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Refining digital care for headache disorders

Enhancing user experience

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Abstract

This was a development project of a digital care path for patients with headache disorders in Helsinki University Hospital. The digital care path was originally produced in 2018. It consists of information for the patient, physiotherapeutic and cognitive behavioral coaching, and a mobile headache diary. The project focused on patient centered care. The goal was to clarify user experience of the current care path and to gather development ideas to better support the needs of patients in their care for headache disorders. User interviews were selected to gain rich data. Altogether eight informants were interviewed.

Analysis of interview material identified six main themes: support, usability, information, personalization, existing content and miscellaneous. Users needed more peer support and support for the use of the care path. They also wished for more information on various subjects such as diversity of migraine symptoms, different migraine types, on new medications and scientific advances among others. Users had experienced some usability issues. Main issue impairing usability concerned mobile headache diary. It should be simpler to reduce data entry burden of patients. This would enhance diary adherence. Users wished for a personalization ability for the care path. There should be sections for more advanced users and possibility to bookmark items especially meaningful to oneself. Moreover, there were various valuable miscellaneous enhancement suggestions, such as more videos would be appreciated. However, there already existed a lot of content as well which users regarded very beneficial.

Subsequently some new features were developed. Features and gathered information were presented to the informants and two HUS customer council members in a workshop for final refinement.

This development project provides valuable user information for future development of the digital care of headache patients and more generally what kind of features users appreciate in electronic services.

Keywords
Digital care path, headache, migraine, tension type headache, user experience, user-centered design, behavioral therapy, mobile headache diary, development

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1 INTRODUCTION

Headache disorders are the second most common disabling conditions in the world when measured by years lived with disability (Global Burden of Disease Study 2016, 2017). Migraine is classified into two categories: with aura or without aura. Migraine headache is described usually pulsating. It is associated with sensitivity to light, sounds, odors and movement, fatigue, inability to function normally and gastrointestinal symptoms, such as nausea and vomiting. Migraine with aura attacks include also visual and speech disturbances, numbness or hemiparesia. The headache lasts typically 4 to 72 hours. Prodromal symptoms include increased appetite, desire for sweet, fatigue, yawning, irritability and feeling cold. Tension type headache is dull, bilateral, less disabling and has no associating symptoms. Frequent intake of acute medication can lead to medication overuse headache which can resemble the underlying headache disorder. It is common that a person with chronic headache has all these three types of headaches.

Migraine is one of the most understated and incapacitating disease. It has a significant negative impact on health-related quality of life (Bakar et al., 2016). It involves mostly people of working age and major costs are produced by sickness leaves and impairment to work. Patients have been mainly offered pain relieving medications and preventing medications. These treatments work quite well in episodic migraine but are inadequate in chronic headache disorders and almost always result in medication overuse complicating the situation further. In addition to genetic factors, lifestyle factors play a major role in the cascade of episodic migraine turning into a chronic life disabling condition.

As technology is developing at a speed and people use their mobile devices in everyday life, digital applications are becoming essential in healthcare services as well. New technology enables more efficient ways of enhancing health. In order to aid the patients to recognize life quality impairing factors and provide them means to revise their lifestyle habits aggravating headache, a digital care path was created by a multidisciplinary team, which I was member of, at Helsinki University Hospital in Hospital District of Helsinki and Uusimaa (HUS) in 2018. The path is based on methods that have scientifically been proven to be effective (Buhrman et al., 2016; Gunreben-Stempfle et al., 2009; Hedborg & Muhr, 2011; Magnusson et al., 2004). It was implemented as a minimal viable product (MVP) and needed to be refined in an iterative manner as we have gained some experience from its use. We have learned that only few patients have carried out the whole path. However, there are very few replies to the feedback requests sent from the path to the users by and they don’t provide sufficient data for developing the path to better support patient needs. This thesis aims to provide feedback from user experience by interviewing patients who have used the path. This aids to develop the path further to better support patient needs in their care. Moreover, thesis increases general understanding how digital care paths should be constructed and what kind of solutions support and motivate patients.

2 HEADACHE DISORDERS

2.1 Migraine, tension type headache and medication overuse headache

Only those headache disorders that are in the scope with regard the currently existing digital care path are delt here. The digital care path is at present directed to patients with migraine, tension type headache and/or medication overuse headache. The care path does not yet contain information on rarer headache disorders.

Prevalence of migraine is 15% in Europe, and it is more prevalent in women aged between 20 and 50 years. Results from the Chronic Migraine

Epidemiology and Outcomes (CaMEO) study show greater disability in people with chronic migraine compared to episodic migraine (Lipton et al., 2016). In Europe, prevalence of tension type headache is 60% whereas chronic headache around 4%. Headache prevalence seems to be increasing during last decade in Europe. (Stovner & Andree, 2010.) Medication overuse headache is a worldwide problem. According to epidemiological studies 4% of the people overuse acute headache medication and 1% of people suffer from medication overuse headache (Wakerley, 2019; Diener & Limmroth, 2004). It is common that the same patient has all three above mentioned conditions at the same time. In health care, the treatment mostly concentrates on pharmacological treatment due to tradition and lack of resources to provide any other treatment.

2.2 Comorbidities

Many medical conditions have been found to be more common in people with migraine as compared to general population. These include for example epilepsy, ischemic stroke, cardiovascular diseases, sleep disturbances, temporomandibular joint disorders, depression, and anxiety. (Burch et al., 2019.) The relationship between migraine and depression is bidirectional, with each condition increasing the risk of the other (Breslau et al., 1994). Epidemiological data in USA show that up to two-thirds of migraineurs suffer from anxiety disorders (Malone et al., 2015). The Hospital Anxiety and Depression Scale (HADS) has been used in the majority of headache studies for screening for depression and anxiety. Comorbidities are more commonly associated with chronic migraine and headache, which carry greater burden of diseases as well. Development of central sensitization and increased activation of the trigeminal nociceptive pathways may be drivers for chronic migraine and chronic daily headache (Buse et al., 2019).

3 NON-PHARMACOLOGICAL TREATMENT OPTIONS

Medications alone are only partially beneficial. They can also cause side effects and thus tolerance issues prevent their utilization. Therefore, other therapy models are needed. Furthermore, pharmacological treatment has been shown to be as effective as non-pharmacological treatment in the prophylaxis of migraine (Holroyd & Penzien, 1990). The effectiveness of non-pharmacological treatment is well illustrated in randomized controlled trials. Combination of medication and behavioral interventions yielded enhanced outcomes in the treatment of both migraine and chronic tension type headache than either treatment regimen alone. (Holroyd et al., 2001; 2010.)

Multidisciplinary treatment concepts are generally accepted as the best available and efficient treatment option for chronic pain patients (Stanos, 2012). Adherence to more than five recommendations for lifestyle changes was associated with a significant, at least 50% reduction in headache frequency (Gaul et al., 2011a). Gaul et al. (2011b) discovered that different concepts from various countries showed high variability of frequency and overall number of psychological treatment sessions. Matsuzawa et al. (2019) found in their literature review that major factors influencing the adherence of the patient to non-pharmacological treatment were attitudes and beliefs, readiness, or motivation to change, lack of knowledge, sense of control, coping styles and self-efficacy, which is defined as perceiving oneself capable of taking actions that will prevent or improve headache episodes.

3.1 Patient education

Patient education is an important and effective part in multidisciplinary headache care. The educational approaches result in increased quality of life, reduced disability and decrease of migraine frequency. (Kindelan-Calvo et al., 2014.) Motivation and adherence to non-pharmacological therapy as well pharmacological therapy may be improved by headache-specific patient education. Education is a crucial element in the treatment of headache disorders and in preventive management in patients with frequent headaches who are at particular risk of escalating medication consumption. However, education takes time, which is not often available. (Steiner et al., 2019). Patients who understand their situation and possible lifestyle factors exacerbating headaches are also more likely to be able to make change.

3.2 Physiotherapeutic interventions

Endogenous opioids, namely endorphins and encephalins mediate analgesia. Endocannabinoids have been hypothesized to synergistically work with the opioid system in producing antinociception. Migraineurs have been shown to suffer from a failure of these both systems (Genazzani et. al, 1984; Van der Schueren et al., 2012). Aerobic exercise at a moderate intensity and prolonged endurance exercise have been shown to increase endorphin levels (Swarz & Kindermann, 1990; 1992). To date there is plenty of evidence on positive impact of exercise on migraine (Hindiyeh, 2013; Köseoglu et al., 2003). Moderate intensity aerobic exercise has also been reported to increase endocannabinoid levels (Sparling et al., 2003). The abnormal levels of endorphins and endocannabinoids could therefore be restored by moderate level exercise and migraine symptoms could be mitigated especially in chronic migraine patients. Studies show that exercise reduces physical disability in migraineurs and increases sense of well-being (Dittrich et al., 2008; Domingues, 2011). In the study by Narin et al. (2003) there was a significant, greater than 50 % reduction, in headache days after 8 weeks' period of exercise three times a week. This is the same magnitude of effect than the requirement for a prophylactic migraine medication in RCT studies. It is remarkable that a same result can be achieved by exercising. Exercise produces in addition decrease in pain levels, relaxation, tranquility, self-trust, and more confident sense of mind that one can cope with migraine.

Luedtke et al. (2016) found in their meta-analysis that interventions used by physiotherapists reduce statistically significantly the intensity, frequency and duration of migraine and tension type. Meyer et al. (2016) showed in their study that a six-week progressive muscle relaxation treatment reduces migraine frequency and normalizes cortical event-related potentials indicating that the method is effective also by electrophysiological measurements.

3.3 Psychological interventions

The effectiveness psychological procedures applied in migraine and chronic headache has been proven (Andrasik, 2003; Holroyd & Drew, 2006; Altieri et al., 2008). The main objectives of cognitive behavioral therapies are "… to increase the patient's control of their headaches, reduce the frequency and severity of headaches, reduce related disability and affective distress" (Holroyd & Drew, 2006). Fritsche et al. (2010) compared the effectiveness of cognitive-behavioral minimal contact program with bibliotherapy for prevention of medication overuse headache in migraine patients. In the study patients were randomly assigned to receive an educational brochure or in addition to a brochure cognitive behavioral therapy. The study showed that both groups improved significantly, almost all patients experienced significantly fewer headache days per month and none of the patients developed medication overuse. The observation period in the study lasted up to two years.

4 DIGITAL CARE PATH FOR PATIENTS WITH HEADACHE DISORDERS

Digitalization of the world is developing at speed shaping our society and how we live our lives. People are using increasingly various gadgets to measure their health and for instance sleep. We are also used to utilizing various digital services in different sectors of life already for a long time. In health sector development has taken place more recently. Especially private sector has invested early developing digital services. Digital services increase the convenience for the patient and aims to serve patient needs better and faster. Especially covid-19 pandemia has boosted this development as maintaining distance has become important.

Digital care path can provide better service for the patient. Central for the care of headache patients is multidisciplinary treatment, which is not often accomplished because of lack of resources to produce the service. For chronic pain syndromes with complex somatic, psychological, and social consequences, a therapeutic intensity as high as at least 100 hours is recommended (Arnold et al., 2009). This is unrealistic to be accomplished with face-to-face contacts. Minen et al. (2016) found in their systematic review that patients are willing to use digitally delivered behavioral headache interventions. Non-pharmacological treatments can for the first time be offered to all headache patients in HUS with digital care path as the treatment is scalable. The care path consists of information, cognitive behavioral tasks, physiotherapy rehearsals and motivation to exercise as well as self-questionnaires and a life quality questionnaire. Patients can report their headache days, intensity of headache, predisposing factors, medications taken and their response and the effect of the attack to their daily functioning.

A digital care path can support the regular care in many ways. It is scalable and can increase the efficiency of healthcare and provide better care for larger populations. The digital care path is convenient to the patient as it can be used regardless of place and time. Patients need information and support to change lifestyle factors aggravating their headache situation. Increased self-consciousness aids to focus on a certain behavior, eliminate precipitating factors and enhance well-being. The care path (Figure 1) provides them means and helps them to be empowered to take responsibility on their own life. The aim of the care path is that although patients still experience headaches, they won’t be overwhelmed by the headaches and have an improved life quality. A headache diary kept on a mobile device is integrated to the path. Patients also have an opportunity to message with a headache nurse. The goal is to empower the patient for self-care in connection with a health-care provider.

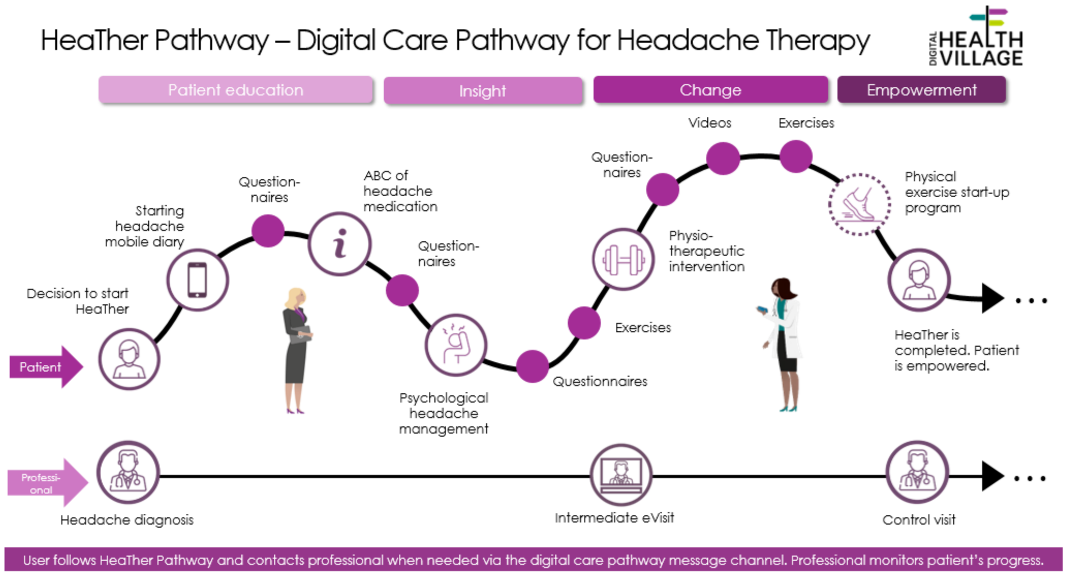


Figure 1. Digital care pathway for headache therapy in HUS. With permission of the project manager for brain diseases, Laura Mäkitie, HUS, Neurocenter.

5 USER CENTERED DESIGN AND USER EXPERIENCE

It has long been recognized that user involvement and user satisfaction is crucial for a successful software design (Harris & Weistoffer, 2009). Vredenburg et al. (2002) define user centered design as "an approach for designing competitive ease of use into the total user experience with products and system". According to the international standardization, ISO 9241-210, user centered design requires understanding of users, tasks, and environments, that users are involved throughout the design and development and the design is refined by user-centered evaluation. The process should be iterative, and the design address the whole user experience. The design team should consist multidisciplinary skills. (ISO 9241-210, 2019.)

Usability is defined as the extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use. (Bevan et al, 2016; ISO 9241-11, 2018.) User experience (UX) considers, in addition to pragmatic characteristics, also hedonic qualities and accounts user's perceptions and responses that result from the use and/or anticipated use of a system, product or service. It also includes accomplishments and is a consequence of brand image, presentation, functionality, system performance, interactive behavior, and assistive capabilities of the interactive system. (ISO 9241-210, 2019.) Sauer et al. (2020) state that UX definition can be classified into three: the holistic view, extension of usability or primarily focusing on emotions and affect. The holistic view of UX includes usability. Zhang and Li (2004) found the perceived affective quality to have an impact on perceived usability, usefulness, and the intention to use a system. Thus, in this thesis UX is used to refine the care path as it acknowledges the whole experience and affects the engagement to use the path. The digital care path is used by the patients and healthcare staff. This thesis focuses to the user experience of patients as they are the users of the actual content of the path.

6 AIMS AND PURPOSE OF THE THESIS

The care path is a game changer in the treatment of chronic headache disorders as it combines non-pharmacological and medicinal treatment and can be offered widely in the form of a digital solution. When building the first version of the care path two patient experience experts read the manuscript through and gave some feedback. It is now obvious that more input from the patients is needed. Only few patients out of four hundred logged into the path have carried out the whole path. There can be a variety of reasons for this. In this thesis, those reasons will be elucidated, and empirical feedback on user experience is gathered how to support better the care of headache patients.

The specific aims of this development project are:

- to clarify the user experience of the digital care path
- to obtain development suggestions from users for digital care

- to produce tangible mock-ups and develop the digital care path

The ultimate purpose is to better support patient needs regarding care of headache disorders. In order to achieve better outcomes and life quality, the care of headache patients demands holistic approach combining multidisciplinary care to medicinal treatment. To gain effectiveness with the digital care path, it is necessary that a greater number of patients walk through the whole path.

7 MATERIALS AND METHODS

Since the most appropriate method of data collection is essential for ensuring the credibility of content analysis (Graneheim & Lundman, 2004), interviews of users of the digital care path were selected. In order to develop the care path, it is essential to obtain insights from the users of current care path. Minen et al. (2016) state that engagement of patients in the development, refinement, and post study iterative improvement of electronic headache care would likely increase adherence and potency of the treatment. Thus, users of the headache care path are the best informants who possess the best knowledge concerning the topic. User interviews were selected as a method because they can provide in depth information. During interviews it is also possible to present more detailed questions when needed in order to fully understand what the participants mean. Interviews were preferred over mailed questionnaires as they can ensure better saturated data collection. Thus, data obtained from the user interviews addresses well the project aims, which ensures credibility and confidence of the project results (Polit & Beck, 2012).

User centered design process consists of specifying the context of use, (identifying people who use the product, what they use it for, and under what conditions they use it), specifying requirements, creating design solutions, and evaluating designs with users (ISO 9241-210, 2019; website of usability.gov, 2021). To involve users a group message was sent from the path to around two hundred pilot users to inquire who would be interested in participating to give their feedback and evaluate design enhancements (appendix 1). The message was sent by a project coordinator who manages digital care paths in HUS. Participation to the interviews was entirely voluntary. The goal was to interview from three to five users. Nevertheless, there were altogether nine volunteers, out of which eight participants were interviewed (for interview questions see appendix 2). Users that had advanced on the path were preferred, because they are probably able to give most valuable feedback about the care path. It is possible and even likely, that patients that are most motivated to take care of themselves and interested in using digital applications were willing to participate. Hence, probably not all insights could be gathered. However, the participants were also able to consider other patients' possible opinions and the interviews enlightened actions to take to activate less-motivated patients to use the path more regularly. For ensuring trustworthiness the guidelines for qualitative studies from Malterud (2001) were used.

Both single (four) and pair (two) thematic interviews were held remotely, since remote interviews were preferred by all the participants. Open-end and structured questions were used (appendix 2). All the feedback was gathered anonymously, no personal, intimate, or medical data was captured. Interviews were recorded with a permission of the interviewees. A 6-step method by Braun and Clarke (2006) was used to perform a thematic analysis of the interview data. Interviews were transcribed, repeatedly read and concepts and sub concepts were generated. Transcription of recordings represents an important role in developing thorough understanding of the captured data (Braun & Clarke, 2006). An inductive thematic analysis was used, where themes and concepts arise from the data themselves (Frith & Gleeson, 2004). Next concepts were evaluated and refined by returning to the transcripts. As a tool, a mind map was used (Braun & Clarke, 2006, p. 19; website of Illumine Ltd, 2015). Data from structured questions were managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at HUS (Harris et al., 2009; Harris et al., 2019). REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. Feedback on user interface was collected and will be later transmitted to HUS IT-services.

Based on the interviews of users and previous knowledge of treating headache patients, a value proposition map was constructed (Website of Strategyzer AG (2021). Next, a session among the development group of three people (product manager, head of digital care paths in Neurocenter and author) was organized to preliminary inform about the results from the interviews and for further comments.

Based on feedback and value proposition canvas, new features were designed using mock-ups as artifacts (Brhel M. et al., 2015) that were presented to the interviewed users (three took part as participation was voluntary) in a workshop for validation. Two patient members of HUS customer council, who had experience from other digital care paths in neurology attended the workshop as well. User involvement has the greatest impact on system success if the users can tell their opinions and make choices from predefined options (Harris & Weistoffer, 2009.)

8 ETHICAL ISSUES

Permission to conduct the project from HUS was applied after the study plan was approved. Since no personal nor medical data was collected, ethical committee approval was not needed. The data consist solely of user opinions about digital care and development suggestions. The study followed the responsible conduct of research (RCR guidelines), formulated by the Finnish

Advisory Board on Research Integrity (TENK) (Finnish Advisory Board on Research Integrity 2012). According to the guidelines researchers are acquired to adopt honesty and integrity in their research activities. The study was conducted with integrity and accuracy when recording, presenting, and evaluating the results. Other researchers' work was considered and respected appropriately. Required permits had been acquired.

The guidelines on ethical principles of research by TENK (2019) promote and ensure respect for all human participants to protect their autonomy and dignity, and ensure that no harm is done to the subjects. The participants replied voluntarily to an information letter (appendix 1) that was sent from the care path. They were informed that whether they participated or not, it would not affect their care. They were able to ask questions in writing or orally. Participants can make a voluntary decision about taking part only after they have received enough information what participation demands from them (Kuula, 2011). They were able to withdraw from the project at any time and attendance to the final workshop was voluntary as well. Privacy issues were respected, and all means were taken to preserve confidentiality at every step. The author was not involved with participants' medical care.

Voluntary participants gave their consent to participate and contacted the interviewer by email. At that time their names were known to the interviewer, but all the interview data was gathered anonymously without any identifiable items. The data cannot thus be tracked back any more to the interviewee. Voluntary and anonymous participation as well as data collection without identifiable characteristics considers vulnerability of subjects.

9 RESULTS

9.1 The extent of experience on the path, perceived technical skills, usefulness, and usability reported by informants

The first question the informants were asked to reply was how far they had advanced on the care path. Replies to this question give perspective how much experience the interviewees have gained about the care path (Figure 2). Seven out of total eight informants had reached *at least halfway* or to the *end* of the care path. Half of the patients had already reached *the end* or *almost the end* of the care path. Only one out of eight had reached *less than halfway* of the care path. None of the informants had only started the care path. In summary, the interviewees had overall a quite comprehensive experience about the care path. Therefore, their replies constitute a reliable basis for development ideas for entire path.

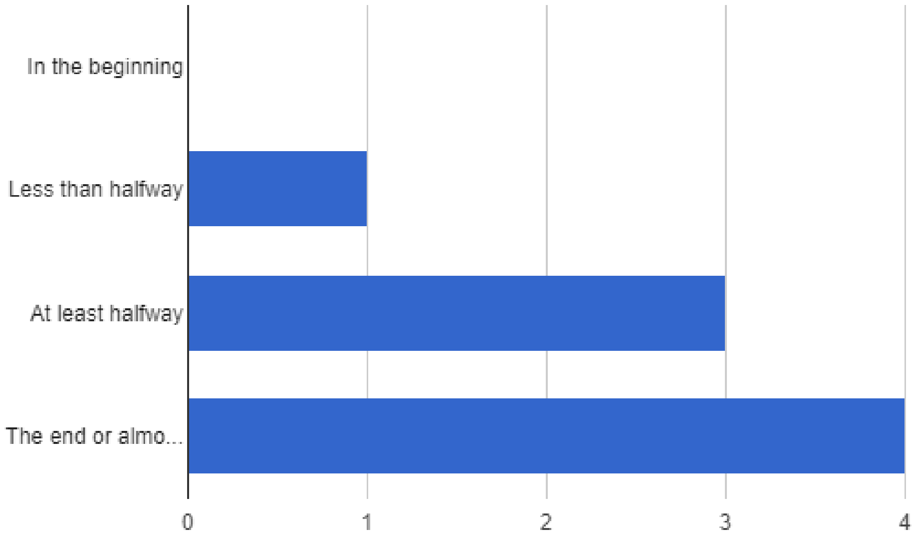


Figure 2. The phase the interviewed participants have reached on the care path.

Six out of eight informants evaluated that they had a *lot of experience* in using electronic services or technical software. Two informants reported that they were only *little experienced* using technical systems. (Figure 3). The informants can thus also represent those patients to whom using electronic services is new and might have more usability issues based on their thin knowledge on technical environments.

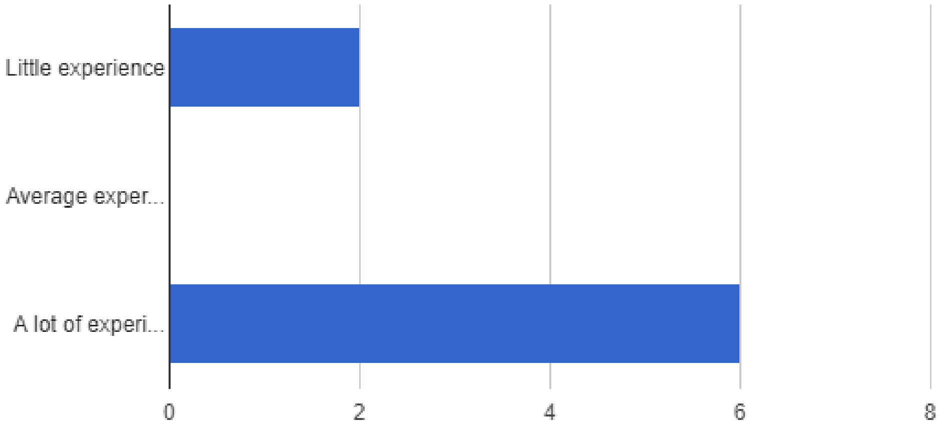


Figure 3. The perceived technical skills of the interviewees.

Half of the users considered the care path *useful* or *very useful* and half *somewhat useful*. Three out of eight regarded that the care path is *very useful*. All informants had benefitted from the care path some way and none felt that it wouldn't be useful at all. (Figure 4). Altogether, during the interviews the informants announced that they were very satisfied that a care path for headache disorders had been created and thought that it is useful for the patients.

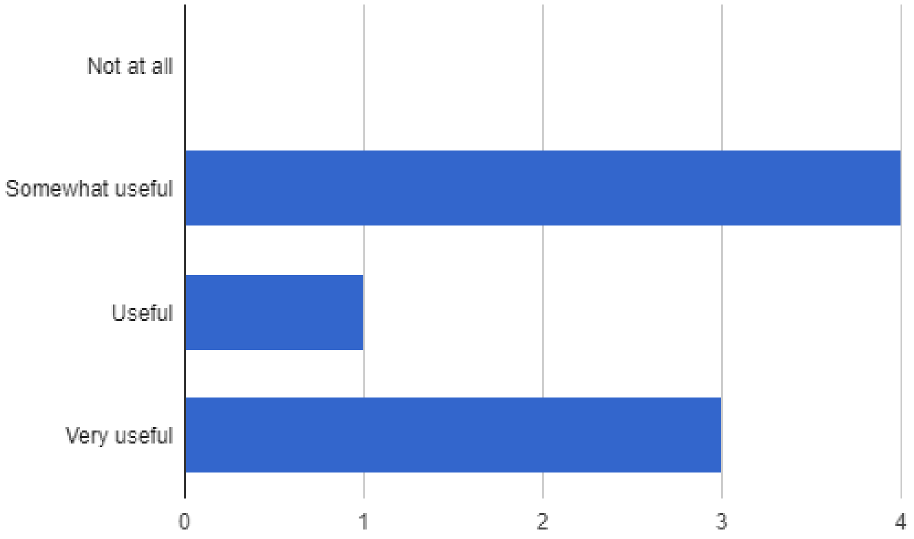


Figure 4. How useful the participants experienced the care path

Five out of eight interviewees felt that the care path is *very easy* to use. One considered the care path to be *easy* to use and two reported that it is *somewhat easy* to use the path. (Figure 5).

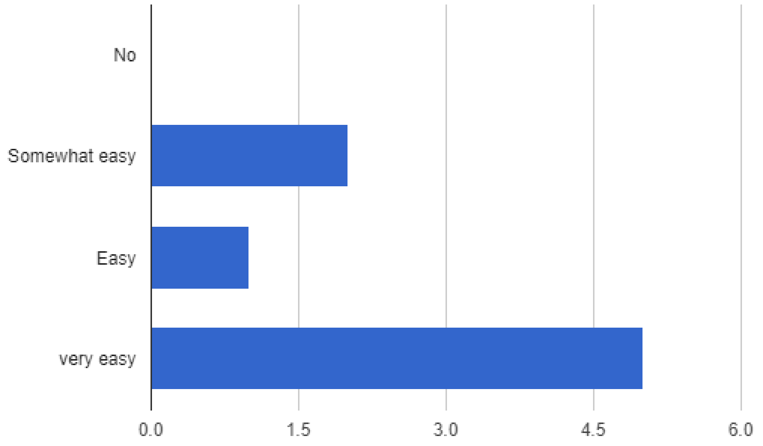
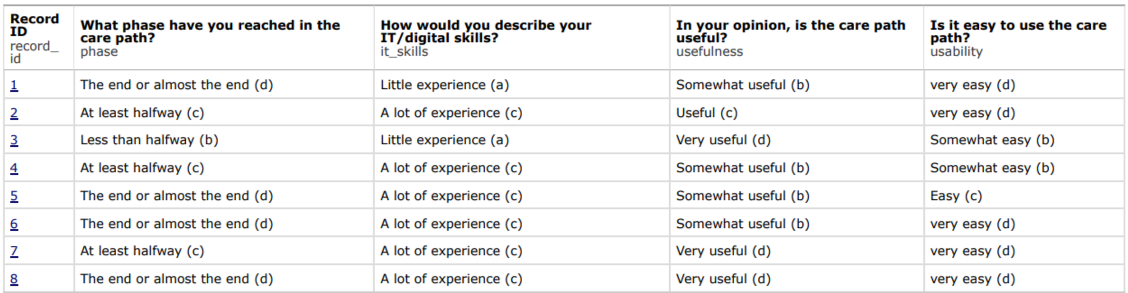


Figure 5. The perceived usability of the care path

From five users who thought that the care path is *very easy* to use, four had *a lot of experience* using technical solutions (Figure 6). Many of them expressed that they were involved using various technical environments in their work. On the other hand, one of the users that regarded the care path to be *very easy* to use, had only *little experience*.

Moreover, one of the two informants who considered the care path to be *somewhat easy* to use had a *lot of experience* using various technical systems and the other had *little experience* with technical environments. Two informants who had a *lot of experience* with technical environments considered the care path to be *easy or somewhat easy* to use. Thus, from experience only one seems not to be able to draw direct conclusions how the users might perceive the usability of a digital service. There must be other factors influencing as well. It might also give more insight to the reasons to clarify more accurately what kind of solutions the user has used previously.



Record ID record_id	**What phase have you reached in the care path?** phase	**How would you describe your IT/digital skills?** it_skills	**In your opinion, is the care path useful?** usefulness	**Is it easy to use the care path?** usability
1	The end or almost the end (d)	Little experience (a)	Somewhat useful (b)	very easy (d)
2	At least halfway (c)	A lot of experience (c)	Useful (c)	very easy (d)
3	Less than halfway (b)	Little experience (a)	Very useful (d)	Somewhat easy (b)
4	At least halfway (c)	A lot of experience (c)	Somewhat useful (b)	Somewhat easy (b)
5	The end or almost the end (d)	A lot of experience (c)	Somewhat useful (b)	Easy (c)
6	The end or almost the end (d)	A lot of experience (c)	Somewhat useful (b)	very easy (d)
7	At least halfway (c)	A lot of experience (c)	Very useful (d)	very easy (d)
8	The end or almost the end (d)	A lot of experience (c)	Very useful (d)	very easy (d)

Figure 6. Comparison of IT skills and usability

Furthermore, although six out of eight informants reported they had *a lot of experience* with technical solutions their perceived usability differed from *somewhat easy* to *very easy.*

9.2 Themes produced from the data

The transcribed interviews were thematically analyzed to identify patterns or themes from the data (Braun & Clarke, 2006; Maguire & Delahunt, 2017; Tuomi & Sarajärvi, 2018). The focus was to gain development ideas. The specific questions that were explored were what needs development, what affects usability of the care path, what would enhance usability and usefulness of the care path, what would encourage utilization of the care path and what content participants would like to be added to the path. Also, beneficial elements of the current care path were elucidated for preservation. Thematic analysis itself used inductive method and was data driven (Braun & Clarke, 2006).

After initial coding manually, themes were mapped using a mind-map (see final themes, sub themes and codes in Appendix 3). Themes were generated, reviewed, and refined repeatedly and final six themes were defined as support, usability, information, personalization, existing content and miscellaneous. Support had two sub themes, peer support and support for the use of the care path. Existing content had two sub themes as well, desirable, and negative. (Figure 7.)

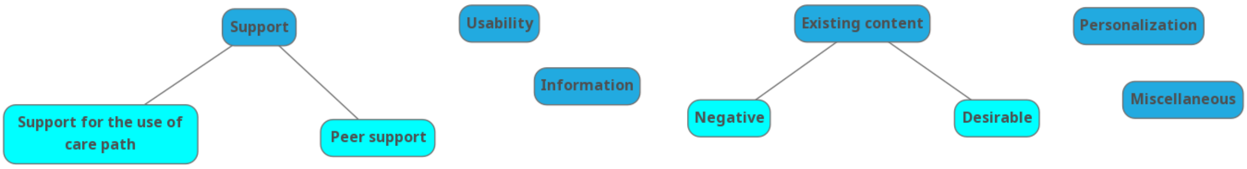


Figure 7. Themes and sub themes

9.2.1 Existing content

The informants listed that desirable features were psychological coaching section, physiotherapeutic interventions, support for adaptation and acceptation having migraine and one's situation with migraine, exercise advice, self-care, learning mindfulness skills, videos and in general multidisciplinary treatment. Messaging with a nurse was also a beneficial feature.

> *"[good was] The part where it was expressed that you have to accept that migraine is part of you, and you have to learn to live with it."*

> *"The messaging contact to the nurse was good. The prescription and reimbursement for a biological medication had expired but was renewed after I sent a message."*

Waiting times before one could go to the next content was experienced negative by many of the informants. One informant also felt that there was repetition in the text of physiotherapeutic interventions section and in the section "learned skills".

9.2.2 Support

Users wished to get more advice in the start for the use of the care path as well as more guidance what the care path includes, how one uses it and can benefit from it. The nurse in the clinic could be responsible for the presentation of the care path. It seemed also that not all the users had understood the purpose of the self-questionnaires to evoke oneself to consider that a certain state of mind or thoughts might provoke migraine. Recognition of provoking or aggravating issues can help with migraine management. A nurse could explain this to the patient when introducing the patient to use the care path.

> *"It would support the use that when one is joined to the care path, nurse would tell what there is and what they are useful for. So, one would understand that it is really beneficial."*
>
> *"* [nurses introduction would clarify] *What is for me, where should I start and what to search for."*
>
> *" A question annoyed: Why are you sad? Of course, because of migraine, don't ask this kind of questions, it is self-evident"*

One user voiced that some of the advice might feel annoying or moralizing and wished for a more emphatic approach. It should be emphasized that although one might not be able to do something, one is still "a good person". The other user commented on it that it is important what is the tone with which things are expressed.

> *"Emphatic attitude towards that we all know how we should live, but what if it is not possible."*
>
> *"If you cannot do these things, you are still a good person."*
>
> *"The tone with which things are described is important."*

On the other hand, some reported having learned on the care path that one should be compassionate with one-self and not demand too much from one-self.

> *“One should learn to be compassionate with one-self, that one should not demand from one-self miracle performances. It is good, in my opinion.”*

Many emphasized that a face-to-face contact is still important and should be included in the treatment. One user expected for a digital service to include a video appointment with the doctor in the beginning or in the end.

> *“When you have thirty years thought that can it be any more normal and then somebody says that it is, acts as an authority. It is the feeling of safety that personal contact creates.”*

> *“As a care path, if there could be a video meeting with the doctor in the beginning or in the end. It could also be with a nurse, but I never met any nurse during my treatment period.”*

Very refreshing idea was promoting messages which could inspire better the users to visit the care path regularly, more than just plain reminder messages to a user who hasn’t visited the care path for a while. The latter ones are currently in use in the care path.

> *“Marketing messages which might inspire to peek into the care path e.g. “Have you noticed that there is a relaxation rehearsal in the care path?”*

Users would also like to have peer support with their headache disorder and living with it. Peer headache patients can best understand what kind of problems and issues patients are going through and what questions puzzle them. Patients also seek for acceptance and acknowledgement of the difficult situation they might be experiencing.

> *“Some kind of comment section where migraine patients could face each other would be nice.”*

> *“Real life patient stories would help to address the issue. It would be nice to read more personal experiences.”*

On the other hand, one user stated that one gets support from the care path that one is not the only one in the world with the problem but there are other people in the same or even worse situation.

> *"You get there such support that you are not alone with this. Other people have an even worse situation."*

9.2.3 Usability

Some of the users experienced usability issues, for example one reported having problems finding the care path while searching for it in Google. Google search won't take you directly to the logging in -page for the care path, but that is located under "omapolku" where all the care path logging in sites is situated on the website of Health Village. Health Village also contains information on diverse health issues and disorders open to public. A more direct link to the logging in site for the care path would be preferred. One user was having issues with returning to the care path after visiting outside links while using the care path with a mobile phone. We were not able to repeat the error, so it might have been a temporary problem, or it has already been fixed. When the care path will be on a mobile application this kind of problems are unlikely to occur.

One user reported having issues with replying to the questionnaires and wished to have a free alternative possibility as well. Some of the users reported that they had hard time finding things in the care path and that one gets easily disoriented when the care path progresses. The outline of the care path is not clear enough. However, they still felt that usability is good enough and requiring minor enhancement.

> *"The big picture gets lost, what is coming next. It was said clearly in the beginning, but when one progresses, it gets confusing where one is and what is coming in current module."*

> *“In basic use fine with minor upgrade. The format is just fine, clear, and well divided into chapters, but the table of contents and progression could be still more clear. I am quite pleased with the care path.”*

Biggest usability issues seemed to exist with the mobile headache diary. Many users reported that because it was too complicated to use, they didn’t use it at all. This of course can cause serious problems with monitoring of the patients on the care path. One user couldn’t use a PIN code for logging in but needed to use every time identification with bank credentials or a mobile verification. Users wished for a possibility to add headache days to the diary afterwards. One reported that this caused all the days accumulate on the same date.

> *“I first started using the diary diligently. But when I have migraine, I can’t see with my other eye, so I have no possibility to add the day then but added them afterwards. It then looked like I would have had twenty migraine days on the same date. Then I started using a paper version.”*

Users reported that the diary is too long and complicated to use. Especially when one has migraine it is demanding enough trying to survive with everyday life and there is no energy or time to do anything extra. When one then adds the days afterwards the work accumulates even more and feels overwhelming. They felt that it should be quicker to use the diary and it should contain less questions. They reported that a date, what kind of headache it was and what medications one took should be enough. Two users commented that these data are usually what they have been asked in the doctor’s visit. Therefore, they felt that there was no need for the other questions. Users also wanted that the diary could be printable.

> *“Headache diary wasn’t very good. It must have been some draft.”*

> *“It should last maximum one minute to fill in the diary or maybe not even that long.”*

9.2.4 Information

Users wished for more extensive and deeper information of broader range of subjects that currently exist in the care path. Many users commented that the information in the care path was quite basic. They wanted to know more about diversity of migraine symptoms, nutrition, migraine treatment in menopause age and various migraine types, e.g., hemiplegic migraine. Especially almost everybody wanted to know more about of new biological medications and experience from their usage, about scientific news, and hot topics among migraine world in general. One idea was to offer a version for a basic user and an advanced user or a “read more” -section. An information package to the employer was also wished for.

> “*…about the diversity of migraine, it is such a generally disabling disease. It is common that it is defined only as a headache.”*
>
> *“If everything concentrates on the pain and if it doesn’t resonate at all to your symptoms, that there is hemiplegic, basilar, abdominal migraine, Horton and equivalent. At least information on all the symptoms that can be related to migraine. Even some doctors have commented that migraine can’t disable speech or cause paralysis.”*
>
> *“I would be very interested to find information about the biological medications which is hard to find. How patients have experienced them and have they benefitted from them. Overall, I have no idea where to find such information.”*
>
> *“There could be information for different stages of migraine patients. There is now good basic information but deeper information about new medications, scientific results and what is happening in migraine community is lacking.”*

One user brought up a need for a list of technological aids from which a migraine patient can benefit. According to the informant questions about these are a common topic often appearing in internet peer groups. An informant wished that the existing comprehensive care path should be provided in the earlier stages of the disease when one would be more receptive for all the information. Moreover, informant stated that it should be provided even already to a child's parents.

> *"It is such a general, but good information, that if one got it when the situation is not yet chronic, it would be easier to accept and acknowledge it."*

9.2.5 Personalization

Some informants thought that the big picture is lost during one progress along the care path. It seemed that the existing table of contents is not enough or clear enough. They would like to remember better the most important sections to themselves so that they could easily return to those and rehearse the skills.

> *"The table of contents should be somehow visible all the time so that one would better remember where one wants to return."*

As many of the users reported the content to be quite basic, they expressed a wish to be able to have more personalized content for example for basic and more advanced use for those who are already familiar with the existing content. One informant wished also to be able to edit the frequency of reminder messages. The informant felt that she would like to have more frequent reminder messages but depicted that this might annoy some of the other users who would be content with less frequent messages. One solution the informant suggested could also be a message: "A tip, if you want more frequent reminding, you can set an alarm on your mobile phone for yourself."

9.3 Value proposition canvas

Based on the results of user interviews, a value proposition canvas was created to describe the tasks the user needs to perform and the pains and gains of the user (appendix 4). Moreover, the value the care path development provides to the patient to create gains and relieve pains are listed on the other side. The jobs patients need to have done are to extend their knowledge of their headache and its treatment, to gain physiotherapeutic tools for self-care, to learn pain management and self-coping skills and to register their headache situation into a mobile headache diary. They use self-questionnaires to evoke their understanding of factors affecting the headache situation in their life and to reflect for discovering new and better ways of reacting and managing the situation by themselves.

The users desired to get more peer support, broader information on various subjects and personalization features. They needed also more support for the usage of the care path. Headache diary should be easier and faster to use in everyday life. More feedback from the questionnaires and tools to manage issues with which the user is having was hoped for.

Many users suffered from the burden of the disease. Frequent attacks and working life are a difficult combination and some of the users had experienced misunderstanding by the employer. Other pains were some usability issues, too narrow information, and lack of peer support. Mobile headache diary is not feasible to use for reporting frequent headaches. Means to support the usage of the care path should also be developed.

Based on interviews gain creators were generated. Gains will be produced by providing information on peer support, new headache medications and their user experiences and enhancing usability by creating preferences which enable the user to bookmark items most beneficial to themselves and to which they want to return repeatedly. Some users wished for more concreate physiotherapeutic rehearsal instructions that they could do at home. There are some already existing instructions on in Health village rehabilitation house to which a link could be provided from the care path. This would assist finding the instructions. More interpretation of the results of the questionnaires and tools to aid with problems the user is facing based on questionnaires could be provided. This would motivate users to reply to the questionnaires and reinforce the feeling of being cared for. It became clear that users need more introduction to the content of the care path and how its usage will benefit them. A frame for presenting the care path and its benefits to the patient by a nurse should be generated to create a standardized way of introducing the care path to the patients. Enhancement of the feasibility of the mobile headache diary will be crucial in monitoring the patients and their care.

The tone of expressions in the care path was scanned and edition proposals were done to better mediate acknowledgement and empathy towards patients. Other pain relives include headache diary development suggestions, better guidance for the use of the care path and information on Finnish Migraine Association peer support groups and events. Moreover, information of new medicines and up to date scientific evidence should be provided.

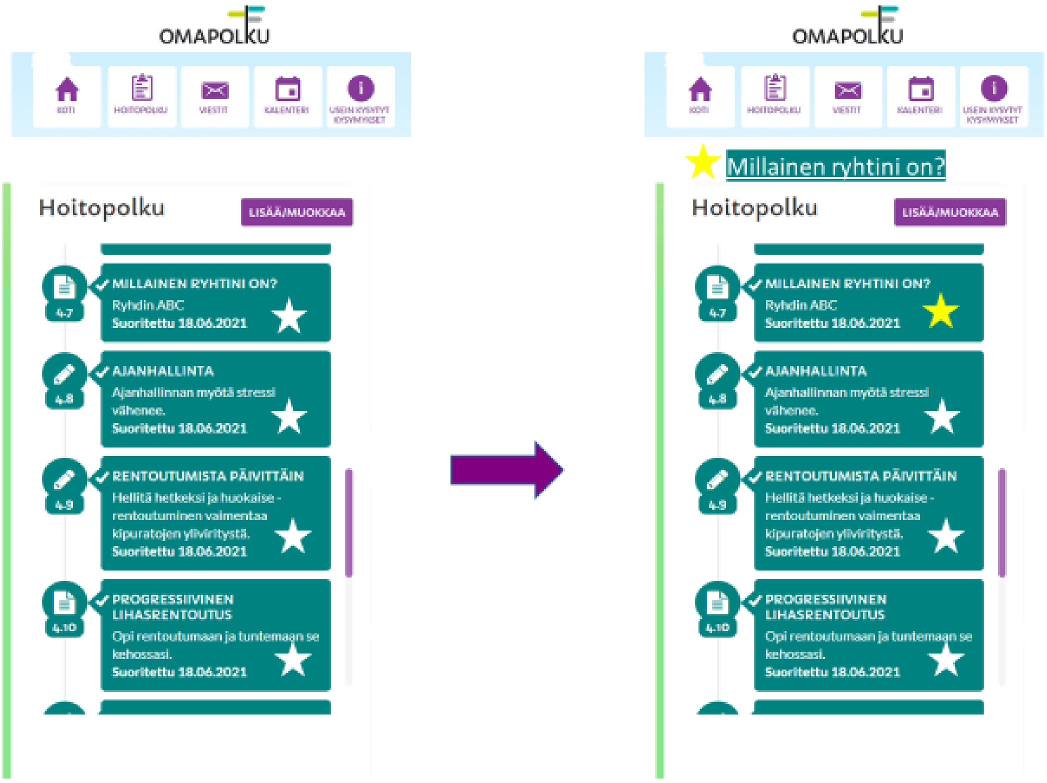
10 DEVELOPMENT OF THE DIGITAL CARE PATH AND THE FINAL WORKSHOP

After analyzing the interviews and creating value proposition canvas, final workshop was organized to get feedback on the development ideas and mock-ups created as tangible examples. There was one informant present, two remotely connected and two customer council members present in the final workshop. Attendance to the workshop was voluntary and all the informants were invited. Beforehand a best date and time for everybody was scanned. The manager of all the care paths in neurology participated remotely as well. Development ideas and mock-ups were presented to the attendees in the workshop, which they were able to comment and there was further free discussion taking place.

Waiting times have already been identified before this thesis as one factor causing many of the users to forget to revisit the path which increases dropouts. Hence, they have already been eliminated. However, many of the users interviewed have probably used the care path already before this modification had taken place and brought up this issue. This further validates the importance that this action was executed.

A free text alternative was wished for by one informant in the interviews. The manager of the care paths in neurology stated that it is unfortunately not possible to have a free choice in all of the questionnaires because of the workload that this would cause for the professionals dealing with the answers.

Some informants expressed that one gets easily lost in the care path and the big picture becomes unclear. They would like those interesting points to especially themselves would be somehow visible all the time. This could be solved with preferences as in a mock-up presented to the attendees in the final workshop (Figure 8.). After pressing the star, it becomes yellow, and preferences are listed above. By pressing the link, one is directed to the section in question. This was very much liked by the informants and customer council members in the final workshop.



Hoitopolku

MILLAINEN RYHTINI ON?
Ryhdin ABC
Suoritettu 18.06.2021

AJANHALLINTA
Ajanhallinnan myötä stressi vähenee.
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RENTOUTUMISTA PÄIVITTÄIN
Hellitä hetkeksi ja huokaise - rentoutuminen vaimentaa kipuratojen ylivirittystä.
Suoritettu 18.06.2021

PROGRESSIIVINEN LIHASRENTOUTUS
Opi rentoutumaan ja tuntemaan se kehossasi.
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Millainen ryhtini on?

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Figure 8. A mock-up how preferences could be implemented.

Major usability issues were experienced with the mobile headache diary. One problem was the inability to report headache days retrospectively. The manager stated that it is possible nowadays to change the date. A member of the customer council pointed out that there is also a need to be able to mark headaches that last over 24 hours and not having to add them every day. This is a valid argument as well and should be taken into account in further development of the mobile headache diary.

For deeper information it was planned to have a “read more” -section for those users who are interested in familiarizing themselves into a more specific information on for example new medications and their mode of action, novel scientific reports, various migraine types, comorbidities and coping in working life with migraine. For nutrition and sleep a link to the Health Village website which anyone is able to visit could be provided as it became clear that users were not aware of its existence (päänsäryn hallintaa elämäntavoilla). As one user was expecting to get more concrete instructions for physiotherapeutic instructions, a link to the rehabilitation house in the Health Village would complement the physiotherapeutic section of the care path (liikunta kotioloissa).

A link to the Finnish Migraine Association was also agreed to satisfy the need for peer support. This way migraine patients are able to find peer group discussion forums more easily (Tukea ja toimintaa - Migreeniyhdistys). The manager informed that it is possible also to organize anonymous Teams meetings for the patients. However, it was felt that it would be bound on a certain time and thus unsure who could participate. Facebook groups were preferred as they can be benefitted whenever it is suitable for the patient. The same problem is with a moderated chat, but a pilot according to one informant could be explored. One informant reported in the interviews that there probably would not be patients with rarer types of migraine present and therefore it would not benefit the informant. Customer council members informed that there is going be peer support offered by three experience experts of Neurocenter as well.

The Finnish Migraine Association also organizes presentations on various subjects and burning questions. Presentations also by a nurse or a doctor in the clinic and an opportunity pose questions afterwards were liked. One informant wished for a summary page were all the links and subjects would be gathered. The manager told that at least at the moment the technical platform of the care path doesn’t enable internal links. Everybody agreed that the headache diary needed development to better support patients’ care.

A list of aids for alleviating migraine symptoms was created based on a user interview and by the help Finnish Migraine Association. It was introduced in the final workshop and the informants complemented it by one item (appendix 5).

Examples of care path content promoting messages were presented. The manager commented that because of privacy issues the messages sent from the care path cannot include any information on a patient’s disease. Messages informing about novel content was especially wished for by the informants.

More videos were wished for in the interviews. A couple examples of what kind of animation videos could be easily created were presented. One described what the digital care path is about and its contents, which could be used as an introduction in the beginning of the care path. The other one described benefits of relaxation rehearsals. They got an enthusiastic reception. It was felt that addition of animations would make the care path more visual and livelier.

11 DISCUSSION AND FUTURE DEVELOPMENT

Before creating the care path for headache patients, a nurse in Neurological outpatient clinic of Meilahti in HUS made a valuable study on what kind of features users would appreciate in the care path (Latvala, 2018). In the study most of responders considered a messaging opportunity with the nurse important. Thus, it is not surprising that in the interviews, messaging opportunity was as well an appreciated feature of the care path. Nowadays this is also possible in the medical record system itself. Physiotherapeutic interventions, relaxation instructions and psychological coaching were as well seen important in the study of Latvala (2018) as they were mentioned among the desired features in the interviews of this study. The patients wished for an opportunity to discuss with peer headache patients or read peer opinions. (Latvala, 2018). Due to privacy issues, it is not possible to arrange this in the headache path itself but information on peer support in the Finnish Migraine Association could be collected to the care path. This way it could be available to all patients using the care path and they could find it with ease. Support how to cope at work with a headache disorder came also up in the study by Latvala (2018), which is interesting as some of the interviewees also expressed burden in working life and wished for material to hand to the employer.

A nurse has an important role in the care of headache patients. This should be strengthened. Interviewees clearly needed more introduction to the care path, to its benefits as well as to the use of the mobile headache diary. A checklist for the nurse could be generated so that every nurse doesn't have to invent it themselves and all patients would get equal and standardized presentation. Patients and their treatment would obviously benefit from demonstration of key features and their utilization in the beginning. This would probably also augment usage of the application.

Since users didn't seem to be aware of that it is not compulsory to reply every time all questions in the headache diary, an instruction text for the usage of the diary would be beneficial to add at the beginning of the diary. This matter also further confirms the central importance of guidance for use of the care path itself and the headache diary. As I tried the headache diary, I noticed some discrepancies. If one leaves preventive medications and predisposing factors blank, the answer is turned "no" instead of being blank. This is something that could probably be solved by changing the structure of the question from a sliding window into a check box.

In the study by Huttunen and Halonen (2018) they found that migraine patients considered that it is important that a headache diary is available in a mobile format and the data sent to the physician or nurse if necessary. Van de Graaf et al. (2021) also state in their review that an electronic headache diary is essential in the care of headache patients, but diary adherence is a problem. The ease-of-use of the diaries need to be improved. Data entry burden needs to be decreased to improve diary compliance. (Van de Graaf et al., 2021.) Moreover, in the study by Huttunen and Halonen (2018) migraine patients were willing to support their self-care with a mobile application. If it is combined with a device measuring symptoms and sleep it could further motivate and encourage patients to adjust their living habits and support their self-care at home. (Huttunen & Halonen, 2018.)

With digital care we can better and more cost-effectively treat underserved populations such as headache patients. Van de Graaf et al. (2021) state that if properly validated on safety and outcome, digital treatment could make care safer, decrease patient burden, be more cost-efficient and more effective in-patient outcome. Digital applications in patient care are still quite novel in larger scales. Most studies on ehealth of headache patients have focused on electronic diaries (Van de Graaf et al., 2021). There is still limited information on effectivity of electronic diaries and treatments for headache patients. However, online relaxation or cognitive behavioral training has showed a reduction in attack frequency or symptoms as compared monitoring alone. (Van de Graaf et al., 2021.) In addition, self-efficacy, migraine management control and migraine related quality of life increased (Sorbi et al., 2015). Therefore, it is important that effectiveness of this digital care path will be also evaluated. An independent study on this has indeed recently been started.

12 LIMITATIONS

As in qualitative studies in general patient number interviewed was here small. However, the goal was to interview 3-5 patients but finally there were even eight volunteers to be enrolled. Furthermore, qualitative research produces rich data providing deep information. Only three out of eight informants were able to attend the final workshop, but it was reinforced by two HUS customer council members. The date for the workshop was attempted to suit as many informants as possible by a beforehand query. Since it was voluntary to participate in the workshop, only four of the informants replied to the survey.

Time and resources to plan new features was very limited. The project provides, however valuable information for future development and implementation even more beneficial digital care path for headache disorders.

13 CONCLUSION

In this development project users of the digital care path for headache patients were interviewed to elucidate how the users have experienced the care path, to find its benefits and deficiencies, and gather development proposals. Six main themes were identified in the interviews, support, usability, information, personalization, existing content and miscellaneous. Based on the interviews and development suggestions new features were planned. Most frequent enhancement proposals and planned new features were presented in a final workshop for further comments. Rich information and ideas gathered in this project serve as a solid basis for implementing even a further beneficial tool for aiding patients and their care providers in the care of headache disorders in future. The project also sheds light on what kind of features patients value in electronic health applications.

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REFERENCES

Altieri, M., Di Giambattista, R., Di Clemente, L., Fagiolo, D., Tarolla, E., Mercurio, A., Vicenzini, E., Tarsitani, L., Lenzi, G. L., Biondi, M. & Di Piero, V. (2009). Combined pharmacological and short-term psychodynamic psychotherapy for probable medication overuse headache: a pilot study. Cephalalgia: an international journal of headache, *29*(3), 293–299. https://doi.org/10.1111/j.1468-2982.2008.01717.x

Andrasik, F. (2003). Behavioral treatment approaches to chronic headache. Neurological sciences: official journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology, 24 Suppl 2, S80–S85. https://doi.org/10.1007/s100720300048

Arnold, B., Brinkschmidt, T., Casser, H. R., Gralow, I., Irnich, D., Klimczyk, K., Müller, G., Nagel, B., Pfingsten, M., Schiltenwolf, M., Sittl, R. & Söllner, W. (2009). Multimodale Schmerztherapie: Konzepte und Indikation [Multimodal pain therapy: principles and indications]. Schmerz *(*Berlin, Germany*)*, *23*(2), 112–120. https://doi.org/10.1007/s00482-008-0741-x

Bakar, N. A., Tanprawate, S., Lambru, G., Torkamani, M., Jahanshahi, M. & Matharu, M. (2016). Quality of life in primary headache disorders: A review. Cephalalgia: an international journal of headache, 36(1), 67–91. https://doi.org/10.1177/0333102415580099

Bevan, N., Carter, J., Earthy, J., Geis, T. & Harker, S. (2016). New ISO Standards for Usability, Usability Reports and Usability Measures. 9731. 268-278. https://doi.org/10.1007/978-3-319-39510-4_25

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology, Qualitative Research in Psychology, 3:2, 77-101. https://doi.org/10.1191/1478088706qp063oa

Breslau, N., Davis, G. C., Schultz, L. R., & Peterson, E. L. (1994). Joint 1994 Wolff Award Presentation. Migraine and major depression: a longitudinal study. Headache, 34(7), 387–393. https://doi.org/10.1111/j.1526-4610.1994.hed3407387.x

Brhel, M., Meth, H., Maedche, A. & Werder, K. (2015). Exploring principles of user-centered agile software development: A literature review. Information and software technology, 61, 163-181. https://doi.org/10.1016/j.infsof.2015.01.004

Buhrman, M., Gordh, T. & Andersson, G. (2016). Internet interventions for chronic pain including headache: A systematic review. Internet interventions, 4, 17–34. https://doi.org/10.1016/j.invent.2015.12.001

Burch, R. C., Buse, D. C., & Lipton, R. B. (2019). Migraine: Epidemiology, Burden, and Comorbidity. Neurologic clinics, 37(4), 631–649. https://doi.org/10.1016/j.ncl.2019.06.001

Buse, D. C., Greisman, J. D., Baigi, K., & Lipton, R. B. (2019). Migraine Progression: A Systematic Review. Headache, 59(3), 306–338. https://doi.org/10.1111/head.13459

Diener, H. C. & Limmroth, V. (2004). Medication-overuse headache: a worldwide problem. The Lancet. Neurology, 3(8), 475–483. https://doi.org/10.1016/S1474-4422(04)00824-5

Dittrich, S. M., Günther, V., Franz, G., Burtscher, M., Holzner, B., & Kopp, M. (2008). Aerobic exercise with relaxation: influence on pain and psychological well-being in female migraine patients. Clinical journal of sport medicine: official journal of the Canadian Academy of Sport Medicine, 18(4), 363–365. https://doi.org/10.1097/JSM.0b013e31817efac9

Domingues, R. B., Teixeira, A. L., & Domingues, S. A. (2011). Physical practice is associated with less functional disability in medical students with migraine. Arquivos de neuro-psiquiatria, 69(1), 39–43. https://doi.org/10.1590/s0004-282x2011000100009

Finnish Advisory Board on Research Integrity. (2012). Responsible conduct of research and procedures for handling allegations of misconduct in Finland. Retrieved December 11, 2021 from https://www.tenk.fi

Finnish Advisory Board on Research Integrity. (2019). The ethical principles of research with human participants and ethical review in the human sciences in Finland. Retrieved December 11, 2021 from https://www.tenk.fi

Fritsche, G., Frettlöh, J., Hüppe, M., Dlugaj, M., Matatko, N., Gaul, C., Diener, H. C., & Study Group (2010). Prevention of medication overuse in patients with migraine. Pain, 151(2), 404–413. https://doi.org/10.1016/j.pain.2010.07.032

Frith, H., & Gleeson, K. (2004). Clothing and embodiment: men managing body image and appearance. Psychology of Men & Masculinity, 5(1), 40-48. https://doi.org/10.1037/1524-9220.5.1.40

Gaul, C., van Doorn, C., Webering, N., Dlugaj, M., Katsarava, Z., Diener, H. C., & Fritsche, G. (2011a). Clinical outcome of a headache-specific multidisciplinary treatment program and adherence to treatment recommendations in a tertiary headache center: an observational study. The journal of headache and pain, *12*(4), 475–483. https://doi.org/10.1007/s10194-011-0348-y

Gaul, C., Visscher, C. M., Bhola, R., Sorbi, M. J., Galli, F., Rasmussen, A. V., & Jensen, R. (2011b). Team players against headache: multidisciplinary treatment of primary headaches and medication overuse headache. The journal of headache and pain, 12(5), 511–519. https://doi.org/10.1007/s10194-011-0364-y

GBD 2016 Disease and Injury Incidence and Prevalence Collaborators (2017). Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet (London, England), 390(10100), 1211–1259. https://doi.org/10.1016/S0140-6736(17)32154-2

Genazzani, A. R., Nappi, G., Facchinetti, F., Micieli, G., Petraglia, F., Bono, G., Monittola, C., & Savoldi, F. (1984). Progressive impairment of CSF beta-EP levels in migraine sufferers. Pain, 18(2), 127–133. https://doi.org/10.1016/0304-3959(84)90880-7

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. Nurse Education Today, 24, 105-112. https://doi.org/10.1016/j.nedt.2003.10.001

Gunreben-Stempfle, B., Griessinger, N., Lang, E., Muehlhans, B., Sittl, R. & Ulrich, K. (2009). Effectiveness of an intensive multidisciplinary headache treatment program. Headache, 49(7), 990–1000. https://doi.org/10.1111/j.1526-4610.2009.01448.x

Harris, M.A. & Weistroffer, H.R. A new look at the relationship between user involvement in systems development and system success, Commun. Assoc.Inf. Syst. 24 (42) (2009) 739–756. https://doi.org/10.17705/1CAIS.02442

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. Journal of biomedical informatics, 42(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., Duda, S. N., & REDCap Consortium (2019). The REDCap consortium: Building an international community of software platform partners. Journal of biomedical informatics, 95, 103208. https://doi.org/10.1016/j.jbi.2019.103208

Hedborg, K. & Muhr, C. (2011). Multimodal behavioral treatment of migraine: an Internet-administered, randomized, controlled trial. Upsala journal of medical sciences, 116(3), 169–186. https://doi.org/10.3109/03009734.2011.575963

Hindiyeh, N. A., Øusz, J. C. & Cowan, R. P. (2013). Does exercise make migraines worse and tension type headaches better? Current pain and headache reports, 17(12), 380. https://doi.org/10.1007/s11916-013-0380-5

Holroyd, K. A., & Penzien, D. B. (1990). Pharmacological versus non-pharmacological prophylaxis of recurrent migraine headache: a meta-analytic review of clinical trials. Pain, 42(1), 1–13. https://doi.org/10.1016/0304-3959(90)91085-W

Holroyd, K. A., O'Donnell, F. J., Stensland, M., Lipchik, G. L., Cordingley, G. E., & Carlson, B. W. (2001). Management of chronic tension-type headache with tricyclic antidepressant medication, stress management therapy, and their combination: a randomized controlled trial. JAMA, 285(17), 2208–2215. https://doi.org/10.1001/jama.285.17.2208

Holroyd, K. A. & Drew, J. B. (2006). Behavioral approaches to the treatment of migraine. Seminars in neurology, 26(2), 199–207. https://doi.org/10.1055/s-2006-939920

Holroyd, K. A., Cottrell, C. K., O'Donnell, F. J., Cordingley, G. E., Drew, J. B., Carlson, B. W., & Himawan, L. (2010). Effect of preventive (beta blocker) treatment, behavioral migraine management, or their combination on outcomes of optimised acute treatment in frequent migraine: randomised controlled trial. BMJ (Clinical research ed.), 341, c4871. https://doi.org/10.1136/bmj.c4871

Huttunen, H., & Halonen, R. (2018). Willingness to Use Smartphone Application Assistant to Support Migraine Treatment. Bled eConference. https://aisel.aisnet.org/bled2018/15

ISO 9241-11, Ergonomics of human-system interaction — Part 11: Usability: Definitions and concepts. (2018). International Organization for Standardization. https://www.iso.org/standard/63500.html

ISO 9241-210, Ergonomics of human-system interaction – Part 210: Human-centred design for interactive systems. (2019). International Organization for Standardization. https://www.iso.org/standard/77520.html

Kindelan-Calvo, P., Gil-Martínez, A., Paris-Alemany, A., Pardo-Montero, J., Muñoz-García, D., Angulo-Díaz-Parreño, S., & La Touche, R. (2014). Effectiveness of therapeutic patient education for adults with migraine. A systematic review and meta-analysis of randomized controlled trials. Pain medicine (Malden, Mass.), 15(9), 1619–1636. https://doi.org/10.1111/pme.12505

Kuula, A. (2011). Tutkimusetiikka. Aineistojen hankinta, käyttö ja säilytys. (Second edition). Vastapaino.

Köseoglu, E., Akboyraz, A., Soyuer, A. & Ersoy, A. O. (2003). Aerobic exercise and plasma beta endorphin levels in patients with migrainous headache without aura. Cephalalgia: an international journal of headache, 23(10), 972–976. https://doi.org/10.1046/j.1468-2982.2003.00624.x

Latvala J. (2018). Päänsärkypotilaan digihoitopolun kehittäminen. [Bachelor’s thesis, Turku University of Applied Sciences]. Theseus. https://urn.fi/URN:NBN:fi:amk-2018113019167

Lipton, R. B., Manack Adams, A., Buse, D. C., Fanning, K. M. & Reed, M. L. (2016). A Comparison of the Chronic Migraine Epidemiology and Outcomes (CaMEO) Study and American Migraine Prevalence and Prevention (AMPP) Study: Demographics and Headache-Related Disability. Headache, 56(8), 1280–1289. https://doi.org/10.1111/head.12878

Luedtke, K., Allers, A., Schulte, L. H., & May, A. (2016). Efficacy of interventions used by physiotherapists for patients with headache and migraine-systematic review and meta-analysis. Cephalalgia: an international journal of headache, 36(5), 474–492. https://doi.org/10.1177/0333102415597889

Magnusson, J. E., Riess, C. M. & Becker, W. J. (2004). Effectiveness of a multidisciplinary treatment program for chronic daily headache. The Canadian journal of neurological sciences. Le journal canadien des sciences neurologiques, *31*(1), 72–79. https://doi.org/10.1017/s0317167100002869

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. All Ireland Journal of Higher Education, 9(3). aishe.org

Malone, C. D., Bhowmick, A., & Wachholtz, A. B. (2015). Migraine: treatments, comorbidities, and quality of life, in the USA. Journal of pain research, 8, 537–547. https://doi.org/10.2147/JPR.S88207

Malterud K. (2001). Qualitative research: standards, challenges, and guidelines. Lancet (London, England), 358, 483–488. https://doi.org/10.1016/S0140-6736(01)05627-6

Matsuzawa, Y., Lee, Y., Fraser, F., Langenbahn, D., Shallcross, A., Powers, S., Lipton, R., Simon, N., & Minen, M. (2019). Barriers to Behavioral Treatment Adherence for Headache: An Examination of Attitudes, Beliefs, and Psychiatric Factors. Headache, 59(1), 19–31. https://doi.org/10.1111/head.13429

Meyer, B., Keller, A., Wöhlbier, H. G., Overath, C. H., Müller, B., & Kropp, P. (2016). Progressive muscle relaxation reduces migraine frequency and normalizes amplitudes of contingent negative variation (CNV). The journal of headache and pain, (17), 37. https://doi.org/10.1186/s10194-016-0630-0

Minen, M. T., Torous, J., Raynowska, J., Piazza, A., Grudzen, C., Powers, S., Lipton, R., & Sevick, M. A. (2016). Electronic behavioral interventions for headache: a systematic review. The journal of headache and pain, 17, 51. https://doi.org/10.1186/s10194-016-0608-y

Narin, S. O., Pinar, L., Erbas, D., Oztürk, V. & Idiman, F. (2003). The effects of exercise and exercise-related changes in blood nitric oxide level on migraine headache. Clinical rehabilitation, 17(6), 624–630. https://doi.org/10.1191/0269215503cr657oa

Polit, D. F., & Beck, C. T. (2012). Nursing research: Principles and methods. Lippincott Williams & Wilkins.

Sauer, J., Sonderegger, A. & Schmutz, S. (2020) Usability, user experience and accessibility: towards an integrative model, Ergonomics, 63, 1207-1220. https://doi.org/10.1080/00140139.2020.1774080

Schwarz, L., & Kindermann, W. (1990). Beta-endorphin, adrenocorticotropic hormone, cortisol and catecholamines during aerobic and anaerobic exercise. European journal of applied physiology and occupational physiology, 61(3-4), 165–171. https://doi.org/10.1007/BF00357593

Schwarz, L., & Kindermann, W. (1992). Changes in beta-endorphin levels in response to aerobic and anaerobic exercise. Sports medicine (Auckland, N.Z.), 13(1), 25–36. https://doi.org/10.2165/00007256-199213010-00003

Sorbi, M. J., Kleiboer, A. M., van Silfhout, H. G., Vink, G., & Passchier, J. (2015). Medium-term effectiveness of online behavioral training in migraine self-management: A randomized trial controlled over 10 months. Cephalalgia: an international journal of headache, 35(7), 608–618. https://doi.org/10.1177/0333102414547137

Sparling, P. B., Giuffrida, A., Piomelli, D., Rosskopf, L., & Dietrich, A. (2003). Exercise activates the endocannabinoid system. Neuroreport, 14(17), 2209–2211. https://doi.org/10.1097/00001756-200312020-00015

Stanos, S. (2012). Focused review of interdisciplinary pain rehabilitation programs for chronic pain management. Current pain and headache reports, 16(2), 147–152. https://doi.org/10.1007/s11916-012-0252-4

Steiner, T.J., Jensen, R., Katsarava, Z., Linde, M., MacGregor, E.A., Osipova, V., Paemeleire, K., Olesen, J., Peters, M. & Martelletti, P. (2019) Aids to management of headache disorders in primary care (2nd edition). J Headache Pain 20**,** 57. https://doi.org/10.1186/s10194-018-0899-2

Stovner, L. J. & Andree, C. (2010). Prevalence of headache in Europe: a review for the Eurolight project. The journal of headache and pain, 11(4), 289–299. https://doi.org/10.1007/s10194-010-0217-0

Tuomi J. & Sarajärvi A. (2018). Laadullinen tutkimus ja sisällönanalyysi. (Second edition). Kustannusosakeyhtiö Tammi.

User-Centered Design Basics. (2021). Website of usability.gov. Retrieved April 17, 2021. https://www.usability.gov/what-and-why/user-centered-design.html

Vredenburg, K. (2002) Designing the Total User Experience at IBM: An Examination of Case Studies, Research Findings, and Advanced Methods, International Journal of Human–Computer Interaction, 14, 275-278. 10.1080/10447318.2002.9669120

Wakerley, B. R. (2019). Medication-overuse headache. Practical neurology, 19(5), 399–403. https://doi.org/10.1136/practneurol-2018-002048

Van der Schueren, B. J., Van Laere, K., Gérard, N., Bormans, G., & De Hoon, J. N. (2012). Interictal type 1 cannabinoid receptor binding is increased in female migraine patients. Headache, *52*(3), 433–440. https://doi.org/10.1111/j.1526-4610.2011.02030.x

Website of Illumine Ltd. (2015). Retrieved October 10, 2021 from http://www.mind-mapping.co.uk/mind-mapping-information.htm

Website of Strategyzer AG (2021). Retrieved May 1, 2021 from https://www.strategyzer.com/canvas/value-proposition-canvas

Zhang, P. & Li, N.A. (2004). Love at First Sight or Sustained Effect? The Role of Perceived Affective Quality on Users' Cognitive Reactions to Information Technology. In Proceedings of the Twenty-Fifth International Conferenceon Information Systems (ICIS),283-296. https://melody.syr.edu/pzhang/publications/ICIS_04_Zhang_Li_TheRoleOfAffectiveQuality.pdf

Tiedote digihoitopolulle

Kehitämme jatkuvasti päänsäryn digihoitopolkua, jotta se palvelisi sinua ja muita potilaita entistä paremmin. Etsimme vapaaehtoisia haastatteluun antamaan palautetta ja kehitysehdotuksia polusta. Kehitysprojekti tehdään ylemmän ammattikorkeakoulututkinnon opinnäytetyönä HUS neurologian klinikan neurologin toimesta.

Tähän kehitystoimintaan osallistuminen on vapaaehtoista, eikä se vaikuta millään tavalla siihen, minkälaista hoitoa saat päänsärkyihisi. Sekä positiivinen että negatiivinen palaute on erittäin arvokasta. Arvostamme suuresti palautettasi!

HAASTATTELU

- etänä tai paikan päällä sairaalassa pienryhmissä tai yksilöhaastatteluna – sovitaan erikseen
- henkilötietoja tai lääketieteellisiä tietoja ei tallenneta
- haastattelun kesto noin 1h
- myöhemmin palautekeskustelu pienryhmässä suunnitelluista kehitysmuutoksista

MIKSI

- tärkeää palvelun ja päänsärkypotilaiden hoidon parantamisen vuoksi

MITEN

- vastaa laittamalla sähköpostiviesti kehittäjäneurologille, että voisit olla käytettävissä
- hoitopolun kehittäjälääkäri suorittaa haastattelun

KIITOS AVUSTA!

Yhteystiedot vapaaehtoiseksi ilmoittautumiseen ja mahdollisia lisäkysymyksiä varten:
Annukka Uusitalo, neurologi
HUS Neurokeskus, neurologian klinikka
XXX
puh. 050 428 XX XX

Haastattelun kulku ja kysymykset

Kehittäjä esittäytyy ja kertaa, että mitään henkilötietoja tai lääketieteellisiä tietoja ei kerätä. Kysyy haastateltavalta lupaa haastattelun nauhoittamiseen.

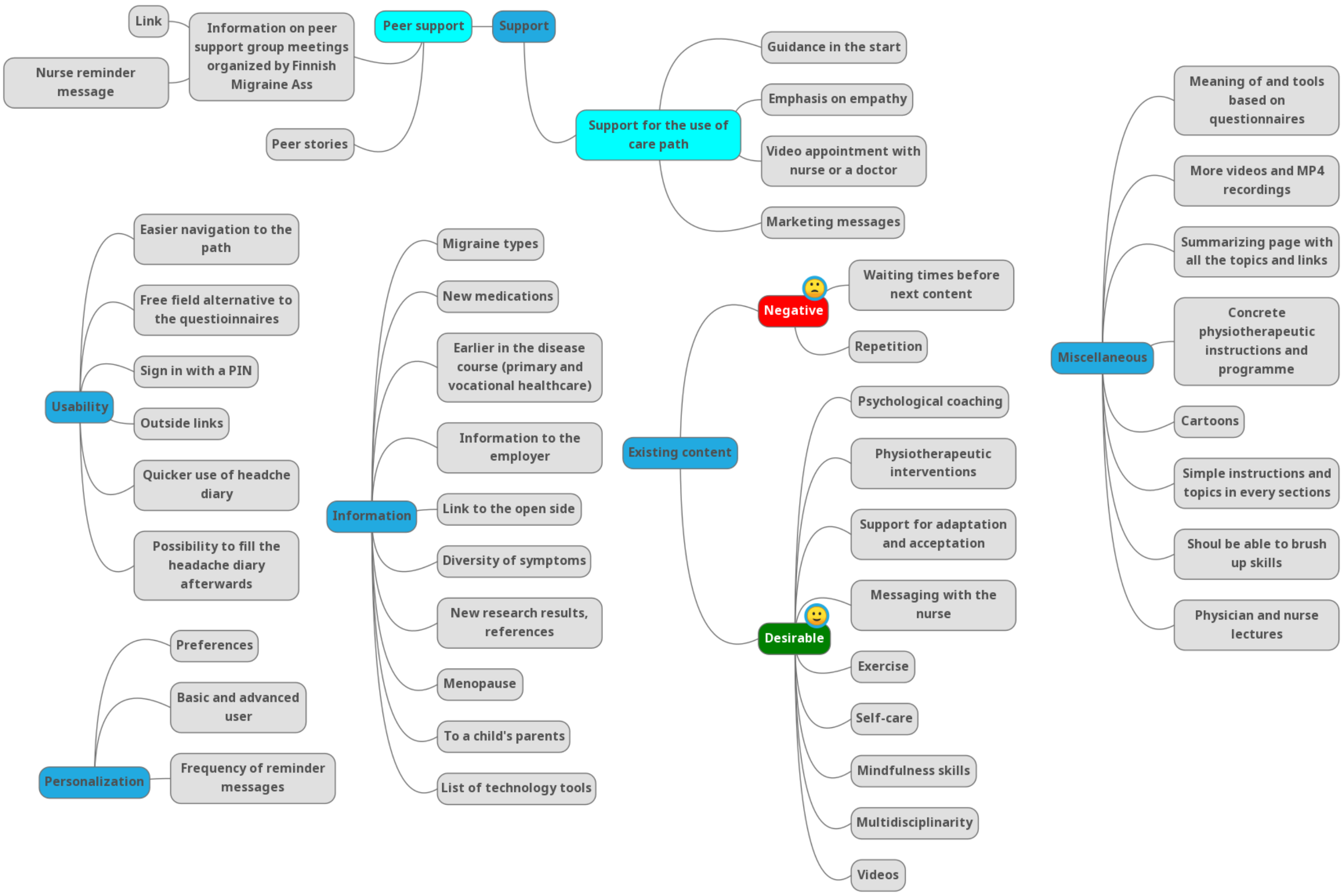
Kysymykset/teemat:

1. Mihin vaiheeseen olet päässyt polulla?
    a. En vielä alkua pidemmälle
    b. Alle puoliväliin
    c. Vähintään puoliväliin
    d. Loppuun tai lähes loppuun
2. Miten kuvailisit tietoteknisiä/digitaalisia taitojasi?
    a. vähän kokemusta
    b. keskimääräisesti kokemusta
    c. paljon kokemusta
3. Oletko kokenut polun hyödylliseksi?
    a. en lainkaan
    b. jonkin verran hyödyllinen
    c. hyödyllinen
    d. erittäin hyödyllinen

    Mitä toivoisit mahdollisesti polulla olevan, jotta voisit saada siitä (vielä) enemmän hyötyä?
4. Onko polkua helppo käyttää?
    a. ei
    b. melko helppokäyttöinen
    c. helppokäyttöinen
    d. erittäin helppokäyttöinen

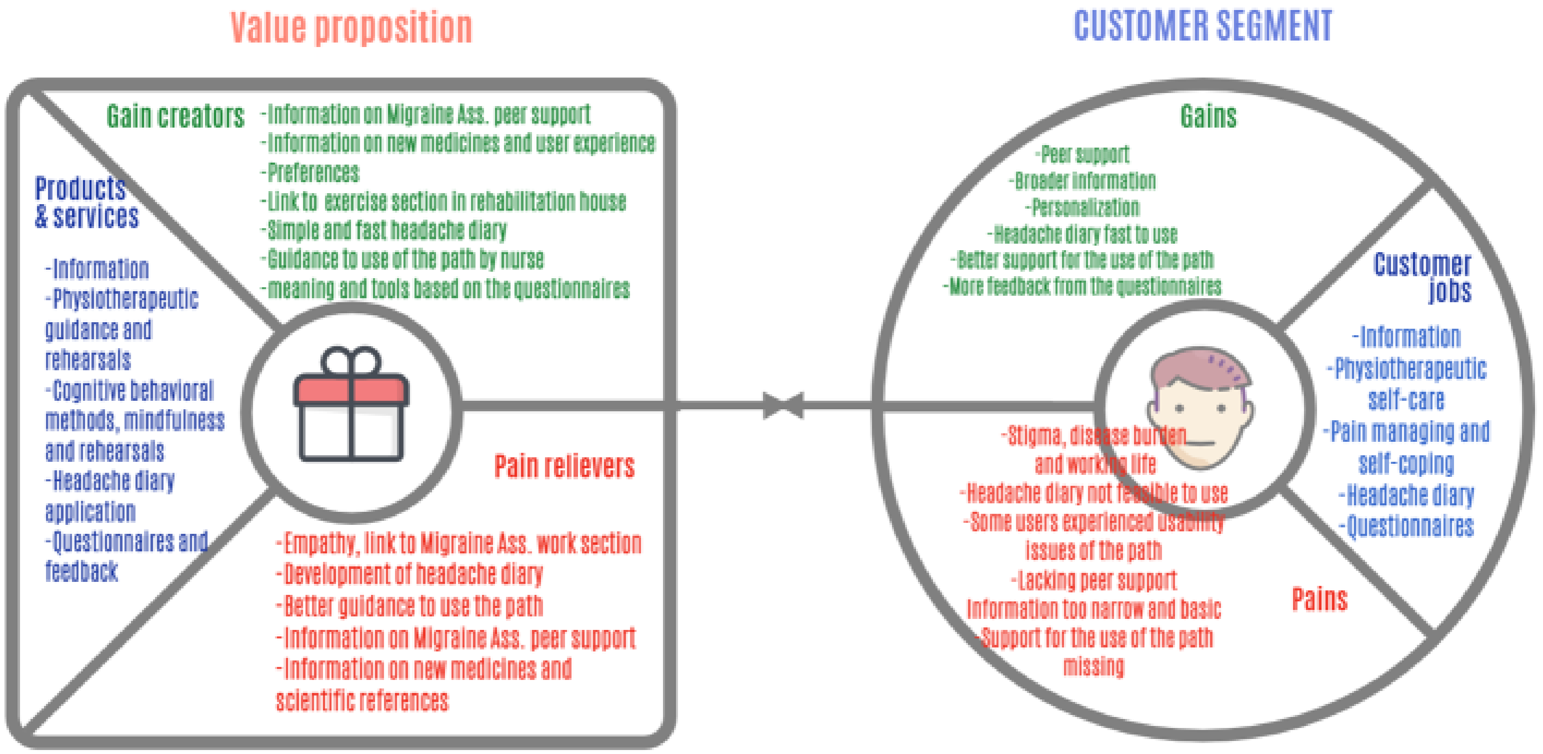
    Mitkä asiat mahdollisesti vaikeuttavat polun käyttöä? Mikä parantaisi sen käyttöä?
5. Mitä hyvää polulla mielestäsi mahdollisesti on? Minkä säilyttäisit ennallaan?
6. Aina ei ole helppoa työskennellä hoitopolulla. Vaikeuttaako jokin seikka digihoitopolulla etenemistäsi? Mikä kannustaisi sinua polun säännölliseen käyttöön ja auttaisi sen läpikäymiseksi?
7. Mikä polulla vaatisi mielestäsi kehittämistä? Miten kehittäisit näitä?
8. Toivoisitko jotain lisättävän polulle? Mitä?

APPENDIX 3


Support
Peer support
Information on peer support group meetings organized by Finnish Migraine Ass
Link
Nurse reminder message
Peer stories
Support for the use of care path
Guidance in the start
Emphasis on empathy
Video appointment with nurse or a doctor
Marketing messages
Usability
Easier navigation to the path
Free field alternative to the questioinnaires
Sign in with a PIN
Outside links
Quicker use of headche diary
Possibility to fill the headache diary afterwards
Personalization
Preferences
Basic and advanced user
Frequency of reminder messages
Information
Migraine types
New medications
Earlier in the disease course (primary and vocational healthcare)
Information to the employer
Link to the open side
Diversity of symptoms
New research results, references
Menopause
To a child's parents
List of technology tools
Existing content
Negative
Waiting times before next content
Repetition
Desirable
Psychological coaching
Physiotherapeutic interventions
Support for adaptation and acceptation
Messaging with the nurse
Exercise
Self-care
Mindfulness skills
Multidisciplinarity
Videos
Miscellaneous
Meaning of and tools based on questionnaires
More videos and MP4 recordings
Summarizing page with all the topics and links
Concrete physiotherapeutic instructions and programme
Cartoons
Simple instructions and topics in every sections
Shoul be able to brush up skills
Physician and nurse lectures

APPENDIX 4

VALUE PROPOSITION CANVAS



Value proposition

Products & services

- -Information
- -Physiotherapeutic guidance and rehearsals
- -Cognitive behavioral methods, mindfulness and rehearsals
- -Headache diary application
- -Questionnaires and feedback

Gain creators

- -Information on Migraine Ass. peer support
- -Information on new medicines and user experience
- -Preferences
- -Link to exercise section in rehabilitation house
- -Simple and fast headache diary
- -Guidance to use of the path by nurse
- -meaning and tools based on the questionnaires

Pain relievers

- -Empathy, link to Migraine Ass. work section
- -Development of headache diary
- -Better guidance to use the path
- -Information on Migraine Ass. peer support
- -Information on new medicines and scientific references

CUSTOMER SEGMENT

Gains

- -Peer support
- -Broader information
- -Personalization
- -Headache diary fast to use
- -Better support for the use of the path
- -More feedback from the questionnaires

Customer jobs

- -Information
- -Physiotherapeutic self-care
- -Pain managing and self-coping
- -Headache diary
- -Questionnaires

Pains

- -Stigma, disease burden and working life
- -Headache diary not feasible to use
- -Some users experienced usability issues of the path
- -Lacking peer support
- Information too narrow and basic
- -Support for the use of the path missing

APPENDIX 5

- Screen filters for a computer and adjustment of the screen brightness
- Night mode -function of a computer and mobile phone to reduce eye strain
- Migraine glasses (FL-41) or coating (for more advice ask the optometrist)
- Color filter softwares for the screen (e.g. f.lux or colofveil)
- Smart lights
- Posture vests
- Smart watches which measure action and physiologic signals
- Window blinds
- Earmuffs for hearing protection or earplugs
- Cold pack