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School of Science  
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Emil Virkki

# Characteristics of Digital Services Contributing to a Positive Patient Experience in Cancer Care

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Supervisor: Professor Marko Nieminen  
Advisor: Joel Lehtikoinen M.Sc. (Tech.)

<b>Author:</b>	Emil Virkki	
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<b>Supervisor:</b>	Professor Marko Nieminen	
<b>Advisor:</b>	Joel Lehikoinen M.Sc. (Tech.)	
<p>In the recent years, the concept of patient experience has emerged as a tool for understanding the patients' experiences of healthcare services. The aim of this thesis is to find characteristics of digital services that contribute to a positive patient experience in the context of cancer care. Kaiku Health, a follow-up and communication application for cancer patients, is used as an example digital service.</p> <p>The study consists of two parts, an analytical evaluation and an interview study. In the analytical evaluation Kaiku Health is analyzed with respect to existing models of user experience, customer experience and patient experience. The interview study is based on the Warwick Patient Experiences Framework and consists of seven in-depth interviews with cancer patients who have used Kaiku Health.</p> <p>Based on the analytical evaluation and interview study, the following characteristics were discovered: Supports Effective Coping Skills; Supports Patients' Sense of Security; Supports Patients' Participation and Internal Locus of Control; Supports Individualized Care; Maintains a Good Care Relationship over the Whole Patient Journey; Supports Patients' Need for Normality; Supports Understandable and Timely Communication; Helps Manage who Knows; and Integrates in Treatment Processes and Organization.</p>		
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<p>Viime vuosina potilaskokemuksen käsite on noussut esiin tapana hahmottaa potilaiden kokemuksia terveydenhuollon palveluista. Tämän diplomityön tavoitteena on löytää sellaisia digitaalisten palveluiden piirteitä, jotka edesauttavat positiivisen potilaskokemuksen muodostumista syövänhoidossa. Kaiku Health, syövänhoitoon tarkoitettu seuranta- ja viestintäsovellus, toimii esimerkkinä tällaisesta digitaalisesta palvelusta.</p> <p>Tutkimus koostuu kahdesta osasta, analyttisestä arvioinnista ja haastattelututkimuksesta. Analyttisessä arvioinnissa Kaiku Healthia arvioidaan suhteessa olemassa oleviin käyttäjäkokemuksen, asiakaskokemuksen ja potilaskokemuksen malleihin. Haastattelututkimus perustuu Warwick Patient Experiences Framework -viitekehikseen ja koostuu seitsemästä Kaiku Healthia käyttäneiden syöpäpotilaiden syvällisestä haastattelusta.</p> <p>Analyttisen arvioinnin ja haastattelututkimuksen pohjalta löydettiin seuraavat hyvää potilaskokemusta edistävät piirteet: tukee toimivia selviytymistaitoja; tukee potilaiden turvallisuuden tunnetta; tukee potilaiden osallistumista ja sisäistä hallintakäsitystä; tukee yksilöllistä hoitoa; tukee hyvää hoitosuhdetta koko potilaspolun ajan; tukee potilaiden normaaliuden tarvetta; tukee ymmärrettävää ja oikea-aikaista viestintää; auttaa hallitsemaan kuka tietää sairaudesta; sekä integroituu osaksi hoitoprosesseja ja -organisaatiota.</p>			
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# Chapter 1

## Introduction

Approximately one in three Finns will get cancer before their 75th birthday (Engholm et al. 2016). In Finland alone, over 30 000 people received a cancer diagnosis in 2014 (“Suomen Syöpärekisterin Tilastot” 2016). Cancer and its treatment are difficult for the patient both physically and psychologically. Adverse effects of cancer can be significant. For example, Kyrдалen et al. (2013) identified erectile, urinary and bowel dysfunction as the most common adverse effects of prostate cancer treatments. Hassett et al. (2006) found that 16% of women undergoing chemotherapy for breast cancer had visited the emergency room or been hospitalized due to treatment-related adverse effects. The psychological effects of cancer are also significant. Zab-ora et al. (2001) found that 35% of cancer patients experience a significantly elevated level of psychological distress. Mary Rucklos Hampton (2000) found that 27% of female and 10% of male cancer patients developed symptoms of post-traumatic stress disorder. Psychological interventions exist, but not all patients want psychosocial support (Redd and Jacobsen 1988).



## 1.1 Digital Therapeutics and Patient Experience

*Digital therapeutics* is an emerging trend of using software applications to augment or replace medication by bringing about behavioral changes in patients' lives. Digital therapeutics are hoped to have less adverse affects than traditional medications and to cost significantly less money to develop. In recent years a number of technology companies developing such solutions have emerged. (Farr 2017) Digital therapeutics have already demonstrated some results. Sepah, Jiang, and Peters (2015) found that a behavior-affecting application helped prevent the pre-diabetes from developing into diabetes. Pinto et al. (2016) found promising results in treating depression in young adults.

The concept of *patient experience* (PX) has emerged in literature over the last few years. Patient experience focuses on the patients' subjective experience of their care as a quality indicator extending the more traditional view of medical quality focusing on technical quality and effectiveness of treatment. (Wolf et al. 2014). The experience of treatment-related digital services has traditionally been examined through the concepts of user experience (UX) or customer experience (CX), but not patient experience. Patient experience could provide a useful framework for understanding the experience of treatment-related digital services. Additionally, the concept of patient experience could have useful practical implications for the design and evaluation of such services.

Kaiku Health is a web-based application that aims to improve the quality of life of cancer patients and survivors. The application allows patients to report treatment outcome data known as Patient-reported Outcome Measures (PROMs) and to communicate easily and securely with the treatment staff. The PROMs reported in the service include adverse effects symptoms and quality of life data that the treatment staff can use to provide better, more individualized care to patients. Kaiku Health is provided for the patient by

the clinic and forms only one of the many touch points the clinic has with its patients.

## 1.2 Objective and Research Questions

This thesis aims to find ways in which digital services can contribute to a good patient experience for cancer patients. The scope of this thesis is narrowed to digital services for cancer patients because the customer company of this thesis, Netmedi Oy, is developing such a service.

Research question: *What characteristics contribute to a positive patient experience in a digital service for cancer patients?*

The research question is examined through Kaiku Health, an example of a digital service for cancer patients. The research question can be divided into three parts. To answer the research question we must understand digital services and their user and customer experience, define what exactly is meant by *patient experience* and to consider what special aspects of cancer treatment and recovery we must take into account. These themes form the conceptual basis for this thesis.

This thesis consists of eight chapters. The first chapter serves as an introduction to the topic, justifies the importance of this study and introduces the research question. The second chapter introduces the theoretical background of this thesis. Chapter three introduces the software application Kaiku Health that is used as an example service in this study. The fourth chapter describes the research methods and their application in this study. The fifth chapter contains an analysis of the application based on the theoretical models introduced in chapter two. Chapter six summarizes the implementation of the empirical research and its results. The seventh chapter discusses the findings and examines the suitability of the research methods. Chapter eight draws conclusions and discusses the implications of this study.

## Chapter 2

# Conceptual and Theoretical Foundation

In this chapter the conceptual and theoretical background of this thesis is introduced, including the concepts of user experience, customer experience and patient experience.

### 2.1 Psychological Effects of Cancer

Being ill with cancer is a very difficult situation psychologically and a major disruption in the patient's life. Zabora et al. (2001) found that 35% of cancer patients experience a significantly elevated level of psychological distress, such as symptoms of depression or anxiety. The level of distress varies by seriousness of diagnosis and burden of treatment, but is also affected by several demographic variables such as age, marital status and income (Zabora et al. 2001). Mary Rucklos Hampton (2000) found that 27% of female and 10% of male cancer patients developed symptoms of post-traumatic stress disorder. Redd and Jacobsen (1988) found that almost 50% patients express symptoms that fulfill the criteria for psychiatric disorders such as adjustment disorder or major depression, but acknowledged that for most patients the symptoms are a temporary stress reaction related to the progression of the

disease, adverse effects of treatment or personal matters. Certain factors are associated with psychological adjustment: severity of side effects, premorbid adjustment, quality of doctor-patient relationship, and adequacy of familial social support (Redd and Jacobsen 1988).

Cancer also affects sexuality and fertility. Sexual dysfunction and infertility are common long-term effects of cancer and treatment. For men the damage in the autonomous nerve system or reduced blood flow to the penis can cause erectile dysfunction. For women, premature ovarian failure and radiation fibrosis are most common and scar tissue can cause pain during intercourse. (Schover 2005)

According to Redd and Jacobsen (1988), psychological interventions such as psychotherapy, social support groups and behavioral therapy have been used with cancer patients. However, not all patients want outside help and prefer to cope using their own resources. Zabora et al. (2001) recommend that patients should be screened for psychosocial well-being as a part of comprehensive cancer care. They state that if elevated levels of distress are not discovered it will endanger the outcomes of treatment, weaken the quality of life and increase costs.

During the treatments patients have a variety of concerns that depend on the phase of the illness. During diagnosis and treatment patients are worried about the illness itself, the inability to do things, the treatments and their future. During palliative care the issues of quality of life, independence and the effect on family become concerns. However, most of these concerns go unnoticed by the healthcare staff. The staff may not have the courage to ask the patients about their concerns for several reasons. They may fear it may be psychologically harmful, for example that asking about suicidal thoughts could result in the patient considering suicide. The staff may also fear that patients will express emotions that the staff cannot handle. They may not experience their communication skills as adequate for eliciting concerns. Additionally, there may not be enough emotional support available for staff. (Farrell et al. 2005)

P. Maguire (1999) claims that patients may also be wary of sharing their concerns. They may believe that anxiety and depression are normal parts of the illness and treatment of cancer. They may fear that if they bring up their concerns the treatment staff will label them as ungrateful or neurotic. Some patients don't want to burden the busy staff. The issue is even more pressing when the staff does not ask questions that would encourage the patient to tell about their concerns, leading patients to believe that the staff is uninterested in their subjective experience. Patients are seldom asked about how they have reacted to treatment or the effects of the treatment on their broader life and emotional well-being. According to Farrell et al. (2005) not eliciting concerns is associated with the development of anxiety and depression later. Many of the patients' concerns could have been alleviated had they been noticed.

To alleviate the stress caused by the disease, cancer patients employ a wide range of coping strategies (Livneh 2000). Possible strategies include information seeking, confronting the illness ("fighting spirit"), denial, using humor and wishful thinking. Some patients, especially in later stages of the disease, seek help from religion. Different cancer types result in different distributions of coping strategies. Appropriate coping strategies vary for example by the stage of the illness and effects of treatment. Coping strategies can be classified as emotion-focused or problem-focused, approach or avoidance and engagement or disengagement. Engagement-oriented strategies are generally associated with better psychosocial adaptation and include problem-solving (solving the problem with focused planning and execution), information-seeking, positive reinterpretation (focusing on the positive, finding the positive things in the situation), confronting the illness or "fighting spirit", seeking social support and humor. Disengagement-oriented strategies are associated with higher levels of emotional distress and worse adaptation and include denial (pushing the anxiety and threat out of mind), wishful thinking (resorting to fantasy and distraction), escapism (praying for cure, resorting to drinking, risky behavior etc.), blaming oneself for the illness and

fatalism, hopelessness and helplessness. (Livneh 2000)

An internal locus of control, i.e. experiencing one can affect the advancement of the disease or that the treatment staff can affect the advancement results in better adjustment. Optimism is associated with better adjustment and is often associated with well-adjusting coping strategies. In general, having an internal locus of control, an optimistic outlook and a minimizing perspective on the effects of the disease result in better adjustment and lower distress. Livneh argues that the treatment staff should help their patients develop coping skills that encourage patients to believe in their own ability to challenge the disease; encourage and help to solve the daily problems brought by the illness such as adverse effects; form and maintain a social support network of family, friends and other patients with the same condition; and reframe negative thoughts and pessimism to focus on remaining abilities, realistic goals and potential future contributions. Cognitive-behavioral coping skills training programs have had positive effects. (Livneh 2000)

Traditionally psychological interventions such as psychotherapy, social support groups and behavioral therapy have been used with cancer patients (Redd and Jacobsen 1988). Digital therapeutics could be used to support the psychosocial well-being of patients. This thesis focuses on the possible role of digital services to support cancer patients' psychological well-being.

## 2.2 User Experience

To understand patient experience, this thesis approaches the concept from the theoretical basis of user experience and customer experience. This is because this thesis focuses in digital services and user experience and customer experience can augment the concept patient experience in this context.

Despite widespread interest in *user experience* (UX) in the field of Human-Computer Interaction (HCI), the term itself has been lacking definition (Law et al. 2009). However, Hassenzahl and Tractinsky (2006) consider that user experience consists of three facets (figure 2.1). First,

user experience is something *beyond the instrumental*: product is seen more holistically than just through its instrumental value. User experience augments mere usefulness and ease-of-use with aesthetic and hedonistic qualities. Second, user experience takes into consideration the *emotion and affect* of the user, both as consequences of use and antecedents for acceptance and use. Hassenzahl and Tractinsky argue that user experience is about creating positive affect but also pose the question if emotions can at all be designed: are they affected by so many situational aspects beyond the designer's control that designers must settle for creating context for emotion? In any case, affect and emotion are subjective. Third, user experience has to do with *the experiential*. It is situated, meaning that the experience takes place in specific situation or context and internal state of the user and in which the product itself is only one element, making the experience complex and unique. The experience is temporally bounded, having a beginning and an end. User experience is also experiential in the sense that it is about what is happening *now*, experience as constant stream of self-talk related to the use of a product, making it subjective and dynamic.

## 2.3 Customer Experience

Customer experience means the internal and subjective response a customer has to any contact with a company, direct or indirect (Meyer and Schwager 2007). Direct contact means direct contact between the customer and the company or its offering including among others the product or service itself, customer service and packaging. Indirect contact involves representations of the product, service or company: advertisements, word-of-mouth, news, reviews etc. Improving customer experience is both about measuring and improving the qualitative aspects of the experience (beyond mere satisfaction ratings) and removing organizational silos by focusing on the customer perspective to create a simple, integrated experience. (Meyer and Schwager

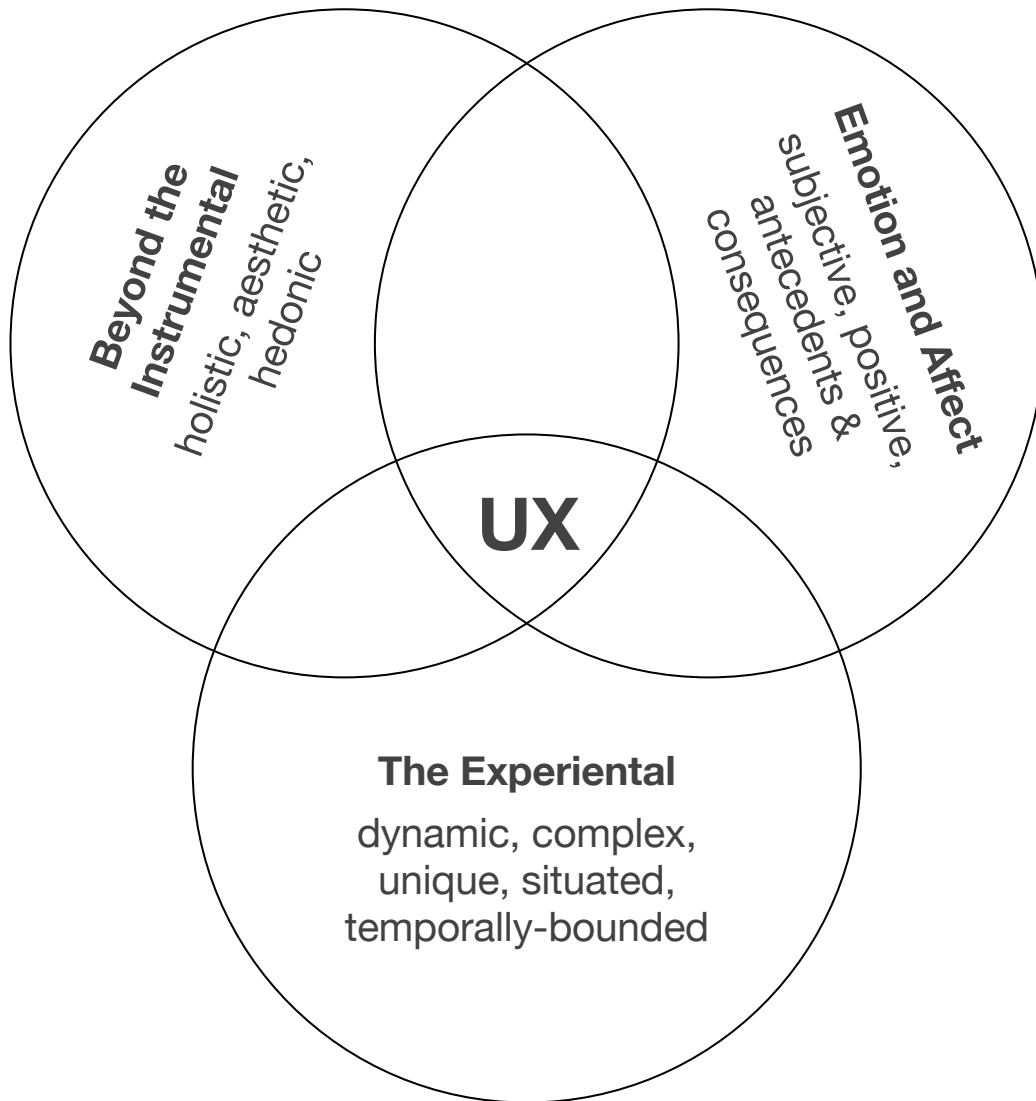


Figure 2.1: The three facets of user experience by Hassenzahl and Tractinsky (2006)



2007)

Customer experience is personal and subjective. It is temporal in that it encompasses the entire set of interactions with the company and its offering over time. It is holistic both in the sense that it involves all contact between the customer and company and in the sense that it involves and engages the customer through different dimensions. These can be expressed as the six components of customer experience: the sensorial, emotional, cognitive, pragmatic, lifestyle and relational components. The *sensorial* component is about producing experiences that stimulate different senses. The *emotional* component is about affecting the mood and affect of customers. The *cognitive* component is about engaging the customers' creativity or problem-solving skills. The *pragmatic* component deals with the utility and ease-of-use of the product or service. Through the *lifestyle* component products and services can accentuate the customers' system of values and beliefs. Finally, the *relational* component allows customers to create a bond with other people, for example through using the product together or by creating a sense of belonging to a community. The way the customer evaluates the experience depends on the customer's unique expectations and how the actual interactions matched them. (Gentile, Spiller, and Noci 2007)

Thus, customer experience can be seen as an extension of the user experience to encompass the customer's interactions not just with the product, but with the whole company or brand. Customer experience as described by Meyer and Schwager (2007) and Gentile, Spiller, and Noci (2007) is similar to user experience in that it is personal, subjective, holistic and temporally bounded. The sensorial component of customer experience can be seen analogous to the aesthetic aspect of user experience's *beyond the instrumental* facet and the cognitive component can be seen relating to the hedonic aspect of the same facet. The emotional aspect can be seen as an extension of the *emotion and affect* facet. Both user experience and customer experience are related to utility and ease of use - Gentile, Spiller, and Noci (2007) expresses this in the pragmatic component, Hassenzahl and Tractinsky (2006) talks

about utility and ease of use more as prerequisites for a good user experience. Gentile, Spiller, and Noci (2007) do, however, add two components that are not expressed in the Hassenzahl and Tractinsky (2006) framework: the lifestyle and relational components.

## 2.4 Patient Experience

In recent years medical practitioners have started to understand healthcare quality more broadly than just technical quality and effectiveness of treatment and have begun giving more attention to the patients' experiences of their care than previously (Wolf et al. 2014). This has given rise to the term *patient experience*. Wolf et al. (2014) performed a literature review to compare and improve existing definitions of patient experience. They discovered 82 academic and non-academic sources published between 2000 and 2014 that contained a definition for or framework describing the term. Of those, 18 contained a unique definition. All the sources that had been dated were from years 2009 to 2014 (Wolf et al. 2014), indicating that interest in the academic world regarding patient experience has only awakened in last few years. There is no commonly agreed definition for patient experience. However, Wolf et al. (2014) did find several characteristics of patient experience that were shared among at least some authors. These were:

- *Continuum of care*: Patient experience is not a matter of just one interaction with the healthcare provider. It is created over a longer timespan, involving several touchpoints between the patient and clinic. These touch points may be related to treatment or be non-clinical in nature, such as billing or wayfinding at the clinic. The patient experience starts forming already before a treatment relationship when the future patient assesses the reputation of the clinic or is exposed to its communications. The organizational culture and participation of healthcare staff have an enormous effect on how the experience turns out.

- *Beyond survey results:* Surveys such as the *Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)* cannot encompass the breadth and depth of the experience. The experience is affected by the rationally understandable clinical performance of the clinic but also by the sensorial and emotional experiences and the patient's expectations.
- *Focus on expectations:* It is important that the patients feel their expectations for the care have been met. These expectations can be clinical or emotional.
- *Aligned with patient-centered care principles:* A good patient experience is in line with patient-centered care principles. The staff must provide care that takes the patient's perspective into account and puts the patients needs first. This requires that in addition to providing competent and high-quality care the clinical staff must coordinate the care between staff members and personalize the care for each patient. The staff must respond in a timely fashion and be reliable.
- *Focus on individualized care:* Care must be tailored for each patient and the patient should be actively involved in their care and decisions regarding their care. Healthcare staff must ensure patients are known as individuals, respected and that their physical and emotional comfort (emotional support, relieving fear and anxiety) is attended to. Staff must be compassionate and empathic and communicate well. The patient should be provided information and educated about their illness and treatment. Family and friends should be involved in treatment.
- *More than satisfaction:* Patient experience should not be equated with satisfaction. It is more complex and multifaceted than mere satisfaction.

Patient experience can be seen as a manifestation of customer experience in the healthcare context. As with customer experience, considering the whole continuum of care or customer journey is vital. Both take into account both direct (e.g. visit) and indirect (e.g. reputation) encounters with the

company or clinic. Both agree, that customer or patient expectations affect the experience and are thus vital to take into account. Customer experience acknowledges that the experience is subjective and internal to the consumer and cannot be encompassed by a simple satisfaction rating. Wolf's patient experience facets contain both "More than satisfaction" and "Beyond survey results".

There are three significant additions to customer experience, though. Firstly, the term itself, patient experience, implies treatment and therefore illness. Wolf et al. (2014) acknowledges that the word *patient* may not always be appropriate in healthcare – for example, calling a person participating in a prevention program a patient may not be fair. In the context of this thesis, calling cancer survivors who are participating in treatment follow-up may not be entirely valid either. However, Wolf et al. (2014) argues that for the sake of consistency the same term should be used of all the people participating as users in the healthcare system. Secondly, patient experience adds the focus on individualized care. In the healthcare sector where human-to-human contact is front and center and staff should know their patients as a person and an individual with individual needs – especially when the illness or treatment is painful or emotional. This is not a necessity when building a good customer experience, for example, in bulk retail. Individualized care also means involving the patient in their care and decisions regarding their care, which is not often necessary outside healthcare. Thirdly, patient experience is in line with patient-centric care principles, which do not exist outside the healthcare domain.

## 2.5 Warwick Patient Experiences Framework

Several factors affect the patient experience. One of the frameworks describing the elements of patient experience is the Warwick Patient Experiences Framework (Staniszewska et al. 2014). The framework was developed based on a scoping study of literature describing factors that affect the experience

of patients with cancer, diabetes or cardiovascular disease. The Warwick Patient Experiences Framework describes seven themes that make up the patient's experience. These high-level, generic themes consist of more concrete sub-themes. The seven themes are: (Staniszewska et al. 2014)

- *Patient as active participant*: Patients can, if they want to, be active participants in their treatment, making decisions together with health-care professionals and self-managing. Patients co-create the health care service and their own health.
- *Responsiveness of services – an individualized approach*: Patients are encountered as individuals, and healthcare services are tailored for their needs, preferences and values. Includes effectiveness and perceived performance of treatment.
- *Lived experience*: The individual, personal experience of living with the condition. Family and broader life need to be taken into account. The effect of lived experience on the self-care. New physical and cognitive needs arising from the condition. Personal experiences, expectations and emotions, including fear, feelings of loss, uncertainty or blame.
- *Continuity of care and relationships*: Availability, accessibility and responsiveness of services. First impressions. Being known as a person throughout the patient journey. Feelings of abandonment when treatment ends or support is not made available. Respect for the patient. Trust in the healthcare professionals built up over time. Partnership in decision-making.
- *Communication*: individual communication, communication methods and styles, communication skills and body language of staff. Listening to the patient. Compassion and empathy. Enabling questions and giving answers.
- *Information*: Patients are provided enough information to facilitate self-care and effective shared decision-making. Information is provided at the right time. The patient may or may not want information. Information sources inside and outside the health service. Information

quality.

- *Support* Need for emotional support and hope. Individual support needs and the health care professionals' support for those needs. Support for self-care. Peer support and the support of family and friends. Practical support. Education. Not wanting to be a burden.

The Warwick Patient Experiences Framework provides good basis for this research. The themes in the framework are generic (Staniszewska et al. 2014), making it possible to apply the framework in different contexts, including software product design. As a holistic framework it does not limit the scope of the research but helps understand the whole experience, making it possible to find surprising aspects of the experience that could be improved with software. The framework takes into consideration both the practical aspects - such as problems in communication - and also the emotional aspects of the patient experience, which are both necessary in designing for experience. The Warwick Patient Experiences Framework has been developed based on scoping study of patient experience -related articles in the fields of cardiovascular diseases, cancer and diabetes (Staniszewska et al. 2014) making it very suitable of use in a cancer treatment context. The framework also has its drawbacks. It has been created as a basis for development of clinical guidelines for healthcare providers (Staniszewska et al. 2014) and thus represents the health care provider's point of view into patient experience. This makes it more useful to apply the framework in developing the health care provider's services, but makes the framework somewhat unbalanced for classifying findings about patients' experiences. The lived experience of the patient is diminished into a single theme, even though it encompasses most of the subjective experience of the disease and its treatment. Also, since the framework has been developed in the context of Great Britain, cultural differences may reduce its applicability in the Finnish context. Since both countries are modern, western cultures, the differences are unlikely to affect the validity of this research.

## Chapter 3

# Kaiku Health and its Use

This thesis focuses on the cancer treatment features of Kaiku Health. Kaiku Health (formerly Kaiku) is a web-based application for follow-up and communication during cancer and fertility treatments.

### 3.1 Kaiku Health

Kaiku Health allows patients to contact their care team at the clinic and to report patient-reported outcome measures (PROMs) such as symptoms and quality of life data. Gathering PROMs is valuable, because it allows the care team to monitor the patients' well-being also outside the clinic. Additionally, web-application-guided follow-up can improve patients' survival and functioning as was shown by Denis et al. (2016) in a study on lung cancer patients. Patient-reported outcome measures on adverse effects have been shown to be as precise as clinician-reported outcomes, with patients reporting slightly more serious adverse effect than clinicians (Basch et al. 2006). The application also allows tracking laboratory values. Kaiku Health supports follow-up programs, which are packages of PROMs and laboratory values that are built for specific cancer types and treatments and allow gathering the necessary data at the right time using automatic timers. The application also allows building follow-up programs customized for each patient.

Kaiku Health is developed by the Helsinki-based digital health company, Netmedi Oy. Netmedi was founded in 2012 and employs over 20 employees in Finland and Germany. Kaiku Health is based on Netmedi's proprietary health platform, which is currently used in over 20 clinics in Europe with more than 20 000 end users and is available in 7 languages.

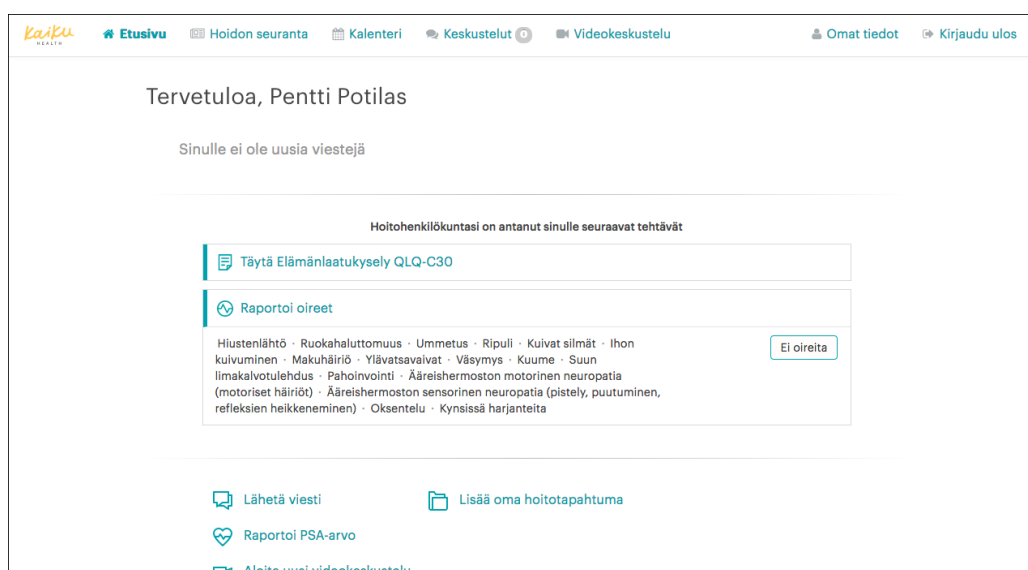


Figure 3.1: Kaiku Health enables real-time follow-up of patient-reported outcomes and easy contact to the care team

Kaiku Health allows patients to report symptoms arising from the illness itself or adverse effects of treatment, allowing treatment staff to react to alarming symptoms and make better decisions regarding the patients' care. Kaiku Health can also suggest self-care instructions for patients based on the symptoms they have reported. The patients can be asked fill-out standard questionnaires regarding their quality of life, helping the care team obtain a comprehensive understanding of the patients' well-being. Using internationally standardized forms such as the QLQ-C30 (Aaronson et al. 1993) or EPIC-26 (Wei et al. 2000) allows healthcare professionals to compare the effects of different treatments on the quality of life of patients. Kaiku Health can automatically calculate the standard grades and scores for the patients'



answers. Patients can also be asked to fill out other forms such as depression screenings or even clinic-specific paperwork.

The application also features a secure communications feature, which the patients can use to contact their own care team when they have any questions or doubts. The chat-like feature also allows sharing of files such as medical certificates. Kaiku Health can also be used for sharing laboratory results. The application can pull the values automatically from the clinic's electronic medical records system or laboratory information management system. The patient can also enter the values manually, for example in cases where the patient measures the values themselves (such as blood pressure) or uses a laboratory outside the clinic. The latter is common practice for follow-up patients living a significant geographical distance from the clinic.

Kaiku Health is built on Netmedi's proprietary health platform, which is also used in other medical fields such as occupational health. The platform is highly customizable and is provisioned as a separate installation for each customer clinic. This allows all application content, including available follow-up programs, forms, potential symptoms and laboratory values to be customized specifically for the clinic's needs. Available languages and visual appearance can also be customized for the client. The platform is based on Ruby on Rails and uses a PostgreSQL database for persistence. The communication between the end-user device and the application is protected using Transport-Layer Security (TLS). The user interface is responsive, making it possible to use the application on a variety of devices from mobile phones to desktop computers. Kaiku Health is CE-marked as a Class 1 Medical Device.

## 3.2 Typical Users

A wide range of cancer patients and survivors use Kaiku Health. The age and gender distribution varies by clinic and depends on the variety of therapies for which the clinic uses Kaiku Health. Kaiku Health users are typically older, as cancer is more prevalent in the older population (Stewart and Wild

2014, 22). The fictional persona in figure 3.2 presents an example of a typical Kaiku Health user, Pentti. Pentti is a persona based on earlier research with patients and staff. Pentti is also used as the protagonist in the following usage scenarios. The persona method, introduced by Cooper (2004), aims to help designers consider the needs of different user groups by creating fictional, but research-based, user archetypes called personas.

### 3.3 Example Scenarios of Kaiku Health usage

The following scenarios provide examples of the use of Kaiku Health. Since the example persona Pentti would use the application in Finnish, the screenshots provided are in the Finnish language. Additionally, the patients interviewed in the empirical study in this thesis have all used Kaiku Health in the Finnish language.

The scenarios are based on the treatment processes used at a private cancer clinic in Finland and discussions with the clinic's staff. The empirical research in this thesis was conducted with patients of the same cancer clinic. The cancer diagnosis can happen at the public sector or at the private clinic. The treatments are performed at the clinic and after the treatments the patient participates in follow-up for at least five years. The follow-up can take place at the clinic or at the public health care center. Patients living far away from the private clinic can visit a laboratory near their home and send the results to the clinic for follow-up.

#### 3.3.1 Scenario 1: Symptom Follow-up

Some time after starting treatments, Pentti's nurse Mari asks if he would like to register in Kaiku Health. She explains that follow-up of the treatment's adverse effects and Pentti's well-being in Kaiku Health is an important part of treatment and that the application also allows Pentti to contact the care team directly from anywhere he likes. Pentti thinks it's important for the care team to have the best possible knowledge on how he is doing, so he

## Pentti, 72 “I really hope it hasn’t spread”

### Background information

**Occupation:** Retired. Worked as a customer manager at an electronics importer before retirement.

**Family:** wife Kaisa, two adult children, two grandchildren

**Residence:** Lives in Hämeenlinna

**Financial status:** Stable financial situation. Has a private health insurance to cover expenses.

### Technology

Pentti is interested in and optimistic about information technology, but not an experienced computer user. In addition to Kaiku Health, he uses email and online banking. Pentti owns a Windows laptop and does not own a smartphone.

### Support

Wife has been the most important source of support through diagnosis and treatment. After treatment was complete, Pentti learned about a peer support group organised by the local cancer association and has attended their meetings a few times.

### Hopes and fears

Hopes to experience his grandchildren growing up. Fears that the cancer may spread.

### Goals

Feeling of safety and control. Wants to do as much as he can to fight the disease.

### Pentti’s Story

A year ago Pentti had an annual doctor’s appointment, and the doctor noticed a significant rise in the PSA (prostate-specific antigen) blood value. Knowing this could indicate prostate cancer, the doctor sent Pentti to a urologist for further examination. Pentti was scared and worried and his wife was wondering what was amiss. “Everything’s fine!” Pentti snapped.

After a biopsy, the urologist diagnosed Pentti with prostate cancer. The diagnosis was a shock and a relief at the same time. When Pentti finally told his wife about it, they both burst out in tears. Pentti had a hard time explaining his condition to his children, and he tried to play down the seriousness of it so that they wouldn’t be too worried.

The urologist and a surgeon agreed that the cancer was curable and proposed a radical prostatectomy, removing the prostate - and the tumour within - via surgery. Pentti didn’t want to wait for weeks or months for a surgery in the public sector and happened to have a private health insurance, so he went to a private clinic for treatment. The doctor at the private clinic recommended radiation therapy, which he said was as effective as surgery but should have less adverse effects. Some time after the radiation therapy had started, he was introduced to Kaiku Health which the nurse told was an easy way to stay in touch with the clinic and track Pentti’s well-being.

The first follow-up after the radiation therapy was six months later. Since Pentti lived far away from the private clinic he had his PSA blood tests done in his local public healthcare centre, but sent the results to the doctor at the private clinic via Kaiku Health. So far, the radiation therapy seems to have worked.

Figure 3.2: A persona description of Pentti, a typical user of Kaiku Health

decides to take Kaiku Health into use. When he gets home he opens the invite email from Mari and registers in Kaiku Health.

A day after his next chemotherapy session he receives an email asking him to report his symptoms. Using a link in the email, Pentti opens the symptom reporting form in Kaiku Health and reports some constipation (figure 3.3). He also reports some other, mild symptoms. After completing the questionnaire Kaiku Health automatically suggests ways that could help reduce Pentti's constipation such as foods and beverages and physical exercise (figure 3.4). Pentti decides to have broccoli as a side dish at dinner. "And maybe some plum custard for dessert", he thinks.

Figure 3.3: Reporting symptoms in Kaiku Health

### 3.3.2 Scenario 2: Quality of Life Follow-up

Three weeks after the treatments have started, Pentti receives an email asking him to fill out a quality of life questionnaire. Pentti opens Kaiku and fills out the form (figure 3.5). The questions are about his physical and psychological well-being. A few days later, when Pentti visits the clinic again, the nurse

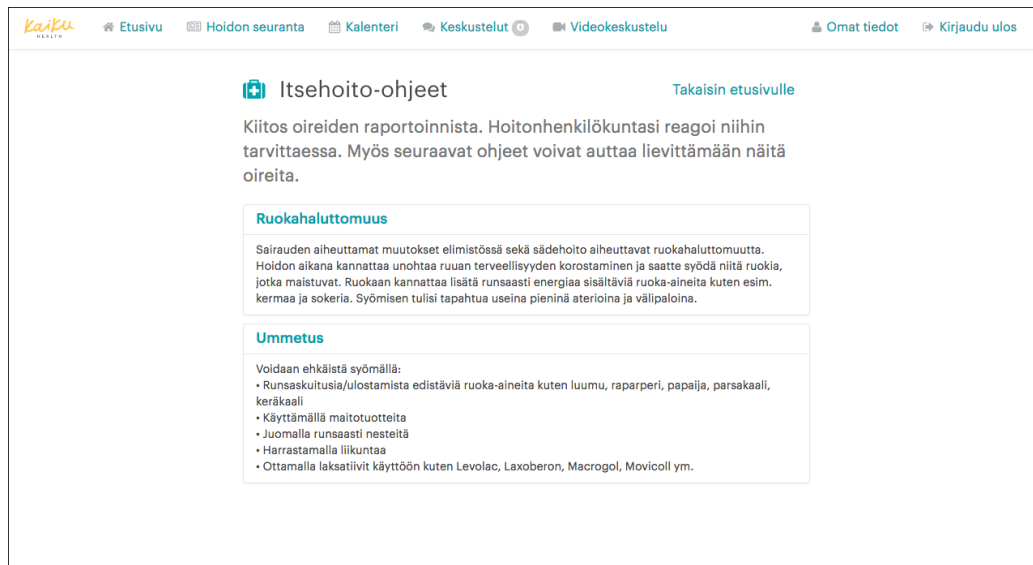


Figure 3.4: Kaiku Health provides the patient with self-care instructions based on the symptoms they have reported

brings up Pentti’s low emotional functioning score and suggests that Pentti go visit the clinic’s psychotherapist. Pentti promises to think about it.

### 3.3.3 Scenario 3: Conversation with Treatment Staff

The treatments have been completed and Pentti is enjoying his retirement. During an early-morning walk with his wife, Pentti notices mild pain in his joints. He doesn’t think much about it but after the pain continues the next day he becomes worried - could it be that the cancer has spread to his bones? In the evening Pentti opens Kaiku Health and sends a message to his care team asking about the pains (figure 3.6). The next morning Pentti receives an email notification that the doctor has answered his question. He opens Kaiku Health and reads the doctor’s reply. “There’s nothing to worry about” the doctor writes and explains that nothing points to the cancer spreading based on Pentti’s lab values, latest magnetic resonance imaging and Pentti’s description of the pain.

**Elämänlaatukysely QLQ-C30**

Selvitämme kyselyssämme joitakin teitä ja terveyttänne koskevia asioita. Pyydämme teitä vastaamaan itse kaikkiin kysymyksiin ympäröimällä parhaiten sopivan numeron. Tässä kyselyssä ei ole "oikeita" eikä "väärää" vastauksia. Pidämme antamanne tiedot ehdottoman luottamuksellisina.

(1 / 2)

\* tarkoittaa, että kysymykseen on annettava vastaus.

Tuntuvatko rasittavat työt kuten painavan ostokassin tai matkalaukun kantaminen teistä työläitä?

Ei lainkaan

Vähän

Melko paljon

Hyvin paljon

Tuntuvatko pitkät kävelymatkat työläitä?

Ei lainkaan

Vähän

Melko paljon

Figure 3.5: Patients can answer standardized quality of life questionnaires in Kaiku Health

**OMAT KESKUSTELUT**

Oma hoitaja

Tekninen tuki

**Keskustelu alkaa**

Hei! Tässä keskustelussa voit olla melhin yhteydessä missä tahansa terveyteesi tai hyvinvointisi liittyvässä asiassa.

keskiviikko, maalisuu 1.

**Pentti Potilas**  
muutama sekunti sitten

Hei,  
Sellaisella asialla otin yhteyttä että huomasin tässä pari päivää sitten kipuja vasemmassa kyynärnivleessä. Ei mitään kovin voimakasta, vähän sellaista ikävän tuntuista vain. Mutta kun puhuttiin silloin Lassen kanssa, että ensimmäisenähän tämä tauti menee sinne luihin, että voisiko olla kyse siitä?  
Kiitoksin,  
Pentti

Kirjoita viestisi tähän

Lisää liite

Lähetä

**Hanna Hoitaja**  
Hoitaja

**Lasse Lääkäri**  
Lääkäri

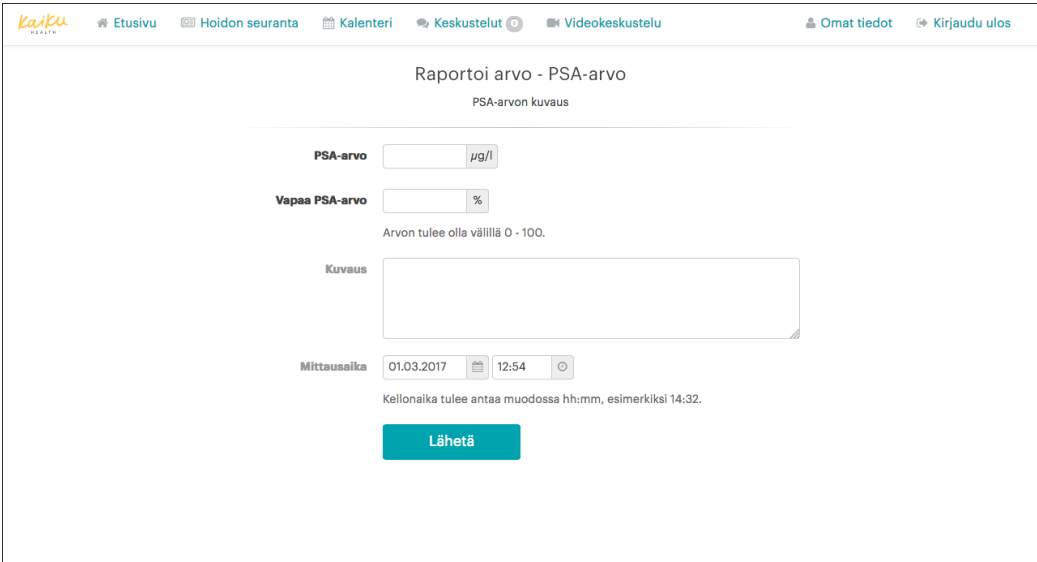
**Pentti Potilas**  
Asiakas

Keskustelussa ei ole liitetiedostoja.

Figure 3.6: Kaiku Health includes a messaging feature, allowing patients to contact their care team when and where needed

### 3.3.4 Scenario 4: Reporting and Following Lab Values

Six months after completing the treatment Pentti is worried. His first follow-up is coming up and he is afraid about what the results will be. Since he lives away from the clinic, he has his PSA blood test taken at the local healthcare center. The results arrive in the mail a week later. Pentti looks at the results and as far as he can tell, they seem fine. Pentti enters the results in Kaiku Health (figure 3.7), knowing his oncologist will have a look at them. Recording all his PSA values in Kaiku Health also allows him to follow his PSA history in one place.



The screenshot shows the Kaiku Health web application interface. At the top, there is a navigation bar with the Kaiku logo and several menu items: Etusivu, Hoidon seuranta, Kalenteri, Keskustelut, Videokeskustelu, Omat tiedot, and Kirjautu ulos. The main content area is titled "Raportoi arvo - PSA-arvo" and "PSA-arvon kuvaus". It contains a form with the following fields:

- PSA-arvo**: A text input field with a unit selector set to  $\mu\text{g/l}$ .
- Vapaa PSA-arvo**: A text input field with a unit selector set to %.
- Kuvaus**: A large text area for providing a description of the results.
- Mittausaika**: A date and time selector showing "01.03.2017" and "12:54".

Below the form, there is a note: "Arvon tulee olla välillä 0 - 100." and another note: "Kellonaika tulee antaa muodossa hh:mm, esimerkiksi 14:32." At the bottom of the form is a blue "Lähetä" button.

Figure 3.7: Patients can track their laboratory values in Kaiku Health

## Chapter 4

# Methods and Data

The research in this thesis consists of two parts. In the first part, Kaiku Health is analyzed using the three models introduced in chapter two. The aim of the analytical evaluation is to find issues that may not arise from the interviews. The second part is an interview study based on the Warwick Patient Experiences Framework and conducted with patients who have used Kaiku Health. The study consists of seven in-depth interviews, which were transcribed and analyzed using narrative analysis (Kohler Riessman 2004). The interview method was chosen because it allows gathering patients' subjective experiences over the whole treatment journey.

### 4.1 Analytical Evaluation

The current version of Kaiku is analyzed using each of the models mentioned in chapter two. The analytical evaluation aims to find aspects of the product that may not arise from the interviews. The model described by Hassenzahl and Tractinsky (2006) is used to assess what issues in user experience should potentially be taken into account when designing communication and follow-up software for cancer patients. The model was selected because it differentiates three clearly defined facets of user experience that can be used individually for analysis. Additionally, Kaiku Health is analyzed using the customer



experience components introduced by Gentile, Spiller, and Noci (2007) to see how different components are present in the service. This model was used because its components approach the experience from another viewpoint than the Hassenzahl and Tractinsky's model and also expands the experience with the lifestyle and relational aspects. Lastly, the Warwick Patient Experiences Framework (Staniszewska et al. 2014) is used for assessing the strengths and weaknesses in the current version of Kaiku regarding patient experience. The framework helps consider the patient experience holistically, but through the lenses of the different themes. Additionally, using the same framework in the analytical evaluation and empirical study makes comparing their results easy.

## 4.2 Interview Study

The empirical research in this thesis consists of in-depth individual patient interviews and the narrative analysis of the interviews transcripts. Interviews were chosen as the method because they allow gathering qualitative information about the patients' subjective experiences across the whole continuum of care relatively quickly and effortlessly and allow following up on interesting emerging aspects. From a practical viewpoint, the company had used interviews successfully in the past to gather experiences of patients over the span of their treatment.

The structure of the interviews is based on the Warwick Patient Experiences Framework (Staniszewska et al. 2014) and on the needs of the company. The Warwick Patient Experiences Framework (Staniszewska et al. 2014) forms the basis for the interview. The interview themes are designed to be concrete and easy to understand for the patient, whereas many of the Warwick themes are abstract and aimed to be understandable and easily applicable from the healthcare provider viewpoint. Thus, all themes in the framework did not become themes in the interview directly – some are included as assisting questions inside the interview themes and some are sim-

ply expected to emerge from the other interview themes such as the patient story. Only the *communication* and *information* themes have been directly mapped into interview themes. The framework theme *support* is combined with questions about social relationships to form the interview theme of *relationships and support*. The other framework themes are not directly mapped into themes but expected to arise from the other themes or questions, especially the patient story. The patient story exercise also includes an explicit assistive question about patient participation, in line with the *patient as active participant* framework theme. In the Warwick Patient Experiences Framework, *lived experience* is a very broad category that encompasses a significant part of the patient experience outside of the healthcare system. It is covered in both the patient story and the social relationships and support themes. The *continuity of care and relationships* and *responsiveness of services—an individualized approach* framework themes are covered in the patient story and also as an assistive question under the *social relationships and support* interview theme.

The company needs related to this interview were gathered in a workshop before planning the finalized interview structure. All interested employees of the company were invited in the workshop. The participants included developers, sales representatives and the chief executive officer of the company. The workshop was facilitated by the author and took the form of a brainstorming session where participants listed questions or topics they wanted to be handled in the interviews. Most topics were related to the product and its use. The topics included:

1. How often did the patient use the product? Why?
2. How did the product feel like to use (positive/negative axis)?
3. Was the content understandable?
4. Peer support via the product
5. Sources of support and which was the most important?
6. Loved ones and the product
7. What is missing from the product -> how could it be even better?

8. Biggest problems during the whole patient journey
9. How has the product affected your communication with the clinic?
10. Question in the end if they would be interested in appearing in a video advertisement
11. Do they feel safe [using the product], why/why not?
12. Concrete situation for the circling [of used features] exercise (described in detail later)
13. Does it feel that there's benefit in filling the forms or adverse effects?
14. Easiness of the product first-use

Most questions from the company workshop were related to the use of the product and patients' perceptions of it. Questions about what the product felt like to use (2), content understandability (3), improvement suggestions (7), experienced safety of use (11), and the experienced benefit of filling out forms and adverse effects (13) were added in the product-related part of the interviews. The question about how often patients used the product (1) was not asked as one question, but instead on a feature-specific level. The specific advice of using a concrete situation in which the product was used (12) was taken into account and added as a question in the discussion about each feature the user circled in the drawing exercise (described in detail later). The question about appearing in a video advertisement (10) was asked after the actual interview because it was not related to the interview topic. There was only one question relating to the patient experience in a broader sense than the product: the question about sources of support (5). It was added as an assistive question in the relationships and support theme.

The topic of peer support via the software (4) and the topic of loved ones and the product (6) were left out as they would have been too leading. The question about biggest problems during the whole patient journey (8) was left out because any major problems would be uncovered during the patient story. The question "How has the product affected your communication with the clinic?" (9) would be covered by other questions, especially in the communication theme and was not included. Easiness of the product first-use

(14) was not included since it would have been difficult for the interviewees to remember - a usability test would be a better method for assessing first-time ease of use.

Topics for a possible group interview were also gathered. These were:

1. Emotions in different phases (visual representation)
2. Worries and questions in different phases
3. Collage: what is the product like
4. Collage: what should the product be like

Eventually, the group interview was left out since there were not enough volunteer patients in the patient panel. The visual representation of emotions in different phases was added to the individual interviews after the pilot interview in hope of getting the interviewees to talk more about their emotions.

The final interviews consist of two parts (see Appendix A) and were planned to last approximately one and a half hours. The first part addresses the treatment process and experience in general. It starts with background information, then discusses the patient's story from the first indication of cancer to the current day. The topics of social relationships and support, communication and information needs are then discussed specifically. After a short break, the interview proceeds with the second part, covering topics specific to the product and experiences using it.

Table 4.1: Interview themes. The complete interview structure, including assistive questions, can be found in Appendix A.

Theme in interview	Description
<i>Part 1</i>	
Paperwork and background information	Filling out interview paperwork and warming up the interviewee with demographic background questions

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Theme in interview	Description
Patient story	Interviewee drawing a timeline of his/her experiences and emotions and, using it, explaining what happened during the continuum of care and what it felt like
Social relationships and support	How the illness and treatment have affected social relationships, what the relationship to healthcare staff has been like and what have been the most important sources of support
Communication	How has the interviewee communicated with the staff and loved ones, and any problems in communication
Getting and finding information	What have the patient's information needs been and how have they been satisfied
<i>Part 2</i>	
Warm-up	Discussing the last time the interviewee used Kaiku Health, general opinion about Kaiku Health
Circling exercise	Circling features used by interviewee; discussion about each feature, e.g. in what situations the interviewee has used it
Discussion about Kaiku Health in general	General feedback about Kaiku Health
Other issues	Anything that wasn't explicitly asked, but the interviewee would like to talk about
Closing and thank you	Thank you, reward, etc.

---

Both parts include a drawing exercise to concretize the matter and to keep the conversation at the task at hand. The first part of the interview starts with a drawing exercise consisting of two parts. In the first part the interviewee is asked to tell his or her story starting from the first cancer-

related suspicion or event and ending in the current day and at the same time marking important events on a timeline drawn on an A3 sheet. In the second part the interviewee is asked to draw a representation of his/her emotions on the same timeline using three colored markers. A red marker is to be used for negative emotions, a green marker for positive emotions and a yellow marker for neutral emotions. The second part of the interview includes an exercise in which the interviewee is presented with two important user interface screens from the product and is asked to mark how often he or she has used different features visible in the interface. Features the interviewee used often should be circled with a green marker, ones that were used less often with a yellow marker and ones that were never used with a red marker. If there are features the interviewee doesn't understand or has never seen before, they are to be marked with a red question mark. The feature circling exercise was part of all interviews. The patient story exercise was added after the pilot interview after it became clear it was necessary to help interviewees talk about their emotions.

## Chapter 5

# Analytical Evaluation

In this chapter Kaiku Health is analyzed using existing models of user experience, customer experience and patient experience.

### 5.1 User Experience Analysis of Kaiku Health

The model from Hassenzahl and Tractinsky (2006) can be applied to the context of software products for cancer patients. The product must be seen *beyond the instrumental*, not just as a tool. User experience of such software must be understood holistically. Instead of just tasks we must focus on users' goals and the meaning of the application in their lives. For instance, the users do not merely follow a laboratory value, they do so because that laboratory value indicates the progression of their disease: has the cancer spread, should they be afraid and is there a need for uncomfortable treatments? Users send messages because it touches their broader life: for example, they may be going on vacation and need to ask if they can interrupt medication during that time because the adverse affects may ruin the holiday. In addition to features we must focus on how the role of the product in patients' lives: what are the benefits of using it. For example, the greatest benefit of the application may not be a specific feature but the sense of security that comes

from knowing that the health care staff is always near and has a clear picture of how the patient is doing. Aesthetic qualities may not be as important in this context as in many consumer products, but the appearance of reliability and safety may be important. The hedonic aspects are important as well: what are the basic psychological needs that the product can fulfill? Sheldon et al. (2001) identify autonomy, competence, relatedness and self-esteem as the most important psychological needs. Fulfilling these needs may well be possible via software. The application can give the patients a sense of control and autonomy by enabling them to track their care. The application may aid with the need of relatedness by fostering continuous, natural communication and relationship with the healthcare staff. Competence and self-esteem can be aided by making the application easy to use. In addition to the most typical needs identified by Sheldon et al. (2001) also security may be a need that is important in the context of cancer care.

The product must also be seen from the perspective of user *emotion and affect*. The emotional context of each patient is subjective. Their illness and situation in life are different and each patient goes through unique emotions during the journey through treatment. Even though those emotions are largely negative, we must strive to reduce negative emotions such as fear and shame seek to create positive emotions, such as sense of control and sense of security. Emotions are both antecedents and consequences of use. In addition to mere utility, emotional aspects such as relieving fear or creating sense of security may play a role in why patients decide to use the product. As consequences, we must make sure we are creating positive and reducing negative emotions and also fulfilling the emotional expectations of users.

We must also take into account *the experiential* when designing software for cancer patients. The treatment is a dynamic process that changes over time. It starts with diagnosis, proceeds to treatments and then follow-up, which may in turn result in new treatments. The treatment phase can be scary and new in the beginning but becomes routine sooner or later. Adverse effects change over time. There is a huge amount of new information in the



beginning of treatment and it is difficult to understand due to the shock of a cancer diagnosis. Most of all the psychological aspects of the disease change over time as people have time to process the initial crisis. The experience is situated, unique and complex. Types of cancer, treatments, situations in life, sources of support, age, coping strategies, physical and psychological effects of cancer are all complex and unique for different patients. The reasons why patients use the product, the situations in which they use it and the way they use it vary between patients and over time. There are countless factors that the designer cannot control. The experience of the product is also temporally bounded; most of the time the product is not in the patient's mind.

## **5.2 Analysis of Customer Experience Components in Kaiku Health**

The current version of Kaiku Health was also analyzed using the customer experience components by Gentile, Spiller, and Noci (2007).

### **5.2.1 Sensorial**

Kaiku Health itself does not stimulate the user's senses very broadly – it is mostly visual. The application's visual appearance could be aesthetically more pleasing but it is not the most important aspect of the product. However, the patient uses Kaiku Health to self-assess adverse effect symptoms such as to pain, taste or fatigue. Unfortunately these sensorial experiences are not very pleasurable.

### **5.2.2 Emotional**

Emotions are an important, central aspect of Kaiku Health. The application can create positive emotions and alleviate negative ones. By letting the patient provide information on well-being, by allowing the patient to track important laboratory values and by having an always-open, low-barrier

communication channel between patient and treatment staff the application fosters a sense of security and control. Receiving good news such as clean laboratory results through the application can be a relief for the patient – on the other hand Kaiku Health can also be the bearer of bad news. Kaiku Health also enables self-reporting of affect as part of quality-of-life follow-up, which can be an emotionally reflective experience for the patient. The way the application speaks to the patients can have an effect on their emotional state. Through small details on copy text the application can help the patient relax. For example, the application greets the patient informally after login.

### 5.2.3 Cognitive

Problem solving and creativity are not at the core of Kaiku Health. Instead, the use should be as effortless and cognitively undemanding as possible. In 2017 the patient interface of Kaiku Health was significantly simplified, reducing the cognitive effort of use.

### 5.2.4 Pragmatic

The pragmatic aspect is very important in Kaiku Health. The application enables patients to actively participate in their treatment by reporting adverse effect symptoms or quality of life or tracking their laboratory values. This way the patients are actively doing things instead of just passively receiving treatments.

### 5.2.5 Lifestyle

Kaiku Health is not a lifestyle product that patients would want to use express their values to others. There are however some beliefs and values that are part of the product: when the patients take Kaiku Health into use, they implicitly acknowledge their status as cancer patients and the values of patient participation and patient-centeredness.

### **5.2.6 Relational**

The relational aspect of Kaiku Health is very important. The application allows patients to communicate with the treatment staff they know from the clinic and hospital. The staff is listed in Kaiku Health with photos. The adverse effect and quality of life data entered in the application is sent to the staff. Additionally, patients can show their laboratory values or other data to loved ones, so that Kaiku Health server as a shared object in communication.

## **5.3 Patient Experience Analysis of Kaiku Health**

The Warwick Patient Experiences Framework (Staniszewska et al. 2014) provides a good basis for analyzing the effect of Kaiku Health currently has in creating a positive patient experience. The framework allows us to analyze the service through the lens of patient experience and its different components to find potential successes and development areas.

### **5.3.1 Patient as Active Participant**

Kaiku Health gives patients the ability to participate in their treatment. The patients can follow the progression of their treatment and the history of their symptoms. Kaiku Health can recommend self-care instructions that the patients can follow themselves. The conversation feature allows patients to ask for information and guidance from the staff when they want to, not only during designated times such as doctor's appointments. The patients have the power to choose if they want to use Kaiku Health or not and if they want to follow the self-care instructions or not.

### **5.3.2 Responsiveness of Services - an Individualized Approach**

Kaiku Health is available around the clock and the patients can decide for themselves if they want to send a message when they want to or make a phone call during the clinic's opening hours instead. Automatic feedback can direct patients to emergency services when needed, even outside the clinic's opening hours. The patient-reported outcomes gathered in Kaiku Health allow the care team to customize the treatment for the patient, such as adjusting medication based on their adverse effects symptoms. By checking the data in Kaiku Health before patient meetings the care team can prepare to talk about the things that are relevant to the patient based on their symptom and quality of life data. Color-coding the symptoms reported by patients can help them understand which symptoms are normal during the course of treatment, resulting in better perceived performance of treatment. Kaiku Health lowers the barrier of asking questions by allowing the patient to ask questions when they arise instead of waiting for the next appointment.

### **5.3.3 Lived Experience**

Some cancer patients decide not to talk about their illness e.g. to their colleagues. Kaiku Health makes it possible to contact the clinic discretely during business hours, even when a phone call in private could be difficult to organize. For patients who are unable to talk due to their illness - such as some head and neck area cancer patients - the text-based conversation feature in Kaiku Health may be the easiest way to communicate. For some patients, it may be easier to write about difficult subjects such as fear than to talk about them in person. Having an easy, direct contact to the clinic can help reduce fear, uncertainty and loneliness for patients, especially for chemotherapy patients who do not visit the clinic very often or for patients who are in follow-up. Reporting symptoms can help reduce suffering by allowing the care team to react to them early and to adjust medication or to alleviate the

symptoms in other means.

### 5.3.4 Continuity of Care and Relationships

Kaiku Health allows direct contact to the care team even after the treatments have ended. Even if the follow-up is done outside the clinic, the clinic can decide to provide consultation for patients via the application. The whole care team is available in Kaiku Health, and their names and photographs are shown on the front page. Kaiku Health greets the patient by name on the front page, providing an individual touch. Kaiku Health is always available. If patients have questions troubling them in the nighttime, they can immediately ask that question via the conversation feature, getting the question out of mind.

### 5.3.5 Communication

Kaiku Health gives the patient control over communication. Using the application allows patients to contact the staff when and where they like. The patients decide if they want to communicate or not. The always-available text-based conversation feature reduces the barrier for asking questions. When patients talk with staff on the phone or in person, it is easy to forget details and numbers discussed. Because the communication in Kaiku Health is text-based, it's possible to return to the details later, at any time. Kaiku Health also makes it possible to bring up difficult subjects such as psychological distress. It may be easier for some patients to answer a questionnaire about their psychological well-being than to bring up their distress to nurse who is akin to a complete stranger.

Kaiku Health does not solve all communications challenges, however. An online service is not suitable for all users: not everyone owns a device necessary for using Kaiku Health, and not everyone wants to learn to use a computer. Also, Kaiku Health does not replace, but rather augments, in person contact that is invaluable for empathy and compassion. Also, especially right

after the diagnosis, patients have a significant need for information, which is easiest to answer during a lengthy conversation with a doctor. During the discussion Kaiku Health could be used to save notes for the patient, so she/he could return to them later.

### **5.3.6 Information**

Kaiku Health currently provides little information by itself. The clinics are responsible for providing the information the patient needs through other means. The clinics may provide information folders or electronic materials for patients. Additionally, the conversation feature in Kaiku Health can be used to provide information to patients or to share material to them. Patients have the power to decide if they want to use the information in Kaiku Health or not.

### **5.3.7 Support**

Kaiku Health makes it possible to find the patients who need most support. Reporting symptoms and quality of life allows the care team to find the patients who need the most attention, be it practical, physical support or psychological support. Those who speak the loudest are not always the ones in need of the most help: Kaiku Health can also help support the people who do not want to be a burden or who are not ready to talk about their support needs, since all the patients report their well-being in the same way. Kaiku Health also helps the healthcare staff identify the specific support needs of a patient, for example by checking their quality of life or symptom data when preparing for the patient's visit to the clinic. The always-available conversation feature of Kaiku Health can lower the barrier to ask questions or ask for help without feeling like a burden.

## Chapter 6

# Empirical Study: Interviews on Patient Experience

This chapter introduces the results of the empirical study in this thesis. The empirical study consists of seven in-depth interviews with cancer patients who have used Kaiku Health.

### 6.1 Data Gathering and Analysis

The interviews were conducted during March and April 2016 at the company office, with the exception of one interview that was conducted at the participant's home due to logistical issues. The interviews were all conducted in Finnish, since all participants were Finnish-speaking. In the end, most interviews lasted for two hours and some even two and half hours. Time for possible overruns had been reserved and there was no hurry. Audio for each interview was recorded and transcribed. A total of twelve hours and eighteen minutes of interview material was recorded.

Invitations (see Appendix B) for the interview were sent to the Kaiku patient panel. The patient panel consists of 12 volunteer users, recruited by email from all users of Kaiku Health at a private cancer clinic in Finland in November and December 2015. The participants of the panel have remained

the same. Seven people registered for the interview and they all participated. Six of the interviewees were male prostate cancer patients over the age on 65. One interviewee was a female breast cancer patient at the age of 35. The patients had received different types of treatment, including radiation therapy, surgery and chemotherapy. Some participants were undergoing active treatment, some were recovering from cancer and some were in a latent phase of incurable cancer. None of the patients were in end-of-life care.

Table 6.1: Patients who participated in the interviews

Gender	Age	Cancer type	Phase and treatment
Male	65	Prostate cancer	Chronic, not currently in active treatment
Male	66	Prostate cancer	Chronic, hormonal medication (pilot interview)
Male	77	Prostate cancer	Chronic, not currently in active treatment
Female	35	Breast cancer	Recovering from curative treatment
Male	73	Prostate cancer	Curative treatment follow-up; had had a separate cancer treated earlier
Male	72	Prostate cancer	Curative treatment follow-up
Male	67	Prostate cancer	Curative treatment follow-up and hormonal medication

The interview method was not without its challenges. It was expected to be difficult to get the patients to discuss their emotions openly. A drawing exercise about visual representation of emotions in different phases, originally intended for the group interview, was added to the individual interviews after the pilot in hope of getting the patients to talk more about their emotions. Also, as with any retrospective method, interviews are limited by the accuracy of human memory. Even with these limitations interviews were considered to be the best available method to cover the complexity of the



patient experience.

A group interview was also planned but eventually left out since there were not enough volunteer patients in the patient panel. It would have not been realistic to find enough volunteers from the panel to conduct both individual and group interviews without using the same participants both in an individual interview and the group interview.

The first four interviews were transcribed word-for-word using the application named F5. Due to scheduling issues, the last three interviews were transcribed using F5 into key points, along with time codes for retrieving exact quotations later. In total, approximately 150 pages containing 65 000 words of transcript was produced. The transcripts were then analyzed using the *thematic analysis* model of narrative analysis as described by Kohler Riessman (2004). The transcripts were read through, anonymized for later usage by the company and then coded in ATLAS.ti. Initially, each interesting excerpt was coded under one of the themes in the Warwick Patient Experiences Framework or, if not applicable, under the category *Other*. Additionally, interesting excerpts relating to the product were coded under the category *Kaiku*, on its own or in addition to the other codes. In the end, the top-level theme *Other* only contained four quotations and was not analyzed deeper. During the coding process it became clear that the *Lived Experience* theme had grown too large, since much of the patients' subjective experiences and emotions belonged under the theme. Thus, the contents of the theme were re-categorized into four subcategories of Lived Experience: *Adverse Effects*; *Emotional and Psychological*; *Social Relationships and Broader Life* and *Other*. The amount of quotations in each theme is shown in table 6.2. The themes were quite high-level, so the findings in the themes were organized into groups that were each expanded into a paragraph description of the findings in the group, along with one or more supporting quotations. The photos produced in the timeline and circling exercises were not directly analyzed but were used to support understanding the content of the transcripts.

Table 6.2: The final number of quotations in each theme

Theme	Number of quotations
Patient as Active Participant	44
Responsiveness of Services - An Individualized Approach	41
Lived Experience - Adverse Effects	47
Lived Experience - Emotional and Psychological	116
Lived Experience - Social Relationships and Broader Life	48
Lived Experience - Other	28
Continuity of Care and Relationships	46
Communication	117
Information	94
Support	51
Kaiku	203
Other	4

## 6.2 Patient as Active Participant

Patients were active in their choice of treatment provider. Three of the seven interviewed patients had started their treatments in the public sector, but had decided to move to the private hospital, most often due to reasons related to the performance of public sector health care. The following excerpt from interview six, quotation 30 illustrates the decision-making:

I'm the one who made the choice that I'll go, that I won't stay in the public sector to wait that... something's found in the follow-up.<sup>1</sup> – Male, 72, Prostate cancer (6:30)

Four patients reported they had been given the possibility to choose between different treatments. One of the patients experienced that he didn't

<sup>1</sup>“Mähän tuon ratkasun tein että mä lähden, en jää odottamaan julkiselle puolelle että... seurannassa havaitaan jotakin.”

receive enough guidance to make a choice. Only one patient reported he was not given a choice between treatments at all while he was a patient in the public sector but he also told that he expected less room for choice in the public sector. Two patients didn't feel the need to partake in treatment decision-making since they had full confidence in their physician. One patient reported that even though his public sector physician did give him a choice, the physician also questioned his choice in an intimidating way.

Prostatectomy or radiation. I didn't know... umm I was given like I had to choose this thing. It shouldn't be like that... I even said to the doctor that I don't have the expertise to choose, could you recommend something but he (claps hands together) "It's up to you to decide"<sup>2</sup> – Male, 77, Prostate cancer (3:12)

I was told it should be done surgically. I researched everything, like I told you earlier in my case when it has spread it should absolutely not be done surgically. And then when I went to the urologist and said that... this doesn't feel good and that I've started to prefer radiation therapy and then hormonal therapy he said "You're making a fatal mistake."<sup>3</sup> – Male, 66, Prostate cancer (2:23)

All the prostate cancer patients keenly followed the same cancer marker, the Prostate-Specific Antigen (PSA) value in Kaiku Health, because the marker is a good indication about the absence, presence and progression of their cancer.

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<sup>2</sup>"prostatektomia ja- tai sitten sädetys. Mä en tienny... öö mulle annettiin niiko että minun pitää ratkaista tää asia. Eihän se sillä tavalla... saa (epäselvää) mä sanoin suoraan... lääkärilleki että että tuota eihän eihän mul ole mitään asiantuntemusta että... voitko sä suositella jotakin mut se (lyö kädet yhteen) 'se on sinun ratkaistavissa'."

<sup>3</sup>"Sanottiin et pitäis leikata. Mä tutkin kaikkee, niinku mä kerroin aikasemmin jo että mun tapauksessa kun on levinnyt niin missään nimessä ei pitäis leikata. Ja sitten kun mä menin urologin luo ja sanoin että... tää ei nyt tunnu oikein hyvältä ja mä sanoin että mä oon ollu vähän taipumassa siihen että... et mä saisin niitä sädehoitoja, sitten hormonihoidoja niin hän sano että 'Nyt teet kohtalokkaan virheen'."

The emotional curve follows the PSA fluctuation... so that as long as the PSA stays the same or very stable... then it's out of mind and then when there's one of these... like in September 2009 there was that okay, now it's started to rise, then there was this kind of [negative emotion] spike.<sup>4</sup> – Male, 65, Prostate cancer (1:7)

Three patients said they used Kaiku Health so that the treatment staff would have the best possible knowledge of their state and well-being.

It's very easy... easy and simple... way to keep [the cancer clinic] informed about what the situation is and they can react based on that if there's a need...<sup>5</sup> – Female, 35, Breast cancer (4:60)

### 6.3 Responsiveness of Services - An Individualized Approach

Six of the seven patients had been diagnosed or treated in the public sector and all of them were more or less disappointed in its performance. Three cited long queues as the reason for seeking help from a private clinic. Two patients felt his concerns or symptoms did not result in action in the public sector. One patient's prostate cancer was incorrectly diagnosed as benign prostatic hyperplasia at the municipal health care center, which delayed the cancer

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<sup>4</sup>“PSA:n heilahtelun mukana tää [tunne]käyrä sitte... eli tota sitte kun... kun se tota... niin kauan kun se pysyy tota vakiona tai hyvin stabiilina... niin niin... asia on niinku... ikäänku lähes pois päiväjärjestyksest, sitte ku taas tulee tämmönen... niinku syyskuussa sit 2009 tuli et okei et nyt se onkin kuitenkin lähteny nousuun ni... ni siinä tuli sit tämmöne [negatiivinen tunne]piikki”

<sup>5</sup>“toi on tosi semmonen helppo... helppo ja yksinkertanen... tapa niiku pitää niin et... [syöpäklinikka] sitte... niinku... selvillä siitä et mikä, mikä tilanne on, on ja he pystyy sit sen mukaan sitte... reagoimaan et onks onks tarvetta”

diagnosis by several years. All the patients that brought up the performance of the private clinic did so in positive light.

I could've gone of course... in the public sector- to the public sector but at that time the queues were really long, they took at least six months... and... I didn't have the courage... have the courage to stay... in public sector treatment<sup>6</sup> – Male, 77, Prostate cancer (3:55)

Three patients brought up how the private clinic took them into consideration as individuals.

I somehow had like a feeling that... you were taken into consideration as an individual and... and I don't know want to like... I mean of course the treatment would have been good in the public sector too but maybe not as individualized and something the staff would really put their heart into<sup>7</sup> – Female, 35, Breast cancer (4:10)

Two patients mentioned that the treatment staff answered questions quickly in Kaiku Health.

The faster the experts can answer your, your questions or, or reports or whatever it is the better. And the safer and better you feel and the, well, the better everything is then.<sup>8</sup> – Male, 66, Prostate cancer (2:85)

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<sup>6</sup>“mä oisin tietenki voinu mennä... julkisella puolella- julkisellekin puolelle mutta tuota siihen aikaan oli hirveen pitkät jonot, ne vei vähintään puoli vuotta... ja... en mä uskaltanu... uskaltanu jäädä... julkisen puolen hoitoon”

<sup>7</sup>“oli jotenki se- tai semmonen niiku fiilis että... et sut otettiin huomioon yksilönä ja... en mä tiä halu- haluu mitenkää... siis totta kai julkiselki ois niinku hyvää... hoitoo saanu mut ehkä semmost niin yksilöllistä ja semmosta paneutuvaa”

<sup>8</sup>“mitä nopeemmin asiantuntijat pystyy vaan vastaamaan sun, sun kysymyksiin tai, tai raportteihin tai mitä vaan sitten siinä onkaan ni... ni sen parempi. Ja sen turvallisempi ja paremmin olo on ja sen no, kaikki on paremmin silloin.”

## 6.4 Lived Experience - Adverse Effects

Five of the seven patients experienced less difficult adverse effects than they expected. Most common adverse effects for these patients were erection disorder, diarrhea from radiation and fatigue. Two of the patients experienced more difficult adverse effects.

Beforehand... I wondered what was going to happen to me, because... when you know you've heard that or thought you knew that it'll send you... you won't be able to get out of bed or you're in a really bad shape [...] if I had still been at work, I wasn't working then, I had already retired, I could almost have gone to work every day so it wasn't that... the side effects in my case were absolutely something that I could well cope with.<sup>9</sup>  
– Male, 65, Prostate cancer (1:12)

so I got pretty bad, bad... damage in the mucous membranes, so that for a couple of years pissing was... was really difficult and painful for me and... there was blood in the urine<sup>10</sup> – Male, 67, Prostate cancer (7:9)

The adverse effects have had varying effects for ordinary life. Three patients had erection disorder, and two stated it had affected their relationship. Two patients had to quit a sporting hobby due to adverse effects. Two patients stated that incontinence or urinary retention affected the way in which

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<sup>9</sup>“etukäteen... tuntu että mikä- mitähän siin sit ittelle tapahtuu (naurahtaa) että... ku tiet- on kuullu tai luullu ainakin tietävänsä et se lyö kyllä... sitten niinku ihmisen ihan... sängyn pohjalle tai hirveen huonoon kuntoon [...] jos oisin ollu töissä, mä en enää ollu töissä silloin mä olin tos jääny jo pois niinku työstäni... melkein olisin pystyny koko ajan käymään töissä että se ei ollu tota... ne sivuvaikutukset ei ollenkaan ollu mun tapauksessa semmosii että niist- niit- niiden kans ei ois just jaksanu niiku... hyvin pärjätä.”

<sup>10</sup>“sain sitten aika pahat, pahat tuota niin... vauriot noihin limakalvoihin, että mulla pari vuotta niin kuseminen oli... oli tosi hankalaa ja kivuliasta ja... verta tuli”

they planned their trips. Two patients stated their mood was affected by the hormonal medication, causing depression or irritability. One patient had to avoid social situations due to infection risk during chemotherapy.

on the other hand the... hormonal medication has affected... my personality... so that there are clear, clearly changes, short-temperedness and that I snarl easily<sup>11</sup> – Male, 67, Prostate cancer (7:48)

Two patients had used Kaiku Health to report their adverse effect symptoms. The other patients only started using the application after active treatments and thus adverse effects reporting was not enabled for them. The two patients that had reported their adverse effects felt that the functionality was useful.

About the reporting instead of telling verbally during the next visit about... what my condition has been and what kind of adverse effects I've had that maybe at that point it's already been forgotten, forgotten that what had happened a few weeks back.<sup>12</sup> – Female, 35, Breast cancer 4:84

## 6.5 Lived Experience - Emotional and Psychological

Four of the seven patients said that Kaiku Health brings a sense of safety because it keeps the treatment staff informed about the patient's well-being and because the treatment staff is always easily available through the application.

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<sup>11</sup> "toisaalta sitten toi... hormonilääkitys on vaikuttanu sitten... sitten... sitten tuota persoonaan... niin että siinä on selvät- selvästi semmosia... muutoksia, nii että... pii-lyhytpinnasuus ja... et niinku ärähtää helposti"

<sup>12</sup> "tosta raportoinnist sen sijaan että kertos sit sanallisesti seuraavalla potilaskäynnillä että... että tota mitä, mikä vointi on ollu ja mitä haittoja on ollu et ehkä siin vaihees sit jo on jo unohtanu, unohtanu et mitä siinä muutamaa viikkoa aikasemmin on tapahtunu"

It has... absolutely been very useful... because for them it- it brings me a kind of sense of security maybe, that the information goes to the clinic and it's an easy, easy way instead of you... calling there yourself and... listing [the adverse effects] and what you need to do now...<sup>13</sup> – Female, 35, Breast cancer (4:59)

Certain phases in the patient journey were described as emotionally very difficult by the patients. Six patients described the waiting time between the diagnosis and treatment as the most emotionally difficult. Two of the chronic patients said that waiting for new treatments after metastases are found is also difficult. One patient said waiting for the diagnosis was the hardest and that the diagnosis was a relief. Two patients whose cancer had metastasised said that receiving the information was difficult, and that it had a permanent effect that the cancer will always be with them. Three patients said that waiting for follow-up blood test results was always more or less scary. One patient brought up that waiting for information about the effectiveness of treatment was difficult. Two patients found the treatments or their adverse effects scary.

Well the first day... I was at the countryside... chopping wood, hobby things, making firewood with a machine and I went and listened to the call and... went back to work, so the shock didn't come immediately.<sup>14</sup> – Male, 67, Prostate cancer (7:3)

So in the afternoon I called [the private clinic] that... [...] I received a diagnosis and won't get treatment for a month and...

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<sup>13</sup>Kyl se... ehdottomasti tosi hyödyllistä on... ollu, ollu koska heille sitte to- se tuo itselle semmost ehkä... turvallisuuden tunnetta et se tieto menee sinne [klinikalle] ja toi se on niiku helppo, helppo tapa sen sijaan et sä ite... soittelisit sinne ja... luettelisit niitä [haittavaikutuksia] ja mitä nyt pitää tehdä“

<sup>14</sup>“No se ensimmäinen päivä... mä olin... maalla... puuhommissa, harrastushommissa tekemässä... klapuja koneella ja kävin sen puhelun kuuntelemassa ja... menin jatkamaan hommia et sitä ei niinku heti, heti se shokki ei tullu päälle.”



that I'm not capable of waiting that long.<sup>15</sup> – Male, 67, Prostate cancer (7:5)

Most of the patients said that cancer had also affected their life in a positive way. Three patients said that the illness had made them worry less about small things. Two patients had stopped to consider the finiteness of life. Two stated they are now more able focus on the present and to enjoy life right now. Other positive effects were also reported.

So you get a kind of different attitude towards life. That it's here and now, kind of carpe diem -stuff that you are now here, you breathe, so you're alive. Do... something for it that you are well now because the day will come that... that it's not so well anymore. That's how it has changed me.<sup>16</sup> – Male, 66, Prostate cancer (2:35)

Three patients brought up that earlier experiences in life had an effect on their emotional experience. Earlier experiences provided perspective or information that was useful for coping.

I like knew how to respond. I knew what it was about when these kinds of fairly large treatments are done and started. That... that probably made it easier, easier this phase here... that this can't be any worse than... the previous one was.<sup>17</sup> – Male, 72, Prostate cancer (6:36)

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<sup>15</sup>“Eli iltapäivällä mä sitten soitin [yksityisklinikalle] että... [...] mä sain diagnoosin ja en pääse hoitoon et kuukauden kuluttua ja... ei kyllä pää kestä odottaa.”

<sup>16</sup>“Niin niin, siitä saa semmosen niinku toisenlaisen niiku asenteen elämälle. Että se niinku tässä ja nyt, se on vähän carpe diem -meininkiä että tota, sä oon nyt tässä, sä hengität, siis olet elossa. Tee... sen... jotankin sen eteen et sä voit hyvin tässä koska päivä tulee että... että ei oo niin hyvin enää. Sillein se on muuttanu.”

<sup>17</sup>“Osasi niinkun suhtautua. Tiesi että mistä on kyse... kun tämmösiä... niinkun suhteellisen isoja hoitoja tehdään ja alotetaan. Että tuota... se vähän niinku varmaan pehmensi, pehmensi tätä vaihetta täällä, täällä että tuota... ettei tämä nyt sen kummempaa voi olla kun... se edellinenkään oli.”

The patients seemed to employ a range of coping strategies such as problem solving, information-seeking, social support, positive reinterpretation, acceptance and fighting spirit. Most patients seemed to have adapted well and only one patient brought up difficulty in adapting.

But I'm a very, very... how would I say... realistic person in the sense that I'm sixty six years old and I've had an amazing life. Absolutely, few people have had such good lives. [...] So... at some point you've got to go anyway. But then, if still I would have a bit more time, because I just had two grandchildren, two little boys, they're a bit over a year now so... it would be nice to see if I could go fishing with them for one more time, right?<sup>18</sup>  
– Male, 66, Prostate cancer (2:26)

there are things caused by other ailments that... that affect more on the psychological side... one can't help one's genes and... these other illnesses have then started to... appear, partially also because I've had the negative stress and it brings them on...<sup>19</sup> – Male, 77, Prostate cancer (3:53)

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<sup>18</sup>“Mutta mä oon hyvin, hyvin näist mitä mä sanosin... realistinen ihminen siinä mielessä et mä oon kuuskytkuus ja mul on aivan järjettömän hieno elämä ollu. Siis kertakaikkiaan, et ei... Harvalla on niin hyvä ollu. [...] Nii tota... joskus pitää lähtee kuitenkin. Mutta nyt sitten, jos vielä vähän lisää kun mä oon saanu kaks lastenlasta nytten niin tota kaks pientä poikaa, ne on vähän päälle vuoden molemmat ni... Ni ois kiva kattoo jos vielä kerran pääsis kalaan niitten kanssa eiks niin?”

<sup>19</sup>“muista vaivoista johtuvia juttuja on on sitte jotka... jotka tuota enemmänkin vaikuttavat... myöskin henkiseen puoleen... että geeniperimällehän ei... ei voi mitään... ja ja tota... näitä muista sairauksia sitten on ruvennu... ilmenemään, osaksi sekkin takia että ku sitä... negatiivista stressiä on ollu, ollu niin ne vähän laukasee...”

## 6.6 Lived Experience - Social Relationships and Broader Life

The seven interviewed patients had differing approaches to telling others about their illness. Four patients had spoken openly about their disease while three patients wanted to limit the information only to closest friends and family. One of the patients said she was worried about how people would react while one was afraid of the cancer diagnosis becoming a stigma. Two patients found it difficult to talk about the illness to close ones. One patient waited three years from the diagnosis before telling anyone outside immediate family, because he needed time to process the diagnosis himself. Two patients told a toned-down version of their situation to specific groups such as children or friends.

I did a clear decision that I'll keep this... inside of me, only... my own children and my close ones and... and the wife then told that to them and with the message that '[interviewee] wants that it won't... be talked about'<sup>20</sup> – Male, 67, Prostate cancer (7:53)

Reactions in the patients' social networks have varied. Three of the patients said that their spouses were initially more scared than themselves. Three patients stated that the cancer hasn't changed their social relationships. One patient said that his social relationships had only strengthened as a result of the illness. One patient said that relationships in the family had not changed, but some of her friends had been scared and had distanced themselves from the patient. Children of one patient had a difficult time adjusting because their mother had died of cancer a decade earlier. Two patients reported that their social network has grown smaller as a result of the illness.

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<sup>20</sup>“Minä ihan selvän päätöksen tein että minä pidän tän... sisälläni, ainoastaan... mun omat lapset ja se lähipiiri mikä siihen kuuluu ja... Ja sen, sen vielä vaimo viesti... heille ja... ja sillä kankeetilla että... [haastateltava] sitte haluaa että siitä ei... puhuta.”

More, more maybe for the wife, for her it was like... like that... she probably thought more about what is going to happen.<sup>21</sup> –  
Male, 72, Prostate cancer (6:18)

Five patients in the follow-up phase said that Kaiku Health was not present much in their everyday life – it was only in mind when they had questions or needed to do laboratory tests or when the treatment staff had contacted them in Kaiku Health. One patient said that reporting adverse effects during active treatment became a weekly, short routine that she experienced as positive.

Not really, no, sometimes it crosses my mind but... it can take weeks that it doesn't. But then when you sometimes open the computer you notice that... you can log in there too. But it always comes to mind when... you go to the blood tests.<sup>22</sup> –  
Male, 73, Prostate cancer (5:55)

## 6.7 Lived Experience - Other

Four patients out of seven said that their expectation of the future was to live a normal life. Two were expecting or hoping for good health.

I'm waiting for a few nice years left... with the mrs. we get to be the winters [abroad] and... summers, summers here and (unclear) should write bit, everyone tells me but I don't know, nobody's interested in these but... I have all sorts of stuff gathered up. But to keep oneself somehow active, exercise a bit and...

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<sup>21</sup>“Enemmänkin, enemmänkin ehkä vaimolla oli, vaimolle oli semmonen... semmonen tuota että... hän varmaan enemmänkin mietti että mitenköhän tässä nyt oikeen käy.”

<sup>22</sup>“No ei oikeastaan kyllä, joskus käy mielessä mutta... [...] kyllä menee viikkojakin, ettei. Mutta sitten kun joskus kun aukasee tietokoneen niin huomaa että... sinnekin voi sitten kirjautua. Mut sillon se tulee aina mieleen kun... kun käy verikokeissa.”

like that. A kind of... smooth landing.<sup>23</sup> – Male, 73, Prostate cancer (5:20)

## 6.8 Continuity of Care and Relationships

All the seven patients felt their relationship with the treatment staff at the private clinic was good. Five patients described the staff as friendly, two brought up the staff's high expertise and three mentioned how the staff has enough time to encounter patients.

[They've] been easy, easy to approach somehow, they... always, always have time and... I've always gotten an answer quickly though different channels if there's been something that has puzzled me and... very friendly and like... attentive in the right way and (laughs) maybe in some cases even motherly in the right way... from the older women. Umm but really competent and like the... being present and giving time.<sup>24</sup> – Female, 35, Breast cancer (4:35)

Three patients had faced challenges with the continuity of care. One patient who had received treatment both in the public and private sectors complained that his medical information is scattered in many non-integrated systems. One patient spent most of his time abroad and had difficulty getting

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<sup>23</sup>“Mää nyt tässä oottelen semmosta et täs on nyt muutama mukava vuosi jäljellä... eukon kanssa saadaan olla talvet [ulkomailla] ja... kesät, kesät täällä ja (epäselvää) pitäs vähän kirjojella kaikki sanoo mut en mä tiedä ei kukaan näist oo kiinnostunu mut... oon mä nyt kasannu kaiken näköstä. Mut pitää itsensä jollain lailla aktiivisena, vähän liikkua ja... ja täm- tämmöstä. Semmonen... tasanen laskeutuminen.”

<sup>24</sup>“[Heitä] on ollu helppo, helppo lähestyä jotenki sillei et heil on... aina, aina aikaa ja... eri kanavia myöten sitte on tosi nopeesti saanu aina vastauksen sit jos on tullu... joku asia, askarruttanu ja... ja sit tosi ystävällistä ja... semmosta... on, sopivan huolehtivaa ja (naurahtaa) ehkä jossain tapaukses myös sopivan äidillistä jotenkin... vanhemmilta naishenkilöiltä. Öö, mut tosi asiantuntevaa ja niiku se... läsnäolo ja... ajan, ajan antaminen.”

a doctor's appointment in Finland. One patient was diagnosed and treated in several different clinics in different countries. Two patients told stories of friends and acquaintances treated in the public sector whose physician changed constantly.

I don't know if it's realistic but when I go to different public clinics or different private clinics that... some time all this information would be visible in one place.<sup>25</sup> – Male, 65, Prostate cancer (1:76)

Two patients explicitly brought up how Kaiku Health had improved their continuity of care.

Well in the end this is an extension of care and that you don't leave anyone behind. [...] I have a team there. A named team, with pictures that 'this is your team' and I can always be in touch.<sup>26</sup> – Male, 66, Prostate cancer (2:64-65)

the reporting, communication, everything... happens pretty much in there, [...] it's also easy for the patient when everything happens almost completely in one place.<sup>27</sup> - Female, 35, Breast cancer (4:81)

## 6.9 Communication

Four of the seven patients brought up that communication also serves a purpose of reassurance. Two patients felt that discussions with physicians

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<sup>25</sup>“onko se koskaan realistis- realismia ku mä käyn erilaisissa... julkisen puolen yksiköissä tai erilaisis yksityisen puolen yksiköissä että että... joskus nää tiedot niiku... joteki tulis yhdessä kaikki nähtävissä”

<sup>26</sup>“Ni täähän on hoidon jatke loppujen lopuksi ja se, että ei jätetä ketään. [...] Et siellähän on tiimi, mulla. Nimetty tiimi, kuvien kanssa että 'täähän on sun tiimi' ja aina voin ottaa yhteyttä.”

<sup>27</sup>“raportoinnit, viestinnät kaikki... kaikki tapahtuu aika pitkälle siellä, [...] se on sit potilaan kannalt myös, myös helpoo kun sul kaikki tapahtuu melkein yhdessä paikassa”

helped them calm down. Two patients felt that reporting adverse effects was reassuring, because the treatment staff would have the best possible knowledge on the patient's well-being.

At that point you feel of course that discussing with the doctor is the most important... his assessment that okay, now it's... gone up a bit, we can let it rise, let's see what the situation is... I'm personally probably a bit like... I could imagine I'm a even bit too sensitive to assess my own situation and the... meaning of the rise in PSA.<sup>28</sup> – Male, 65, Prostate cancer (1:18)

Four patients brought up that the way the application itself communicates is important. Two said that the content in the application is easy to understand. Three patients said that the application occasionally uses medical language that is difficult to understand. Two of them also brought up that the application occasionally communicates in an unnatural way, for example when asking about fever:

At least about the fever because there's only the [option]... if it's over... if it's at least thirty-eight degrees fever, but then if you have thirty-seven to thirty-eight or closer to thirty-eight then it's either like... none at all or then over thirty-eight so in [the application] could also be the... also be like a lower fever too.<sup>29</sup>  
– Female, 35, Breast cancer (4:57)

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<sup>28</sup>“Siinä vaihees kok- kokee tietysti et se lääkärin kanssa keskustelu on tärkeintä että tota... hänen hänen arvionsa siit et okei no se on nyt... vähän noussu antaa nousta, katel- katotaan mikä tilanne on... et mä oon mä ite henkilökohtasest mä oon varmaan niiku... voisin kuvitella et mä oon vähän turhanki herkkä niinku sit sillei itte arvioimaan sitä omaa tilannettani ja tota... sen PSA:n nousun merkitystä”

<sup>29</sup>“ainakin toi kuumeesta kun siel on [vaihtohtona] vaan se... jos on yli... jos on vähintään kolkytkaheksan kuumetta, mut sit jos on se kolkytseittemän viiva kolkytkaheksan tai jos on lähemmäs sitä kolmeekymmentkaheksaa sit se on niiku joko, joko... ei ollenkaan tai sitte yli kolkykaheksan ni siinä [sovelluksessa] ehkä vois olla se... myös sit semmonen niiku alhasempiki kuume.”

It is important that the staff introduces the application in person. Two patients remembered that they had been offered the opportunity to use Kaiku Health in person, and one stated that he had missed any printed material about Kaiku Health.

[Doctor 1]... I'm his patient, he said 'do you want to use this [service]' and I said ok, absolutely<sup>30</sup> – Male, 77, Prostate cancer (3:7)

Umm I somehow missed Kaiku somehow... it was probably written down somewhere but I completely missed it<sup>31</sup> - Male, 66, Prostate cancer (2:101)

The most common communications methods in addition to face-to-face appointments were telephone (all patients), Kaiku Health messages (six patients) and email (four patients). One patient had sent SMS messages to nurses. Patients used phone calls mostly when the matter was urgent or required dialogue. One patient said that text-based mediums are better for communicating numerical information. Two patients brought up that during radiation therapy most communication happened face-to-face because patients visited the clinic every day for treatments. One patient brought up the need for person-to-person communication:

[Doctor 1] was going home, but he cancelled it. And he was with me from four to six, two hours he sat with me and told me in great detail what this [prostate cancer] like really is.<sup>32</sup> – Male, 66, Prostate cancer (2:5)

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<sup>30</sup> “[Lääkäri 1]... oon hänen potilaansa, niin tota sano että ‘haluat sä... tommosteen [palveluun] mennä mukaan’ mä sanoin et ok, ilman muuta”

<sup>31</sup> “ää Kaiku jotenki jäi... se varmaan luki jossaki, mut mä nyt- se meni ihan mun ohii”

<sup>32</sup> “[Lääkäri 1] oli lähdössä kotiin, mut se peruutti sen homman. Ja hän oli mun kans sitten neljästä kuuteen, kaks tuntia istu mun kanssa ja kerto ihan kädestä pitäen että mitä tää [eturauhassyöpä] nyt oikeesti niiku sitte niiku on.”



All the patients were happy with the way the staff at the private clinic communicates, even though one complained that doctors occasionally use hard-to-understand language. Two patients had bad experiences in communicating with public sector staff.

[Doctor 1], he has treated me nicely, he tells everything, he gives background, I can ask him anything.<sup>33</sup> – Male, 72, Prostate cancer (6:46)

Six of the seven patients used Kaiku Health for messaging with staff. Topics of the communications included questions about treatment or illness, reporting well-being and practical matters. The patient that had not sent messages said he had not had any need for messaging. The messaging feature had its benefits. Two patients brought up that it was convenient to have the discussion history in one place and to be able to return to it later. Two patients brought up that that they were able to send a message whenever they needed and receive an answer during the next business day. One patient brought up that messaging was more convenient than phone calls because discussing the illness over the phone could have been embarrassing in certain situations and messages can be attended to at a more appropriate time.

Kaiku also works as a tool for dialogue, of course there is a small delay but quite quickly I've gotten an answer so far, I've been answered within 24 hours. So it works well enough. Phone, yes, but if you have something... something with numeric information or such then it's better it's gathered somewhere, that it's in writing.<sup>34</sup> – Male, 66, Prostate cancer (2:56)

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<sup>33</sup> “[Lääkäri 1], hän on suhtautunut mun mielestäni hienosti, hän kertoo kaikki, kaikkee, hän kertoo taustoja, häneltä saa kysyä mitä vaan.”

<sup>34</sup> “Kaiku toimii kyllä myöskin dialogin välineenä se on vaan sit siin on pieni viive mut aika nopeesti kyllä on toistaseks vastattu mulle, et vuorokauden sisällä on vastattu. Et kyllä se toimii ihan hyvin. Se puhelin, joo, mutta jos sul on jotain semmosta... mis on numerotietoo sun muuta ni se on paljon parempi et se kerätään johonkin, elikkä se on kirjotettuna”

Well a thing like this has its benefits, I mean... you always have a document, things like that so that if... you want to get back to it you can see, if you've gotten an answer then the answer is saved there.<sup>35</sup> – Male, 72, Prostate cancer (6:86)

## 6.10 Information

Four patients out of seven experienced information mostly as a reliving factor. Three patients brought up that receiving too much information could also be a source of anxiety.

then when it's found [sic] to be cancer then I started of course to look for... also a bit online about what... information there is and... it started to dispel... dispel what was maybe the fear of death in the beginning, but then when you were able to prove yourself or to tell yourself that it doesn't kill you that quickly even in the worst scenario and that there are treatment options anyway<sup>36</sup> – Male, 65, Prostate cancer (1:10)

So it might be that the [more specific] information [about the illness]... would bring me... pain<sup>37</sup> – Male, 77, Prostate cancer (3:15)

Six of the patients had sought information online and five had received information from the treatment staff. Three patients mentioned that they

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<sup>35</sup>“Onhan tämmöessä omat etunsa eli... sulle jää aina dokumentti, kaikkee tämmöstä että jos... ja... ja tuota niin... öh... Jos sä haluat palata siihen asiaan sä näät, jos sä oon saanu vastauksen ni se vastaus on siellä tallessa.”

<sup>36</sup>“sit ku todetaan [sic] että syöpä sit siin rupes tietyst ettii... netistäki jonkun verran kaivelemaan että mitäs tota... asiast kerrotaan niin niin... että... se... sit se niinku häipy... häivenee se... se tota... no voi se varmaan kuolemanpelko sitte... aluks tai joku tämmönen mutta sit niiku sitä ittelleki pysty todistamaan tai tot- väittämään et ei tää nyt ole niin nopeesti tappava edes huonoimmas tilantees ja että hoitokeinoja löytyy kuitenkin”

<sup>37</sup>“niin saattaa olla että se [tarkempi] tieto [taudista] sitten... luo mulle... tuskaa”

also paid attention to cancer-related information in the media. Four patients had participated in public lectures about prostate cancer. Three patients bought up that not all information found online is reliable.

with the doctor we always... [...] like did an update on what's available abroad... since in Finland we have this and this but if there's something new abroad.<sup>38</sup> – Male, 65, Prostate cancer (1:46)

And and, after that I've read so much about this that I could probably do an approbatur degree on this thing (laughs), I've really read a lot.<sup>39</sup> – Male, 66, Prostate cancer (2:5)

Four patients had gathered patient information or print materials for themselves. One of them mentioned he had gathered information but it wasn't well organized. One patient said she had received some materials but did not want to gather paper around her since plenty of information is available online.

then when I've gotten these papers... at the doctor's appointment if I've gotten the lab results on paper then I've... saved them to a folder yes.<sup>40</sup> – Male, 65, Prostate cancer (1:75)

Five of the patients said that they had received enough information. One patient said that in the beginning there was even too much of it:

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<sup>38</sup>“lääkäriin kans kyllä aina... [...] sillan ikäänku päivitettiin siinä et no mitä nyt on maailmalla... ku Suomes on tämmöstä ja tämmöstä mut onko maailmalla jotain... uutta.”

<sup>39</sup>“Ja ja, tota sen jälkeen mä oon opiskellu tätä niin paljon et mä voisin varmaan approbaturin suorittaa ainakin tässä hommassa (naurahtaa) et mä oon todella lukenu paljon.”

<sup>40</sup>“sitte ku oon saanu ihan paperilla... siel lääkärikäynnin yhteydes jos oon saanu paperilla ne labratulosteet ni oon... neki oon tallentanu sitte tota... niinkun paperitulostenakin mappiin kyllä.”

Well maybe in the beginning there was somehow so much information that you weren't maybe even able to channel it at that point<sup>41</sup> – Female, 35, Breast cancer (4:46)

Two patients suggested that Kaiku Health could be used as a place for gathering the patient's medical data more broadly than just related to cancer treatments. Only one patient had used the self-care instructions in Kaiku Health and experienced them as only slightly useful. One patient said that he didn't think Kaiku Health should be used to give general information about the treatments.

I always got the most important information when I went to receive the cytostatic drugs, from the nurse that if I for example had dry nails then what I should do<sup>42</sup> – Female, 35, Breast cancer (4:70)

## 6.11 Support

Six of the seven patients had not utilized peer support. Three explained they didn't feel a need for peer support. The youngest patient brought up that she didn't feel she would have belonged in the support groups:

I also checked out some of those peer support groups but it somehow didn't... I didn't feel that they were for me, I think it's also an age question... especially since the magazines that I get from there, they're like... the magazine is called *Cancer* and it's people on their sixties and seventies and their stories and... the

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<sup>41</sup> “No ehkä siinä alussa tuli jotenki niin paljon tietoo et ehkä sit ei välttämät siin vaihees osannu oikein... kanavoida”

<sup>42</sup> “tärkein tieto tuli ku kuitenkin aina sit se niinku systostaatti... hoitokerran yhteydessä hoitajalta että... ois nyt hyvä, jos ois vaikka kuivat, kuivat tota... kynnet ni, ni ni laitas nyt mitä, mitä miten pitää toimia”

colors and everything are somehow like... death and anxiety<sup>43</sup> –  
Female, 35, Breast cancer (4:36)

One of the patients had initially participated in support groups and then became a volunteer for a peer support hotline. He felt that peer support had been very useful:

I started going to peer support... meetings and... I think it helped its part with the... coping.<sup>44</sup> – Male, 77, Prostate cancer (3:43)

Six patients agreed that their spouse was the most important source of support. Immediate family was mentioned by four patients. One of the patients said that his wife, adult children and a friend diagnosed with the same illness were important sources of support but that the most important one was his sister. One patient brought up the people at the patient association. Five of the patients had more than one source of support.

Of course the wife, wife has been... [the most important support] you don't appreciate it in the sense that the wife is always there and the support is often such that you don't even notice it yourself. But... second... are the people from the patient association.<sup>45</sup> – Male, 77, Prostate cancer (3:64)

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<sup>43</sup>“katoin kyllä myös niit mitä... jotain semmosia vertaistukiryhmiä mut jotenki ei se... en sit kokenu niitä niiku semmosiks niiku omiks, must tuntu et ehkä se... niinku ikäkysymyski on, on sit jotenki että ne... varsinkin ne ne lehdet mitkä sielt tulee kotiin ja ne on niiku... sen lehden nimi on *Syöpä*, siis se on niinkun kuus-seittemänkymppisiä ihmisiä ja heidän tarinoitaan ja... värit ja kaikki jotenkin sellast niinkun... niinkun kuolemaa ja ahdistusta”

<sup>44</sup>“mä rupesin käymään vertaistuki... palavereissa ja... osaltaan se varmasti... auttoi siihen... jaksamiseen”

<sup>45</sup>“tietenki vaimo, vaimo on... ollu [tärkein tuki], sitä vaan ei... osaa niinkö siinä mielessä arvostaa että kun... vaimo on aina siinä läsnä ja tuota se tuki on monta kertaa... semmosta ettei sitä niinko huomaakaan itse. Mutta... sitten toisena... tulee... tämä tämä potilas... yhdistyksen porukka.”

The support received took many forms. Two patients brought up how close ones showed how they care. Two patients said that their close ones had a forward-looking attitude and didn't pity. Three patients brought up practical help such as helping with cooking or financial aid.

Well firstly, that I said already was financially but it's been over since I got the loan but... she has... she's like very concerned but concerned in a right way so that she doesn't harp on about how I am. I get the feeling that somebody cares.<sup>46</sup> – Male, 66, Prostate cancer (2:45)

## 6.12 Kaiku

All of the seven patients had used Kaiku Health on a desktop or laptop computer. Three patients had also used it on a tablet computer and two had used the application using a smartphone. The youngest patient preferred to use Kaiku Health with a smartphone and tablet with the laptop being an exception.

No, I'm... I have an old Nokia and a Communicator as another phone, both of them work. I didn't bother to get into smartphones. I have a laptop and with that I get enough... connections.<sup>47</sup> – Male, 73, Prostate cancer (5:58)

Kaiku Health was described as reliable by three patients, friendly by three patients, matter-of-fact by two patients and fast by two patients. Other

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<sup>46</sup>“No ensinnä, sen mä sanoin just rahallisesti mut se nyt on menny ohi tos ennen lainaa mut tota... hänellä on, hän on hyvin niiku huolissaan, mutta sopivalla tavalla huolissaan ettei se niiku mee jankutukseksi miten, miten mä voin. Tulee semmonen olo että joku välittää.”

<sup>47</sup>“Ei, mä oon... mul on vanha Nokia, ja kommunikaattori toinen puhelin, molemmat toimii mitä mä käytän. Mä en oo älypuhelimiin viittiny lähtee. Mul on läppäri, jolla mä riittävästi saan... yhteyksiä.”

adjectives were used by individual patients. One patient couldn't think of any adjectives.

Easy to approach. Friendly. Fast. (longer pause) Mhmm...  
Reliable. Maybe those, those come first to mind.<sup>48</sup> – Female, 35,  
Breast cancer (4:85)

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<sup>48</sup>“Helposti lähettyävä. Ystävällinen. Nopea. (pidempi tauko) Mhmm... Luotettava, tämä... Ehkä ne, ne tulee nyt ekana mieleen.”

## Chapter 7

# Discussion

In this chapter the existing literature and the analytical and empirical findings of this thesis are discussed and a set of characteristics for digital services promoting a positive patient experience are deduced. Additionally, the research methodology in this thesis is scrutinized and possible future developments for Kaiku Health suggested.

### 7.1 Related research

Tsianakas et al. (2012) researched the patient journeys of breast and lung cancer patients through interviews of patients and treatment staff, ethnography and a co-design process and identified a number of issues. Many of the issues were overlapping with the findings in this thesis. The researchers brought up that patients are especially vulnerable at certain stages of the journey and pointed out that creating trust between the patient and medical professionals is vital at these times. Support was needed especially after the diagnosis. Patients expressed the need that the diagnosis be communicated sensitively. Patients faced problems in the continuity of care – for example they needed to explain their situation over and over to different doctors and nurses, which also eroded trust in the system. Patients also felt they had received enough information and emphasized the importance of receiving



timely and understandable information in person. (Tsianakas et al. 2012)

Some issues discovered were different from the findings in this thesis since the context, depth and participants of the study were different. Patients expressed bad experiences from inpatient care, such as unpleasant staff or lack of psychosocial support. Waiting times at the clinic were long. Day surgery seemed chaotic to patients. Administrative processes caused mistakes and delays in the process. (Tsianakas et al. 2012)

Nanton et al. (2009) researched the role of information in mediating the potential negative psychological effects of uncertainty in prostate cancer patients during their patient journey using focus groups and individual interviews. The researchers made several discoveries that are in line with the empirical findings in this thesis. Earlier life events helped patients to put the cancer diagnosis in a broader perspective. For example patients who had undergone coronary bypass surgery or had had information about prostate cancer before diagnosis had a milder emotional response to the diagnosis while other men described the diagnosis as an experience of shock. Most patients, especially the older men, positively reframed their situation into living from day-to-day or gratefulness about life. Many actively avoided the thought of cancer unless there were symptoms or an upcoming PSA test forcing it into mind. Upcoming PSA tests caused anxiety. The way medical professionals communicated was important: the communication needed to create reassurance, knowledge and understanding in patients. When communicating the diagnosis the physician needed to create trust, confidence and hope in the patient. Many patients did not want to participate in the decisions regarding their care because they had full confidence in the staff or didn't think they had the expertise to do so. All patients felt they had received enough information. Some patients were happy with basic information while others wanted deeper information on the mechanisms of treatment and searched for it from numerous sources. In some aspects adjustment to cancer required giving up something, for example in the case of impotence, and this required adaptation of its own. (Nanton et al. 2009)

Nanton et al. (2009) also found issues not discovered in this thesis. Uncertainty about the treatment process and a sense of non-urgency in staff caused anxiety in patients. The patients had all adjusted to life with cancer and uncertainty. This required the maintenance of “normality”, for example through adjustments in day-to-day activities to minimize adverse effects. Some patients fought the uncertainty through a adopting a healthy lifestyle. Social support groups were utilized by those who had adopted a problem-solving coping strategy. In palliative care, practical matters and supporting the family became central and most patients wanted to know how much time they had left – but didn’t have the courage to ask.

Walsh et al. (2011) researched the needs of patients, carers and medical professionals toward cancer care coordination using individual interviews and focus groups. In line with the findings in this thesis, timely delivery of services was crucial for the psychological well-being of patients and caregivers as was timely and understandable information.

Walsh et al. (2011) also discovered issues beyond the findings of this thesis. They found that patients needed help with administrative aspects of care and with navigation through the complex healthcare system. Patients also needed financial support and support services. Allocation of a key contact person for the patient was deemed important. Effective communication, information sharing and cooperation between healthcare professionals were vital. Assessing the patient’s physical, psychological and support need was a prerequisite for providing individualized care.

## **7.2 Characteristics of Digital Services Promoting a Positive Patient Experience**

### **7.2.1 Supports Effective Coping Skills**

Even though most patients in the interview had adapted well psychologically, those who have not adapted well are probably less likely to participate in in-

interviews. Digital services should support coping skills and strategies that are related to better adjustment and lower distress. Livneh (2000) recommended that treatment staff support patients' coping skills that encourage them to believe in their ability to challenge the illness; help solve everyday issues, such as adverse effects, caused by the illness; encourage seeking social support of family, friends and peers; and direct patients to reframe their illness to focus on realistic goals, remaining abilities and possible future contributions. An internal locus of control, a positive outlook and a minimizing perspective on the effects of the illness were related to lower distress and better adjustment (Livneh 2000).

In addition to the staff's efforts, these skills can be supported by digital services, either directly or indirectly. For example, psychosocial interventions such as peer support can be recommended to patient based on their quality of life data or phase of treatment. This could be effective, since based on the interviews few patients utilized peer support. Coping skills training programs can be implemented as part of the service. In addition to direct, explicit means, the service can indirectly guide patients towards effective coping skills. For example, participation in treatment through reporting adverse effects symptoms can direct patients toward an active problem-solving coping strategy and support an internal locus of control.

### **7.2.2 Supports Patients' Sense of Security**

Based on the interviews, certain phases in the patient journey, such as waiting for treatment after diagnosis and waiting for test results in follow-up were especially difficult psychologically. This is also in line with the findings of Nanton et al. (2009) and Tsianakas et al. (2012). At these moments the responsiveness of services and staff is vital.

Digital services can support a sense of security in patients and the most interviewed patients brought up how Kaiku Health had increased their sense of security. From the interviews it is clear that patients found it soothing to be able to contact the treatment staff at any time and that the barrier to

contact was low. Additionally, knowing that the treatment staff had the best possible information of the patient's well-being seemed to increase the sense of security. The feeling of control created by participation in treatment such as tracking laboratory values and reporting adverse effects symptoms may also increase the sense of security, as can the routines related to the use of the service.

The role of information in creating a sense of security seemed mixed. Some level of information was clearly needed and many patients gathered information for themselves, but not all patients wanted extensive information and felt it could be more harmful than helpful. Information for supporting patients' decision making was occasionally lacking. These findings are in line with Staniszewska et al. (2014). Patients must be able to control how much information and what information to receive.

When designing digital services for cancer patients the software itself should not come in the way of the sense of security. The application must look and feel trustworthy and reliable and the patients must be able to trust that the information they report reaches the healthcare staff.

### **7.2.3 Supports Patients' Participation and Internal Locus of Control**

According to Livneh (2000), an internal locus of control was a coping characteristic that was related to better adjustment and lower distress. Understanding one's own situation, knowing the next steps in the treatment process and meaningful participation in the treatment can facilitate a sense of control. The importance of understanding and navigating the treatment process was described by Tsianakas et al. (2012), Nanton et al. (2009) and Walsh et al. (2011).

Allowing patients to take action and participate in their treatment can also support a problem-solving coping strategy, which Livneh (2000) described as well-adapting. Kaiku Health facilitates this participation by allowing patients to report quality of life and adverse effect symptom data,

track their laboratory values and by helping their self-care with context-aware instructions. Additionally, the low-barrier conversation feature gives the patient more power to ask questions than more traditional methods. Patient participation in treatment should not mean busywork; the participation must be meaningful and useful to the patients themselves or the treatment staff.

Based on the interviews and Nanton et al. (2009) not all patients want to be active participants and decision-makers. Digital services should create ways in which patients feel comfortable participating. They can be gently pushed towards more active participation with the design of the service, but in the end patients must be able to opt-out of such functionality.

#### **7.2.4 Supports Individualized Care**

The need for individualized care was expressed in the interviews. Digital services make it feasible to gather and process more data that can be used for individualizing treatment. Adverse effect symptoms and quality of life data are already being gathered. Additionally, digital services make it easy to screen patients' psychosocial well-being as recommended by Zabora et al. (2001) and to perform assessment of physical, psychological and support needs of patients which Walsh et al. (2011) described as a prerequisite for individualized care.

The design of the software must support treating the patient as an individual. Cold or technical designs will not be effective – a warm, personal visual appearance and tone of voice is required. Personal touches such as greeting by name in the design can help. The design of the software must support patients with different cancer types, prognoses, abilities, preferences and devices.

### **7.2.5 Maintains a Good Care Relationship over the Whole Patient Journey**

A good relationship between patient and staff is vital. Redd and Jacobsen (1988) mentioned the quality of the doctor-patient relationship as a factor connected to adjustment. Walsh et al. (2011) brought up the patients' need for a dedicated contact person. The importance of a good relationship between patient and staff also came up in the interviews. Unnecessary changes in the staff that is in touch with the patient can disrupt the continuity of care and should be avoided. Based on the interviews Kaiku Health supported the continuity of care. Kaiku Health could be useful in solving the continuity problems mentioned in the interviews and Tsianakas et al. (2012) by providing a central location for treatment-related information.

Digital services should not disregard the aspect of relationships. A good relationship extends over different touchpoints – having the same people present in the service as in person at the clinic is valuable. Showing names and pictures of the people one communicates with is a small but important detail that fosters relationships.

### **7.2.6 Supports Patients' Need for Normality**

Nanton et al. (2009) brought up patients' need for normality. Digital services can aid normality in a very concrete way by helping with the management of adverse effects, an issue brought up by both Nanton et al. (2009) and the interviews in this thesis. Kaiku Health also facilitates more indirect ways to support normality by allowing the patients to decide when and where to read and reply to messages allowing them to forget the application and focus on normal life at other times. For example, in the interviews one of the patients brought up that phone calls can take place at an inappropriate time. Most patients agreed that the service was not in mind most of the time, but was available when needed. In general digital services should help patients maintain their normal activities and routines.

### **7.2.7 Supports Understandable and Timely Communication**

Staniszewska et al. (2014), Nanton et al. (2009) and Tsianakas et al. (2012) all brought up the importance of communication. Based on the interview Kaiku Health's chat-like communication channel can lower the barrier to asking questions and makes it possible for patients to get their questions out of their head at the time of need instead of waiting for the next business day. During a phone call or personal appointment information can be missed whereas in Kaiku Health patients can return to the information again and again. Kaiku Health does not replace face-to-face meetings or phone calls, which are more suitable for complex dialogue and emotional support, but rather augments them. For example, after discussing face-to-face key points could be added in Kaiku Health for later reference. The treatment staff's written communication skills must be adequate for Kaiku Health to contribute to a positive patient experience.

Even though good usability is important – especially when users are older, like most cancer patients are – it's not enough. The software must also be a good communicator. It doesn't help that the staff is understandable and emotionally warm if the application they use to communicate is difficult to understand or emotionally cold. The application must use understandable language and concepts and to be tactful and reassuring in its communication. This is especially important at the most difficult times during the patient journey such as after diagnosis and before upcoming tests.

### **7.2.8 Helps Manage who Knows**

Many patients brought up in the interviews that they wanted to control who knows about their illness and who doesn't. Patients feared people's reactions or felt shame. Kaiku Health allowed patients to use the application when it was convenient for them, helping them manage who knows.

### **7.2.9 Integrates in Treatment Processes and Organization**

These characteristics are difficult to fulfill without the healthcare organization considering its processes and touchpoints holistically. To create a simple integrated experience as mentioned by Meyer and Schwager (2007) the organization must consider patient experience as a whole in which the digital service is only one part.

A good relationship between patients and staff requires conscious effort from the healthcare organization. A contact person or care team must be assigned and available through the whole patient journey. In order to provide responsive communication – through an application or otherwise – the organization and processes of the healthcare provider must be in good shape. Different communications channels – digital, face-to-face, physical mail and telephone – complement each other and must form a cohesive whole from the patients' point of view.

It must be considered how the service is marketed and introduced to patients. Based on the interviews, visibility at the clinic or in printed or electronic materials is not enough – the treatment staff must take time to introduce the service to patients. In addition to the practical benefits of a system, also the emotional benefits should be communicated.

## **7.3 Methodological Considerations**

The interview method allowed collecting the patients' subjective experiences over the whole patient journey. The method resulted in a very large and rich dataset, and the whole potential of the dataset could not be utilized in this thesis. The interview method also has its downsides. As the patient journey can be very long it is likely patients have forgotten important details and events from long ago or remembered them differently from reality. Patients may have skipped interesting details or events because they considered them



unimportant.

For some patients, admitting their fear or other weaknesses seemed difficult. In general, the emotional aspects of cancer or coping strategies did not come up explicitly as often or in as much detail as expected, but often came up indirectly, “between the lines”. For example, use of reframing coping strategy came up as living day-to-day or gratefulness about life; fear and anxiety as haste to get to treatment. Some patients talked more openly about emotions than others.

One of the interviews was conducted at the patient’s home. Emotions were discussed more openly in this interview but this could also have been a coincidence. Otherwise the topics that emerged in interview were not different from the others. Close ones or the home were not mentioned any more often than in other interviews. However, the patient was able to show materials and demonstrate his use of the service, which resulted in richer data about the use of the application.

The interviews included two drawing exercises, which seemed beneficial. The timeline exercise in the first part seemed to help concretize and focus the telling of the story and help the patients talk about their emotions. It was added after the pilot interview in which the emotional aspects of the patient journey were not brought up as much as expected. The circling exercise in the second part was included in all interviews and seemed to help patients remember their use of the application and concretize their talk through referring to the features visible in the pictures. There were some challenges. Patients still had trouble remembering what features they had used, as there could be substantial time since use. Additionally, since the user interface has changed over time it may have been difficult for patients to recognize the features they had used long ago. The drawing exercises both aided and hindered data analysis. On one hand the concrete timeline and circled features made it easier to understand when things had happened or which features were used and which were not. On the other hand patients referred to features and points in time by pointing and using terms like “at

this time” or “this feature” which was difficult to understand using the audio recording. Inferences using other context on the recording and the pictures themselves needed to be made and it is possible that some of those inferences were incorrect. Using video instead of audio would help with this issue.

Running a group interview with participants suffering from the same cancer type was also considered, in the hope that more information about emotional aspects of the patient experience could be uncovered. Unfortunately there were not enough volunteer patients available to conduct a group interview without reusing the participants from the individual interviews. Thus, the group interview was not done.

The Warwick Patient Experiences Framework (Staniszewska et al. 2014) was a suitable theoretical basis for this thesis. The framework supported designing the interview structure, and included many factors, which may have otherwise been forgotten. It was also an adequate basis for the classification of the data. The downsides of the framework were related to its focus on the usefulness for service providers: the themes of the framework were unbalanced for analyzing the experience from the patients’ point of view. For example, the theme *lived experience* grew very large and had to be split into four subthemes during analysis. Some other themes such as *communication* also became fairly large, but this was expected since the example service focused heavily on communication. Since the Warwick Patient Experiences Framework was already used as a basis for the design of the interview, it may have been beneficial to create the classification themes from scratch during the data analysis. This could have helped discover even more insights from the data.

The selection of participants in the interview was quite biased. First of all the participants had signed up for the patient panel and the interviews themselves. This most likely excluded those whose physical symptoms or adverse effects were worse or who had not adapted well psychologically. The participants were most likely more active and motivated than average. Secondly, the patient panel was recruited from the users of Kaiku Health at the

same private clinic in Helsinki. The reason for this was that the patients of the clinic were easily available, Finnish-speaking and there was a large enough pool of users to recruit from at the time of the research. At the time of the research, most users at the clinic were prostate cancer patients. Additionally, all the patients were Kaiku Health users because one aim of the interviews was to gather information about the use of the service. Due to these factors most of the interviewed patients were older males diagnosed with prostate cancer and who were being treated at a private clinic and using Kaiku Health.

The biases in participant selection could affect the results in several ways. Patients of a private clinic likely have more bad experiences from the public sector than others. Since most of the patients were prostate cancer patients, certain adverse effects may be over- or underrepresented. Most patients were older which may affect coping and the ways they use digital services. For example, the 35-year-old patient preferred using different devices than others to access the service. Since all of the interviewed patients were Kaiku Health users, the perspective of why patients don't want to use a digital service were not exposed. In general, the stories of the prostate cancer patients interviewed in this research were consistent with the stories of prostate cancer patients who had not used Kaiku Health but were interviewed earlier as part of product development research at the company. Additionally, the amount of participants was quite small. In the future, a larger study with a broader selection of patients should be conducted. The patients should include males and females of different ages, treated in the public and private sectors and some using and some not using a digital service for follow-up.

## **7.4 Possible Future Developments for Kaiku Health**

By applying the characteristics to Kaiku Health itself, a number of improvement possibilities emerge. In the future, Kaiku Health could support pa-

tients' coping even further. For example, peer support between different users suffering from the same condition could be provided directly in the service. A coping skills training program based on cognitive-behavioral therapy could be provided. Psychosocial screening of patients could be implemented and the service could automatically recommend suitable interventions such as peer support or alert treatment staff to offer psychotherapy. Kaiku Health could also help elicit patients' concerns. Eliciting concerns and screening for psychosocial well-being could also increase the patients' sense of security.

Kaiku Health could facilitate patients' internal locus of control by helping them understand where in the treatment process they are, what lies ahead of them and to give patients a sense of progression through the treatments. For example, showing the amount of radiation therapy sessions left could help them have a sense of accomplishment and a goal to look forward to. In the future Kaiku Health could provide even more opportunities for the patients to actively participate in their treatments. In addition to relieving physical adverse effects, Kaiku Health could provide guidance for psychological well-being or diet, allowing for deeper patient participation. Exercise goals could be set based on the progression of care or patients' self-reported physical ability, supporting individualized care. Kaiku Health could even be made available directly for patients whose clinic does not provide Kaiku Health for patients allowing them to participate in their treatment. In this case, the conversation features would need to be disabled, but the application could still be used for tracking one's care, providing feedback based on reported outcomes, information tailored to one's diagnosis and a centralized location for storing treatment-related data.

Even though maintaining a good care relationship with the clinic is important, Kaiku Health could also support other simultaneous care relationships. Cancer patients may need to visit general practitioners or other doctors during or after the treatments, and these doctors may not be familiar with cancer treatments. Kaiku Health could also work as a summary of the treatment that could be shown to these doctors upon visit, reducing the need for the

patients to explain their special needs relating to the cancer treatments every time.

Kaiku Health could support understandable and timely communication even further. Cancer patients receive large amounts of information and it can feel overwhelming. The follow-up programs in Kaiku Health could be used to customize the provided information based on the cancer type and treatment, so that patients are not overwhelmed by unnecessary information. Since follow-up programs are designed to change during the course of treatment, it is also possible to provide information based on the progression of the treatment – i.e. at the appropriate time. Kaiku Health does give self-care instructions based on the symptoms patients report, but this could be taken further. The application could provide feedback about quality of life data, such as suggesting psychotherapy or offering a contact to peer support for people who could benefit from them.

Kaiku Health should be further integrated in the processes and organization of customer clinics. Service design methods could be utilized during implementation projects to engage staff and plan together with them how to integrate Kaiku Health as part of the patient journey, how to ensure timely communication through Kaiku Health and how to communicate the value of the service to patients.

## Chapter 8

# Conclusion

The objective of this thesis was to find ways in which digital services can contribute to a good patient experience for cancer patients, formulated more specifically as the research question *What characteristics contribute to a good patient experience in a digital service for cancer patients?*. In this thesis it was discovered that such characteristics are:

- Supports Effective Coping Skills
- Supports Patients' Sense of Security
- Supports Patients' Participation and Internal Locus of Control
- Supports Individualized Care
- Maintains a Good Care Relationship over the Whole Patient Journey
- Supports Patients' Need for Normality
- Supports Understandable and Timely Communication
- Helps Manage who Knows
- Integrates in Treatment Processes and Organization

The characteristics are mutually dependent and affect each other. For example, an internal locus of control and a good care relationship contribute to the patients' sense of security. Internal locus of control, participation of patients and supporting normality all support effective coping skills on their part.

Since cancer and its treatments are emotionally difficult, the psychosocial well-being of patients must be at the core when designing and implementing services. Fulfilling the characteristics requires not only good design of the digital service itself, but also a successful implementation as part of the clinic's offering, communication, culture and processes.

In the best case, the characteristics discovered in this thesis allow the designers of digital services for cancer patients to direct their product development efforts toward areas that improve the patient experience. The characteristics can work as a tool of discussion when considering new features or discussing the benefits and drawbacks of different design options. The characteristics can also be used to justify the usefulness of digital services as part of comprehensive cancer care. From a theoretical standpoint this thesis serves as an opener of discussion toward the role of digital services in patient experience.

In the future a deeper study into digital services and patient experience in cancer care should be conducted, aiming to validate or augment these characteristics. The research should consider different digital services focusing on different needs and a broader selection of patients. Different cancer types and phases of illness, variety of ages, both genders, public and private clinics and participants from different cultures should be included. Also the viewpoint of treatment staff and friends and family of patients should be considered. Also the organizational aspects to patient experience and the role of digital services as part of the broader health service are worthy of further research.

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## Appendix A

### Interview structure

# Potilashaastattelut – runko

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## Mukaan

- Lupalappu x 2
- Nauhuri
- Tulostetut näkymät
  - A3 Printattu etusivu, jossa myös itsehoito-ohjeet -nappi
  - A3 Printattu ”Hoidon seuranta” -sivu
  - Näkymistä pitää löytyä: keskustelu, haitat, lomakkeet, raportit, itsehoito-ohjeet, kalenteri
- Ohjeet ympyröintitehtävään
  - Vihreä = olen käyttänyt usein
  - Keltainen = olen käyttänyt joskus
  - Punainen = en ole käyttänyt
  - Punainen kysymysmerkki = ei tiedä mikä tämä on
- Tussit ympyröintitehtävään
- Leffaliput x 2
- Muistiinpanovälineet
- Mehua ja keksejä
- Tyhjä A3 aikajanaa varten
- Kynä aikajanaa varten

## Lupalappu, kysyttävää, allekirjoitus, nauhoitus (5 min)

- Peitä liikeanturi, jotta valot eivät välky
- Tarkista paljonko haastateltavalla oli aikaa varattuna
- Selitä lupalappu
- Selitä yleisrakenne: 45-60 min yleistä, 45-60 min Kaikua
- Puhelin lentotilaan, nauhuri käyntiin

## Yleinen osa (50 min)

### Taustatiedot

- Ikä
- Ammatti
- IT-aidot

### Oma tarina (30 min)

- *Piirtotehtävä: piirrä ja kerro oheiselle aikajanalla oma tarinasi ensimmäisestä epäilystä tähän päivään.*
- *Piirtotehtävä: piirrä aikajanalle syöpään liittyen kokemasi tunteet ja niiden kehittyminen ajan myötä. Punainen = negatiiviset, keltainen = neutraalit, vihreä = positiiviset*
  - *Esim: pelko, stressi, väsymys, toivo, ilo, viha, inho, suru, luottamus...*
- Millaisia odotuksia oli alussa? ...Miten ne muuttuivat?
- Mikä oli vaikein vaihe tässä kokemuksessa? ...Miten pääsit sen yli?
- Miten syöpä ja hoidot vaikuttivat muuhun elämään?
- Millaisia haittavaikutuksia oli? ...Miten niitä lievitettiin?
- Entä mikä oli pelottavinta? Mikä auttoi pelkoon?
- Entä ahdistavinta?
- Tuntuuko, että olet päässyt vaikuttamaan omaan hoitoosi?
- Mitä odotat tulevaisuudelta?
- Onko tämä kokemus muuttanut sinua?

### Sosiaaliset suhteet ja tuki (10 min)

- **Miten syöpä on vaikuttanut sosiaalisiin suhteisiin?**
- Mikä oli vaikeinta ihmissuhteisiin liittyen?
- Kuka on ollut tärkein tukesi? ...Miten? ...Miksi?
  - Entä muu tuki?
- Millainen on suhteesi hoitohenkilökuntaan? (Lääkärit, Hoitajat)
- Oletko hyödyntänyt vertaistukea?
  - Kerro siitä.
  - Miltä vertaistuki tuntui?

### Viestintä (5 min)

- **Miten viestintä hoitohenkilökunnan kanssa on sujunut?**
- Mitä eri viestintäkeinoja olet käyttänyt hoitoon liittyen?
  - Kenen kanssa?
  - Missä vaiheessa?
  - Miltä se tuntui?
- Mikä viestinnässä on ollut vaikeinta?
- **Entä viestintä omaisten tai muiden ihmisten kanssa?**

### Tiedon saanti ja etsiminen (5 min)

- **Kerro tiedontarpeestasi syöpään liittyen**
- Miten se muuttui eri vaiheissa?
- Mistä sait tietoa?
- Etsitkö tietoa itse? Mistä?
- Saitko riittävästi tietoa, tai liikaa?
- Oliko tieto sellaista kuin tarvitsit?

(Tauko tarvittaessa, 5-10 min; varmista tauon jälkeen että nauhuri pyörii)

## Kaiun käyttö (40 min)

### Alkulämmittely (5 min)

- Kerro siitä kun viimeksi käytit Kaikua.
- Mitä mieltä olet Kaiusta?

### Ympyröintitehtävä (5 min)

- *Merkitse näihin kahteen sivuun ne asiat joita olet tai et ole käyttänyt, viime aikoina tai aiemmin hoidon aikana. Kun olet valmis niin käymme läpi kunkin näistä.*

### Keskustelu kustakin ympyröinnistä (yht. 15 min)

- *Tässä kysytään aika monta kysymystä, mutta vastaa vain niihin kysymyksiin joihin muistat vastauksen.*
- **Kerro siitä kun käytit tätä ominaisuutta viimeksi**
  - Missä vaiheessa hoitoa/seurantaa se oli?
  - Mihin tarkoitukseen käytit ominaisuutta?
  - Missä paikassa tai tilanteessa käytit ominaisuutta? ...Millä laitteella?
  - Oliko ominaisuutta mielestäsi helppo käyttää?
  - Miltä ominaisuuden käyttö tuntui?
- **Entä miten käytit ominaisuutta tyypillisesti? Missä vaiheessa hoitoa/seurantaa?**
- **Miksi käytit usein / harvoin / ei koskaan? Miksi juuri siksi?**

### Keskustelu Kaiusta yleisesti (15 min)

- Puuttuiko kuvista jokin käyttämäsi ominaisuus?
- Mikä oli ympyröimistäsi asioista oli hyödyllisin? ...Miksi?
- Mikä oli vähiten hyödyllinen? ...Miksi?
- Mikä Kaiussa on mielestäsi toiminut erityisen hyvin? ...Entä huonosti?
- Mikä on ollut vaikeaa käyttää?
- Onko jokin asia Kaiussa tuntunut epämiellyttävältä? ...Entä erityisen hyvältä?
- Miten Kaiun käyttösi on muuttunut ajan myötä?
  
- Jos Kaiku olisi henkilö, niin millaisin sanoin kuvailisit häntä? ...Miksi?
- Miten Kaiku on vaikuttanut henkiseen hyvinvointiisi?
- Miltä Kaiun käyttö on tuntunut verrattuna muihin viestintäkanaviin?
- Onko Kaiku tuntunut henkilökohtaiselta?
- Onko Kaiun käyttö tuntunut turvalliselta?
- Miten Kaiku on toiminut osana arkea?
  
- Oliko Kaiusta hyötyä kun kaipasit tietoa syövästä?
- Onko sisältö (lomakkeet, haittavaikutukset, itsehoito-ohjeet...) ollut ymmärrettävää?
- Tuntuuko, että lomakkeiden / haittojen täytöllä on todella vaikutuksia?
- Miten Kaiku on vaikuttanut suhteeseesi hoitohenkilökuntaan?
  
- Käytätkö muita digitaalisia palveluita hoitoon liittyen?
  - Mikä ollut paras? Miksi?
  - Mikä ollut huono? Miksi?
  - Oletko kerännyt itsellesi jotain materiaaleja tai papereita talteen?
- Tuleeko mieleen jotain kehitysehdotuksia Kaikuun?



## **Muuta**

- Tuliko mieleen jotain, mitä en keksinyt kysyä?

## **Kiitokset**

- Kiitos
- Nauhuri pois
- (vapaata kuuntelua)
- Leffaliput
- Onko käytettävissä videomainokseen?

## Appendix B

# Invitation for interview

Subject: [Kaiku-käyttäjäpaneeli] Kutsu haastatteluun

Hyvä vastaanottaja,

Etsimme osallistujia haastatteluun, jonka tarkoituksena on hahmottaa, kuinka Kaikua tällä hetkellä käytetään, miten se istuu hoidon kokonaisuuteen ja kuinka Kaiku voisi olla jatkossa entistäkin hyödyllisempi.

Haastattelut pidetään viikoilla 14 ja 15 NetMedi Oy:n toimistolla Helsingin keskustassa. Tarkka aika sovitaan kunkin osallistujan kanssa erikseen. Haastattelun kesto on noin puolitoista tuntia ja kiitokseksi osallistumisesta saat kaksi elokuvalippua. Viikolla 13 järjestetään yhden vapaaehtoisen kanssa pilottihaastattelu.

Ilmoittaudu haastatteluun täällä: [link redacted]

Haastattelua käytetään Kaiun jatkokehityksen lisäksi aineistona Aalto-yliopistolle tehtävässä diplomityössä. Kaikkea syntynyttä materiaalia käsitellään luottamuksellisesti ja

hyvien tutkimuskäytäntöjen mukaisesti.

Mikäli sinulla on kysyttävää, älä epäröi ottaa yhteyttä allekirjoittaneeseen.

Saat tämän viestin, koska olet ilmoittautunut Kaiku-käyttäjäpaneeliin. Mikäli et halua enää viestejä käyttäjäpaneelistä, ota yhteys [emil.virkki@netmedi.fi](mailto:emil.virkki@netmedi.fi).

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Emil Virkki  
Käytettävyysasiantuntija  
NetMedi Oy

[emil.virkki@netmedi.fi](mailto:emil.virkki@netmedi.fi)  
+358 503398627