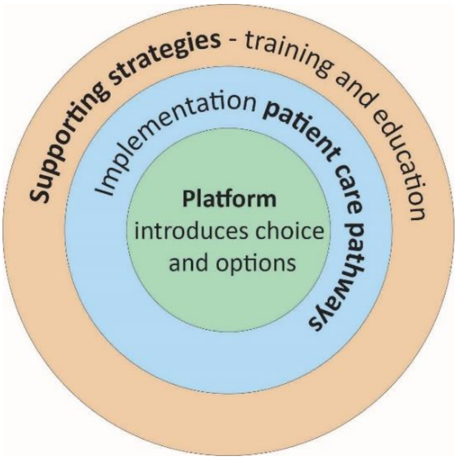


Figure 12 – Layered strategy to promote shared decision making

Challenges and uncertainties

The interviewees were eager to point to the challenge they are facing: SDM is a culture change for both patients and medical practitioners. To achieve SDM in practice, both parties need to participate. *"In fact, it affects both healthcare practitioners and patients".* The interviewees indicated that the involvement and support of both parties from the start of the project have been important, as they enriched and strengthened the platform's design. The design process was iterative; Various user studies have contributed to better understanding of the challenges around SDM and changes to the platform's design. At the time of the interview, the interviewees indicated that the team was still open to well-motivated changes.

The interviewees expressed that medical practitioners, policy makers and patients' representatives are generally positive towards the idea of SDM when the model is introduced at conferences or meetings. However, they emphasised that, even though people agree with the idea of SDM in theory, they need stimuli and guidance to really establish the required culture change in practice. This is especially challenging, as people are not necessarily unsatisfied with current practice. *"What we want to promote [SDM] goes against all habits and traditions of both healthcare staff and patients. Nobody is asking for it, and nobody will do it without being pushed".* The interviewees conveyed that they consider the theory-based motivation part of the platform, as well as the development of a structure around the consult central for promoting SDM. However, these tools and processes are mere supports for SDM that intend to facilitate an open dialogue between a medical practitioner and a patient during a consultation. Eventually, this open dialogue is imperative for SDM.

The interviewees expressed that the platform should not distract from this open dialogue and is, therefore, kept basic in both design and content. Film snaps with medical practitioners are included in the information part to support understanding. A lot of consideration has gone into the production of the film snaps to avoid bias and build trust. Film snaps with patient narratives have been added to the motivation part to encourage people to study the information on the website. The interviewees' explained that the team's main motivation to include these narratives on the platform is that they know that patients value such narratives and spend more time on websites that include patient narratives. The interviewees clarified that their way of applying the film snaps with patient narratives is unique in that the patients talk about their experience in taking part in their treatment choice, not about which choice they made. This was a deliberate decision to avoid bias. One of the interviewees elucidated that, ideally, the patient narratives would come from patients who had actually participated in SDM. However, as SDM has not been practiced in Norway previously, it was impossible to include such patients. Furthermore, people who are new to SDM would not have been familiar with their narratives, as the concept is rather different from what they are used to experiencing.

The team has added a reflection section on the platform. The interviewees described that their motivation was 'there's no harm in trying'; although clear scientific evidence for its effects was lacking, it is known that patients value being able to reflect. The interviewees expressed that the development of a motivational and information platform that is part of a system to support SDM is more important for them. Whether specific elements of the platform, such as the reflection part, contribute to SDM will not be evaluated. Only the project's goal of realising SDM will be assessed once the platform is finished and implemented in practice.

The interviewees expressed that the team is convinced that the culture change is one that eventually will endure, but that they want to realise this change in a respectful way. *"It is a bit like coloured tv, it has come to stay. It is not something you say no to, but the question is whether we do it in a respectful way".* At the time of the interview, the team was concerned about handing some responsibilities over to others and introducing the project into daily practice whilst maintaining the same level of quality. They expressed concerns related to people's understanding of the complexity around SDM. *"There are some professional quality criteria that must be followed. If not, [SDM] will not be what is supposed to be".*

Despite the challenges and uncertainties that the team had been experiencing, the team members' statements showed that they have learned a lot during the development process. The next paragraph focuses on these learnings.

Striking the right balance

The development of the content and structure of the platform appeared to be a balancing act. At several instances during the interview, the interviewees referred to searching for a balance. First, they expressed that the team had a strong focus on offering sufficient information to help patients make a well-reflected decision. At the same time, they aimed to offer only that information that patients need to be able to make a choice. *"What do I [as a patient] need to reach the point where I can express my preferences to a medical specialist?"* The interviewees explained that making decisions related to the amount of information was a challenge for the team, as they know that patients prefer to receive as much information as possible.

Second, the interviewees further explained that a lot of consideration had gone into the formulation of the text. They emphasised that there are some evidence-based guidelines, but that user testing is imperative for optimising the text. The challenge is that text should be understandable, but not too simplified to empower patients. The expertise of the patient should be credited. The patient should get a chance to familiarise himself or herself with important terminology. Nevertheless, the text should not become too complicated. *"This is about formulating a medical message so that people understand it whilst maintaining the medical or scientific content".*

Finally, the interviewees explained that the team not only considered what information to present, but also how to present it visually: simple and clear to be easy to navigate and understand, but interesting enough for people to use the platform. A combination of text and film snaps is used to maintain people's attention and to support understanding. The challenge was to make the platform interesting, but maintain the focus on the goal of realising SDM in a consult and supporting this kind of communication. *"It is not only about which information you offer, but also about how it is structured. This determines if it is used or not".*

In summary, the findings of the expert interview provide an insight into how a project initiated by a medical practitioner was developed into a national strategy to promote SDM. The experiences that the interviewees expressed show how their understanding of SDM developed, resulting in a focus shift from the development of a platform as single intervention to the development of implementation and support strategies to ensure its use in practice. Their statements indicate the importance of involving both medical practitioners and patients in the development process to ensure that the platform fits in the healthcare service.

Discussion

In SDM, the expertise from both the patient and medical expert are recognised. An important insight by the development team was that this might be needed to be emphasised in the decision aid. Comparing the approach of the team to the other digital platforms reviewed the desk research study (section 6.1) shows there were two other digital platforms that provide an argument on why patients should participate in the treatment decision, pointing to effects on lifestyle. Explaining the reasoning behind SDM is, thus, not a topic that is standardly included on digital platforms. Informing patients that there is a choice to make and why their involvement is important is the first step in the SDM process (Elwyn et al., 2012). Kienlin (2015) showed that patients can be reluctant to become involved in SDM when they regard the medical practitioner as the expert. A change in attitude needs to be established before such patients become interested in discovering the different treatment options and considering their preferences. The case study of the Kidney School (section 7.1) shows only providing information on options during an education program can be insufficient, as patients might just expect to receive extra information, not being aware that they are offered to actively take part in treatment decisions. According to the learning theory, people attend to information that is viable with their mental world (Savery & Duffy, 2001). Therefore, if people do not have a mind-set towards SDM, they might not use their time and energy to investigate the available information about different treatment options. However, if a patient is motivated to participate in SDM, he or she is much more likely to investigate the information on the different options that are presented on a digital platform. As SDM is a process, and a decision aid is a tool to support the process, the motivation for a patient to participate in the treatment decision should not necessarily be included in the decision aid. The motivation can be mediated in other ways. However, motivating a patient to participate and changing their attitude towards SDM is an important first step to move away from traditional paternalistic decision-making processes. According to the learning theory, repeating a message through different mediation techniques increases the likelihood that it is acknowledged (Hjelsvold, 2017). Therefore, including a message that conveys the motivation to participate in SDM from a patient perspective at the start of the decision aid, similar to the material displayed by this development team, might foster the SDM process. Furthermore, the developers argue that people who were not informed by their physician about SDM might find the decision aid online. For these individuals, it appears relevant to include arguments for SDM in the decision aid, as they might not otherwise understand that they have a choice.

The three information websites that were analysed in the desk research study (section 6.1) included narratives of experienced patients, two in the form of videos, the third in the form of personas. The studies on education programs (section 5.2 and 7.1) showed that many programs invited experienced patients to support education and that patients reported feeling appreciative of their presence. The developers interviewed on the design of their *decision aids, however,* indicated that they were concerned that patients would be biased by these stories. Their decision aid therefore did include patient narratives in the form of videos, but the patients in these videos did not talk about which treatment option they chose. They only discussed their experience of participating in the treatment decision. The developers deliberately did this to avoid biasing users regarding treatment options.

A call for service design

Digital platforms, such as information websites and decision aids, might be used as support tools for the SDM process. Such digital platforms can support medical practitioners in presenting unbiased information concerning treatment options (Kasper et al., 2010). Decision aids are also intended to help reflect upon the information and reach informed preferences

(Elwyn et al., 2012). As digital platforms are supporting tools, they do not necessarily need to meet all the requirements that a clinical guideline document or a patient law prescribes. The requirements can be met by other supplementary interventions. The developers that were interviewed affirmed this matter, explaining that their experience with developing a decision aid made them realise that a decision aid is a part of a system of supporting strategies. It is a tool that can be used in combination with other tools and strategies to support SDM. Furthermore, the developers realised that, to ensure the use of the decision aid in practice, the development of a supportive system around the platform is key. The focus of the project has, therefore, shifted focus from the development of a tool to the development of a holistic program to support SDM. From a design practitioner perspective, service design appears to be a relevant approach to develop a holistic program.

For the websites that were reviewed (section 6.1) it is unknown if they were introduced in clinical practice with supporting strategies, or if they were developed as an independent intervention. The same goes for the analysis of face-to-face education programs (section 5,2); the articles that describe these programs provide little information on how they are implemented into practice. Both reviews show that education solutions vary greatly in set-up and content. Furthermore, they do not always meet the requirements that are posed to patient education programs in clinical guidelines (section 3.2), nor the information needs expressed by patients (section 5,1), These insights show the relevance of applying a service design approach when developing education programs, as service design allows the design of holistic healthcare services of which several interventions may be part.

The importance of being aware of a platform's context is underlined by the constructivist learning theory. According to this theory, in order to obtain the most benefits from an educational service, the service should match the learner's knowledge level (Hjelsvold, 2017). Being aware of the information a patient and their next-of-kin have received from other interactions with medical specialists earlier in the patient journey will help the development team of a digital platform decide the material that needs to be included on the platform. Understanding the knowledge level of the user is especially important for developers of digital platforms, as the user will generally not have the possibility to ask questions directly. One of the benefits of a digital platform is that people can access it at any time and from anywhere with access to the Internet. The interview with the developers showed that considering the patient pathways can support a team in developing a strategy regarding when and how patients are introduced to the platform, and what information to present on it

The goal when designing services for healthcare is to improve care for the patient whilst providing healthcare practitioners with a satisfying work experience (Hans, 2015). In addition to being a support in determining the content of the digital platform, service design could support development teams, as the process of SDM is best supported through a holistic strategy. As the expert in the interview explained, not only does the platform need to be designed, but an implementation strategy also needs to be developed, and the medical practitioners need to be trained to use the tools and provide guidance to patients in the SDM process. The latter is very important, as the responsibility for the facilitation of the SDM process lies with the medical practitioner (Charles et al., 1997). The interactions that take place between patients and medical practitioners, in addition to their behaviour during consults, are critical for achieving SDM. Digital platforms can and should not replace the entire SDM process. Individuals dealing with a serious illness should have the opportunity to discuss questions concerning their illness and treatment methods with a healthcare professional.

The involvement of stakeholders in the design process is an important pillar in service design, as they know their own needs and preferences best (Bechmann, 2010). The developers that were interviewed indicated that the involvement of stakeholders, such as medical practitioners, and patients from the start of the project helped them develop a platform that supports the culture change that is required for SDM. Their involvement helped to ensure that the platform was user-friendly and had relevant content. Furthermore, this helped the developers to construct a holistic strategy that supported the platform's implementation in current practice. The challenge with a service design approach is that the process does not have a clear ending (Bechmann, 2010). The interview with the developers showed that this was a challenge in the project, as the scope of the project has changed and extended over time. The developers' remarks on being open for well-substantiated suggestions for change indicates that their decisions had not yet been 'set in stone'.

Contribution to medical practice

For medical practitioners who want to develop an educational intervention to support SDM, the insight from the team that even though people agree with the idea of SDM in theory, they need stimuli and guidance to really change their practice, is relevant to be aware of. Furthermore, the team's insight that developing an independent intervention is insufficient to realize SDM, is an insights that medical practitioners can benefit from. To have realistic expectations, medical practitioners should realize at the start of a project that decision aids are mere supports, while open communication during a consult is key to SDM. Digital platforms can and should therefore not replace the entire SDM process.

It has been argued that the required detail of information that is offered to patients and their next-of-kin on digital platforms needs further investigation (Stacey et al., 2014). This study shows that the discussions should not only focus on the content of a specific intervention. Decisions on the content of the intervention should rather be taking with regard to the information that is offered in the rest of the care service. This shows that a service design approach is relevant for the development of patient education programs. Service design allows the development of supporting strategies, and the design of a solution that can be implemented in patient care pathways, in addition to the development of the educational intervention itself.

Relevance for designers

This study shows that applying a service design approach can support developers of education or decision support programs in deciding what information to include in a specific part of the service offer. Elwyn et al. (2012) have described SDM as a three-phase process. Education and/or decision support programs may be used to support the SDM process. However, these programs can only cover parts of the three phases of the SDM model (section 5.2 and 7.1). The weight of education programs commonly lies on phase 2, teaching patients about their options. Decision support programs commonly cover phase 2 and part of phase 3, as they present patients with treatment options and support them in forming informed preferences. Regarding SDM from a service design perspective shows that the healthcare service should include additional complementary interactions to ensure that the SDM process is holistically supported, as neither patient education programs nor decision support programs cover all three phases. To realise SDM, a service should also provide support for phase 1, motivating patients to participate in the decision, and it should allow for deliberation on options in the form of a discussion between healthcare practitioners and patient, which is the final part of phase 3.

Designers can learn from specific insights that the team has obtained during the project; a) Only providing information on options is insufficient, patients should be informed that they have a choice to make. b) Anchoring the intervention in patient care pathways and the development of supportive strategies to ensure the correct timing and use of the decision aid. As these projects thus require a holistic approach, service design is relevant. c) Patient stories on their experiences with a treatment may introduce bias, as the effect of treatment on patients is individual, while new patients might come to prefer the treatment that the experienced patient with whom they identify undergoes. d) The formulation of the content is a balancing act between delivering sufficient information and avoiding information overload, between patient empowerment and keeping the content understandable, and between visual simplicity and attractiveness of the website's design.

7. Face-to-face pre-treatment patient education programs

This chapter focuses on face-to-face pre-treatment patient education programs. Section 7.1 presents a case study in which two contemporary offers of face-to-face pre-treatment patient education programs for people with CKF and their next-of-kin were examined. Section 7.2 presents a co-design workshop and evaluation study that were conducted in the follow-up of the first study. This follow-up study was organised with the goal of reducing the gaps that were identified in the study.

7.1 Mind the Gap – A case study on pre-treatment patient education[13]

Abstract

Studies on pre-treatment education programs show that such programs can have significant benefits for patients. It remains however unclear which aspects of education programs contribute to or constrain SDM. The aim of the study was therefore to gain in-depth insights into how patient education programs are organised in practice and to build knowledge of the motivations behind their structure. Additionally, the study aimed to investigate the experiences of both medical specialists and patients with these programs to gain knowledge of how specific aspects of these programs contribute to empowering or constraining patients to take part in treatment decisions.

Interviews with the organisers of two education programs were conducted. In addition, the group sessions of one of these programs and interviews with three patients that had participated in this program were done.

In addition to providing insight into the set-up and history of these two programs, the interviews with the organisers provide knowledge on the intentions and pedagogic approaches of the organisers of these programs. The interviews with participants and observations showed that gaps may occur between intentions, expectations, and experiences. The insight into how the programs have changed and the motivations behind their formats insights are of relevance for medical practitioners who want to develop similar programs. This study furthermore contributes with suggestions on practical aspects that designers may reflect upon when developing a pre-treatment education program for patients.

Aim of the study

In chapter 5, two literature review studies are presented. The first review (section 5.1), provided insights in the information needs of patients with CKF and their next-of-kin when facing a treatment choice. The second review (section 5.2), contributed with insights into how contemporary education programs are structured, but provided little insights into which aspects of these programs contribute to their effectiveness.

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[13] The text below is partly based on an article that was published in the Proceedings of the 4th European Workshop on Practical Aspects of Health Informatics (PAHI 2017), called 'Co-Design in Specialist Care - Aspects to Consider' (Vis, 2017). This article presented part B of the study. The original article can be found in Appendix C.

The overall goal of this thesis is to acquire a better understanding of aspects that can support the (re)design of such education programs. This study aimed to contribute to this goal, by investigating face-to-face education programs further to gain in-depth insights into how patient education programs are organised in practice and to build knowledge of the motivations behind their structure. Additionally, this study aimed to investigate the experiences of both medical specialists and patients with these programs, to gain knowledge of how specific aspects of these programs contribute to empowering or constraining patients to take part in treatment decisions. Even though a broad range of pre-treatment education programs are practiced internationally (Harwood and Clark (2013), and each program is unique, investigating the programs and communicating their effects will help to develop better pre-treatment education programs, in general (National Kidney Foundation, 2015). The specific research questions that this study aimed to answer were: How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organised? And 2: Which aspects of face-to-face education programs may support or constrain shared decision making?

Effective education depends on the alignment between learning objectives and the learning activities (Biggs, 1999). Checking whether an education program supports its objectives may lead to insights for its improvement, as knowledge building is not a linear information mediation process, but rather involves second-order understanding (Krippendorff, 2006). The insights from this study intent to contribute to a better understanding of aspects of education programs that support SDM. This knowledge can support service designers in the development of better pre-treatment education programs.

Method Case 1: The Kidney School

Methodological Approach

An explorative, single case study (Yin, 2003) built on qualitative research methods was conducted to study pre-treatment patient education in its context and to attain access to first-hand data. Methodologies that evolve around open-ended questioning of individuals and observations were applied.

Study Design

The case study was built upon three sets of data: interviews with healthcare professionals who organised the program, observations during the group sessions of the education program and interviews with patients that had participated in the program. Face-to-face interviewing was employed for the interviews. The interview guides for both studies were semi-structured and listed key themes to discuss. Non-participatory direct observations were realised to collect real-life, first-hand data. The observers paid attention to language use, attitude and behaviour of the presenters, as well as to interactions between the presenters and participants.

Case 1: The Kidney school

An established pre-treatment patient education program of an academic hospital in Norway, called the Kidney School, was selected as study case. The Kidney School provides an education prpgram that is intended for people who are expected to soon need to start renal replacement therapy and their next-of-kin. The program at this hospital was selected as study case as the hospital was one of the first hospitals in Norway to set up such an education program. The hospital now has more than fifteen years of experience with the program. Comparable programs have since been started in other hospitals in Norway. Furthermore, the hospital is located in central Norway, close to the university. The program at this hospital consists of a one-hour consult with a nurse and three afternoons with group sessions. These sessions are organised twice a year. Each afternoon consists of three presentations of 45 minutes with 15-minute breaks in between. Healthcare professionals and experienced patients who have started on treatment give the presentations.

Study Participants

The case study consists of an expert interview with the two nurses who organised the program, observations of the group education sessions they facilitated and individual interviews with three patients. The selection of participants for the expert interview was based on purposeful sampling (Patton, 2002). The two nurses who run the Kidney School were asked if they wanted to participate in an interview. Recruitment was organised by the second supervisor, as she has a background in nursing and knew one of the nurses responsible for the program. This made it easier to obtain access to execute research. The subjects of study during the observational study were the presenters at the group education sessions as well as the patients and their next-of-kin, who participated in the group education program. One presentation was not observed, as the presenter expected that the presence of the researchers could negatively affect the education session and, therefore, did not consent to observation. To recruit participants for the patient interviews, the nurses sent an invitation letter to eleven of the thirteen patients who participated in the program in 2015. Two patients were not invited, as their personal circumstances were taken into consideration. Three patients responded to the letter after a reminder was sent to them.

Data Collection

Table 9 presents an overview of the applied data collection methods, including some practical details. First, an expert interview was conducted in which both nurses responsible for the organisation of the program were interviewed together. The aim of this interview was to collect data on what information is included in the program and why, and how this information is communicated to the participants. The main research question for the interviews was "What is the role of the Kidney School in the informing of patients and their

Study method	Study participants	Timing	Researchers
Expert interview	Two nurses who organised the program	11 March 2015, 2 hours	PhD candidate, 2nd supervisor
Observation	Presenters at group education sessions	14, 15, 21 April 2015, 3x 3 hours	PhD candidate, 1st and 2nd supervisors
Participant interview	Three patients	January 2016, 3x 1 hour	PhD candidate and master student

Table 9 - Overview of data collection methods

Introduction	intro + informed consent
Background	Responsibility / role of interviewees?
Main topics	Can you explain what the Kidney School is? • Goal? / For whom? • Practical information on organisation • What information is transmitted? • Cooperation • What does the patient's journey look like? • Patient's role in decision making? • Motivation for start of program • Experiences with the program • Changes in the program?
Conclusion	Something not discussed? Thank for participation.

Table 10 - Interview guide of expert interview with nurses

next-of-kin?" Pre-defined topics concerned the goal, target group, organisation, content and history of the program. Table 10 presents the interview guide of the interview in key words. The interview was conducted by two researchers to facilitate a group conversation and took place at the office of the two nurses. Written informed consent was obtained from both nurses before the start of the interview.

Second, non-participatory direct observations (Robson, 2011) of the three-day education program at the Kidney School were attained. The goal of this part of the study was to collect first-hand insights on how and what information is mediated during the group education sessions in reality. Presenters gave written informed consent before the start of their presentation. During each presentation, two researchers acted as non-participating observers, focusing on the language use, attitude and behaviour of the presenters. The observers individually transcribed their notes the same day or the day after the observations to reduce the influence of recall.

Third, three patients who had attended the observed group sessions partook in individual interviews. The main research question for these interviews was: "How do patients experience the program at the Kidney school?" Pre-defined topics concerned expectations, content, contact with others and relevance. Table 11 presents the interview guide of the interview in key words. These interviews were conducted by the first author and a master's student in industrial design. The interviews were conducted in meeting rooms of public buildings (e.g. hospital and library). During the expert interview and the patient interviews, open questions addressing the pre-defined topics were formulated. Participants gave written informed consent before the start of the interview. During the interviews, the researchers took short notes. The interviews were audio-recorded and transcribed verbatim and anonymised afterwards.

Introduction	intro + informed consent
Background	Started on treatment? If yes, how long?
Main topics	*Group sessions* • Expectations • Content / Info (interests, missing, obsolete) • Contact with others • Relevance • *Individual consult* • Had individual consult? • First contact with Kidney School • Experiences • Content / Info (interests, missing, obsolete) • Other info sources (brochures / Internet
Conclusion	Something not discussed? Thank for participation.

Table 11 - Interview guide of patient interviews

Analysis Process

The interview transcript and observation notes were shared between the PhD candidate and the first and second supervisors. The PhD candidate started analysing data when the expert interview and the observations had been conducted, prior to the patient interviews. NVivo10 (QSR-International, 2015) was used to structure the data. The Constant Comparative Method, as described by Boeije (2002), was used for data analysis (section 4.2.4). Supports such as memo writing, close reading and re-reading have been applied throughout the analysis process, which relied on hermeneutic interpretation of the transcribed texts. The focus lied on finding meanings in the experiences through the interpretation of linguistic expressions and acts (Alvesson & Sköldberg, 2009). Insights were obtained by investigating the structure of the information, the views of the different stakeholders (patients and nurses), including their expectations, and studying what happened in reality. The process of analysis involved the formulation of concepts and the assignment of lines of data to them (meaning units), as well as the development of categories and their features by seeking relationships across the defined concepts (Holloway, 2005). During the analysis process, concepts were eventually renamed and their boundry descriptions were formulated and revised. Therefore, analysing was a circular process in which the understanding of the text was supported by the merging of the new insights with the researchers' pre-understanding, leading to a new understanding (Holloway, 2005). During this process, the first author wrote memos to track thoughts and decisions. The process resulted in a tree structure with the main categories and underlying related concepts. For quality assurance, the temporary descriptions and concepts were constantly compared to the original transcript and notes of the researchers.

After the initial analysis, the three researchers came together for a discussion about their individual impressions of the data. The discussion focused on the formulated concepts, their descriptions and the interpretation of their meaning. The group reflection process that emerged through these discussions led to new insights. The first researcher went back to the original transcripts with these new insights to deepen her understanding of the meaning of the experiences and to put this into writing. This text was then discussed during a second meeting. This meeting focused on how the findings of each data source came together and on which points they differed. The deductive discussions contributed to the (re)formulation of categories and a framing of their boundaries and relations to each other. It resulted in a descriptive statement of the diverse intentions and expectations in addition to what happened in reality.

Method Case 2: Dialysis network

Methodological Approach

Originally, the plan was to conduct an explorative, comparative case study (Yin, 2003) in which two single case studies would be compared. This would have enabled us to investigate the commonalities and differences between the two programs. To allow for comparison, the second case study would have built on a similar dataset consisting of three sets of data: interviews with healthcare professionals who organised the program, observations during the group sessions of the education program and interviews with patients who had participated in the program. However, the methodoligical approach was changed when the group sessions for the second case were canceled by the organisers, as too few patients had subscribed. Consequently, the observations and interviews with patients about their experience of the program had to be canceled. A third party was approached with the question of whether they would be interested in participating in the study. As this third party did not want the patients in their program to be contacted, it was decided to continue the study with the second party. Qualitative interviews with two organisers of a pre-treatment education program were conducted to obtain an understanding of the structure of the program and the motivations that lie behind its set-up.

Study Design

The qualitative study was built on face-to-face interviews with healthcare professionals who are involved in the organisation of the education program. The interview guide was similar to the interview guide that was used during the study of the Kidney School (Table 10).

Case 2: Dialysis network

A pre-treatment education program of a specialised dialysis clinic in the Netherlands called "Dialysis Network"[14] was selected as the study object. The clinic's education program is intended for people who soon need to start renal replacement therapy and their families. This clinic was selected because it has a long history of offering home haemodialysis (almost 50 years). Today, the clinic supports all types of dialysis. The clinic was established in 1998 as the result of a merger between an institute for home haemodialysis in central Netherlands, which was connected to the regional academic hospital and founded in 1968, and an independent organisation that focused on in-centre self-care that was founded in 1975. In 2001, a collaboration with an academic hospital in central Netherlands was started, where they now

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[14] N.B. The name "Dialysis Network" is used as an alias to preserve anonymity.

manage the dialysis department. Nowadays, the clinic has three dialysis centres in central Netherlands and delivers in-centre care to 250 to 300 patients and home haemodialysis care to about 150 patients. Some of these home care patients are under care at one of the forty-five hospitals nationwide with which the clinic collaborates, but receive support from the clinic to perform home haemodialysis. Some of these patients have previously undergone in-centre dialysis. The clinic thus has a double role: They are an independent clinic, but also a partner for other hospitals.
The clinic takes care for all the practicalities around dialysing at home, such as home adjustments, training and the delivery of materials. The clinic organises home haemodialysis care for three types of patients: those who perform full self-care after receiving an 8- to 12-week training, those who need some support after training and those who are fully dependent on a nurse to perform the dialysis sessions.

Study Participants

Two expert interviews were conducted with two professionals involved in the organisation of the program. The selection of the first participant for the expert interview was based on purposeful sampling (Patton, 2002). The PhD candidate contacted the 'care manager' of the clinic by phone. During the phone call, I informed him about my research and the reason for my interest in the organisation where he worked. After the agreement, I sent an email to the care manager with additional information about my project and the aim of the interview. The care manager was responsible for the organisation of all care-related tasks at the company's three clinics and at the homes of patients who are accepting medical care. The care manager had been working at the clinic for six years. After the interview, the care manager brought me into contact with a nurse who is specialised in dialysis and was responsible for the practical organisation of the education program. The nurse had been working at the clinic for twelve years. Via email, I made an appointment for an interview with this nurse.

Study method	Study participants	Timing	Researcher
Expert interview 1	Care manager	4 November 2015, 1 hour, Utrecht	PhD candidate
Expert interview 2	Nurse who organised the program	22 December 2015, 1 hour, Amsterdam	PhD candidate

Table 12 - Overview of data collection methods

Data Collection

Table 12 presents an overview of data collection through two expert interviews, including some practical details. The aim and set-up of the interviews was similar to the expert interview that was held with the organisers of the education program at the Kidney School: to collect data on the information that is included in the program and why and how this information is communicated to the participants. The main research question for the interviews was, "What is the role of the Dialysis Network in the informing of patients and their next-of-kin?" The interviews were conducted by the PhD candidate and took place at the offices of the interviewees. The experts were interviewed separately, as they worked at different locations. Written informed consent was obtained from both experts before the start of the interviews.

The interview guide was semi-structured. The interviews were audio-recorded. Open questions addressing pre-defined topics were formulated during the flow of the interviews and the PhD candidate took short notes. The PhD candidate transcribed the interview records verbatim afterwards to support analysis.

Analysis Process

The PhD candidate analysed the interview transcripts of both expert interviews. To be able to compare the findings from the case study on the Kidney School with the data from the expert interviews in the program by the Dialysis Network, the transcripts of both expert interviews were analysed with the assistance of directed qualitative content analysis (Hsieh & Shannon, 2005). The themes that were used for data analysis reflected the categorised findings of the first case study. Data analysis, thus, relied on deductive reasoning. NVivo10 (QSR-International, 2015) was used to structure the data. Data that did not belong under one of the predefined themes was analysed inductively by applying the Constant Comparative Method. Coding and categorisation led to the formulation of additional insights. After the initial analysis of the transcripts, I sent the description of my findings to my second supervisor. We met to discuss my interpretation of the findings, focusing on the motivations behind my interpretations. The disocussion addressed the formulated concepts, their descriptions, and my interpretation of their meaning. After this discussion, I went back to the original transcripts with the new insights that had developed in the discussions with my second supervisor in mind. Reflecting over the discussion and reading through the data anew deepend my understanding of the meaning of the of specific expressions from the interviewees.

Findings – Mapping intentions, expectations and experiences, discovering gaps

The overall goal of this thesis is to acquire a better understanding of aspects that can support the (re)design of such education programs. This study aimed to contribute to this goal, by collecting in-depth insights on how patient education programs are organised in practice and by acquiring knowledge of the motivations behind their structure. The findings presented in the following paragraphs answer the first research question, which was: How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organized? An overview of two pre-treatment education programs and their set-up is presented

Description of the Kidney School (Case 1)

The nurses explained that the Kidney School is a program for pre-treatment education of patients and their next-of-kin. The Kidney School was started in 2000 as a project that was funded by a commercial medical company, offering two nurses a 50% position each. One year later, the project was taken over by the hospital and incorporated in the outpatient clinic. The program is still run by two nurses, with a 50% post at the Kidney School and a 50% post at the outpatient clinic.

Figure 13 depicts a generalised patient journey of people with diminished kidney functioning at this hospital. The blue circle indicates the current program at the Kidney School. After patients

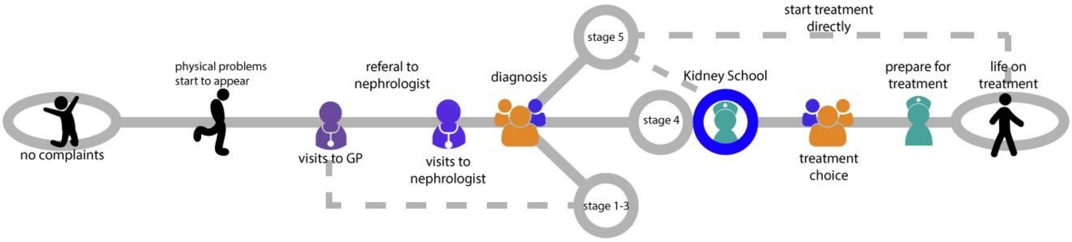

Figure 13 - A generalised patient journey for chronic kidney failure patients

have been referred to a nephrologist by their general practitioner, they are diagnosed according to their remaining kidney function (stage 1-5). People are usually referred to the Kidney School by their nephrologists when it is expected that they will need to start renal replacement therapy within the coming year (stage 4). Patients that are referred later (stage 5) or those who develop renal failure acutely are also invited to participate. These patients have often already started treatment prior to participation in the Kidney School. Participation is voluntary, but patients might be required to pay a small participation fee.

Set-up of the program at the Kidney School

The program consists of an individual consult of one hour with one of the two nurses who run the Kidney School and three afternoons with group sessions. The nurses' intention with the first consult is to introduce the participants to the topics that will be further discussed during the group sessions. The individual consults take place in the nurses' office.

The group sessions are organised twice a year and consist of three-hour sessions over three afternoons. Usually, there are around 15-20 participants, depending on the number of newly referred patients and how many of them are accompanied by their next-of-kin. Forth-five minutes are reserved for each topic. A multi-disciplinary team of medical professionals, including a sociologist, a priest, nephrologists, a physiotherapist, a dietician and specialised nurses give the presentations. Furthermore, experienced patients who have started renal replacement therapy contribute in the presentations about treatment methods. A member from the patient society also gives a short presentation. Although the nurses have a preferred set-up of the group sessions, the order of the presentations differs in each course, due to the full schedules of the medical professionals and limited availability of larger meeting rooms.

The participants have the possibility to schedule an additional individual meeting after the group sessions with one of the nurses to discuss any further questions or concerns. Furthermore, the nurses can make an appointment with a nurse working with one of the dialysis types for individuals who want to learn more about that treatment.

The nurses' intentions and pedagogic approach

The Kidney School is set up for people who soon need to start renal replacement therapy, but have not yet selected a treatment method. Next-of-kin are also invited, as two people remember more than one. The nurses' goal with the Kidney School is twofold: 1) helping patients and their next-of-kin accept their situation and 2) informing them about treatment options in order to discuss their preferences with their physician. As one nurse pointed out*: "It is your choice. What will fit best into your life?"*

The blue-coloured rows in Table 13 indicate presentations that mainly support living with CKF. The white rows indicate presentations that mainly support treatment choice. In addition, these presentations also support coping when an experienced patient is involved as a presenter.

It is the nurses' intention that people first have an individual consult with one of them before they participate in the group sessions. The nurses' motivation to foster these actions is to encourage the participants to start thinking about the subject in order to be better prepared for the information they receive during the group sessions. Over the years, the nurses have changed their approach to the individual consults, as they realised that focusing on the patient and their specific questions is more useful than briefly addressing every topic. The following statement by one of the nurses illustrates this: *"I've found out that it is easier to adapt the information to the person I have in front of me. It is more useful, relevant and interesting for him or her".* One of the benefits of this approach is that the nurses can adapt the educational approach to the individual state of the patient. A disadvantage is that patients receive different

Day	Time	Who	Topics
1	11.50-12.00	Organising Nurses	Welcome participants
	12.00-12.45	Hospital's Priest	Challenges, pitfalls and coping strategies when chronic illness becomes part of daily life.
	13.00-13.45	Nephrologist	What is the function of the kidneys? How does kidney failure develop? and What medical treatments are there?
	14.00-14.45	Sociologist	Your rights in relation to chronic illness
2	12.00-12.45	Nephrologist	Transplantation and kidney donation
	13.00-13.45	Physiotherapist	Physical activity, active hour
	14.00-14.30	Kidney donor and receiver	My experiences of donating a kidney. My experiences of receiving a kidney.
	14.30-14.45	Patient society	Information on the patient society
3	12.00-12.45	Dietician	Diet with kidney failure
	13.00-13.45	PD nurse and patient	Peritoneal dialysis (PD)
	14.00-14.45	HD nurse and patient	Haemodialysis (HD)

Table 13 – Overview of the program at the Kidney School, April 2015

information during individual consults and, thus, are differently prepared for the group sessions. To help start the conversation, the nurses make use of a ring binder with images and keywords related to the various topics.
Non-Norwegian-speaking patients are educated through individual consults only, as the group sessions are in Norwegian. Educating non-Norwegian-speaking people is experienced as a challenge, due to language issues and cultural differences. Furthermore, the nurses can be unsure about the patient's reading abilities and their knowledge of biological mechanisms.

The intention with the group sessions is to discuss the various topics more in depth. After each topic, there is a 15-minute break to give the participants some time to relax. One nurse explained: *"There is a break between each hour and we try to air the room and so forth to provide them with the best possible learning conditions, as they are often tired".* The nurses have evaluated the group sessions several times via questionnaires that the participants filled out at the end of the last group session. Based on this feedback, the group sessions were shortened from five to three hours a day, as it required a lot of energy from the participants and some information was too detailed (e.g. blood tests). Practical reasons, such as the effort needed to arrange the course, also played a part in this decision. Experienced patients have been given a larger role than before, as participants appreciated their presence. The nurses carefully select these experienced patients and invite them to talk about their treatment during the group sessions in order to help patients understand the practicalities of the treatment. Through these talks, the participants can also associate themselves with the experienced patient and see that their situation is not hopeless. *"It is really important that they see that there is a real patient that can deal with this. Then, they might be able to do this, as well".*
Throughout the program, the nurses use a range of education strategies to give participants the opportunity to learn the most. They use various materials such as a ring binder, parts of dialysis machines, presentation slides, information brochures and a DVD to help the participants remember the information: *"Yes, well, I think that in a learning process, we are looking for points of reference where new information can fit in".*

Description of the Dialysis Network (Case 2)

In contrast to the program at the Kidney School, the program from the Dialysis Network is not only intended for pre-treatment education of patients and their next-of-kin, but also for other family members. Patients are recommended to bring their partner, siblings or children. They are allowed to bring up to three people. The program is intended for those who will soon need to start renal replacement therapy. The nephrologists who work for the hospital that is connected to the clinic refer their patients to the program. The program organisers usually remind the nephrologists about an upcoming course to ensure that patients are aware of it. Participation in the program is voluntary; consequently, some patients never attend.
Patients who develop acute CKF are first given the chance to stabilise on in-centre haemodialysis and to become accustomed to being reliant on treatment before they are informed about other treatment options. The organisation intends to become better in following up with their patients regularly to discuss whether they might wish to reconsider their choice.

Set-up of the program at the Dialysis Network

The clinic's main education method are group sessions, which are organised twice a year at the policlinic. The group size varies depending on the number of newly diagnosed patients, but the clinic aims to have about 8 to 10 participants per session. The program consists of four group sessions, each lasting 1.5 hours. The sessions are given four weeks in a row, one session per week, in the afternoon. The sessions are spread out to give participants the opportunity to digest the information a bit, as the program is rather intense. Each session has a specific theme: 1) the function of the kidneys and facing a treatment choice, 2) haemodialysis, 3) peritoneal dialysis, 4) transplantation. The order of the program is fixed, although sometimes the second and third session are interchanged, due to the availability of the presenters. The program has evolved over the years. Recently, conservative treatment has been added, mainly because of the growing number of elderly patients. The duration and time of the day has varied from morning to evening. They found the afternoon to be the best time slot, as medical practitioners need to be available and patients are tired at the end of the day. However, they are aware that this time slot can be difficult for those who have a job.

After the group education sessions, patients are followed up with an individual consultation. The clinic has some additional materials available to patients. The clinic has its own information brochure developed on home haemodialysis, which patients can order. Furthermore, they offer phone contact with experienced patients to allow patients to ask questions to peers. Additionally, they make use of a book on dialysis that is published by the Dutch Kidney Organisation.

The organisers' intentions and pedagogic approach

The goal with the program is to give patients the opportunity to decide for themselves which treatment they want. The clinic aims to support them in choosing a treatment that fits best with their life, although this might mean that patients choose a treatment that is not necessarily the best from a medical perspective. This goal setting is reflected in the clinic's mission statement: "*Delivering optimal care that fits with our patients' lifestyle*". A challenge for the clinic is that SDM is not common practice. Medical practitioners outside the clinic, therefore, do not often encourage active participation in treatment choice, and the concept is new for many patients. Nevertheless, the clinic expects that this will change. To the clinic's experience, it is difficult to predict who wants to actively participate in the treatment choice. Therefore, they offer the program to every patient, independent of age, social or cultural background. However, communicating with patients who do not speak Dutch or English is a challenge. The nurses try to find someone who can help in the communication, but they discussed the opportunities for misunderstandings; the patient needs to understand the information provided, but the practitioner also needs to understand that the patient has understood what was said. Consequently, none of these patients are currently on home haemodialysis, as training them and being sure that they understand and master the treatment is too difficult.

Group sessions are the main education method, as these meetings provide the participants the possibility to interact and discuss their experiences, thoughts and concerns with each other. During the group sessions on haemodialysis and peritoneal dialysis, experienced patients joined to share their personal experiences with one of these treatments. The patient on peritoneal dialysis also performs part of the treatment in front of the group. The experienced patients are invited to build confidence amongst participants that they can perform self-care, as well. In-centre dialysis is not represented by an experienced patient, as most of the participants have visited a dialysis clinic before they come to the training and know what this treatment looks like. The group education sessions are offered in Dutch, but some of the materials are available in English. People with various expertise, such as social workers and dieticians, give presentations. After the final group session, the participants receive a ring binder with information that was provided during the sessions. The group sessions are followed up by an individual consultation. The aim of these consultations is to gain insight into a patient's personal situation and address personal questions and concerns.

This order of group sessions first, followed by an individual consultation, is deliberate to ensure that every patient at least knows a bit about each treatment option before focusing on the patient's individual situation. In these consultations, the focus lies on a patient's lifestyle, values and beliefs to help them make a personal choice, rather than on the medical treatment. *"Discussing dialysis is less interesting. Ok, there are four variations, but treatment is unavoidable anyway".*

A challenge for the nurses are patients who do not want to think about their future or their illness. Here, the nurses need to be careful how they introduce treatment options and their necessity and start with the basics. A colleague has created a ring binder with images and pictures that represent the various topics that may be relevant to discuss. The images in the ring binder are used to explain things. Some of the images may be confronting, such as the image of a catheter. The department has a doll, which can be used to show how peritoneal dialysis is performed; however, this is hardly used, as patients have been already shown this during the group sessions. Furthermore, HD filters may be used to explain the mechanism behind HD. After the individual consult, patients receive additional information leaflets and an overview of links to websites with more information. Eventually, patients can come back for a second consult if they need more support in making a choice. The organisers recognise that they provide a lot of information, but that patients might not learn everything, as this quote illustrates: *"It's a lot of sending and hoping that it is remembered".*

As the Dialysis Network is a clinic that delivers not only pre-treatment education, but also supports patient care on treatment, they experience some additional challenges that are related to this second care phase. In the Netherlands, insurance companies are pushing for more dialysis care at home. Consequently, the number of home haemodialysis patients that needs support is quickly increasing, leading growing pressure on the available healthcare personnel that can support these people. As the clinic is independent, it has a section that is responsible for client relations, which offers information packages and training to medical practitioners about home haemodialysis. As the number of competitors is growing, the clinic has started to make use of social media to promote awareness of home haemodialysis. Even though the clinic has contracts with 45 hospitals and offers the pre-treatment education program to these hospitals, the hospitals are free to decide to organise their own pre-treatment education program, which might not pay much attention to home haemodialysis as an option. Economic motives may influence a hospital's decision concerning how to present this option, as having dialysis beds empty in their own ward is economically less beneficial.

A second aim of this study was to gain knowledge of how specific aspects of face-to-face education programs contribute to empowering or constraining patients to take part in treatment decisions. The findings that are presented in the following paragraphs provide an answer to the research question: Which aspects of face-to-face education programs may support or constrain shared decision making?

The participant's expectations of the Kidney School (Case 1)
From the interviews with participants, it came forth that it was unclear to them what exactly the program would be about. Motivations for participation related to receiving extra information from a trustworthy source, the program being recommended by their nephrologist, and for some, the expectation of meeting peers and sharing experiences with them. They expected to learn more about the disease and how to live with it and meet peers. As one of the interviewees said: *"I wanted to get advice and tips on how I can live a good life from now on, and to come into contact with others whom are in the same situation. It often feels a bit lonely".*

What was experienced during the Kidney School (Case 1)
It is not always possible to have an individual consult before the group training, as some patients are rushed into starting dialysis due to acute renal failure or sudden quick degradation of the kidney function. Therefore, patients come differently prepared to the group sessions. This variety is a challenge for the nurses: *"What they are interested is very individual",* as well as for the participants in the group sessions: " *We had different backgrounds and needs".* Educating patients effectively is experienced as challenging by the nurses, as they try to provide information to a variety of people who have been diagnosed for a different length of time and who have different coping levels. Some of the patients are very interested and eager to learn, others do not want to know anything and seem to deny that they are in a serious situation. The nurses realise that no one wants a chronic illness, which gives them the feeling that it is a difficult topic to address. *"It [Renal replacement therapy] generally does not fit into anyone's life.... It is unwanted".*
The nurses strongly recommended bringing a next-of-kin, as two people remember more than one. In practice, this can be difficult for patients. Due to the timing and place of the group sessions, the participants that were interviewed could not bring anyone, even thought they would have liked to do so. Usually, they were able to bring someone to the individual consult.

Observations of the group sessions showed that the teaching at the Kidney School was mostly top-down and little interactive. Most presenters made use of presentation slides. The presenters were briefly introduced at the start of their presentation. At the end of a presentation, one of the nurses thanked the presenter and applauded him together with the

participants. The presenters entered right before the start of their presentations and left directly afterwards. This made the participants feel that there was little room for questions. As one of the participants noted: *"They used the allocated time, there remained little time for questions".* Consequently, they had many unanswered questions at the end. *"Then you sit there with some questions that did not got answered".* An exception was the priest, who started the session by sitting down and encouraging the participants to share their stories. This was also noted by a participant: *"It was rather a dialogue between patient and supervisor, I would say".* The dietician also took a more interactive approach, encouraging the participants to talk with their neighbours by giving them short assignments in between. Although the presenters mostly used daily language, their presentations came across as academic. Professional terms were occasionally used, often followed by a brief explanation. Furthermore, it seemed as if some of the presenters saw the patients and their next-of-kin as a distinct group, to which they themselves did not belong. They presented themselves as being the expert. This was exemplified through their language use, body language, and is underlined by their doctor's uniform, which signals expertise and power. They came across as academic. The following observation illustrates this*: "He stands with the arms crossed on the chest or with the hands in the pocket and uses professional language, talking about 'we' (as doctors) and 'you' (as patients)".* The observations showed that the presenters who specifically asked if there were questions during their presentation received more questions. There seemed to be barriers for participants to speak up if not directly asked if they had questions.
The observers noted that the attention of the participants differed per topic. Low attention was indicated by people moving around in their chair, interacting with their neighbour, looking around the room or sighing. Examples of topics that received less attention were sick leave and pension. A topic that received a lot of attention was regarding what one can do to delay dialysis start. Giving real-life examples and using daily language, as well as body posture of the presenter and making eye contact with the participants, seemed to help in maintaining attention. By asking questions, the participants for input presenters regained the attention of all participants.

Some presentations were given by two presenters: a medical professional and an experienced patient. The language used by the experienced patients was found to be more informal and personal; their body postures were more open and their clothing was informal. This diminished the perceptible distance between the presenter and the participants. The medical professionals gave practical, theoretic information, whereas the experienced patients talked about their personal experiences and motivations. During these presentations, the medical professionals explicitly recognised the importance of a patient's experience, referring to them as experts. The following observation note illustrates this: " *The PD nurse turns to the experienced patients and tells the group that she is really lucky to have an expert standing by her side".* During the presentations with experienced patients, the participants seemed to stay more interested and they asked more questions. When replying, both presenters supplemented each other's answers from their own viewpoint. This seemed to encourage other participants to ask questions. Thereby, these presentations became more like a dialogue between the participants and the two presenters. The atmosphere seemed more relaxed. The participants

indicated that it was easier to relate to the presentations of the experienced patients than to the presentations of medical experts, because of language use and recognition. *"It is perhaps easier to relate to those that have gone through it themselves and can tell us things based on their own experiences".* The participants valued the presence of the experienced patients and would have liked to have more time for discussions with them. Recognition seems to be important to the participants, meeting others in their age group with similar conditions: "*She was my age, whereas most are much older. I do not know that many in my age [group]".*
The observers noted that the presentations about treatment options during the group sessions did not cover all options that are supported by the hospital. Furthermore, the information that was given on the different treatment options did not cover similar subjects. The focus mainly lied on positive aspects of the treatment, and negative effects and risks were hardly included. This hinders a fair comparison between treatment options. From the expert interview, it became clear that the three most common treatments were prioritised, due to the limited time that was available. According to the nurses, other treatment methods might be addressed during the individual consults when the participant comes with direct questions about these procedures.
According to the patients, some information in the group sessions was too general, whereas information on how the disease progresses, the different scenarios for outcomes, what life on treatment is like and the options for support with each treatment was lacking. One participant told us: " *What about [those of] us that have to live with it and try to achieve the best possible life?"*

The participants experienced an information overload during the group sessions. They needed time to digest the information and would have liked to have more time for questions and discussions afterwards. This is exemplified here by a quote of one of the participants: *"You need some time to digest the information. If there was some time in between, you might have some questions when you return".* In combination with the language used by the medical professionals, the participants did not learn as much as they could. "*I got enough information, but I did not understand it",* one participant said. The participant interviews showed that they were aware of the possibility of choosing between dialysis types. However, they thought that the choice of whether to get a kidney transplantation was made by their medical professionals.

The participants felt that there was little time allocated for contact with other participants during the course, because of the set-up of the group sessions, the diversity of the participants and the group size. However, they did value meeting their peers, stating: *"I think there was too little room to exchange stories actually. It was not set up such that we could get to know each other".* The observers noted that participants who had come together mostly interacted with their next-of-kin, whilst those who had come alone talked to their neighbour if he or she was alone, as well. Interactions during the presentations can be described as turn-taking; when one participant asked a question, the other participants listened to the presenter's answer. The participants waited until the dialogue between these two individuals was finished before posing their own question(s). Apparently, there was a barrier for starting a conversation with other participants, perhaps because they had not been introduced to each other.

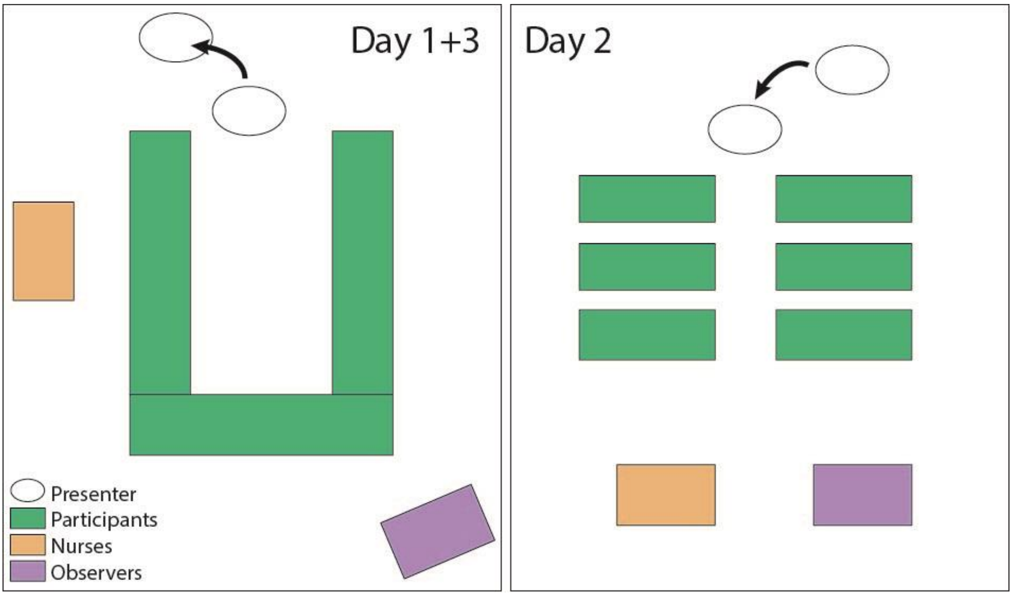

Figure 14 – Table setting in both rooms

During the three-day course, two different rooms were used, each having a different atmosphere and arrangement. The nurses preferred using the second room. Due to this room being unavailable, they had to find another room for the first and third day. Figure 14 indicates the setting of both rooms.
In both rooms, most presenters stood in front of the participants. Many of them stood a bit to the side. The U-shaped table setting created a circle in which participants faced each other. However, some had to turn their chairs to see the presentation slides. The table setting in rows ensures that participants focused on the presenter. This setting was more school-like, and interacting with people other than their neighbour was more difficult for the participants. The participants had different opinions of which set-up they preferred. Two participants who mainly wanted to receive information preferred sitting in rows, as it was easier to look at the presentation screen. The participant that preferred the U-shaped table setting said that interacting with others was easier in this setting. This was also the impression we received during the observations; the U-shaped table setting enabled dialogue, whereas the sitting in rows created a setting for top-down teaching.

Experiences with the individual consults

It is a challenge for the nurses to evaluate how much and what information a participant needs. They try to manage this by focusing on what the participant is concerned about and to encourage dialogue, instead of the consult becoming a one-way flow of information. The nurses experience time pressure, as they have some topics they want to discuss with every patient. *"An hour is short when they have some questions. Therefore, we often have to divide it [the time spent on each topic]".* The nurses felt that that they have too little time to go into detail. The participants appreciated the individual conversations. However, as this statement from a participant exemplifies, the terminology used by the nurses was difficult to understand for some: "*It was too much jargon. Even though it [the individual consult] was really important and it was good that we got it, I felt that I lost track".* It seems that it may be too much information at once for the patients.

The nurses were sometimes challenged by instructions from medical specialists telling them to prepare the patient for a specific treatment, or telling the patient what treatment they think is best. The nurses usually inform these patients about other treatments anyway. One nurse explained: *"We have to take into account that this patient might actually have to dialyse, so we have to inform them about dialysis, as well".* The interview with the nurses also showed that they sometimes make authoritarian decisions. During the individual consults, they evaluate the patient's suitability for the different treatment options and consider medical contraindications. When they consider a person ineligible for a treatment or, on the contrary, best suited for a specific treatment, they do not discuss every option with that patient. *"We try to choose peritoneal dialysis for those that live at a home for the elderly, for example".* Lack of experience with specific treatment options seemed to influence the assessment of the nurses. *"If they are really interested in home HD, we usually refer them to the self-dialysis department for more information".*

The patients indicated that it would have been useful to receive more personal follow-up after the group sessions, as it is then that they have many questions. *"Often there are things you come to think about afterwards. So, if it would have been possible to have a conversation then, that would have been nice".* The nurses said that a second consult is possible, but that few people make use of it. *"We can always inform them on more occasions if it is necessary, but there are only a few that want that".* The participants were aware of the possibility, yet they had not made use of it. There seemed to be a barrier for the participants to ask for an additional individual consult.

Discussion

In this case study, pre-treatment education programs were studied from a human-centred perspective. The study provides qualitative insights into the practice of providing pre-treatment education and the subjective experiences of both the organisers and participants of such programs. The organisers in both cases expressed that their program has evolved over the years; the timing, content, group size and duration of the group sessions has changed However, the described experiences with both programs indicate that there are still possibilities to improve them. The in-depth study of the Kidney School (Case 1) uncovered gaps between intentions, expectations and experiences. Despite the good intentions of the organisers, and the changes they have made to the program in recent years, the finding of these gaps indicate that the program might not be as effective as it could be. Constructivist learning theory, insights from the Dialysis Network program (Case 2), as well as insights from similar programs described in literature are used to discuss how these gaps might be mitigated.

A gap was found between the organisers' intentions with the program and the expectations of the participants. The participants expected to become better informed, in general, and to meet peers, whilst the nurses aimed to support the patients in discussing personal preferences with their doctor and to help them cope with their disease. To ensure effective education, learning objectives should clearly state what the participants are expected to learn (Biggs, 1999). Savery and Duffy (2001) emphasised the importance of making learning objectives clear to the participant. They describe how the motivation to learn comes from the will to function more effectively in one's world. The personal motivation for learning and a person's perception of the significance and relevance of the problem affects what an individual learns (Savery & Duffy, 2001). Making intentions and the need for learning explicit and communicating this to the participants may help manage participants' expectations, supporting the alignment between intentions and expectations. Therefore, including a clear intention statement in the invitation letter might be a means to reduce this gap.

The participants indicated that they would have liked more information on the effects on their life and opportunities for support. Others have described similar information needs, such as patients being interested in treatment time and frequency, information about who is performing the treatment and dietary restrictions (see section 5.1.1). Some patients are more interested in the effects on daily life than the effectiveness of the treatments (Davison, 2006), as they wish to maintain a life that is as normal as possible (Morton et al., 2010). The individual consultations provide room for addressing patients concerns. At the Dialysis Network, the focus on an individual's lifestyle, values and beliefs is central. The program might benefit from a stronger focus on these topics to support SDM in the group sessions.

Gaps were found between the intentions with the program and the applied education methods and learning materials. Teaching methods should encourage participants to undertake the learning activities that guide them in achieving the learning objectives (Biggs, 1999). Furthermore, a program is most effective when it matches the individual's ability to learn, the individual's previous knowledge of the topic and when the program's teaching style is compatible with the individual's preferred learning style. If a program is situated too far from the individual, he or she can become bored, distracted, frustrated or even discouraged (Hjelsvold, 2017; Wilson et al., 2009). The observations of the group sessions showed that teaching at the Kidney School (Case 1) was mainly top-down, and there were instances when the participants did not seem to pay attention. This might be because they lacked interest in the topic and were, therefore, not motivated to learn. It might also be that there was a mismatch between the teaching style or the level of difficulty of the content.

Teaching was observed to often be a linear information exchange from the presenters to the participants. Constructivist learning theories describe how learning does not take place through a linear exchange of information, but rather that learning is the result of an active thinking process (Mayer, 2004). The focus of practitioners should lie on learning, not on teaching (Goovaerts et al., 2015). Furthermore, the constructivist learning theory recognises that different learning styles exist. Traditional teaching methods such as lecturing can, therefore, be ineffective for people who prefer more visual or interactive ways of learning

(Kolb, 1981). To ensure that people with different learning styles may benefit from an education program, one needs to accommodate for different types of learners by offering the information in various formats. Offering both group and individual sessions appears to be beneficial from a learning theory perspective, as both formats make use of different teaching techniques and materials. However, the observations showed that some of the group sessions were only sporadically interactive and applied a lecture style. These sessions might benefit from the integration of more varied teaching techniques.

Providing more space in the program for guided dialogues could foster learning. The challenge lies in stimulating students to not only collect new information, but to help them relate this information to their previous knowledgebase in order to create meaning out of it. Guided dialogues with peers and teachers can support the shaping of concepts and the elaboration of knowledge, enriching an individual's understanding of a topic (Biggs, 1999; Savery & Duffy, 2001). Participants may learn from observing what their peers are doing in a group assignment and overhearing their discussions (Dougiamas, 2009). Therefore, fostering group discussions and providing short exercises, similarly to the nutritionist and priest at the Kidney School, may be beneficial; such exercises offer another way of learning, which may be beneficial for participants who do not benefit as much from lectures. Participants can be encouraged to ask questions by asking them to share what they just learned (Rodgers, 2006). Furthermore, the observations show that sitting in rows is associated with traditional classroom teaching, whilst sitting in a U-shape creates space for dialogue and interaction. Reflecting upon the set-up of the room should, therefore, not be neglected when developing an education program.

The expressions by the nurses show that they provide individual guidance to the patients during the one-on-one consultations. The nurses expressed focusing on individualisation and dialogue, specifically the importance of establishing a patient's pre-existing knowledge and their current concerns. This relates to the concept of the Zone of Proximal Development, as described in the constructivist learning theory (Vygotsky, 1978) (see section 2.3). The importance of individual guidance is recognised by other scholars who have investigated pre-treatment education (Goovaerts et al., 2015; Rodgers, 2006).

The organisers at the Kidney School (Case 1) explained that the individual consultation is intended to prepare patients for the group sessions. Although individualisation usually affects the learner positively, we argue that it is problematic when it is used to prepare patients for a group program. The different knowledge background of the patients, their individual learning abilities and the individualised guidance that they receive during the individual consult lead to patients starting the group sessions at different knowledge levels. The interviews showed that this difference in backgrounds was experienced as challenging by both the organisers and the participants of the program. Therefore, we advise using learning methods that bring participants up to a comparable knowledge level, when wanting to prepare participants for group sessions. One could consider offering education materials that people can use to prepare at home, such an information website or paper folders, or more advanced learning materials, such as a serious game where people progress through various levels (see section

6.2). When participants come prepared to the group sessions, more time can be spent on answering questions from the participants and peer dialogues to enable them to learn at their own speed. The organisers of the Dialysis Network program (Case 2) made a deliberate choice to start the learning process with the group sessions directly and to follow them up with an individual consultation afterwards. The participants in this program were, therefore, not specifically prepared for the group sessions beforehand. Instead, the organisers of this program used the group sessions to provide participants with basic information that applies to everyone. After the group sessions, participants were invited to an individual consultation to provide them the opportunity to focus on personal questions and concerns.

At the Kidney School (Case 1), participants are not automatically offered an additional individual consultation, although they can ask for it. The fact that the participants in the interview indicated a need for further individual follow-up, whilst the nurses' statements demonstrated that they were unaware of this need, indicates that there might be a barrier for participants to ask for an additional individual consultation themselves. Mollicone et al. (2013) described how patients in their program are followed up with a phone call by a nurse 30 to 90 days after their education program, and then every 180 days, until a treatment choice has been made. Such phone calls can potentially lower the threshold for patients to ask for more support. Participants may benefit from individual follow-up, as they selectively attended to information that they considered relevant at that time, as participants in the group sessions. After the group sessions, their knowledgebase has grown, and they might become interested in or develop a need for additional information.

The participants at the Kidney School experienced that there was limited time for digesting information and asking questions. A high information load is detrimental for learning (Gibbs, 1992). The program at the Dialysis Network (Case 2) is structured differently, with shorter sessions and longer time in between the sessions. The organisers of the program at the Dialysis Network have deliberately set up the program to give participants time to digest the information before they attend the next meeting. Furthermore, patients are allowed to bring more family members to help remember the information given during the sessions. Another remedy could be to distribute a printed copy of the presentations after the group sessions, which would enable the participants to refer to some resources once they are home. This is what the organisers at the Dialysis Network did during their program. Links to further reading may also be attached to the materials, and information that patients can access at home can be studied at any time. This approach gives the participants freedom to learn when they have the energy and mind-set to learn. In addition, participants do not have to memorise everything at once. These documents also could be sent to those who could not attend the course to enlarge the program's reach.

The organisers of both programs have recognised the participants' appreciation of education by peers, which was also described by Harwood and Clark (2013). The participants' need for information on practicalities and lifestyle effects (section 5.1) might explain their appreciation of presentations given by experienced patients. The experienced patients are familiar with the practicalities of the treatment and how these factors have affected their life. However, the findings from Kidney School (Case 1) show that, in this program, the possibilities for contact with peers were less than what the participants had expected. In this case, more contact between the participants and the experienced patients might be realised by fostering interaction and reserving time for discussion, instead of using top-down education methods with little room for questions. However, the use of expert patients is controversial, and care should be taken that decision making does not become biased. The organisers at the Kidney School (Case 1), indicated carefully selecting the experienced patients, and Warwick et al. (2014) advised instructing expert patients before they are involved in a program.

The group sessions provide a unique opportunity to ask questions to medical professionals in a less formal setting than a consultation, meet peers and learn from people who have had similar experiences. Different members of the multidisciplinary team of medical professionals can teach participants about aspects related to their expertise. Meeting peers can support coping through recognition, by knowing that one is not alone. Experienced patients may support coping through recognition and showing that it is possible to have a life whilst on treatment. However, gaps existed between the intentions of the program and experiences in practice.

The observations showed that the coherence between the presentations was lacking. Sometimes information overlapped, and only in a few instances did a presenter refer to another presentation when a related topic was discussed. The organisers at the Kidney School explained that they have a preferred structure for the program, but that it was not always possible to follow this due to the limited availability of the medical specialists and meeting rooms. The changing order of the program makes it harder for practitioners to refer to each other, as they do not know what is discussed before and after their own presentation. Furthermore, the observers noted that the presentation slides differed in layout and level of detail. Applying the hospital's graphic profile to the presentation slides can help to create some visual coherence between the presentations.

The observations of the group sessions at the Kidney School showed that there was no official welcome or time for the participants to introduce themselves to each other, whilst the participants indicated that they would have liked more contact with their peers during the group sessions. An introduction round might encourage interaction between participants and make it easier for them to ask questions during the group sessions. By using 15 minutes before the start of the course as an introduction session, the organisers also have a chance to briefly repeat the intention of the course and indicate that it is absolutely recommended to ask questions to the presenters during their talks. Furthermore, the participants can briefly introduce themselves to each other, lowering the threshold for later posing questions. This might encourage them to interact with each other during the breaks. Optionally, each course day could start with a few minutes of dialogue during which participants are asked to talk about their impression of the previous session, or what they look forward to that day.

A gap was found between the intention of the programs to facilitate treatment choice and the practice of the medical professionals. The interviews with participants showed that they had difficulty understanding the information. They indicated that the use of terminology hindered their understanding. The observers had also noted that the language use by the professionals during the group sessions came across as academic. Being well-informed is essential for decision making (Barnett, Ogden, & Daniells, 2008). The observations of the group sessions showed differences in the behaviour and language use of the presenters. The medical specialists tended to focus on facts and data, whilst the nurses talked about practicalities. These differences reflect the paradigms that lie behind their different fields of expertise. Experts may unintentionally give incomplete explanations, as they do not realise that some information is not common knowledge, but specific to their expertise (Savery & Duffy, 2001). Davison (2006) found that professional language use creates a barrier for patient empowerment. Using words like food instead of nutrition, or sport instead of physical activity, could make a difference. However, as the developers of a decision aid expressed, chronic patients need to be given the chance to learn the terminology to empower themselves (see section 6.1). Dougiamas (2009) explained, although terminology may sometimes help, at other times, it is best to avoid such language, depending on the person to whom a message is addressed. In the case of participants for whom the topic is new, using terminology might hamper their understanding, even though they might later benefit from knowing the terminology. Therefore, it seems beneficial to use some central terms and accompany them with an explanation to support chronically ill patients who are familiarising themselves with the subject.

Physician preference and lack of information were found to contribute to participants not being offered the full range of treatment options at the Kidney School. Others have previously found that non-medical factors, such as the experience of a centre (Covic et al., 2010), physician preference and reimbursement policies can influence usage of the different treatments (Goovaerts et al., 2005). Statements from the organisers at the Kidney School indicate that participants sometimes were not informed about all available treatment options during the individual consultations, following a one-sided assessment of the patient's suitability for the treatments. The limited time available during the group sessions led to a focus on the three most common treatments in the program at the Kidney School, leaving out other treatment options that are available at the hospital. The Dialysis Network program was found to have a slightly different focus, aiming to find a treatment that fits best with the patient's lifestyle. The observations at the Kidney School further showed that the presentations on treatment options did not cover similar subjects, making comparison difficult. The international guidelines advise discussing preparations for treatment start, care while on renal replacement therapy and eventual withdrawal of renal replacement therapy for each available treatment (Atai & Johnson, 2012; Covic et al., 2010; Levin et al., 2008; National Kidney Foundation, 2015; Warwick et al., 2014). Taking this as a basic structure for each presentation about treatment options could help ensure that each presentation addresses similar topics.

For both programs, the diversity and dissimilar information needs of the participant group were a challenge. The organisers experienced that some patients had not accepted their condition and had not learned to cope with it yet. Consequently, they had difficulty informing these patients about treatment options. According to Duteau (2013), people first need to be supported in giving meaning to their new situation (learning to cope) before treatment options can be discussed effectively. People need to learn to understand their new world (Alvesson & Sköldberg, 2009). When people cope, they bring this understanding into practice. The diversity in information needs and the amount of information were recognised as challenging by the participants at the Kidney School. The observations showed that the program contained parts that are relevant during different stages of the disease trajectory. By presenting this in one package, part of the information is inevitably redundant to some. Furthermore, combining presentations to facilitate coping with presentations on treatment options might be confusing for participants. It is, therefore, suggested to split up the course into two intervals, or to hand over the responsibility of supporting patients learning to cope to the multidisciplinary care team that provides the diagnosis; this method would ensure that people have learned to cope, to some extent, before joining the program on treatment choice. Offering one section to patients who are in an earlier stage could ensure higher relevance for the participants who need support in learning to cope, which would additionally reduce the information load. Furthermore, when discovered in time, a healthy diet and physical exercise can slow down the degradation of the kidneys and postpone the start on renal replacement therapy. As not everyone will necessarily become dependent on renal replacement therapy, patients in earlier stages can, thus, benefit significantly from learning to cope and living well with CKF (Jia, Bi, Lindholm, & Wang, 2012; Morony et al., 2015). When treatment start can be postponed, longevity and quality-adjusted life years increase and costs for society are reduced. As it is difficult to foresee the speed with which the kidney function will degrade, offering the right information in a timely manner is a challenge. We, therefore, recommend offering a program to support coping for everyone who has been diagnosed with CKF, independent of the stage of their disease progression. The program by the Dialysis Network does not specifically address topics that support coping, but focuses specifically on providing information on treatment options. However, they also report that they meet patients during individual consults who do not want to be informed about treatment options. The group sessions are probably ineffective for such patients. They might not have attended the group sessions, or if they did, they might not have learned much about the treatment options, as this is not a topic in which they were interested.

Relevance for medical practitioners

The study contributes with insights on what other clinics have learned through years of experience with organising face-to-face education programs. In particular their insights related to the appropriate timing of such interventions seems relevant. Although the insights are based on the qualitative experience of two centres, medical practitioners that want to develop a similar education program, may consider what the organizers of both programs have learned through experience: Group sessions should not be too long, are best organised in the afternoon, and should only address the basics of the most relevant topics to avoid information overload. Furthermore, group sessions are best spread over several days to allow participants to digest the information. In addition, the presence of experienced patients can help new patients to cope with their disease by being an example of someone that has a life, despite being dependent on renal replacement therapy. Furthermore, the experienced patients can provide new patients with the confidence that they are able to perform self-care. These insights form an addition to clinical guidelines documents, which merely present which topics to include, but which present little practical advice on how to set-up and structure such education programs (section 3.2 and (Gordon & Lash, 2011).

Considering information from a social constructivist perspective entails regarding information not as a static entity but as the result of the interpretation of the received information (section 4.1). The interviews with patients indicated that, although they received a lot of information, they did not understand everything. When evaluating the effectiveness of patient education programs, it seems therefore imperative to not only measure to what extent a program actually leads to knowledge increase among participants, as is commonly done through standardized pre- and post-intervention surveys (section 5.2). Such quantitative surveys do not provide insights into how people experience the program, an insight that can help uncover why a program may not be as effective as intended. On the basis of the knowledge obtained in this study, it is therefore recommended to additionally conduct a qualitative review of a program, including interviews with participants, to obtain a better understanding of barriers to learning.

Relevance for designers

The insights from this qualitative study provide some suggestions on practical aspects that designers may keep in mind when developing a pre-treatment education program for patients. The insights that this study contributes with regarding the aspects of education programs that can support or constrain SDM, can support designers in developing appropriate solutions that overcome these constrains.

This study shows the importance of informing patients about the intention of an education program prior to its start. Neglecting this may reduce the effectiveness of the program, as patients who have different expectations are less likely to reach the intended learning goals. Furthermore, the study shows the importance of matching a program with patients' prior knowledge level, their ability to learn and their preferred way of learning. Creating a holistic overview of the healthcare service, will help designers in deciding what information to present in a specific intervention. Designers should be aware that patients might have a reduced ability and interest to learn, due to their illness. In the case of CKF, patients have reduced concentration abilities and get tired more quickly. Their margin information overload is therefore lower. Designers are additionally recommended to consider designing a program with a low threshold for participation; e.g. a clear invitation describing the benefit of participation, reducing travel and subscription barriers. Furthermore, designers may reflect upon how they can support patients in learning at their own speed, when they have the time and energy to learn.

As people have different preferred learning styles, designers are recommended to reflect upon how they can meet the needs of various people with the service they are designing. When deciding on the type of intervention(s) to develop, designers should not only consider learning styles, but also the pros and cons of different teaching formats in relation to the learning effect they want to achieve. In the case of the Kidney School, group sessions were used for mediating quite factual information and linear instruction methods were used. The strength of group sessions however is that they allow for dialogue and interaction. Group sessions can provide patients with a unique opportunity to ask questions to medical professionals in a less formal setting than a consultation, meet peers and learn from people who have had similar experiences. Guided dialogues, a format that may be used in group sessions, is not the best format for learning factual information, but it allows for a different kind of information exchange more focused on discussing questions, motivations and experiences.

Patients expressed a need for more information on the effects of their daily life and opportunities for support. This is in line with the findings from the literature review on patients' information needs (section 5.1). When developing a pre-treatment education program, designers are therefore advised to consider the inclusion of lifestyle-related information in addition to presenting factual information on the benefits and disadvantages of treatment options from a medical perspective. Group sessions are one alternative of implementing such more qualitative information.

A barrier for SDM that came forth from the studies is that, despite good intentions, information included in programs may be biased. Designers should carefully reflect upon how information is formulated, to ensure that the information is well-balanced. Another challenge that designers will have to reflect upon is how to implement an intervention and gain the support of the medical practitioners that have to change their practices. This study showed that the effect of an intervention can be reduced when medical practitioners outside the program do not support it; e.g. SDM is not common practice yet.

Data triangulation: Informing patients through face-to-face education programs

Two sections of this thesis describe studies on face-to-face education programs; 1) A systematic literature review (section 5.2) focussed on internationally practiced pre-treatment education programs for adults with CKF, while 2) a case study (section, 7.1) qualitatively investigated two local programs. The results of both studies were triangulated to increase confidence in the findings related to the research question: *How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organised?* Below, an overview is given of the findings from both studies that support each other.

Through the literature review, descriptions of various education programs from different countries around the world were found. The scientific papers commonly described an education program as it is practiced at a single centre, although also some multi-centre studies were found. This may indicate that many programs have been developed by individual centres. The qualitative studies of the Kidney School and the Dialysis Network were in line with this finding; One of the two programs was initially set up with help of a commercial company, but was developed further by the clinic itself. The other clinic had developed its program independently.

The education programs that were analysed in the literature review and the two programs that were studied qualitatively for this project commonly made use of several education strategies; in addition to conversations, printed materials with text and images are standardly used. Sometimes medical equipment is shown and some programs offer videos additionally. Programs furthermore commonly consisted of multiple sessions and were often given at the hospital during office hours. Many programs offered only individual consultations, while some offer group sessions in addition. The literature review and interviews with the organisers of two education programs showed that when group sessions were organised, often a multidisciplinary team of educators was involved. Practitioner roles that were commonly involved were nephrologists, specialized dialysis nurses, dieticians, and social workers. About half of the programs invited experienced patients as additional educators. The interviews provided an insight into the motivations that may lay behind the inclusion of experienced patients. For the organisers of the Kidney School, the motivation to include experienced patients was twofold: 1) They were able to support patients in coping by showing that you can still live well, despite being dependent on treatment, and 2) As they live with the treatment, they can provide a different kind of information on what treatment entails. The motivation for the organisers at the Dialysis Network to involve experienced patients that perform self-care, is to build confidence amongst participants that they can perform self-care as well. The interviews with participants of the Kidney School program showed that patients appreciated the presence of experienced patients as they provide insight into what it is to life with treatment, and would even have liked more time for dialogue with them.

The literature review and the interviews showed that the format and content of education programs varied considerably. Differences were found regarding whether a program consisted of individual sessions, group sessions, or a combination of the two. When combined, some programs started with group sessions, followed by one or more individual sessions, while other programs offered these in reverse order. The duration and frequency of education programs was also found to differ considerably. At the Kidney School an individual consultation, followed by three three-hour group sessions were offered, while the Dialysis Network offered four group sessions of one and a half hours each, followed by one or more individual consultations. Furthermore, there were more days in between the group sessions in the latter program. Interviews with the organizers of both programs showed that the length of sessions is a concern for them, as patients get tired more easily. The programs also varied in scope. Some focused specifically on treatment options, while other programs included a broader range of topics to support patients in coping with the disease and adapting to a new lifestyle. This difference in focus was found to be unrelated to whether the program was aimed at patients who have time to prepare themselves to start treatment and patients who acutely require treatment. This difference is notable as clinical guidelines advise practitioners to include a broader range of topics in patient education (section 3.2). To provide a holistic service, education programs that focus on treatment options specifically, will therefore need to be supplemented with other information services to provide support for lifestyle changes.

The findings from the systematic literature review and qualitative studies on education programs were furthermore triangulated to increase confidence in the findings concerning the research question: *Which aspects of face-to-face education programs may support or constrain shared decision making?*

The literature review and qualitative research on two education programs showed that practitioners globally made different choices regarding the variety of options to present. Some presented only dialysis options, others focused specifically on transplantation options, others included both dialysis and transplantation options. Some programs presented conservative care as an additional alternative others did not. Furthermore, in some programs, only the options that their clinic supported were presented. This means that patients in these clinics were not offered specific dialysis or transplantation options. The interview with the organisers of the education program at the Dialysis Network revealed that the economic motivations of care providers and insurance companies can influence the options presented to patients. The interview with the organisers of the Kidney School showed additionally that time constraints and unfamiliarity with treatment modalities may also be reasons to not present certain options.

Many of the scientific papers on education programs included in the systematic literature review described that practitioners tried to avoid bias when presenting treatment options to patients. The case study of the Kidney School showed that despite such intentions, bias may occur. For example, when presentations on treatment options cover unlike topics and focus mainly on the positive effects of each treatment, it becomes difficult for patients to compare the different options. Critical reflection on programs regarding the possibility for bias is therefore necessary.

The literature review and interviews with the organisers of two programs showed that many education programs relied significantly on written information. For people with low literacy levels, this may be a barrier to SDM. Both studies furthermore underlined the paucity of solutions for people who do not master the national language sufficiently. Some scientific articles describing education programs mention that informational brochures were offered in several languages. However, group sessions were commonly offered in the national language only. People in these patient groups were underrepresented in the studies included in the systematic literature review. The organisers of both programs that were studied in section 7.1 indicated that educating patients who are not fluent in the national language was a concern and a challenge for them, as they were afraid of misunderstandings. Specifically, the organisers of the program at the Dialysis Network indicated that this resulted in these patients not being offered all treatment options, as they could not offer them proper training for self-care haemodialysis.

The systematic literature review and qualitative studies of education programs showed that many of the programs were offered to both patients and their next-of kin. The literature review on factors that patients consider when making a treatment decision (section 5.1) showed additionally that patients commonly involve their next-of-kin in treatment decision-making. Next-of-kin being offered the same information as patients may be an aspect of education programs that supports SDM, as educating patients' next-of-kin allows them to become better informed as well. Furthermore, as the nurses from the Kidney School expressed, two people remember more than one.

The qualitative review of two education programs helped uncover two additional constrains to SDM that were not discussed in the articles included in the systematic literature review: 1) Patients who are not yet coping with their disease are difficult to educate, 2) Patients may regard the education program as a valuable opportunity to learn more about their disease, but may lack the understanding that the program aims to stimulate their participation in SDM.

A concern for SDM is that patients may not be ready to learn about treatment options when they have not yet accepted their diagnosis (Watson, 2013). Interviews with the organisers of two programs provided indications that educating patients who are not coping is challenging and problematic. There appears to be a need to support patients in coping with their diagnosis prior to informing them about treatment options to support SDM. This is what the organisers at the Kidney School tried to do by first offering an individual consultation and having a preferred order for the group sessions. However, the case study on this clinic showed that there were two specific barriers for SDM related to coping. The timing of the information was problematic for patients, who experienced an information overload due to the short timeframe between the sessions and indicated that some topics were not or no longer relevant for them. Furthermore, organisation of the program in a preferred order may be obstructed by practicalities such as the availability of presenters and meeting rooms. Consequently, presentations to support coping and presentations on treatment options became mixed. The case study showed additionally that a lack of support for SDM across the healthcare organisation presents a barrier. Although the education program was set up with the intention of informing patients about treatment options so that they can participate in their treatment decision, this goal may not be achieved when the medical practitioners involved do not support SDM.

The case study of the Kidney School showed that gaps might occur between the organisers' intentions, the participants' expectations, and both parties' experiences in practice. We found that when an education program that intends to support SDM does not communicate this goal clearly, participants may be solely motivated to participate to become better informed. These patients may not realise that they can actively contribute to the treatment decision. Consequently, these patients may not come to evaluate the information they receive in relation to their own lifestyles, values, and beliefs, but only regard the education program as a convenient service. Another barrier to SDM that became apparent through the case study was the lack of chances for patients to ask questions. Some educators' presentations were a linear exchange of information, and some educators distanced themselves from the participants through their language use and body language, both of which may have caused this problem. Consequently, participants felt that they were not given sufficient opportunity to ask questions, and participants did not understand all of the information that was offered to them. Furthermore, participants expressed a need for more specific information on effects on lifestyle during the group sessions. The observations showed that presenters who asked if the participants had questions, provided real-life examples, made eye contact with the participants, and used daily language better maintained participants' attention and received more questions. More dialogue emerged in particular when experienced patients participated as it was easier for the participants to relate to these presentations.

The interviews with the organisers of two education programs additionally helped uncover an aspect that may support SDM, which was not discussed in the articles that were included in the systematic literature review: The delivery of individual guidance to meet information needs. During individual consultations, the nurses focused on individual information needs. They applied various education strategies during these consultations to stimulate patients to engage in a dialogue with them instead of the consultation being a one-way flow of information. By focusing on the patients' questions and concerns, they tried to guide individual patients in learning about the topic.

Conclusions regarding face-to-face pre-treatment education programs

Many programs have been developed by individual centres, resulting in a large variety of practices. Programs differ in timing, format, involved educators, topics covered, and materials used. As programs are developed at individual centres, it is difficult for others to learn from them. Furthermore, as these programs additionally have been evaluated through various evaluation measures, it is difficult to make cross-case comparisons and to draw conclusions on which aspects of face-to-face education programs contribute or constrain SDM. Further research into the effectiveness of different formats is needed to enable the formulation of guidelines that can form the basis for the development of new programs (section 8.3).

The variety of topics that are covered in the various programs, shows the importance of maintaining a holistic view on the total care service instead of focussing specifically on a particular intervention. In addition to becoming informed about their treatment options and the content of care, people who have been diagnosed with a chronic disease need further support in coping with the disease and adapting to a new lifestyle. To provide a holistic service, education programs that focus on treatment options specifically, will therefore need to be supplemented with other services to meet the needs of patients.

The studies showed furthermore that there is a large variety regarding which treatment options are presented to patients. Economic motivations, time constrains and unfamiliarity with specific treatment options may be motivations for care providers to not present all treatment options. Designers and medical practitioners should be aware that when they decide not to present all treatment options in a program, they make a preliminary treatment choice for the patients by discarding some of the treatments options. Whatever the reason, the differences in the options presented to patients at different clinics have ethical consequences related to the degree of autonomy that patients have in selecting their treatment. Furthermore, when patients at different clinics within the same country are presented with different choices, inequalities arise on how patients are cared for. A restricted presentation of treatment options is a barrier to (true) SDM and equal access to care. It is important to discuss the option set when developing a new program, to ensure that this decision is made deliberately and that people are aware of the motivations behind the decision and the effects this has on SDM.

Next step The case study at the Kidney School showed that, although parts of the program work well, there is room for improvement. Therefore, the next section focuses on redesigning the program. The next step focussed on the application of the co-design methods and service design tools, with the goal of learning how such methods can be applied in a specialist healthcare context. We wanted to study if this method can support a multidisciplinary healthcare team in redesign a program to better meet the needs of patients and their next-of-kin.

7.2 Closing the Gap – Applying design methods to facilitate program development[15]

Abstract

The case-study on a patient education program showed that mismatches may occur between the intentions of service providers, the expectations of patients who receive the service, and both parties' experiences in practice (section 7.1). This study aimed to investigate if the application of design methods can facilitate program development to reduce these gaps.

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[15] The text below is partly based on an article that was published in the Proceedings of the 4th European Workshop on Practical Aspects of Health Informatics (PAHI 2017), called 'Co-Design in Specialist Care - Aspects to Consider' (Vis, 2017) The original article can be found in Appendix C.

A co-design workshop was organised to improve the patient education program offered at the Kidney School. The intention of the workshop was to realise changes that would benefit both participants and organisers of the program. During the workshop, service design methods were applied.
The study shows that the application of a co-design workshop and service design tools can be valuable for the development of healthcare services, but that there are some specific challenges designers need to aware of. Designers are recommended to reflect on ethics, thinking over the possible effects that a workshop may have on the relationships between participants over time. Furthermore, designers are recommended to anticipate if specific aspects of healthcare contexts (hierarchy, working in disciplines and unfamiliarity with co-creative tools) may affect the workshop.

Aim of the study

The findings from a case study on a patient education program for people who soon need to start renal replacement therapy and their next-of-kin (section 7.1) informed this follow-up study. In the preceding study, gaps were found between the intentions of the organisers, the expectations of the participants and both parties' experiences of the pre-treatment education program. This indicates that there is still room for improvement despite the changes that have been introduced in the past years. This study therefore aimed to investigate the following research question: *How can design methods support the (re)design of patient education programs?* More specifically, this study aimed at obtaining insight into how co-design workshops in which service design tools are applied can be used in healthcare context. The aim of the co-design workshop itself was to generate ideas for changes of practice to optimise the program at the Kidney School, reducing the gaps between intentions, expectations and experiences. The workshop's aim was communicated to workshop participants as follows: *"To optimise the Kidney School's service to the benefit of patients and their relatives, as well as the nurses that organise the program"*.

Method

A co-design workshop in which service design tools were used was organized. The medical practitioners that are involved in the patient education program were invited to contribute to the program's development as co-designers. The choice for a co-design workshop was motivated by the importance of including practitioners in the process in order to ensure a solution that fits with their practice (Björgvinsson, 2008). The preceding case study on the existing program at the Kidney School (section 7.1.) informed the formulation of the workshop's goal, as well as the development of assignments and materials for the workshop.

Study Design

In a meeting with the two nurses who organised the program at the Kidney School, the idea to conduct a co-design workshop was introduced. During this meeting this approach, as well as the aim of the workshop and its timeframe were agreed upon. The aim of the workshop was to *"optimise the Kidney School's service to the benefit of patients and their relatives, as well as the nurses that organise the program"*. The timeframe for the workshop was agreed to be 2 hours, This timeframe was chosen as the nurses knew how difficult it could be to schedule in

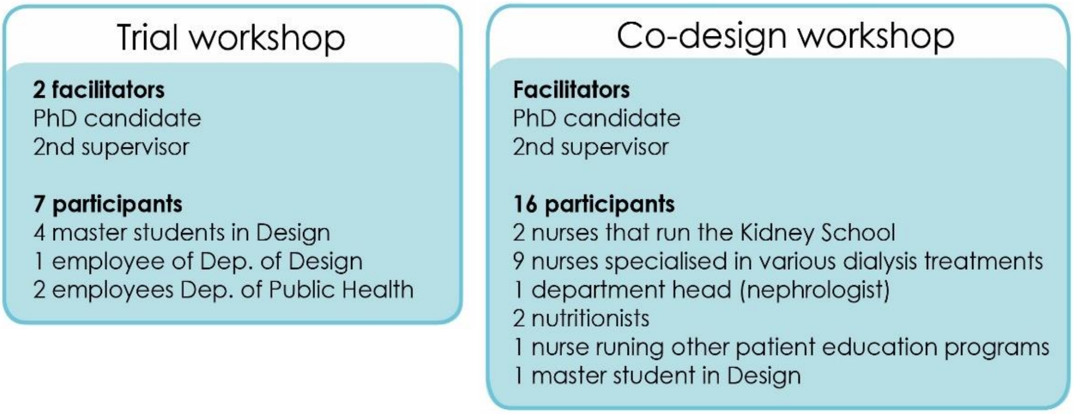
time for the Kidney School in the calendars of the other medical practitioners who are involved in the teaching. With this relatively short timeframe, it was decided to focus on obtaining new ideas during the workshop, and to not spend time on ideation on implementation strategies. It was decided that this would be done afterwards by the two nurses who were in charge of the organisation of the program in collaboration with the PhD candidate (designer). Practicalities such as obtaining permission from the department head, timing, inviting participants and booking a room were also discussed. These topics were discussed to align expectations (Pirinen, 2016). The workshop was set up and prepared by the PhD candidate. The insights from the preceding study helped her tailor the assignments and materials to the specific case.
A pilot workshop was organised to assess whether the assignments were clear and the timeframe was appropriate. Furthermore, it allowed the facilitators to practice and test the materials. After the pilot workshop, the facilitators shared their experiences. This helped them to better align their approaches and led to some slight changes in the workshop plan.

Study Participants

For the pilot workshop, four master students and an associate professor from the Department of Design at the Norwegian University of Science and Technology (NTNU) were recruited. The master students were selected based on their contribution to a healthcare project during a master course the preceding semester about Design for Society. The associate professor was invited, as she had previously contributed to human-centred design and healthcare research. Two employees from the Department of Public Health and Nursing were also invited, as these two employees are familiar with nursing practices.

Although the healthcare context is complex, and hierarchies exist between medical practitioners in different professions (Bowen et al., 2013), it was decided to invite every medical practitioner involved in the Kidney School to participate in the co-design workshop. The motivation for this decision was that changes to the service “need to be grounded in what it means to be a competent practitioner and in future visions of new embodied practices” (Björgvinsson, 2008). As the practitioners will need to make changes to their practices, their support is essential.

The PhD candidate invited two nurses that were responsible for the program at the Kidney School. These two nurses invited the other medical practitioners that were involved in the Kidney School through face-to-face conversations. The nurses gave an information letter in which the goal and background of the workshop were explained. Contact details were included, in case of any questions. Additionally, the PhD candidate invited nurses working in a department that organises courses for patients with various other diagnoses. These nurses were invited, as they provide a similar service, but might have very different experiences and approaches. Such external insights may, therefore, foster ideation. Furthermore, the PhD candidate invited master students from the Department of Design at NTNU with experience in designing for people with chronic illnesses. The expectation was that human-centred designers are familiar with creative techniques and, thus, may be able help other participants to use them. In addition, human-centred approaches are used to consider situations from the perspective of various people in different roles, which can help ensure that the needs of both service providers and service receivers are considered during the workshop (Yang & Sung, 2016). Figure 15 presents an overview of the individuals that were involved in both workshops.



Trial workshop

2 facilitators
PhD candidate
2nd supervisor

7 participants
4 master students in Design
1 employee of Dep. of Design
2 employees Dep. of Public Health

Co-design workshop

Facilitators
PhD candidate
2nd supervisor

16 participants
2 nurses that run the Kidney School
9 nurses specialised in various dialysis treatments
1 department head (nephrologist)
2 nutritionists
1 nurse runing other patient education programs
1 master student in Design

Figure 15 - Overview of facilitators and participants in the co-design workshops

Workshop set-up

Table 14 presents the assignments and materials for the workshop, as well as its time plan. The two-hour workshop was held at the hospital's nephrology department, so that most participants did not have to travel. The workshop started and finished en plenum. After the warm-up exercise, the participant group was split in two. They worked in two separate rooms, so that the groups would not disturb each other. During the workshop a post card describing the Kidney School's aim lied on the table, as well as a printed copy of workshop rules. The 'rules' consisted of positive reminders to e.g. listen to each other, to be positive, to share thoughts and to be open to new thoughts from others.

Appendix D presents a description of the workshop including the invitation, facilitation guide and materials that were used for the workshop at the Kidney School.

Data collection

The PhD candidate and her second supervisor facilitated the workshop. Being the main researchers who had conducted the preceding study, the facilitators had built up an empathic understanding of the experiences of both patients and organisers. This helped us in posing relevant probing questions during the assignments, as we were both familiar with challenges that needed to be addressed. These questions were included in the facilitator guide. Instead of stating that something was found to be a challenge, the questions were formulated positively. Examples are: "How could we ensure that the presentations cover relevant topics?" and "What could be changed to make planning of the group sessions easier?" Posing probing questions helped to ensure that the workshop participants considered both the organisers' and patients' perspectives.

Upon agreeing to participation, a participant received an official invitation in form of a postcard, with information on the time and place of the workshop as well as a small sensitising

Timing	Assignment	Materials
10 min	**Introduction**, en plenum.	Facilitation guide, workshop rules
10 min	**Warm-up** exercise, en plenum. Name + description of your favourite shopping experience.	Post-cards, post-its + pens
15 min	**1** – Map information needs of patients in three different phases of their disease, two groups.	Simplified Patient Journey Map, post-its + pens, poster with three participant groups
45 min	**2** – Analysis of the current Kidney School, its aims and ideas for improvement, two groups.	Brainstorm exercise. Detailed patient journey map, Assignment 1, post-its + pens, probing questions (Personas, card stock)
10 min	Break	
10 + 10 min	**3A** - Design the 'ideal' Kidney School, two groups. **3B** - Presentation to other group, en plenum.	Assignment 2, post-its + pens
10 min	Closure, en plenum.	Evaluation forms

Table 14 - Overview of workshop assignments and materials

assignment, asking them to describe a good shopping experience they have had. Sensitising assignments aim to trigger people to think over aspects of their personal time to prepare them for the workshop (Visser, Stappers, van der Lugt, & Sanders, 2005). The assignment was deliberately kept very open and easy to give everyone a chance to contribute.
To account for the lack of presence of patients and their next-of-kin, the assignments and materials that were prepared for the workshop included references to patients. For example, one of the assignments was to map the information needs of patients as their disease progressed and discuss what information needs the Kidney School should meet. Three personas of patients were developed to support the discussion, in case workshop participants needed to be supported in thinking about patient needs.

The learn about the use of design methods in healthcare settings, the PhD candidate wrote a narrative account (Robson, 2011) on her experiences of preparing and facilitating the co-design workshop. The co-design literature has stated little about how specific contexts, such as specialist care in hospitals, can affect the effectiveness of the methods and tools. More context specific advice could benefit the organisers and facilitators of workshops for this context. By reflecting on decisions and resulting experiences, workshop organisers become conscious of how to make use of a method and learn from it. Sharing these learnings helps to optimise methods (Steen, 2011).

Results

This study aimed to investigate how design methods can be used to support the redesign of patient education programs. A co-design workshop in which service design tools were applied was organized, with the aim of generating ideas *"to optimise the Kidney School's service to the benefit of patients and their relatives, as well as the nurses that organise the program"* and to investigate how to use design methods in healthcare practice. The findings regarded the latter are first presented through narrative on the PhD candidate's experiences of preparing and facilitating the co-design workshop. This is followed by an account of the workshop's practical results.

Applying design methods in a healthcare context – a designer's reflections

Deciding whom to invite as participants

Inviting the medical practitioners that are involved in the program was very important, as they are the ones that will eventually need to make changes to their practices. Although service receivers are commonly included in co-design workshops as experts of their experiences, I decided not to invite patients and their next-of-kin to this workshop. This decision was based on my consideration not interfere in the relationships between the patients, next-of-kin and medical practitioners. The relationship between newly diagnosed patients and their medical team is precarious. For chronic patients a good relationship with their medical team is important, as they will have to collaborate over a long time. During a co-design workshop, patients and medical specialists would be expected to interact with each other in a non-traditional setting. Additionally, power distances between medical specialists and patients exist, which might obstruct effective collaboration between these two parties during the workshop. Nonetheless, one of the disadvantages of not including patients and their next-of-kin is that their needs might not be considered.

I decided to invite external participants as they can bring in other perspectives and support creativity. Externals that have experience with similar services might have very different experiences than the team that works with the service that is being re-designed.

Preparing the workshop assignments and materials

The decision not to invite patients or their next-of-kin, who are important stakeholders, affected the workshop's structure. To mitigate for the absence of this important party, I formulated the assignments and materials from a patient perspective; Instead of a service blueprint, patient journey was developed to visualise the current service offer. Personas of three patients were developed, and a list of probing questions was added to the facilitator guide to ensure that the challenges we had observed would be addressed during the ideation assignments.[16]

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[16] A User Journey Map provides an overview of the series of direct interactions that take place during a specific timeslot between a service provider and a service receiver, from the receivers perspective. User Journey Maps are often used to display an existing service, to build empathy, and to evaluate the existing service (Stickdorn & Schneider, 2011). A User Journey Map often includes pre-service and post-service activities, providing an overview of the context in which a service takes place. It allows a design team to ensure that the service fits in its

With limited time available, we decided to focus on obtaining new ideas, not on implementation strategies. This was done afterwards in collaboration with the nurses that organize the program. When deciding upon the structure of the workshop and what materials to use, I tried to find a balance between detailedness and time needed for explanation. Scenarios, for example, could stimulate creativity but time would be needed to let the participants interpret them. A Patient Journey Map helps to visualize the existing service and is quicker to explain, but contains less information.

Another consideration related to how creative and free the assignments could be for people that are unfamiliar with co-design workshops. I decided, for example, not to use 'being someone else', an assignment that lets the participants view the topic from the perspective of someone that normally is not involved in the service. Although I have good experiences with this exercise from previous workshops, I expected that the hospital context with its hierarchic roles might hinder the participants to freely take on such a role. The sensitizing assignment was introduced to tune participants to start thinking of what constitutes to positive service experiences. I deliberately gave the participants one small assignment, as I was afraid participants would not do the assignments if they thought it would take too much time.

The language use for the assignments and materials was purposefully adapted to the workshop participants; during the pilot workshop words such as 'meeting with kidney doctor' were used, while medical terminology, such as 'consultation with nephrologist' was used in the workshop with medical professionals. Questions that the facilitators could use as probes during the workshop were included in the facilitator-guide. These 'probing-questions' focused on specific challenges that had come forth in the pre-study. Instead of stating that something was found to be a challenge, open questions where formulated to approach the challenges more positively. Examples of such probing question are: 'How could we ensure that the presentations cover relevant topics?', and 'What could be changed to make planning of the group-sessions easier?'.

Helping a medical researcher become a workshop facilitator

The quality of the outcome of a workshop is affected by the skills of its facilitators. I decided to ask the researcher who had been involved in the pre-study to facilitate the workshop with me. Even though this researcher with a nursing background was inexperienced with facilitating creative workshops, she was very familiar with the project and had an emphatic understanding of the situation for both the service providers and the service receivers. This enabled her to pose relevant questions to the participants, thereby ensuring that the participants focused on the challenges that we had discovered during the pre-study. Furthermore, she is very experienced with conducting qualitative research that involves interviews and observation.

To help the second facilitator build confidence in her role as facilitator, and to test the assignments and materials for the workshop, we organized a pilot workshop. Prior to the pilot

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context (Yang & Sung, 2016). Personas present archetypical persons through a short narrative in which key aspects of a person's life are mediated, including needs, goals and behaviors (Hanington & Martin, 2012).

workshop, we went through the facilitator guide together, discussing the intention of each assignment and the intended use of the materials that were prepared for each assignment. We also discussed the role and responsibilities of a facilitator during co-design workshops. To help us further align our approaches, we had a discussion after the pilot workshop during which we discussed our experiences and the things we were uncertain about. Furthermore, we discussed how to handle in certain scenarios, such as what to do when participants would be very quiet, or when disagreements would arise between participants.

Conducting the workshop

During the workshop, we, the facilitators, first introduced ourselves, explained the goal of the workshop, our role as facilitator, what was expected of the participants and the set-up the workshop. Furthermore, we explained some workshop rules, which stated i.a. that challenging ideas are meant to be constructive and that it was important to try to be open to new thoughts. Second, the sensitizing assignment from the post-card was used as a warm-up exercise in the workshop. The workshop started with a warm-up exercise. Due to the unexpectedly high number of participants in the workshop, the warm-up exercise took longer than planned. The other facilitator and me considered asking just a few participants to share their thoughts. However, we decided not to do so, as we wanted everyone to say something to the rest of group before the start of the actual workshop. We expected that it would help the participants to speak up during the assignments if they had already said something to the group on forehand. Each participants was asked to introduce themselves with their name and a memory of a good shopping experience. We wrote down key-words of their stories and summed these up at the end.

After the general kick-off, the group was divided over two rooms according to job-position. The first workshop assignment showed that participants needed time to become used to the designerly way of working with brainstorming techniques. At the start, participants were hesitant to speak out, and the facilitators had to prompt the participants for input. Thick description? – *Because the group stayed quiet after I had introduced the assignment, I asked participant c directly 'C, what information do patients need when they are diagnosed with stage 1-2 CKF?' Then I asked, 'D, do you know some other information needs?'* Gradually, the participants became more talkative. They started to share their thoughts without one of the facilitators having to ask them for input. Dialogues emerged where participants shared their thoughts more easily. The facilitators noticed that the participants became very engaged in the discussions. We no longer had to ask them for input. Everyone participated and the conversation kept going. However, the participants seemed uncertain about writing their ideas on post-it notes and had to be frequently encouraged to write down their ideas. The presence of the design student in one group was valuable, as she could help the other participants in her group at the start, showing them how it was done and writing notes when someone else did not do it themselves. In the other group, the facilitator acted in a similar way. This made it more challenging for this facilitator to urge the participants to write down ideas themselves and stay in her role as facilitator*. I had written down the first ideas that were mentioned, to show the intention of the exercise. Then I pointed the participants to the felt pens and told them to write down the next ideas themselves. However, as they did not do it, I started writing* *down the things they mentioned, as I did not want to disrupt their discussion each time to ask them to write down what they had just said.*

Assignment 2, formed the body of the workshop. It was intended to converse and to generate new ideas, based on the insights that had been collected in assignment 1. The facilitators additionally used the predefined probing questions, to draw attention to some challenges that we had observed during the pre-study, but which had not been mentioned by the participants in assignment 1. During the second and third assignments, in particular, the two external participants (a nurse involved in the organisation through a similar kind of service and a master student in design) fostered creative thinking by suggesting new topics. *The designer, for example, suggested the possibility of making a website with an instruction video, and starting a chat-group for patients and their family.* The two external participants also challenged current practices most. *The external nurse asked for example: 'What is actually reason that you do it like this? Have you considered doing it differently?'* The first reactions to such remarks were a bit defensive. These instances were few, but it was useful to have a printed overview of workshop rules to remind the participants to maintain a positive mind-set and to be constructive.
We found it very useful to have prepared probing questions on forehand, to bring up specific themes. We did not consider it necessary to introduce the personas, as the participants had constructive discussions and seemed to have a shared notion of patients and their needs. Two times I referred to the list of key-words on positive service experiences that was made during the warm-up exercise, asking the participants to consider what they associated with a good service experience and how this could be resembled in the Kidney School.

The discussions on which ideas supported the design of the 'ideal' Kidney School, and what would be needed to make it even better (assignment 3) started very carefully. Like during the first assignment, we had to encourage the participants to explain which ideas they liked and for what reason, addressing some participants directly. Eventually, the discussions started going and participants did not need to be prompted anymore.
During the break, we decided to skip assignment 3b, due to the delay that was caused by the longer warm-up exercise and because we noticed that the participants were less familiar with each other than expected. The facilitators presumed that the participants might not feel comfortable with presenting their group's results to the other group, whom they did not know so very well. Instead, the facilitators gave a summary of what each group had discussed to the other group. The facilitators then closed the session by reciting the goal of the workshop and what had been accomplished. They explained how the process would continue, and participants were given the chance to ask questions.

Workshop results

The pilot workshop allowed the facilitators to test the workshop's assignments and materials. Sharing their experiences in a discussion afterwards helped the facilitators to further align their approaches. The discussion also led to some slight changes in the workshop plan:

- It was decided to cancel Part B of the second assignment, which was to review the current service with help of three personas and to ideate on how the current service may be improved for these three personas specifically. This was decided as it took the participants some time to read through the descriptions of the personas, and as the facilitators felt that the workshop participants did not really need the extra stimuli to stimulate ideation. It was, therefore, decided not to directly introduce the personas during the actual workshop. Instead, the facilitators would keep the personas at hand, in case the participants needed extra stimuli for ideation.
- The facilitators developed a list of questions related to the patient experience that they could pose to the participants during the second assignment. This was done to encourage workshop participants to reflect upon specific events and interactions that we had found to be challenging during the pre-study, e.g. it helped us to point the attention of the workshop participants to certain events.
- A 10-minute break was added to the program after the second assignment. We expected that a short break would benefit ideation for the third assignment.
- The pilot study included a separate assignment to select ideas according to three criteria: most interesting, best to realise, and after the second assignment. This assignment was merged with the third assignment, as it was found to be too specific and of little added value. Participants had to select the best ideas for three different criteria: best fit with objectives, easiest to implement and best value regarding the participant experience.

Recruitment of participants for the actual workshop by the nurses went well, as more participants than expected signed up. Most participants were female nurses working at the same department. Those who were involved in the Kidney School but had other professions generally did not attend, accept for two nutritionists and one of the nephrologists.

The warm-up exercise was a rather open assignment. This enabled each participant to contribute, including those who had forgotten to prepare it (about half of the participants). Participants enthusiastically shared their stories and smiled in reaction to stories from others. We furthermore noticed that every participant also mentioned their job-position when they introduced themselves. The facilitators wrote down keywords, which resulted in a long list of keywords and phrases that participants related to good service experiences. Some examples of the keywords listed were: ‘Show knowledge and expertise’, ‘Take time’, ‘Good at explaining’, ‘What I ask for’, ‘Humour’, ‘Not too defensive, not too aggressive’ and ‘Short waiting time’. The keywords could be used in discussions during the following assignments.

After the warm-up exercise, the participants were divided into two groups according to job position. Assignment 1, the mapping of information needs, resulted in descriptions of:

1) Topics that patients ask questions about, such as what they can do themselves to slow the progression of the disease, future perspectives and where they can find more information.
2) Difficult emotions that the patients experience and the nurses observe, such as uncertainty, loss, shock.

3) Challenges that the nurses experience, such as patients who refuse to accept help, nurses wishing to protect patients whilst they need to inform them about the illness and its consequences, uncertainty regarding whether a patient really understands the information and will act accordingly.

Assignment 2, formed the body of the workshop. It was intended to converse on possibilities for changes, based on the insights that had been collected in assignment 1. The facilitators additionally used the predefined probing questions, to draw attention to some challenges that we had observed during the pre-study, but which had not been mentioned by the participants during assignment 1. We found that the ideas from the healthcare practitioners mostly concerned things they could change about their own practices. Their ideas often focused on communication styles, rather than technical alternatives. Examples of suggested ideas were: stimulating dialogue, actively involving patients, providing handy and concrete information (e.g. food and how salt can be replaced). The external participants presented proposals that were perhaps less evident than suggestions by the other participants. The external nurse, for example, asked: Could something happen in-between the group sessions? Like homework, something to prepare them?.

Assignment 3, the selection of ideas that could support the ‘ideal' Kidney School, resulted in the following ideas by group A, whom focussed mainly on what could be changed to the group sessions.

- *Away from traditional lectures* - soften the form of teaching - do not talk all the time - show dialysis department - show a film of dialysis? (too scary?)
- *Give them an overview, not too much details* - what's good enough? - be concise and concrete (eg food> taste)
- Balance between *activities* - Get patients to participate - Group work – Split into small groups.
- *Dialogue* - Get them to open their mouths - Clear framework for what they can share
- *Ask questions* - 1st day: What kind of expectations / interests do they have? > spend the last hour on conversation about these themes. Ask them at the end: What will be important to you on the way ahead? - task: discuss management strategies and challenges you have> create joint competence - summarize in general
- *Experience* - Exchange of experience as part of the sessions - Listen to the stories of other patients.
- *At home in own time* - Brochures - links to information sources – internet
- *Other ideas* - The framework of the invitation - Relaxation during the course (according to what we learn them) – preparation-assignments /tasks they can work with between meetings

Group B, who ended up taking a broader approach to the patient education service, came up with the following ideas:

- *Feeling of being taken care of* – you are not alone
- *Coordinate info* – who gives what, when, without rushing it - Relevant info (shielding) -

every 3 months individual follow-up consult - Phone contact with nurse (no question is stupid) - Nutritionist: Dietary advice, individually adapted, also for relatives – info on transplantation by patient and nephrologist together - offer to talk to PD patient

- *Conversation service* - for patients, next-of-kin and their children
- *Group teaching* - Group discussions - smaller groups speak more / individual groups for patients and relatives - facilitate info without bias – session from transplanted + doctor together
- Website that is simple and safe: information to the patient, links, information video.
- *Take choices*: possibility to change dialysis form along the way
- *During treatment*: Dialysis school > Conversations between patients

Discussion

Deciding who to include in a project, through which methods and during which stages, is an essential part of a project's preparation phase (Steen, Manschot, & De Koning, 2011). However, different options exist on who to involve when, also within the field of co-design (E. B. N. Sanders, 2008b). Active involvement of stakeholders creates shared ownership (Stickdorn & Schneider, 2011), drives innovation (Buur & Larsen, 2010) and ensures that these different needs are addressed (Steen et al., 2011). Service receivers are commonly included in co-design workshops as experts of their experiences (E. B. N. Sanders, 2008b). Patient involvement in the development of healthcare services is becoming more recognized and service design methodologies are being applied to innovate public healthcare services (NHS Institute for Innovation and Improvement, 2009). However, when organising a co-design workshop, designers will need to anticipate possible consequences of participant selection. The participant-group and its traits with respect to formality, climate, participation, conflict, decision-making, responsibility and communications should be considered (NHS Institute for Innovation and Improvement, 2009). This study shows that ethical considerations might also be relevant, especially reflecting upon the possible effect of participant-selection on long-lasting relationships. In this case, the designer decided not to include patients as to not interfere in the existing relationships between medical professionals and their patients. Especially in the case of chronic illness, it is important that the relationship between patients and their medical team is rooted in mutual trust. Trust has to be established and maintained over time (Paliszkiewicz, 2011). A workshop should not have a negative effect on this. During a co-design workshop, patients and their medical specialists would be expected to interact with each other in a non-traditional setting.

The disadvantage of not including patients in the workshop is that their needs might not be embedded in solutions. Inviting the medical practitioners that are involved in the program was however deemed very important, as they are the ones that will eventually need to make changes to their practices. When you design for a practice, it is important to include the practitioners in the process, as the process 'needs to be grounded in what it means to be a competent practitioner and in future visions of new embodied practices.' (Björgvinsson, 2008). Two articles describe how designers in healthcare settings dealt with the dilemma. Their projects present two alternative approaches.

1) Bowen et al. (2013) describe a project on developing better outpatient services for older people. They started with separate groups of patients and healthcare staff, to record personal stories and make emotional map. Next the teams were mixt and collaborative discussions were held on priorities for improvement, prior to conducting a co-design workshop in which also designers were involved as participants. The authors describe that their decision was motivated by prior experiences where medical professionals became defensive, and patients felt not being listened to.
2) Gaudion, Hall, Myerson, and Pellicano (2015) describe a project that aimed to improve everyday experiences of people with autism in home environment. In the first phase, designers build empathic understanding through triadic interactions with a person with autism and a carer. Next, people with autism and cares received assignments they could do at home, without the presence of a designer. Finally, a co-design workshop was organized in which carers and designers collaborated.

The workshop suggests that letting ‘insiders’ invite their colleagues may be an effective approach to participant recruitment. The nurses that were responsible for the program and who were open to change invited their colleagues. Although more medical practitioners than expected participated, not all specialisms were represented. Most workshop participants were female nurses working in the same department. Although this reflects the main part of employees at the department, more diversity in professional background and gender would have further supported shared ownership, and strengthened ideation (Buur & Larsen, 2010; Yang & Sung, 2016). A priest, physiotherapist and social worker are involved in the program, but could not attend. However, the outcomes of the workshop may come to affect their way of working as well.

Careful planning, the selection of appropriate methods, and taking time to prepare the materials increases the chance for the workshop to be effective (Lucero et al., 2012; Steen et al., 2011). As each project is different, designers should be able to apply methods or tools flexibly, carefully selecting the ones that fit best with the project’s aim (Yang & Sung, 2016). It is the designer’s task to decide which tools, materials and assignments to use, and arrange the space for the workshop to take place (Lucero et al., 2012; Reay et al., 2016). Empathic abilities, communication, and adaptation skills are important for a designer in the preparation of a co-design workshop (Gaudion et al., 2015). The pre-study was very important for me as it helped building empathy with the service providers, patients and their relatives and provided me with a thorough understanding of the case and the needs for change. When deciding not to invite patients and their next-of-kin who are the service receivers, one needs to find a way to mitigate for the absence of this important party. The combination of the workshop’s structure, pre-study and the involvement of facilitators that had strong empathy towards the case enabled us to ensure a focus on patient needs. Furthermore, healthcare practitioners are patient-focused, which supported us in addressing patient needs in addition to the needs of the medical practitioners themselves. However, the fact that medical practitioners are patient-focused reflected also in the ideas that they generated, which were strongly related to their daily practice. This is a common challenge with designing for services, as the needs and concerns of people form the starting point for ideation, not a technology or process (Björgvinsson, 2008). We considered it therefore very valuable that external participants joined the workshop. Bowen et al. (2013) concluded that including designers as external participants is valuable, but warn that their inclusion can have a negative effect on feelings of ownership among other participants, and Pirinen (2016) found that prejudices, can affect the effectiveness of collaborations. This implies the importance of balancing the participant groups with regard to internal and external participants and stimulating an open mind-set among the participants. Furthermore, externals are unfamiliar with the service and thus have a knowledge-gap. Yang and Sung (2016) therefore suggest letting externals build empathy by letting them to partake in a pre-study. Involving externals in a pre-study can however be an emotionally intense experience in healthcare contexts (Reay et al., 2016), might pose ethical dilemmas, and might be difficult to realize due to medical regulations. We therefore invited an external participant who has experience with a similar service for another patient group.

Some have experienced participants with negative expectations towards the project at the start and concluded that it might affect their willingness to contribute to discussions (Bowen et al., 2013; Gaudion et al., 2015). This contradicts our experience. Like Yang and Sung (2016), we found the participants to be very engaged and motivated to contribute, with more participants signing-up than expected and active participation from the start. Perhaps our approach supported this; the nurses that run the program and who were open to change, invited their colleagues and invited them to take part in the workshop. Additionally, the workshop focused on aspects related to their everyday practice, which stimulates motivation to participate (Pirinen, 2016). Furthermore, workshop deliberately started with a sensitizing assignment, to which all participants could contribute and that was unrelated to their work. However, we also noted that participants at the start were hesitant to express their thoughts and share ideas. E. B. N. Sanders (2008b) has recognized that engaging people in a creative process can be challenging, as many are not used to working creatively and might think they are not able to. Specialist healthcare is a complex context, with strong hierarchies between professions; working in silos occurs due to specialisation, and risk aversion is a common notion (Bowen et al., 2013). The participants worked in various disciplines and were less familiar with each other than expected. This might explain, why they, at the start, were hesitant to express their thoughts and share ideas. The workshop illustrates that within this setting, the inclusion of external experts as workshop participants can be very valuable to stimulate idea generation. The involvement of an external medical practitioner who provided similar services strongly supported ideation, as she brought in a fresh look and could question why things were done as they were. This fostered discussion and idea generation amongst all participants. The involvement of a designer turned out to be valuable, as well. It was evident that this creative way of working was new to the medical practitioners and that they needed to be supported. Designers are familiar with design tools and are used to consider the application of technology. They are aware of production processes and their constraints (NHS Institute for Innovation and Improvement, 2009; E. Sanders & Stappers, 2008). Designers can, thus, support non-designers in using design tools and support ideation on possible technological solutions, in addition to reflecting on changes to daily practice. Despite the benefits of including designers and other service providers, it is important to seek a balance between internal and external service providers, designers and non-designers, as the internal team should have a feeling of ownership over the ideas to facilitate effective implementation of the selected ideas in their practice.

Organising this workshop with medical practitioners further illustrated the importance of taking care in gradually building up the creativity level of the exercises to give non-designers a chance to become accustomed to a new way of working and expressing themselves. As empathic facilitators have an important role in the workshop outcomes (NHS Institute for Innovation and Improvement, 2009), I deliberately decided that my second supervisor, who had been involved in the pre-study and has a background in nursing, would facilitate one of the workshop groups. Her empathic understanding enabled her to pose relevant questions to the participants. This illustrates that facilitators do not necessarily need to be designers. They may also be field experts who have an empathic understanding of the situation.
Designers will need to reflect upon what role they take during a workshop. Co-design does not allow a designer to act as both facilitator and active contributor to ideation. It is the facilitator's task to be impartial and to create an open environment of trust that supports meaning making, and where people can equally share (NHS Institute for Innovation and Improvement, 2009; Pirinen, 2016). Being a designer in the role of facilitator may be challenging, as facilitators should refrain from introducing personal ideas to participants. Designers in the role of participant act at a different power level and take part in discussions more equally than designers in the role of facilitator. A designer as participant is therefore free to bring in ideas, while the workshop outcomes will still be anchored among the stakeholders through ownership.

The findings of this study illustrate that the application of design approaches in healthcare services may be beneficial and can lead to new insights and the improvement of healthcare services. The findings furthermore show that when applying design approaches in a healthcare context, some specific aspects need to be considered, namely; ethical reflections on possible effects of a workshop on the relationship between participants and the sector's unfamiliarity with creative methods.

Relevance for medical practice

The study shows that collaboration across disciplines can benefit healthcare services. In this case, a multidisciplinary team of medical professionals who are involved in the Kidney School collaborated effectively. Additionally, the organisers of the Kidney School established contact with another nurse, working at the same hospital, but for a different patient group, offering a similar service.

The feedback from the nurses, shows furthermore that medical practitioners may benefit from collaborating with designers. Designers can support medical practitioners, who tend to focus on medical needs, to think more holistically over the diverse needs of patients and their next-of-kin. Such insights can benefit the development of a patient education services.

Relevance for design

This study shows that the application of a co-design workshop and service design tools can be valuable for the development of healthcare services, but that there are some specific challenges of which designers need to aware.

Building up empathic understanding of the experiences of both patients and organisers through conducting interviews and observations may help designers in preparing and facilitating a workshop as it gives them an empathic understanding of the healthcare context and unfulfilled needs.

When preparing a co-design workshop, designers should carefully reflect upon which stakeholders to invite, and what the pros and cons of this selection are. Although bringing together different perspectives ensures that the needs of the different stakeholders are represented, ethical considerations are needed on what indirect effect a workshop can have on the long-term relationships between participants. This study shows that it is important to reflect upon this, in addition to making an allowance for the possible effects of participant selection during the workshop itself, as has been suggested by others (NHS Institute for Innovation and Improvement, 2009). Especially in the healthcare contexts, relationships between medical professionals and patients are precarious. In this case, it was decided not to invite patients and their next-of-kin as participants. Others have solved the participation dilemma in healthcare settings differently (e.g. (Bowen et al., 2013; Gaudion et al., 2015)). This study presents an alternative approach that designers might consider.

Designers may consider the inclusion of external participants as well. This study illustrates that within a healthcare setting, the inclusion of external experts as workshop participants can be very valuable for idea generation. The involvement of external medical practitioners who provide similar services can support ideation, as they bring in a fresh look and can question why things are done as they are, comparing this with their own practice. The involvement of designers as participants can be valuable as they are familiar with design tools and are used to considering the application of technology. However, it might be needed to overcome their knowledge-gap related to the specifics of the healthcare context, to increase empathy.

Decisions concerning participant selection affect the set-up of the workshop, as does the culture of the healthcare context, which may still be hierarchic, and working is silos might impede collaboration across disciplines. Organising this workshop with medical practitioners illustrated the importance of taking care in gradually building up the creativity level of the exercises to give non-designers a chance to become accustomed to a new way of working and expressing themselves.

As the healthcare context is complex, designers may consider involving people without a design background, but with an empathic understanding of the context to help facilitate a workshop. This study shows that such facilitators may support the adequate and respectful facilitation of a workshop. The study furthermore shows that conducting a trial workshop prior to an actual workshop, can support such facilitators without a design background to familiarize themselves with design tools and to gain confidence in their role as facilitator. Designers may furthermore consider gaining the support from medical professionals in recruiting participants for a workshop. Although this study consists of a single case, the findings indicate that recruitment by colleagues may be an effective approach to ensure the participation of healthcare practitioners with full schedules.

Processing the workshop's results

The ideas that had been generated during the workshop were gathered in one overview by the PhD candidate. A similar overview was made of the ideas that had been generated during the pilot workshop. One week after the workshop, I met the two nurses who organize the Kidney School to discuss follow-up actions and come to an agreement on an implementation strategy to realise the suggested changes. In preparation of this meeting, Prior to the meeting, the nurses and I individually selected ideas that we thought were relevant, interesting or promising. During the meeting, we shared which ideas we had selected and for what reason we had selected them. During the following discussion we discussed which ideas we deemed most relevant and promising and agreed upon the ideas we would develop further. An action plan was made on how to implement and realise these ideas. In addition, we discussed the development of an evaluation scheme that the nurses can use themselves without the help of a designer. The nurses would contact the external nurse who had participated in the workshop and who was responsible for the organisation of a similar service to learn about the evaluation scheme that her group used.

The two facilitators of the workshop also met to reflect upon their experience of the workshop, discussing what went well and what they have learned from this workshop that they could apply to future participatory activities.

7.3 Assessing the effect of a co-design workshop on a patient education program

Abstract

The findings of the case-study (section 7.1) showed that the intentions of the organisers of a patient education program, the expectations of its participants, and both parties' experiences of the program may be different. A co-design workshop applying service design tools was organized to reduce these gaps (section 7.2). The goal of this study was to evaluate if design methods can support the (re)design of patient education programs. This was done by assessing the effects of the implemented changes that had been introduced to the program after the workshop through an interview with the organisers of the program and observations of the redesigned program.

The findings illustrate that the application of design approaches in healthcare services may be beneficial and can support changes to healthcare services. However, resource constrains regarding time and budget may hinder the realisation of ideas in healthcare practices. Lack of authority of the organizers of a patient education program over the other healthcare

practitioners that are involved in the program may lead to suggested changes not being implemented in practice and to unintended changes to the structure of the program.

For designers, this study contributes with the insight that actively involving service providers to review the effectiveness of changes to their service, may provide valuable insights. It may be difficult for designers to distinguish tendencies and changes when new service receivers are involved, as each service receiver has a different background and relationship with the service provider and thus reacts differently to the service offer.

Aim of the study

A case-study on a patient education program for people who soon need to start renal replacement therapy and their next-of-kin showed that gaps may occur between the intentions of the organisers, the expectations of the participants and both parties' experiences of the program (section 7.1). A co-design workshop was organised to optimise the program's service to the benefit of patients and their relatives, as well as the nurses that organise the program. Additionally, the workshop intended to investigate how design methods can support the (re)design of patient education programs (section 7.2). The goal of this study was to evaluate the effect of the workshop by assessing the effects of the implemented changes that had been introduced to the program after the workshop. This was done to evaluate if the application of service design tools in a co-design workshop can positively contribute to the (re)design of patient education programs. The research question that this study thereby aims to answer is: *Can design methods support the (re)design of patient education programs?*

Method

The effects of the changes to the group sessions that were introduced after the co-design workshop (section 7.2) were studied through observations of the new group sessions and an expert interview with the two nurses that organised the program.

Study design

Non-participatory direct observations were made during the 'new' group sessions. The aim of these observations was to gain first-hand insight into how the suggestions for changes that had been developed during the co-design workshop were realised in practice, and what effects these changes had. This was done through the interpretation of both verbal and bodily expressions of the presenters and participants during the group sessions.
An expert interview was conducted to gain insights into how the nurses who organised the program experienced the 'new' group sessions as well as their perception of the effects of the implemented changes. The main research question for the expert interview was: *"How did you, as organisers, experience the redesigned program?"* Predefined topics concerned the their experience of introducing changes to the program, their perception of how the changes played out in practice and their thoughts about the future of the program.

Study Participants

The study subjects for the observations were the presenters at the group sessions. This time, there were two new presenters, compared to the previously observed group sessions: a new nutritionist and a new physiotherapist. They replaced colleagues that had obtained another job. The selection of participants for the expert interview was based on purposeful sampling. The same two nurses who were interviewed in the first part of the case study (section 7.1) were interviewed again. These nurses have years of experience with organisation and facilitation of the program. Therefore, they can provide insight into how the newly introduced changes affected the group sessions, as they can compare these sessions with preceding sessions and observe differences.

Data collection

Non-participatory direct observations were made of six of the presentations. The three sessions on the last day of the course could not be observed, as the PhD candidate had other obligations that day. On the first day, prior to the start of the group sessions, I introduced myself to the participants of the group sessions and gave them an information letter that included information about the project as well as my contact details. During the program, I sat in the back of the room in order to interfere as little as possible during the presentations. When participants came to me during a break, I answered their questions about my project. Presenters of the observed group sessions gave written informed consent before the start of their presentations. Observation notes were transcribed the same evening to reduce the influence of recall (Denscombe, 1998).

The two nurses who organised the program were interviewed together in order to supplement each other, supporting the richness and reliability of responses (Denscombe, 1998). The interiew was conducted by the PhD candidate and took place at the office of the nurses. Written informed consent was obtained before the start of the interview. The interview was audio-recorded. During the interview, open questions addressing the pre-defined topics were formulated and short notes were taken.

Data analysis

Directed qualitative content analysis (Hsieh & Shannon, 2005) was used to analyse the observation notes of the ‘new’ group sessions and the transcript of the expert interview. The themes that were used for data analysis reflected the categorised findings of the first study, i.e. the practical aspects that could be improved. Data analysis, thus, relied on deductive reasoning. The data that did not belong under one of the predefined themes were not further analysed, as the goal of this study was to asses if the changes to the program had contributed to the improvement of the program on the specific points for improvement that had been found in the preceeding study. After a first analysis round, the PhD candidate discussed her interpretations of the data with her second supervisor to increase trustworthiness of the findings, as deductive reasoning introduces a risk for bias (Hsieh & Shannon, 2005).

Findings

Implemented changes

During the interview we discussed the changes that the nurses had implemented after the workshop. One of the main topics that had been discussed during the workshop was findings ways to move away from traditional classroom lectures. As a result of the discussions around this topic, changes that focused on fostering interactivity amongst participants as well as between participants and presenters were introduced to the group sessions. Specifically, the following changes were introduced:

1) The nurses reserved some time at the start of each day for group discussions about the expectations of the upcoming presentation and reflections on the presentations from the preceding day.
2) Presenters were requested to directly ask if participants had questions and consider giving the participants short assignments that they could work with in small groups of 3 to 4 participants.
3) The presenters were asked to stay during the break following their presentation to give participants a chance to ask questions to a medical specialist in a more informal setting, without having to speak out in front of the group and having to be waitlisted for a special consult.
4) The tables were arranged in a U-shape throughout all group sessions to foster interactivity amongst the participants and create less of a lecture-like setting.
5) The presentation on kidney donation by a nephrologist and the separate presentation by a kidney donor and an experienced patient were merged into one longer session. The three presenters presented the topic together. Previously, only the presentations on dialysis options were presented by a medical practitioner and an experienced patient together. Due to the positive experiences with this set-up, this technique was also utilised for the session on transplantation.

The nurses also introduced an evaluation form that participants were asked to fill out at the end of each day anonymously. Participants were asked to rate each presentation session on a five-point Likert scale (from very good to very bad) and could write down any comments in free text fields. This evaluation form was developed with help of the external nurse who had participated in the co-design workshop. This external nurse has experience with the organisation of a patient education program for another patient group.

The nurses explained that they had decided not to introduce other changes at this point, due to time and resource constraints. Therefore, the idea to add extra information to the website on the program at the Kidney School and its aim, as well as links to further reading, was postponed. The idea to introduce some 'homework' to help participants prepare for and reflect upon the group sessions was postponed for the same reason.

Facilitating interaction through prompting for questions

During the expert interview, the nurses explained that the activity and involvement of participants differ from course to course. Sometimes, the participant groups are open, whilst at other times, they are more closed and quiet. This time, the participant group was exceptionally quiet. The nurses had the impression that the participants did not feel like they had anything in common with the others and, thus, nothing to talk about. The nurses' expressions showed that it surprised them that it was so quiet, even during the breaks and the presentations when experienced patients joined. It also disappointed them a bit, as one of the reasons to organise these sessions is to give patients a chance to ask questions. *"It's very nice when people participate and ask questions, and that things are happening, right? And when you see people talking to each other, that's very nice. And then you feel afterwards that it is nice to organise this".*

The observations showed that despite that presenters said that participants could ask questions, their behaviour and body language did not always support this. Some presenters gave a more traditional lecture, distancing themselves from the participants physically and mentally by standing behind a lectern. Other presenters used a few slides and tried to set up a dialogue. The latter usually came across as more open for questions. However, the participants hardly replied to any of the presenters, even when a presenter specifically asked if there were questions, or when a presenter asked the group for input and waited for a response. Only occasionally did a participant respond in these instances. None of the participants posed a question when not asked directly. I observed that the nurses tried to set up dialogues by asking questions to presenters. Even though the participants appeared to be listening, they did not pose questions themselves.

The observations showed that the combination of three presenters with different backgrounds presenting information about kidney transplantation and donation led to dialogues amongst the three of them. During these dialogues, topics were enlightened from each presenter's standpoint, providing a broad perspective. Observations of the group sessions before the workshop (section 7.1) had shown that participants asked more questions and seemed more relaxed during presentations that were given by a medical practitioner and an experienced patient together. During the observations of the 'new' group sessions, I did not notice a difference in the atmosphere. However, during the expert interview, the nurses told me that participants had indicated that they appreciated these presentations on the evaluation schemes that they had filled out.

The nurses provided suggestions for how this situation could have arisen. They wondered if it could have to do with the group's composition, being small and in different disease stages. They also expressed that some participants might have felt hesitant to ask questions, as the few questions that were posed by participant on the first day were rather personal. The nurses felt a bit powerless to avoid this in future, as this expression shows: *"It is difficult. [...] Everyone who has been here [for an individual consult] is invited, regardless of age and how far his or her disease has progressed. We do not have enough patients to divide them into different groups. So, it's just the way it is*". Although it took some effort to organise the sessions, many patients did not join the group sessions. The nurses had some assumptions for patients' motivations not to join, but did not know the exact reasons.

The effects of changes to facilitate interaction

At the start of each day, 15 minutes were reserved for group discussions on expectations for the upcoming sessions and reflections on the sessions from the preceding day. The nurses had prepared some questions for the participants. I observed that it was difficult for the nurses to obtain responses from the participants. Perhaps this had to do with the participants' state of mind. The observer noted that, during the introduction round at the start of the program, the first two participants expressed a bit more about themselves, whilst the rest only briefly mentioned their name, followed by the expression 'patient' or 'next-of-kin'. They did not appear to be interested in getting to know the other participants. During the interview, the nurses indicated that, despite this experience, they would stick with this change. Eventually, they would adjust the program for the second and third day if they encountered another group that was very quiet.

Most presenters stayed during (part of) the break. Some of them specifically indicated that they would stay and have time to answer individual questions. I observed a few participants making use of these possibilities. Some presenters proactively approached participants at the coffee table, others sat down next to me or the two nurses who organised the sessions. Many participants remained seated and only briefly stood up to get some coffee. Sometimes participants would talk to their next-of-kin. They did so in a very low voice, even during the breaks. The nurses expressed that, whilst they usually experience the breaks to be a bit short, this time they felt that the breaks took a long time and that the participants were waiting for them to continue. They said that they felt that the quietness during the breaks also negatively affected the atmosphere during the sessions. The quietness made them a bit uncomfortable, as the following expression illustrates: *"It made me feel as if I had to finish as quickly as possible. (laughs)"*

A kidney donor and someone who had received a kidney transplant joined the presentation on kidney transplantation by a nephrologist. The nurses expressed that the participants provided positive feedback on this combination and that they themselves considered this a positive change. During the group sessions, I observed that letting a topic be presented by a specialist together with an experienced patient fostered dialogue and provided a broader view on the topic, as presenters could supplement each other's explanations.

The effects of the introduction of an evaluation form

The nurses explained that few participants had written comments in the free text fields, but that those who did indicated that they appreciated the personal insights from the experienced patients about the different treatments. Furthermore, the nurses expressed that they had sent a summary of the evaluation to all presenters. The two new presenters specifically appreciated the feedback and indicated that they would reflect upon the comments.

The nurses further indicated that some participants wrote that the information in some sessions that covered topics other than treatment options was a bit too general. The nurses recognised that this experience is concerning. *"If it becomes very general, they might lose interest, because this is not really what they want to know".* On the other hand, the nurses seemed to assign part of the responsibility for such remarks to the participant group and its dynamics, expressing that this usually is less of a problem when the participants ask questions. The presenter can then provide them with specific information that addresses their interests. Furthermore, the nurses indicated that, due to the number of patients being low and the participant group being diverse regarding their disease progress, it is difficult to ensure the relevance of every topic for each participant. At the same time, the nurses struggle to determine what information to offer. The nurses explained that they perceive that participants are mainly interested in information that is relevant for them at present, whilst the nurses also want to provide them with information that they will need in the future.

Unintended changes

During the interview, the nurses pointed to an event that had happened on the third day of the group sessions (the sessions on this day had not been observed, as I was unable to attend). This event had not been planned. The nurses described how one of the experienced patients deliberately sat himself amongst the participants, instead of standing in front of the group as the other presenters usually did. Consequently, this experienced patient blended in with the participant group. The nurses explained that this changed the group dynamics. They had the impression that it encouraged the participants to ask questions and, therefore, regarded it as a positive change.

Another unintended change was that there were two new presenters who had taken over for their colleagues. As the nurses can only brief these new presenters, but the presenters prepare their presentations themselves, this led to unintended changes. Some of these changes were considered positive, whilst one particular change was regarded as negative. One of the sessions had previously included short assignments that participants had to do in small groups. This fostered discussion amongst them. The new presenter had not reserved time for these small assignments, but rather presented information in a top-down, lecture-like manner. The nurses indicated that they would ask the presenter to change this for the next time.

An unintended effect of the co-design workshop became clear during the expert interview. The nurses expressed that they found the presence of the external participants during the workshop very enriching. They had contacted the nurse who organised a comparable service several times afterwards to discuss how she approached certain things. This led them to consider the introduction of more changes to foster interactivity and to move further away from a traditional lecture style. The discussions with this other nurse had also helped them in developing the evaluation scheme that they had handed out to the participants at the end of each day.

Remaining challenges

Despite the changes that had been introduced in the group sessions, there is room for improvement. The nurses had reflected over the feedback they had received from the participants and their own experiences of the last sessions. They emphasised that the set-up of the session on nutrition, in particular, needed to be changed before the next time. They had noticed that participants were confused afterwards and deemed it important to focus more on the patients' need for information about what they can do themselves to delay treatment start. Furthermore, they wanted to reintroduce small group exercises that had previously been part of the session. Another change that they were considering was the introduction of a new session that specifically focused on supporting participants in making a treatment choice.

The interview revealed another problem: the nurses lacking agency over the presentations given by other presenters. The nurses explained that they only provided new presenters with advice prior to upcoming group sessions, and only to those who specifically asked for it. Few discussions took place between the nurses and presenters who had contributed in previous sessions about the presentations and how they went. This lack of an opportunity to provide feedback was sometimes problematic. The nurses expressed being aware of some problems. In their reflection on the group sessions, they specifically payed attention to the information that was offered and how it was mediated. The following quote presents one of their reflections: *"It would have been better if the sessions on diet and about physio had been a little more active. That there was a little more variety in … not just plain lectures, in a way".* The nurses' statements further showed that they were a bit cautious about how information was mediated and what information was stressed. *"I've been concerned about not scaring away people [when presenting treatment options]"*. However, as presenters organised their own presentations, and there was little room to provide feedback to presenters, it was difficult for them to ensure that such changes became implemented. The lack of authority of the nurses towards instructing presenters also affected the structure of the program. The order of the sessions was dependent on the availability of the presenters. *"The best thing would be to have a doctor who talks about kidney failure on the first day. To start with this, but it's so difficult, because they are so busy".*

Recommendations to organisers of similar programs

The nurses recognised that their profession biased them, focusing on providing medical information to patients. They suggested that the involvement of external parties can support the construction of a more holistic education program. When asked what advice they would give to others who organise similar programs, the nurses expressed that their main advice would be to involve experienced patients. They explained that experienced patients mediate information differently and are more focused on the practical aspects of life on treatment. According to the nurses, this could support understanding and coping. *"Then it becomes a different experience for them, I think. And I believe that this is rather important for those who sit there and listen to their stories, because it isn't professional-theoretical, but rather practical-theoretical. Therefore, it becomes easier to understand for them, I believe".* Furthermore, the nurses thought that it was important to involve various specialised medical practitioners in the group sessions. Specialised medical practitioners could provide more specific information than the nurses. The interview showed that involving them in the group sessions was also motivated by the fact that waiting lists for appointments with specific specialists were long. Inviting specialised medical practitioners to present during the group sessions was, therefore, some kind of remedy. *"You refer them, and then they have to wait for half a year. […] It's so long for the patient to go and wait, so the motivation to talk to a nutritionist has disappeared. Therefore, we found out that it's very important that we have it in*

the group sessions, so they get a little more [information]". However, during the observations, I found that the nurses also have a lot of knowledge of the various topics themselves. They frequently supplemented a specialist's answer during the group sessions. This indicates their awareness of patients' information needs.
Additionally, the nurses said that it was important to facilitate dialogue, as this provides the participants with an extra opportunity to ask questions outside of the normal consultations, and participants can learn from the questions that are posed by others. The nurses further expressed that it is important to limit the duration of the sessions, as participants are not used to such a program and are feeling ill, and not to spread out the program over a long period to maintain a sense of flow and group feeling. *"Don't get it too spread out, then they almost forget that they have been here".*

Discussion

After the workshop, various ideas were implemented that focused on moving away from traditional lectures, amongst others, through fostering group discussions. Group discussions provide an alternative way of learning that is more effective for specific kinds of learners (Hjelsvold, 2017). Interactivity supports learning, as people may learn from observing peers. It is a multi-dimensional way of learning (Dougiamas, 2009). When learners ask questions, teachers are provided with some insights regarding the degree to which the individual learner has knowledge of the topic, and can adapt the information they provide to the individual's needs accordingly. Fostering interactivity is not only important for learning, but it also supports SDM. Patients should be helped to structure information and trained to relate it to their own situation (Rodgers, 2006). Therefore, only providing information is not enough to provide for SDM. People should be helped in linking the information to their personal situation, values and needs. To accomplish this, a setting must be created that facilitates active participation from patients in discussions. This creates an information exchange between two or more parties. The aim should be to support responsiveness and interaction when communicating (Kasper et al., 2010). The observations showed that the occasions when a participant posed a question occurred when a presenter directly asked if there were questions. This indicates the importance of presenters regularly taking a break and asking if something is understood.

Investigating if the implemented changes had a positive effect on interactivity by observing one course was difficult for the external researchers. In a group, people adapt their behaviour by observing the behaviour of others. When others ask questions, one does so more easily as well; when others are quiet, it is less likely that one will ask questions (Dougiamas, 2009). Insights from the nurses who organised the program were very valuable, as they have a lot of experience with the group sessions and know the general trends of such sessions. The nurses indicated to keep the changes in the subsequent sessions, despite this group being relatively quiet. They thought it rather had to do with the specific characteristics of this group, than with the changes being insufficient. However, they also expressed to eventually adjust the program for the second and third day if they again encounter a group that is very quiet. This shows the nurses' flexibility in trying out new things and their experience that changes should not be dismissed directly, as they might have a positive effect for other participant groups. It also reflects the value of including experienced-based knowledge when investigating the effect of changes in practice. The statements from the nurses also show that they reflected over what worked well and what could be improved after the workshop and the latest group sessions. The needs of service receivers may change over time, due to demographic changes of the patient group and the attainment of new medical insights. Healthcare practices will need to evolve over time to adjust for such changes.

Some unintended changes to the program became apparent during the study. This shows the vulnerability of the program. The program is dependent on knowledge transfer when a new presenter takes over. It shows the importance of the nurses who organised the program having the possibility to guide new presenters. However, the interview with the nurses showed that the nurses could give advice, but had limited control over how a presenter filled in his or her time slot. Due to the hierarchic culture and the division in silos, they nurses lack the authority to provide the presenters with more rigid instructions, which could ensure the continuity of the lectures. Although unintended changes may turn out positively, planning for an intended change is better as it guarantees the continued development of the sessions. The lack of authority over the other involved medical practitioners may also hinder that changes are implemented.

A challenge that still needs to be addressed, is that not every patient joins the program. Consequently, the number of participants is low, even though it takes some effort to organise the group sessions. The nurses have certain assumptions, but do not know the exact reasons for patients not to join. Investigating this further and introducing practice changes to lower barriers for participation would be beneficial for both parties. More participants may benefit from the information that is provided in the program, and the nurses might feel that it is more worth the effort of organising the sessions when more patients benefit from it.

As service design takes a holistic approach, some ideas might require the buy-in from external actors for realization. Consequently, they might be difficult to implement in practice. This risk is especially pertinent in healthcare, as healthcare often is delivered in silos (Wolstenholme et al 2010). Such situation can be frustrating for participants and they might even come to doubt the effectiveness of the design project (Bowen et al., 2013). In this project, a selection of ideas was made after the workshop. Resource constrains, such as time and budget, influenced the prioritization of ideas. The two nurses took on the responsibility for implementing the selected changed, as making internal participants responsible for the implementation supports the realization in practice as they enjoy credibility among their colleagues (Pirinen, 2016).

Relevance for medical practice

The study shows that collaboration across disciplines can benefit healthcare services. After the workshop, the organisers of the Kidney School maintained contact with another nurse, working at the same hospital, but for a different patient group, offering a similar service.

The feedback from the nurses, shows furthermore that medical practitioners may benefit from collaborating with designers. Designers can support medical practitioners, who tend to focus on medical needs, to think more holistically over the diverse needs of patients and their next-of-kin. Such insights can benefit the development of a patient education services.

Relevance for design

The study indicates that collaboration across disciplines, established through co-design workshops, can benefit healthcare services. Furthermore, the study points out that actively involving the service providers, to collaboratively review the effectiveness of changes to their service can provide valuable insights. Each service receiver has a different background and relationship with a service provider. Consequently, it may be difficult for a designer, who is an outsider, to distinguish the effect of changes to a service when new service receivers are involved.

Additionally, the study shows that the development of an evaluation scheme that patients fill out, may support service providers in ideating on possibilities for improvement and the implementation of novel approaches without the further involvement of designers.

8. Contributions and conclusion

This chapter presents reflections on the strengths and limitations of the research and on its contributions for the design field regarding design research, design education, and design practice. The discussion addresses how design can contribute to informing patients through education programs, how service design approach can contribute to the improvement of patient education programs, and how design can contribute to the development of tools to support patients in shared decision making (SDM). Furthermore, the chapter presents the thesis' contributions to the health services sector, suggestions for further research and reflections on SDM. The chapter concludes with a brief conclusion of the thesis.

8.1 Reflections on the strengths and limitations of the research

Social constructivism

Following the social constructivist paradigm, trustworthiness, authenticity, and transferability are used as quality criteria for reflecting upon the strengths and limitations of the thesis. Trustworthiness, or how well a study's findings reflect reality, is parallel to internal validity as used in positivism (Guba & Lincoln, 1994). Authenticity is an issue that is specific to qualitative research, concerning whether the findings reflect the diversity of meaning and experiences of all participants involved in the study. Authenticity is strongly related to credibility. The credibility of a study depends on how the research was conducted and how trust in the correctness of interpretations was created (Given, 2008). Transferability, or the generalizability of findings, is parallel to external validity in positivism (Guba & Lincoln, 1994).

The studies included in this thesis were conducted under the social constructivist paradigm, and a large part of the thesis is built on qualitative studies. The qualitative approach allowed for the collection of rich insights into people's experiences of a phenomenon. A limitation of qualitative studies and inductive analyses is the limited suitability for generalizing the findings. The findings can therefore not be used to formulate a theory or guidelines for practice. This would require additional quantitative insights. The insights from this study present provisional premises that are up for further scientific scrutiny. A number of the insights are indirectly transferable to other patient education and decision support programs, as they support understanding of such phenomena and can be used to improve similar educational services (Holloway, 2005). Examples of phenomena to which the insights are transferable are patient education for people with other medical conditions and patient education of patients with chronic kidney failure (CKF) after they have made a choice for a form of self-care therapy.

Qualitative data collection through interviews and observations

At the start of this project, the project description was relatively open. In such cases, researchers have the opportunity to formulate an objective that lies close to their personal interests. Thereby, a researcher's pre-understanding plays a role in the problem selection. A researcher's background affects the aim of the study, while the aim of a study guides method selection. A researcher's background thus impacts the research process (Alvesson & Sköldberg, 2009). During my education in industrial design engineering, I discovered that I

prefer to apply a human-centred design approach. In human-centred design, human needs drive design, while technological functionality has traditionally been the driver for innovation and design (Krippendorff, 2006).
The aim of this thesis was to acquire a better understanding of aspects that can support the (re)design of pre-treatment education and decision support programs for chronic patients and their next-of-kin. The formulation of the objective indicates that technologies are regarded as a means to an end and not an end in itself. The thesis did not focus on the optimization of one specific technology. Rather, the findings provide arguments for which technologies might be applied based on the needs of stakeholders and for how these technologies might be optimized so that they can be used effectively.

Qualitative research methods are an appropriate methodology to explore individual experiences (Malterud, 2001). Qualitative methods provide researchers with in-depth understanding of a specific event, enabling them to contextualize their findings. However, the data give restricted insight into how common the described experiences are. Another limitation of social constructivist studies applying qualitative methods is that these studies provide insights in constructions that informants previously held. Meanings change over time when new events are experienced and interactions with others take place (Guba & Lincoln, 1994). During the project, one particular event stood out that clearly exemplified the temporality of the obtained insights: After conducting the expert interviews with Dialysis Network, I got permission to observe the group sessions that they organised. However, that fall, only a few patients signed up for the group sessions. The group sessions were therefore cancelled. The next spring, when I contacted the Dialysis Network again, I was informed that they were reconsidering if they should continue with the group sessions or if they should offer the information in another format.
Changes are not necessarily as evident or impactful as in this case. Another example of meanings that changed over time occurred during the second interview with the nurses who organised the Kidney School. One of the nurses expressed that she thought it might be interesting to add a specific session to the group sessions on SDM. She indicated that the co-design workshop had stimulated her to scrutinize their way of working and objectives further, which had led her to this idea. Possibly, discussions in the media on SDM also influenced her reflection.

One major strength of this thesis is that, by interviewing the organisers of two education programs and the developers of a decision aid, who are key players, the researchers got access to privileged information (Denscombe, 1998). During two interviews, two key players were interviewed at the same time so that they could supplement each other’s statements. This led to richer, more trustworthy responses (Denscombe, 1998) and enabled the participants to reflect upon their experiences (Morgan, 1993). However, since the participants were colleagues, they each might have felt reluctant to contradict the other, especially since they had been employed for different lengths of time. In one expert interview, it was not possible to interview the key players at the same time because their offices were located in different cities.

Therefore, the strengths and limitations of other group interviews do not apply to these specific interviews.

During the data analysis of qualitative studies, data strings are decontextualized. Consequently, there is a risk for losing the connection between the interpretation of meaning and the specific context in which something was observed or said. This may lead to a misinterpretation of the data. However, since the amount of data per sub-study of this research project was relatively low, this potential risk for misinterpretation was low. It was possible for the researcher to maintain a good overview of the various transcripts during data analysis, and preliminary findings were validated against the original transcripts to ensure that no misinterpretations had occurred due to de-contextualization (Malterud, 2012).
The researcher's understanding of meaning of qualitative data is second-order, which encompasses another risk for misinterpretation. Observations of a phenomenon and interview data are not interpreted from a tabula rasa, but from the researchers' pre-understanding (Alvesson & Sköldberg, 2009). Another important question regarding the quality of the presented findings is if they are sufficiently authentic. Authenticity is not merely dependent on which methods are used; it depends also on the process of interpretation and data analysis. To reduce the risk for misinterpretation, to ensure authenticity, and to support the credibility of the findings, the transcripts and observation notes of each of the interviews were shared with at least one other researcher. Through discussions, the researchers' individual interpretations were juxtaposed. This deepened our individual understandings of the events. The discussions focused on coming to consensus on the meaning of the data. Intersubjective agreement through discussions in which motivations behind individual interpretations are shared improves the trustworthiness of the findings. Such discussion furthermore supports the fairness of findings, as it helps to ensure that the findings cover the diversity of views and perspectives. Furthermore, such discussions stimulate reflexivity among researchers (Guba & Lincoln, 1994).

The trustworthiness of the various studies that were conducted for this thesis differs per sub-study due to practical constraints. For the study described in section 7.1, my first and second supervisors and I engaged in several rounds of discussions during the analysis phase. I performed the other studies, the findings of which I discussed with only my second supervisor due to time limitations. The expert interviews that were conducted in the Netherlands were held in Dutch. As my supervisors speak Dutch, they were not able to read through the transcripts and form their own interpretations of the data. To account for this, one of my supervisors thoroughly scrutinized the reasoning for my interpretations of the data. The credibility of the findings of each expert interview was strengthened as respondents were given the opportunity to provide feedback on the findings.

Performing a case study

The thesis includes a single-case study of a face-to-face education program (section 5.3). Case studies can be used to explore an event, to inspire the design project, or to study the effects of innovations (Hanington & Martin, 2012). The employed methodology helped capture important information about the program from a variety of sources, providing a comprehensive view of the education program. More specifically, the study provided qualitative insights into the practice of providing pre-treatment education and the subjective experiences of both the organisers and participants of such programs. However, the methodology and study design induced some limitations with regard to conclusions. Case studies allow the study of complex contemporary social phenomena, helping answer research questions that start with ‘why’ or ‘how’. They do not provide insights into the prevalence of a phenomenon (Yin, 2003). The study provides insights into how the organisers and participants of the Kidney School experienced the education program and additionally showed gaps between the organisers’ intentions and what happened in practice during the group sessions. The study could not provide insights into how many participants had the same experiences. The study’s transferability is high due to the detailed descriptions of the case and the educational program.

The limitation of performing a single-case study is that the conclusions are less strong than the conclusions from multiple-case studies. Multiple-case studies lead to more generalizable results, as the findings from the various cases can be compared (Yin, 2003). Initially the goal was to study three cases and perform cross-case comparisons. However, the second case study (on the Dialysis Network) was discontinued when the group sessions I wanted to observe were cancelled. Another actor that might have been interesting to study declined to participate, as they did not want their clients to be contacted. Furthermore, the plan was at first to study the development of a decision aid holistically. This would have been the third case. However, after the interview with developers (section 6.1), the study was discontinued for two reasons: 1) The patients involved in the development of the decision aid were few and we did not want to burden them with an additional study, as they were already involved in user-testing and reference groups. 2) The interviews with the organisers of the Kidney School and with the developers of the decision aid showed that their intentions and approaches differed considerably, which would make between-case comparisons difficult. Although the case study consisted of a single case and although the program at the Kidney School is unique, describing a program, investigating it holistically, and communicating its effects will help in developing better pre-treatment education programs (National Kidney Foundation, 2015). The literature review showed that there is a broad range of other pre-treatment education programs practiced internationally (section 5.1.2). Some of the findings from the case study may be transferred to other cases, despite this diversity. For example, the finding that gaps may occur a) between the intentions of the organisers of a program and the expectations of participants, b) between the intentions of the organisers and their experiences in practice, and c) between the expectations of participants and their experiences in practice, is transferable to other patient education programs. Specifically, the findings underline the importance of evaluating education programs not only on their effectiveness regarding knowledge gain, but also regarding the initial intentions of the organisers and the experiences the program provides.

To ensure validity, data triangulation and observer triangulation were applied during the case study (Robson, 2011). Collecting data through different techniques and from different sources (data triangulation) led to a rich data set that provided in-depth insights into the case and strengthened the validity of the study. Three researchers worked together in data collection and analysis for the study presented in section 7.1. The three researchers that collaborated in this study each had different experiences and professional backgrounds in industrial design engineering, nursing, and philosophy. This diversity supported the credibility of the study, as it influenced our questions, interpretations, and reasoning. The risk for misinterpretation was diminished through collaborating in data collection and group discussions. Two researchers were present during each interview as well as under each observed presentation (observer triangulation). With our different backgrounds, each researcher noted different issues, resulting in the collection of a richer data set. Through group discussions on individual interpretations, a collective understanding of the experience emerged. The data triangulation and observer triangulation (Robson, 2011) were complementary, providing insights from different perspectives. However, as two researchers observed each group session, the naturalness of the situation might have been obscured, especially as the participant group was relatively small. To minimize the effect of our presence, we acted as non-participating observers, sitting outside the group in the back of the room. Contact with the participants was kept to a minimum, but when questions were posed directly, we answered these. A disadvantage of taking the role of non-participating observers was that participants could not be asked for clarifications or motivations.

Patient interviews were also conducted. Eleven of the thirteen patients and their next-of-kin who had participated in the observed group sessions were invited to participate via an informational letter. Three persons replied that they were willing to participate. Consequently, the study relies on the subjective experiences of relatively few persons. Furthermore, the three participants that were interviewed were among the younger patients who had participated in the program. It would have been informative to interview older participants as well, as older persons might have experienced the program differently, as they may have had different lifestyles and needs. Orsino, Cameron, Seidl, Mendelssohn, and Stewart (2003), for example, found that, depending on age, people want information on slightly different topics. Interviewing older participants might thus have led to additional insights. The same goes for next-of-kin, who might have experienced the program differently and who possibly had different information needs.

Reflection on the workshop and the evaluation of its effect

When setting up a plan for a co-design workshop, organisers should carefully consider who to invite as participants and reflect on what affect this might have on the atmosphere during the workshop as well as on the participants' relationships afterwards (NHS Institute for Innovation and Improvement, 2009). For healthcare settings, the relationships between medical practitioners in various roles and those between medical practitioners, patients, and their next-of-kin are important to consider. Additionally, the findings underline the importance of preparing materials and assignments that match the participants' experience with creative activities and of deciding what role designers will take. From an academic perspective, these two insights are not novel. Other design researchers working with co-design workshops have described similar findings. Additionally, the findings were based on insights from a single workshop in a healthcare setting. The organisation of several workshops and comparison between them would have strengthened the trustworthiness of the insights. For the healthcare sector, this study however does provide an example of how co-design workshops may be applied as a method to optimize healthcare services. For me personally, the organisation and facilitation of this workshop was a learning experience. Although I had experience with organising and facilitating similar workshops for other industries, I learned that the specific context of the healthcare sector required a slightly different approach.

To determine if a co-design workshop is a suitable method, the specific goal of a project needs to be clear (Steen et al., 2011). In our case, the pre-study (section 7.1) informed the design process. The findings of this study motivated the decision to organise a co-design workshop and supported the formulation of workshop goals as well as the tasks and materials for the workshop. Regarding the workshop itself, three factors strengthened the credibility of the workshop:

1. The designer had previous experience with organising and facilitating co-design workshops, which helped in preparing relevant assignments and materials for this workshop.
2. The workshop assignments and materials were tested in a trial-workshop.
3. Two of the workshop's facilitators had an intimate understanding of the healthcare context and the specific problems addressed in the workshop, which allowed them to pose relevant questions.

Most workshop participants were female nurses working in the same department. Although this reflects the majority of the department's employees, more diversity in professional background and gender might have strengthened idea generation and might have further supported feelings of shared ownership (Buur & Larsen, 2010).
Pirinen (2016) warns that a university led service design project that includes co-design frequently becomes *'a superimposed one-off activity with weak connection to actual end solutions and with relatively little value or impact on the participating organisations' core activities, aside from a change of mind-set towards more user orientation or some incremental development ideas'* (p. 33).

The results from the workshop at the Kidney School were more incremental than innovative. However, this might not be a disadvantage. As the nurses who organise the Kidney School were the ones who had to implement the changes, it was important that they felt both able to realise the changes and had a sense of ownership over the changes. Although the evaluations of the workshop and the resulting changes to practice were limited, the interview with the nurses did indicate that their mind-sets changed and that they became more aware of their way of working and the motivations behind their approach. Furthermore, the interview showed that they continued to think about issues that might be changed in the future. Continuously introducing incremental changes and reflecting on their effects will provide insights into what changes work and what changes have less of an impact, resulting in the gradual optimization of the program.

For the evaluation of the effect of the implemented changes, there were some methodological shortcomings. Evaluating the effects of changes was difficult for the researchers, as the characteristics of the group in the evaluation differed considerably from the previously observed group sessions. It was therefore difficult to obtain insights on what effect the changes had through observations. The findings of the evaluation therefore relied on the experienced-based impressions of the organisers of the Kidney School as articulated in the interview after the educational group sessions. Ideally, several group sessions with various groups of patients should have been observed. This would have led to insights in patterns based on richer data, leading to better saturation of meaning. However, due to time limitations, this was not possible.

Reflection on the literature reviews and desk review studies

Both literature reviews were conducted by me individually (section 5.1). Independent article selection following inclusion and exclusion criteria by more than one researcher would have strengthened the trustworthiness and credibility of both review studies. Collaboration during data analysis would have further strengthened the credibility of the review, as researcher triangulation entails that researchers engage in discussions and come to consensus on the findings (Robson, 2011).

Thematic analysis was used to identify recurring themes in the different data sets (V. Braun & Clarke, 2006). Themes were formulated deductively. The benefit of thematic analysis is that it results in a higher abstraction level by carefully examining which elements diverse studies have in common. However, by focusing specifically on predefined variables, considerations of the context may be neglected. Other limitations of both literature reviews are that the findings were partially based on literature reviews by other scholars and that they included few additional original research studies. Thereby, the contributions of both literature reviews to the scientific community are somewhat limited. However, both reviews were primarily conducted with the aim of synthesising insights from various previous studies to inform this project.

The first review concerns patients' information needs (5.1.1) and includes descriptive quotes to illustrate the codes, which strengthens the credibility of the findings. Furthermore, both reviews made use of graphic representations, in the form of tables and a mind-map, to clarify the findings. One limitation is that none of the included articles concerned studies conducted in Scandinavia. Studies from this geographic area might have provided relevant insights, as the focus of the project lies on the situation in Norway.

For the two desk research studies (section 6.1), conventional content analysis was applied. This analysis method could fail in recognition of key categories, which may result in findings that do not accurately represent the data (Hsieh & Shannon, 2005). To omit this risk, my first supervisor and I separately formulated the themes for analysis. We compared and combined our lists prior to the data analysis. We discussed the analysis of the first desk research study together. During analysis, we tried to objectively look for commonalities and differences between the designs following the predefined themes. By engaging in discussions, we came to consensus on the findings. The findings provide an indication of which aspects the website designs have in common, but they do not provide indications of whether these aspects support patients with SDM. The trustworthiness of the findings of both desk review studies is somewhat limited, as both studies were based on a small number of websites. The inclusion of more websites would have provided stronger indications. However, it was a deliberate decision to focus on information websites from Northern Europe. Consequently, the number of relevant websites was limited. The second study focused on decision aids. At the time the study was conducted, decision aids were a relatively new tool. Consequently, there were few online decision aids available that could be included in the review. The studies did not involve patients and their relatives, who are the target group for these websites. Involving target users could have strengthened the credibility of the findings.

8.2 Contributions of the thesis

The changing needs for medical care, along with a growing amount of care needed for the management of chronic conditions, has led to a growing interest in SDM. The aim of SDM is to empower patients, by supporting them to take part in treatment decisions. This should ensure that patients begin the treatment that is best in line with their lifestyle, values, and beliefs (O'Connor, Graham, & Visser, 2005). This is especially important for chronic patients, as they require lifelong treatment.

In this thesis, CKF is used as an example of a chronic illness for which the implementation of SDM is meaningful. Internationally, several guideline documents for clinical practice give advice on how to make treatment decisions for CKF (Atai & Johnson, 2012; Covic et al., 2010; Levin et al., 2008; National Kidney Foundation, 2015; Warwick et al., 2014). Although the documents include some statements on what information to provide to patients, they provide little practical advice on how to offer this information to patients. There is a need for research on how to inform patients with CKF about their treatment options (Gordon & Lash, 2011) and how to support them in participating in treatment decisions (National Kidney Foundation, 2015).

Pre-treatment education and decision support programs for patients and their next-of-kin are important touchpoints in specialist healthcare services. They may be used to support the SDM process. The aim of this thesis is to acquire a better understanding of how patient education and decision-making programs may better support SDM and how designers can (re)design such programs. This thesis builds on design theory, constructivist learning theory, and insights from qualitative studies that were conducted for this thesis. The main contributions of this thesis concern the design field, regarding design research, design education, and design practice. As the thesis aims to support the improvement of health services, the thesis also contributes to this field.

In the following, the thesis' contributions to the design field will be discussed first, followed by a discussion on its contribution to health services.

8.2.1 Contributions to design

This thesis contributes to the field of Design for Health (Lab4Living). Design for Health embraces various kinds of design practices and design research that have the intention to contribute to health and wellbeing (Wildevuur, 2017). Although the thesis contributes with knowledge that is relevant for the various kinds of design practitioners and design researchers who work with health, the discipline of Human-Centred Service Design stands at the core of this thesis (section 2.1).

In human-centred design, human needs form the drivers for design (Krippendorff, 2006). In service design this translates into a focus on the delivery of holistic service experiences that appeal to both service receivers and service provides (Bechmann, 2010). The goal when designing for services in healthcare is to deliver better care to patients whilst providing healthcare practitioners with a satisfying work experience (Hans, 2015). Service design has close links to other design disciplines, such as product, interaction and graphic design. This thesis therefore includes contributions that are relevant for human-centred designers in various disciplines.

In their search for solutions, designers collect, reassemble, and integrate knowledge from different fields and adapt this to the specific needs and contexts of the problem at hand (Buchanan, 1992). This thesis contributes with knowledge that designers can use when working on human-centred projects in healthcare settings. This thesis provides several types of contributions to design. It encompasses; survey, opinion, empirical research and methodological contributions. The first three types of contributions (survey, opinion and empirical research) contribute with knowledge that is specifically relevant for designers whose work concerns pre-treatment patient education programs for chronic patients and their next-of-kin. More precisely, the thesis provides insights into the information needs of patients' pre-treatment choice. It also provides insight into what current services offer, showing how aspects of these current offers may support or constrain SDM. Designers can use this knowledge when (re)designing akin service offers. The methodological contributions of this thesis are relevant for a broader group of designers; those whose work concerns service design or participant involvement in healthcare settings. These contributions are specifically focused on applying human-centred design in the context of specialist healthcare services. The thesis contributes with knowledge on how co-design events may be organized in this context and the ethical considerations designers should make when (re)designing a healthcare service for chronically ill people.

Survey contributions to design

The thesis provides some survey contributions (Wobbrock & Kientz, 2016) to the design field by synthesizing findings of previously conducted studies. The knowledge that these survey contributions comprise is mainly of practical relevance for designers that work on the (re)design of education services for people with CKF regarding treatment options.

The scoping literature review on patients' considerations regarding treatment options, and their experience of the information mediation trajectory (section 5.1) provides an answer to the research question: *What information needs do people with CKF and their next-of-kin have when they need to consider renal replacement therapy?*

Through a scoping literature review of qualitative studies, this study contributes with knowledge regarding topics that patients and their next-of-kin have reported to consider when deliberating on treatment options, and how these topics relate to each other. In addition to providing this overview of topics, the study shows that people's interpretations of topics depends on individual values and lifestyles. This knowledge aids designers in determining what information to include in a holistic service offer and in specific interventions of such a service. Especially information concerning the effects that treatment may have on daily life is important to include.

Additionally, the study contributes with insights regarding the barriers that patients and their next-of-kin have reported to experience regarding treatment decisions. Designers can use this knowledge to develop solutions that meet these barriers. Specifically, designers should carefully reflect upon the timing of information and how information is presented and formulated, accounting for people with various learning styles and knowledge levels. Furthermore, the study provides designers with insight into some political challenges that may form a barrier to SDM, such as SDM not being supported by all involved medical practitioners. Although designers will usually not be expected to solve these, knowing that these challenges may occur will help them to better facilitate discussions with stakeholders.

The systematic literature review of educational interventions on treatment options for people with CKF (section 5.2) provides an answer to the research question: *How are current education programs for people with chronic kidney failure and their next-of-kin designed and organized?*

Through a systematic review, comprising three previously conducted systematic reviews and twelve original research articles, this study contributes with knowledge regarding how education programs on treatment options for people with CKF may be organized when a face-to-face format is chosen. The study thereby constitutes an addition to study 5.1 on which topics to address, by presenting practical examples of how such education services may be organized.

The data could not be used to provide an answer to the second research question: *Which aspects of these education programs may support or constrain shared decision making?* The large diversity in structures of programs and the variety of measures applied to evaluate the effect of programs inhibited this. More empiric research that allows cross-case comparison is needed. Designers may use the insights into the structure and information mediation strategies used by others as a basis to (re)design a similar program. However, as evidence for the effectiveness of program components is lacking, designers should critically reflect upon them.

The review of online, publicly available information websites and decision aids for people with CKF and their next-of-kin (section 6.1) provides an answer to the research questions: *How are current information websites and decision aids on renal replacement therapy structured?* And 2) *Which of their aspects support or constrain SDM?*

Through two desk research studies, comprising seven websites, this study contributes with knowledge regarding how the Internet is used to educate patients on treatment options for CKF, and how contemporary online solutions support or constrain SDM. This study thereby constitutes an addition to clinical guideline documents and study 5.1 on which topics to

address, as it provides knowledge on how such education services may be organized online. The study contributes with an overview of how others have structured their websites, which information they present and the mediation strategies that they use. Designers may use this as a basis for the (re)design of a website, or to benchmark their design.
Based on the findings, designers are recommended to better account for universal design guidelines to support people with cognitive disabilities. Furthermore, designers are advised to better adhere to the IPDAS criteria for decision aids (O'Connor et al., 2005), that recommend displaying information in various formats to support understanding. The study additionally shows that contemporary solutions make little use of the additional information mediation strategies that the Internet offers compared to traditional printed brochures. Designers are recommended to consider the application of more interactive and visual ways of mediating information. Finally, designers are recommended to only use websites as part of a more extensive service offer, as people individually assign meaning to treatment-related topics (insight from study 5.1). This signifies that information websites should be supplemented with options for dialogue to meet the decision support needs of patients.

Opinion contribution to design

In addition to the survey contributions regarding contemporary education practices, this thesis provides an opinion contribution (Wobbrock & Kientz, 2016). Section 6.2 offers an argument for the use of serious games as a supplement to face-to-face and website-based programs. This argument is inspired by the insights from other studies conducted for this thesis. Study 5.2, 6.1 and 7.1 discussed that contemporary education practices mainly rely on linear information-mediation strategies. This is problematic, as such strategies are not effective for all types of learners. Study 5.2, 6.1 and 7.1 revealed furthermore that although pre-treatment education programs and decision support programs partially overlap regarding the information that they provide on treatment options, their objectives may be different. Pre-treatment education programs may have the objective of supporting patients in coping with their disease, while they do not necessarily aim at supporting patients in becoming active agents in the treatment decision-making process. Decision support programs generally focus specifically on supporting patients in making a treatment choice, and do not usually include information that intends to help patients cope with their disease. An education program and a decision support program may therefore be used as complementary tools in a healthcare service to support SDM. Even if the two are used complementary, the linear information-mediation strategies that both types of services were found to apply are problematic for certain kinds of leaners. Study 5.1 furthermore identified patients' need for dialogue. People assign different meanings to the information regarding treatment options and value the opinions of their next-of-kin regarding treatment options, lifestyle and values.

The goal of the argument in section 6.2 is to stimulate reflection and discussion concerning possibilities for providing alternative education strategies. Patients can benefit from more visual or interactive ways of learning. Furthermore, more active ways of learning may help them discuss their meanings and concerns. Designers may use the examples of serious games that are provided in the argument as inspiration for their own projects.

Empirical research contributions to design

The thesis furthermore provides various empirical research contributions (Wobbrock & Kientz, 2016) to the design field through the accomplishment of various qualitative studies. The knowledge that these empirical research contributions present is mainly of practical relevance for designers that work on the (re)design of education services for people with CKF regarding treatment options.

Considerable differences exist between what information is presented in decision aids, how decision aids present information and the support they provide to patients in reflecting upon their treatment options (section 6.1). An expert interview with two developers of a decision aid (section 6.3) provides an answer to the research question: *What motivations may lie behind the differences in the design of online decision aids?*

Through an in-depth interview with two developers, this study contributes with arguments for the application of a service design approach when designing such interventions; A holistic overview over a healthcare service, can support developers of education and decision support programs in deciding what information to include in a specific part of the service offer. The study additionally provides knowledge regarding the need to develop an implementation strategy in addition to the website itself. The study furthermore contributes with experienced-based insights of the development team that can support developers of new platforms and enables them to learn from the considerations and experiences of another development team.

The systematic literature review of educational interventions on treatment options for people with CKF and their next-of-kin (section 5.2) showed that mainly quantitative assessment measures had been used to evaluate the effect of face-to-face patient education programs. However, qualitative studies may provide another kind of relevant data, which can help in answering why and how questions concerning a program's effect. Section 7.1 therefore takes a qualitative approach to provide an answer to the research questions: 1) *How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organised?* And 2: *Which aspects of face-to-face education programs may support or constrain shared decision making?*

Through a case study, two contemporary offers of face-to-face pre-treatment patient education programs for people with CKF and their next-of-kin were examined. This study contributes with insights on aspects of patient education programs that may support or constrain SDM. Gaps were found between intentions of the organisers, expectations of participants and experiences in practice. An example of such a gap was the difference between the nurses' intention to support participants in discussing treatment options with their physician, while the participants regarded the program as an opportunity to receive information from a trustworthy source. Designers can use the knowledge that this study contributes with when (re)designing patient education programs; It can help them develop propositions that overcome these constrains.

The findings of the systematic literature review on patient education programs (section 5.2) and of the case study (section 7.1) were triangulated to strengthen the confidence in the findings. Centres have developed programs individually. Programs commonly include several education strategies and consist of multiple, mostly one-on-one sessions at the hospital, during office hours. Jet, the format, duration and content of these programs differs significantly. Often a multidisciplinary team of educators was involved. Experienced patients contribute to half of the programs.
Barriers to SDM relate to the variety of options that are presented. This differs considerably between centres. Furthermore, many programs provide written information, which can be problematic for less-literate patients. Additionally, there is a paucity of solutions for people who do not master the national language sufficiently.

The case study of a face-to-face patient education program showed that gaps may occur between intentions of the organisers, expectations of the participants and experiences in practice (section 7.1). A co-design workshop with medical professionals involved in the program was organized to develop changes to the program to mediate these gaps (section 7.2). A qualitative assessment of the redesigned program was organised to evaluate the effects of the changes that had been introduced following the workshop (section 7.3). The review provides an answer to the research question: *Can design methods support the (re)design of patient education programs?*
Through an expert interview with the organisers of the program and observations of the redesigned group sessions, this review shows that collaboration across medical disciplines, established through co-design workshops, can benefit healthcare services. The study furthermore contributes to design with the insight that the active involvement of service providers can provide valuable insights when reviewing the effectiveness of changes to their service. It also shows that evaluation tools can be developed that support medical practitioners to iterate, without the further involvement of designers.

Methodological contributions to design

The thesis provides some methodological contributions (Wobbrock & Kientz, 2016) to the design field by reflecting upon the application of design methods that were used to collect empirical data for this thesis. The knowledge that these reflections provide informs human-centred design practice and research in healthcare settings.

Reflections on the organization of a co-design workshop that applied service design tools (section 7.2) provide an answer the research question: *How can design methods support the (re)design of patient education programs?*
Through the organisation of a co-design workshop with medical practitioners, this study shows that the application of a co-design workshop and service design tools can be valuable for the development of healthcare services. However, it also shows that designers need to be aware of some specific challenges when applying these methods in a healthcare context. Designers are recommended to make ethical considerations regarding the possible effects that participation in a workshop may have on the relationships between participants over time.

Additionally, this study illustrates that within a healthcare setting, the inclusion of external experts as workshop participants can be very valuable for idea generation. The involvement of non-designers as facilitators may be very valuable when such facilitators have a thorough understanding of the context and the problem that needs to be addressed. Furthermore, designers are recommended to anticipate if specific aspects of healthcare contexts (hierarchy, working in disciplines and unfamiliarity with co-creative tools) may have an effect during the workshop, and to adopt the assignments accordingly.

Section 6.2 describes the development of a concept for a serious game. The intention was to further develop this game concept, as to provide an artefact contribution (Wobbrock & Kientz, 2016). The aim of this design initiative was to develop a prototype for a serious game to reveal and explore new possibilities for patient education practices. It intended to apply more interactive and visual ways of learning, to present an alternative to the linear education strategies found in study 5.2, 6.1 and 7.1. Ethical reflections during the development process let to the decision to discontinue the prototyping process. The ethical reflections that are provided at the end of section 6.2 constitute a methodological contribution to the design field regarding participant involvement in healthcare projects. It specifically adds to discussions concerning vulnerability and costs versus benefits of conducting a co-design study.

Placing the thesis' methodological contributions to design in context

Design is increasingly recognized as a discipline that can add value to health (Wildevuur, 2017). The contributions of this thesis focus specifically on applying human-centred design in the context of specialist healthcare services. The thesis provides knowledge on how co-design events may be organized in this context and the ethical considerations designers should make when (re)designing a healthcare service for chronically ill people. A scoping literature review of recently published articles on human-centred design and co-design for healthcare was conducted. The findings from this literature review help place the contributions of this thesis to the design field in context and shows how it adds knowledge to the existing literature.

The growing interest of co-design for the re(design) of public service has stimulated discourse on the benefits and challenges of applying co-design in this sector (Pirinen, 2016). The thesis specifically adds to the growing discussion in design that asks for more critical reflection on how participants are involved in design (Munteanu et al., 2015; Vines, Clarke, Wright, McCarthy, & Olivier, 2013), and how methods affect people that participate in design (Bowen et al., 2013). There is a need for developing best practices for designing with vulnerable people (Vines, McNaney, Lindsay, Wallace, & McCarthy, 2014).

Section 7.2 contributes with insights regarding the use of co-design workshops that employ service design tools for the development of healthcare services. According to Steen et al. (2011), co-design is critical to service design projects, as the innovation of services requires the integration of stakeholder needs and the coordination of supply mechanisms. The approach can be applied effectively and provides valuable results in the healthcare sector (Yang & Sung, 2016).

Section 6.2 contributes with ethical reflections about vulnerability of participants and the likelihood for a satisfactory solution to become implemented in practice. These reflections relate to the question on whether the proposed benefits of the study justify the effort and time of both participants and researchers. This is in line with the Framework for Ethical Decision Making , which suggests to ask questions such as 'What options produce most good and least harm?', and 'What options serve the community as a whole, not just some of its members?' (Velasquez et al., 2009).

Participant selection: Contemplating possible long-term effects

The main methodological contribution of section 7.2 lies in its holistic and dynamic approach to the organisation and facilitation of a co-design workshop for the redesign of a healthcare service. The study exhibits the necessity for designers to reflect upon the indirect effects that a co-design workshop may have on the long-term relationships between participants. Such reflections need to come in addition to considerations around participant selection and its effect during the co-design event, for which guidelines exist (NHS Institute for Innovation and Improvement, 2009). When working with chronic illness, it is important to reflect upon possible long-term effects on relationships between participants as patients and medical practitioners rely on a relationship that builds on trust. Patients with CKF have reported that trusting their medical practitioner makes it easier for them to accept the information that they receive (Harwood & Clark, 2013; Hussain et al., 2015; Murray et al., 2009; Walker et al., 2016). Trust has to be established and maintained over time. According to Paliszkiewicz (2011) trust is dynamic and changes over time, and it does not follow a linear pattern. Trust may decrease when one of the parties breaches it.

During co-design workshops, people engage in creative interactions of making. This is very different from the interactions that normally take place during a medical consult. Prior to study 7.2, the possible effects of participant selection on relationships between participants after the workshop were considered. It was decided not to invite patients and their next-of-kin as participants. The small size of the patient-group contributed to this decision, as it meant that there was a considerable chance that patients would be asked to collaborate with members of their own medical team. Consequently, existing relationships between medical practitioners and patients would be directly affected.

Vines et al. (2013) point to the necessity of asking questions about our motives of involving people in design. They write about participatory design for human-computer interaction in general sense[17], and problematize decisions made *in preparation of* and *during* participatory events, and how these affect the quality of participant involvement in design (Vines et al., 2013). In the UK, the NHS has developed a guideline for facilitators to help facilitators prepare for and facilitate workshops that aim to improve patient services (NHS Institute for Innovation and Improvement, 2009). In this guide, facilitators are recommended to reflect upon the possible effects that participant selection may have *during* the workshop. Examples of

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[17] Participatory design, or co-creation is broader than co-design. For a definition of both terms, see (E. Sanders & Stappers, 2008)

reflections relate to the climate one wants to create, to the kind of interactions one wants to stimulate, the conflicts that may arise and how to deal with conflicts, as well as how participant selection may influence how individual participants feel (NHS Institute for Innovation and Improvement, 2009).
This thesis contributes to the discussion on participation in design, by proposing that in healthcare, and in other settings that involve long-lasting participant relationships that build on trust (e.g. schools, public welfare agencies), a specific ethical consideration has to be made additionally; Designers should reflect upon the possible long-term effects of participation on relationships between participants *after the workshop*. Having a good relationship with their medical team is especially important for chronic patients, who rely on delicate relationships that are based on trust. Along the same line, Filipe, Renedo, and Marston (2017) argue that it should be recognized that power dynamics may change through the process of engaging in participatory events.

In contexts that involve relationships that build on trust, it would be fruitful for human-centred designers to draw on service design when conducting, planning and assessing co-design workshops. As described in section 2.1.1, service design aims to create holistic services experiences by ensuring coherence between the various service interactions ('touchpoints') that take place over time and space (Snelders, Van de Garde-Perik, & Secomandi, 2014). Coherence is important as it is recognized that each service interaction contributes to the overall experience of the service. The aim is therefore to design touchpoint experiences that supports the intended overall service experience. To do this, service designers need to anticipate the effects that a touchpoint can have on its participants. When participatory design events are regarded as touchpoints, it becomes evident that there is a need for human-centred designers to reflect on the effects that an event can have on participants during and after the event, in addition to considering what participants bring to the event.

Others have also recently taken up the discussion on long-term effects of participatory events, although they have done this for different reasons. Bratteteig and Wagner (2016) argue for more research into outcomes of participatory projects, claiming that this can strengthen designers' understanding of what participatory events can contribute in various contexts. In a similar vein, Bossen, Dindler, and Iversen (2016) argue for the need to conduct more systematic evaluations, stating that these can provide more valid proof that participatory projects deliver on their aim. Saad-Sulonen, Eriksson, Halskov, Karasti, and Vines (2018) also argue that designers need to reflect more on the effect of participatory event, stating that this can support them in the articulation of the impact of their work. Additionally, Saad-Sulonen et al. (2018) argue for reflections on a longer timescale by stating that there is a lack of discourse on how participation evolves over time during, between, and beyond participatory events. They propose that better insights into the effects of participatory events on participants could support designers in the planning of separate events that feed into each other. An article by Marshall et al. (2014) connects to the discussion of linking events to each other. Marshall et al. (2014) argue that considerations regarding the wellbeing of participants *during* participatory events is important, especially when working in sensitive contexts. They suggest that providing experiences that positively enhance the wellbeing of workshop participants during the design process has the potential to establish long-term participant engagement. Long-term commitment is important for in community-based projects, which often have a longer time span. Health projects, and projects with other 'vulnerable' groups may build on long-term engagements with targeted communities (Vines et al., 2014).

In summary, the discourse on the need for designers to reflect upon the long-term effects of a workshop on participants is not entirely new. However, the discourse so far lacked an ethical focus regarding effects that participation in a participatory event may have for participants. My point here is to argue for careful reflection on possible long-term effects on participant relationships as a result of participation in a participatory event. This does not imply that patients and their relatives should necessarily be excepted from participating in co-design workshops, but rather to say that designers should be considerate and flexible in how they handle the participant-selection dilemma in healthcare context. Based on the insights from study 7.2, designers are recommended to anticipate possible effects of participatory events when preparing such events.

Participant selection: Accounting for vulnerability and costs vs benefits

The main methodological contribution of section 6.2 lies in its call for designers to make ethical reflections about vulnerability of potential participants and on whether the proposed benefits of the study justify the effort and time of both potential participants and researchers. After conducting study 6.2 we planned a follow-up co-design study. Our reflections prior to this follow-up study uncovered that when working with people who are in a particularly vulnerable situation (e.g. being diagnosed but not having started treatment yet) requires designers to make some additional reflections regarding the ethics of doing research with people in such conditions. Based on the insights from this study, it is proposed that reflections regarding the costs and benefits for potential participants are essential for ensuring that research is conducted ethically. This is in line with suggestions regarding the evaluation of future actions in the Framework for Ethical Decision Making (Velasquez et al., 2009). Robertson and Wagner (2012) also discuss the ethical aspects in form of value for participants. They recognise that participatory design projects frequently are limited in scope and often do not deliver a product that becomes available to participants. In a similar vein, Robertson and Wagner (2012) claim that it is the designer's responsibility to reflect on what is offered to participants to ensure a rewarding experience.

During this PhD project, the possible effects of participant selection and the benefits it would provide for potential participants, as well as their vulnerability were repeatedly considered. For study 6.2, it was decided not to invite persons who had just been diagnosed with end-stage CKF as participants nor their next-of-kin. This decision was motivated by the fact that people who have just been diagnosed and who have not started treatment are especially vulnerable due to the uncertainty around how their disease will progress and how they will respond to treatment. Additionally, they do not know what their life on treatment will be like. Furthermore, in our specific case, we were working on supporting SDM, a practice that is not common yet. Informing patients about a service that they themselves might not have access to, was deemed inappropriate as it might undermine these patient's trust in their own healthcare team. In addition to considering the vulnerability of potential participants and how our study might affect these participants, we reflected upon the possible benefits that the study might bring them and us. Due to the specific context of this PhD project, it was deemed that the study would most likely have little direct effect on medical practice. Chances for realisation of a solution that would be ready to be implemented and maintained in practice were expected to be small.

Wright née Blackwell, Lowton, Robert, Grudzen, and Grocott (2017) have discussed the vulnerability of patients and how it affected their study as well. They conclude that researchers need to be flexible and realistic about patients' and their next-of-kin's capacity to engage in research processes and design events. Wright née Blackwell et al. (2017)'s motivation for this statement is that the health of patients might be changing and unpredictable. A situation that is difficult to handle for the patient's and their next-of-kin themselves, but also for researchers. Wright née Blackwell et al. (2017) describe that they changed their data-collection method from group meetings with patients and family-members to one-on-one interviews as they found that the participants were unwilling to participate in group discussions. Likewise, Vines et al. (2013) have argued for more awareness among designers that not everyone might want to participate in participatory design events. Borgstrom and Barclay (2017) have conducted participatory design in palliative care settings. They claim that it is of particular importance to consider the emotional impact of such studies on both the participants and researchers, and to provide space and support for their emotional responses. Additionally, they propose that it is essential to consider when to involve patients and for how long (Borgstrom & Barclay, 2017).

Vines et al. (2013) point to the necessity for researchers and designers to reflect upon their motives for organising participatory events. Concerns regarding costs versus benefit have been raised by other scholars as well, though rather through studying the effect of participatory events, than by anticipating possible effects on forehand. Bowen et al. (2013) have previously claimed that there is a paucity of research on how participants have experienced participatory design events and how it has affected them. They describe a study on how participants experienced participating in a co-design project for the NHS in the UK. Bowen et al. (2013) found that the method supported the establishment of positive working relationships among different participant groups, but also found some that the method had some issues. Issues with participants' experiences related to: freedom to participate, resource use versus value, logistical difficulties, participants feeling disrespected at some instances, the level to which participants felt they contributed to the design of solutions, expectations about change, and external constrains (Bowen et al., 2013). Another paper presents a study on what participants gained from a participatory design project. Bossen, Dindler, and Iversen (2010) studied the experiences of participants in a participatory design project at primary schools in Denmark. They found that participants had mostly positive experiences. Yet, a few frustrations were reported concerning the project resulting in technology focus, frustrations about realization of ideas, specifically related to funding, and cost versus benefit. Another study by the same researchers describes participant experiences on the design of new exhibition space for a museum. It showed that some participants were uncertain about the gains of the project. Bossen, Dindler, and Iversen (2012) They reported issues regarding participants having different agendas, expectations about the projects outcome, the perceived lack of project management, external constrains, and technology-centricity.

The three studies mentioned above all refer to disappointment among participants regarding their expectations of suggested changes being implemented in practice. Clemensen, Larsen, Kyng, and Kirkevold (2007) have previously articulated expectation management of participants as a concern that designers need to address. Also Vines at al (2014) have pointed to the importance of managing the expectations of participants, stating that it may be difficult for participants to return a solution at the end of a project, while they might have come to rely on it. Both argue that design researchers need to make clear agreements on how far the research project will support the development of new clinical practice, and what will happen when the research project ends. They warn that neglecting this may raise conflicts or result in participants being set back (Clemensen et al., 2007; Vines et al., 2014). Filipe et al. (2017) problematize the notion that participatory events often rely on voluntary involvement of particularly patients. They criticize such endeavours on ethic grounds, referring to social justice, inclusion and economic solidarity and claim that it is necessary to refund expenses.

Designers may also need to adjust their expectations of the extend to which a participatory event can initiate actual, sustained change in medical practice. Study 7.2 uncovered that realizing changes of practice in the healthcare sector may be inhibited by the hierarchic hospital culture and be dependent on the commitment of two internal employees. It might be difficult for designers to provide much support for the implementation of ideas as they lack close connection to the medical practitioners whom the changes involve. Pirinen (2016) found that the implementation of changes into practice is best achieved when internal participants drive it, as their colleagues regard them as credible, opposed to external actors who lack insider knowledge. However, we found authority issues. The nurses could propose changes, but did not have the authority to change the practices of other medical practitioners. Borgstrom and Barclay (2017) describe similar challenges. They found that it was difficult to maintain commitment from staff and that support from management was essential. Pirinen (2016) found that poor commitment at management level might result in a lack of commitment for change among practitioners. Moreover, he found that to change medical practice, commitment from management might be insufficient to motivate medical practitioners to change their practices.

McNaney et al. (2018) argue that it might be needed to involve participants through co-inquiry, as they found that some patients felt that research had been ‘conducted on them, rather than with them’ (McNaney et al., 2018). In their article, they furthermore point to design researchers’ responsibility to communicate results to participants. They claim that the results of research are insufficiently accessible to its participants. Moreover, McNaney et al. (2018) point design researchers to contemplating which participants actually participate in participatory events and whether this group represents the whole patient group, or that the voices of some people are not being heard. Munteanu et al. (2015) have also contributed to the discourse on how vulnerable people are involved in design research. Instead of focussing of the effects for participants, they address in their article the challenges that designers may come to face when conducting research with such participant groups. For example, they create awareness among designers that studies might bring them in situations that are highly emotionally charged (Munteanu et al., 2015).

In summary, the discourse on costs versus benefits for participants in participatory design projects is not entirely new. However, the discourse so far lacked a focus on ethics-related reflections concerning the vulnerability of potential participants and whether the benefits outweigh the costs of participation. Based on the insights from study 6.2, designers are recommended to anticipate possible costs and gains of participatory events when preparing such events.

Dealing with the effects of participant selection

Section 7.2 and 7.3 demonstrates that designers can mitigate the effects of not inviting an important stakeholder to a co-design workshop, by adapting the set-up of the workshop, assuring that this party's needs are represented through assignments and materials.

Bringing together different perspectives in a co-design workshop is recommended, as it ensures that the needs of the different stakeholders are represented (Steen et al., 2011), it stimulates creative thinking (Buur & Larsen, 2010), and it helps to create a feeling of ownership among the participants (Stickdorn & Schneider, 2011). Service receivers are regarded as experts of their experiences and are therefore commonly included in co-design workshops (E. B. N. Sanders, 2008b). However, as argued above, designers might sometimes decide to exclude a specific group from direct participation in a workshop. Vines et al. (2013) argue that by preselecting certain groups of participants over others, the potential outcomes become limited, as the voices of certain groups are lost. However, study 7.2 demonstrates that designers can mitigate this effect, by carefully reflecting upon how decisions regarding participant selection might affect the outcomes of a workshop, and by ensuring that the voice of the stakeholder group that is absent is represented nonetheless through the workshop materials and assignments.

The author argues that the decision not to invite an important stakeholder group (in this case patients) to a workshop requires profound consideration of the set-up of the workshop and the assignments. As Steen et al. (2011) has phrased it, effective co-design requires the selection and application of appropriate methods that are adapted to the specific project. Assignments and materials for the co-design workshop had to be adapted to reduce the effects of patients not participating. The author claims that it is fundamental that the designer has sufficient empathic understanding of the stakeholders' needs and the challenges that needed to be addressed when developing the materials and assignments for a workshop. This has also been noted by Pirinen (2016) who articulated that designers need to invest in getting to know the complexity of the organization and the logic behind its structure prior to co-design events.

Designers need this, as education poorly prepares them in designing for vulnerable people (Vines et al., 2014). Empathic understanding may be obtained through qualitative methods, such as interviews and observations.

Designers should be aware that despite the possibility to represent patient's needs in workshop through materials and assignment, excluding patients and family-members most likely affects the outcome of a workshop, as their participation would have contributed to discussions and ideation. Although the workshop outcomes might thus have been different had patients participated, the findings from the workshop and its evaluation (section 7.2 and 7.3) show that our approach allowed us to maintain a focus on patient needs throughout the workshop. This study thereby provides an alternative approach to the participant dilemma in healthcare; The researchers first obtained a thorough understanding of the situation through individual interviews with healthcare staff and patients, as well as through observations of the healthcare service. Second, a co-design workshop with healthcare staff and designers was organised. Patients and their next-of-kin were not invited, but the patient perspective was incorporated through the design of workshop materials and assignments.

Others have solved the participant dilemma in healthcare settings differently. Variation exists regarding who is involved in co-design projects in healthcare, patients, their next-of-kin and medical practitioners are not necessarily involved equally (Borgstrom & Barclay, 2017). Wright née Blackwell et al. (2017) used a patient-family film during a co-design event to represent their voice during the workshop. This worked so well that the film was extended after the workshop. The extended film was introduced as a training tool for new medical practitioners. Gaudion et al. (2015) involved adults with autism, family or support staff, and designers in a project for adults with autism. They split the interactions in three phases; First, they organized triadic interactions between an adult with autism, a family member or support staff member and a designer. Second, adults with autism were given exercises that they could make together with a family member or a support staff member at home. Finally, a co-design workshop involving support staff and designers was organized. Bowen et al. (2013) also applied a stepped process were patients and healthcare staff first engaged in two separate workshops. At the end of the second workshop, patients and healthcare staff met to share their ideas and engage in a collaborative discussion on priorities for improvement. The third phase consisted of co-design workshop in which patients and healthcare staff participated in mixed groups.
Long et al. (2017) describe a study in which participants were all from the same stakeholder group (here: carers). They found that participants identified and emphasized with the stories of others and that their interactions were supportive. They found that this resulted in an environment where participants felt safe to share things they might not have shared with others. McNaney et al. (2018) have also contributed to the discourse on participant involvement by arguing for enabling participation through engaging patients as co-researchers; To involve them from the generation of research questions to the development of a prototype. McNaney et al. (2018)'s motivation lies in their finding that participants felt that clinical research was conducted on them, rather than with them.

As the examples above show, the author of this thesis is not the first to argue for a holistic and dynamic approach to the organisation and facilitation of a co-design workshop for the redesign of a healthcare service. Rather, the knowledge that is obtained through study 7.2 and 7.3 contributes to the ongoing discourse on the effectiveness of different approaches for participant inclusion and participant representation in participatory events. This aids the design community in improving its methods as it uncovers the benefits and disadvantages of various formats.

In summary, the insights from study 7.2 and 7.3 contribute to the ongoing discourse of participant inclusion in design. It provides an alternative approach that designers may apply when they deem the involvement of a specific participant group as troublesome. Designers can formulate assignments and materials such that they bring in the perspective of the absent group, thereby ensuring that the needs of this group are represented nonetheless during the participatory design event.

The influence of the healthcare context during a workshop

Study 7.2 exemplifies challenges that designers and workshop facilitators may experience when conducting a workshop in a healthcare setting. Retrospection of a method and how it unfolded in practice can inform future projects (Saad-Sulonen et al., 2018; Steen et al., 2011). Through retrospection, study 7.2 contributes with insights that relate to the effects of participant selection *during the workshop* itself. Organising this workshop with medical practitioners illustrated the importance of taking care in gradually building up the creativity level of the exercises to give non-designers a chance to become accustomed to a new way of working and expressing themselves. Furthermore, it shows that the inclusion of external participants may support ideation and that it can be valuable to invite non-designers with a medical background to facilitate a co-design workshop.

Applying design methods in a healthcare context can be challenging for designers. Specialist healthcare is a complex context, with strong hierarchies between professions; working in silos occurs due to specialisation, and risk aversion is a common notion (Bowen et al., 2013). Another challenge for designers is that the methodologies applied in health are very different from those applied in design (Wildevuur, 2017). Study 7.2 shows that designers may consider gaining the support from medical professionals in recruiting participants for a workshop. Although this study presents a single case, the findings indicate that recruitment by colleagues may be an effective approach to ensure the participation of healthcare practitioners with full schedules. It might also be that participants were motivated to participate as it gave them an opportunity to contribute to the future of their own work practices.
Pirinen (2016) found that co-design initiatives were more easily undertaken if they connect to the participant's everyday work. No other design literature was found that provided arguments for or against this approach. It seems that there is a lack of attention for discussing effective means of participant recruitment in the contemporary participatory design discourse.

Griffioen, Melles, Stiggelbout, and Snelders (2017) state that there is a paucity of literature on the supplementary application of service design approaches to the traditional research approaches that are typically used in healthcare. They regard this supplementation as vital and argue that better results may be achieved through applying the 'best of both worlds' of design research and health services research. They argue that this may be achieved by applying a service design approach with a multidisciplinary team including not only stakeholders and service designers, but also healthcare researchers with expertise of the specific service (Griffioen et al., 2017). Study 7.2 may be regarded as an example of such a project. The study highlighted that there is indeed value in this approach, but it also uncovered some challenges. We found that participants with a healthcare background may be hesitant to adopt creative ways of working. It is therefore important that designers not only select assignments that contribute to the workshop's aim, but also select assignments the participant group is able to perform. The latter has been phrased by Steen et al. (2011) as imperative for realizing an effective co-design workshop.

Study 7.2 supports the guidelines from the NHS (NHS Institute for Innovation and Improvement, 2009) by arguing for sensitivity regarding what participants (in this case medical practitioners) may want to do, or may not want to do during a workshop. In a similar vein, Marshall et al. (2014) argue that activities should be pleasant and support autonomy, competence, and relatedness of participants. Participants should feel that they are capable of doing the workshop assignments, and that the activities are rewarding (Marshall et al., 2014). Although designers should be careful when selecting assignments, they should not dismiss applying participatory assignments. The value of participatory methods lies in their ability to envision and shape new ways of working that meet the needs of various stakeholders, in addition to contributing to the designer's empiric understanding of what various activities mean to various actors (Spinuzzi, 2005).

Several other scholars have contributed to the discourse on the kind of materials and assignments that may be appropriate to use in service design projects. Pirinen (2016) found that the use of visual representations (which they call 'boundary objects') supports the alignment of interests as well as the sharing of knowledge among participants with different backgrounds. Likewise, Hyvärinen, Lee, and Mattelmaki (2014) found that visualisations of service journeys were appreciated especially for offering a person-centric perspective, opposed to plain text documents and charts. Hyvärinen et al. (2014) claim that the visual representation of service journeys creates a shared understanding that can form the ground for discussions on possible futures.

Some scholars have published related articles that focus specifically on the design of healthcare services. It is recognized that the hierarchic culture of healthcare context may form an initial hurdle for social interactions to take place during a co-design workshop. Yet, some found that when the right atmosphere is created, medical practitioners can come to appreciate being given the opportunity to discuss things more holistically, independent from their professional roles (Clemensen et al., 2007; Pirinen, 2016). Moreover, Wright née Blackwell et al. (2017) found that a co-design workshop can stimulate continued interaction after a co-design workshop between participant groups who previously had not engaged in constructive discussions, due to them working in different departments. Study 7.2 supports Wright née

Blackwell et al. (2017)'s finding, showing another case where new collaborations emerged during and carried on after a co-design workshop. Hyvärinen et al. (2014) acutally argue that one of the main roles of design is to provide a platform and tools for collaboration to emerge and evolve even after the project has ended.

Study 7.2 illustrates that within a healthcare setting, the inclusion of external experts as workshop participants can be very valuable for idea generation. The involvement of external medical practitioners who provide similar services can support ideation, as they bring in a fresh look and can question the practice that is being (re)designed, comparing this with their own practice. These insights support Yang and Sung (2016), who also suggest that the inclusion of external designers and professionals could stimulate holistic and creative thinking. Study 7.2 provides additional detail to the insights presented by Yang and Sung (2016) by showing what roles such external participants can take on. This study illustrates furthermore that the involvement of designers as workshop participants can be valuable as they are familiar with design tools and are used to consider the application of technology. Although we did not experience this as problematic, Yang and Sung (2016) argue that it might be needed to overcome the knowledge-gap of external participants prior to a workshop to increase empathy. Wright née Blackwell et al. (2017) also argue for the benefit of including external participants. They found that the presence of an external researcher enhanced discussions among participants with unlike backgrounds, as the external researcher was regarded as being unbiased. Clemensen et al. (2007) also argue for the inclusion of designers as participants in co-design events. They argue that designers should become role-models for the other participants by convincingly displaying creative tasks. This intends to overcome the resistance of the other participants without a design background to engage in the assignments.

Although we found that participants with a medical background were hesitant to use design methods, the workshop nevertheless facilitated constructive, solution-oriented discussions. Bowen, Durrant, Nissen, Bowers, and Wright (2016) state that the design community should learn from the collaborations that emerge in practice, accepting that they are complex and dynamic. They argue that collaborations are not necessarily unequal when various participants express themselves in different ways (Bowen et al., 2013). Bowen et al. (2016) refer to academic-industry collaboration. Study 7.2 shows that this applies to the healthcare sector as well; Non-design participants were hesitant to use the materials, but did engage in discussions. Study 7.2 contributes with relevant insights by providing insight into emerging complex interactions during a co-design workshop for a healthcare service. The study additionally contributes with insights on how designers may anticipate on these complex interactions to ensure an effective outcome: a) The facilitator can assume the 'maker'-role or b) a workshop participant with a design background can do this.

Based on study 7.2, it is argued that, designers may consider involving people without a design background but with an empathic understanding of the healthcare context to help facilitate a workshop. The healthcare context is complex while it is important for the quality of facilitation that facilitators have sufficient empathic understanding of the context that the workshop aims to improve. Professionalism and credibility of facilitators is key for breaking down hierarchic barriers and creating a collaborative environment (Pirinen, 2016). Study 7.2 shows that facilitators with healthcare background may support the adequate and respectful facilitation of a workshop. The study furthermore shows that conducting a trial workshop prior to an actual workshop, can support such facilitators without a design background to familiarize themselves with design tools and to gain confidence in their role as facilitator. Pirinen (2016) found furthermore that some parties expressed a wish to obtain facilitator training and a toolbox, so that they could perform co-design workshops themselves. Perhaps the design community should not be too protective about their methods, but support others in utilizing co-design methods. The NHS can be regarded as an example; They have developed a guide for workshop facilitation to support the quality improvement of healthcare services (NHS Institute for Innovation and Improvement, 2009). One outcome of study 7.3 was that the nurses had developed an evaluation tool in collaboration with an external participant. This tool became used to evaluate group sessions and inspired constant reflection on practices and needs for change.

In summary, study 7.2 contributes with insights that relate to the effects of participant selection *during the workshop* itself. Designers may consider asking internal healthcare practitioners to help recruit their colleagues. Organising this workshop with medical practitioners additionally illustrated the importance of taking care in gradually building up the creativity level of the exercises to give non-designers a chance to become accustomed to a new way of working and expressing themselves. Furthermore, the study exemplified that the inclusion of external participants can support ideation and that it can be valuable to let non-designers with a medical background facilitate a co-design workshop.

8.2.2 Contributions to health services

The scoping literature review on patients' considerations regarding treatment options, and their experience of the information mediation trajectory (section 5.1) provides an answer to the research question: *What information needs do people with CKF and their next-of-kin have when they need to consider renal replacement therapy?*

Through a scoping literature review of previously published articles on qualitative studies, this study contributes with knowledge regarding topics that patients and their next-of-kin have reported to consider when deliberating on treatment options, and how these relate to each other.

The overview of topics is more extensive than contemporary clinical guideline documents. In addition to presenting this overview of topics, the study shows that people's interpretations of these topics is individual and subjective. Medical practitioners can use the knowledge that this study provides to adapt their information services, to ensure that relevant topics are included and to allow space for discussions on the meaning of this information for the individual patient.

The insight that patients are very concerned with the effects of treatment on daily life and what the reality of being on treatment will be like, might be transferable to other chronic diseases. As is the insight that the meaning they prescribe to various topics is individual.

The systematic literature review of educational interventions on treatment options for people with CKF and their next-of-kin (section 5.2) provides an answer to the research question: *How are current education programs for people with chronic kidney failure and their next-of-kin designed and organized?*

Through a systematic review of three previously conducted systematic reviews and twelve original research articles, this study contributes with knowledge regarding how education programs on treatment options for people with CKF may be organized when a face-to-face format is chosen. The study thereby presents an addition to clinical guideline documents and study 5.1 on which topics to address in patient education programs, as these include little practical information on how such education services may be organized. Based on the combined insights from study 5.1 and 5.2, medical practitioners are recommended to carefully reflect over including conservative care as a treatment option or not. The study additionally shows that investing time to educate patients can have significant knowledge and health benefits, and affects patients' treatment preferences. This provides an argument for investing resources in the development of such programs.

The large diversity in structures of programs and variety in measures of the effects of programs that were described in the reviewed literature, inhibited the provision of an answer to the second research question through this study. More empiric research that allows cross-case comparisons is needed to answer the second research question: *Which aspects of these education programs may support or constrain shared decision making?*

Face-to-face patient education programs

The systematic literature review of educational interventions on treatment options for people with CKF and their next-of-kin (section 5.2) showed that mainly quantitative assessment measures had been used to evaluate the effect of patient education programs program. However, qualitative studies may provide another kind of relevant data, which can help in answering why and how questions concerning a program's effect.

Section 7.1 therefore takes a qualitative approach to provide an answer to the research questions: 1) *How are current face-to-face education programs for people with chronic kidney failure and their next-of-kin designed and organised?* And 2: *Which aspects of face-to-face education programs may support or constrain shared decision making?*

Through a case study, two contemporary offers of face-to-face pre-treatment patient education programs for people with CKF and their next-of-kin were examined.

This study contributes with insights on what other clinics have learned through years of experience with organising face-to-face education programs. In particular, their insights related to the appropriate timing of such interventions and a focus on avoiding information overload are relevant. As is their insight that the involvement of experienced patients is valuable. These insights form an addition to clinical guidelines documents, which merely present which topics to include, but which present little practical advice on how to set-up and structure such education programs. The study furthermore shows the value of qualitatively assessing programs regarding their effectiveness, as gaps may occur between intentions of organisers, expectations of patients and both parties' experiences of a patient education program.

The findings of the systematic literature review on patient education programs (section 5.2) and of the case study (section 7.1) were triangulated to strengthen the confidence in the findings. The triangulation strengthened the insight that many programs have been developed by individual centres, resulting in a large variety of practices. Programs differ in timing, format, involved educators, topics covered, and materials used. As programs are developed at individual centres, it is difficult for others to learn from them. Furthermore, as these programs additionally have been evaluated through various evaluation measures, it is difficult to make cross-case comparisons and to draw conclusions on which aspects of face-to-face education programs contribute or constrain SDM. Further research into the effectiveness of different formats is needed to enable the formulation of guidelines that can form the basis for the development of new programs.

The case study of a face-to-face patient education program showed that gaps might occur between intentions of the organisers, expectations of the participants and experiences in practice (section 7.1). A co-design workshop with medical professionals involved in the program was organized to develop changes to the program to mediate these gaps (section 7.2). A qualitative assessment of the redesigned program was organised to evaluate the effect of the changes that had been introduced following the workshop (section 7.3). The review provides an answer to the research question: *Can design methods support the (re)design of patient education programs?*

Through an expert interview with the organisers of the program and observations of the redesigned group sessions, the assessment uncovered the value of collaboration across disciplines, established through co-design workshops.

Online patient education programs

The systematic literature review of educational interventions on treatment options for people with CKF and their next-of-kin (section 5.2) focussed on face-to-face education programs. However, patients may also find information online. It seemed therefore relevant to investigate this medium further. A review of online, publicly available information websites and decision aids for people with CKF and their next-of-kin (section 6.1) answers the research question: *How are current information websites and decision aids on renal replacement therapy structured?*

Through two desk research studies, comprising seven websites, this study contributes with knowledge regarding how the Internet is used to educate patients on treatment options for CKF, and how contemporary online solutions support or constrain SDM. This study thereby presents an addition to clinical guideline documents and study 5.1 on which topics to address, as it provides knowledge on how such education services may be organized online. The study contributes with an overview of how others have structured their websites, which information they present and the mediation strategies that they use. The study shows that, similar to study 5.2, there is a spread in which information is presented and how it is presented. Furthermore, this study shows that significant differences in the level of detail of the information exist. The insight from study 5.1 that people assign various meanings to treatment-related topics, signifies that these websites should be used as part of a more extensive service offer to meet the decision support needs of patients.

Section 6.1 showed that considerable differences exist between what information is presented in decision aids, how decision aids present information and the support they provide to patients in reflecting upon their treatment options. An expert interview with two developers of a decision aid (section 6.3) provides an answer to the research question: *What motivations may lie behind the differences in the design of decision aids?*

Through an in-depth interview with two developers, this study contributes with the insight that even though people agree with the idea of SDM in theory, they need stimuli and guidance to really change their practices. Furthermore, this study contributes to the awareness that the design of a website alone is insufficient to realise SDM. Websites are mere supports. Facilitating open communication during a consult is key. Interventions should always be regarded as part of a holistic care context. This shows that a service design approach can be relevant for the development of patient education programs.

Development of patient education programs
The case study of a face-to-face patient education program showed that gaps might occur between intentions of the organisers, expectations of the participants and experiences in practice (section 7.1). Reflections on the organization of a co-design workshop in which service design tool were applied (section 7.2) provide an answer the research question: *How can design methods support the (re)design of patient education programs?*

Through the organisation of a co-design workshop with medical practitioners, this study shows that multidisciplinary collaboration on the development of patient education programs can be valuable and stimulate changes of practice. A co-design workshop that applies service design tools presents a method for facilitating such collaborations. Additionally, this study shows that the development of patient education programs may benefit from collaboration between medical practitioners and designers; Designers can support medical practitioners who tend to focus on medical needs, to think more holistically over the diverse needs of patients and their next-of-kin.

A theoretic argument for the use of serious games as a supplement to face-to-face and website-based programs was constructed (section 6.2) to answer the research question: *How can serious games support the SDM process?*

This argument was inspired by the insights from other studies conducted for this thesis. Study 5.2, 6.1 and 7.1 showed that contemporary education practices mainly rely on linear information-mediation strategies. Such strategies are not effective for all types of learners. At the same time, study 5.1 identified the need for dialogue, as people assign different meanings to the information regarding treatment options. By including examples of serious games that have been successful in similar healthcare contexts, this discussion shows that there is potential for serious games to support the SDM process in: 1) changing patients' attitudes towards treatment decision making, 2) supporting patients deliberating on treatment options and 3) teaching people to communicate their preferences and actively participate in decision making. The goal of this contribution is to stimulate reflection and discussion concerning possibilities for providing alternative education strategies to benefit patients that prefer more visual or interactive ways of learning and to help them express their meanings and concerns.

8.3 Suggestions for further research

Further research is needed on the effectiveness of education and decision support programs for patients with different culture and language backgrounds. The interviews with the organisers of an education program in Norway and of a similar program in the Netherlands (section 7.1) showed that even though all patients have the same rights to care, not everyone has the same access to care services. The organisers of both programs explained that the group sessions they organise are only offered to participants who are sufficiently fluent in the national language, which is spoken during the group sessions. The organisers of both programs added that they experienced educating patients who do not speak the national language during individual consultations as a challenge due to communication issues and cultural differences. They point to chances for misunderstanding, as the patient needs to understand the information that they provide, but they also need to understand what the patient says. The organisers of the Dutch program expressed that, consequently, none of these patients were on home-haemodialysis, as training them and being sure that they understood and mastered the treatment was too difficult. The systematic review of education programs (section 5.1.2) showed that this might not only be a problem for these specific programs. In the studies included in the review, patients from non-native ethnicities were sometimes excluded from participation, and in other studies they were underrepresented.

Reduced access to healthcare services may be a problem for many patients, not only those with different language or cultural backgrounds. The literature review showed that patients with visual, hearing, or cognitive difficulties, as well as low-literate patients, were sometimes excluded from participation in the studies. Furthermore, none of the studies investigated the effectiveness of a program per sub-group. Consequently, it is unknown how effective programs are for people with these challenges. It is, however, important to offer education to all patients, as there are indications that patients who take part in these services enjoy better health, are better informed, and make different treatment choices (section 5.1.2). There is a need to investigate the access to education programs for people with these challenges specifically, to discover the size of these problems and to identify approaches that could reduce inequality in healthcare services. This is especially relevant for programs that provide education to people with lifestyle-related chronic illnesses, as the prevalence of such illnesses is higher among people from lower socio-economic classes (World Health Organization, 2015).

Regarding the requirement for individualized information, the desk research studies (section 6.1) indicate that these problems might be similar for digital platforms. The findings point out that digital platforms take little account for differences in cultural and language background among patient populations. Accounting for such differences might benefit patients with such backgrounds. In the case of CKF, the Norwegian association for kidney patients has an information brochure on haemodialysis that is intended for immigrants. The brochure contains information in English, Arabic, and Urdu. This brochure furthermore includes images of people of various ethnicities, ages, and genders. Figure 16 shows some of the images included in this leaflet. The analysed digital platforms did not include images that displayed the diversity of a patient population (section 6.1). A study of a patients group's perception of images that portray differences within the patient population could provide arguments on whether including such images can be beneficial.

As with the effectiveness of education programs for the above-mentioned groups, there is a need for more extensive research on the specific information needs of people in various age groups. Elderly patients' experiences were not included in the case study of an education program in Norway (section 5.3). The studies included in the systematic review of education programs (section 5.1.2) commonly reported the average age of participants in the intervention and control group. However, they did not report if this age was similar to the average age of the overall patient population. Furthermore, none of these studies seemed to have investigated the effectiveness of the programs for participants in various age groups. Despite this seeming lack of research, it has been suggested that people in different age groups have different information needs (Orsino et al., 2003). The literature review on information needs (section 5.1.1) showed that patients most commonly reported concerns regarding keeping their lives as normal as possible. The daily lives of people in various age groups differ. It seems probable that patients in different age groups and with resulting differences between family situations have different information needs. The organisers of an education program in the Netherlands (section 7.1) and the developers of a decision aid (section 6.1) expressed that the will to participate in SDM is unrelated to age. People in various age groups should thus be offered information relevant to their participation in SDM.

Like the effectiveness of approaches for patients with different culture and language backgrounds, patients with visual, hearing or cognitive difficulties, low-literate patients, and patients in various age groups, research on the motivations of current non-users of education and decision support programs regarding their decision not to make use of the service is sorely needed. Participation in the education programs offered by a clinic in the Netherlands and a clinic in Norway was voluntary (section 7.1). Interviews with the organisers of both programs showed that not all patients who were offered the service

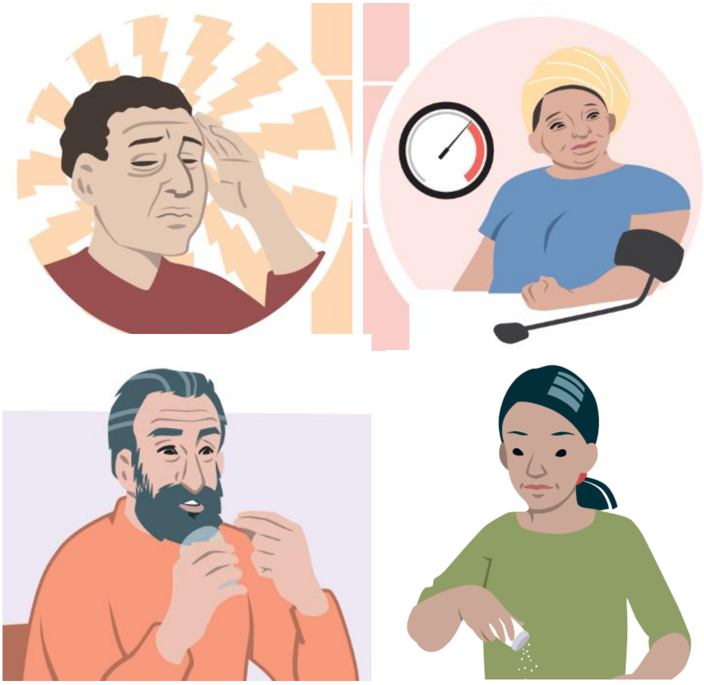

Figure 16 – Images from a patient leaflet for people of various ethnicities (Landsforeningen for Nyrepasienter og Transplanterte, 2008)

partook in it. The organisers did have some thoughts patients' motivations for not attending. However, they had not investigated the matter further and did not know how many patients it actually concerned. Further research into patients' motivations for not attending could provide insights into how the healthcare service may be improved. If barriers for participation can be removed, more people can benefit from these service offerings.

While access to care services and information needs are important to investigate, the effectiveness of a program also depends on its design. The systematic review of education programs (section 5.1.2) and the desk research study on information websites (section 6.1) showed that the designs of education programs and websites differ significantly in regards to both the topics they address and the information mediation strategies they apply. More research on the effects of differently structured programs is needed to enable the nephrology community to formulate universal guidelines for patient education that individual clinics may apply. Research on existing education practices may provide insights into which information mediation techniques are most effective for various sub-groups of patients (such as elderly, working class, immigrants), while still being efficient for healthcare providers. Efficiency is important to take into account, as resources in healthcare (such as money, staff, and space) are scarce. Specific aspects to investigate are variations in timing (one bulk of sessions versus various smaller bulks of sessions spread in time), structure (group sessions, individual sessions, or a combination), different materials (paper leaflets, websites, PowerPoint slides, machine parts), and places (at home or in a clinic). Investigating the most effective time to offer information and the order in which to present information may help patients learn by reducing information overload. Research should also specifically investigate how the order in which different education methods are offered affects a program's effectiveness. The clinic in the Netherlands and the clinic in Norway, for example, both offered individual consultations and group sessions (section 7.1). However, they offered them in different orders, each having their own motivations for doing so. Researchers may investigate if more time spent using techniques like teaching face-to-face teaching is actually best, or if the added benefits of specific offers do not justify the effort.

Another aspect of education programs worth examining further is the effect of experienced patients' involvement. In many of the education programs analysed for the systematic review (section 5.1.2) as well as in both education programs that were studied qualitatively (section 7.1), experienced patients contributed to the programs. While concerns for bias were not expressed directly, some programs indicated that they selected specific experienced patients, while others prepared them prior to involving them in education. However, the developers of a decision aid expressed concerns for biasing patients, as patients may identify themselves with some of the experienced patients. Other academics have expressed similar concerns (Winterbottom, Bekker, Conner, & Mooney, 2012).The organisers of both of the studied programs (section 7.1) indicated that they experienced that the presence of experienced patients had positive effects on participating patients, contributing to coping, self-efficacy, and better understanding of treatment options. The observations of group sessions showed that the experienced patients used more informal and personal language, their body postures were more open, and their clothing was more informal than the presenting medical practitioners. This diminished the perceptible distance between a presenter and the participants. During the presentations with experienced patients, the participants seemed to stay more interested, and they asked more questions. Additionally, there is a need for a standardized research approach. The diversity of measures applied to study the effects of education programs, as well as the diversity in study objectives, is problematic, as it makes it difficult to compare individual studies with one another and perform a meta-synthesis to compare various forms of education programs.

Offering structured guidance to patients to deliberating between options is one of the International Patient Decision Aid Standards Collaboration (IPDAS) criteria (O'Connor et al., 2005). However, the IPDAS criteria provide no advice on what kind of guidance to provide. The desk research study on decision aids (section 6.1) showed that decision aids provide various forms of decision-making support, including different kinds of assignments and questions. There is a need to perform comparative studies on the effectiveness of the various approaches. Such a study will provide insight into what kinds of exercises offer the best support for treatment discussions between patients and family members and between patients and medical practitioners. Many of the decision aids studied here made use of linear methods of learning. Learning theory, however, claims that precisely structured and concise information may be challenging for learners. Learners might get the impression that their reasoning should be structured similarly (Felder & Silverman, 1988). Patients may consequently think that they are not capable of contributing to treatment decisions, as the treatment decision-making process in reality is a complex, non-linear process.

Randomized controlled trials of decision aids generally evaluate the effectiveness of the decision aid as an intervention to standard practice. In about a quarter of the RCTs, a simple decision aid is compared to a detailed one (Stacey et al., 2014). However, no studies have been found which specifically looked at the effect of different types of tasks on the same platform. Such comparative studies can provide an indication of what kinds of assignments stimulate the formation of informed preferences. In their interview, the developers of a decision aid stated that 'there is no harm in trying' (section 6.1), indicating the knowledge-gap related to the patient reflection. It might be worth investigating whether decision aids can be improved by turning them into serious games. Serious games can function as a support for various types of learners by providing them guidance on a learning path, in contrast to digital platforms with static content, which can rather be regarded as 'a source of knowledge' to which learners must actively attend (Dougiamas, 2009).

8.4 Reflections on shared decision making

The findings of the *studies on education programs (section 5.1.2 and 5.3) and the studies on information websites and DAs (section 5.2)* exemplify the framing problem (Wirtz et al., 2006). The findings *showed that differences exist between the numbers of treatment options that are presented to patients.* Some programs present all options, while others focus specifically on dialysis or transplant options. *Conservative care is also sometimes presented as an alternative option.* Furthermore, some programs present only general information, while others differentiate between the various treatment alternatives in detail (e.g. explaining HD in general or explaining the differences between in-centre HD, self-care HD, and home-HD). These variations show that different views on framing, and perhaps even on SDM, exist. When medical practitioners decide only to offer information on dialysis options, the choice between transplantation, dialysis, and conservative care is already made. *Variations between option sets have ethical consequences for patients regarding their freedom of choice and their freedom to control their own bodies (bodily agency).*

There is a need for debate, both on how to determine the option sets that are presented to patients, and on who is authorized to make such decisions. Practical, economic, and societal effects need to be addressed. The discussion should focus on whether every patient should be offered a choice between all treatment alternatives. If patients are not offered all options, they cannot act freely upon the world, as the specific circumstances of a situation limits their possible actions (Lopez and Willis (2004). However, offering each treatment option to all patients may lead to rising healthcare costs. Additionally, the efficiency of the healthcare system may decline, and it may cause capacity problems.

The discussion on the framing of the option set should also include discussions on possible future scenarios. A shift in care practices from paternalism to SDM may lead to a growing number of patients on specific treatments. It is important to discuss whether healthcare providers can support the possible changing care needs that are the result of this paradigm shift. *As* the healthcare system in Norway is publicly funded*, the discussion on the option set is also a political one. Possibly, g*overnment regulations need to be formulated to protect societal interests. ***Discussions on the option set should also address the question of whose benefit decisions are being served: the individual patient, a specific patient group, or all patients who receive care (Hans, 2015). If some patients groups are offered more expensive treatment alternatives, less funding may be available for other patient groups.***

Some other aspects related to SDM have not been addressed in this thesis, but these are still important for the realisation of SDM practices. The first step towards the realisation of SDM is to ensure that clinicians and other medical professionals support the underlying ethical motivation of SDM (Elwyn et al., 2012). How to best realise this change of mind-set needs to be investigated further. Another challenge for SDM that requires further investigation is the divide between healthcare services delivered by general practitioners and healthcare services offered by specialists. To realise optimal healthcare services, the overall patient journey should be effective and efficient. However, the existing divide between these groups of healthcare providers complicates the delivery of a holistic service. There is no party that oversees the organisation of the complete patient journey, while contrasting interests and cultures exist. Care provided by general practitioners is often cheaper. However, general practitioners may lack specialist knowledge or skill.

Another important aspect that needs to be clarified is for which medical conditions SDM is appropriate. SDM is not always the best approach to decision-making in healthcare. In critical care situations, paternalistic handling is needed to avoid further harm to patients due to a delay in treatment. In the case of CKF, where the condition of a patient deteriorates over a longer period, there is generally time for consideration. However, in the case of an acute onset of kidney failure, treatment needs to begin immediately. If the condition becomes chronic and the patient's condition has stabilized, the patient might be given the opportunity to reconsider treatment options, starting a SDM process. A specific challenge in such cases is that patients may have become used to the treatment they were started on and, as a result, could be reluctant to consider alternative treatment options (Pipkin et al., 2010). How to best introduce SDM to such patients needs to be investigated further. The realisation of SDM does not only require healthcare practitioners to change their mind-sets: The concept is also new to many patients. As Barratt (2008) points out, patients generally want to be well-informed, but the desire to take part in treatment decision-making is individual. Because of this, a conversation on the patient's preferred role in the decision-making process seems appropriate. At what time and how to discuss this may be investigated further. Furthermore, the present thesis has not addressed SDM for the treatment decisions of children or young adults. Patient laws generally describe from what age children may be involved in treatment decisions and from what age their opinions need to be taken into consideration. The involvement of children in SDM processes is complicated, as their parents are an additional actor in the SDM process. Furthermore, research needs to be done on how best to inform children about treatment options and how to best involve them in discussions.

This thesis's discussion of the SDM process stops at the point when a decision for a specific treatment has to be made. How this decision is actually made and what processes may facilitate it were not further investigated. Marla L. Clayman, Gulbrandsen, and Morris (2017) suggest that patients may revisit the decisions that were made during consultations, and they propose that this may cause treatment non-adherence. They therefore argue that there is a need to follow up with patients to check if they still agree with the decisions. As decision regret may occur after treatment start, it seems important to regard follow-up on treatment decisions as part of the SDM process and to develop a practice for regularly evaluating decisions with patients. How to best organise this may be investigated further.

Elwyn, Frosch, and Kobrin (2016) have criticised studies on the effects of SDM for having too narrow of a focus. They state that more attention needs to be paid to aspects such as the short and long-term impacts of SDM on medical practitioners. One aspect of SDM that I myself have wondered about is how medical practitioners deal with the changing ideological roles that they need to inhabit during the SDM process. When patients are referred to them, medical practitioners are in the traditional role of the 'medical expert' who is responsible for diagnosing the patient. Once the diagnosis has been made and the patient is informed, the patient and medical practitioner may start the SDM process. In the first phase of this process, 'choice talk', it is the responsibility of the medical practitioner to explain to patients that they have a choice to make and to inform them why they are involved in the decision (Elwyn et al., 2012). During this phase, a medical practitioner may need to change roles from 'medical expert' to 'supportive medical practitioner' to obtain the best outcome. During the second phase, 'option talk', the medical practitioner may again need to assume the role of 'medical expert', as it is their responsibility to inform patients about their treatment options in detail. In the third phase, 'decision talk', it is the responsibility of the medical practitioner to facilitate a discussion on treatment preferences and experiences, ensuring that both parties express their thoughts and collaboratively come to a decision. During this phase, the medical practitioner might again assume the role of 'supportive medical practitioner' to reduce the power distance and lower barriers, allowing patients to share their thoughts.

During this project, I noticed similarities between the above-described situation for medical practitioners and the situation design practitioners find themselves in when working with co-creation in service design projects. In these projects, design practitioners also need to switch roles. In preparation of a co-design workshop, a designer takes on the traditional 'expert' role, being responsible for setting up the assignments for the workshop and preparing the needed materials. During the workshop, the designer may need to switch hats when assuming the responsibility for the facilitation of the workshop. As a facilitator, a designer's role is to guide the workshop participants, stimulating them to ideate and discuss. However, facilitators should refrain from contributing to ideation themselves. During the facilitation of a workshop, designers should thus step out of their expert role and provide participants with agency over ideation and problem solving. After the workshop, the designer might need to take on the 'expert' role again when developing selected ideas further into prototypes and eventually implementable solutions. Investigating how medical practitioners and designers experience and deal with these changing ideological roles might provide insights into how SDM and service design processes can be improved by offering better support to the practitioners responsible for carrying out each step of the process.

8.5 Conclusion

Pre-treatment education and decision support programs for patients and their next-of-kin are important supports for the SDM process. The thesis contributes with insights into the design of contemporary programs, and discusses how they may be (re)designed to better support SDM. Insights were obtained by studying contemporary service offers from a human-centred design perspective and applying a service design approach. The thesis additionally builds on design theory and constructivist learning theory.

Findings provide insights into aspects of contemporary service offers that support or constrain SDM. Moreover, the thesis provides insights into the information needs of patients' pre-treatment choice. Designers can use this knowledge when (re)designing pre-treatment education and decision support programs for patients and their next-of-kin. Additionally, the findings contribute new insights to the field of design for health, specifically focused on the context of designing for specialist healthcare services. The thesis demonstrations the value of obtaining a holistic understanding of contemporary practices by applying a combination of study techniques and shows how co-design can be used to (re)design healthcare services. The thesis contributes to contemporary participatory design discourse by providing insights into ethical considerations that are relevant for designers to make when planning a co-design event that supports the (re)design a healthcare service.
Furthermore, the thesis provides insights that support providers of healthcare services. The thesis demonstrates that a service design approach is a relevant approach to develop SDM programs, as both SDM and service design are concerned with the facilitation of a process. A service design approach can help healthcare service providers obtain an overview of their care processes. The approach can also be used to identify gaps in the service process and to define remedies to reduce these gaps.

Chronic disease management is long-lasting, contrary to acute care. Considering a patient's values and beliefs is deemed important in the management of chronic illness, as the effects of the treatment on daily life are lifelong. The participation of patients and their next-of-kin in treatment decision making helps ensure the best possible quality of life (O'Connor et al., 2005). The realization of effective patient education and decision support programs is important, as such programs can meet knowledge deficiencies and enhance motivation to participate in SDM. SDM leads to people more often opting for a form of home- or self-care (Goovaerts et al., 2005; Jager et al., 2004; Manns et al., 2005). It has been suggested that pre-treatment patient education plays an important part in this (Chanouzas et al., 2012; Lacson et al., 2011; Moran & Kraus, 2007; Pipkin et al., 2010). Furthermore, patients that have taken part in treatment decisions have less health related problems as they adhere better to treatment requirements (Marrón et al., 2006). For healthcare providers, moving care out of the hospital relieves the pressure on professional caregivers (Chanouzas et al., 2012), and results in more hospital beds remaining available for people that require acute care (Lehoux et al., 2004). . Considering the growing number of people who require care due to the higher prevalence of chronic illness it is important to develop pre-treatment education and decision support programs that better meet the information and support needs of patients and their next-of-kin.

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Home Haemodialysis and Gamification – A new approach to information mediation

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Abstract
Chronic kidney failure is a medical condition that is becoming more prevalent worldwide. Home haemodialysis (HHD) thereby presents a treatment option, which can provide substantial benefits over other dialysis methods, for medical professionals as well as for patients. Among others it contributes to better quality of life, can empower patients, and results in a lower mortality risk. Additionally, HHD is comparatively economical compared to hospital treatment, and relieves the pressure on professional caregivers. Despite these advantages, patients do not choose this treatment due to several hindrances, mainly related to knowledge, attitude and skills. Among others timely provision of clear information on treatment and its effects is necessary for informed decision making.

This article sets out to introduce gamification as a concept and tool in providing patients with information on HHD. After discussing the HHD information process and the concept of gamification in the first section, the second section investigates three cases of HHD information platforms in relation to existing possibilities and the potential for introducing gamification elements. Section three discusses benefits and disadvantages of gamification for HDD information. Section four describes potential impacts of gamification in information systems for healthcare and indicates possibilities. Section five summarizes the findings of this research and suggests topics of investigation. The result of this research is meant to contribute to the development of better HHD information platforms for people with CKF, to allow them to make knowledgeable decisions.

Keywords: Home haemodialysis, gamification, information mediation, chronic kidney failure, design approach

Introduction

Western society faces an increasing number of chronically ill people, which is partly due to the growing population of elderly (Rørslett and Kolberg, 2014) and lifestyle related diseases (Smith et al, 1999). These circumstances challenge the current healthcare systems. Reconsidering where care takes place can help to keep the healthcare system sustainable in future.

Chronic kidney failure (CKF) is one of these medical conditions that is becoming more prevalent (Nierstichting, 2015) and for which home treatment is possible, if a patient in ineligible for kidney transplantation . Home haemodialysis (HHD) is a treatment method that has substantial benefits over other dialysis methods, for both medical professionals as patients. For patients HHD results in a better quality of life (Chanouzas et al, 2012), it can empower them (Ageborg et al, 2005), and it results in a lower mortality risk (Curtin et al, 2004). Additionally, HHD is more economical than hospital treatment (Pike et al, 2013), and relieves the pressure on professional caregivers (Lehoux et al, 2004). Despite these advantages, patients do not choose this treatment due to several hindrances, mainly related to knowledge, attitude and skills (McLaughlin et al, 2003). Among others timely provision of clear information on treatment and its effects is necessary for informed decision making (Little et al, 2001).

The Norwegian Patients’ Rights Act (Helse- og omsorgsdepartementet, 1999) states that patients have a right to be informed about their medical condition, the content of the health care, possible risks and side effects and to participate in treatment discussions. The provided information should be understandable for the individual patient. However, if this is done properly for people with CKF is debated (Morton et al, 2010). Best practices for patient information platforms for people with CKF are not defined yet (Murray et al, 2009).

This paper examines three current patient information platforms in order to analyse their presentation of information concerning CKF. Further the paper discusses the possibility of enhancing the current patient information platforms by creating gameful experiences. The goal of this paper is to contribute to the development of better patient information platforms, and to facilitate decision-making of people with CKF and their relatives.

The concept of Gamification

Gamification is the design strategy of introducing game-elements in a non-game context (Deterding et al, 2011). Examples of game elements are challenges, levels, themes, badges, leaderboards (Hamari et al, 2014). Health related gamified applications are becoming more prevalent and can be categorized into activities, e.g. preventive, therapeutic, assessment, educational and informative (Sawyer, 2008).

Virtual Conversations by Syandus is an example of a gamified application for patient education. By joining a virtual, personal support group patients engage in a conversation related to their informational and emotional challenges with their situation (Syandus, 2015). According to Fox (2009) interactive, computer-based patient education programs can increase interest and response among users, might positively influence health outcomes, can support medical professionals in patient education, and might reduce contact hours. Table 1 presents an overview of the advantages and disadvantages of the use of gamified computer-based programs for patient information platforms, compared to ore traditional products as folders, leaflets and consults with nurses.

Table 1. Advantages and disadvantages of gamification vs traditions patient information platforms

Advantages	Disadvantages
Freedom of use - Can be used at home - Can be used anytime - Adaptable to knowledge level - Adaptable to interests	Less personal - Sick persons might rather interact with medical professionals - Sick persons like to be cared for - Less empathic than nurse - Does not work for everyone in every situation
Recall is stimulated - Multimedia techniques to represent data - Possibility for repetition - Enjoyment stimulates knowledge uptake - Engages users and holds their interest	Information is limited - Data is represented in a simplified format - Uses extrinsic rewards to stimulate intrinsic motivation for learning -
Time reduction - Shorter consultation time needed - More focussed consults	Time investment - More difficult to update with new info (program flow, experience might be affected)

The elements (Fox, 2009, Hamari et al, 2014) presented in table 1 can be considered for introduction of gamification on patient information platforms. In the following, three current patient information platforms are presented and analysed.

Method

In order to allow for a discussion of the possibility for improvement of patient information platforms by use of gamification, the current status quo is explored by studying three platforms. The three platforms were evaluated with help of conventional content analysis (Hsieh and Shannon, 2005). The three selected platforms were considered most relevant in relation to predefined criteria.

1. Dianet is a non-profit expertise center for renal replacement therapies. The organization strives to deliver optimal care that matches the lifestyle of the patient, by taking a personal approach in promoting health and quality of life for kidney patients. Dianet gives freedom of choice on treatment method by communicating medical, social and technical possibilities (Dianet, 2014).

2. Njurdagboken, «The Kidney diary», is a website facilitated by the Swedish Kidney association (Njurförbundet) and produced in collaboration with the Karolinska University Hospital and the University Hospital in Linköping. The website is intended for kidney patients and their relatives. The goal of the website is to make people feel more informed, capable,

confident and motivated, and to encourage people to be involved in their care (Pagels et al, 2014).

3. Mine Behandlingsvalg «My treatment choice», is an online platform that focusses on enabling patient participation in treatment choice. The platform is developed by University hospital of North Norway and Takepart Media & Science. The platform is intended to build understanding of treatment options and to support assessment in relation to the patient's lifestyle (University hospital of North Norway, 2014).

Results

None of the three patient information platforms currently incorporate gamified elements and information is presented differently on each platform. To exempify this, figure 1 shows the page with information on HHD of each of the three platforms, which is followed by a brief summary of the main characterists of each page.

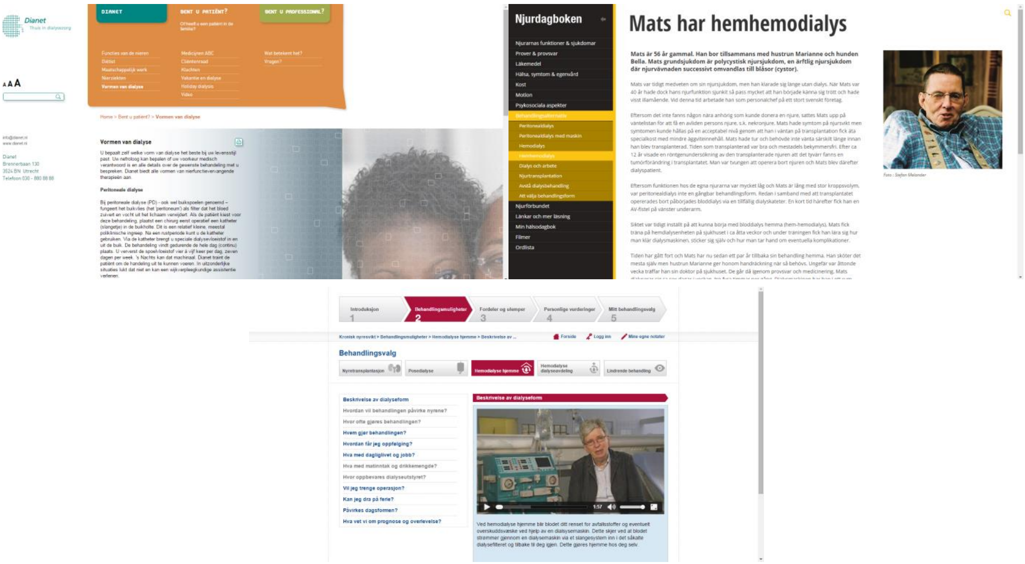

Figure 1: Homepages Dianet, Njurdagboken and Mine Behandlingsvalg

On Dianet information is mainly presented in text with a personal writingstyle. The website has a separate section with videos in which patients tell about their motivation to choose a specific treatment method or about their experiences with the treatment. Dianet is the only platform that provides information about dialysis for children. The videos on this topic focus specifically on the parents, not on the children.

Njurdagboken uses personas (a written personal story of a patient) in which the motivation for selecting a specific treatment by the persona is mentioned, followed by a brief, formally written explanation of the treatment itself. Links to external webpages for further reading are somethimes included. On Njurdagboken a pdf-file can be downloaded. This is a diary for CKF patients which they can use to make a record of their medical condition.

Mine Behandlingsvalg use videos issueing medical professionals and patients, and short texts with a personal style of writing. The patients tell opennly about their experiences with the treatment. Additionally, it has a page with FAQs related to the different treatment methods. Mine behandlingsvalg is the only platform of the three that has an interactive part. After log-in one can evaluate the information about the treatment methods in relation to one's personal values and lifestyle as a means to support in treatment decision making. Furthermore, notes can be taken.

Discussion

Conventional content analysis is an appropriate method for obtaining knowledge and understanding of a phenomenon and to describe it. However, this analysis method could fail in recognition of key categories. This can result in findings that do not accurately represent the data (Hsieh and Shannon, 2005). To omit this risk, the criteria where formulated separately by the authors and compared and reformulated afterwards. Conventional content analysis is similar to the initial analysis phase of Ground Theory, but it does not go as far as theory development. However, that theory formulation is not the intention of this paper.

The analysis showed that none of them currently incorporate gamified elements. Yet, gamifing elements of patient information platforms can possibly lead to beneficiary outcomes, if implemented correctly (Allam et al, 2015).

Making use of interactive elements enables adaption of the platforms to eventual visual, auditory, memory and ambulatory hindrances, so that elderly can also make use of them (Fox, 2009). Regardless of age, people should be given the opportunity to choose the treatment method (Little et al, 2001) and with the larger part of the CKF population being elderly, design including this group is relevant. Additionally, personalisation can be realized more easily with a digital solution than with traditional paper leaflets.

Despite its advantages, gamified platforms can and should not replace the entire information service. People that deal with a serious illness should have the opportunity to discuss questions concerning their illness and treatment methods with a healthcare professional. Especially since gamification does not work for everyone in every situation (Hamari et al, 2014). Consequently, other alternatives should also be accessible, even as gamification seems to be an effective alternative.

The authors see several possibilities for intrudction of gamified elements to the current patient information platforms. The information on CKF and its possible physical and psychosocial effects could, for example, be communicated via an interactive story, where players go around in a virtual, animated world. The same goes for the discussion of different treatment methods and their consequences for diet, associated benefits and risks, and practicalities. This would change the information flow and involve the user more actively than is the case with the current platform designs.

Regarding the explanation of the process, users could for example ‘try’ each treatment on a virtual patient, so they can learn how a treatment is executed and which aspects need to be considered. Such a game-like exercise could possibly raise insight into the effects on their daily practises with a specific treatment. Another possibility is to redesign of the decision support tool that is used in Mine Behandlingsvalg. This is now based on questions that need to be answered by the user, but one could also think of representing similar questions in a quiz-like setting or let users evaluate treatment methods by allocating points to aspects of each treatment.

The downloadable pdf-file on Njurdagboken, which is a diary on the medical condition for CKF patients, can be made more attractive by transferring it to an online platform and inclusion of game-elements. It consists of tables that patients can fill out and they can make notes below. If transferred to an online environment, these tables can be translated to graphs, in which one could indicate goals, for example.

Conclusion

The increasing number of chronically ill people, challenge the healthcare system. HHD is a treatment method for CKF that has multiple benefits for both patients and medical professionals. However, choosing self-care can be a difficult decision due to hindrances related to knowledge, attitude and skills (McLaughlin et al, 2003). A patient information platform can be an important stepping-stone in overcoming these barriers (Pipkin et al, 2010).

Gamification has the advantage over plain information supply that it engages users and motivates their participation (Hamari et al, 2014). Therefore, it is assumed that by gamifing elements, knowledge intake by patients is stimulated. Based on this literature study, the idea of introducing gamification seems promising. However, more research and development would be beneficial too adapt the gamification elements to these specific users groups (Allam et al, 2015). Before a gamified information platform can successfully be introduced, topics such as HHD follow up by healthcare porfessionals , are important issues that need consideration. Furthermore, attention has to be paid to the storage of probable private data.

This paper has given an introduction on the potential impact of implementing gamified elements in patient information platforms. Results are meant to contribute to the development of better information platforms for patients and their relatives. This is important, since no matter which treatment option the patient chooses it will have a significant impact on their live, as well as on the lives of their family.

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Kid-Ney's Journey: a Game to Support Treatment Selection for People with Chronic Kidney Failure

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Abstract— **The number of people suffering from chronic kidney failure is rising, due to the growing population of elderly, longer life-expectancy, and the increasing number of people with other lifestyle related diseases that affect the kidneys. People with severe chronic kidney failure are dependent on some form of kidney replacement treatment to survive. They are often eligible for several treatment methods and here the patient should be involved in the decision making, especially when the medical outcome is expected to be similar. This is important, as people are the experts on their life, values and believes and the different treatment methods each have unlike effects on daily life. However, knowledge is a barrier for these patients to actively take part in such discussions with their medical professional. This paper discusses a game-concept that is developed to give people more insight in the effects of a treatment on daily life, as well as helping them to evaluate the different treatment methods. The goal of this paper is to contribute to the development of additional patient information sources that focus on values and beliefs, and the effects of treatment on daily life, in order to empower patients in discussions with their medical professionals.**

Keywords— game-based learning; game development; serious games; chronic kidney failure; shared decision making

I. INTRODUCTION

The number of people suffering from chronic kidney failure is growing, due to the growing population of elderly [1], longer life-expectancy, and the increasing number of people with other lifestyle related diseases like Diabetes Mellitus and Cardiovascular diseases [2, 3]. It is not uncommon for people to suffer from a combination of these diseases [4, 5]. In the U.S. in 2012 358 new patients were diagnosed with chronic kidney failure per million inhabitants. In Norway and the Netherlands, these numbers were 103 and 120 respectively [3]. Risk factors for developing chronic kidney failure are smoking, overweight, an unhealthy diet and too little physical activity, also hereditary factors might play a role [4].

Chronic kidney failure is a condition in which the function of the kidneys is strongly reduced. As a result, harmful particles remain in the blood 'poisoning' the body. Additionally, the fluid balance might be deranged, leading to too little precipitation of water. Often the kidney function slowly degrades over time. A healthy diet and physical exercise can help slow down the degradation with years. However, at a certain point kidney replacement treatment is needed to survive. This might be some form of dialysis or a kidney transplant [6-8] . People are often eligible for several treatment methods and comparable medical outcomes might be expected of the different techniques [9].

Fig. 1 displays the different treatment methods that are commonly used today. For many patients a kidney transplant is the most preferred treatment method, as it is associated with a better quality of life and lower costs [3]. However, not everyone is eligible for a kidney transplant, these people will need to undergo a form of dialysis in order to survive or they can opt for palliative care. Although kidney transplant rates in Norway, the Netherlands and U.S. are among the highest worldwide, waiting lists are increasing [3]. The people on the waiting list are often dependent on dialysis meanwhile. Haemodialysis in the hospital is by far the most commonly used form of dialysis globally [3, 10]. Saran, Li [3] found substantial differences in distribution of treatment methods between and within countries. Non-medical factors such as physician preference, reimbursement policies and availability within the healthcare services do also play a role here [11]. It is suggested that home treatment is underused [12], and might be undergone by 25% of patients [13]. In the U.S., Netherlands and Norway in 2012 rates for peritoneal dialysis (which is performed at home) lied between 9-16%, while less than 2% of the people where on Home Hemodialysis [3, 14].

Usually a nephrologist discusses the different treatment methods with a patient. Often these consults are brief and patients feel overwhelmed by the amount of information. Few patients feel that they are fully informed when they need to discuss their preferred treatment method [15], while ideally a choice is made as a shared decision between patient and physician [14, 16]. Besides medical factors, social and practical factors should be taken into account, as patients are the experts on their life, values and believes. It is therefore important to explain what the disease is and which treatment methods exist, so that patients and caregivers are empowered to actively take

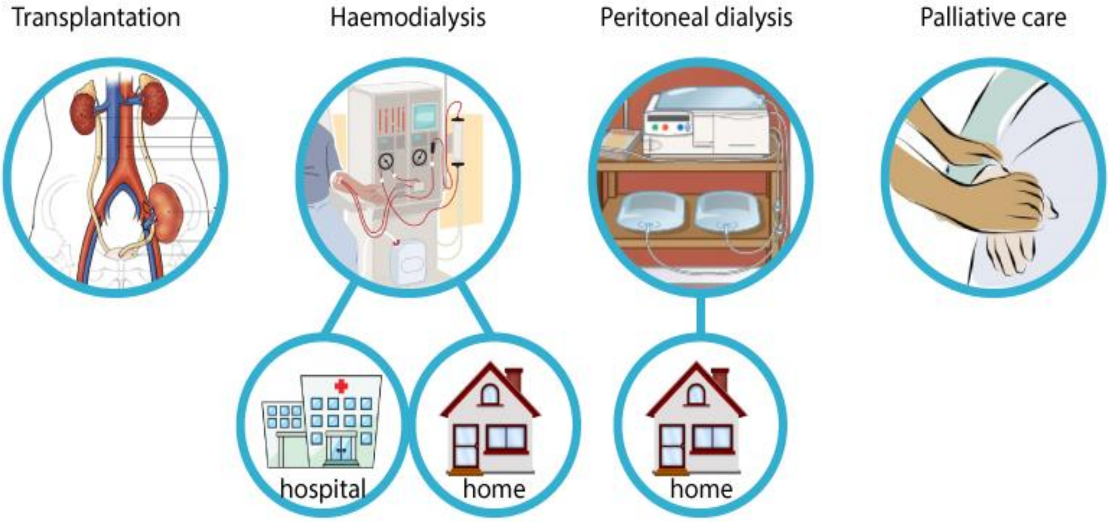


Fig. 1 Renal replacement therapy, overview of treatment methods

part in the decision making process. This is required by law in most countries [17, 18].

To take part in decision making, patients need to be provided with understandable information about practicalities of the treatment and its effects [9]. However, it is questionable whether this is done sufficiently [19] and best practices have not yet been defined [20].One difficulty is that it is much information for the patient to consider and process, while people often feel tired and nauseous, have a high blood pressure, headaches, and itching due to their illness [14, 16]. Yet, better informed people are more likely to choose a form of home treatment [21]. Home treatment is associated with longer life and less hospitalizations [22, 23], is found to be more economic than hospital treatment [24], and to relieve the pressure on professional caregivers [25]. Flexibility in treatment scheduling and reduced travel time are important benefits of home treatment for patients [26].

Considering the aspects above, people should be able to choose the treatment that fits best to their lives. This means, among others, that they need to be aware of which treatment methods exist, and they need to be enabled to make a choice. Additionally, as the rising number of chronically ill and elderly stresses the current health care systems, it is needed to reconsider where care takes place. Informing people better is a good step in getting more people to start with home treatment. This paper discusses a game-concept that is developed to give people more insight in the effects of a treatment on daily life, as well as helping to evaluate the different treatment methods. The goal of this paper is to contribute to the development of additional patient information sources that focus more on values and beliefs, and the effects of treatment on daily life.

II. MEHTODS

A. Developing the game-concept

In August 2015, the University of Twente in the Netherlands organized a one-week summer school; CuriousU. A course in Serious Gaming was one of the eight courses that were offered. During the hands-on course participants were given practical tasks to learn about game-design by doing. Scrum [27] was used to divide the course in smaller subtask, with each sprint resulting in a practical deliverable. In-between the sprints, the participants were presented with theory on game design, such as player methods, game mechanics and dynamics. The Game of Games [28], a game developed to guide game-developers through the design process of developing a game was used to structure the course.

Eight participants partook in the course, of which the author was one. The lecturers had given the opportunity to formulate an assignment related to the author’s PhD-project, by forehand. Together with three other participants, the author worked on the following assignment: ‘Develop a game-concept in which people with chronic kidney failure are stimulated and helped to make a choice for a treatment method. As a team you should decide whom will be playing the game, in which context will the game be played, how much time the game will take to play and describe which benefits the patient has by playing the game’.

B. Evaluating the game-concept

Four students of the product design department at the Norwegian University of Science and Technology, evaluated the game-concept. These students were asked, because they had just taken part in a Game Design course where they developed game-concepts for board-games. Therefore they did not only have experience with user-centered design [29], but were also familiar with game mechanisms. Furthermore, their age matched that of the target-group.

The author explained the goal of the game to the students and the situation in which the game is envisioned to be played. The author did not give the students any instructions on how to play the game. The students could look this up in the attached manual. The author asked them to play the game and to indicate if something was unclear or if they thought something needed to be improved. Meanwhile the author observed them play [30]. Afterwards the students and author had a group-discussion [30], in which the students were asked for feedback. Additionally, an expert-review [31] was conducted. The author discussed the game-concept with a nurse specialized in working with people with chronic kidney failure. The discussion focused mainly on the content of the dilemma-cards and how this could be optimized.

III. RESULTS

A. *The initial game-concept*

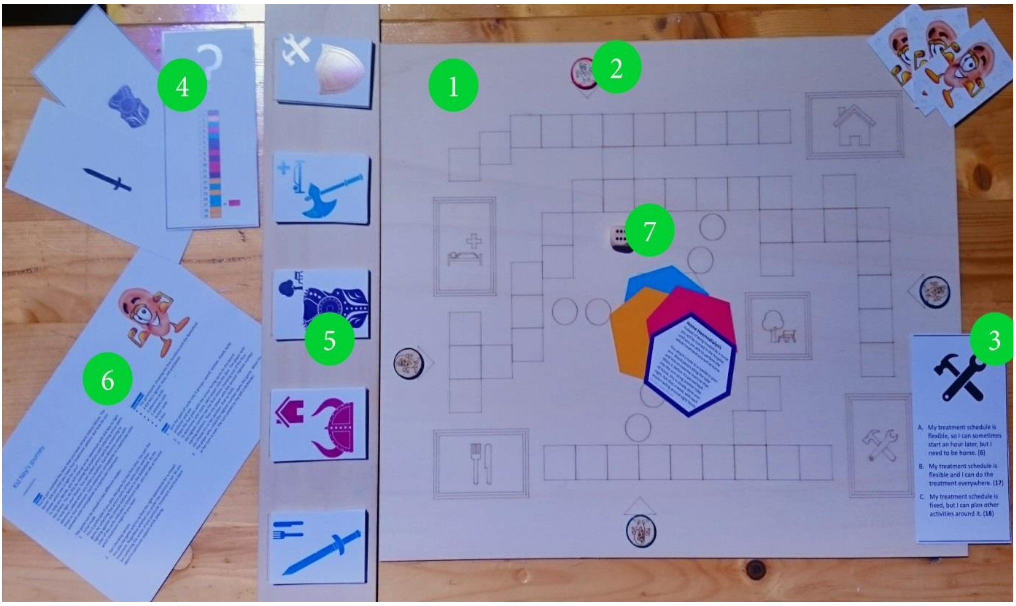
During the Serious Gaming course the students came-up with a game-concept called Kid-Ney's Journey. An image of the prototype they made is displayed in Fig. 2. The image shows the (1) playingboard, (2) pions, (3) dilemma-cards, (4) answer-cards, (5) armor-cards, (6) manual and (7) dice).

The game is targeted at people in the age of 21-40 years old, who need to start treatment soon, and at their spouses or close relatives. The goal of the game is to give these people insight in the effects of a treatment on their daily life and to help them weighting the advantages and disadvantages of each treatment method. The intention of the game is to stimulate a dialogue between the people that will be living with the consequences of the treatment daily, e.g. both the patient and the close family. The game can be played by two to four players, is intended to last for 20-30 minutes and can be played at home, or in the waiting room of the hospital.

The storyline of the games is that each player needs to collect armor to defend their Kid-Ney against the disease. The goal in the game is to collect a complete armor in one color for their Kid-Ney, in order to be able to be strongest when fighting the disease.

A player collects pieces of armor by visiting the five locations on the board by throwing the dice. In each location the player is presented with a set of four dilemmas, which have been formulated according to possibilities and constraints that come with each treatment. An example of such a dilemma is: 'My treatment schedule is fixed, but I can plan other activities around it.'. By choosing one of the options, the player receives an armor-card of a specific color. The color represents a specific treatment method. Once a player has collected five different pieces of armor in the same color, the player goes to the 'Battlefield' in the middle of the board. Here the player needs to answer the final question: 'Which treatment method represents your color of armor: A kidney transplant, Haemodialysis in the hospital, Peritoneal Dialysis or Haemodialysis at home?' The game is won by answering this question correctly.

It was decided to develop a board-game, partly for the practical reason that it takes less time to develop a prototype. Therefore, it was possible to have a playable, presentable prototype by the end of the course. Additionally, the team wanted to design a multi-player game that could be played by several players simultaneously to stimulate discussion among the players. A board-game gathers people around a table, and



A. My treatment schedule is flexible, so I can sometimes start an hour later, but I need to be home. (6)
B. My treatment schedule is flexible and I can do the treatment everywhere. (17)
C. My treatment schedule is fixed, but I can plan other activities around it. (18)

Fig. 2 Kid-Ney's Journey board game

has therefore a low barrier for direct conversation.

During the course, several ideas for games and game-concepts where developed by the participants. Each idea was abstracted or inspired by existing, well-known and easy to play games, such as ‘Game of goose’ and ‘Trivial Pursuit’. This was a deliberate choice, as the group wanted to develop a game that has a low threshold to start playing, and of which the rules are easily and quick to understand. This to avoid that people would spend time on reading a long manual or discussing uncertainties about the rules. The game will probably be played once or at most a few times during the short period in which a decision on treatment method needs to be made.

The story-line of the game is a bit sarcastic, with Kid-Ney collecting a harness to defend himself for the disease. However, the group considered this to be a usable metaphor, as a treatment protects the patient against the detrimental particles that poison the body and keeps the patient alive. In this way treatment acts as a kind of harness. The group imagined further that sarcasm could be appreciated by the target-group, but were also aware that such sarcasm might not be appreciated by people outside the target-group, especially elderly might prefer a more serious storyline.

B. The re-designed game-concept

Based on the group-discussion with the students who evaluated the game, and the expert-review the game-concept was adapted. In the new design the following changes were implemented:

1. Treatment-methods: It was decided to focus the game on the three main dialysis options and to leave out kidney transplantation. This was done for two reasons: a)Transplantation is often the preferred treatment method as it is considered to result in the best quality of life [32]. As a result the dilemmas concerning transplantation had to be strangely formulated to avoid them from standing out. This was considered to be too superficial. b) People on the waiting list for a transplant will need to go on dialysis treatment in the meantime. Even though these people have chosen transplantation as preferred option, they will need to make a choice on what dialysis treatment they will undergo meanwhile. With waiting lists becoming longer, more and more people will need to make this choice.

2. Lay-out of the board: How to move from start-position to playfield and between the tiles of the field and the five locations was not clear. The line-drawings on the board were therefore adjusted. Additionally, the distances between the five locations were shortened, to avoid that people have to use several turns to get to a location, and the rules was added that if you throw a six, you can move to any of the five locations directly. This was done to speed-up the game.

3. Icons: The meaning of icons to indicate the five locations appeared to be ambiguous. Therefore some icons where replaced and text was added.

4. Dilemmas: Not all dilemmas on the cards were clear as some formulations are long. Furthermore, different tenses were used in the statements. These dilemmas were reformulated and shortened. Additionally, the card-design was changed, so that each player can see which dilemma they selected previously.

IV. DISCUSSION

Involving a medical professional in the development process is seen as beneficial, as they are experts on the practicalities of treatment and know what concerns and questions patients often have. In collaboration with medical experts who frequently are in contact with patients, it is possible to phrase the dilemmas such that they represent dilemmas that patients indicate to struggle with in language that they are familiar with (e.g. food not nutrition, sport vs physical activity). Involving a medical profession directly in the concept-generation process, as a co-designer, can even be more beneficiary, as expert knowledge can directly be implemented during the process co-creation in the idea-generation and concept-development phase. The same goes for involving patients and caregivers that have gone through the treatment-selection process in the design process. They are experts on what they have experienced, what they struggled with, which aspects they considered, and what support they would have liked to have had. However, due to density of the Serious Gaming course, the students did not have the possibility to find and bring in a medical experts nor patients and caregivers.

The author had chosen to find students to help with the development of a serious game after having mapped the current situation via a literature study, analysis of various online information platforms [33] and interviews and observations of a program at St. Olavs hospital in Trondheim, Norway aimed at educating patients and caregivers about the disease and the different treatment methods that exist (article under review). These studies showed that the available information focusses on the practicalities of the treatment, while information that addresses values, beliefs and effects on daily life are neglected. Furthermore, the language used often contains jargon or difficult words. The benefits of a serious game that people can play at home are:

- Freedom of use; People can learn in a safe environment (home) at any time and re-play the game several times.
- Engagement; Playing a game with people is more engaging that reading an information leaflet individually [34, 35].

On the other hand the author was aware that the information in the game might needed to be simplified, and that one needed to be careful with what rewards to use as using extrinsic rewards to intrinsically motivate people to play is not sustainable [34]. Furthermore, patients that feel very sick, like to be cared for and patients and caregivers might rather interact with a medical professional. Therefore, the author considers the game as an additional information source, not as a replacement for the current information sources.

People diagnosed with chronic kidney failure and their spouses indicate that they lack the skills and knowledge to make a decision in the treatment selection process [36]. Instruments to support decision making can empower patients to take an active role in their treatment. This is important, as active patients have better treatment outcomes and less hospitalizations [22, 23]. The game-concept addresses the knowledge and tries to stimulate people to start a discussion with relatives. However, if this game meets the needs of the patients and spouses sufficiently, needs to be tested with actual patients. The first game-concept has been evaluated by people in the same age-group as the target-group. The game has not yet been tested with actual patients, as this is a vulnerable group. The author considered testing with the target-group not beneficial enough at this moment to justify the burden for these people. Furthermore, permission of the medical ethical committee would need to be obtained first, which takes time. Next steps in the development process are to evaluate and eventually redesign the game-concept with people within the same age-group as the target-group, before testing it with actual patients.

The game-concept presented in this article is targeted at patients in the age of 21-40 years. This was a choice made by the student-team that developed the game-concept. This choice was based on the fact that the students are in this age-group. With no possibilities to involve patients or obtain user-insights during the one-week period of the course, this choice allowed them to rely on their own insights on what aspects play a role in this period of a human life. Furthermore, the students thought this age-group to be especially exposed to effects on social life when needing to start treatment. However, the median age of people with chronic kidney failure is 60.5 years, with a range of 1 to 95 years [3]. Regardless of age, people should be given the opportunity to choose their treatment method [9]. With the larger part of the patient population being elderly, design including this group is relevant. Therefore, more research and development would be beneficial too adapt the game-concept to diverse users groups.

In order to realize shared decision making in consultation with medical professionals another barrier will need to be overcome. The doctor is still seen as the expert, both by some medical professionals as by some patients [37]. Doctors are professionals when medical aspects are concerned, however, patients are the experts on their own life. This barrier is not addressed by this game-concept, as it is partly a political one and requires a shift in culture. The game-concept aims to increase the patients' knowledge so that they can take part in discussion with their medical professionals on equal grounds.

There are also ethical challenges that will need to be overcome before the game-concept can be introduced in practice. Today not all hospitals can offer all the different treatment methods. This often leads to variation in treatment selection that is presented to patients. Thus, the question is whether investments should be made to give every patients access to the same selection of treatment methods, or whether the game-concept should be adaptable to the treatments that can be offered at a specific healthcare-facility. The first may lead to rising costs, decline in efficiency of the healthcare system and can cause problems with capacity. The latter means that not all patients receive the same opportunities.
Furthermore, there might be contra-indications for some patients to specific treatment methods. Should these patients learn about the treatment methods that they are not eligible for? An option could be to decide to develop an online game-concept to solve these challenges. This will effect interaction between players. On the other hand, the benefit of online games is that it can be adapted to eventual physical and cognitive hindrances of players. Additionally, multimedia techniques can be used to stimulate knowledge uptake and engagement [35].

There is a vast amount of health related gamified applications being developed that address various phases of patient journeys. They can be categorized as preventive, therapeutic, assessing, educational and informative [38]. In the case of chronic kidney failure there are opportunities for the introduction of games or game-elements in all these categories. In some categories there are already examples to be found. For example, when people are diagnosed with chronic kidney failure, it does not always mean that they need to start with dialysis treatment immediately. If the kidneys still function well enough, it is often tried to postpone treatment start as long as possible. Sometimes treatment start can be postponed for years. People in this phase might be helped with a game to keep them motivated to adhere to their diet and training schedule. The Dutch Kidney organization has just developed an application for this purpose, called Coach4Life [39]. To create awareness about lifestyle related diseases, preventive applications have been developed. Although many health-related gamified applications and games are being developed with multiple purposes, an example of a game that educates patients about the effects of different treatments on their life has not been found. Another area in which games might be applied in the future is in education of patients that have chosen some form of self-care. Once people have chosen treatment that involves self-care, they will need to be taught how the treatment is performed and when to contact medical professionals in case of any discrepancy.

V. CONCLUSION

This paper has discussed the development of a game-concept for people with chronic kidney failure and their caregivers to support them in making a choice for a treatment method. The game-concept was developed based on the insights that came forth in previous studies. An important step has yet to be made, which is testing and evaluating the game with patients and caregivers. Before this is done, the new concept will first be evaluated with people in the same age as the target-group, to ensure that the concept is playable, interesting, and meaningful.

The game can be a supplement to patient education performed by medical professionals, and supports the patient in learning about qualitative influences of the treatment methods on life. Despite its advantages, it is not intended to replace any part of the current information service, which focusses more on the practicalities of the different treatment methods. People who suffer from a serious illness must have the opportunity to discuss questions concerning their illness and treatment methods with a healthcare professional.

Giving patients and caregivers the opportunity to participate in the selection of a treatment method is not only relevant for people with chronic kidney failure. There are other examples to be found of disease for which several treatment methods exist and for which the medical outcome is expected to be comparable. An example of such a case is prostate cancer, where active surveillance, hormone therapy, surgery and radiation therapy are some of the treatment options [40].

This paper has given an introduction on the potential of using a game to support patients and caregivers in treatment selection. Results are meant to contribute to the development of better information supply to patients and their relatives to support informed decision making. This is important, since no matter which treatment method the patient chooses it will have a significant impact on their live, as well as on the lives of their family. Furthermore, it has been shown that better informed people have better health outcomes and make different choices, by opting for home treatment more often [22, 23].

ACKNOWLEDGEMENT

Thank you to Dr. G.W.J. Bruinsma and L. Collou, MSc. whom organized the Serious gaming course and gave me permission to write my own assignment. Thank you to the students that participated in the course and helped to develop the game: C. Barreira, V.C. Maduro, I. de Vent. Your dedication and creativeness was inspiring. Thank you to S. Nakrem, for the expert review on the content of the cards. Thank you to the students in Game Design course for evaluating the initial game-concept.

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Co-Design in Specialist Care – Aspects to Consider

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Abstract. Co-design workshops are a way to stimulate collective ideation between designers and non-designers. Co-design is increasingly applied in healthcare contexts. The application of co-design methods in projects on healthcare services requires careful preparation, as healthcare contexts are complex. By describing the process of preparing and facilitating a co-design workshop for the redesign of a healthcare service in an academic hospital, the author elucidates aspects that organizers should consider when preparing co-design workshops for similar contexts: Organizers should carefully consider whom to invite to the workshop, and what the pros and cons of this decision are. Organizers should consider the inclusion of designers and other experts as workshop participants as well as considering the effects of the inclusion of patients or healthcare professionals with different responsibilities. Furthermore, the representation of current non-users should be considered, as not everyone has the same access to care. The hierarchic roles that are typical for healthcare settings require organizers to adapt workshop tools and materials to the participants to provide them with a safe space to articulate their ideas and experiences.

Relevance To Practice - This article contributes with empirically grounded advice on aspects for workshop organizers to consider when preparing workshops for healthcare contexts. The aim is to contribute to the optimization of co-design workshops in healthcare contexts, specifically those that focus on optimizing healthcare services.

1 Introduction

Co-design workshops are increasingly used to optimize healthcare services. The co-design literature describes generally how to organize co-design workshops, but says little on how specific contexts, such as specialist care in hospitals, can affect the effectiveness of the methods and tools. Workshop organizers can benefit from more context specific advice. By reflecting upon experiences with the organization of a co-design workshop for specialist care, the author elucidates context specific aspects that organizers should consider when planning co-design workshops for similar contexts. The article focuses on the process, rather than on the ideas that came forth during the workshop. In addition to providing practical, context specific advice, the author hopes to inspire non-designers to consider co-design workshops as a possible approach to optimization of healthcare services.

1.1 Co-Design

Co-design, as defined by Sanders and Stappers [1], refers to collective creativity by designers and non-designers in design processes, through sketching, the making prototypes or artefacts. People become partners in the design process, actively contributing to ideation and development. Co-design workshops bring designers and non-designers together and stimulate them to make things together. Design-by-doing engages people, provides for effective dialogues by offering alternative ways of communicating [2], supporting the discussion of possible future scenarios [3] and improving the collaboration between people in different roles [4]. Although the prerequisite for co-design workshops is to have both designers and non-designers participating, the workshop organizers and facilitators do not necessarily have to be designers.

Services are characterized by multiple points of contact between service-provider and service-receiver over time. When you buy coffee in the supermarket, you buy a product. When you buy coffee at a restaurant, you receive a service; the waiter comes to you to take your order, prepares you a cup of coffee, brings it to your table, and cleans your table and the cup after you are finished. The goal of service design is to design for holistic experiences that appeal to the service-receivers, while being effective, and efficient for the service-provider [5]. Service design therefore includes "the design of the overall experience of a service, as well as the design of the process and strategy to provide that service." [6]. Ideally, both service-providers as service-receivers are involved in the design phase [7]. However, although one can design for a practice, the practice itself cannot be designed, since practices are dependent upon human interactions and changing contexts [2]. Co-design workshops can be used to strengthen the focus on the people affected by the service, stimulating more innovative ideas that better comply with people's needs, leading to better service experiences [4]. In healthcare contexts, patients and their family are usually the service-receivers, while medical personnel are service-providers. The involvement of patients in the development of public services is becoming more recognized [8].

2 Method

By reflecting on decisions and resulting experiences, workshop organizers become conscious of how they make use of a method and learn from it. Sharing these learnings helps optimizing methods [9]. A co-design workshop on the redesign of a healthcare service in an academic hospital in Norway is used as an example case to discuss co-design workshops as a method for service optimization or development. The hospital service that was redesigned is a pre-treatment education program called the 'Kidney School'. This service is offered to people with Chronic Renal Failure and their spouses and is intended to help them cope and to inform them about available treatment methods to empower them to take part in treatment discussion with their physician. The service consists of individual consults and group-sessions. Participation is voluntary. Two nurses with a 50% post at the Kidney School and a 50% post at the outpatient clinic run the program.

2.1 Workshop Preparation I – a Pre-study

Before preparing a workshop, it is important to determine what the workshop should contribute. Based on this decision, the workshop organizer can decide which tools, materials and assignments to use, arrange the space for the workshop to take place [10, 11]. Empathic abilities, communication, and adaptation skills are important in the preparation of a co-design workshop [12].

A pre-study was done to build empathy with the service-providers, as well as the service-receivers; The nurses were interviewed about their intentions, the service was observed to study the service in its context, and to get access to first hand insights, and patients were interviewed about their experiences. The insights were used to identify challenges that needed to be addressed. In a meeting with the two nurses that run the Kidney School, the suggestion to conduct a co-design workshop and its aim were agreed upon. Practicalities such as obtaining permission from the department head, timing, inviting participants, and booking a room were also discussed. Such prior discussions contribute to the successfulness of a workshop and support the alignment of expectations [13]. When preparing for a workshop, one has to set a realistic goal given the participant group and available time [8]. The aim of the workshop was defined as: 'Optimizing the Kidney School's service, to match the expectations of patients and their relatives, and to better meet the needs of the nurses that organize the program'. With limited time available, it was decided to focus on obtaining new ideas, not on implementation strategies. This would done afterwards in collaboration with the two nurses.

2.2 Workshop Preparation II - Developing the Workshop's Structure

The insights from the pre-study helped tailoring the workshop to the specific case. They were used to prepare the workshop's assignments and materials. Careful planning, the selection of appropriate methods, and taking time to prepare the materials increases the chance for the workshop to be effective [4, 10]. As each project is different, workshop organizers should be able to apply methods or tools flexibly, carefully selecting the ones that fit best with the project's aim [14].

Deciding who to include in a project, through which methods and during which stages, is an essential part of a project's preparation phase [4]. Including people as partners in design ensures that the designed solutions are relevant for the different parties involved [10, 14, 15]. Although the healthcare context is complex, the organizer (the author) decided to invite every medical professional that is involved in the Kidney School, as active involvement creates shared ownership [16, 17]. This is important, as the practitioners are the ones that will eventually need to make changes to their practices. Although service-receivers commonly are included in co-design workshops as experts of their experiences [1], the organizer decided not to invite patients and their next-of-kin. An organizer should consider the participant group and its traits with respect to formality, climate, participation, conflict, decision-making, responsibility and communications [8]. Based on these traits and ethical considerations, the organizer decided not to include patients as to not interfere in their relationships with medical professionals. During a co-design workshop, patients and medical specialists would be expected to interact with each other in a non-traditional setting. Specialist healthcare has a paternalistic tradition, and although changes are happening, power distances between medical specialists and patients are still common. Collaboration between these two parties might be obstructed by this tradition. Additionally, the relationship between patients and their medical team is precarious. For chronic patients a good relationship with their medical team based on mutual trust is important, as they will have to collaborate over a long time. The disadvantage of not including patients in the workshop is that their needs might not be considered. This decision consequently effected the assignments and materials that were prepared for the workshop. For workshops to be successful, suitable methods need to be selected and adjusted to the specific context of the project [4]. The first two assignments challenged the workshop participants to evaluate the service from a patient's perspective. Patient Journey Maps were used to visualize the current structure of the program as well as its context. A User (or Patient) Journey Map provides an overview of the series of interactions that take place over time between a service-provider and a service-receiver, from the receiver's perspective [18]. They are used to display an existing service to allow for its evaluation [16]. To ensure that the service fits in its context, pre-service and post-service activities are included [14]. Images or quotes can be added to make the User Journey Map more vivid [17] Figure 1 presents a simplified version of the Patient Journey Maps that was used in the workshop. Additionally, three personas of patients, were prepared. Personas present archetypical persons through a short narrative in which key aspects of a person's life are mediated, including needs, goals and behaviors [19]. They can be used to help workshop participants build empathy with other people. The personas can be found in the appendix (in Norwegian). Both design tools were intended to support the participants in taking on a patient perspective and considering patients' needs while evaluating the existing service and ideating on possibilities for improvements.

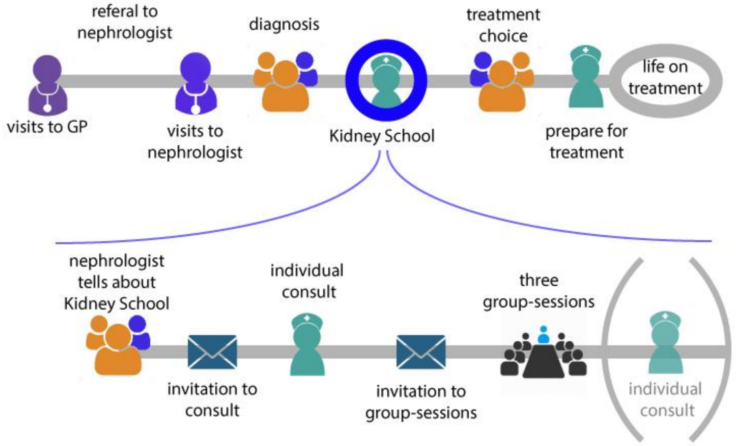


Fig. 1: Simplified Patient Journey Map for the Kidney School

The organizer furthermore decided to invite providers from similar services and designers as external participants. Providers of similar services might have very different experiences than the team that works with the service that is being re-designed. This can stimulate ideation. Designers are familiar with creative techniques and design tools and can thus help other participants to use these. Human-centered designers are additionally used to considering situations from the perspective of different people, which can help ensuring that the needs of both service providers and service receivers are considered during the workshop [14]. The organizer decided furthermore that the organizer herself, who has a background in design, and a researcher with a background in nursing, would facilitate the workshop. Both had contributed to the pre-study and were therefore familiar with challenges that needed to be addressed in the workshop. The pre-study had given them empathic understanding of patient experiences, which helped them in posing relevant probing questions under the assignments to ensure that the patient perspective was considered by the workshop participants. These questions were included in the facilitator-guide. Instead of stating that something was found to be a challenge, the questions were formulated positively. Examples are: ‘How could we ensure that the presentations cover relevant topics?’, and ‘What could be changed to make planning of the group-sessions easier?’ Credible facilitators contribute to the quality of facilitation [13].

When the workshops assignments and materials had been prepared, a trial workshop was organized to check if the assignments were clear, doable within the timeframe, and if they produced the desired results. Furthermore, it allowed the facilitators to practice, and to test the materials. After the trial workshop, the facilitators shared their experiences. This helped them to align their approaches better and led to some small changes in the workshop’s plan; The Patient Journey Maps and Personas were found to be complementary tools, as they provide insights from different perspectives. Introducing empathic tools in a workshop takes time, as participants need to study them before they can effectively work with them. It was therefore decided to keep the personas as a back-up in case the facilitators thought ideation would benefit from more diverse insights into patient needs and experiences. The same was done with a stock of cards that represent technologies that can be used in a service. The facilitators could introduce these in case extra stimulus was needed for ideation. Figure 2 gives an overview of the activities that were performed in preparation of the workshop and who participated.

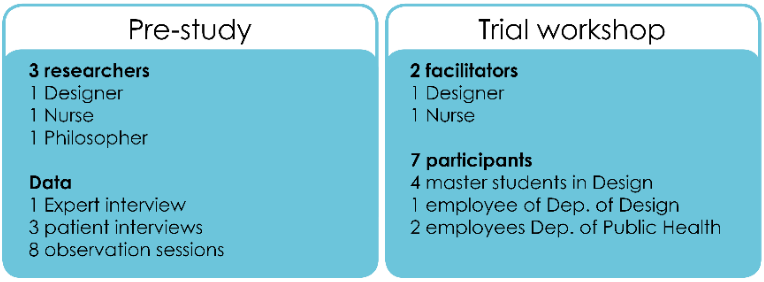


Fig. 2: Overview of conducted studies

2.3 Participant Recruitment

The workshop organizer invited two nurses that run the Kidney School. These two nurses invited the other medical professionals that are involved in the Kidney School through face-to-face conversations. They gave an information letter in which the workshop organizer explained the goal and background of the workshop. Contact details were included, in case of any questions. The workshop organizer, following the same approach as the nurses, recruited external participants for the workshop; nurses working in a department that organizes courses for people with various diagnoses and master students in design with experience in designing for people with chronic illnesses. Upon agreeing to participation, the participant received an official invitation in form of a post-card, with information on the timing and place of the workshop as well as a small sensitizing assignment, asking them to describe a good shopping experience they have had. Sensitizing assignments aim to trigger people to think over aspects of their personal time, to prepare them for the workshop [20]. The assignment was deliberately kept very open and easy to give everyone a change to contribute.

2.4 The Workshop

The two-hour workshop would be held at the hospital's nephrology department, so that most participants did not have to travel. Table 1 displays the final set-up of the workshop, including its time-schedule and an overview of the materials. The facilitators would first introduce themselves, explain the goal of the workshop, their role as facilitator, what was expected of the participants and the structure of the workshop. Furthermore, they would discuss the workshop rules, which stated i.a. that discussions should be constructive and that it is important to be open to new thoughts. Before the start of the actual workshop, a warm-up exercise would done, based on the sensitizing assignment that stood in the invitation. During this exercise, one of the facilitators would write down key-words from the participants' stories to provide an example of the way-of-working that would be expected from the participants during the following assignments. After the warm-up exercise, the group would be divided over two rooms according to job-position to ensure diversity in each group.

The language-use for the assignments and materials was purposefully adapted to the workshop participants; during the trial-workshop words such as 'meeting with kidney doctor' were used, while medical terminology, such as 'consultation with nephrologist' was used in the workshop with medical professionals. This was done as language use can form a barrier for effective communication [13].

The facilitators would close the workshop by reciting the goal of the workshop and what had been accomplished in the workshop. They would explain how the process would continue and participants would get the chance to ask questions. In order to receive feedback on the co-design workshop's process and facilitation, an evaluation form would be handed out to the participants at the end of the workshop. Participants could either fill out the form immediately or to hand it in later. Additionally, the organizer planned a meeting with the master student two days after the workshop, to discuss how she had experienced the workshop. One week after the workshop the workshop organizer would meet with the two nurses that run the Kidney School to discuss formulate follow-up actions and to discuss their experiences.

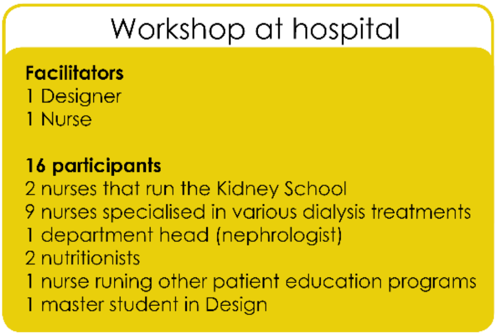
Timing	***Assignment***	***Materials***
10 min	Introduction, en plenum.	Facilitation guide, workshop rules
10 min	Warm-up exercise, en plenum. *Name + description of your favourite shopping experience.*	Post-cards, post-its + pens
15 min	1 – Map information needs of patients in three different phases of their disease, 2 groups.	Simplified Patient Journey Map, post-its + pens, poster with three participant groups
45 min	2 – Analysis of the current Kidney School, its aims and ideas for improvement, 2 groups.	Brainstorm exercise. Detailed Patient Journey Map, Assignment 1, post-its + pens, probing questions (Personas, card stock)
10 min	Break	
10 + 10 min	3a - Design the 'ideal' Kidney School, 2 groups. 3b - Presentation to other group, en plenum.	Assignment 2, post-its + pens
10 min	Closure, en plenum.	Evaluation forms

Table 1: Workshop set-up

3 Findings

Recruitment by the nurses went well, with more participants signing-up than expected. Most participants were female nurses working at the same department. The priest, physiotherapist and social worker involved in the Kidney School did not attend. Figure 3 provides an overview of workshop participants.

After the introduction the warm-up exercise was done. Due to the unexpected high number of participants, this exercise took longer than planned. Prior to the workshop, the facilitators considered asking just a few participants to share their thoughts. However, they decided not do so to ensure that everyone had said something to the rest of group before starting with the assignments, to engage and to activate each participant. As the exercise was quite open, each participant could contribute, including those that had forgotten to prepare it (about half of the participants).



Workshop at hospital

Facilitators
1 Designer
1 Nurse

16 participants
2 nurses that run the Kidney School
9 nurses specialised in various dialysis treatments
1 department head (nephrologist)
2 nutritionists
1 nurse runing other patient education programs
1 master student in Design

Fig. 3: Overview of workshop participants

Although not asked for, most participants mentioned their job-position. Participants enthusiastically shared their stories and smiled in reaction to stories from others. The facilitator wrote down key-words of their stories on what they associated with a good service experience and summed these up at the end. It resulted in quite a long list of relevant key-words, which was useful in later discussions. The group was split in two. The design student and the nurse who is involved in a similar service were each placed in a different group.

Assignment 1 - The participants needed time to become used to brainstorming in a group; At the start they were a hesitant to speak out. The facilitators had to prompt the participants for input. Gradually the participants became more talkative started openly sharing their thoughts with the others in their group. By the end of the first exercise, the facilitators did no longer have to prompt any of the participants as all were participating and contributing. During the assignment, the participants had to be reminded frequently to write their ideas on post-it notes. The design-student did this for the participants in her group at the start, showing them how it was done. In the other group, the facilitator did this. This made it more challenging for her to stimulate the participants to write down ideas themselves and to stay in her role as facilitator. In the discussion with the master student it came forth that she also had noticed that the participants were very engaged in the discussions, but seemed uncertain about writing their ideas on post-it notes.

Assignment 2 –The two external participants stimulated creative thinking by bringing new topics to the table and challenging current practices. This was especially evident during the second assignment, but also during the other assignments they contributed to the discussion. Discussions between the participants were mostly constructive, although sometimes a participant became defensive. This happened in instances were a professional from another discipline asked why things were done as they were. These instances were few, but it was useful to have a printed overview of workshop rules to remind the participants of them. We found that the ideas of the healthcare practitioners mostly concerned things they could change to their own practice. Their ideas often focused on communication styles, rather than technical alternatives. The external participants came with proposals that were perhaps less evident than suggestions by the other participants, such as introducing homework and setting-up a chat-group for patients, opposed to ideas as reserving more time for a difficult topic or changing the order of the topics that were already part of the program.

The facilitators did not consider it necessary to introduce the personas, as the participants had constructive discussions, and seemed to have a shared notion on common characteristics and needs of patients. This was evident from the discussions among the participants. Furthermore, explaining them would take time, and might get the participants out of their flow. Yet, the facilitators liked having them available in case it would have been needed to stimulate ideation and to bring in more focus on patient needs.

Break - During the break, the facilitators decided to skip the second part of assignment 3 due to the delay that was caused by the longer warm-up exercise, and as they had noticed that the participants were less familiar with each other than expected. The facilitators presumed that the participants therefore might not feel comfortable with presenting their group's results to others they did not know very well. Instead, the facilitators decided to give a brief summary of what each group had discussed to the other group. The facilitators found that it was very important to have conducted a trial-workshop and to have discussed several scenarios in preparation of the workshop. This helped them take this decision quickly.

Assignment 3 – The discussions on which ideas were most promising started very carefully. The facilitators had to ask the participants for input. As during the first assignment it took some time before the discussion started going and the participants did not need to be prompted anymore.

Few participants filled out the evaluation form after the workshop. Feedback was mainly positive, mentioning appreciation for the structure of the workshop, the materials that were used and sticking to the timeslot. Some participants indicated that the workshop could have been longer, to allow more time for ideation. The two nurses that run the program indicated to have especially valued the presence of the two external participants. The involvement of externals stimulated them to reflect upon their practice, made them aware of certain aspects of their practices, and helped them to clearer define the importance of the program. During the meeting with the nurses a selection of ideas was made. In preparation of this meeting the nurses and designer had individually made a selection of ideas they thought were relevant, interesting or promising. During the meeting these ideas were discussed and an action plan was made. Additionally, attention was paid to the development of an evaluation-aid that the nurses can use themselves without the help of a designer.

4 Reflection and Discussion

The discussion below presents a reflection on the decisions that were made in preparation of the workshop and what happened during the workshop. By comparing this with scientific literature on experiences from similar cases, advice for organizers of co-design workshops for specialist healthcare contexts is formulated. The discussion aims to show the importance of carefully considering who to invite, and of preparing materials and assignments that match with the participants' experience with creative acts of making.

4.1 Who to Invite and How to Invite Them?

From this study we learned that in specialist healthcare context organizers of co-design workshops cannot standardly invite people from all stakeholder groups to participate. It is necessary to reflect on what effect it might have on the future relations between stakeholders. Patients are in a very precarious situation being dependent on help from medical specialists. In the case of this service, the patient's situation is extra delicate; they have just been diagnosed with a life-threatening chronic disease that will require lifelong treatment. Building and preserving a good relation with their medical team is important for such people that are likely to get treatment over several years.

The decision to not invite an important group of stakeholders, strongly affected the workshop's structure. Including people with different needs drives innovation [21], and ensures that the different needs are accounted for [4]. When taking such a decision one thus needs to find a way to compensate for this. We tried to reduce the effect of this decision by formulating assignments and materials from a patient perspective. We belief that the combination of the workshop's structure, pre-study and the involvement of facilitators that had strong empathy with the case, enabled us to ensure a focus on patient needs. Others have solved this challenge differently. Gaudion, Hall, Myerson and Pellicano [12], did include autistic adults in their pre-study, while healthcare professionals and family members were involved in ideation and implementation instead. The NHS Institute for Innovations and Implementation lets medical professionals and patients work separately first. In later stages of the design process they are brought together. The NHS decided to do so after having experienced situations were medical professionals became defensive, while patients felt they were not listened to [22]. Based on these insights and experiences, the author recommends workshop organizers for specialist healthcare contexts to carefully question who to involve when, and what the effects of such a decision could be.

From this study we learned that letting 'insiders' invite their colleagues can be a very successful approach to participant recruitment. The nurses that run the program and who were open to change invited their colleagues. Although more medical professionals freed-up time to participate, not all medical specialists that are involved in the service joined. Most of the participants were female nurses. The priest, physiotherapist and social worker involved in the Kidney School did not attend. A larger variety of professions could have benefited ideation and ownership over the ideas. They are important actors in the program, have different experiences than nurses, and their support for the program is important, as they can introduce the program to a new patient. What a successful strategy for stimulating participation of specialized medical professionals could be, remains to be studied.

Others have experienced participants with negative expectations towards the project at the start and concluded that it might affect their willingness to contribute to discussions [12, 22]. This somewhat contradicts our experience. Like Yang and Sung [14], we found the participants to be very motivated to contribute. Participation in the workshop was voluntary and focused on aspects related to the everyday practice of the medical practitioners. This stimulates motivation to participate [13]. The fact that a colleague who could very well explain the necessity and relevance of the workshop invited them might have helped. Based on these insights we recommend workshop organizers to consider if participant recruitment might benefit from 'insiders' taking this responsibility instead of designers or department heads.

From this study we learned that the inclusion of external experts as workshop participants can be very valuable for idea generation. Healthcare professionals are people-focused. The ideas that they generated in this workshop were strongly related to practice. This is a common challenge with designing for services as the needs and concerns of people form the starting point for ideation, not a technology or process [2]. Designers however, are not only people focused, but often also technology focused, and aware of production processes and their constraints [1, 8]. Designers as participants can therefore suggest technologic ideas. Although we found the inclusion of designers as participants to be valuable, others warn that it can have a negative effect on feelings of ownership among other participants [22], and that prejudices towards what designer can do, can affect the effectiveness of collaborations [13]. This implies the importance of balancing the participant groups with regard to designers and non-designers.

Additionally, we learned from this study that bringing in external professionals that provide similar services strongly supports ideation. Such participants bring in a fresh look and can question why things are done the way they are. However, this can lead to instances were a participant becomes offensive. In such cases, it is practical to have clear workshop rules on how to formulate suggestions and ideas. Based on these insights and experiences, the author recommends workshop organizers for healthcare context to consider how the recruitment of not only designers, but also of other external participants. It is recommended to seek a balance between internal and external participants, as the internal team should have a feeling of ownership at the end of the workshop.

Empathic facilitators provide an important contribution to the workshop outcomes [8]. In our case, we deliberately decided that the nurse who had been involved in the pre-study would facilitate one of the workshop groups. Even though the nurse did not have any previous experience with the facilitation of creative workshops, she was very familiar with the project and knew exactly where the pain-points for both the service-providers and the service-receivers lied. This enabled her to pose relevant questions to the participants. Furthermore, specialist healthcare is a complex context, with strong hierarchies between professions, where working in silos occurs due to specialization, and where risk aversion is a common notion [22]. A facilitator who understands with what preconceptions the participants come in to a workshop can manage. Based on these insights and experiences, the author recommends workshop organizers to consider to invite people who are familiar with the problems that need to be addressed and the context of the service to facilitate a workshop. They might need to facilitate a trial-workshop first, to become confident and to align approaches, but their familiarity with the topic will be beneficial for the quality of facilitation.

4.2 What Assignments and Materials to Prepare?

Engaging people in a creative process can be challenging, as many are not used to working creatively and might think they are not able to [1]. This was also challenging in this workshop. The workshop deliberately started with a sensitizing warm-up exercise to which all participants could contribute without any preparation and that was unrelated to their work, to trigger engagement. This worked quite well. However, at the start of the first and third assignment, where the tasks were more focused and related to their practice, the participants became hesitant to speak up. The facilitators had to actively engage participants to start the group ideation process. Furthermore, it was evident that this creative way of working was new to them. They needed to be supported. Based on these insights and experiences, the author recommends workshop organizers to take extra care in gradually building up the creativity level of the exercises, so that non-designers can get used to a new way of working and expressing themselves.

A Patient Journey Map helps to visualize the existing service. Like Yang and Sung [14] and [13] we found that visualizations are helpful in discussions as they support shared understanding. Although the maps contain information on the context of the service, they usually do not contain information on which people are not reached by the service, or when individuals drop out. Especially in specialist healthcare it is important to consider non-users. Not everyone has the same access to care while the most vulnerable people might be the ones that could benefit most from a service. From this workshop we learned that facilitators who pose some probing questions concerning this stakeholder group can make participants aware of this group and motivate them to come up with solutions for them. The author recommends organizers of workshops for healthcare settings to consider non-users and how they can be represented in the workshop.

A limitation of this discussion is that it is based on the insights of just one study. Although the insights are supported by previously described studies from others, more studies are needed to strengthen the insights. For example, more studies are needed to determine an effective balance between internal and external participants. The goal should be to collect enough insights for advice and recommendations to be changed into guidelines for practice.

5 Conclusion

While preparing and facilitating a co-design workshop on the redesign of a healthcare service in specialist care, the author realized that some characteristics of the healthcare context influenced the approach and needed special attention to ensure effectiveness. By describing and reflecting on the process of preparing and facilitating the workshop, the author elucidated aspects that workshop organizer should take into consideration when preparing workshops for similar contexts.

Careful preparation of a workshop is essential. Organizers should consider whom to invite to the workshop, and what the pros and cons of this decision are. Although bringing together different perspectives ensures that the needs of different people are represented, ethical considerations on what indirect effect this can have on the long-term relationships between participants are needed. Especially in the healthcare contexts, relationships between medical professionals and patients are precarious. Furthermore, organizers should consider the inclusion of external participants. They can stimulate creativity by challenging current practice, and approach the problem from a user-centered, holistic perspective.

Organizers should additionally carefully adapt workshop tools and materials to the participants, taking context and culture into account to create an environment of trust and competence. Traditional hierarchies in healthcare context might hinder participants from openly sharing their thoughts and ideas. Providing participants with non-traditional way of communication and having a facilitator that knows the setting well, can help in creating a more open environment. Furthermore, current non-users of healthcare services should be considered, as not everyone that could benefit from the service might have easy access to it.

Acknowledgements The author would like to thank the co-facilitator for her contribution to the project. Furthermore, she thanks the nurses that organize the Kidney School for helping obtain permission from their department head and recruiting colleagues for participation. The author thanks the workshop participants for their enthusiasm and their willingness to contribute.

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Appendix D – Workshop description

Invitation to the workshop

When someone had indicated that they were willing to participate in the workshop, after being invited in a conversation and receiving the information letter, people received a post-card with the official invitation and a sensitizing assignment. Figure 1 shows the invitation.

Takk for at
du blir med!

4 januari
kl.12.30-14.30
Gastrobygget, M5
Workshop Nyreskolen

Hei!

Vi setter stor pris på at du stiller opp til workshopen om Nyreskolen. I workshopen skal vi se på det nåværende opplegget fra Nyreskolen fra både helsepersonels og pasientens perspektiv.

Før vi møter på workshopen har jeg en liten oppgave til deg: Beskriv en god kjøpe-opplevelse som du har hatt og hvorfor du synes at den var god.

Gjerne ta med kortet til workshopen.

Med vennlig hilsen,
Carlijn

*Figure 1 – Invitation post-card with sensitising assignment on the back *in Norwegian*

Facilitation guide

Intro – 12.30-12.40 (10min)

- Introduction of facilitators Sigrid and Carlijn

Carlijn informs participants about the following:

- Goal of the workshop, refer to paper with printed description
- Goal of the Kidney School service:
    - Inform patients about treatment alternatives
    - Inform patients about disease trajectory
    - Support patients in participating in treatment decisions
- Explanation of workshop 'rules'
- Explain the workshop structure.

Exercise 0: Warm-up – 12.40-12.50 (10min)

- Goal: To become better known with each other and the workshop theme (healthcare services)
- 1: Carlijn: Write post-its with positive associations and sums them up at the end.

Divide the group in two :

Group 1 - Sigrid: xx, xxx, xxxx, ..

Gruppe 2 - Carlijn: xx, xxx, xxxx, ..

Excerise 1: Information needs of the variety of patients 12.50-13.05 (15min)

Introduction of the simplified timeline (Figure xx).

Goal: Map information needs of patients in three different phases of their disease: 1) Enough kidney function remaining, but follow-up by general practitioner, 2) Need to start treatment within the coming 6 months, 3) Need to start treatment immediately.

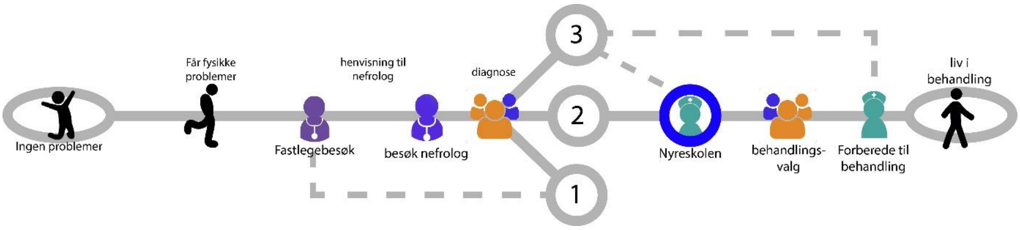
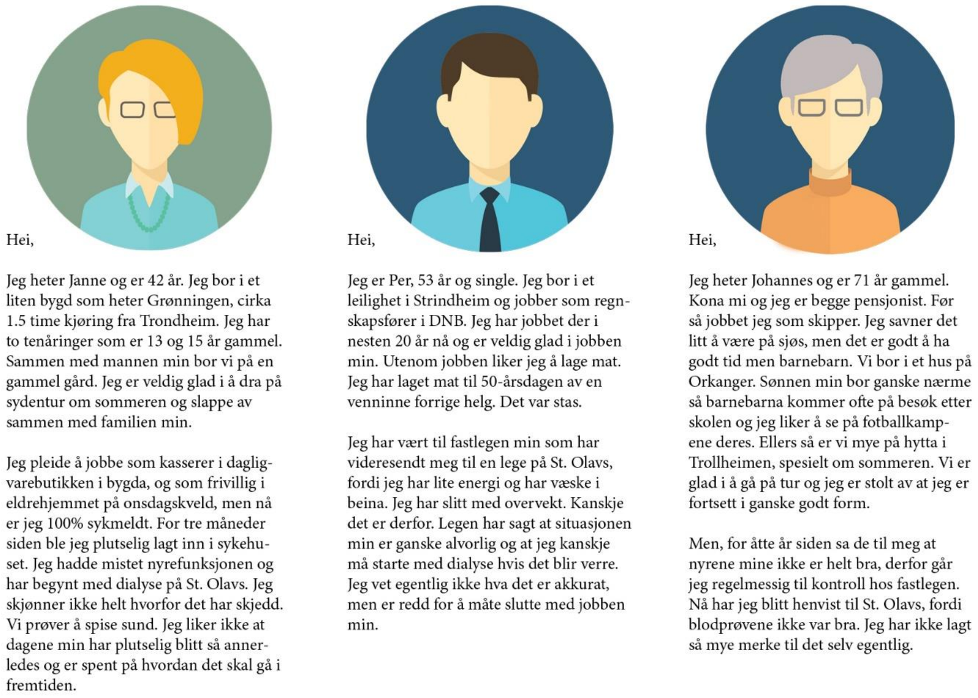


*Figure 2 – Simplified timeline of patients with CKF at this hospital *in Norwegian*

Participants write on post-its that they paste on paper with timeline

Eventually the Personas may be introduced (Figure 3)



Hei,

Jeg heter Janne og er 42 år. Jeg bor i et liten bygd som heter Grønningen, cirka 1.5 time kjøring fra Trondheim. Jeg har to tenåringer som er 13 og 15 år gammel. Sammen med mannen min bor vi på en gammel gård. Jeg er veldig glad i å dra på sydentur om sommeren og slappe av sammen med familien min.

Jeg pleide å jobbe som kasserer i dagligvarebutikken i bygda, og som frivillig i eldrehjemmet på onsdagskveld, men nå er jeg 100% sykmeldt. For tre måneder siden ble jeg plutselig lagt inn i sykehuset. Jeg hadde mistet nyrefunksjonen og har begynt med dialyse på St. Olavs. Jeg skjønner ikke helt hvorfor det har skjedd. Vi prøver å spise sund. Jeg liker ikke at dagene min har plutselig blitt så annerledes og er spent på hvordan det skal gå i fremtiden.

Hei,

Jeg er Per, 53 år og single. Jeg bor i et leilighet i Strindheim og jobber som regnskapsfører i DNB. Jeg har jobbet der i nesten 20 år nå og er veldig glad i jobben min. Utenom jobben liker jeg å lage mat. Jeg har laget mat til 50-årsdagen av en venninne forrige helg. Det var stas.

Jeg har vært til fastlegen min som har videresendt meg til en lege på St. Olavs, fordi jeg har lite energi og har væske i beina. Jeg har slitt med overvekt. Kanskje det er derfor. Legen har sagt at situasjonen min er ganske alvorlig og at jeg kanskje må starte med dialyse hvis det blir verre. Jeg vet egentlig ikke hva det er akkurat, men er redd for å måte slutte med jobben min.

Hei,

Jeg heter Johannes og er 71 år gammel. Kona mi og jeg er begge pensjonist. Før så jobbet jeg som skipper. Jeg savner det litt å være på sjøs, men det er godt å ha godt tid men barnebarn. Vi bor i et hus på Orkanger. Sønnen min bor ganske nærme så barnebarna kommer ofte på besøk etter skolen og jeg liker å se på fotballkampene deres. Ellers så er vi mye på hytta i Trollheimen, spesielt om sommeren. Vi er glad i å gå på tur og jeg er stolt av at jeg er fortsett i ganske godt form.

Men, for åtte år siden sa de til meg at nyrene mine ikke er helt bra, derfor går jeg regelmessig til kontroll hos fastlegen. Nå har jeg blitt henvist til St. Olavs, fordi blodprøvene ikke var bra. Jeg har ikke lagt så mye merke til det selv egentlig.

*Figure 3 – Peronas representing three different patients, inspired by patient interviews and observations of Kidney School *in Norwegian*

After exercise 1: Briefly repeat aim of the Kidney School

Exercise 2: Analysis of current Kidney School service – 13.05-13.50 (45min)

Goal: Analysis of the current Kidney School, its aims and ideas for improvement.
Explain service design approach to services and its analysis: What happens around the service, who is involved, which steps (touchpoints) does it include, which activities take place. Is the service coherent? Does it meet its goal? Does it cover the information needs of patients in group 2 and 3 (use results from exercise 1).
Introduce detailed timeline (Figure 4).

Brainstorm: Encourage participants to have a fast tempo and explain that anything is possible at this stage. The aim is to have fun, and stretch thinking at the same time. Participants write on post-its that they paste on paper with detailed timeline of the Kidney School (Figure xx)

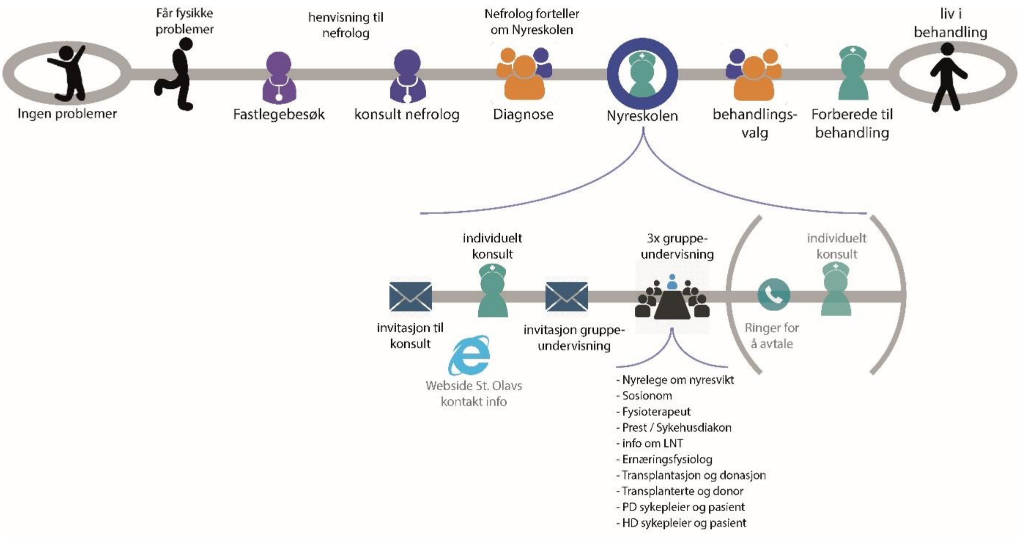


*Figure 4 – Detailed timeline of patient journey at local hospital *in Norwegian*

Questions that may be posed during the excersize:

- What are the pros and cons of the current service offer? Are there alternatives for reaching the same goal?
- Are we missing something to reach Nyreskolens goals?
- Are patient's information needs covered?
- How can we:
    - make ensure that the topics are interesting and relevant for the participants?
    - use the information load for the patient? (now short timeframe)
    - make sure that the participants also get utbytte av kurset lengre i tid?
    - give participants to chance to ask more questions? (time \ stimulate)
    - give participant the change to interact more with peers?
    - make it easier to organise the group sessions? *for the nurses
    - make it easier to organise the whole program?
- *Non-users:* Are there people who currently not participate and what may their motivation be? > Are there opportunities to motivate - interest them? What can we do to stimulate use?
- *Channels:* What can happen digitally or where is personal contact important? What would happen if we changed the channel?
- *Timing:* What if people would come into contact earlier? What if the GP would know about us?
  How can the service establish regular links to its customers over time?
  How can we realise a better transistion between the different interactions? What would happen if the Nyreskolen was intended for everyone with a diagnosis for kidney failure? (also early stages).
  Is their an area on which we want to focus on further? *one or more of the touchpoints.
- How can we use the website?
- How can we use the waiting room?
- Which other information sources may patients use?
- How can we improve communication about the Nyreskolen?

Eventuelly introduce the inspiration cards from AT-ONE – might help to think of other platforms

Eventuellyt introduseres Personas - Design the ideal service for them.

- How would Nyreskolen best add up to each individual?
- What motivations can patients have for participating in the Nyreskole? Can we offer something extra that does not exist today? (eg a link to information as they may. Can read in advance?)
- How are we reaching them now? Which channels work best?
- What type of relationship does each of our Customer Segments expect us to establish and maintain with them?

Break 13.50-14.00 (10min)

Excersize 3: **Design of the ideal Kidney School** –14.00-14.20 (20min)

Goal 3A - Design the 'ideal' Kidney School. Select the best ideas from exercise 2, restructure the current service offer of the Kidney School by developing a new service journey.

Eventually when its difficult to decide: Provide them with colored stickers and ask them to paste orange stickers with ideas that provide the best service experience for patients, green to those ideas that contribute best to the Kidney School's aim, purple for those that best to realize. What should be core activities?

Goal 3B - Presentation to other group,

Closing 14.20-14.30 (10min)

Carlijn sums up and repeats:

- Goal of the workshop
- Goal of the Kidney School service
- Sum up what was done during the workshop
- Explain what will be done with the ideas.
- Ask if anyone has questions or wants to comment anything

Narrative description of the workshop

The facilitators first introduced themselves, explained the goal of the workshop, their role as facilitator, what was expected of the participants and the structure of the workshop. Furthermore, they discussed the workshop rules, which stated i.a. that discussions should be constructive and that it is important to be open to new thoughts (figure 2 – in Norwegian). Before the start of the actual workshop, a warm-up exercise was done, based on the sensitizing assignment that stood in the invitation. During this exercise, one of the facilitators wrote down key-words from the participants' stories to provide an example of the way-of-working that would be expected from the participants during the following assignments. After the warm-up exercise, the group was divided over two rooms according to job-position to ensure diversity in each group.

The first two assignments challenged the workshop participants to evaluate the service from a patient's perspective. Patient Journey Maps were used to visualize the current structure of the program as well as its context. A User (or Patient) Journey Map provides an overview of the series of interactions that take place over time between a service-provider and a service-receiver, from the receiver's perspective (Hyvärinen et al., 2014). They are used to display an existing service to allow for its evaluation (Stickdorn and Schneider, 2011). To ensure that the service fits in its context, pre-service and post-service activities are included (Yang and Sung, 2016). Figure 2 shows the detailed patient journey map that was used in the second exercise. Additionally, three personas of patients, were prepared. Personas present archetypical persons through a short narrative in which key aspects of a person's life are mediated, including needs, goals and behaviors (Hanington and Martin, 2012). They can be used to help workshop participants build empathy with other people. Both design tools were intended to support the participants in taking on a patient perspective and considering patients' needs while evaluating the existing service and ideating on possibilities for improvements. The personas are displayed in figure 3 (in Norwegian).

The language-use for the assignments and materials was purposefully adapted to the workshop participants; during the trial-workshop words such as 'meeting with kidney doctor' were used, while medical terminology, such as 'consultation with nephrologist' was used in the workshop with medical professionals. This was done as language use can form a barrier for effective communication (Pirinen, 2016).

The facilitators closed the workshop by reciting the goal of the workshop and what had been accomplished in the workshop. They explained how the process would continue and participants got the chance to ask questions. In order to receive feedback on the co-design workshop's process and facilitation, an evaluation form was handed out to the participants at the end of the workshop. Participants could either fill out the form immediately or to hand it in later. Additionally, the organizer planned a meeting with the master student two days after the workshop, to discuss how she had experienced the workshop. One week after the workshop the workshop organizer met with the two nurses that run the Kidney School to discuss formulate follow-up actions and to discuss their experiences.