

SINI LEINONEN

**DESIGN PRINCIPLES
OF EHEALTH SERVICES
FOR CHRONICALLY ILL PATIENTS**

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ABSTRACT

Sini Leinonen: Design principles of eHealth services for chronically ill patients
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Patient experience is a significant factor in the life quality of chronically ill patients, and it can be improved by providing effective eHealth services. Design principles are meant to promote good practices and avoid common mistakes in the development process of software. To ensure that future eHealth applications would support good patient experience a solution to the problem “Designers and developers of eHealth services for chronically ill patients lack a comprehensive set of design principles that support good patient experience?” was researched.

The research consisted of two parts. First, a scoping review was conducted to find what design principles already exist for the purpose of designing eHealth for the chronically ill. The review found 119 principles in 21 articles, which were then categorized into 15 new principles. Next, an empirical case study was carried out, where kidney disease patients (N = 19) and the clinicians (N = 8) responsible for their care were interviewed. The interviews were semi-structured retrospective interviews and the topics revolved around their needs and experiences related to eHealth and care. The results of the qualitative interviews were combined with the 15 principles, which showed that almost all principles were supported by the case study.

The principles were divided into four categories. Two categories, “Focus on the users” and “Ensure ease-of-use”, contain principles which are applicable to most eHealth services. They cover principles which help avoid usability issues and support user-centered methodologies. The other two, “Support self-management” and “Connect patients and professional healthcare”, contain the principles which are specifically for eHealth services designed for the chronically ill. They cover principles which support the independence of patients by enabling self-management but also provide the support of professional healthcare.

The principles should support organizations who do not have resources to conduct large scale user research. They are applicable to cases where the eHealth service is not very specialized for a niche use case and the patients and clinicians do not have unique needs that other chronically ill patients and their clinicians do not share.

Keywords: design principles, chronic disease, eHealth, human-computer interaction, patient experience

The originality of this thesis has been checked using the Turnitin OriginalityCheck service.

TIIVISTELMÄ

Sini Leinonen: Kroonisesti sairaiden potilaiden eHealth-palveluiden suunnitteluperiaatteet
Diplomityö
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Potilaskokemus on merkittävä tekijä kroonisesti sairaiden potilaiden elämänlaatuun vaikuttamisessa. Potilaskokemusta voidaan parantaa tarjoamalla hyödyllisiä ja toimivia eHealth-palveluita. Suunnitteluperiaatteet ohjelmistokehityksessä tukevat hyvien toimintatapojen seuraamista ja yleisien virheiden välttämistä. Jotta eHealth-palvelut tulevaisuudessa tukisivat hyvää potilaskokemusta, selvitettiin ratkaisu tutkimusongelmaan ”Kroonisesti sairaiden potilaiden eHealth-palveluiden suunnittelijoilla ja kehittäjillä ei ole kokonaisvaltaista suunnitteluperiaatelistaa, joka tukee hyvää potilaskokemusta”.

Tutkimus koostui kahdesta osasta. Ensimmäiseksi tehtiin kartoittava kirjallisuuskatsaus artikkeleihin, jotka esittelevät jo olemassa olevia suunnitteluperiaatteita kroonisesti sairaiden potilaiden eHealth-palveluiden suunnittelemisen tueksi. Katsauksessa löydettiin 119 periaatetta 21 artikkelissa, jotka kategorisoitiin 15 uudeksi periaatteeksi. Tämän jälkeen tehtiin empiirinen tutkimus, jossa munuaistautipotilaita (N = 19) ja heitä hoitavia terveydenhuollon ammattilaisia (N = 8) haastateltiin. Teemahaastatteluissa haastateltavilta kysyttiin heidän tarpeistaan ja kokemuksistaan liittyen eHealthiin ja hoitoon. Näiden kvalitatiivisten haastatteluiden tulokset yhdistettiin aiemmin löydettyihin 15 suunnitteluperiaatteeseen, mikä todisti, että empiirinen tutkimus puolsi lähes kaikkia periaatteita.

Periaatteet jaettiin neljään kategoriaan, joista kaksi, ”Keskity käyttäjiin” ja ”Varmista helppokäyttöisyys”, ovat sovellettavissa useimpiin eHealth-palveluihin. Nämä kaksi kategoriaa sisältävät periaatteet, jotka tukevat käytettävyyttä ja käyttäjälähtöistä suunnittelua. Toiset kaksi, ”Tue omahoitoa” ja ”Yhdistä potilaat ja ammattimainen terveydenhuolto”, ovat erikoistuneet kroonisesti sairaiden eHealth-sovelluksiin. Näissä olevat periaatteet tukevat potilaan itsenäisyyttä tukemalla omahoitoa, mutta myös mahdollistavat ammattimaisen terveydenhuollon tuen.

Suunnitteluperiaatteet ovat tarkoitettu tukemaan organisaatioita, joilla ei ole resursseja laajaan käyttäjätutkimukseen. Periaatteet ovat sovellettavissa tapauksissa, joissa eHealth-palvelun käytötarkoitus ei ole kovin epätavallinen. Potilailla ja ammattilaisilla ei myöskään tule olla muista kroonisesti sairaista potilaista ja heitä hoitavista ammattilaisista merkittävästi poikkeavia tarpeita.

Avainsanat: suunnitteluperiaatteet, krooninen sairaus, eHealth, ihmisen ja tietokoneen vuorovaikutus, potilaskokemus

Tämän julkaisun alkuperäisyys on tarkastettu Turnitin OriginalityCheck –ohjelmalla.

PREFACE

Ennen kaikkea haluan kiittää terveydenhuollon ammattilaisia ja erityisesti ihania potilaita, jotka osallistuivat tähän tutkimukseen. Olen oppinut paljon haastattelemisesta, mutta myös siitä, mikä on tärkeää elämässä. Ihailen positiivisuuttanne, joka kestää huonompienkin aikojen yli, mutta ymmärrän myös surut ja vihat, jotka liittyvät kroonisen sairauden kanssa elämiseen. Toivoisin, että voisin auttaa teitä enemmän, ikävä kyllä minusta ei tullut nefrologia, olen liian herkkähermoinen.

Before anything else, I want to thank the clinicians and especially the wonderful patients for taking part to this study. I have gained so much experience not only in interviewing users but in what matters most in life. I admire your positivity even during the harder parts of life with a chronic illness, but I also understand the frustrations coming with it. I wish I could help you more, unfortunately I did not become a nephrologist, I am too squeamish.

Thank you to my family for teaching me the values of both technology and humanities. Thank you to my family and friends for pushing me when I feel like looking at my phone for 19 hours straight rather than writing. Thank you for understanding when I still do it, against your advice. Also, thank you to my dog, Hulda, for making me go out sometimes too.

Thank you to the team at Aalto University. Johanna Kaipio, thank you for supervising this thesis and inspiring me to choose this field via your doctoral dissertation. Kaisa Väänänen, thank you for supervising this thesis and providing much needed non-medical perspective.

Helsinki, 22.4.2021

Sini Leinonen

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SYMBOLS AND ABBREVIATIONS

AKI	acute kidney injury
APD	automated peritoneal dialysis
CAPD	continuous ambulatory peritoneal dialysis
CKD	chronic kidney disease
COVID-19	Coronavirus disease 2019
ESKD	end-stage kidney disease
GDP	gross domestic product
HCI	human-computer interaction
HD	hemodialysis or hemodialysis in a hospital
HHD	home hemodialysis
HUS	Helsinki University Hospital
ICT	information and communication technology
ISO	International Organization for Standardization
PD	peritoneal dialysis
PRE	predialysis
PX	patient experience
SD	hemodialysis in a satellite clinic
UCD	user-centered design
eGFR	estimated glomerular filtration rate
eHealth	the use of ICT for health
mHealth	eHealth on mobile platforms
WHO	World Health Organization

1. INTRODUCTION

“The sum of all interactions shaped by an organization’s culture that influence patient perceptions across the continuum of care” is one definition of patient experience (PX)¹. The importance of PX and patient-centered care has been acknowledged in several countries after the 2013 Francis Report called for “fundamental change in culture” to strengthen patients’ influence in their own care² (Royal College of General Practitioners 2013). Ensuring good patient experience is especially important for chronically ill patients. Their patient experience can even impact their quality of life, since treatment is continuous and contact with the hospital is regular (Wadd et al. 2011).

Sum of all interactions is one part of patient experience (Wolf et al. 2014). A significant number of interactions with the care system happen through digital healthcare or eHealth services (Hyppönen, Ilmarinen 2016), thus improving digital healthcare applications should also improve patient experience. eHealth applications and websites provide information related to health, resources, and services³. Digital healthcare is useful for the chronically ill since it is widely recommended to use eHealth for supporting self-management of chronic illness (Eysenbach et al. 2015). In addition to self-management support, digital health services can cover other needs of chronically ill patients, including delivery systems, clinical decision support, clinical information systems and education (Eysenbach et al. 2015).

eHealth services can affect the work of healthcare professionals, since chronically ill patients are normally in regular contact with clinicians. Digital health applications can be used by clinicians for example, for communication or clinical decision support. The eHealth services, where a patient can directly communicate with a healthcare professional and combining self-management applications and clinician support lead to better patient self-management and self-efficacy (Lancaster et al. 2018). Clinicians have also

¹ The Beryl Institute. Patient Experience 101 - Why?. Available: https://www.theberylinstitute.org/page/PX101_Why [2021, Apr 2]

² Ahonen, H., Asiakas-/potilaskokemus mukana valvonnassa – mistä on kysymys?. Available: <https://www.valvira.fi/-/asiakas-potilaskokemus-mukana-valvonnassa-mista-on-kysymys> [2020, Jun 5]

³ World Health Organization. eHealth at WHO. Available: <https://www.who.int/ehealth/about/en/> [2021, Apr 2]

noted clinical benefits when using these systems with chronically ill patients (Morton et al. 2017).

To guide the design process of eHealth services for the chronically ill and the clinicians responsible of these patients, many different sets of design principles have been created. Because of the amount, overlapping, and different presentation styles of the guidelines, the task of designing a successful eHealth service can still be challenging.

1.1 Objectives and scope

Chronic kidney disease patients need long term treatment and patients with end stage kidney failure can be treated with dialysis. Like for other chronically ill patients, patient experience is a significant factor in the quality of life for kidney disease patients. Chronic kidney disease patients need dialysis treatment if they develop end stage kidney failure⁴. Dialysis treatment is typically needed at least three times a week and it can be done at independently at home, in a satellite clinic or in the hospital⁵. Peritoneal dialysis is only done at home, but hemodialysis can be done in any of the before-mentioned locations. The best option for the patient's wellbeing is often home dialysis, since it can be scheduled flexibly, and the prognosis is better⁶.

CleverHealth Network has started a project consortium eCare for Me, of which goal is to create artificial intelligence (AI) -assisted solutions for several patient groups⁷. One project under the consortium is focused on creating an eHealth application for home dialysis patients⁶. Currently home dialysis in Finland can be complicated for both the patient and the healthcare unit providing the treatment⁷, which affects the patient experience of home dialysis patients. The overall aim is to create application that patients could use already during predialysis stage to recognize if they are suitable for home dialysis and continue to use throughout their dialysis phase. This eHealth application would gather monitoring data, facilitate communication, and manage equipment orders, making home dialysis problem-free for all parties.

⁴ National Kidney Foundation. Dialysis. Available: <https://www.kidney.org/atoz/content/dialysisinfo> [2020, May 6]

⁵ Munuaistalo. Dialyysihoito. Available: <https://www.terveyskyla.fi/munuaistalo/dialyysihoito> [2020, Jun 5]

⁶ CleverHealth Network. Home dialysis. Available: <https://www.cleverhealth.fi/en/development-of-home-dialysis/> [2020, May 6]

⁷ CleverHealth Network. eCare for Me project consortium. Available: <https://www.cleverhealth.fi/en/ecare-for-me> [2021, Apr 13]

In this project, the focus of Aalto University research team is on usability of eHealth solutions and patient experience⁸. Collaborators include Helsinki University Hospital (HUS)⁹, Kaiku Health¹⁰, Gillie.ai¹¹, Intito¹² and others. Kaiku Health is the main developer of the home dialysis support application. Gillie.ai creates AI models that analyze dialysis patients and provide information for health care professionals. Intito is responsible for creating a platform for home dialysis patients to order dialysis supplies.

The two main approaches to design relevant to this thesis, and to the Aalto University project, are human- or user-centered design (UCD) and experience-based design. According to an ISO standard (ISO 9241-210 2019) UCD is an approach to interactive system development that focuses specifically on making systems or applications easy to use. User-centered design process consists of four key activities: understanding and specifying user requirements, understanding, and specifying the context of use, iteration of design solutions and, evaluating the solutions with the users against requirements (McClelland, Suri 2005).

Experience-based design draws from the experiences of firsthand users of systems to form the design (Locock et al. 2014). Experience can be described as “how well people understand it, how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it” (Bate, Robert 2006). Identifying the touchpoints, where the participants interact with a service, makes it possible to design desirable experiences by shaping those moments.

User-centered design focuses on understanding the characteristics and needs of users, while patient-centered design concentrates on patients’ needs. Since experiences are subjective and often invisible to others, they are harder to research than needs and characteristics, which are used in human- or patient-centered design. Experiences cannot be directly observed, thus the basis for experience-based design are stories and storytelling. The main issue with this is that words are only a reconstruction of something that has already happened and the true experience in the moment cannot be encapsulated perfectly. Experience-based design benefits from varying methods that research the

⁸ Aalto University. eHealth in Home Dialysis: Usability and Patient Experience. Available: <https://www.aalto.fi/en/department-of-computer-science/ehealth-in-home-dialysis-usability-and-patient-experience> [2021, Apr 15]

⁹ HUS. Homepage. Available: <https://www.hus.fi/> [2021, Apr 13]

¹⁰ Kaiku Health. Homepage. Available: <https://kaikuhealth.com/> [2021, Apr 13]

¹¹ Gillie.ai. Homepage. Available: <https://www.gillie.io/> [2021, Apr 13]

¹² Intito. Homepage. Available: <https://intito.fi/> [2021, Apr 13]

same narrative, to capture more information than what would be possible with only one method. (Bate, Robert 2006)

This thesis utilizes some of the data collected in the interviews, organized by the Aalto University research team, which were conducted with kidney disease patients and the clinicians responsible for their care. The goal of this thesis is to provide design principles of eHealth services for chronically ill patients and the principles will be based on literature findings and the interview data. Simple and comprehensive list of design principles will support the developers within eCare for Me -consortium and elsewhere to create better eHealth solutions improving the users' patient experience.

1.2 Research questions

The main objective of this thesis is to help design upcoming eHealth applications which are meant for chronically ill patients and the clinicians responsible of their care. Simplest way to aid the developers are the design principles, which are synthesized in this thesis from two research components. These two research components correspond to the research questions and the end goal related to design principles is the main research problem.

RP: Designers and developers of eHealth services for chronically ill patients lack a comprehensive set of design principles that support good patient experience.

RQ1: Based on literature, what design principles exist for designing eHealth services for chronically ill?

Literature is scoped for existing guidelines for designing eHealth services for chronically ill. These instructions go by several different terms, such as principles, guidelines, implications and recommendations and they are of different levels of validation and concreteness. The findings will be summarized as a comprehensive set of design principles, which are presented with their prevalence in the reviewed articles and clear explanations.

RQ2: Based on empirical research, what needs do kidney disease patients and the clinicians responsible of their care have for an eHealth service?

Predialysis patients', dialysis patients, and clinicians' needs for an eHealth application are the subject of the empirical case study. These patients are one subgroup of chronically ill patients, who would benefit from well-designed eHealth applications. The study consists of interviews. The healthcare professionals will be interviewed first and the patients after them. Professionals will be asked about their experiences related to providing

care for kidney disease patients whereas the aim with patients is to form a comprehensive image of their life with the disease. Needs for an eHealth service will be derived from the relevant parts of these interviews.

1.3 Research approach summary

This thesis is divided into a scoping review and an empirical case study. The process is shown in Figure 1: Research approach below.

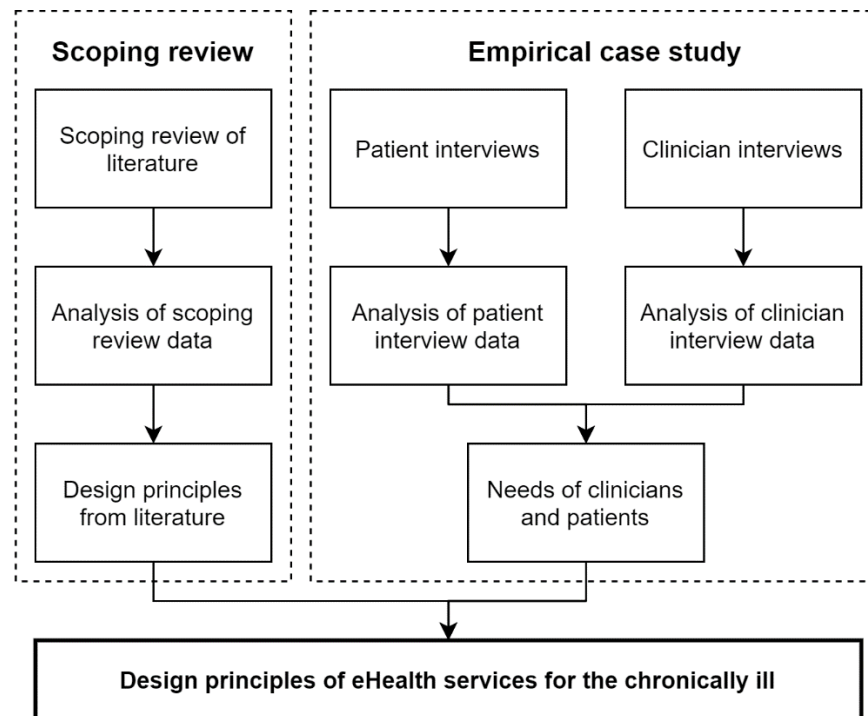


Figure 1: Research approach

The scoping review is focused on finding existing design principles of eHealth services for the chronically ill from literature. A collection of principles will be formed based on the lists presented in the relevant articles found in the review. The principles are then categorized into a new and concise list of guidelines, which will cover all findings from the literature.

The case study is centered around researching eHealth service -related needs of dialysis patients and their clinicians. To understand them, semi-structured interviews are conducted. Both user groups were asked about their tasks related to the care of the kidney disease and experiences of existing eHealth services. Patients were also asked about the strengths and challenges of their current care.

The interview data is then analyzed by coding the interview notes and forming a theory about what needs do the interviewees have for an eHealth service. The results are then divided under the principles from the scoping review, to show whether the case study supports the results of the literature review.

1.4 Structure of the thesis

Chapter 2 provides background about the terms and topics of this thesis, chronic illness, patient experience, eHealth, and design principles. Chapter 3 contains the scoping review and its results. Literature is scoped for current design principles or other similar “sets of instructions” aimed at aiding the design of eHealth solutions for chronically ill.

Chapter 4 is focused on providing necessary background from literature, needed for understanding the themes and subject of the case study. This chapter is mostly medical information about kidney diseases and patients.

Next, in chapter 5, the methods and process of the case study are described. First, theoretical background of methods is presented, then the effect of COVID-19 pandemic on the methodology is explained, and finally the process of clinician interviews, patient interviews, and analysis of the interview data are explained.

Chapter 6 presents the results from the case study. The results about care tasks are divided to matters concerning clinicians’ independent tasks, cooperative tasks, and patients’ independent tasks to showcase which needs concern both user groups and which only one. The results that apply to other themes than care directly is described after.

Chapter 7 combines the results of the scoping review and the case study to form the main contribution of this thesis, a list of design principles of eHealth for the chronically ill. Chapter 8 contains discussion and conclusions, where the answers to the research questions are summarized, the study is evaluated, and future research suggestions are provided.

2. BACKGROUND

This chapter will go over the central terms of the thesis which are needed to understand the scoping review and the case study. First, chronic illness is defined, and the societal impact of chronic diseases is explained. Next, patient experience and the components forming it are introduced. Third, eHealth is defined, and its applications are presented. Finally, this chapter introduces design principles and how they can be used with eHealth.

2.1 Chronic illness

Chronic illness is a disease that lasts for a year or longer and the disease needs regular medical attention or limits activities and daily life¹³. In Finland national illnesses, which are all chronic, include cardiovascular diseases, diabetes, asthma and allergies, chronic lung diseases, cancer, memory disorders, musculoskeletal disorders, and mental health disorders¹⁴. Other chronic illnesses exist, such as chronic kidney disease, but they are not prevalent enough to be considered national illnesses in Finland.

The effects on society caused by chronic illnesses are varied and considerable. Chronic illnesses cause 60% of all deaths worldwide¹⁵, and almost 90% of deaths in high income countries (Busse et al. 2010). All ages can be affected by chronic illness. The most common risk factors for chronic disease are hypertension, tobacco use, high cholesterol, low fruit and vegetable intake, overweight and obesity, sedentary lifestyle, and alcohol abuse (Busse et al. 2010). Chronic illnesses affect the economy negatively, from household and individual level by causing more people to be out of work or less educated, to gross domestic product (GDP) and its growth rate (Busse et al. 2010). The estimates of the negative impact of chronic illness to GDP ranges from 0,02% to 6,77% (Suhrcke 2006).

There are four main strategies within Europe for battling chronic illnesses. A major factor is *prevention and early detection*. Preventative operations mostly target reducing the risk factors, such as tobacco use and obesity. Since chronic diseases increase the complexity of health problems, healthcare providers have needed *new qualifications and care*

¹³ Centers for Disease Control and Prevention. About Chronic Diseases. Available: <https://www.cdc.gov/chronicdisease/about/index.htm> [2021, Apr 2]

¹⁴ Terveysten ja hyvinvoinnin laitos. Yleistietoa kansantaudeista. Available: <https://thl.fi/fi/web/kansantaudit/yleistietoa-kansantaudeista> [2021, Apr 2]

¹⁵ World Health Organization. Integrated chronic disease prevention and control. Available: https://www.who.int/chp/about/integrated_cd/en/ [2021, Apr 2]

settings. Care has improved by *coordinating the strategies* against individual illnesses and by *creating integrated care models* for comprehensive care. eHealth can be integrated into these strategies and it is especially useful for integrated care models. (Busse et al. 2010)

2.2 Patient experience

Patient experience was coined as a term in the early 80's (Kash, McKahan 2017) but during the last decade it has solidified its status as an important part of measuring the quality of healthcare from the patients' point of view (LaVela, Gallan 2014). No clear consensus of a definition has been formed, but the Beryl Institute description of PX "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care"¹⁶ brings to attention the scope of the term, including the whole care path and organization culture.

While patient experience covers the entire care experience, which can last for years and consist of multiple touchpoints with different services and people, user experience is defined as "a person's perceptions and responses that result from the use or anticipated use of a product, system or service" by the International Organization for Standardization (ISO) (ISO 9241-210 2019). This means that all different services offered to the patients have their own individual user experiences, which affect patient experience.

There are nine main factors that affect patient experience, which can be grouped according to Figure 2. The factors and the grouping are adapted from the bachelor's thesis of Sini Hölsä (2019). The stakeholders are a patient who receives care, nursing staff which includes all healthcare professionals involved in the patient's care and a healthcare organization, which manages healthcare facilities and the nursing staff.

¹⁶ The Beryl Institute. Patient Experience 101 - Why?. Available: https://www.theberylinstitute.org/page/PX101_Why [2021, Apr 2]

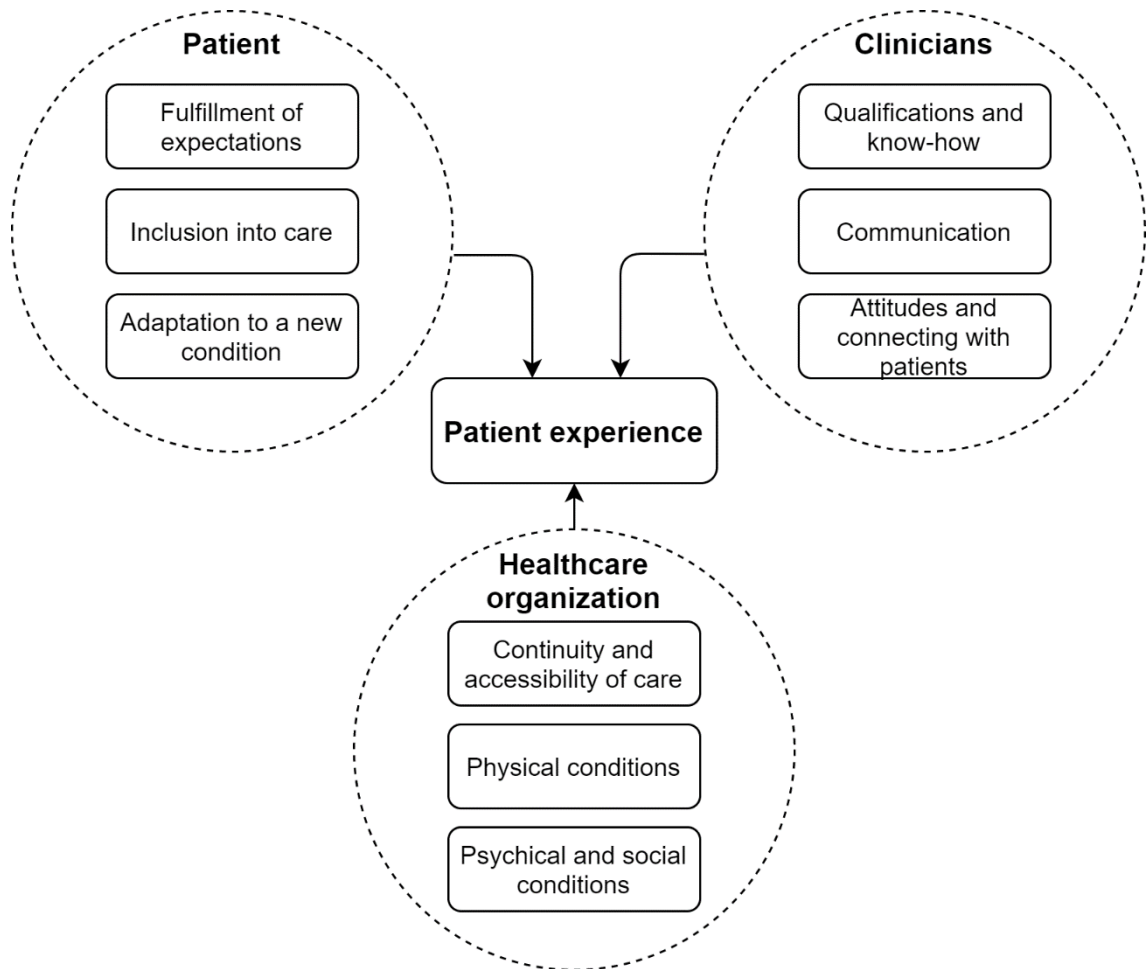


Figure 2: Factors affecting patient experience

When evaluating patient experience from the patient's point of view, it is mostly affected by how well **patient's expectations are fulfilled** (Wolf et al. 2014). The expectations are formed based on previous care experiences¹⁷ and how the nursing staff communicates with the patient throughout their care path (Bowling et al. 2012). Subjects of expectations can include cleanliness of facilities, timeliness of appointments, opportunities to share frustrations and worries and alleviation of symptoms and issues (Bowling et al. 2012), but the subjects which are most important to the patient affect the experience the most (Charmel 2010).

If the patient feels that they can **affect their own care by being included in decision making** and that they informed enough to do so, it affects their patient experience positively (Bleich et al. 2009, Staniszewska, Bullock 2012, Tong et al. 2009). To ensure that

¹⁷ Suomen Lääkäriliitto. Vuorovaikutus potilaan ja lääkärin kohtaamisessa. Available: <https://www.laakariliitto.fi/laakarin-etiikka/potilas-laakarisuhte/vuorovaikutus-potilaan-ja-laa-karin-kohtaamisessa/> [2021, Apr 2]

the patient is included and informed, the nursing staff is required to communicate effectively with the patient (Staniszewska et al. 2014), including explanations of how the treatments will affect the patient's life (Bowling et al. 2012).

Combining an illness, its treatments, and other parts of life, such as family and work is especially difficult for chronically ill patients, but also very important (Wadd et al. 2011). To **adapt to a new condition** the patient must accept their illness (Hagren et al. 2001, Curtin et al. 2002), learn how to live with uncertainties related to their future (Zalai et al. 2012) and organize their life around the required treatments (Wadd et al. 2011).

The **qualifications and know-how of nursing staff** affect how the patient experiences their care (Ojiako et al. 2010). The staff should be able to reduce symptoms, support and calm the patient (Bowling et al. 2012, Foot, Fitzsimons 2011) and ensure the continuity of care (Staniszewska et al. 2014) without unnecessary treatments (Bowling et al. 2012). The nursing staff is required as a communicator between the patient and healthcare facilities (Robinski et al. 2015) and their **communication skills** are more important to the patient's experience than their medical or technical qualifications (Golda et al. 2018). Good communication is built from understandable language and terms (Dawood, Gallini 2010) and engages the patient to the suggested treatment options (Golda et al. 2018). Last nursing staff's responsibilities that affect patient experience are the **attitudes toward patients and ability to connect with the patients** (Ojiako et al. 2010). Patients need to be met with respectful attitudes, humane treatment, empathy, and warmth. This ensures that the patient adheres to their treatment (Mustajoki 2006), provides safety and support in a changing life situation (Zalai et al. 2012) and enables the patient to share their experiences, which results in better care (Vänskä 2016).

Healthcare organizations manage staff, facilities and treatment options and their decisions affect the **continuity** (Tong et al. 2009) **and accessibility of care**. Accessibility depends on the travel times from patients' homes to the facilities. Long distances and changing staff worsen patient experience (McQuoid et al. 2017, Foot, Fitzsimons 2011). The organizations also determine the **physical, psychical, and social conditions of healthcare facilities** (Naidu 2009). Cleanliness, equipment, and how easy the facility is to navigate are parts of the physical condition (Bowling et al. 2012), which affect patient experience directly by answering to patient's expectations and indirectly by impacting the quality of care (Naidu 2009, Ojiako et al. 2010). Well-planned shifts ensure that the nursing staff is not tired or in a rush, which results in appointments being on time (Golda et al. 2018), care personnel being attentive to patients and lessened risk of malpractice

(Glegg, Hoens 2016, Vänskä 2016). Thus, shift distribution, and general working environment affect patient experience through the psychological and social environment in facilities (Glegg, Hoens 2016, Vänskä 2016).

2.3 eHealth

World Health Organization (WHO) defines eHealth as “the use of ICT for health”¹⁸. Recently WHO has adopted “digital health” as a broader category encompassing previously mentioned variants of eHealth and developing areas such as big data, genomics, and artificial intelligence (World Health Organization 2019). For this thesis digital health as a whole is not important, the focus is on eHealth and its specializations. Mobile health (mHealth) is a subset of eHealth (World Health Organization 2019). Where eHealth utilizes ICT in general, mHealth specializes on using mobile wireless technologies (World Health Organization 2019).

eHealth is a commonly used for self-managing chronic illnesses. Chronically ill patients benefit from persuasive design features, which are also used for users seeking to change their lifestyle precautionarily, since chronic illnesses often require diet or exercise changes. eHealth can aid chronically ill patients also by providing remote consultation, monitoring and care with clinicians, e.g. electronic prescriptions. Healthcare providers can also manage the care of chronically ill patients easier by utilizing eHealth in health information systems or by analyzing data for clinical decision-making support. (Barbabella et al. 2017)

The eHealth Enhanced Chronic Care Model (eCCM) encompasses most features which are present in eHealth solutions for chronically ill in addition to the parts of care which happen in a traditional way, face-to-face or in hospitals (Eysenbach et al. 2015). eCCM was extrapolated from Chronic Care Model, which is a well-established and validated framework promoting a comprehensive approach to caring for chronically ill¹⁹. eCCM consists of context of use, categorized features and a complete feedback loop (Eysenbach et al. 2015) and the environments where the model should be applied are community, health systems, eCommunity and eHealth (Eysenbach et al. 2015). The feature categories are self-management support, delivery system design, clinical decision support, clinical information systems and eHealth education. The feedback loop illustrates the

¹⁸ World Health Organization. eHealth at WHO. Available: <https://www.who.int/ehealth/about/en/> [2021, Apr 2]

¹⁹ Improving Chronic Illness Care. The Chronic Care Model. Available: http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2 [2021, Apr 2]

productive interactions between a patient and a practice team, which lead to improved outcomes in terms of care. Patients should be active and informed to be able to participate in their own care and providers should be available quickly to increase patient satisfaction (Eysenbach et al. 2015).

2.4 Design principles

Design principles are instructions for designers and developers, which are created to avoid redoing work that others have already done before. The principles are a collection of knowledge about which design solutions and practices have been the most successful in previous products. The focus and presentation of design principles varies vastly, and many terms are used interchangeably to describe these sets-of-instructions for design. (Fu et al. 2015)

eHealth applications can be used for many different purposes, which is evident from the WHO definition, resulting in varying features and target groups. When thinking about the needs of people who use eHealth for following their daily water intake and the needs of chronically ill patients who use eHealth for self-managing their disease, a conclusion of the needs being vastly different is quickly formed. Since the products in the eHealth field can be almost anything, not many principles, besides general software design principles, can be applied in full to the whole field. As the scoping review in the next chapter shows, several more specific sets of instructions have been introduced for eHealth but none of them have gained enough popularity to guide a significant number of other designers. If an easy to use set of principles would be created for each major type of eHealth applications, it would allow designers to refine the applications. Finetuning, rather than reinventing the basics every time, may improve the quality and usefulness of the products.

3. SCOPING REVIEW OF EXISTING EHEALTH DESIGN PRINCIPLES

As stated in the introduction, one of the research questions for this thesis is “Based on literature, what design principles exist for designing eHealth services for chronically ill?” A scoping literature review was carried out to answer this. The first subchapter introduces the databases and search terms used, 3.2 provides an overview to the findings and the grouping and descriptions of the principles are in chapter 3.3.

3.1 Databases and search terms

The initial literature search was conducted in Scopus, using search phrase combining following terms and their synonyms: *chronic disease*, *eHealth*, *design principles*. Since information technology as a field has progressed quickly during the last few decades, results were limited to the years 2010-2020. Language was limited to English. The search resulted in 261 articles, of which 44 were chosen for detailed review based on their abstracts.

After reading the 44 chosen articles fully, 18 of them were deemed relevant for the scope of this review. The first review demonstrated that some search terms used first weren't useful for the scope of the research, for example *framework* and *model*. It was also noted that “principles” is often replaced by “implications” or “recommendations” in many articles that present similar lists of design instructions. The keywords attached to each relevant article in Scopus were compared and the most common ones were combined to form a new search phrase containing terms *chronic disease*, *design implications*, *design recommendations*, *design principles*, *human-computer interaction*, *disease management*, *eHealth*, *mHealth* and *telemedicine*. The databases that were scoped in the review and the number of articles found in each are presented in Table 1.

Table 1: Databases and articles of the review

Database	Search results	Relevant articles (no duplicates)	Duplicates
Scopus	261	18	First search
ACM	32	1	1
EBSCOHost	1	0	1
ProQuest	29	2	3

Most articles were found in Scopus. Limiting the search terms yielded less results but a slightly larger number of them were relevant for this thesis. Each search after the reformation of the search phrase also resulted in some duplicate articles, that were already found in Scopus.

3.2 Overview of findings

The sets-of-instructions found in the articles were analyzed to find common topics and themes. Types of the design guidelines varied by each author; some gave feature recommendations while some had their focus on design methodology. Another variable was the main chronic illness in focus, especially in the case studies. None of the articles designed a product for chronic kidney disease patients specifically, but end-stage renal disease patients were involved in some of the articles related to multimorbidity.

Altogether there were 119 instructions from 21 articles, meaning that on average each article presented over five design principles. The original principles with the corresponding sources are displayed in Attachment A. The result of analysis is presented below in Table 2, showing topics that covered all principles. Many of the original instructions could have been placed in several categories, especially “explain features, data and care plan” and “visualize data and ensure its interpretability” had a lot of overlap, but the latter covers only visualizations of data, which are entered by user and the explanations related to those. “Support self-management and behavior change” and “support patient activation” also had some overlapping themes but patient activation aims to empower the patient to take control of their own well-being and care, while self-management is more focused on motivational features supporting taking measurements and frequent use.

It is also worthy of noting that some numbers of appearances or frequencies might not be representative of that principle’s importance to the entire field, since some articles didn’t focus on eHealth service design principles as a whole, but on a more specialized part of an eHealth service. This shows mainly in “Support for learnability”, where three of eight instances of the principle came from one article.

Table 2: Results of the scoping review

<i>Design principle</i>	<i>Frequency</i>	<i>Features</i>
1. <i>Use participatory or user-centered methodology</i>	13	Participatory design, user-centered research, patient-centered research

<i>2. Visualize data and ensure its interpretability</i>	13	Numerical data visualized, provide predictions and dependencies, interpretability of data
<i>3. Support self-management and behavior change</i>	13	Motivational features, support and prioritize self-management tasks
<i>4. Make the system usable</i>	10	Miscellaneous usability guidelines
<i>5. Explain the features, data, and care plan</i>	9	Definitions, educational material, credibility
<i>6. Tailor the system for different users or enable personalization options</i>	9	Personalization, tailoring for different user groups
<i>7. Support learnability</i>	8	Familiar features from other systems, tutorial
<i>8. Enable easy data entry, transfer and sharing</i>	7	Sharing data, transfer data to/from the system, automated data entry, minimal effort
<i>9. Enable support structures online and offline</i>	6	Address existing support networks, support for building new relationships
<i>10. Try to combat poor adherence and adoption rates</i>	6	Gamification, useful features for the patient's needs
<i>11. Support patient activation</i>	6	Empower the patient to be an active party in their own care
<i>12. Make the system interconnected with current services</i>	5	Multiplatform use, interconnectivity with existing healthcare information systems and social media
<i>13. Connect healthcare professionals and patients</i>	5	Communication options with professionals, provide user's health data to professionals

<i>14. Provide a care plan</i>	4	Personalized care plan made for the user by professionals
<i>15. Provide information about healthcare professionals' qualifications</i>	3	Aid credibility by explaining healthcare professionals' education background and other qualifications

The methodology used in the articles fell into three categories, a case study, and a literature review (6/21), only a literature review (4/21) and only a case study (11/21). Since the background of the case studies was explained using literature sources, most likely literature and previous research affected the principles created in each article but to a varying degree. It was also noted out of 17 articles involving a case study, 12 specified using some user-centered research and design methods, of which four used participatory design methods.

The review showed that there isn't a clear consensus of which design principles should be followed when designing for chronically ill. There is also a research gap in design principles for eHealth services for kidney disease patients. Most of the articles used user-centered research and design methods, and many of them recommended them in their guidelines for others too. This is considered when the research methods for the case study are decided.

3.3 Grouping and describing the principles

Analysis of the instructions found in the scoping review resulted in 15 design principles. To help understand the relatively large amount of principles, they were thematically grouped into four categories as shown in Figure 3.

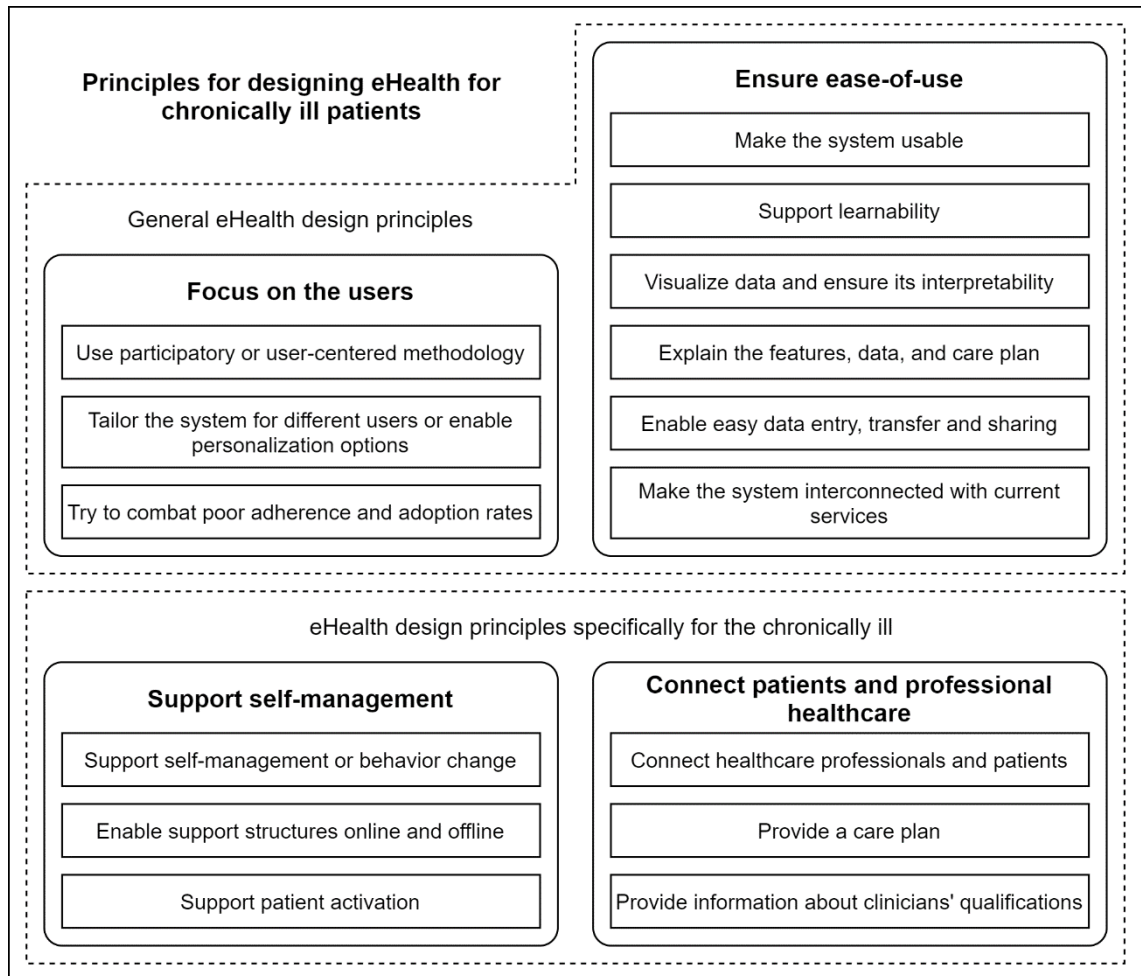


Figure 3: Categories of the design principles

All four categories are applicable for designing eHealth for chronically ill patients and the clinicians responsible for their care. Two categories are general eHealth design principles which are likely useful for most eHealth service projects, whereas two categories are specialized for services where the users are either chronically ill or clinicians who care for chronically ill patients. Some of the principles from “Support self-management” and “Connect patients and professional healthcare” might be also useful for some eHealth services that are not designed specifically for the chronically ill, e.g. when applications that support dieting could benefit from self-management principles. The division between general and specialized principles is not absolute, but still useful to understand the difference of generalizability between these two groups. The categories and principles are discussed in more detail in this chapter.

General eHealth design principle: Focus on the users

The principles within this group promote user-centered design methodologies and answering to the needs of the users. Poor adoption and adherence rates are also combatted by building features that are necessary for the users and by making the service engaging to use.

Use participatory or user-centered methodology

Sources: (Issom et al. 2020, Berg et al. 2018, Miller et al. 2014, Carr et al. 2017, Weiss et al. 2013, Brzan et al. 2016)

A central theme in the articles mentioned above was the importance of knowing the intended users and designing for their needs. In addition to patients and their experiences, medical experts were considered important to involve to the design process, since they are often another end-user group. Modern software development normally calls for involvement of users in the design process, but the articles emphasized the complexity of health-related applications, making user research even more important than in an average software development project. Participatory design specifically, as opposed to general user-centered design, was seen as a solution to get larger part of limited target groups to use the application in addition to providing design suggestions.

Tailor the system for different users or enable personalization options

Sources: (Doyle et al. 2019, Meier et al. 2020, Win et al. 2016, Balatsoukas et al. 2019, Sultan et al. 2019, Brzan et al. 2016, Storni 2014)

In this context, tailoring means customization for a certain user or user group, which is done by the developers or healthcare professionals creating the eHealth application. Personalization is done by the user, but support for it must be programmed into the software. Most of the instructions which this principle is based on were very similar, which was not the case in most other principles. The majority told to consider user's personal needs, meaning that the service would not be entirely the same for all users. Some provided the alternative way to give the user the power to personalize their experience and transform the service to fit their own preferences.

Try to combat poor adherence and adoption rates

Sources: (Berg et al. 2018, Issom et al. 2020, Cafazzo et al. 2012)

These three articles stated that poor adherence and adoption rates are common problems with eHealth applications, but it can be combatted with some design decisions.

Suggestions for growing adoption rates were controlling data flows and implementing disease-modifying functionalities. Controlling data in this context meant that the eHealth service would be made the most practical place to store their health data, by ensuring privacy and interpretability of data but providing easy ways to share their information when needed. Disease-modifying functionalities include features that support pain relief and other parts of disease self-management.

Poor adherence should be considered throughout the design process. Existing design theories, such as gamification, should be utilized to increase adherence from the beginning of the process. Targeted information helps the patient to understand the system at their own health literacy level, while teaching them more about self-managing their disease. This should help the patient's long-term interest in using the service, since the application isn't too complicated while being useful.

General eHealth design principle: Ensure ease-of-use

This category contains principles that focus on general usability which should be ensured in all software development projects, such as responsiveness and good error-handling. Additionally, this group covers the user-friendliness of general eHealth features, such as data handling and presentation. These features are not specific to eHealth services of chronically ill patients, for example an application that tracks the user's activity also needs to present the activity data clearly.

Make the system usable

Sources: (Miller et al. 2014, Grandhi, Osatuyi 2018, Cafazzo et al. 2012, Anokwa et al. 2012, Cooley et al. 2018, Win et al. 2016, Carr et al. 2017, Balatsoukas et al. 2019)

This principle is a collection of miscellaneous usability-focused suggestions from the articles above. When designing the service, what-if questions should be explored to avoid errors for end users. The system should be reliable, fast, and responsive, even in cases where the internet connection is not particularly fast or stable. The interface should be easy to interact with, support multimodality and be visually pleasing. No mechanic should be over-emphasized to avoid numbing the users.

Support learnability

Sources: (Jalil et al. 2014, Balatsoukas et al. 2019, Anokwa et al. 2012, Miller et al. 2014, Brzan et al. 2016)

Learnability combats complexity. None of the instructions this principle is based on called directly for learnability, but all suggestions do relate to making the application easier to learn. Familiar features, such as internet browser and familiar metaphors, like windows were recommended. Touchscreens are usually easy to learn, especially when combined with minimal, large, and consistent widgets. A tutorial for beginners is helpful if it is designed well. When building support for learnability, developers should avoid removing mechanics or features, especially without informing the users, since it will force the users to learn new use patterns.

Visualize data and ensure its interpretability

Sources: (Jalil et al. 2014, Carr et al. 2017, Brzan et al. 2016, Balatsoukas et al. 2019, Cafazzo et al. 2012, Win et al. 2016, Meier et al. 2020, Anokwa et al. 2012)

These articles underlined the importance of visualizing data, rather than presenting it in a numerical format. Graphs, dependencies, predictions were suggested as form of data presentation. Visual data should make the information more interpretable, but data interpretability was mentioned a few times without bringing up visualization with it too. Other ways to clarify numerical data are overviews, interaction with parameters and visualizations, and variety of information summary types.

Explain the features, data, and care plan

Sources: (Carr et al. 2017, Balatsoukas et al. 2019, Cooley et al. 2018, Brzan et al. 2016, Win et al. 2016, Meier et al. 2020, Issom et al. 2020)

eHealth services are often complex, which means that the system should be as easy to understand as possible, with little outside instruction. To achieve this, features and data should be explained within the application. Many systems provide the user with some sort of plan of care, which shouldn't be hidden and the medical concepts it is based on need to be explained. Additionally, all medical information and guidance must be up-to-date and backed up by credible sources.

Enable easy data entry, transfer and sharing

Sources: (Ekberg et al. 2010, Brzan et al. 2016, Anokwa et al. 2012, Alharbey, Chatterjee 2019, Carr et al. 2017, Cafazzo et al. 2012)

This principle discussed the design of data-related operations. Most importantly, data should be easy to add into the system. Automation, by synchronizing devices or by

providing alternative input methods to typing, such as voice entry or image recognition, ease input processes. In addition to making the process easier, the system should make it faster than the previous method the user used. To achieve this, the data handling operations should avoid repetition.

Since many eHealth applications are used for self-managing diseases that require regular check-ups by healthcare professionals, sharing or transferring data is very important. If the medical experts do not have access to the application and the patient's data, the information should be transferable out of the application. On the other hand, some eHealth applications use motivational features such as goals, which are more effective if the patients' achievements can be shared in social media or to chat applications.

Make the system interconnected with current services

Sources: (Brzan et al. 2016, Issom et al. 2020, Grönvall, Verdezoto 2013, Berg et al. 2018)

Interconnectivity to existing services makes the new system easier to use. If the service is connected to the patient's electronic health record, healthcare professionals can follow patient's data without having to adapt to new interfaces and patients do not need to export their data manually. Compatibility with many platforms and operating systems ensures that the application is accessible to as many users as possible. If the system is connected to any external software, privacy and safety should be ensured. This is especially important to consider if the service is to be integrated into social media.

eHealth design principles specifically for the chronically ill: Support self-management

Supporting self-management of chronic diseases is one of the most important tasks of eHealth, as discussed in chapter 2. The principles within this category aim to enhance the effectiveness of eHealth for this task. Additionally, the patients' independence from clinicians and healthcare organizations is aided by enabling support structures.

Support self-management and behavior change

Sources: (Grandhi, Osatuyi 2018, Balatsoukas et al. 2019, Ongwere et al. 2018, Doyle et al. 2019, Brzan et al. 2016, Cooley et al. 2018, Miller et al. 2014)

The articles mentioned here instructed the developers of eHealth applications to prioritize self-management activities and support behavior change features. The instructions

that formed this principle were more focused on individual features than most others. Recommended features were alerts, tips, monitoring different parameters, such as weight or blood pressure, forums, social networks, and other motivational functions.

In addition to general advice of including self-management, some articles gave more specific advice. The applications should teach the patients how to self-manage and the mechanics should support rather than undermine the patient's effort to manage their disease. Undermining can happen if the system is too complex, but if self-management activities are prioritized, this can be avoided.

Enable support structures online and offline

Sources: (Ekberg et al. 2010, Weiss et al. 2013, Ongwere et al. 2018)

These three articles found in the scoping review recommended providing different support features online. Support is vital in many ways for chronically ill patients. Treatments and symptoms might last the patient's entire life, which can be scary for newly diagnosed people especially. Firsthand knowledge from peers can dissolve fears and set an example of success. In addition to providing peer support structures, building in connections to medical professionals can also help patients, especially with care information. eHealth services should also in some way consider the real-world support structures patients already have, such as family, other patients and friends and not undermine those connections.

Support patient activation

Sources: (Cooley et al. 2018, Grönvall, Verdezoto 2013, Carr et al. 2017, Alharbey, Chatterjee 2019, Storni 2014)

For eHealth interventions to be effective, the patient needs to be empowered to take responsibility and interest of their own health. The patient should be activated to seek information about treatments and their own wellness. eHealth services can provide education and health data analyses which can assist the patient's control of their health. Additionally, the patient should be encouraged to be involved in the design of eHealth services and their care plan within the application.

eHealth design principles specifically for the chronically ill: Connect patients and professional healthcare

The previous group of principles promoted the independence of the patients whereas this group aims to provide support from professional healthcare from organizational level to individual clinicians. Even though the independent self-management is important, patients should know what their care plan is and who the clinicians using the service and caring for them are. Patients and clinicians should also be able to contact each other when there is a need, e.g. for medical questions or routine tasks such as renewing prescriptions.

Connect healthcare professionals and patients

Sources: (Balatsoukas et al. 2019, Alharbey, Chatterjee 2019, Cooley et al. 2018, Ongwere et al. 2018, Sultan et al. 2019)

Chronic illnesses usually require regular contact with healthcare professionals for check-ups. If the patient can discuss their health data or symptoms with a nurse, a doctor, etc. within the service, their issue might be solvable without a visit to the clinic. This might motivate the patient to use the eHealth service and it is a cost-effective option for healthcare providers compared to clinic visits.

Provide a care plan

Sources: (Ongwere et al. 2018, Ekberg et al. 2010, Grandhi, Osatuyi 2018)

The individual situation of each patient varies. Their illness can be severe or mild, progress in varying speeds, be affected by other conditions and so on. The patient might have other limitations which alter their treatment plan, for example a diet choice. Because of this variance, the patient benefits from a personalized care plan, which either considers their used eHealth services or is centered only on them. The care plan must be made by a healthcare professional to ensure quality of care. A care plan can also help understand why the patient is asked to do certain things, for example follow their blood pressure, which in turn can help them be motivated to keep using the eHealth application.

Provide information about healthcare professionals' qualifications

Sources: (Ekberg et al. 2010)

If an eHealth service involves healthcare professionals, the patients should know their official titles and education if it is unclear from context. Some patients might be more

suspicious of advice if it is not clear that it is provided by educated healthcare professionals, rather than from software developers or others. When information is clearly sourced, it is easier to gain the trust of the users.

4. CASE STUDY BACKGROUND

This chapter focuses on explaining the necessary theoretical background required to understand the subjects and themes of the interview research. Clinical background of the patients from the disease to different forms of treatment will be introduced along with factors affecting their patient experience. The study at Aalto University, of which these interviews were part of, was conducted to support the development of eHealth services for kidney disease patients by collecting qualitative data about the needs related to eHealth of the patients and clinicians. In this thesis the data is used to generalize the principles emerging from the literature to be applicable to kidney disease patients also. The patient experience of kidney disease patients and other chronically ill will also be compared to highlight the differences and why the case study is necessary.

4.1 Kidney diseases and their societal impact

Usually kidneys remove surplus liquid and control fluid osmolality, acid-base balance, various electrolyte concentrations and removal of toxins²⁰. The function of kidneys can suffer because of a chronic kidney disease or an acute kidney injury. Acute kidney injury (AKI) is most often caused by reduced blood flow to kidneys²¹ but can also result from damage to kidney tissue or urinary tract obstruction²². The diseases and factors that result to mentioned causes include, but are not limited to, major surgeries, severe infections, medication, and heart attack²³.

If AKI is diagnosed in its early stages, treatment options include fluid therapy and removing the causes for the conditions, for example quitting harmful medication or removing urinary tract obstructions. Less than 10% of acute kidney injuries are severe enough to require dialysis treatment either temporarily or permanently.²¹

Chronic kidney disease (CKD) changes the structure and function of kidneys irreversibly over a long period of time, from months to years (Webster et al. 2016). Several different

²⁰ Munuaistalo. Dialyysihoito. Available: <https://www.terveyskyla.fi/munuaistalo/dialyysihoito> [2020, Jun 5]

²¹ Saha, H. Äkillinen munuaisten vajaatoiminta. Available: <https://www.terveyskirjasto.fi/dlk00854> [2021, Apr 2]

²² Munuaistalo. Mitä akuutilla munuaisvauriolla tarkoitetaan?. Available: <https://www.terveyskyla.fi/munuaistalo/akuutti-munuaisvaurio/mit%C3%A4-akuutilla-munuaisvauriolla-tarkoitetaan> [2021, Apr 2]

²³ Munuaistalo. Akuutin munuaisvaurion riskitekijät. Available: <https://www.terveyskyla.fi/munuaistalo/akuutti-munuaisvaurio/akuutin-munuaisvaurion-riskitekij%C3%A4t> [2021, Apr 2]

diseases may lead into CKD, such as diabetic nephropathy or polycystic kidney disease²⁴. Diagnosis is often made in routine check-ups or after the disease progresses, since in early stages the patients are often nearly asymptomatic of their CKD (Webster et al. 2016). Symptoms result from uraemic retention solutes accumulating in the body, creating uraemic toxins which cause biochemical and physiological effects, such as itches and cramps, shortness of breath, cognitive changes, and several gastrointestinal abnormalities (Webster et al. 2016). Acute kidney injury has similar symptoms²¹.

The prevalence of CKD varies by country, in Finland 5—10% of population is affected (Webster et al. 2016). Chronic kidney disease, that has progressed to a state, where the patient's kidneys retain only 10—15% of normal kidney function, is called end-stage kidney disease (ESKD) and over any five-year period under 2% of those affected with CKD develop ESKD (Webster et al. 2016). AKI and CKD are closely linked, underlying CKD is a risk factor for AKI and individuals who suffered dialysis-requiring AKI are vulnerable to CKD and ESKD, latter requiring long-term dialysis or a kidney transplant (Hsu, Hsu 2016). 0,1% of the population of Finland were in dialysis treatment for ESKD (1 987 patients) or had received a kidney transplant (3 203 patients) at the end of year 2019 (Helve et al. 2021)

The societal impact of dialysis and kidney transplant patients in Finland is notable. Even though the prevalence is not very high, the cost of active care is over 100 million euros in a year. The mortality of severe kidney diseases is also high, the survival rate of patients in active care (dialysis or kidney transplant) after 5 years is only 60%. On the other hand, the risk of premature death of patients in active care has decreased by 40% since 2000, because of increased quality of care. These factors underline the importance of developing better and more affordable care for kidney disease patients, which can be achieved as proven by previous successes at reducing mortality rate. (Helve et al. 2021)

4.2 Clinical pathway and treatment options of kidney disease patients

Clinical pathway is a multidisciplinary plan of care for a specific clinical problem consisting of steps with timeframes or criteria-based progression and it transforms accepted guidelines of care into local structures (Kinsman et al. 2010). Presenting the clinical pathway of kidney disease patients helps understand the impact of the disease to everyday

²⁴ Saha, H. Krooninen munuaisten vajaatoiminta (uremia). Available: <https://www.terveyskirjasto.fi/dlk00587> [2021, Apr 2]

life and all the treatment options. The steps and criteria for progression in clinical pathway of kidney disease patients in Finland corresponds well to international Chronic Kidney Disease Evaluation and Management Guideline (Levin et al. 2013), making it a good example.

Patients are often asymptomatic and kidney diseases are found in regular check-ups, where a possible sign of a kidney disease is found. The patient will be referred to further testing. Examinations for chronic kidney disease start with blood work and urine samples, followed by ultrasonography of kidneys and in some cases a kidney biopsy. If abnormalities are found and chronic kidney disease is diagnosed, the patient will be sent for further treatment to a nephrology unit.²⁵

After diagnosis, risk factors connected to kidney diseases will begin to be treated conservatively. Conservative treatment includes medication, nutrition therapy and a healthy lifestyle. Medication is used to ease symptoms, slow the advancement of kidney failure and to treat causes of cardiovascular diseases, which also predispose the patient to kidney failure. Kidney patients should not eat substances that poorly functioning kidneys cannot filter out, such as potassium and phosphorous. Also, eating habits that reduce the risk of cardiovascular diseases are also beneficial for kidney disease patients. Quitting smoking, exercising, taking care of hygiene to avoid infections are the most important actions in a healthy lifestyle for kidney disease patients.²⁶

4.2.1 Predialysis

If it is known that the patient's kidney disease will progress to stage where they need dialysis, the patient will be moved into predialysis phase. This usually happens when the kidneys retain only 20% of their functionality. Predialysis includes conservative care of the disease but also preparatory actions for eventual dialysis. The aim is that the patient chooses their dialysis type when it is estimated that they will need dialysis within a year. Dialysis does what normally functioning kidneys should do; remove both toxins and excess liquid and control acid-base balance. There are two types of dialysis, peritoneal dialysis (PD) which is only done at patient's home and hemodialysis (HD) which can be

²⁵ Munuaistalo. Miten munuaistauti todetaan?. Available: <https://www.terveyskyla.fi/munuaistalo/tieto-munuaistaudeista/miten-munuaistauti-todetaan> [2021, Apr 2]

²⁶ Munuaistalo. Elämää munuaistaudin kanssa. Available: <https://www.terveyskyla.fi/munuaistalo/krooninen-munuaistauti/el%C3%A4m%C3%A4-munuaistaudin-kanssa> [2021, Apr 2]

done at home, at locations for independent dialysis or in a hospital by healthcare professionals. The choice of dialysis form depends on the patient's independency and lifestyle, including work, social network, travels, studies.²⁷

In case the patient chose peritoneal dialysis, catheterization will be done 3-4 weeks before the first dialysis. If needed, dialysis can begin right after the surgery too. For hemodialysis a vascular fistula is needed and unlike for peritoneal dialysis, the surgery must be done 4-6 weeks before dialysis. In some cases, where urgent dialysis is needed, hemodialysis can be executed through a central venous catheter. Hemodialysis can also utilize a graft and a temporary or permanent hemodialysis catheter.²⁷

In case the condition worsens to a stage where estimated glomerular filtration rate (eGFR), which measures kidney functionality, is less than 10 ml/min and the patient has symptoms related to kidney failure, active treatment, dialysis and sometimes a kidney transplant, is needed concurrently with conservative treatment. If the patient's overall condition is poor because of other serious illnesses and dialysis would only worsen their life quality, even end-stages of kidney disease can be treated conservatively, without dialysis or transplant.²⁷

4.2.2 Peritoneal dialysis

Peritoneum is a membrane lining the abdominal cavity and covering the abdominal organs²⁸. Peritoneum is semipermeable, which makes it utilizable as an artificial kidney²⁹. During the dialysis, dialysate is infused through the peritoneal catheter to the abdominal cavity for varying amounts of time and then drained out repeatedly. Toxins and excess liquid will move through the peritoneal membrane to the dialysate, removing them from the patient's body (Ellam, Wilkie 2015). The dialysis is either automated (automated peritoneal dialysis, APD), where the dialysis device autonomously executes the dialysis while the patient is sleeping, or assisted (continuous ambulatory peritoneal dialysis, CAPD), where the patient changes the dialysate bags by hand²⁹.

²⁷ Munuaistalo. Dialyysiin valmisteleva hoito (predialyysi). Available: [https://www.terveyskyla.fi/munuaistalo/dialyysihoido/dialyysiin-valmisteleva-hoito-\(predialyysi\)](https://www.terveyskyla.fi/munuaistalo/dialyysihoido/dialyysiin-valmisteleva-hoito-(predialyysi)) [2021, Apr 2]

²⁸ Merriam Webster. Peritoneum. Available: <https://www.merriam-webster.com/dictionary/peritoneum> [2021, Apr 2]

²⁹ Munuaistalo. Vatsakalvodialyysi eli peritoneaalidialyysi. Available: <https://www.terveyskyla.fi/munuaistalo/dialyysihoido/dialyysi-kotona/vatsakalvodialyysi-eli-peritoneaalidialyysi> [2021, Apr 2]

Peritoneal dialysis is always done at the patient's home, another private location, such as travel destination or assisted e.g. in a nursing home, but not in the hospital. The dialysis has a lower impact in the patient's life than dialysis in an institute, since the APD can be done while the patient is sleeping and CAPD isn't limited to locations where the patient has access to a dialysis machine, meaning they can do it anywhere. Patients do need to visit a clinic for control check-ups and take responsibility of their care at home, which can be taxing to some people. The most common complications are related to constipation, which impairs the functionality of the catheter. The surrounding skin of the catheter output can get infected, which is treated with antibiotics. The most serious complication is peritonitis, which often results in temporary hospitalization.²⁹

4.2.3 Hemodialysis

In hemodialysis the patient's blood is directed through a dialyzer in a dialysis machine, which filters out toxins. Hemodialysis is a flexible treatment option, since in addition to being able to utilize several different vascular accesses, in Finland it is used in hospitals for patients who need full assistance, in clinics where the patient operates independently and at home.³⁰

Hemodialysis does not restrict patient's life much, except for the time requirement. The patient can even travel if they plan the trip beforehand and ensure that there is a hemodialysis clinic close by. The vascular fistula or venous catheter can cause some issues, such as stenosis or infections. Complications related to infections can be minimized by taking care of hygiene carefully.³⁰³⁰

4.3 Dialysis patient experience

Chapter 2.2 discussed what determines patient experience. The patient experience of kidney disease patients varies through the three main phases of care, diagnosing the disease, conservative care, and active care. The life of kidney disease patients differs the most from other chronically ill patients during active care, when they need dialysis treatment. This chapter further analyses what defines the patient experience of dialysis patients. According to Hölsä (2019), out of those determinants the most relevant for patients in active care are *adaptation to a new condition, inclusion into care and communication*.

³⁰ Munuais- ja maksaliitto. Hemodialyysi. Available: <https://www.muma.fi/sairaudet/munuaiset/dialyysihoito/hemodialyysi> [2021, Apr 2]

Patient's lifestyle might change drastically when their illness progresses to a stage requiring dialysis. Dialysis treatment itself takes several hours off the patient's week, which sometimes causes early retirement. End-stage kidney disease often has more severe symptoms, which affect the patient's life. These changes require capability to *adapt to a new condition*.³¹(Hölsä 2019)

Kidney disease treatment options are varied. The choices between peritoneal dialysis and hemodialysis, home dialysis and dialysis in other locations and different forms of conservative treatment are important. If the patient is *included into decision making related to their care*, their patient experience is enhanced. (Hölsä 2019)

The importance of *communication* with healthcare professionals is especially important during active care, when the patient is often responsible of their own care. The healthcare professionals need to give clear instructions to the patients, to ensure that they will feel informed enough. The availability and accessibility of communication channels with the healthcare professionals also affect how the patients experience their care. (Hölsä 2019)

³¹ Munuaistalo. Dialyysihoito. Available: <https://www.terveyskyla.fi/munuaistalo/dialyysihoito> [2020, Jun 5]

5. METHODS AND PROCESS OF THE CASE STUDY

This chapter is an introduction to the methods used in the case study, which collects experiences of kidney disease patients related to their care now and in the past. Chapter 5.1 presents the theoretical background behind the methods, 5.2 describes which changes had to be made because of the COVID-19 pandemic, 5.3 explains the recruitment process, 5.4 describes the clinician interview process, 5.5 explains the patient interview process, and 5.6 describes how the interview data was analyzed.

5.1 Theoretical background of methods

The methods used in the case study are grounded in user-centered and experience-based design frameworks introduced in chapter 1. First, the different qualitative interview methods are introduced, then visual timelines and customer journeys and lastly, the process of qualitative data analysis is described.

5.1.1 Qualitative interviews

Qualitative interviews are one of the most used research methods in the field of human-computer interaction (HCI) since qualitative data of users' experiences and needs is essential in most HCI design projects (DiCicco-Bloom, Crabtree 2006). Interviews can be divided into three types, structured, semi-structured and unstructured (Wilson 2014). Since structured interviews mostly produce quantitative data, they will be excluded from further examination.

Semi-structured interviews are based on themes or broad questions that are preplanned (Wilson 2014). The interviewer needs to improvise new questions related to the interviewees' answers during the session. The predetermined questions guide the interviewer to cover all the necessary bases that are needed for the research. The lack of strict question structure allows the interviewer to probe deeper into subjects that emerge during the discussion (Qu, Dumay 2011). Semi-structured interviews should be used when there is enough knowledge about the topic that some questions can be formed but finer details are missing (Wilson 2014). In user experience studies, they can be used at any point of product development (Qu, Dumay 2011).

In unstructured interviews there are no preplanned questions and the interview is close to a natural conversation, that is guided by the interviewer (DiCicco-Bloom, Crabtree 2006). The topic is known beforehand, but the questions differ by each interviewee. The goal of the interviewer is to get the other person relaxed, which should result in honest answers (Wilson 2014). Unstructured interviews are most useful when there is little knowledge about the perceptions of the interviewee (Wilson 2014). For example, when first impressions of a product are being gathered or a very personal topic is being explored, the unstructured interview method is at its best.

Semi-structured interview method has most of the strengths of both structured and unstructured interviews. Since the interviewer can prepare themes and broad questions beforehand, it is likely that all the interviews cover the same topics. This helps making the results comparable with each other and the data can be used to form conclusions of consensus among the interviewees. Semi-structured interviews aim to capture a comfortable two-way conversation feeling, while still being thorough and methodical by covering the necessary topics. Unstructured interviews are better than semi-structured interviews for exploring difficult topics if there is no knowledge of it beforehand and for invoking a natural conversation -feeling. On the other hand, unstructured interviews do not produce data that can be used to form consensus conclusions. Semi-structured and unstructured interviews both require the interviewer to be skilled to avoid forming questions that are suggestive and result all the interviewees answering the same way.

5.1.2 Visual timeline and customer journey

Timeline methods are used to organize significant life events chronologically to help participants form clear narratives (Berends 2011, Patterson et al. 2012). Visual timeline gives the participant freedom to share their experiences in their own way, while organizing their thoughts related to the events (Bagnoli 2009). The timeline can be filled in with not only text, but also drawings, colors, stickers, etc. which gives the participant freedom to express themselves in ways that they feel comfortable with. Timelines enable rich and unique explorations of data (Mannay 2010, Mannay 2016) and they capture the meaning and context attached to significant life events better than traditional qualitative interviews (Leung 2010). This makes the method especially useful for illustrating participants' narratives of their journeys (Sheridan et al. 2011).

Customer journey conceptualizes customer's experience with an organization during a purchase cycle across multiple touchpoints (Meyer, Schwager 2007). Patient journey is a customer journey in a hospital context, which consists of touchpoints where patient

and provider share action and information using person-to-person communication or system-hosted communication (Gualandi et al. 2019). Analysis of a patient journey, illustrated in a visual timeline, can show which touchpoints affect the patient experience positively and negatively. Experience-based designers utilize these recognized touchpoints by transforming the negative moments to positive and strengthening the positives (Meyer, Schwager 2007).

In addition to providing better context to experiences, timelines conquer other common issues related to more traditional qualitative research methods. Visual timelines can lessen the power imbalances between interviewer and interviewee, which are often an issue in interviews. Empowering the interviewee by giving them freedom of choice of how they choose to share their journey, shifts the power balance towards the interviewee while also facilitating interactivity and enriching the context. (Gualandi et al. 2019)

5.1.3 Analysis of qualitative data

The interpretation and analysis of qualitative data are always susceptible to subjectivity (Lazar et al. 2017). By following a well-tested process when analyzing the data, a large part of the subjectivity can be eliminated, and the results will be more accurate. Qualitative analysis consists of three stages (Corbin, Strauss 2015). First, there is a data set which contains information about a topic, whose main components should be identified after via analysis. After this, the components are studied to understand their nature and the relations between them. Finally, the knowledge gained from analyzing individual components is used to better understand the original topic and make deductions about it.

If the research topic is new and there is no literature with established theories, emergent coding approach, based on grounded theory, must be used (Lazar et al. 2017). Grounded theory, first introduced in 1967 (Glaser et al.), is an inductive research method, where research starts with data and the aim is to develop a well-grounded theory from it. Traditionally, research starts with a theory and data collection phase aims to prove it. Grounded theory operates the opposite way. To ensure that the theory truly emerges from the data itself, researches should analyze it with a creative and open mind. More detailed process guidelines haven't been agreed upon since some think that guidelines limit the analysis process and hinder the creation of the theory (Lazar et al. 2017). Strauss and Corbin (2015) have suggested procedures which are widely followed, even though there is much opposition (Lazar et al. 2017).

The procedure, which follows grounded theory, introduced by Strauss and Corbin consist of four steps: open coding, development of concepts, grouping concepts into categories and formation of a theory. In the open coding stage, the content is read through to recognize patterns or phenomena. Each of these interesting issues are given a name or code. If the codes emerge directly from the data, the procedure is called in vivo coding. Other code-naming option is “researcher-denoted concepts”, where the researcher finds a descriptive word to describe the phenomenon seen in the data. (Corbin, Strauss 2015)

In the second stage codes are grouped into higher level concepts, which are then further grouped into categories in the third stage. In the final stage the aim is to create explicit causal connections and correlations between the concepts found in the data to form a theory. The analysis process is often iterative, where even after creating the theory, the researcher might have to go back to coding to see the data from the perspective of the newly created theory. (Corbin, Strauss 2015)

5.2 Effect of COVID-19 pandemic on the methodology

During the preparation and planning phase of the project Coronavirus disease 2019 (COVID-19) spread to Finland³². To hinder the spread of the pandemic and to protect the patients, HUS prohibited visitors to their hospitals³³ and stopped the recruitment of their patients for research projects. The national guidelines in Finland aligned with this, asking to limit social contacts, work remotely and that people in risk groups would stay at home if possible³⁴. Starting from August 2020, recruitment ban was limited to research that could not be done remotely. Our empirical research was converted to be organized entirely remotely.

Trust is harder to form when the interviewer and interviewee are not face-to-face (Shuy 2002, Hermanowicz 2002), which impacted our entire process and way of communicating with the interviewees, especially with the patients. To help form a trusting relationship between the interviewer and interviewee, the interviewees were called on the phone after recruitment. Phone calls are more intimate than consent and information forms and calling allowed us to introduce the project and the research team more personally. The

³² Terveiden ja hyvinvoinnin laitos. Tilannekatsaus koronaviruksesta. Available: <https://thl.fi/fi/web/infektiotaudit-ja-rokotukset/ajankohtaista/ajankohtaista-koronaviruksesta-covid-19/tilannekatsaus-koronaviruksesta> [2021, Apr 3]

³³ HUS. Ohjeita potilaille ja vierailijoille. Available: <https://www.hus.fi/potilaalle/Sivut/Ohjeita-potilaille-ja-vierailijoille.aspx> [2020, Jul 7]

³⁴ Valtioneuvosto ja ministeriöt. Tietoa ja neuvontaa koronaviruksesta. Available: <https://valtioneuvosto.fi/tietoa-koronaviruksesta> [2021, Apr 3]

calls also permitted the patients to ask any questions they would have kept to themselves if not prompted by us. To accommodate to the likely technical difficulties during the already tight interview timeslot, we introduced preliminary assignments. The patients filled in the visual timelines beforehand and the clinicians filled in general care path of their patients. The assignments were discussed together during the interview.

5.3 Recruitment of clinicians and patients

In the clinician interviews the goal was to get a comprehensive but small sample of clinicians with different expertise. Altogether eight clinicians were interviewed, of which two were nephrologists and six were nurses, whose information is presented in Table 3 below.

Table 3: Clinician information

Identifier	Profession	Patients' dialysis
C1	Nephrologist	HHD
C2	Nephrologist	SD
C3	Nurse	PD
C4	Nurse	HHD
C5	Nurse	PRE
C6	Nurse	HD
C7	Nurse	SD
C8	Nurse	SD

The first column are the identifiers later used with the quotes in chapter 6. The second column is their profession and the third one shows which patients the clinician is responsible for (hospital hemodialysis (HD), home hemodialysis (HHD), peritoneal dialysis (PD), satellite hemodialysis (SD), and predialysis (PRE)). The clinicians were recruited by a HUS research nurse. On the permission of the clinicians, their email addresses were given to our team, which we then used to contact the healthcare professionals to schedule the interview. HUS internal mail was used to send back the consent forms and other attachments, which were then given to us by the research nurse.

The patients were again recruited with the aid of HUS research nurses. The nurses contacted patients, who were already taking part to HUS's own research related to smart

devices in dialysis care. The 19 recruited patients were from four different treatment options: six peritoneal dialysis patients, three home hemodialysis patients, five satellite clinic hemodialysis patients and five predialysis patients. Their information is presented in Table 4 below.

Table 4: Patient information

Identifier	Sex	Age (years)	Dialysis
P1	Female	> 60	PD
P2	Male	30-60	SD
P3	Female	> 60	PRE
P4	Male	> 60	SD
P5	Female	30-60	PRE
P6	Male	> 60	PRE
P7	Male	> 60	PD
P8	Female	> 60	PRE
P9	Male	30-60	PD
P10	Male	> 60	PD
P11	Male	30-60	PD
P12	Female	> 60	SD
P13	Male	> 60	SD
P14	Male	> 60	PRE
P15	Male	30-60	HHD
P16	Male	> 60	SD
P17	Male	> 60	HHD
P18	Female	30-60	HHD
P19	Male	> 60	PD

The first column are their identifiers, second and third columns show their sex and age group and the fourth one is their treatment option.

During the patient recruitment phase, all data from HUS to Aalto was pseudonymous, meaning that no patient names were exposed to us before consent forms were signed. When a patient showed interest to participate, an information handout and a consent form were delivered to the patient. If the patient decided to take part to the research, they sent the filled form to the Aalto University research team by mail, making the patient a verified participant.

Next, the patients were called. Phone calls were added to the process after safety measures related to COVID-19 pandemic transformed the interview process to be organized remotely. Phone calls provided a moment to introduce the project and the team personally. Personal contact was hoped to make it easier for patients to contact us if they had questions and to form trust and familiarity. The interviews were also scheduled in during the call.

The preliminary assignment of the patients was mailed to them two weeks before the scheduled interview. The assignment package consisted of a background questionnaire and a patient journey timeline layout, stickers for describing emotions visually, and a return envelope. Background questionnaire asked questions related to demographic information and treatment, since HUS is not allowed to give us any information about patients. This means that all data comes from the participants themselves. When the patient had filled their timeline and background questionnaire, they sent them back to Aalto research team by mail.

5.4 Clinician interview process

The recruited clinicians were sent a preliminary task (Attachment B) attached to the email where the interview was scheduled. The task was to fill in and modify a care path of the patient group the clinician is working with. In addition to filling in the different steps on the care path, the clinicians were asked to write down how they communicate with patients and other stakeholders during each care phase. Lastly, the professionals listed all the digital services they use for their work. For this thesis the most relevant data from this pretask was the listing of the necessary digital services, since it illustrates some of the needs the professionals have for an eHealth service. Other information was used to ensure we understood the care paths and to gather information about the clinicians' work tasks.

The clinician interviews were conducted in a video call using Microsoft Teams with two interviewers. One interviewer asked questions and the other wrote notes. The interviews were recorded, and the recordings were used to complete the interview notes afterwards.

The goal with the interviews was to gain a better understanding of the patients to help form the patient interview questions, but also to gather the clinicians' needs related to eHealth services. Following user-centered design process, the clinicians were interviewed in a semi-structured manner (Attachment C). The themes the professionals were asked about are the preliminary task, dialysis patient education process, patient characteristics and future of dialysis care.

5.5 Patient interview process

Since the main goal of the project was to improve patient experience of home dialysis patients, the methods for the patient interviews were chosen to support this. There are implications that combining patient-centered and experience-based design improves PX (Bate, Robert 2006, Mannonen et al. 2017). The scoping review presented earlier also found that some subtype of user-centered design was used in most of the articles which created design principles at least partly based on a case study, which further supports the chosen approaches in for all interviews, clinicians included.

Semi-structured retrospective interviews were used as the main method for gathering patient experiences and needs. The interviews were in retrospective, since the themes revolve around the experiences of patients, which cannot be observed in the moment. Semi-structured interviews are almost as good for discussing sensitive subjects in a natural, open manner, as unstructured interviews while making the data of each interview comparable to a degree, like structured interviews. The patient interview questions were designed to gather experiences related to four themes that we thought would influence the design of an eHealth service. The themes were patient journey, treatments and care takers, devices and services, visions of future.

The patient journey theme discussed a timeline pretask which was part of the preliminary assignment package. The timeline layout was filled with milestones as guidance, such as "first symptoms" or "diagnosis" and an example timeline (Attachment D) was attached. The main task was to draw a visual timeline of their patient journey, where they filled in significant events, experiences, and emotions throughout their life with the disease on the layout. The aim was not to get diagnostic information, but to recognize important experiences that formed their patient experience. The timeline and related interview

questions complement each other in forming a rich narrative of the patient journey. Timelines as a method also are fitting to the overall patient-centered and experience-based nature of this study.

The base interview structure (Attachment E) was modified based on the returned timeline pretask, to ensure that the interviewer didn't ask about topics the patient had already covered but did ask about unclarities on interesting topics related to the timeline. The semi-structured interviews were conducted remotely, either in a conference call by phone or a video call in Microsoft Teams, based on the participant's preference. The interviews were recorded for a transcription. The participant was interviewed by a main interviewer, while background tasks such as taking notes were done by a scribe. The scribe also ensured that the main interviewer stayed on topic and covered all the interview themes. The main themes were patient journey, experiences about the care, experiences about current equipment, processes and digital solutions, and visions about the future.

5.6 Analysis process of interview data

The data used consisted of interview notes written during the interview and completed afterwards with the help of interview recordings. This ensured that the notes are comprehensive. Additionally, the interview recordings were used for collecting the direct quotes presented in chapter 6. The data analysis process for both patient and clinician interview data started with reading the interview notes until the researchers felt familiar with the content. After this, common themes were identified from the text. The interview questions were used as a guideline, since naturally they covered most of the phenomena in the notes. Insight was also gained from the research questions of planned publications, such as this thesis. Combining these three perspectives, a codebook was formed, and the data was coded according to that. This corresponds to the open coding stage in the analysis procedure suggested by Strauss and Corbin (2015). The codes were researcher-denoted concepts.

A large part of the interview data is not relevant for this thesis, so the next stage was to pick the codes that can have information related to the goals of this thesis. The modified codebooks with applicable codes are presented below in Table 5 and Table 6.

Table 5: Clinician interview codebook

Code (clinician)	Explanation
---------------------	-------------

Patient's task	Self-management and other illness-related tasks that patients must do
Work task	Clinician's own work tasks
eHealth	eHealth services that are currently in use and experiences using them
Suggestion	Suggestions about how to improve care in the future

Table 6: Patient interview codebook

Code (patient)	Explanation
Tasks	Self-management and other illness-related tasks that patients must do
Difficulties	Negative experiences related to care or other factors affecting patient experience
Successes	Positive experiences related to care or other factors affecting patient experience
Suggestion	Suggestions about how to improve care in the future

The interview notes corresponding to each code were grouped according to the topic the quotations referenced. For example, many patients talked about the dialysis machine in under the "difficulties" code and many also expressed suggestions related to it. These quotations were then grouped under one theme, home dialysis machine. Finally, the raw quotes were transformed into text, explaining the results. The results are presented in chapter 6 and the process of forming design principles based on the results is in chapter 7.

6. CASE STUDY RESULTS

Clinicians and patients both do care tasks independently of each other, but also in cooperate with some. Here the results of the case study are presented under these categories, which are further divided to the themes that were most discussed by each user group. Some interview themes from the patient interviews do not fit this structure, they are presented separately in chapter 6.4. The main topics covered in this chapter are shown in Figure 4.

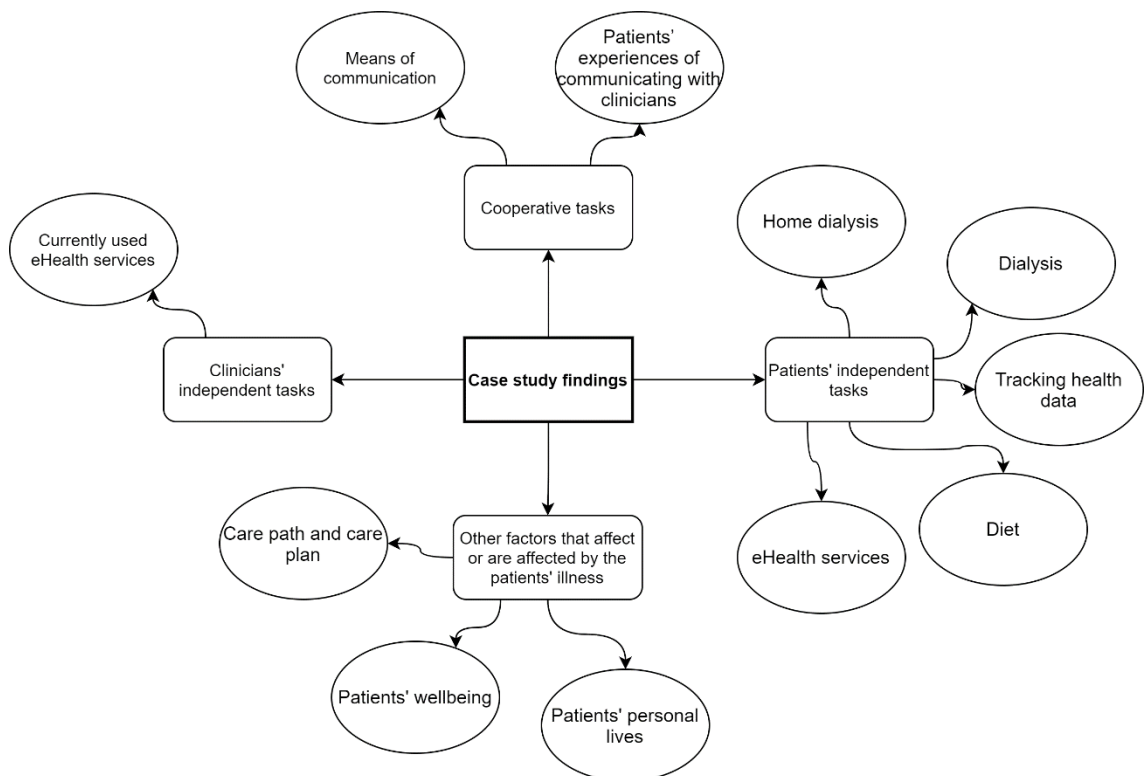


Figure 4: Case study findings

More detailed findings are covered in the following chapter as follows: chapter 6.1 describes clinicians' independent tasks, chapter 6.2 describes cooperative tasks, chapter 6.3 covers patients' independent tasks and finally chapter 6.4 describes other factors that affect or are affected by the patients' illnesses. The figures in each subchapter can be seen as continuations to further subnodes of the map presented above.

6.1 Clinicians' independent tasks

Independent work for clinicians includes tasks such as writing or reading medical reports, supply orders, making appointments for the patients or altering the patient's prescriptions. Most of these tasks require an eHealth service, such as a patient information system. The main findings related to this topic are shown in Figure 5.

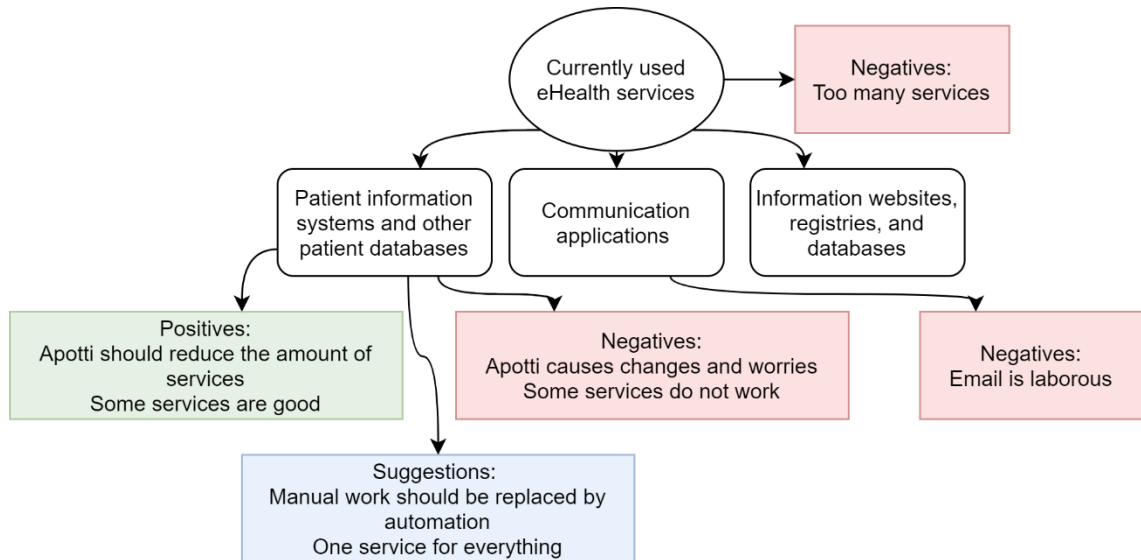


Figure 5: Main findings related to clinicians' independent tasks

The clinicians listed **over 10 eHealth services**, which can be categorized into patient information systems and other patient databases, communication applications and information websites, registries, and databases, that are used by them. It is important to note that not all clinicians use the same services and not all services are used daily. For example, doctors, satellite dialysis nurses and home dialysis nurses have some application the others do not use. Some of the digital platforms are used daily, such as email, but some are only used only for research in rarer situations.

Currently the main patient information system is changing from Uranus to Apotti, which also is the cause for some overlap in the services, but it is still unclear to the interviewed clinicians which services will be redundant in the future. Apotti should reduce the amount of services by providing more functionality on one platform. The different patient information systems contain patients' medical reports, scheduled appointments, and blood test results.

A couple clinicians expressed hope that in the future some of the **manual work would be replaced by better integration** between the dialysis machines and the new patient information system. Two satellite dialysis clinicians noted that Uranus has not been used

in the satellite clinics but Apotti will be used there in the future. This causes major changes in the work routines. A few clinicians expressed worries related to Apotti.

“Well it’s probably the first challenge, in the near future, Apotti. Because we are a satellite, we have never used Uranus. So now we need to learn new ways to work, because it’s a bit complicated -- It’s probably not designed to work for the satellite, because almost no one knows how we work here.” – C7, satellite dialysis nurse

“Well I would like, I don’t know if it’s possible, that there would be one, like one program where we could get everything we need. -- That was the plan with Apotti, but we’ll see if we get something like that to work.” – C8, satellite dialysis nurse

Two different services are used to track predialysis patients’ health information. The information on the registries is used to monitor the patients’ kidney health. If important markers from the blood work are too poor, the patient’s care needs to be changed. One of the applications has some degree of automated synchronization where all data does not need to be manually input. The other one is updated manually. One clinician uses both at their job. They had issues with the automated one and said that it was supposed to be fixed but it was not. They still say they have interest to get the automated service synchronized with Apotti.

“It [automated application] doesn’t work reliably as the replacement of [the manual one]. I have found issues there myself.” – C5, predialysis nurse

The dialysis machines also have three information systems of which two synchronize with each other and with Apotti. The two synchronizing services provide information about current and previous dialysis treatments and the dialysis recipe can be changed on one of the services. The third service provides similar functionality but for the other dialysis machine manufacturer, but it’s not compatible with Apotti. The clinician using it has been satisfied with it.

“It [the third service] is an excellent service. -- It provides us with so much information.” – C3, peritoneal dialysis nurse

For communication the clinicians use several different systems. Email is the most common way of communication between different clinicians.

*“Email is the number one still, even though **everyone feels that it’s laborious**, in the sense that it fills up during the weekend when you’re not working. 30 unread emails are waiting on Monday.” – C6, hospital hemodialysis nurse*

Microsoft Teams is a video conference software, that is used for remote meetings. Yammer and WhatsApp have also been used for communication. Yammer and Whatsapp are not used by everyone. None of the other communication methods excluding email evoked any comments about use experiences.

The clinicians use a few different websites and databases to find information related to kidney disease care. They also update the Finnish kidney disease registry yearly. The registry contains data about patients who receive dialysis treatment or have received a kidney transplant. These services were not commented further by the clinicians.

6.2 Cooperative tasks

Some of the tasks of clinicians and patient require both to be present and cooperating. These types of situations are usually communication-related, either face-to-face or through other means, such as a phone call or a Teams video call. The main findings related to this topic are presented in Figure 6.

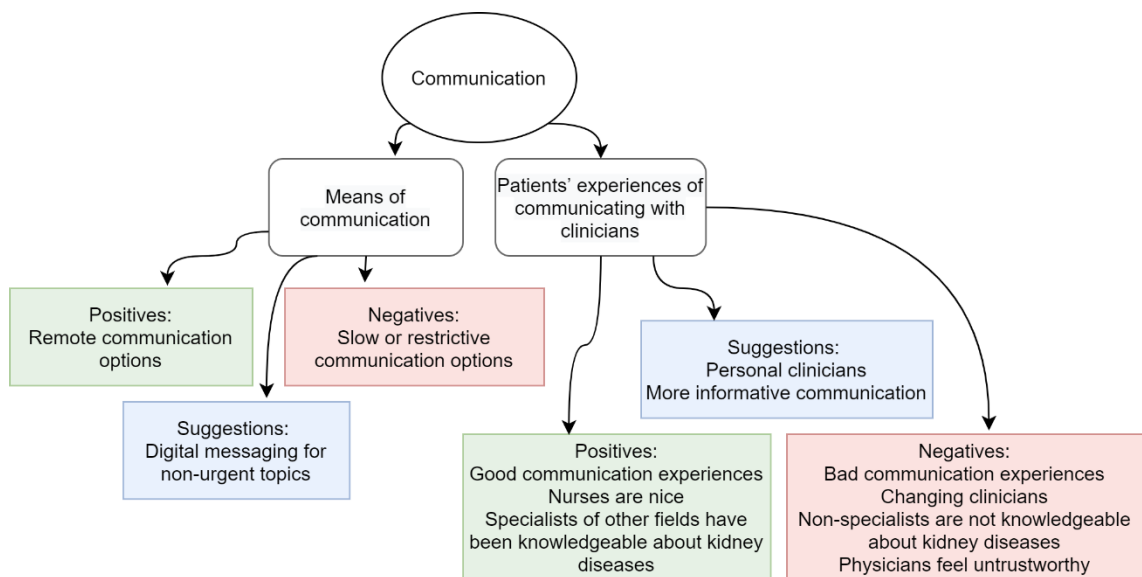


Figure 6: Main findings related to cooperative tasks

This chapter includes findings related to different means of communication and patients' experiences of communicating with clinicians. Typical communication events can be unplanned, such as patients calling nurses to ask help in problem situations or preplanned, such as regular checkups. Physician appointments are normally held in the hospital, but during COVID-19 pandemic, some have been organized remotely.

According to the clinicians, the most common means of communication are phone calls. Patients had varying opinions about different communication methods. Some digital

communication methods, such as **video calls and remote checkups gained praise** by two patients. One patient dislikes messages since they're slower than phone calls. One patient said that the call times to contact the hospital are too restrictive.

“— I think I suggested that could we do it remotely, I didn't want to go to the hospital to collect corona infections. They couldn't contact me, but I had Teams so I then called the doctor. I showed that “this is what my fistula looks like” and the doctor was on the other side of the screen. It worked just fine.” – P18, home hemodialysis

“The call time is an hour or two some morning and since I'm sleepy in the mornings, it's usually already over when my morning routines are done” – P7, peritoneal dialysis

“I would rather do it through the internet, so I wouldn't need to go anywhere, like checkups and everything” – P11, peritoneal dialysis

Many patients had **issues with different healthcare professionals** at different point of their care path. A couple patients found it unpleasant that doctors and nurses are changing, and many patients **found it tiring to explain the same things to different clinicians**. One patient said they think they should have a personal doctor too, which would be the same person always. A couple patients also said that doctors, who aren't specialized in kidney diseases, are too unfamiliar with the diseases and their care. Some interviewees said that they feel like they **cannot trust physicians**, compared to nurses. Many patients hoped to get **more information and details about their care** from the clinicians.

“At first when I visited the doctor during predialysis, it was me getting annoyed about them not telling me what is happening now. It was always “let's continue as we have this far”. I did use some non-chosen words [expression of frustration].” – P15, home hemodialysis

“All normal clinic visits like for an ear infection or for my bad knees, I have to start by telling that I have a chronic illness. And the one who is supposed to help usually says something like “What is dialysis?” or “Dialysis? At home?”. “– P18, home hemodialysis

“—I have said to my personal nurse, that if I could change it so that they would make the decisions about my care rather than the doctor, I would. I trust the nurse a lot more” – P9, peritoneal dialysis

On the other hand, almost all the patients have been **satisfied with communication with the healthcare professionals** at least at some point of their care path. A few patients also said that they had been taught thoroughly and successfully to the home dialysis treatment. Many patients complimented **the nurses for being nice**, although a few patients had come across **clinicians that were irritable** and at times unfriendly. A few patients said that other special healthcare workers had been knowledgeable and made sure that their treatments did not negatively affect the care of kidney diseases.

“Well I have a really good.. source at the hospital. They’re really amazing people, who always tell me [everything]. – I trust those professionals” – P3, predialysis

“They’re the best nurses in the world” – P4, satellite dialysis

Communication methods between the patient and the hospital gained some improvement ideas. Two patients said they want to have digital messaging to contact the hospital about minor and non-urgent subjects like renewing a prescription. One of these patients said they want this because the call times are short and too early for them personally. The new patient information system has support for this type of communication.

“[about eHealth-related suggestions] A communication thing, that if I need a prescription or something I really don’t want to start calling during a short call time and queueing” – P9, peritoneal dialysis

6.3 Patients’ independent tasks

All kidney disease patients must take some responsibility of their own care. The specific tasks depend partly on the patient’s treatment form, for example, home dialysis patients must do their dialysis treatments independently, whereas predialysis patients don’t have dialysis at all. The main themes and findings are presented in Figure 7 below.

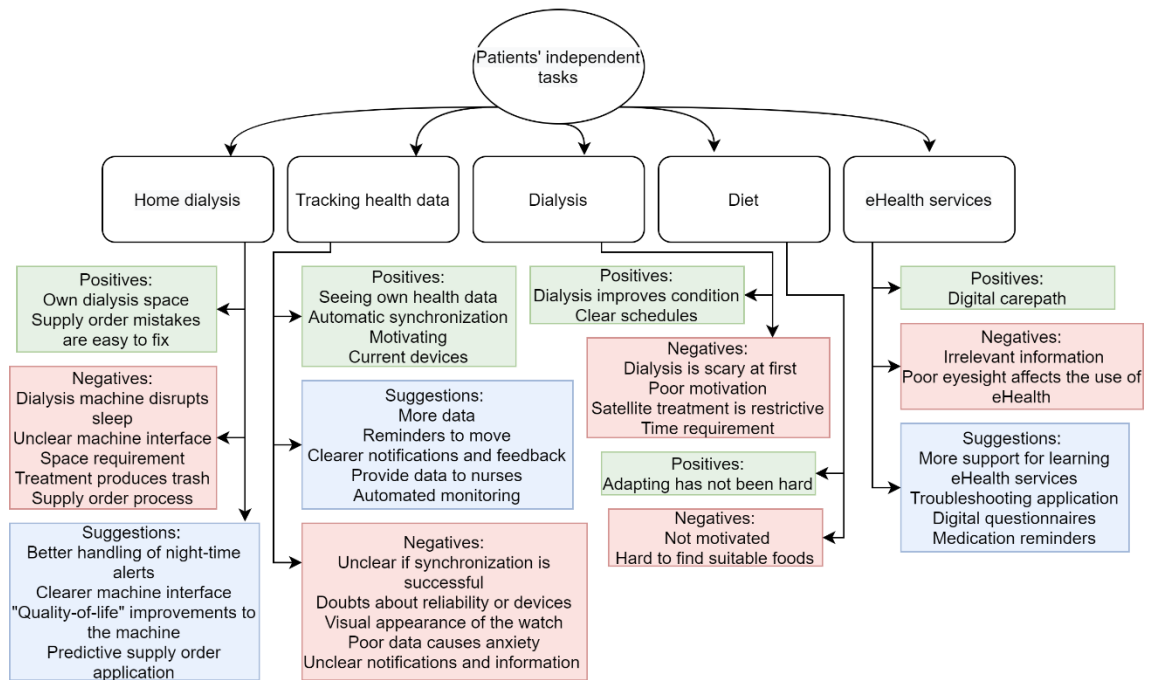


Figure 7: Main findings related to patients' independent tasks

Home dialysis and related tasks are in chapter 6.3.1, tracking health data is in chapter 6.3.2 and dialysis, excluding home dialysis, diet and eHealth services are covered in chapter 6.3.3.

6.3.1 Home dialysis and related factors

Home dialysis patients have a lot of extra tasks that are not included in responsibilities of the other patient groups. In addition to the dialysis itself, there are other related tasks, such as ordering supplies for the dialysis and taking care of the trash it produces.

The home dialysis machines caused a lot of complaints. A lot of patients thought that the **machine beeped warnings too easily**, especially related to outflow in peritoneal dialysis. This was found to be especially annoying since it wakes up the patients who do dialysis overnight. One patient also thought that the machine is noisy by default. Machine caused issues and alerts unrelated to outflow too for many patients. One patient said they feel like they cannot rely on the machine, because they had had problems with it. One patient said that the machine interface is unclear, but learnable.

"I have learnt the machine. Sometimes at the start, it was a bit tricky but I have gotten it to work just fine" – P11, peritoneal dialysis

“During the outflow there was always an alarm about it not working. I woke up many times in a night, like four or even five times, to the machine beeping.” – P19, peritoneal dialysis

Home dialysis treatment also caused issues that are unrelated to the machine. One patient pointed out that home dialysis requires a lot of space. Some interviewees said that the treatment **produces a lot of trash**, especially cardboard. On the other hand, two patients said that they were happy with the space they have at home for the dialysis machine and supplies.

“Once a week or every two weeks I take the boxes apart so that they take less space and go take them to some place that takes cardboard trash. It’s an extra thing that I need to do. Otherwise I would have cardboard everywhere.” – P7, home hemodialysis

“We have it wonderful, since we have a spot upstairs, out of sight in everyday life. Only I use the room, it stays clean and nothing else gets in there. The things are safe here.” – P18, home hemodialysis

Supply order process for home dialysis raised some complaints among patients. A few patients thought that **ordering supplies through email is outdated or labor-intensive**. A couple patients had also made a mistake with orders, where they hadn’t ordered enough materials. This wasn’t a commonly recurring issue though. On the other hand, one patient was happy about how a mistake with the supply order was fixed quickly.

“Shit system because I have to do it [send an email] every time. In theory it works just fine but using email as an interface is so early 21st century.” – P9, peritoneal dialysis

The dialysis machine inspired the patients to give improvement suggestions. A few patients said that they want the dialysis machine to **work better related to outflow issues and waking up the patient** because of those issues. A couple of patients also said they think the **interface of the machine should be clearer**, so no learning would be required. The following improvement ideas were each brought up once: the machine should be less noisy, the machine should have a remote controller, peritoneal dialysis should last a shorter time, the dialysis machine should work remotely and not necessarily in the same room, the dialysis should have a stop-and-play function, the peritoneal dialysis liquids could go into a tank rather than be in bags and lastly, one patient wished for a transportable dialysis machine. Information sharing and synchronization also inspired

some suggestions for improvement. One interviewee said they think dialysis data from the machine should automatically synchronize with a database online, so they would not need to write it down.

“They should invent a machine that forcefully puts these liquids in and out and not this that needs to be sweet-talked to work.” – P7, peritoneal dialysis

“There are no other issues, but it would be really good if it would be the size of a suitcase, so I could take it with me. But that’s not possible because it needs 70 liters of liquids.” -P17, home hemodialysis

A few interviewees said they want to have a **supply order application that would predict what the patient needs to order**, based on normal usage amounts. One interviewee said that they wish they would have more say about supply delivery times.

“Some app that would ask, when you do your treatment, which supplies you have used and how much. Then it would have a default, that you normally use. Then you would just check “one of the default”.” – P15, home hemodialysis

6.3.2 Tracking own health data

While Aalto University was researching patient experience and the interviews were held, HUS was conducting a study about kidney disease patients and health data tracking. The patients were provided with a smart scale, blood pressure meter, health and wellbeing watch and a smart phone. The first three collect health data about the patient and the data is synchronized into the phone, which also makes the data available to the researchers. The phone has applications where the patient can see their own data. The results in this chapter especially are affected by the study at HUS.

Many patients said that they think it’s **valuable to them to see their health data** related to the study at HUS. Automatic synchronization of data between the scale, blood pressure meter and the phone were complimented as well-functioning and useful feature by two patients. One interviewee said that doing the measurements every day is motivating them. Satisfaction with the current devices was also mentioned once. A patient also said that both the scale and the blood pressure meter have worked with no issues.

“I think it has been quite interesting, especially the weight and fat percentages and others, to track. Although, it has been kind of boring since it has been just one straight line.” – P8, predialysis

“It has worked well, the synch to this phone, it has been immediate.” – P14, pre-dialysis

According to the patients, the scale, that is currently in use for the monitoring study, is unreliable and often doesn't work in some way. For many patients, it's **unclear whether synchronization between the devices has happened successfully**. It was also brought up that the measurements from the blood pressure meter attached to the home dialysis machine and the one provided by the hospital for the monitoring study don't match.

*“I have no control over the information. If I measure my blood pressure, I press BT-button and then it should be delivered, but I don't know if it actually did. The same goes for the scale, *beep* and maybe it synchronized.” – P13, satellite dialysis*

“Well the scale sometimes shows me errors, but when I step on it again, then it works. I haven't understood why.” – P2, satellite dialysis

Some patients were **unsatisfied with the visual appearance of the watch**. Sleep data collected by the watch causes anxiety in a few patients, if their sleep is poor quality, they feel that knowing it does not help. A few patients had had **issues with finding and understanding information** on the phone's application. Some warning messages on the phone were in English, which caused one patient to not understand them. A few patients had not noticed messages on the phone because they do not check it.

“The graph it draws is rubbish. I don't value knowing that I have woken up six times. I don't know if I should be worried.” – P18, home hemodialysis

“I don't like the watch. I have lived 20 years without one, it was just annoying. This one doesn't sit well on my wrist, a big lump.” – P13, satellite dialysis

The patients gave many different suggestions about tracking or viewing more information. The activity watch received two improvement suggestions, a patient wanted it to collect more data, such as heart rate and steps and another patient wished the watch would remind to move and give feedback related to the activities. One patient said they want to track the amount of water in their body. It was also mentioned once that the devices should inform clearly when the measurements synchronized to remove uncertainty.

A few improvement ideas were given about how the data is displayed currently. An interviewee wished to see more history data about sleep and two patients said they did not understand what the feedback from the watch meant concretely. For example, what qualifies as “good” activity level. Two patients said they want to see the data collected about them more easily.

“It would be nice, if I could see my sleep for more than two days.” – P9, peritoneal dialysis

“If I would understand the graphs, then I could check them myself too. These should have instructions so I would get it too.” – P10, peritoneal dialysis

Some patients also brought up points that are related to clinician support with health monitoring. A patient said that, all tracking information they collect about themselves, should be available to their personal nurses. Another one said that the monitoring should be automated and always on, rather than the current situation where the patient calls the nurse and the data is then checked. Currently the monitoring data from the scale, watch and the blood pressure meter is not available to clinicians outside of the HUS study team.

6.3.3 Other independent care tasks

Other independent care tasks include general opinions about dialysis and care that do not only concern home dialysis patients. This includes general dialysis opinions, miscellaneous care tasks and eHealth.

Many patients said that their **first dialysis treatment is scary**. One patient said that dialysis doesn’t feel motivating since they don’t have any symptoms. **Satellite dialysis feeling restrictive** was a commonly shared opinion. Dialysis also overall takes a lot of time. Although, for many patients, starting **dialysis had improved their condition**. One satellite dialysis patient mentioned that they were happy with the clear schedules and routines related to it.

“It’s positive that it follows the same schedule. It would be hard if it would be unclear, if they would bounce me around.” – P13, satellite dialysis

“When I started [the dialysis] at the hospital, I was nervous. But let’s say that after a month it started being a routine. – But then when I got home and started them again, I sometimes thought that I can’t do this at all and this goes all wrong all the time.” – P15, home hemodialysis

“The treatments mess up my normal life.” – P13, satellite dialysis

One patient said that adapting to the new diet has not been an issue, but many patients said that they are **not always motivated enough to stick to the kidney diet**. Some patients also said that it can be **hard to find foods that are suitable** for their kidneys but also to their individual needs.

“I would say that I have information about the diet and exercise and so on. It’s more about if I follow it or not.” – P8, predialysis

“Well of course it’s hard, when you think about the diet of a diabetes patients and the diet of a kidney patient. You have to keep your tongue in the middle of the mouth [idiom about being careful]. It’s a balancing act.” – P8, predialysis

Digital kidney care path is a website meant to support patients to choose the right dialysis option for them. In addition to containing information and questionnaires about each treatment option, the service has a messaging function for communicating between the patients and clinicians. The interviewed clinicians said that it is **not very widely used**, but the messages sent by the patients on it are still checked regularly. Still, two patients said that the service is good and useful.

“Kidney care path is really good in my opinion. It doesn’t answer all.. but not all things have an answer. But it’s really good.” – P1, peritoneal dialysis

Other websites that are meant to provide information about kidney diseases caused complaints. One patient said that the websites have a lot of information that is not relevant to them. Another one said that these websites do not answer all questions. One interviewee said that the physical home dialysis instruction leaflet they received is clear and simple.

“Information websites always have to be so basic that a tiny portion is relevant to me. They just stress me out for no reason.” – P9, peritoneal dialysis

At least two of the interviewed patients have issues using eHealth services because of poor eyesight. Two of the currently used eHealth services, where patients can see their own health information, were criticized by one patient but the same services were complimented by another. These services are not designed specifically for kidney dialysis patients. A **hybrid model** where digital and analog option would exist side-by-side was suggested a few times. An interviewee mentioned that they wish there would be more support for learning digital services.

“I cannot really see well, even if the screen is zoomed in.” – P12, satellite dialysis

“I think now we need an overlap-period where we have a hybrid, many different options to take care of things. Not only digital. Future generations could have only digital.” – P5, predialysis

Related to eHealth services, two patients said that they want to have an application informing about normal problems and their solutions. A wish for digital questionnaires rather than paper ones was also voiced. One patient said they wish that some application would remind them to take their medications.

“A clear application, about some basic failures and fixing them, or problem situations, that happen during the machine. Maybe a video explanation about them, that when you need to press a button at the back of the machine, clearly show which button. – But I was thinking myself too that it’s a bit like – has to be fool-proof.” – P15, home hemodialysis

6.4 Other factors that affect or are affected by the patients’ illnesses

Patient experience is also dependable of other factors, not related to care tasks. Patients talked about their wellbeing, personal life topics and care as a larger concept. The main findings related to these topics are presented in Figure 8

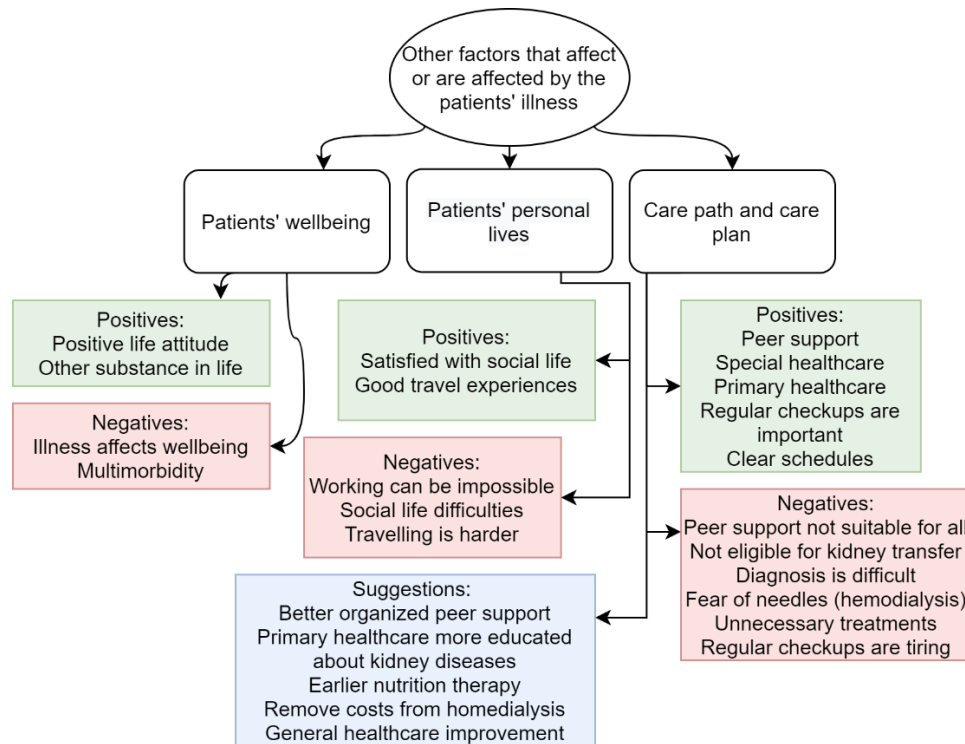


Figure 8: Main findings related to other topics

Different factors deteriorated patients' wellbeing and energy. A few patients said that they **do not want to think about their illness**. A few patients said that the **illness affects their wellbeing negatively**. Two patients said that since both them and their spouse are chronically ill, it affects everyday life negatively. Another one said that because their condition is poor, they aren't doing mentally well either. A patient also said that merely knowing that they have a disease affects their well-being. One patient said that having multiple chronic illnesses is tiring and feels unfair. A few patients found that **positive life attitude is very important**. One interviewee said that they are happy about having other substance in their life than just the illness. A patient was happy with their studies.

"Well it feels, since I have the other illnesses too, kind of unreasonable." – P2, satellite dialysis

"It's wonderful that I have other substance in my life than just the disease." – P5, predialysis

"If I may compliment myself a bit, I think I am a positive person and I have been able to accept everything that has come my way." – P12, satellite dialysis

A couple patients said that they are not able to do physical work anymore and a few patients mentioned that they have been **denied disability pension** and instead receive fixed-term rehabilitation subsidy for a year at a time.

Social life was difficult for many, especially because of the COVID-19 pandemic, which affected how often patients could meet other people. Many patients still said that they are happy with their social life and one patient said that organizing parties is fun and important to them.

“It’s not lonely at all, our life.” – P3, predialysis

“This [social life] is enough for me, I don’t need anything more at the moment. Of course, it would be nice to sometimes go somewhere. We went to the theater with my wife every now and then, in the good old days, a few times a year. And with relatives too.” – P7, peritoneal dialysis

Many patients said that **if they want to travel, a lot of planning and preparation work is required**. This affects mostly patients in active dialysis treatment, since they need to plan with healthcare professionals how their dialysis will be organized. Hemodialysis patients will go to a dialysis clinic near their destination whereas peritoneal dialysis patients will do their treatment at their destination via CAPD. Although, many **patients who had travelled were also satisfied with the experience**.

“I will travel less and gatherings further away have stopped. I can meet my friends and acquaintances close by. With this system I can’t really go farther.” – P10, peritoneal dialysis

“Only thing is that when we visited our cottage in the late summer, then we have to take stuff with us, pack the liquids and everything. It’s then a bit.. It works fine there too.” – P1, peritoneal dialysis

Two patients brought up that they enjoy the support they get from their peers. One patient in predialysis stage was worried about contacting peers. An interviewee also said they think that doctors should tell about Facebook groups focused on kidney diseases. It was also mentioned that especially patients who get their diagnosis in a surprising manner and might have to start dialysis quickly, should receive peer or conversational support.

“I’m a member of Uumu, that organization for kidney and liver patients. I have gotten a lot of peer support from there. It has been nice but now it has been on hold since the spring [2020], because we cannot meet.” – P1, peritoneal dialysis

“[About not taking part to peer support group in Facebook]: Perhaps it’s a bit of that fear, that I hear things from there, that may cause something unpleasant in me. Or like, “Oh my goodness, could that happen to me too” and so on. So that. Maybe that’s the reason. I want to protect myself still.” – P8, predialysis

Most patients expressed their **satisfaction with special health care**, either related to kidneys diseases or other illnesses. Although, a few patients said that they had been **happy with primary health care** too.

“When you compare this to the health center stuff, well this is special health care of course.. Just exemplary, I couldn’t ask for anything more. It has really stuck with me. At all times I feel like I am in safe hands. Only positives [experiences] from there. Nothing negative.” – P1, peritoneal dialysis

“An amazing health center and a public health nurse and a personal nurse for many years now, they’re great.” – P3, predialysis

There were also a few **problems with the treatments and diagnosis processes**. Some patients complained about not being able to get to the kidney replacement wait list, either because of age or poor condition. One patient said that diagnosis was difficult and another mentioned that starting treatments took too long. Two patients brought up that primary health care professionals should be educated about rarer diseases to ensure quicker diagnosis. A few patients also mentioned fear of needles, which affects how they feel about hemodialysis and blood tests.

“In the satellite I can’t look when they inject the needle, it hurts every time. They say that you get used to it, but you don’t!” – P13, satellite dialysis

“Naturally it made me a bit depressed, when they tell you directly, that you will not be put on the queue [for a kidney transfer] since you’re so old and you have all these other diseases. – It’s decided, even if my own brother would give me his kidney, it doesn’t help. I just have to settle for this.” – P7, peritoneal dialysis

“They didn’t know the exact diagnosis, I didn’t get it immediately, they did all sorts of tests then and it just didn’t get any clearer. I only got it now, around May Day, when they took tests.” – P5, predialysis

Many people brought up that **some treatments feel unnecessary**, for example regular bloodwork or repeated kidney biopsies. On the other hand, one patient said that regular

check-ups are important and another one said that clear routines with blood tests and other check-ups is nice.

“At that point I got angry about having to go every three months and I said to them that I will only come every six months.” – P15, home hemodialysis

A lot of direct suggestions related to the care path were given by the interviewed patients. A few patients suggested that **nutrition therapy should be earlier**. One patient said they wish gene therapy would improve, so that genetic diseases could be fixed. An interviewee said that in their opinion primary health care should be improved overall and it should be more systematic. One person said that in the future, they should not pay anything for doing home dialysis, since it is cheaper for the society to do it at home rather than at the hospital.

“Then this nutrition therapy came kinda late, after I had gotten ill. It should have been right after it. But it took many months until I had it. And then I had found all of the information on my own. So it was too late by then. – I think it would have been important, that it would be on time.” – P6, predialysis

“It’s probably cheaper for the society that you take care of yourself at home. So these payments there, why do you pay these serial treatment payments when you take care of yourself at home, does this make any sense?” – P5, predialysis

7. ANALYSIS OF THE PRINCIPLES AND THE CASE STUDY RESULTS

In this chapter the results from the case study and the literature review will be discussed side-by-side to see how the scoping review principles and case study findings relate to each other. The connections between the results are illustrated in Figure 9 below. Attachment F has a more detailed description, where the individual findings are placed under the lower-level principles, rather than the main themes and higher-level categories presented here.

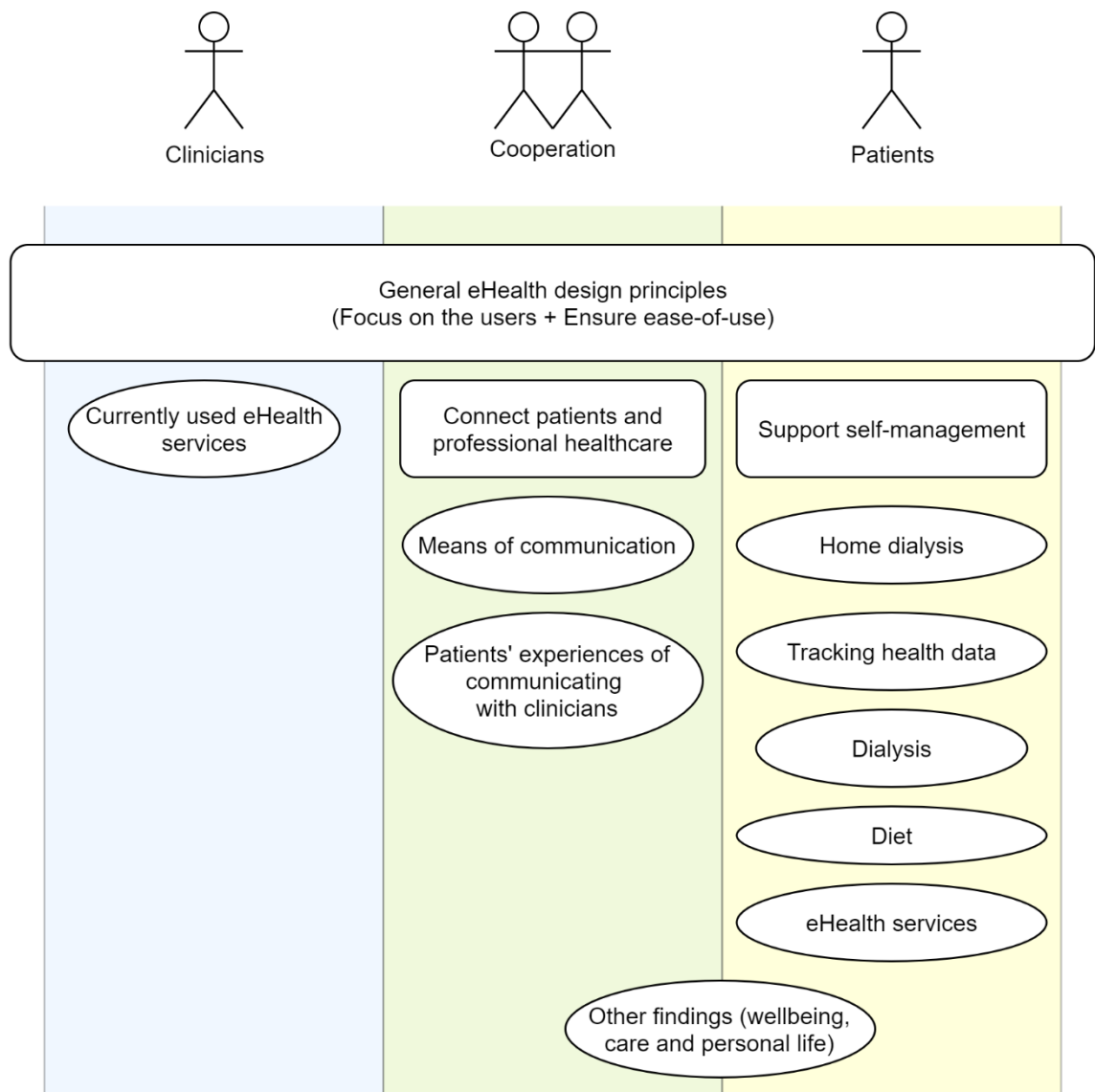


Figure 9: Connections between principles and findings

The principle groups are shown as rounded squares, the topics of the findings from the case study are illustrated as ellipses. The ellipses are divided to lanes under the three actor-types introduced in chapter 6. The principles affect every finding theme below them.

The principles within the categories “Focus on the users” and “Ensure ease-of-use” affect all eHealth services, since they are related to usability and user needs, which means that they also affect all the topics found in the case study. This connection is discussed in chapter 7.1. Connecting patients and professional healthcare and the cooperation-related findings are presented together in chapter 7.2. Chapter 7.3 discusses the connection of “Support self-management” principles and the themes related to patients’ independent experiences. There is a close relation here since most of the patients’ independent tasks are self-management. The topic of patients’ wellbeing, care and personal life is in between the “Cooperative” and “Patient” lanes and in between the principle categories “Connect patients and professional healthcare” and “Support self-management” since especially care path is related to patients’ independent tasks but also care plans provided by healthcare organizations.

7.1 Usability issues, user needs and general eHealth design principles

“Focus on the users” and “Ensure ease-of-use” can better the user experience related to all topics that the patients found issues with. Since the principles in these categories mainly focus on usability, such as principles “Make the system usable” and “Support learnability”, and trying to make the systems features correspond to the needs of the users, such as principle “Use participatory or user-centered methodology”, following them is an effective way to enhance positive experiences and mitigate negative ones.

Issues, such as the new patient information system not fitting into satellite dialysis clinic use and information websites containing information that is not relevant to users, could have been avoided if users were asked about their needs. On the other hand, patients and clinicians found some services to be pleasant to use and if they could have participated to the design process of other applications, the successful features could have been recognized by users who know what is effective and useful, making the new systems better too.

Both clinicians, and patients, had come across services and devices that simply did not work. These types of findings indicate major usability issues, which worsen the user experience severely. Interviewees discussing unclear features and data presentation in

addition to basic tasks, such as ordering supplies, being laborious also indicate usability problems, where the expectations, habits and knowledge of users do not match the system. All these types of issues could be mitigated by following the principles within the general eHealth design principles.

7.2 Communication and connecting patients and professional healthcare

Chronically ill patients require regular contact to professional healthcare, from organizational level to individual clinicians. The case study found that the communication experiences of patients were very mixed, almost all had had positive and negative experiences. Some of the issues cannot be answered by eHealth design, such as personalities clashing, but many problems could be avoided by following the principles within this category.

Patients had problems with restrictive communication, either due to the length of respond-times or the restrictions of short call times. eHealth services should try to provide contact methods which would make communication effortless. Patients were also unhappy with having to explain their condition and situation to many different clinicians and many wished for personal physicians and nurses. eHealth services should ensure that the clinicians have information at hand about the patients to provide seamless communication and effective use of time for both parties.

Patients were also dissatisfied with the skill and knowledge of some healthcare professionals. Following the principle "Provide information about healthcare professionals' qualifications" could perhaps help the patients to understand the expertise of each clinician and to show that they are knowledgeable and trustworthy as professionals. Patients were generally happy about having clear schedules and routines related to their care, which is why principles such as "Provide a care plan" are important.

7.3 Patient independence and support self-management

Patients had many positive experiences and new suggestions related to the health data tracking study at HUS, showing the positive impact of successful self-management to the patient experience. Some patients had motivation issues related to different parts of their care, such as dialysis or diet, which could be answered by principles such as "Support self-management and behavior change" which aim to provide motivational features.

"Enable support structures online and offline" can mitigate the fears, obstacles and other negative experiences related to wide variety of topics in the patients' lives. Peers can

provide aid by sharing their advice and experiences, but other support structures can be enabled in eHealth services too. Patients also had difficulties with pension, work life and social life, which all have institutions and organizations responsible for helping people struggling with these issues. eHealth services can provide ways to contact these organizations.

Patients wanted more information related to several different topics throughout the interviews, which shows that patients have interest to features supported by “Support patient activation”. Some patients also wished for higher level of independence in a form of troubleshooting application, so they would not need to contact clinicians, which is a type of eHealth service.

7.4 Coverage of the principles

This chapter discusses to which extent do the principles created in chapter 3 cover the findings of the case study. As mentioned in the introduction of chapter 7, the individual findings were distributed under the principles which could enhance positive findings and mitigate negative ones. Some of the findings had no relations with the principles and this chapter discusses which findings could not be categorized and why.

eHealth cannot affect all things related to the care of dialysis patients. Most of these factors are related to the dialysis, its requirements, and the dialysis machine. The nightly alerts and duration of dialysis treatments are decided by manufacturers of the machine and medical professionals. Some minor help could be enabled by the principles and eHealth. If there would be a troubleshooting service, as suggested under “Support patient activation” some of the issues might not feel as significant and “Enable support structures online and offline” could help with other support related to this.

The patients also discussed healthcare as a larger concept, which again is mainly out of reach by eHealth services designed for self-management of chronic diseases. Another topic were the personalities of the clinicians. These are partly related to the “Connect healthcare professionals and patients” principle, but how people get along with each other, cannot be changed by an eHealth service.

The principles overlap partly as explained in the chapter about the scoping review and it shows in some principles affecting larger parts of the interview topics and some less so. This is especially related to “Try to combat poor adherence and adoption rates”, which got no support from the case study. The case study in this thesis did not focus on adherence or adoption rates, which means that there are no notes from the analysis results

here. The scoping review showed that these factors are helped by enabling motivational design, such as gamification features and providing useful features to the users. The feature needs are scattered under other principles and most of the results related to motivating patients are either in “Support self-management and behavior change” or “Support patient activation”. Otherwise, the principles found in the scoping review corresponded covered the findings from the case study well, supporting the relevance of the results of this thesis.

8. DISCUSSION AND CONCLUSIONS

This chapter is focused on discussion about the thesis and its conclusions. Chapter 8.1 goes over the research questions and their answers, chapter 8.2 evaluates the study, and 8.3 suggests future research.

8.1 Answers to the research questions

This thesis is built on one research problem, which was divided into two research questions.

RP: Designers and developers of eHealth services for chronically ill patients lack a comprehensive set of design principles that support good patient experience.

RQ1: Based on literature, what design principles exist for designing eHealth services for chronically ill?

RQ2: Based on empirical research, what needs do kidney disease patients and the clinicians responsible of their care have for an eHealth service?

The first research question was approached by conducting a scoping review about articles presenting different lists of design principles for designing eHealth for the chronically ill. The review was successful, and 119 principles were found in 21 different articles, which were then thematically categorized into a list of 15 principles. The review process and the resulting principles with detailed descriptions are presented in chapter 3.

The second research question was answered by an empirical study with kidney disease patients and their clinicians. Qualitative data was gathered in semi-structured interview, which was then analyzed using standard methodology. The process is presented in chapter 5. The results are in chapter 6.

The research problem itself was a fusion of the two questions, the two parts of the study. The principles found as an answer to RQ1 were relevant to the issues and successes of kidney disease patients and their clinicians. Each principle was supported by the data collected in the empirical study, except “Try to combat poor adherence and adoption rates”. The principle was still decided to be relevant, since needs related to it were scattered under other principles. This was affected by adoption rates and adherence not

being part of the interview questions, which meant that this topic was not discussed with the interviewees. The support from the empirical study to the principle list further enforced them as being correct and useful for enhancing good patient experience.

This means that the main contribution of this thesis is this list of design principles:

General eHealth design principle: Focus on the users

Use participatory or user-centered methodology

Tailor the system for different users or enable personalization options

Try to combat poor adherence and adoption rates

General eHealth design principle: Ensure ease-of-use

Make the system usable

Support learnability

Visualize data and ensure its interpretability

Explain the features, data, and care plan

Enable easy data entry, transfer and sharing

Make the system interconnected with current services

eHealth design principles specifically for the chronically ill: Support self-management

Support self-management and behavior change

Enable support structures online and offline

Support patient activation

eHealth design principles specifically for the chronically ill: Connect patients and professional healthcare

Connect healthcare professionals and patients

Provide a care plan

Provide information about healthcare professionals' qualifications

8.2 Evaluation of the study

This chapter evaluates the study, diving into the relevance and limitations in chapter 8.2.1 and discussing generalizability and transferability in chapter 8.2.3

8.2.1 Relevance and limitations

The relevance of the thesis is limited by frameworks and models existing for similar purposes, such as the eHealth enhanced Chronic Care Model or eCCM, which was discussed in chapter 2.3. Although, there is need for both. The original Chronic Care Model includes change concepts which are “the principles by which care redesign process is

guided”³⁵. The eHealth version does not include these, meaning that there is only a higher-level model, no guidelines for designing systems and services.

The scoping review was important to do, since to the best knowledge of the author, a clear list of design principles for designing eHealth for the chronically ill does not exist. The review supported it, seeing that 21 different articles were found, and the lists presented in each one was different. None of the articles followed a structure like this thesis does, where existing principles were used as the base and analyzed together with the results from a case study. This is interesting, as the aim of design principles themselves is to avoid reinventing the wheel. Perhaps in the future other similar studies could validate the principles presented here to new patient groups, rather than inventing their own set of instructions. The scope of the review seemed successful because many relevant articles were found. The initial search into Scopus could have been more limited, to avoid discarding over 200 results as irrelevant, but limiting search terms could have also resulted in missing relevant articles.

The scoping review found that kidney patients were not the focus of any of the reviewed articles, meaning that there was a research gap in articles about kidney disease patients. Including clinicians also bring a new perspective. Though, some of the articles discussed multimorbid patients, where kidney diseases were sometimes one of the diseases the patient had. Most of the patients interviewed for this thesis were also multimorbid, meaning that some overlap most likely happened.

The data collected from the empirical study is limited by the recruiting process and methodology. Recruiting was handled by HUS and the patients were recruited from the tracking device study participants. Since recruiting and introduction to the study was done by medical professionals, the patients especially may have expected the study to be more medical or fact-based rather than experience-based, as it was supposed to be. This might have led to some patients feeling as if they are meant to tell medical facts, rather than their feelings and experiences throughout their patient journey. This showed sometimes in the visual patient journeys, where some patients had filled in mainly medical events, such as diagnosis. Some patients also seemed uncomfortable to talk about softer values, such as emotions. On the other hand, interviewing people who are less open is valuable for representativeness of the data.

³⁵ Improving Chronic Illness Care. The Chronic Care Model. Available: http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2 [2021, Apr 2]

However, how well the interviewees represent the whole population of kidney disease patients is brought down because the patients were recruited from the device study participants. The participants are probably more open to new aspects to their care, since they volunteered to two studies about these aspects. They are also likely less burdened by their care or illness since they have the resources to take part to two studies. Also, most of their experiences related to health data tracking are affected by the on-going study by HUS. Interviewees also did not cover all patient groups, since no patients in hospital dialysis were successfully recruited. The clinician interviews focused more on facts about their work, which limited the relevancy of the data about their experiences, but basic needs, e.g. what functionality do they need, were well-covered.

Because of the restrictions related to meeting people caused by the COVID-19 pandemic, the methods had to be completely remote. As discussed before, trust is harder to form remotely and for people with limited technical skills, taking part into a study remotely may feel overwhelming. This was mitigated by introducing introductory calls and phone calls as an interview option.

8.2.2 Generalizability, transferability, and purpose of the principles

The principles are divided into two main groups, general eHealth design principles and eHealth design principles specifically for the chronically ill, which clearly show to which application each category and individual principle can be applied to. If an eHealth service is designed for a niche purpose, not self-management support, communication, or other common eHealth service applications, only the general eHealth design principles are applicable. The literature, combined with the empirical study from this thesis, cover many different patient groups, resulting in the principles being usable for most chronically ill patients. If a patient group has any unique needs, the principles might not apply completely. However, considering that home dialysis is a relatively unique treatment form, and the principles were still usable for kidney disease patients showcases the generalizability.

Some of the principles may be transferable to other eHealth applications for users who are not chronically ill. The application must be aimed to motivate the user to change their behavior or to stick to a healthy lifestyle, since a lot of the guidelines concern self-management. The main difference is that these users most likely would not be care as much about connecting with clinicians, their qualifications and care plan, meaning that principles within “Connect patients and professional healthcare” are not transferable.

The principles provided here are meant to guide the developers and designers of eHealth services for the chronically ill. The aim is to improve the quality of eHealth by supporting organizations which may not have the resources to conduct larger scale studies about their users. Presenting these design considerations in this format, provides a “checklist”, which is easy to understand by anyone. The principles are as simple and generalizable as possible for the moment, for the main contribution of this thesis to be useful to as many eHealth development projects as possible.

8.3 Future research

New chronically patient groups could be researched using the same structure as in this thesis, where needs emerging from the case study would be compared against existing principles. This would be especially useful for rarer diseases, since many different illnesses were already researched in the articles found in the scoping review. Conducting research like this would either further validate these principles or present limitations to the generalizability.

Further research about the needs of clinicians caring for the chronically ill is needed, since they were not considered in many of the scoping review articles. The transferability of the principles should also be researched, especially for eHealth applications designed for regular, not chronically ill, users who need motivational features, e.g. for losing weight.

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ATTACHMENT A: SCOPING REVIEW PRINCIPLES

The principles from the original sources found in the review are presented here under the final principles discussed in the thesis.

Generic software design principles:

- Make the system usable
 - Overemphasizing particular mechanics (Miller et al. 2014)
 - Usability (Grandhi, Osatuyi 2018)
 - Fast, discrete transactions (Cafazzo et al. 2012)
 - Visual appeal is enjoyable for patients, which can be achieved through colors and sound (Jalil et al. 2014)
 - Facilitate navigation (Cooley et al. 2018)
 - Optimize for Speed and Responsiveness (Anokwa et al. 2012)
 - Assume Unreliable or Disconnected Servers (Anokwa et al. 2012)
 - Interactivity (Win et al. 2016)
 - Explore 'what if' questions (Carr et al. 2017)
 - Multimodal human-agent interaction (Balatsoukas et al. 2019)
- Support learnability
 - The use of familiar metaphors such as windows are helpful but also leads the patient to perceive the tablet as a standard computer (Jalil et al. 2014)
 - Touchscreens are fast to learn and enjoyable by patients (Jalil et al. 2014)
 - An internet browser in the system may help patients (Jalil et al. 2014)
 - Anthromorphism and mapping between the chatbot and real world (Balatsoukas et al. 2019)
 - Model User Interface on Existing System (Anokwa et al. 2012)
 - Do not terminate a mechanic without informing the user (Miller et al. 2014)
 - Use Minimal, Large, and Consistent Widgets (Anokwa et al. 2012)
 - Include the tutorial for using the app (Brzan et al. 2016)

eHealth design principles:

- Use participatory or user-centered methodology
 - Offer a real solution to self-management problems faced by patients: the app should meet patients' requirements and do better than any alternative and should be cheaper (Issom et al. 2020)
 - Health interventions are often complex in their nature. RCT design is one way of evaluating the effects of an intervention but it is in itself inadequate

- for truly capturing complex interactions. Design your study with multiple methods of analysis and consider the contamination of the control group as technology evolves during the study period. (Berg et al. 2018)
- Adjust per-protocol criteria after intended usage or conduct a dose-response analysis to properly evaluate the effect of the intervention within the RCT design (Berg et al. 2018)
 - Design for the user demographic (Miller et al. 2014)
 - Know Your Intended Users (Carr et al. 2017)
 - Be aware of limited target populations. If the number of possible participants is low, consider starting the intervention in multiple study centers simultaneously to avoid prolonged study periods and thereby outdated technology. (Berg et al. 2018)
 - Employ ecological systems theory and principles of community-based participatory research (Weiss et al. 2013)
 - Understand the current situation (Carr et al. 2017)
 - Bear in mind that the majority of participants will not actively engage in discussions in peer support forums. Therefore, a larger critical mass of participants is needed in interventions based on effects of social support. (Berg et al. 2018)
 - Target community-wide outcomes and participation of local community groups (Weiss et al. 2013)
 - If your intervention consists of a forum for peer support, consider engaging a study facilitator from the target group for the entire study period to boost activity (Berg et al. 2018)
 - Take a patient-centered approach: make sure the app improves patient outcomes; and the app is validated in terms of clinical outcomes (Issom et al. 2020)
 - Include medical experts in the development of apps (Brzan et al. 2016)
- Visualize data and ensure its interpretability
- Visual data is more important for the patients than numerical data (Jalil et al. 2014)
 - Presentation of Outputs (Carr et al. 2017)
 - Patients want to visualize data in graphs plotted in x-y axes (Jalil et al. 2014)
 - Enable analysis of the data and the patterns in the gathered data in order to observe the interactions between blood glucose level, food intake and physical activity (Brzan et al. 2016)

- Include prediction of blood glucose level based on gathered data (Brzan et al. 2016)
- Data visualization (Balatsoukas et al. 2019)
- The role of data collecting rather than decision making (Cafazzo et al. 2012)
- Real-time monitoring (Balatsoukas et al. 2019)
- Interaction with parameters and visualizations (Carr et al. 2017)
- Interpretability (Win et al. 2016)
- Complement the CA with a system for collecting vital parameters in order to analyse the data and provide personalised information about the individual's current health status (Meier et al. 2020)
- Support a Variety of Summary Types (Anokwa et al. 2012)
- Overview/preview (Balatsoukas et al. 2019)
- Explain the features, data, and care plan
 - Provision of definitions (Carr et al. 2017)
 - Explanations (Balatsoukas et al. 2019)
 - Communicate clinical concepts effectively (Cooley et al. 2018)
 - Include the up-to date educational material about diabetes (Brzan et al. 2016)
 - Presentation of context (Win et al. 2016)
 - Credibility (Win et al. 2016)
 - Documentation of the methodology (Carr et al. 2017)
 - Integrate educational health information into the CA to help the user interpret the personal sensor data and health status for sustainable health awareness (Meier et al. 2020)
 - Providing patients with disease-specific instructions (Sultan et al. 2019)
- Tailor the system for different users or enable personalization options
 - Consider the whole person, their co-morbidities, age-related impairments and current status of conditions (Doyle et al. 2019)
 - Enable a goal-oriented and domain-specific conversation flow with a personality that meets user expectations (Meier et al. 2020)
 - Patient tailored information (Win et al. 2016)
 - Relevance of content to patient's needs (Balatsoukas et al. 2019)
 - Tailoring to the unique needs of the patients (Sultan et al. 2019)
 - Develop different versions of apps for each diabetes type (Brzan et al. 2016)

- Enable the CA to access various input and output devices to adapt to the user preferences and to communicate the data adequately with an information-focused interface (Meier et al. 2020)
- Patient should be allowed to take ownership of the technology by adapting it to their unique situation and concerns (Storni 2014)
- Personalisation (Balatsoukas et al. 2019)
- Enable easy data entry, transfer and sharing
 - Support for a free flow of information (Ekberg et al. 2010)
 - Ad hoc information sharing (Cafazzo et al. 2012)
 - Enable saving data transfer and sharing (from external devices, diabetic patient to medical expert, between family members (child/parents, elderly person/guardian, etc.) (Brzan et al. 2016)
 - Enable easy data entry (voice recognition, image recognition, data transfer from other devices, built-in smartphone sensors) (Brzan et al. 2016)
 - Discard Any Functionality that Duplicates Work (Anokwa et al. 2012)
 - The design should reduce effort that patients spend with regard to use, entering their health-related readings data and updating existing ones. (Alharbey, Chatterjee 2019)
 - Flexible inputs, saving, and sharing (Carr et al. 2017)
- Connect healthcare professionals and patients
 - Communication with a healthcare professional (Balatsoukas et al. 2019)
 - The design should aid patients to communicate their symptoms with other supporting elements (such as caregivers) in their health environment (Alharbey, Chatterjee 2019)
 - Promote communication with clinicians (Cooley et al. 2018)
 - Medical provider interactions: Facilitate doctor-to-doctor communications, Report substances patients use for self-medication that were not prescribed by doctors (Ongwere et al. 2018)
 - Viewing of telemonitoring data by clinicians (Sultan et al. 2019)

eHealth for patients:

- Support self-management and behavior change
 - Managing and Tracking Preventive Care (Grandhi, Osatuyi 2018)
 - Behaviour change (Balatsoukas et al. 2019)
 - Motivate lifestyle changes (Ongwere et al. 2018)
 - To effectively support self-management (Doyle et al. 2019)
 - Include the tips for better self-management of specific type of diabetes (Brzan et al. 2016)

- Alerts (Balatsoukas et al. 2019)
- Ensure patient safety (Cooley et al. 2018)
- Mechanics are system-oriented and support, not undermine (Miller et al. 2014)
- Emotional self-management (Balatsoukas et al. 2019)
- Support PwMs and ICs to progressively learn how to digitally self-manage, with context-relevant prompts (Doyle et al. 2019)
- Prioritise self-management activities to reduce complexity (Doyle et al. 2019)
- Enable at least basic self-management tasks, such as monitoring blood glucose level, monitoring insulin dosage and/or other medications, nutrition, physical exercise and monitoring body weight (Brzan et al. 2016)
- Include motivational features for health behavior change (forums, social networks, reminders, alerts, etc.) (Brzan et al. 2016)
- Enable support structures online and offline
 - Support for building of relations between members on several levels in the community (Ekberg et al. 2010)
 - Peer to peer and with other members (Ekberg et al. 2010)
 - Address the interdependence between online support and real-world support (Weiss et al. 2013)
 - Narratives and experience-based knowledge (Ekberg et al. 2010)
 - Care, treatment, and social support (Ongwere et al. 2018)
 - Address the individual's existing social networks (e.g. family, friends, and co-workers) (Weiss et al. 2013)
- Try to combat poor adherence and adoption rates
 - When designing a Web-based intervention, use existing design theories to utilize the full potential of the technology and increase adherence, especially with regard to social support (Berg et al. 2018)
 - Be realistic when calculating your sample size. Take the risk of losing participants and poor adherence to the intervention into account. (Berg et al. 2018)
 - Controlling data flows (eg, shareability, privacy, and quality information) could influence patients' motivation to start using apps by storing data on personal data cooperatives, implementing existing interoperable standards, using algorithms, and hiring content moderators (eg, physicians and expert patients) to monitor content creation and the quality of information (Issom et al. 2020)

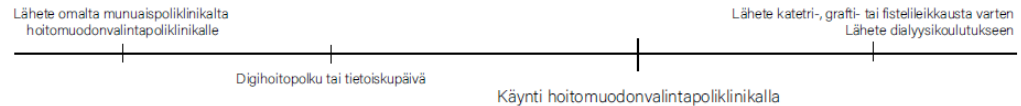
- Overcoming decision inertia (Cafazzo et al. 2012)
- Targeted information (eg, alerts when approaching limits and access to other patients' self-care practices) could influence the long-term engagement by providing patients with knowledge adapted to their health literacy levels, user interface matching their digital literacy levels, and information adapted to their disease-specific knowledge, and if necessary, offer assistance to interpret the information (Issom et al. 2020)
- Disease-modifying functionalities (ie, pain relief and regulation of hematological variables) to reduce poor adoption rates by providing patients with continuous blood oxygen meters, specific autoinjectors, and smart software that includes algorithms that are able to manage and make sense of the big datasets generated (Issom et al. 2020)
- Support patient activation
 - Support patient activation (Cooley et al. 2018)
 - Assess and Assist the Individual Health Locus of Control (Grönvall, Verdezoto 2013)
 - Active Information Seeking and Reinforcement (Grönvall, Verdezoto 2013)
 - User-directed explorations and analysis (Carr et al. 2017)
 - The design of assistive technology should empower patients with respiratory diseases with integrated means that increase their awareness level and bolster their intentions. (Alharbey, Chatterjee 2019)
 - Patient should be encouraged to actively intervene in the open-ended negotiation of the very terms under which their condition is described, understood and discussed (Storni 2014)
- Provide a care plan
 - Care and treatment strategies (Ongwere et al. 2018)
 - Problem definition -> problem resolution -> solution statement (Ekberg et al. 2010)
 - Care and treatment financial strategies (Ongwere et al. 2018)
 - Scheduling and Coordination of Preventive Care (Grandhi, Osatuyi 2018)
- Provide information about clinicians' qualifications
 - Access to information about what needs to be learned to be a full practitioner or respected member in the community (Ekberg et al. 2010)
 - Participation in the culture of the practice (Ekberg et al. 2010)
 - Access to information about the community and practice (Ekberg et al. 2010)

eHealth for clinicians:

- Make the system interconnected with current services
 - Consider the possibility to connect the apps with the patient electronic health record (EHR) (Brzan et al. 2016)
 - Enable the compatibility with different operating systems for smartphones by using packages that are available for different platforms (Brzan et al. 2016)
 - Be compatible with the existing health care information system infrastructure: implement interoperability standards by design; and answer privacy and safety requirements (Issom et al. 2020)
 - Individual and Care Network's Local Awareness (Grönvall, Verdezoto 2013)
 - Keep the design of the forum for peer support simple and avoid divisions. Web-design is often costly if the researchers do not possess the skills themselves or team up with researchers from other fields. Consider integrating your intervention into existing social media (but be aware of ethical pitfalls if you cannot guarantee the security and confidentiality of data). (Berg et al. 2018)

ATTACHMENT B: PRELIMINARY TASK FOR THE CLINICIANS

Predialyysipotilaan hoitopolku hoitomuodonvalintapoliklinikalla



Käyttämäsi sähköiset palvelut:

Esim. Potilastietojärjestelmät, Teams, Facebook-ryhmät

1. Tarkastele yllä olevaa hoitopolkua hoitomuodonvalintapoliklinikalta sekä toisella arkilla olevaa hoitopolkua kotihemodialyysiyksiköstä. Tee niihen täydennyksiä tai muokkauksia. Voit esimerkiksi kirjoittaa, mitä kyseisen käynnin aikana yleensä tehdään tai miten aika varataan potilaalle käyntiä varten. Lisäksi voit merkitä potilaan muut hoidot tai käynnit toisissa yksiköissä.
2. Pohdi kommunikaatiosi potilaan ja muiden potilaan hoitoon liittyvien tahojen kanssa. Miten ja milloin vuorovaikutat heidän kanssaan? Merkitse hoitopolkuun ohjeessa olevilla numerokodeilla, miten kommunikaatio toteutui.
3. Mitä sähköisiä palveluita käytät työhösi liittyen? Listaa käyttämäsi viralliset ja epäviralliset palvelut hoitopolun alle. Virallisia palveluita ovat esimerkiksi potilastietojärjestelmät ja epävirallisia esimerkiksi erilaiset Facebook-ryhmät, jotka liittyvät työhösi tai ammattiisi.

Figure 10: Example pretask of a predialysis nurse

ATTACHMENT C: CLINICIAN INTERVIEW QUESTIONS

Example interview script for a home dialysis nurse.

Esitettävien läpikäynti

- Tapaat potilaat ensimmäisen kerran hoitomuodonvalintapoliklinikalla. Mitä siellä tehdään?
- Valitseeko potilas hoitomuodon hoitomuodonvalintapoliklinikan käynnin yhteydessä? Ketä siellä on paikalla?
- Kun potilas on valinnut hoitomuodokseen kotihemodialyysin, mitä sen jälkeen tapahtuu?
- Käykö potilas jossain muualla hoidettavana hoitomuodonvalinnan aikana?
- Kuinka kauan tämä hoitopolku kestää?
- Mitä dialyysikoulutuksessa tehdään?
- Kuinka usein potilas käy seurantakäynneillä?
- Mikä on sinun roolisi tämän hoitopolun eri vaiheissa?
- Hoitopolun eri vaiheet:
 - o Miten hän päätyy tänne? Mitä hänelle tehdään siellä? Mikä on sinun roolisi tässä hoitopolun vaiheessa? Miten se näkyy potilaalle?
 - o Käykö potilas lisäksi jossain muualla hoidettavana?
 - o Mitä potilas tekee, jos hänelle tulee komplikaatiota tai ongelmia dialyysin kanssa? Tai muita haasteita?
- Olet merkannut eri kommunikaatiotavat hoitopolulle:
 - o Miten näitä käytetään?
 - o Miten kommunikaatio eri sidosryhmien (potilaiden, lääkäreiden, yksiköiden) välillä mielestäsi toimii tällä hetkellä?
- Onko hoitopolun aikana jotain tekijöitä, jotka vaikeuttavat/helpottavat työntekoasi?
- Mitä sähköisiä palveluja käytät?
 - o Miten yhteys potilaisiin? Yhteys muihin potilaan hoitohin liittyviin tahoihin?
 - o Dialyysikoneet?
 - o Miten käytät niitä ja kuinka usein?
 - o Miten koet niiden vaikuttavan työntekoosi?

Dialyysipotilaiden koulutus

- Miten tulevia dialyysipotilaita koulutetaan ja ohjeistetaan predialyysivaiheessa ja ennen dialyysihoidojen alkua?
- Ohjataan potilaita kotidialyysiin? Miten?
- Miten dialyysipotilaiden kouluttaminen/opastaminen jatkuu koko dialyysihoidon ajan?

Yksikkönne dialyysipotilaat

- Kuvailisitko tyypillisiä dialyysipotilaita? Minkä ikäisiä he ovat? Onko heillä muita sairauksia? Onko heillä perhettä? Miten usein he käyvät dialyysissä/hoidoissa?
- Mitkä tekijät sinun mielestäsi vaikuttaa siihen, että kyseisiä potilaita on juuri kotihemodialyysissä?
- Mikä on mielestäsi sinun tai muun hoitohenkilökunnan rooli dialyysimuodon valinnassa?

Dialyysin tulevaisuus (5 min)

- Mitä haasteita ja huolenaiheita dialyysihoidoissa mielestäsi on?
- Millaisena näet dialyysihoidon tulevaisuuden, jos mikä vaan olisi mahdollista? Nyt saa haaveilla!

ATTACHMENT D: PRELIMINARY TIMELINE TASK EXAMPLE FOR THE PATIENTS

MINUN MUNUAISTAUTIPOLKUNI

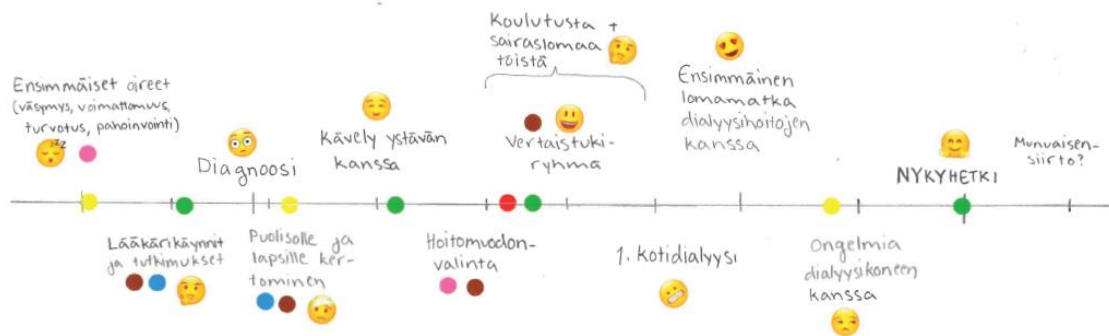


Figure 11: Patient pretask timeline example

ATTACHMENT E: PATIENT INTERVIEW QUESTIONS

Teema 1: Potilaspolku itse kuvattuna (merkitykselliset asiat, ei vain lääketieteelliset)

- Potilaspolun läpikäyminen
- Millainen hoitopolku on ollut (ensimmäisistä oireista, käyty sairaalat, hoidot, testit suurpiirteittäin, erityisesti eri dialyysimuodot)
 - Mistä lähteistä on saanut tietoa ja hakenut sitä sairauteen liittyen?
 - Millainen asumistilanne ja elinympäristö, onko tapahtunut muutoksia, tyytyväisyys?
 - Millainen sosiaalinen piiri on ollut sairauden aikana (perhe, suku, ystävät, onko tyytyväinen sosiaaliseen elämäänsä ja sen vilkkauteen)
 - Miten on voinut henkisesti potilaspolun aikana, millaisia tunteita on esiintynyt?
 - Kuvaile mitä teet ja mitä tapahtuu yhden tavallisen dialyysikerran aikana
 - Miten motivoituneeksi ja osaavaksi tuntee olonsa hoitoihin liittyen?
 - Millaisia haasteita on ollut, esimerkiksi katkoksia hoidossa?
 - Mitkä ovat vahvimpia muistoja sairauteen liittyen?

Teema 2: Kokemukset hoidosta ja mahdollisesti eri hoitomuodoista

- Hoidon muutokset
 - Miten muutokset hoitoihin valmisteltiin ja tiedotettiin?
 - Miksi muutoksia on tullut?
 - Miten sopeutuminen uusiin tilanteisiin hoitojen muuttumisen myötä on sujunut? Mikä vaikuttaa sopeutumiseen?
 - Minkä takia on päätynyt nykyiseen hoitomuotoon?
- Ammatillaiset
 - Miten hoitaneet terveydenhuollon ammattilaiset ovat tukeneet ja vaikuttaneet hoitomuodon valintaan?
 - Miten kommunikointi ja yhteistyö on yleisesti sujunut ammattilaisten kanssa?
 - Millaisiksi on kokenut ammattilaiset, esimerkiksi asenteiltaan tai luonteeltaan?

Teema 3: Kokemukset nykyisistä laitteista, ratkaisuista, palveluista, sovelluksista

- Mitä fyysisiä laitteita ja järjestelmiä, esimerkiksi dialyysilaitte, kuuluu oman sairauden hoitoon?
 - Miten käytät niitä?
 - Tyytyväisyys?
 - Onko HUS:n tutkimuksesta tullut laitteita käyttöön?
 - Mitä käytössä?
 - Kuinka pitkään ollut?
 - Tyytyväisyys?
- Mitä sähköisiä palveluita käytät itse säännöllisesti omaan sairauteen liittyen
 - Oletko valinnut tehdä jotkin asiat ei-sähköisin tavoin, esimerkiksi naamakain tai paperilla, vaikka ne olisi voinut tehdä sähköisesti?
 - Mitä muita palveluita tiedät, joita muut (munuaissairaat) käyttävät, miksi et käytä itse?

Teema 4: Tulevaisuuden visioita

- Millaisia asioita odotat tapahtuvan potilaspolullasi tulevaisuudessa? Millaisia muutoksia toivoisit tapahtuvan tulevaisuudessa?
- Onko mitään toiveita tai ideoita hoitoa tukeviin sähköisiin ratkaisuihin liittyen, voi olla pieniä ehdotuksia tai isoja konsepteja

ATTACHMENT F: CATEGORIZATION OF FINDINGS WITHIN PRINCIPLES

Here each individual finding from the case study is distributed under the principle which has the closest connection to it, either by helping support good experiences or mitigating negative ones. Pluses are positives, minuses negatives, question marks are suggestions. The theme of the findings is in brackets after it.

FOCUS ON THE USERS

Use participatory or user-centered methodology

- +Some of the existing services are good (clinician work services)
- Apotti not suitable for satellite clinic use (clinician work services)
- A lot of different tasks (clinician work services)

Tailor the system for different users or enable personalization options

- Information websites for patients have irrelevant information (eHealth services)
- Poor eyesight makes using some eHealth services difficult (eHealth services)
- Fear of needles affects how patients feel about some operations (care path)
- The study watch is ugly (tracking health data)
- ?A hybrid model, where paper and digital options would both exist (eHealth services)

vices)

Try to combat poor adherence and adoption rates

none

ENSURE EASE-OF-USE

Make the system usable

- Some services used by clinicians do not work (clinician work services)
- Using email is laborious (clinician work services)
- The scale is unreliable (tracking health data)
- Unclear if data is synchronized from measuring de-vices to the phone (tracking health data)
- Some notifications on the study phone are in English (tracking health data)
- Some notifications on the study phone have been missed (tracking health data)
- Dialysis machine is sometimes unreliable (home dialysis)
- ?Clear notification about the status on synchronizing data between study devices.

(tracking health data)

Support learnability

- Unclear home dialysis machine interface (home dialysis)
- ?More support for learning to use eHealth services (eHealth services)

?Stop-and-play function to the dialysis machine (home dialysis)

?Clearer home dialysis machine interface (home dialysis)

Visualize data and ensure its interpretability

+Seeing own health data is valuable (tracking health data)

-Some data is unclear (tracking health data)

?Show more history data (tracking health data)

?Show all own health data (tracking health data)

Explain the features, data, and care plan

+Education to home dialysis treatment was good (communication experiences)

-Study phone's application is unclear (tracking health data)

-Some patient eHealth services are unclear (eHealth services)

-Some treatments and tests feel unnecessary to the patients (care path)

-Blood pressure meter measurements from the study do not match measurements from the home dialysis machine's meter (tracking health data)

?More informative communication from the clinicians (communication experiences)

?Nutrition therapy should be earlier on the care path (care path)

Enable easy data entry, transfer and sharing

+Automatic data synchronization between the study devices (tracking health data)

+Supply order mistakes have been fixed (home dialysis)

-Ordering supplies using email is laborious (home dialysis)

-Making mistakes in the supply order process is possible (home dialysis)

?Replace manual work by automation (clinician work services)

?Add automatic dialysis data synchronization from the machine to a database (home dialysis)

?An application that would predict and suggest supply orders based on normal usage (home dialysis)

?Provide questionnaires digitally (eHealth services)

Make the system interconnected with current services

+Apotti is coming and it should connect all services into one platform (clinician work services)

-Doubts about Apotti succeeding in replacing multiple services (clinician work services)

-Clinicians use many different services (clinician work services)

?One service for everything (clinician work services)

SUPPORT SELF-MANAGEMENT

Support self-management and behavior change

- +Tracking health data is motivating (tracking health data)
- +Adapting to the new diet has not been an issue (diet)
- +Current devices from the study are good (tracking health data)
- +Starting dialysis treatments has improved condition (dialysis)
- Dialysis is not motivating if there are no symptoms (dialysis)
- Poor feedback causes anxiety (tracking health data)
- Not motivated to stick to the diet (diet)
- Hard to find suitable foods (diet)
- Regular checkups and tracking are tiring (care path)
- ?Reminders to be active (tracking health data)
- ?Better and clearer feed-back (tracking health data)
- ?Collect more detailed data (tracking health data)
- ?Reminders to take medication (eHealth services)
- ?Remove costs from home dialysis (home dialysis)

Enable support structures online and offline

- +Support from peers is valuable (personal life)
- +Satisfied with current social life (personal life)
- +Positive life attitude helps (wellbeing)
- +Having other substance in life than the illness is valuable (wellbeing)
- First dialysis treatments are scary (dialysis)
- COVID-19 pandemic makes seeing other people difficult (personal life)
- Peers might tell information the patient is not yet ready to hear (personal life)
- Being multimorbid is depressing (wellbeing)
- Poor condition affect mental well-being negatively (wellbeing)
- Not able to do physical work (personal life)
- Being denied permanent disability pension (personal life)
- ?Inform patients better about the existence of Facebook support groups (personal

life)

Support patient activation

- +Digital kidney carepath is good (eHealth services)
- +Some health information websites are good (eHealth services)
- Information websites do not answer all questions (eHealth services)
- Thinking about the disease is unpleasant (WELLBEING)
- Satellite dialysis treatment is restrictive (dialysis)
- ?Provide more information and better support for looking it up independently (care

path)

?An application to support and instruct in trouble-shooting situations (eHealth services)

CONNECT PATIENTS AND PROFESSIONAL HEALTHCARE

Connect healthcare professionals and patients

- +Good communication experiences (communication experiences)
- Messages are slower than phone calls (means of communication)
- Call times are restrictive (means of communication)
- Bad communication experiences (communication experiences)
- Constantly changing clinicians mean that the patients need to explain same things repeatedly (communication experiences)
- ?Remote and video-based communication options (means of communication)
- ?Personal nurses and physicians (communication experiences)
- ?Digital messaging for minor and non-urgent matters (means of communication)
- ?Provide study data to the personal nurses (tracking own health data)
- ?Monitoring should be always on, not only when the clinicians are called about it (tracking own health data)

Provide a care plan

- +Satellite dialysis treatments follow a clear schedule (dialysis)
- +Regular checkups follow a clear schedule (care path)
- +Regular checkups are important (care path)
- Not being eligible for a kidney transfer (care path)

Provide information about healthcare professionals' qualifications

- +Specialists of other medical fields have been knowledgeable about kidney diseases (communication experiences)
- Clinicians who are not specialized in kidney diseases, do not understand them (communication experiences)
- Physicians feel untrustworthy (communication experiences)
- ?Primary health care clinicians should be more educated about kidney diseases (care path)